

BioethicsBytes Extended Commentary

The Future of Our Families? – *My Sister's Keeper* (Picoult, 2004)

Introduction to this resource

Welcome to this *BioethicsBytes Extended Commentary*. These are intended to provide all readers - teachers, learners and members of the public alike – with a more in-depth discussion of issues raised by media presentations of developments in biology and biomedicine. They are supplementary to the posts on the *BioethicsBytes* website, and elaborate themes identified in the main commentaries.

In general, they deal with one or more very specific bioethical issues raised by featured books, films or programmes. They focus on specific quotes, or exchanges, in the source material that illustrate moral concerns or ethical concepts that have application beyond the context of the programme. The extended commentaries draw on a wider range of media and academic texts than can be presented on the main website, and, as such, can provide readers with additional resources on specific topics.

The focus in this commentary is on the specific use of Pre-implantation Genetic Diagnosis (PGD) in order to produce a donor for an older child, a so-called saviour sibling or, in the tabloid press, a “designer baby” (although this term is misleading and therefore best avoided). PGD is the subject of a number of other resources produced by the *BioethicsBytes* team, including a [☞ Bioethics Briefing](#), a [☞ Guide to Streamed Media](#) and a review of three documentaries on the topic (see [☞ Designer Babies – three documentaries – BioethicsBytes, July 12th 2007](#)).

Please note that this commentary reveals aspects of the plot, including the ending of the novel

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Last updated: September 5th 2007



Introduction to The Future of Our Families – *My Sister's Keeper* (Picoult, 2004)

This extended commentary explores some of the bioethical issues around the creation of a, so called, 'saviour sibling', as featured in Jodi Picoult's 2004 novel *My Sister's Keeper*. In particular, the novel will be discussed in the context of the 2004 Human Fertilisation and Embryology Authority (HFEA) report on 'preimplantation tissue typing' (HFEA, 2004). While Picoult's story is set in the US, many of the ethical concerns that have made the use of Preimplantation Genetic Diagnosis (PGD) solely for tissue-matching to a pre-existing individual¹ controversial are common to both the UK and US. The HFEA Ethics and Law Committee's (the ECL) 2004 review document (ECL, 2004), upon which the final report was based, is also used to examine some of these common concerns.

Taken together, these documents outline several of the ethical issues that were involved in the decision to allow the use of this technology for the purposes of obtaining an embryo that was tissue matched to a seriously ill sibling for the purposes of umbilical cord blood donation.

These are:

1. The welfare and best interests of the child to be born
2. The instrumentalisation of the child
3. Consent and comparability with donation from existing siblings
4. The long-term experience of the child

These issues are all elaborated in Picoult's novel, which – given its fictional nature – explores how they may manifest themselves in family situations of the future. This extended commentary illustrates how this is done with reference to the characters and dialogue found in *My Sister's Keeper*, though also makes reference to Picoult's documented motives in writing the book, and comparable real life cases.

1. The welfare and best interests of the child to be born

As suggested in Box 1, the welfare and best interests of any saviour siblings selected following tissue-typing of embryos prior to implantation were the ethical principles of primary concern to the HFEA when reviewing the use of these techniques for this purpose. Concern for the new child itself is also reflected in the wider ethical literature. Pennings *et al.* (2002), for example, captures this concern in terms of a 'best interests test'. This test stipulates that any medical intervention – whether that be PGD/HLA-typing itself, or any later procedure for which the new child is a *de facto* non-consenting donor – must accord with this principle. They state that: "if no consent can be obtained...we rely on the best interests of the person" (2002: 536). The question of whether PGD accords with this principle is directly comparable to the HFEA's concerns (as described in Box 1), though they frame this issue in terms of the physical risks of PGD. However, with respect to *My Sister's Keeper*, it is more sensible to examine, firstly, whether or not it is in Anna Fitzgerald's best interests

¹ Often referred to as Human Leukocyte Antigen (HLA) typing, this use of PGD involves removing one or two cells from the early embryo (usually around the eight cell stage) for genetic testing. However, where PGD is traditionally used to diagnose disease in the embryo itself, HLA-typing involves comparing the embryo's genes for a series of cell-surface proteins in order to determine their suitability as a tissue match for an existing individual. This is particularly controversial where no genetic test is carried out (e.g. where the sick child's disease is not associated with a particular genetic mutation), and thus PGD offers no *direct* benefit to the embryo itself.

to be born as a saviour sibling for her sister Kate, and secondly, whether her further donations accord with Pennings *et al.*'s test. While the first of these issues is implicitly discussed within the novel², it is the second concern that is at the heart of *My Sister's Keeper* – particularly insofar as it relates to whether or not it is in Anna's best interests to donate a life-saving kidney to Kate.

BOX 1: Background to the UK Regulatory Framework

In the UK, fertility treatment, and any type of testing or research on embryos is regulated by the Human Fertilisation and Embryology Authority (the HFEA). In 2001 they ruled that the type of treatment required to create a 'saviour sibling', like Picoult's Anna Fitzgerald, should not be provided in the UK (see [☞ HFEA to allow tissue typing in conjunction with preimplantation genetic diagnosis – HFEA Press Release, 13th December 2001](#)). They decided that where preimplantation genetic diagnosis (PGD) provided no direct benefit to the embryo itself – i.e. where it was carried out solely for tissue typing and not in order to screen embryos for genetic disease – this was an unacceptable use of the technology. While the HFEA's concerns largely revolved around the safety of PGD rather than ethical concerns regarding the creation of 'saviour' children, their decision was still underpinned by some of the ethical principles discussed in this extended commentary. Given the lack of evidence at the time regarding the long-term effects on the child of removing one or two cells from the blastocyst for testing, they concluded that this "intervention imposes risks without benefits"¹, and as such would not be in the best interests of the child being created. This risk/benefit calculation (a form of utilitarian calculation) was based on the HFEA's responsibility to consider the welfare of the child, as laid down in the 1990 Human Fertilisation and Embryology Act.

However, in 2004 (following the Hashmi case, outlined in Box 4) the HFEA modified this policy to allow tissue typing solely to produce a 'saviour sibling' (see [☞ HFEA agrees to extend policy on tissue typing – HFEA Press Release, 21st July 2004](#)), stating that "our review of the evidence available does not indicate that the embryo biopsy procedure disadvantages resulting babies compared to other IVF babies"². While this clearly suggests that their assessment of the acceptability of this use of PGD was still based on a the risk v. benefit analysis of the welfare of the child, their press release at this time also suggests that they began to take the welfare of the family – as an indirect benefit to the child itself – into account in their policy decisions. This alteration paved the way for the licensing of PGD for tissue typing alone in cases like that of the Mariethoz, outlined in Box 5.

¹ Suzi Leather, quoted in Tizzard, Juliet. 'Saviour Siblings': a child to save a child. Available online at <http://www.ccels.cf.ac.uk/archives/issues/2004/tizzard.pdf> [Accessed: 25th July 2007].

² HFEA. (2004). *HFEA agrees to extend policy on tissue typing*. HFEA Press Release. Available online at <http://www.hfea.gov.uk/en/1046.html> [Accessed: 25th July 2007].

In terms of opposing views on this question, it is the character of Sara who is most adamant that it is in Anna's best interests to act as a donor for Kate, since "growing up in an intact family" (Pennings *et al.*, 2002: 536) is arguably concordant with this. Picoult herself notes: "I don't think she meant for Anna to be at the mercy of her sister...I think she was only intent on doing what had to be done to keep that family intact" (From [☞ A conversation with Jodi Picoult about My Sister's Keeper – jodipicoult.com, accessed July 23rd 2007](#)). The HFEA report reiterates this sentiment: "if a medical procedure 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" (HFEA, 2004: 7). This introduces the idea that Anna's best interests and welfare are intimately tied up with those of her family – a family that will be devastated should Kate die. This is summed up by Glitter: "the social, emotional and psychological best interests of a person depend upon the happiness in the family in which he grows up" (2006: 1012).

² In terms of the best interests test, the ethical argument for Anna's birth/creation as a saviour sibling might run something like this: since it is arguably in any child's best interests to be born, rather than not being born, and that "the child once born will benefit if his or her sibling survives" (Pennings *et al.*, 2002: 536), it is in Anna's best interests to be born as Kate's saviour.

However it is not only Anna's social, psychological, and emotional best interests that are at stake in *My Sister's Keeper*; her physical wellbeing is also a key issue, as is highlighted in the following exchange between narrator Campbell Alexander (Anna's lawyer) and Dr Chance (Kate's doctor):

'...this kidney donation – are there risks associated with the procedure?'
 'No more than for most surgeries,' Dr Chance says.
 'Could Anna die from complications of this surgery?'
 'It is highly unlikely, Mr Alexander.'
 '...How will having a single kidney affect her for the rest of her life?'
 ... 'Increased chance of hypertension. Possible complications during pregnancy.' Dr Chance glances up. 'Donors are advised to refrain from contact sports to eliminate the risk of harming their remaining kidney.'
 I clasp my hands behind my back. 'Did you know that Anna plays hockey in her free time?'
 He turns towards her. 'No. I didn't.'
 'She's a goalie. Has been for years now.'

(Picoult, 2004: 326)

What we see here is that Anna's life will be affected by the donation of a kidney to Kate. This seems particularly problematic given testimony on the transplant by Dr Bergen (a member of the ethics committee reviewing Kate's treatment). He suggests that when the committee considered whether or not Kate should have the transplant, they were split as to whether or not it was in *her* best interests. He says that Kate's condition may have deteriorated to such a point that the operation may do more harm than good, and that - given this - "Anna would undergo a serious operation for no reason at all" (Picoult, 2004: 295). However, in other passages, the ethical acceptability of Anna's previous donations are also called into question vis-a-vis her best interests. For example, when Campbell cross-examines Sara (Anna's mother):

'So, how old was Anna when she first donated an organ or tissue to her sister?...cord blood was taken from Anna moments after birth, isn't that right?'
 'Yes,' Sara says...
 'How old was Anna the next time she donated some body part to Kate?'
 ... 'She was five when she gave donor lymphocytes'
 'What does that involve?'
 'Drawing blood from the crooks of her arms.'
 'Did Anna agree to let you put a needle in her arm?'
 'She was five years old,' Sara answers
 'Did you ask her if you could put a needle in her arm?'
 'I asked her to help her sister'
 'Isn't it true that someone had to physically hold Anna down to get the needle in her arm?'
 ... 'Yes'
 'Do you call that voluntary participation, Mrs Fitzgerald?' ... 'The first time you took lymphocytes from Anna, were there any side effects?'
 'She had some bruising. Some tenderness'
 'How long was it before you took blood again?'
 'A month'
 'Did she have to be held down that time, too?'
 'Yes, but - '
 'What were the side effects then?'
 'The same.' ...
 '...you took blood from Anna a third time.'
 'It took that long to get all the lymphocytes,' Sara says. 'It's not an exact procedure.'

'How old was Anna the next time she had to undergo medical treatment for her sister's well-being?' ... '...when she was six.'
... 'She donated granulocytes to fight Kate's infection...'
'Another needle stick?'
'That's right'
'Did you ask her if she was willing to donate the granulocytes?' ... 'Did you ask her?' ... 'Added up like this, it doesn't seem quite so innocuous, does it?'

(Picoult, 2004: 287-288)

While Dr. Chance suggests that she has not suffered "significant medical harm from these procedures" (Picoult, 2004: 326). The discomfort suffered by Anna here is clearly a welfare consideration (not just for saviour siblings, but for any child donor). However, in general the suffering of the saviour sibling, particularly when it is cord blood alone that is being donated, is seen as ethically acceptable *when balanced against the best interests of the recipient* (though the HFEA's report suggests that this would also apply in the case of bone marrow donation). In this sense it does seem acceptable that "one child must suffer a small disadvantage in order to help a sibling a lot" (Pennings, 2002: 537). This is something Picoult elaborates on in an interview for BBC Radio 4's *Book Club* ([☞ Jodi Picoult \(May 2007\) – BBC Radio 4, first broadcast at 16:00, on May 6th 2007](#)): speaking on the axiom that 'you should love all your children equally', she states that in practice this translates to "we hope everyone gets a moment in the sun" (time in 00:07:13). When a child is in crisis they inevitably become the focus of their parents' attention. The HFEA now acknowledge this openly in their press release concerning the 2004 policy change on the use of PGD for HLA typing to create a tissue matched sibling for cord blood transplant (see [☞ HFEA to allow tissue typing in conjunction with preimplantation genetic diagnosis – HFEA Press Release, 13th December 2001](#)). However, *My Sister's Keeper* illustrates exactly what might happen should this understandable parental focus develop into a form of 'tunnel vision'. The HFEA states that it "does not have the power to impose a condition on a license that would prohibit any future attempt to obtain bone marrow for the treatment of siblings, should a cord blood donation fail" (HFEA, 2004: 7) - a limitation on the HFEA's authority that does make *My Sister's Keeper* a realistic vision. However, they also note that, in practice, "solid organ donation [e.g. a kidney] is extremely unlikely to be held to be in a child's best interest" (HFEA, 2004: 7). Thus, while the balancing of the interests of saviour and sick sibling is obvious in HFEA decision-making regarding the acceptability of using PGD for HLA typing alone, it is sometimes absent from theoretical discussions of this issue. This seems to be one of the key strengths of Picoult's book, in which the author writes each chapter from the perspective of a different participant in the story. Her use of multiple narrators allows for multiple viewpoints concerning, amongst other things, what constitutes the best interests of the saviour sibling.

Putting aside Bergen's comments regarding the risks to Kate of undergoing a kidney transplant, it seems clear that it is in her best interests to live rather than to die (though within the book this is, admittedly, ambiguous). However, it seems that this argument could be extended to other family members. It does seem to be in their best interests for Kate to live too, and therefore, for Anna to donate tissue to her - whether that be cord blood, bone marrow, or a kidney. The question here is whether or not it is justifiable to include the best interests of either the sick sibling, or the family as a whole, in any ethical decision-making regarding both, the creation, and subsequent donor status of children like Anna.

2. The instrumentalisation of the child

Among ethicists, the possible instrumentalisation - or 'commodification' (Berry and Engel, 2005; Sheldon and Wilkinson, 2004b) - of the child is a serious concern implicit in the creation of saviour siblings. In general, the debate around this issue draws on the second formulation of the categorical imperative in Kantian ethics: that is "to treat humanity ... always as an end and never merely as a means" (Kant, 2006 [1785]: 28). In contemporary moral philosophy this is interpreted as an injunction to never treat people *solely* as means-to-ends, but always as ends-in-themselves (for an elaboration of this in relation to transgenic animals, see [☞ Making "creatures that work for us" – Animal Farm \(3\) – BioethicsBytes, June 20th 2007](#)). However, Pennings *et al.* note that "it is generally agreed that using someone as a means is not unethical. In fact we do it all the time. An action should only be condemned when it treats a person solely as a means" (2002: 536). This raises the question of under what conditions might a child be said to have been instrumentalised (that is, treated solely as a means)? Is it when they have been conceived to save a marriage? Or when they have been born to provide a playmate for an existing child? Is a child instrumentalised if it is born "as a means of obtaining 'lots of money from the government and a council house' " (From [☞ Parenting – neglected field in the curriculum? - Dr Sue Dale Tunnicliffe, teachingexpertise.com \[Accessed on August 7th 2007\]](#))? For some, the creation of a child as a saviour sibling is actually less instrumentalising, since "of all the reasons people have children ... this is one of the better ones: to save a life" (From [☞ More babies being born to be donors of tissue – Gina Kolata, New York Times, June 4th 1991](#))

Pennings *et al.* imagine another hypothetical scenario: suppose the recipient child dies and the donor child is left to "fill the void" (2002: 536)? Is the child being treated merely as a

BOX 2: The Nash Family, Colorado, 1999

According to Dickens (2005), this is generally considered the "initial or index" saviour sibling case, insofar as it was the first time PGD had been used for the purposes of obtaining a tissue matched embryo¹. It concerns the Nash family, whose 6 year old daughter Molly, suffered from Fanconi Anemia². In 1999, Molly was suffering bone marrow failure and myelodysplastic syndrome, and her surgeon suggested that "the best hope of treatment is a transfer of stem cells found in the umbilical cord blood of a sibling because the recipient's body is not likely to reject the cells" (Glitter, 2006: 977).

However, the Nashes - unlike the Ayalas (see footnote 1) - opted to have IVF and PGD rather than try to conceive a donor child naturally. This allowed them to both avoid having a second affected child (the chances of this being 1 in 4), and to guarantee that the embryo implanted would be a full tissue match for Molly.

This procedure required 4 cycles of IVF, the creation of 30 embryos (Berry and Engel, 2005), and the implantation of 5 of these (Boyle and Savulescu, 2001). Finally, on the 29th of August 2000, Adam Nash, Molly's 'saviour sibling' was born. Shortly after his birth doctors collected the blood needed for Molly's transplant from the umbilical cord, and - on the 26th of September 2000 - the required stem cells were transplanted into Molly. This treatment was apparently successful: "Molly showed bone marrow recovery after four weeks, and three years later her haematopoietic and immune systems were normal" (Glitter, 2006: 979).

For more information see [☞ Couple select healthy embryo to provide stem cells for sister - BMJ News, 14th October 2000](#).

¹ The Nashes, however, were not the first couple to try to conceive a child for the purposes of saving an existing ill child. In 1990 the Ayala's announced that they intended to conceive a saviour sibling for their 19 year old daughter, who was suffering from leukemia. The difference was that they intended to do this by natural means (i.e. without the use of IVF and PGD/HLA-typing). They were successful and, according to Boyle and Savulescu, the donor child "is now a healthy four year old, and, by all accounts, as loved and cherished as her parents said she would be. The bone marrow transplant was a success and [the recipient] is now a married, leukemia-free bank clerk" (Boyle and Savulescu, 2001: 1240).

² Fanconi Anaemia: "an inherited rare but fatal disorder associated with leukemia and predisposition to cancer" (Dickens, 2005: 94).

means-to-an-end here? Overall, it is generally accepted that wanting a child “that can also save a sibling” (2002: 536) is no less – and possibly even more – acceptable than wanting a child for any of the other reasons above³. In this sense the reasons offered above and those underlying the desire to create a saviour sibling are judged as having little relevant moral difference. Given this the question for the HFEA – and for society more broadly – is whether or not it is acceptable for the medical profession to intervene (i.e. to carry out procedures or actions they would not otherwise perform) in order to all this to happen.

As is implied in Kant’s original second formulation of the categorical imperative, assessing whether or not someone (or something) has been instrumentalised relies to a large extent on examining how they are treated. Currently, in the case of saviour siblings, this is difficult. As is outlined in Box 2, Adam Nash – the first child selected using PGD to be tissue matched donor – is still only seven years old, and there are few other such children available to consider. Further, it is the HFEA’s responsibility to assess what the future consequences might be of approving a particular application by particular people at a particular time, something which is especially problematic when it comes to looking at how a given child is likely to be treated in the future. Thus, the parents’ *intentions* in conceiving the child are often taken as a proxy for this, and in debates on the acceptability of saviour siblings it is these that are scrutinised. In terms of the categorical imperative one must therefore ask: do the parents intend to treat the child solely as a means-to-an-end – in other words, solely “as an instrument to cure another child” (Pennings *et al.*, 2002: 536)?

With respect to the fictional Fitzgeralds in Picoult’s *My Sister’s Keeper*, was Anna conceived solely as a means to an end? The scene that (chronologically) follows Brian and Sara’s recognition that Jesse is not a tissue match is highly relevant to this question. When Dr Chance refers to siblings other than Jesse, Sara begins to acknowledge “a family ... I never *intended*” (Picoult, 2004: 65, my emphasis). The impression that Brian and Sara never intended to have more children, for any reason, is strengthened by Sara’s comparison between Brian and Kate, and herself and Jesse. She says of Brian and Kate, “pale towheads bent together, they are a matched set” and then “Jesse looks more like me – skinny, dark, cerebral. Brian says this is how we know our family is complete: we each have our clone” (all Picoult, 2004: 25). These, and many other similar statements in the book, suggest that Anna was indeed born only for, and because of, Kate. Thus it could be reasonable to suppose that Sara conceived Anna solely with the intention of her cord blood saving Kate’s life. Other passages in the book even support an argument that Anna was always intended to be a source of more than umbilical cord blood alone. It seems likely, for example, that Sara and Brian had always intended for her to be a bone marrow donor should that be required (see page 61, for example). In terms of her parents’ intentions in conceiving her, it does seem that Anna is highly instrumentalised in *My Sister’s Keeper* – a depiction that does not bode well for real-life saviour siblings.

One advantage of using fiction as a way of considering ethical issues facing society today is its ability to explore situations that have not (as yet) arisen in reality. Within the case of *My Sister’s Keeper*, it allows us to examine, not only the intentions of parents who decide to use PGD for HLA typing allow, but also, their subsequent treatment of the saviour sibling as he/she grows older. Thus, as suggested above, though Anna may have been conceived solely to be a cord blood and bone marrow donor for Kate - i.e. as a means-to-an-end - this is not the

³ Though the justification made for sex selection for the purposes of family balancing, for example to ‘complete a family’ or to ‘obtain a gender balance’, appear to be judged differently in this respect.

way that she is treated. Throughout the book Anna is treated as an end-in-herself and not solely as a means, though this is difficult to convey through any particular quote. Nevertheless, it emerges through particular scenes and reminiscences: for example where her mother 'rescues' her from her divided bedroom (pages 53-54); or where she is stargazing with her father (pages 196-197). However, that Anna is valued as an end-in-herself is probably best illustrated in the final few scenes of the book, particularly Kate's epilogue (pages 405-407), and Sara's description of her body – which, if she were to be treated solely as a means, be the most valuable part of her - as “the husk that once held my youngest” (Picoult, 2004: 401).

Overall, *My Sister's Keeper* highlights nicely that consideration of parents' *intentions* in creating a child may not be enough to determine whether being born as a saviour sibling instrumentalises the child to such an extent that it renders the practice of PGD for HLA typing alone unethical. The parents' actual treatment of that child may be very different from that indicated by their reasons for conception.

BOX 3:
The Hashmi Family
UK, 2001

The Hashmis were the first couple in the UK to apply for, and be granted, a license to carry out PGD with HLA-typing for the purposes of creating a 'saviour sibling'. The Hashmi's son, Zain, was born in October 2000, with the recessively inherited blood disorder, beta thalassemia - a serious condition. As Sheldon notes "Zain has to undergo regular blood transfusions and may die unless a suitable tissue donor can be found for him, the best chance of finding such a donor lying in the birth of a compatible sibling" (2005: 403). With no other compatible sibling, the Hashmis conceived another child shortly after Zain's birth¹. The baby did not suffer from beta thalassemia, but was not an HLA match for his brother. In the following months the Hashmis searched for a tissue matched - or allogenic - donor, though given the problems associated with such transplants and the urgency of finding a donor, they approached the HFEA for a license to carry out PGD, firstly for the purposes of screening embryos for beta thalassemia, and secondly to conduct HLA typing in order to obtain a embryo matched to Zain. In the words of Dickens "the HFEA interpreted the UK 1990 act to afford it authority to license these procedures" (Dickens, 2005: 94), and in 2001 the Hashmis obtained their license and produced 14 embryos. Unfortunately for Zain, none of these were both disease free and an HLA match, and, before they could begin further cycles of IVF, a court action was brought by the group Comment on Reproductive Ethics (CORE).

CORE claimed that PGD should "only be used in the interests of the child conceived" (Berry and Engel, 2005: 4) and that the HFEA had exceeded its authority in granting this license (Sheldon, 2005: 404). The argument between the HFEA (supported by the DoH during the appeal) and CORE revolved around how the term 'suitable', as it appears in the 1990 Human Fertilisation and Embryology Act, should be interpreted. The Act states that the HFEA may license "practices designed to secure that embryos are in a suitable condition to be placed in a woman" (Human Fertilisation and Embryology Act 1990, Schedule 2, s. 1(1)(d)), with the HFEA arguing that "Mrs Hashmi would be entitled to regard an embryo as unsuitable unless it was both free of abnormality and a perfect blood match for Zain" (Sheldon, 2005: 405) and CORE that it referred only to an embryo "capable of becoming a healthy child who is free of abnormalities" (Sheldon, 2005: 405).

While CORE won its initial case in December 2002, this decision was overturned in April 2003 by the court of appeal, following which the Hashmis resumed their treatment and later that year a disease-free, tissue-matched embryo was successfully implanted. However, in December 2003, Mrs. Hashmi miscarried. In 2004 the Hashmis had had six unsuccessful cycles of IVF, and with advancing maternal age also becoming a relevant factor, they ceased their attempts to create a saviour sibling for their son.

¹ According to Sheldon (2005), the Hashmis conceived this child with the intention of creating a saviour sibling.

3. Consent and comparability with donation from existing siblings

The issue of consent is central to both Picoult's *My Sister's Keeper* and the HFEA's review of their 2001 interim policy on PGD for HLA tissue typing where there is no risk of genetic disease and, thus, the creation of saviour siblings. In the novel, Anna Fitzgerald's court case is ostensibly about whether or not she is capable of giving – or more correctly refusing to give – consent for the donation of one of her kidneys to Kate (though it also concerns her parents' ability to consent on her behalf to non-therapeutic medical treatment that may not be in her best interests). In legal-ethical parlance this is referred to as 'competency'. The HFEA, on the other hand, were less concerned about minors and parents competency to give consent in theory. Instead their review focussed on existing, formal procedures (both medical and legal) regarding who could – and could not – give consent on behalf of a non-competent minor, under what circumstances such consent was valid, and what levels of support, back-up and monitoring are (and should) be provided. Specifically, they assessed current provisions in cases they deemed comparable to situations saviour siblings might experience in the future. In doing this the HEFA's ELC reviewed relevant case law relating to consent for both bone marrow donation and solid organ donation (and a range of other non-therapeutic medical interventions), proposed for non-competent minors.

Firstly, it is around the issue of consent that the grounding of *My Sister's Keeper* in the real world is established. Many of the legal and ethical issues Picoult writes into Anna's court case are echoed in real-life cases. For example, the similarities between Picoult's account of how Anna's treatment is viewed by medical professionals and the courts and the way comparable cases are considered in the UK is striking – particularly since the novel is set in the US. One example of this is when Brian (Anna's father) tells Sara (Anna's mother) that he is effectively withdrawing consent for Anna's kidney donation. Sara responds that, if "at least one of her parents is capable of supporting this petition...he [the judge]'s going to find in her favour" (Picoult, 2004: 254). This appears to reflect the situation in the UK regarding the need for *both* parents to consent to non-therapeutic treatment - like bone marrow donation – for one of their children. In an annex to their 2004 report, the ECL note that, in such cases, "the consent of one parent is not sufficient" (Annex E, point 5). They suggest that where parents disagree, a court – effectively the only other authority that may consent for a non-competent minor – should decide. Other examples include the way clinical teams would not normally involve an ethics committee when evaluating the acceptability of bone marrow donation by a non-competent minor, something Dr Bergen admits never happened in Anna's case either: he states that the ethics of carrying out this procedure on Anna "wasn't the issue at stake" (Picoult, 2004: 294). Further, that Picoult puts Anna's age at thirteen is also significant: it is at this age – where a minor moves from being a child to being a teenager – that the ambiguity and/or tension between consent given by a parent and that given by the minor patient appears to arise. Within the book, Dr Bergen notes that "consent isn't necessary until age thirteen. We rely on parents consent until that point", and that "once a child reaches adolescence, although they can't give formal consent, they have to agree to any hospital procedure" (Picoult, 2004: 293). And, while these are not formal criteria, one Australian study of 120 children, parents and medical professionals involved in non-lifesaving orthopaedic treatment suggested that minors became competent to decide about treatment between the ages of 10.3 and 14 years (Thomas, 2004).

In general, minors are judged to be incompetent – that is not capable of giving direct/formal informed consent – unless they can pass the, so called, Gillick test. Established in *Gillick v*

West Norfolk and Wisbech Area Health Authority [1985] 3 All ER 402 (HL), this requires that the minor show “not merely an ability to understand the nature of the proposed treatment...but a full understanding and appreciation of the consequences both of the treatment in terms of intended and possible side-effects and equally important, the anticipated consequences of a failure to treat” (*Re R (a Minor)(Wardship: Medical Treatment)* [1992] Fam.11, 26 cited in Thomas, 2004). Essentially this is what Anna’s court case (and her guardian *ad litem*, Julia’s assessment of her⁴) is intended to establish: is Anna Fitzgerald, at age 13, Gillick competent or not?

While “the parental right to consent terminates when a child is deemed *Gillick*-competent” (McLean, 2000) is considered a guiding principle in medical ethics, and is legally binding in England and Wales, bone marrow and solid organ donation are considered special cases of non-therapeutic medical intervention. Though the HFEA report that “bone marrow donation from one sibling to another is an established procedure in the United Kingdom” (HFEA, 2004: 5), and hence relatively “routine” (HFEA, 2004: 7) in terms of the consent required, this is not the case elsewhere (Thomas, 2004), nor is it with respect to solid organ donation. Indeed, Article 20 of the European Convention of Human Rights and Biomedicine⁵ outlaws donation of non-regenerative organs by incompetent persons, and similarly principle 4 of the WHO Guiding principles on Human Organ Transplantation specifically forbids living child organ donations. However, according to the ECL (2004) this has never been tested in court. Though Anna’s court case is specifically about her medical emancipation from her parents, these principles expose what may be the only weak point in Picoult’s book: it is unlikely that any court in any country in the world would, at present, compel even a non-Gillick competent minor to donate an organ against their will or wishes. In Anna’s case this might manifest itself in a refusal to grant medical emancipation, but a prohibition on Anna’s kidney donation specifically.

This is acknowledged in the book by at least three of the characters. Dr Bergen states “it goes without saying that no hospital in the country is going to take a kidney out of a child who doesn’t want to donate it” (Picoult, 2004: 294); Judge DeSalvo repeats this “Anna, no hospital in this country will take an organ from an unwilling donor” (Picoult, 2004: 85); even Campbell tells Anna “no one can make you donate an organ if you don’t want to” (Picoult, 2004: 20). To some extent this should invalidate Anna’s petition: whether she wins or not, no court nor doctor can, nor would, force her into donation. However Anna, as a thirteen year old girl, recognises one authority above that of the doctor and courts; that of her parents. For her, they are not only the ultimate authority, but also seem to have control over all her donations, past and future, and in this sense her case goes above and beyond the immediate issue of the donation of one kidney. This sentiment is captured in a number of her statements. In response to Campbell telling her that no one would ever *take* her kidney, she says “Oh really?” (Picoult, 2004: 20). Her full response is worth noting in this regard:

‘The first time I gave something to my sister it was cord blood and I was a newborn. She has leukaemia...and my cells put her into remission. The next time she relapsed, I was five and I had lymphocytes drawn from me... When they stopped working they took bone marrow... When Kate got infections, I had to donate granulocytes. When she relapsed again, I had to donate peripheral blood stem cells.’
‘Obviously, you’ve agreed to be a donor for your sister before.’

⁴ In Picoult’s words a guardian *ad litem* (GAL) “is appointed by the court to be a child’s advocate during proceedings that involve a minor” (Picoult, 2004: 106)

⁵ To which the UK is not signatory.

She hesitates, then shakes her head. 'Nobody ever asked.'
'Did you tell your parents you don't want to donate a kidney?'
'They don't listen to me'... 'They don't really pay attention to me, except when they need...something.'

Given Bergen's statement regarding the age at which minors are even consulted about consent, it may be that this is the first operation for which Anna has been in any way involved in the decision-making process, despite that fact that her treatments – as described in her own words above – seem to have become progressively more invasive. In this respect Anna's description of her donations to Kate is reminiscent of another concern associated with the debate over saviour siblings; the 'slippery slope'. However, the slope Anna describes sliding down is different from the one preoccupying bio-ethicists today.

Conventionally, the slippery slope is conceptualised in terms of an 'escalation' in selection using PGD. Where PGD has traditionally been used for the screening of embryos during IVF to *select against* inherited genetic mutations associated with disease, its use in determining HLA type alone – as a way to *select for* a tissue matched embryo – is seen as a disturbing shift by some observers; as the next step towards 'designer babies'. The rationale behind this is that "if we allow something to happen which, considered in itself, is acceptable or only slightly bad, it will later cause something else to happen which is very bad or clearly wrong" (Sheldon and Wilkinson, 2004b: 534), where – in this case - selecting for tissue type is the 'something' that seems acceptable, and selecting for "eye colour and sex" (Quintavalle in [Pro-life challenge to embryo testing – BBC News, July 12th 2002](#)) which is generally seen as much more problematic. Scientifically, as well as for organisations like the HFEA that must justify and be publicly accountable for their regulation of embryological selection techniques, this type of slope seems slightly far fetched. Anna's other slope however - from cord blood donor, to bone marrow donor, to solid organ donor – seems, both, more realistic, and much closer at hand. *My Sister's Keeper* illustrates just how easy it might be, within a family where one child was born as a donor for another, that consent for incrementally more invasive procedures might be assumed.

Upon consideration of the evidence regarding consent, the HFEA were satisfied that today's systems would provide sufficient protection for tomorrow's Gillick-competent saviour siblings. Given this, *My Sister's Keeper* acts as a warning not to let these standards regarding consent develop in the way they did for Anna. Additionally, this discussion raises another issue: the comparability between donation (of cord blood, bone marrow and/or solid organ) by a saviour sibling and an existing sibling. While the HFEA have generally used this comparison to examine how saviour siblings might be treated, and be affected by the circumstances surrounding their birth, any comparability can also be used to evaluate the bioethical acceptability of their creation. Pennings *et al.* (2002) call this the 'post-natal test'. This method of evaluating whether or not a particular non-therapeutic medical procedure should be carried out suggests that, if it is acceptable to submit an existing minor sibling to that procedure, then creating one for that purposes is no less ethical. In terms of *My Sister's Keeper*, this brings us to Jesse – Anna's brother, and Kate's 'non-saviour' sibling.

With respect to the post-natal test noted above and its implications for the acceptability of Anna's birth, would Jesse's parents have treated him the same way as they treat Anna had he been an allogeneic donor? Sara's statement that "I thought it might be Jesse who could save her. I wanted it to be Jesse" (Picoult, 2004: 65) is revealing concerning how he may have been treated had he been a match for Kate. At this point in the story the Fitzgeralds are

looking for a bone marrow donor for Kate, and Jesse is the obvious first choice: as Dr Chance says “getting a transplant from a stranger who’s a match is much more dangerous than getting one from a relative – the risk of mortality greatly increases” (Picoult, 2004: 61). This is mirrored in reality. Pennings *et al.* note that, while individuals have only two HLA haplotypes – one inherited maternally, and the other paternally, there are “several million HLA types stored in many national ‘Registries’” (2002: 534) and, given this, that the risk of “HLA mismatches are increased...using unrelated donors...and this generally translates into higher incidence of transplant related morbidity and/or mortality” (2002: 535). Given this, it seems highly likely that Jesse, had he been a match, would have been ‘used’ by his parents in much the same way as Anna – as a donor of whatever matched tissue was required to treat her acute promyelocytic leukaemia (APL) and keep her alive. Thus, applying the post-natal test, if we judge that the non-therapeutic procedures carried out on Anna here, would have been ethical if the sibling in question had been Jesse, then this would indicate that Anna’s creation as a saviour sibling was also ethical.

Pennings *et al.* (2002) examine the ethics of carrying out the types of non-therapeutic procedures discussed in *My Sister's Keeper* – ones that may be required of real saviour siblings – on existing, non-saviour siblings. Where the prospective matched donor is an existing sibling, the donation of umbilical cord blood - the first tissue Anna donated to Kate - is not generally considered to be a possibility, though this may change given increasing requests for cord blood banking facilities (see [☞ RCOG advice on Umbilical Cord Blood Banking and Storage – RCOG Press Release, June 13th 2006](#)).

BOX 4:
The Whitaker Family
UK, 2002

The case of the Whitaker family, who applied to the HFEA for a license to carry out PGD for tissue typing in 2002, has frequently been compared to that of the Hashmis, detailed in Box 3 (e.g. Sheldon, 2005; Sheldon and Wilkinson, 2004a). The Whitakers also had a young son, Charlie, suffering from a form of anemia. Their son had Diamond Blackfan anemia (DBA), a condition which, while associated with a genetic mutation, is thought to be sporadic rather than inherited. The Whitaker's son - like the Hashmi's - also had to undergo "painful daylong blood transfusions" (Sheldon and Wilkinson, 2004a: 140) with the best prospect of a cure being a tissue matched stem cell transplant. Having found a clinic that would undertake the IVF and PGD necessary to produce such a saviour for Charlie, they applied for a license, however, the HFEA rejected their application.

The HFEA argued that, unlike in the case of the Hashmis where the PGD served two purposes - screening embryos for genetic disease AND for HLA markers - the Whitakers would be using PGD solely to create a donor for Charlie, as his condition was not deemed hereditary and hence no genetic test existed for it. As Sheldon and Wilkinson note, because of this the HFEA saw these two cases as "relevantly different" (2004a: 141): where the Hashmi's PGD would benefit both the unborn sibling and Zain, the Whitaker's PGD would only benefit Charlie. It was for this reason - that the embryo itself would derive no direct benefit from the PGD - that the Whitaker's application was declined. While they did have a second child naturally during this period their new daughter was not a tissue match for her older brother.

Following this, the Whitakers pursued their objective of a saviour sibling abroad (an example of ‘fertility tourism’ and illustrating the difficulty of legislating within one nation state). In October 2002, they travelled to the same Chicago clinic that had treated the Nash family (see Box 1), and in June 2004 Mrs Whitaker gave birth, in the UK, to their third child Jamie - Charlie's saviour sibling. Stem cells from the new baby's umbilical cord blood were then transplanted into Charlie, a procedure which also seems to have been successful.

However, Pennings *et al.* also note that “in Western countries, the chance of having an HLA-identical sibling is no more than 15%” (2002: 534); that Jesse is not a match for Kate is therefore unsurprising. That Jesse is a ‘non-saviour’ sibling has arguably had an enormous

effect on his own psyche and his engagement with the family. It may serve as a paradigm of the treatment and experience within a family in which a 'saviour' sibling failed to save.

4. The long-term experience of the child

At present, the long-term effects of being born as a saviour sibling are unknown: as the Human Genetics Commission states: "As yet there is little evidence about...situations in which a saviour sibling has been born; the children are still young and very few in number" (HGC, 2006: 50). The ongoing use of such children as donors, in terms of welfare and consent, has been discussed. Here, the ethical questions focus on, firstly, how *being* a saviour sibling affects relationships with other members of the family, and secondly, how *knowing* one is a saviour sibling affects the child's experience of life, and their social and psychological development⁶.

With respect to relationships with other members of the family, consideration of the following two scenarios often dominates ethical discussions. Firstly, the experience of being a saviour sibling in a family where treatment of the sick child is successful, and secondly, the experience of being a saviour sibling in a family where treatment of the sick child is not successful and the sick child dies. To date, however, there has been much less discussion of what the long-term experience of saviour siblings might be in cases like that illustrated by *My Sister's Keeper*; that is, what would be the child's experience of life as a saviour if treatment of their sibling works initially, only to fail at a later date? How would this situation affect the child's relationships with other family members? *My Sister's Keeper* does offer some clues here, though there is little detail in the book regarding how members of the Fitzgerald family related to each other during the periods in which Kate was well, and further, the relationships as we can observe them are structured around Anna's dual status as both, 'saviour', and 'donor'. There are however points at which both Anna, and other characters, reflect upon Anna's overall personality and her role and status within the family. These may be indicative of how saviour siblings may fare in families should the initial cord blood transplant fail. The most significant of these is where Anna, reflecting on her place within the family, thinks – and inadvertently says - "*I'm invisible*" (Picoult, 2004: 52). Anna's statement here – being neither positive, nor wholly negative - is indicative of the way her saviour sibling status seems to structure family relationships throughout the book. This status has had a clear influence on family dynamics, although whether it has specifically altered their 'normal' course in any significant or damaging way remains ambiguous. In their 2004 policy review, HFEA relied on evidence gathered from existing sibling tissue donors and their families to address such a question. This suggested that the extent to which saviour sibling status might negatively affect family relationships might depend greatly on the temperament of the saviour child, the style of family communication and levels of extended family support, though also the parents levels of anxiety (ECL, 2004, annex c: 5).

⁶ The state of *knowing* one is a saviour sibling seems comparable with that of *knowing* one is likely to suffer a genetic disease – knowledge obtained through predictive genetic testing. This is referred to in terms of the 'burden of knowledge' (see [☞ *Burden of knowledge – BioEthics Education Project \(BEEP\)*, last accessed: September 3rd 2007](#)).

In the case of saviour siblings the ‘burden of knowledge’⁷ refers to the experience of a child who knows that they were born (only) to save the life of an older sibling. The presumption here is that the child is indeed told and comprehends the reason for their birth (though this may not necessarily be the case). While some of the sources of concern outlined above seem likely to be the same here, there is the added issue of the extent to which knowing one is a saviour sibling would affect identity. In Anna Fitzgerald’s case it is clear that she both knows and understands the reasons for her birth, and that this *raison d’etre* plays a significant role in her personal identity. This is highlighted clearly in the opening pages of the book where Anna states “they chose little embryonic me, specifically, because I could save my sister Kate... unlike the rest of the free world, I didn’t get here by accident. And if your parents have you for a reason, then that reason better exist. Because once it’s gone, so are you” (Picoult, 2004: 8); and again as she sits watching people in the laundrette: “sometimes...[I]...try to imagine what it would be like to be the person whose clothes are spinning in front of me...and I can’t. All I can ever see is me, being a donor for Kate, each time stretching to the next” (Picoult, 2004: 90)”.

In the first quote above, Anna is apparently referring to what would happen to her if Kate were to die, and though it is not a literal statement, it does suggest how Anna’s knowledge of her saviour sibling status ties her to her sister; a tie that she refers to later in the book: “Kate and I are Siamese twins; you just can’t see the spot where we’re connected” (Picoult, 2004: 90). Picoult also comments on this connection – though also suggests how it may affect Kate in a similar way: “Kate and Anna...aren’t able to separate from each other and grow into distinct individuals” (From [☞ *A conversation with Jodi Picoult about My Sister’s*](#)

[Keeper – jodipicoult.com, accessed July 23rd 2007](#)). This seems an important observation. While discussion in, for example, the regulatory sphere (necessarily) concerns only the ethical implications of knowing one is a saviour, the knowledge that one is the ‘saved’ may also have a long-term impact on a child’s life experience.

BOX 5:

The Fletcher & Mariethoz Families UK, 2005 and 2006

Jodie Fletcher, born in July 2005, has recently been called “Britain’s first “designer” baby” ([☞ *A sibling to be my saviour – The Sunday Times, May 14th 2006*](#)). She is the first saviour sibling to have been both conceived and born in the UK after her parents obtained an HFEA licence to undergo IVF with PGD for HLA typing alone in 2004, following the HFEA’s change to its preimplantation tissue typing policy (see [☞ *HFEA agrees to extend policy on tissue typing – HFEA Press Release, July 21st 2004*](#)). The Fletcher’s son Joshua was born with Diamond Blackfan Anaemia (DBA) – the same condition as Charlie Whitaker (see Box 4). While the Whitaker’s had to go abroad for their treatment, the HFEA’s subsequent review of policy (see Box 1) now allows for the creation of saviour siblings in cases where the existing child’s disease is not genetically inherited.

The HFEA’s decision regarding the Fletchers – and the subsequent success of their treatment – has apparently smoothed the way for other families to undergo similar procedures. For example, the Mariethoz family, whose daughter Charlotte also suffers from DBA, successfully applied for permission to have PGD for HLA typing alone. They are presently undergoing treatment (see [☞ *Couple win right to ‘saviour sibling’ – The Independent, May 5th 2006*](#)).

⁷ The concept of the ‘burden of knowledge’ emerged within bioethics in the mid-1990’s. It is traditionally used to refer to the psychological implications of knowing about one’s genetic inheritance via genetic testing, specifically knowledge of genes associated with diseases a person may suffer in the future – for example, Huntington’s Chorea (see [☞ *Wachbroit, R. \(1996\). “Disowning Knowledge: Issues in Genetic Testing”, Institute for Philosophy and Public Policy, Volume 16, No. 3/4*](#)). However, the state of knowing one is a saviour sibling seems comparable with that of knowing one is likely to suffer a genetic disease, further both are obtained through predictive genetic testing.

Concluding remarks

While there are a number of other ethical issues that are implicit in the creation of saviour siblings, for example the number of cycles of IVF required and the number of non-matched embryos created in this process, this BioethicsBytes Extended Commentary has attempted to draw out and elaborate some of the most pertinent bioethical themes that appear and are explored in Jodi Picoult's 2004 novel *My Sister's Keeper*. It has looked at how theoretical arguments concerning saviour siblings are played out in this realistic, though fictional, family situation, and considers possible insights into how future saviour siblings might be viewed and treated in reality. Given this, and the comparisons made with real social, legal and ethical situations considered by the HFEA, it seems appropriate to end this commentary with a final question; could the scenario depicted in *My Sister's Keeper* ever occur in real life?; Could the saviour siblings noted in boxes 2, 3, 4 and 5 above, really end up in the same situation as Anna Fitzgerald – petitioning their parents for medical emancipation?

While, what seems to Anna to be an ongoing, never ending, cycle of donations, is clearly the reason she brings her court case, the heart of the issue is also whether she should have to donate a kidney to her sister Kate, and this appears to define some kind of dividing line between the events in the book and any that might occur in reality. In the book, Anna seems to be fighting for her right to *refuse* to donate her kidney, whereas current arrangements would seem to place real saviour siblings on the other side of that line. In reality it seems that, in the case of solid organ donation by a minor, a very serious justification would be required to *permit* this procedure to go ahead. Solid, non-regenerative organ donation, seems to be at the very edge of what it would be acceptable to allow a non-competent minor (and in some countries even a competent one) to undergo, and it is certainly not something a matched, non-saviour, sibling would be expected to do. Given that this is a functioning legal prescription as well as an ethical one, this suggests that *My Sister's Keeper* is not a vision of the future that we can expect to see. Legal constraint would prevent the need for court action like Anna's; and the HFEA's case-by-case approach to the licensing of PGD for HLA-typing alone (i.e. where there is no risk the new embryo has a specified genetic disease) makes it unlikely that an application where the expressed intention was to create a matched solid organ donor would be approved.

In this sense, as is discussed above, while it may be ethical to create a saviour sibling with the expressed intention of it being both a cord blood and bone marrow donor, it is not ethical to create a child in order for it to donate solid, non-regenerative, organs – a prospect that raises the spectre of 'spare parts babies' (see [☞ Concern over 'spare parts' babies – BBC News, January 31st 2006](#)) and gives rise to the kind of vision of society depicted in Kazuo Ishiguro's (2005) *Never Let Me Go* (see [☞ Human cloning – Never Let Me Go - BioethicsBytes, August 26th 2006](#)) or *The Island* (see [☞ Therapeutic cloning – The Island - BioethicsBytes, July 24th 2006](#)). This would seem to be another slippery slope, though one against which the HFEA's current arrangements appear to protect us. Thus, even though the scenario in *My Sister's Keeper* is unlikely to occur anytime soon – given the ethical and legal constraints discussed above – a 'technical fix' that might physically prevent the slide down this slope can be derived from the literature.

According to both Pennings *et al.* and the HFEA, transplant of haematopoietic stem cells – such as those derived from umbilical cord blood – requires a lower degree of HLA match than either, bone marrow, or solid organ transplant, to achieve the same success rate. Rocha and Gluckman quantify this, stating that a successful stem cell transplant from umbilical cord

blood can be achieved with “one or two in six HLA mismatches” (2007: 1906), whereas bone marrow transplants typically require an “eight in eight, or ten in ten” (2007: 1906) match. Thus, given a situation where we, as a society, might want to allow a transplant derived from umbilical cord blood, but prohibit bone marrow and/or solid organ transplant (i.e. embarking on Anna’s slippery slope), one might consider the utility of licensing PGD for HLA-typing alone on the express condition that the embryos implanted were matched only to the extent required for successful stem cell transplant. Not only would a lowering of the current threshold for acceptable HLA-matching reduce the number of discarded embryos, and hence the number of cycles of IVF undertaken, but it might also produce a scenario in which an individual might be a suitable donor of cord stem cells, but not adequately matched to be solid organ or bone-marrow donor. As such, they would be *de facto* protected from later pressures to be involved in further donations. In this way, a number of the ethical concerns associated with the creation of saviour siblings would be alleviated and situations such as that depicted in *My Sister's Keeper* would be prevented.

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