

## REPRODUCTION

## Should selecting saviour siblings be banned?

S Sheldon, S Wilkinson

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By using tissue typing in conjunction with preimplantation genetic diagnosis doctors are able to pick a human embryo for implantation which, if all goes well, will become a "saviour sibling", a brother or sister capable of donating life-saving tissue to an existing child. This paper addresses the question of whether this form of selection should be banned and concludes that it should not. Three main prohibitionist arguments are considered and found wanting: (a) the claim that saviour siblings would be treated as commodities; (b) a slippery slope argument, which suggests that this practice will lead to the creation of so-called "designer babies"; and (c) a child welfare argument, according to which saviour siblings will be physically and/or psychologically harmed.

positive arguments for reproductive liberty). This is because banning the use of PGD to create saviour siblings will lead to the death of a number of children who could have been saved by sibling donation. And given that a ban will be fatal for a section of the population, the onus of proof rests clearly with the prohibitionists who must demonstrate that these children's deaths are less terrible than the consequences of allowing this particular use of PGD. As Glover puts it<sup>8</sup>: "You have got to have a very powerful reason to resist the means by which a child's life can be saved."

In what follows, we divide the prohibitionist arguments into three categories. First, there is the idea that saviour siblings would be wrongfully instrumentalised, treated as mere means rather than ends-in-themselves, or treated as commodities. Secondly, there are arguments according to which the creation of saviour siblings would either cause or constitute a move towards the creation of "designer babies". Finally, there are arguments which focus on the welfare of saviour siblings.

## MEANS, ENDS, AND COMMODIFICATION

The idea of deliberately creating a saviour sibling often provokes comments like these:

It is totally unethical. You are not creating a child for itself<sup>9</sup>

We would have very serious concerns that he is a commodity rather than a person<sup>10</sup>

The trouble really is that this child as it grows up has been brought into the world because it is a commodity.<sup>11</sup>

Such comments run together two distinct worries: concerns about people having children for the wrong reasons, on the one hand, and concerns about the way in which the child will be treated by his or her parents, on the other. Thoughts of the second kind are really concerns about the welfare of the resultant child and so we will discuss these in a later section, focusing for the time being on the idea that deliberately conceiving a child is wrong if done for certain kinds of reason. Clearly, conceiving *can* be wrong if done for the wrong reasons. Conceiving a child in order later to eat it or torture it would be uncontentious, if extreme, supporting examples for this principle. The real question then is: Which reasons are the wrong reasons? One answer is that a child should be wanted *for his or her own sake* and not for some other purpose<sup>12</sup>:

Recent high profile cases in Australia,<sup>1</sup> the UK,<sup>2</sup> and the USA<sup>3</sup> have brought to the public's attention a new kind of embryo selection. By using HLA (human leucocyte antigen) typing, popularly known as "tissue typing", in conjunction with preimplantation genetic diagnosis (PGD), doctors are now able to pick an embryo for implantation which, if all goes well, will become a "saviour sibling",<sup>4</sup> a brother or sister capable of donating life-saving tissue to an existing child. In the UK, the most recent case to reach the courts and the newspapers is that of the Hashmis.<sup>5</sup> Their son, Zain, has  $\beta$ -thalassaemia, a blood disorder which could be cured using tissue from the umbilical cord of a sibling, but only if the sibling is a tissue match. The Human Fertilisation and Embryology Authority gave permission for the Hashmis to select a saviour sibling for Zain. This decision was swiftly challenged in the courts, with the UK High Court finding that the selection of a saviour sibling was unlawful.<sup>6</sup> In May 2003, the Court of Appeal overturned this decision, declaring that tissue typing can be authorised under current legislation.<sup>7</sup>

Prior to the recent Court of Appeal ruling, it looked as if this form of preimplantation selection might be prohibited in the UK and our aim in this paper is to assess whether this and similar bans are defensible. Our focus throughout is on cases where doctors plan just to use umbilical cord tissue, as opposed to those in which the use of non-renewable solid organs (such as kidneys) is intended, and we concede from the outset that the latter raise additional objections that (for reasons of space) we do not consider here. We will concentrate on critically assessing the arguments for prohibition (rather than, for example,

See end of article for authors' affiliations

Correspondence to: S Wilkinson, Centre for Professional Ethics, Keele University, ST5 5BG, UK; s.wilkinson@peak.keele.ac.uk

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The commonest objection to this procedure is that it is wrong to bring children into existence “conditionally”. This objection finds its philosophical foundation in Immanuel Kant’s famous dictum, “Never use people as a means but always treat them as an end”.

As an argument against selecting saviour siblings, though, this is defective in at least two ways (as Boyle and Savulescu, quoted above, go on to point out). First, it relies on a misreading of Kant’s “famous dictum”. This does not prohibit treating people as means, but rather prohibits treating them *merely* or *solely* as means. As Harris notes<sup>13</sup>: “We all ... [treat people as means] perfectly innocuously much of the time. In medical contexts, anyone who receives a blood transfusion has used the blood donor as a means to their own ends ...” So there is nothing objectionable about creating a baby as a “means to an end” provided that it is also viewed and treated as a human being.

A second more practical objection to this argument is that it does not adequately distinguish between creating a child as a saviour sibling and creating a child for some other “instrumental” purpose—for example, “completing a family”, being a playmate for an existing child, saving a marriage, delighting prospective grandparents, or providing an heir. Perhaps these things are different from creating a saviour sibling but, if they are, the difference *isn’t* that they are any less “instrumental” for in all these cases, the child is used as a means.

The concern then cannot really be about having a child as a means since people frequently do this and it is not in itself objectionable. What might be objectionable, from the Kantian view, is creating a child *solely* to advance some further end. For example, it would obviously be wrong to create a saviour sibling and then just to discard him or her once it had “served the purpose”. But this is clearly not what is proposed and so, overall, this argument fails, as a purely ethical argument and *a fortiori* as a case for legal prohibition.

## DESIGNER BABIES AND SLIPPERY SLOPES

A second argument against permitting the deliberate creation of saviour siblings is that to do so would be to step onto a slippery slope towards allowing “designer babies”.<sup>5</sup> This argument combines two distinct objections. The general form of the first is that if we allow something to happen which, considered in itself, is either acceptable or only slightly bad, it will later cause something else to happen which is very bad or clearly wrong (this being what is at the bottom of the proverbial slope). So applied to saviour siblings, it says that if we allow the creation of saviour siblings (which is only slightly bad) this will lead to something much worse: the creation of fully-fledged designer babies. As Quintavalle puts it “the new technique is a dangerous first step towards allowing parents to use embryo testing to choose other characteristics of the baby, such as eye colour and sex”.<sup>14</sup>

So the claim is that we will start off by allowing the deliberate creation of saviour siblings and “slide down the slope” towards permitting the selection of embryos on wholly frivolous grounds.

The second version of the slippery slope argument is either a point about consistency or a *reductio ad absurdum*—that is, an attempt to refute a position by showing that it has absurd implications. Lying behind it is the following argument:

- (1) Allowing the selection of saviour siblings isn’t morally different from allowing people to choose “designer” characteristics (for example, hair colour).
- (2) *Therefore*: (from (1)) if we ban one, we should ban the other. Conversely, if we allow one, we should allow the other.

- (3) Allowing people to choose designer characteristics is wrong and should be banned.
- (4) *Therefore*: (from (2) and (3)) allowing the selection of saviour siblings is wrong and should be banned.

This kind of argument can be used in two closely related ways. First, it is asserted that people who oppose designer babies but not saviour siblings are inconsistent and should really oppose both. Secondly, there is an attempted *reductio* of the view that selecting saviour siblings should be permitted: the idea being that this has the (supposedly absurd, or at least unpalatable) implication that selecting embryos with designer characteristics should also be permitted.

The objections to these “slope” arguments fall into three main categories. First, one could reject the premise (shared by both arguments) that allowing people to choose embryos with designer characteristics is wrong. Secondly (specifically in relation to the consequence based argument), one could argue that allowing the selection of saviour siblings won’t, or needn’t, cause us to become “permissive” about designer babies. Finally (specifically in relation to the consistency or *reductio* argument), one could argue that saviour siblings and designer babies are relevantly different and therefore one can oppose the latter and not the former without inconsistency.

Purely for the sake of argument, we will grant that allowing people to choose embryos with designer characteristics is wrong and should be prohibited and move straight onto the second objection.<sup>15</sup> This says that allowing the selection of saviour siblings won’t, or needn’t, cause us to become permissive about designer babies. There are at least three reasons for supporting this objection. The first is that those who propound the empirical slippery slope argument rarely, if ever, support it with any hard evidence. *Merely asserting* that saviour siblings are the “first step towards allowing parents to use embryo testing to choose other characteristics” is inadequate. The second is that it is very easy to envisage how, through careful regulation, a “slide down the slope” might be averted. In particular, there is no reason why selection can’t be allowed for some purposes but not others. Indeed, that is the present position and there is no reason to believe that such a position couldn’t be maintained, if Parliament (or a regulatory body such as the UK’s Human Fertilisation and Embryology Authority) decided that that is what it wanted. So a slide is not inevitable. Thirdly, and finally, there is the fact that to get a fully-fledged designer baby—that is, one in whom numerous traits were selected for—a very large pool of preimplantation embryos would be required from which to select, thus imposing considerable extra cost, discomfort, and inconvenience on would-be “designer parents”, and acting as a deterrent.

The third objection to the slippery slope argument is that saviour siblings and designer babies are morally different, and therefore there is nothing inconsistent about opposing one but not the other. Obviously there is a preliminary complication about what exactly counts as a “designer baby” but, for the sake of argument, let us just stipulate that a designer baby is one selected for his or her superficial characteristics (for example brown eyes, black hair, or tallness). Given this definition, is selecting a saviour sibling relevantly different from selecting a designer baby?

One reason for answering “yes” is the following. In the saviour sibling case, but not in designer babies case, there is a very weighty reason for using PGD—saving an existing child’s life. But the same cannot be said of designer babies because the reasons for choosing a designer baby (insofar as there are reasons at all) are generally trivial—such as a mere fondness for particular hair colour. So the *prima facie* case for permitting saviour sibling selection is much stronger than that for permitting designer baby selection because there are

important reasons for the first but not the second. This constitutes a relevant difference between them and explains why one could without inconsistency oppose the latter but not the former. There is of course much more to be said about how we might in general distinguish important from trivial reasons and we do not claim that this will always be a straightforward matter. But at least in this case the distinction seems relatively clear and unproblematic, for it is hard to deny that saving a child's life is a much more weighty consideration than getting a child with one's preferred hair colour.

We conclude therefore that the slippery slope or designer babies objection fails to justify a ban on the creation of saviour siblings because: (a) even if there is a "slope" there is no reason to believe that a "slide" down it is inevitable and (b) there are important differences between saviour siblings and designer babies which the slippery slope argument overlooks.

### THE WELFARE OF THE CHILD

Finally, those who oppose the deliberate creation of saviour siblings often make claims about the welfare of those children who will be thus created. These claims are based on a widely held moral belief (one enshrined in English Law) that, when making decisions about the use of reproductive technologies, we are under an obligation to take into account the welfare of any child created.<sup>16</sup>

The fundamental empirical premise of the child welfare argument is that saviour siblings will, on average, have worse lives than either (a) children conceived "naturally" or (b) other children created using PGD. The second comparator, (b), is of particular relevance if what is argued is that there is nothing wrong with PGD per se but that its use in this context is wrong. Given that the use of PGD for other purposes (that is, screening for a variety of genetic disorders) has been widely accepted, it seems appropriate to take the latter as our main focus.

Two types of damage are suggested by the proponents of the child welfare objection: harm to physical health caused directly by the PGD process and psychological harm. Let's start with physical health. Given that we are considering only the use of umbilical cord stem cells, any physical health problems for the saviour sibling must be caused by the PGD process itself (since no postnatal intervention using the child is envisaged). Is PGD physically harmful to the child thus selected? A recent editorial in *The Lancet* suggests that "embryo biopsy for PGD does not seem to produce adverse physical effects in the short term, but it is too early to exclude the possibility of later effects".<sup>17</sup> What we *can* say though is that, as far as direct effects on physical health are concerned, there is no reason to think that saviour siblings will be any worse off than other children created using PGD. So a child welfare argument based on physical health considerations will either simply fail (because the evidence of harm is inadequate) or will prove too much, counting not only against the creation of saviour siblings but against *all* uses of PGD. Either way, the argument doesn't successfully single out saviour sibling selection for especially restrictive treatment.

An obvious response to this is to claim that a future child should be exposed to the risks of PGD only if she will probably derive enough benefits to outweigh those risks—a view that we will call the *net benefit principle*. On this view, the potential person is rather like an existing patient and doctors should expose her to risk only if, on the balance of probabilities, she will be a net beneficiary. If this principle is accepted, then (it is argued) there is an important difference between using PGD to select a saviour sibling and using it to screen for a serious genetic disorder since only

the latter procedure benefits the child created, and so only the latter can be ethically acceptable.

However, this net benefit argument relies on some confused thinking about what it means to "benefit an embryo". It appears to depend on something like the following model. When we screen for a disorder, an embryo (D) is subjected to an intervention (T) which has the following effects:

- (1) T prevents D from having a serious genetic disorder.
- (2) T involves as yet unknown long term health risks for D.

So subjecting D to T can (according to this model) be justified solely by reference to D's interests because the benefit of (1) outweighs the harm or risk involved in (2). In saviour sibling cases, however, things seem importantly different. For an embryo (S) is subjected to an intervention (T\*) with the following effects:

- (1) T\* will make S (more likely to be) a donor for an existing child.
- (2) T\* involves as yet unknown long term health risks for S.

T\* cannot be justified by reference to S's interests since there is no benefit for S and some risk and so, if we accept the net benefit principle, inflicting T\* on S is wrong. This then provides the (supposed) ethical basis for allowing pre-implantation screening for genetic disorders, while not allowing saviour sibling selection—namely, that only the former conforms to the net benefit principle.

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

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

This style of argument raises a number of thorny philosophical problems which we cannot explore in any depth here. One obvious difficulty, for example, is the question of whether it really makes sense to say of an individual that they were benefited by events that caused them to exist. But there are more practical and more decisive objections too. The most relevant for our purposes is that the argument just outlined applies equally to screening for genetic disorders and saviour sibling selection. For if the relevant benefit is being caused to exist (rather than being cured of a genetic disorder) then clearly both D and S stand to gain more or less equally in this respect—since both are caused to exist by the selection process and probably would not have existed without it. And furthermore this will apply (again, more or less equally) to *all* selected embryos, except in those few cases where the life in question is so bad that it is "not worth living". So the net benefit principle (even if true) fails to justify drawing a moral distinction between screening for genetic disorders and saviour sibling selection.

We turn now to the idea that saviour siblings will be psychologically scarred. There seem to be two linked but

analytically separate concerns here: first, that a future child may suffer psychological harm if she finds out that she were wanted not for herself, but as a means to save the life of a sibling; and second, that a child conceived for this reason is likely to enjoy a less close and loving relationship with its parents who are less likely to value and nurture the child given that they wanted it primarily to save the life of the sibling.<sup>18</sup> However, even if we concede for the sake of argument that it would be hurtful or upsetting for a specially selected sibling (A) to discover that she had been conceived for the primary purpose of saving the life of an existing child (B), it seems unlikely that A would be *less* happy than another, randomly selected sibling (C) who was unable to act as a tissue donor. For it could surely be argued here that A would benefit from B's company and may well derive pleasure from knowing that<sup>21</sup> he has saved B's life. Furthermore, as Robertson *et al* point out:

the fact that the parents are willing to conceive another child to protect the first suggests that they are highly committed to the well-being of their children, and that they will value the second child for its own sake as well.

In contrast, imagine the psychological impact on C, born into a bereaved family and later to discover that she was a huge disappointment to her parents because of her inability to save B's life. Of course, a full consideration of the issue of psychological harm would involve marshalling substantial bodies of empirical evidence (not something that we can do here). But while this discussion remains entirely speculative, we can at least say that it is far from obvious that considerations of child welfare should count against, rather than for, the practice of saviour sibling selection.

Next, we want to look at a more philosophical response to the child welfare argument and ask: If it were established that saviour siblings were (on average) less happy than other children, would this fact be sufficient to justify banning the selection of saviour siblings?

We need to start by making a general distinction between two kinds of policy. First, there are "make people happier" policies; these aim to make actual (present or future) people happier than they otherwise would be.<sup>20</sup> Secondly, there are "prevent unhappy people" policies, which aim to prevent unhappy people from coming into existence. Make people happier policies are ubiquitous. Prevent unhappy people policies, on the other hand, are much rarer and often highly controversial because they are seen as "eugenic". An example of a prevent unhappy people policy would be encouraging the termination of fetuses with severe physical impairments (or at least this is one possible rationale for such a policy).<sup>21</sup>

Within this category (prevent unhappy people policies) a further distinction can be drawn. First, there are policies that aim to prevent the creation of A so that B (who will be more happy than A would have been) can be created instead. B, in a manner of speaking, takes A's place. Kuhse and Singer provide what seems to be a clear example of this way of thinking (emphasis added)<sup>22</sup>:

If the test shows that the foetus does have Down's syndrome, the woman is able to have an abortion. The same happens with women who are shown to be carriers of the gene for haemophilia: the foetus can be checked to see if it has the disease. If it does, the woman can have an abortion, and then try again, so that she can have a normal baby. Why do we regard this as a reasonable thing to do, even when the handicap is one like haemophilia, which is quite compatible with a worthwhile life? ... [Because] we are offsetting the loss of one possible

*life against the creation of another life with better prospects.*

Secondly, there are policies that simply aim to prevent the creation of A (without any appeal to "substitution")—the thought being that, if A were to be born, she'd have a not merely low, but a *negative* quality of life, one such that she'd be "better off dead". As Glover puts it<sup>23</sup>:

some kinds of life are perhaps worse than not being alive at all ... if it makes sense for people to see death as in their interests, there seems a parallel possibility of parents or doctors thinking that not being born may be in the interests of a potential child.

Many regulations governing reproduction are of the "make people happier" kind. Other legislation, though, is not about making actual children happier but is, rather, about reducing the number of "disadvantaged" children born—either directly, through prohibition, or indirectly, through measures which are calculated to discourage. Such legislation clearly falls into the "prevent unhappy people" category. But can child welfare considerations justify such restrictions?

These restrictions could be defended in one (or both) of two ways. The first justification is that they lead to the "replacement" of less happy future people with more happy ones. The second is that they prevent misery and suffering by stopping the births of people with "negative quality lives". Let's take the second justification first. This is extremely unlikely to work against saviour sibling selection, even if any children created face very severe psychological problems. For, in the absence of other unconnected problems (for example severe painful illness) the chances of saviour siblings having *negative* quality lives are remote. Are we *really* expected to believe that these children will live lives that are worse than not being alive at all? Also relevant here are thoughts about how our attitudes to saviour siblings cohere with our attitudes to children with disabilities. For in the debate about prenatal screening, selective termination, eugenics and suchlike, the thought that people with severe and painful disabilities are "glad to be alive" is (rightly) taken seriously. If we allow (as we should) that these people, faced with extraordinarily unfavourable circumstances, have lives worth living, then surely we must also allow that most saviour siblings will have lives worth living too.

So proponents of restrictive regulation are forced to fall back on the first justification: selecting saviour siblings should be banned because this will lead to the children who would otherwise have been created in this way being "replaced" by a roughly equal number of other "happier" children (children who would not have existed at all if saviour sibling selection had been allowed). This, though, is problematic because there are general theoretical reasons for not allowing *any* arguments of this sort (replacement arguments) to influence the regulation of reproduction. The main one is that if arguments of this type are acceptable, then there seems no reason to restrict their application to particular practices like saviour sibling selection. Once we start thinking in this way, it is hard to limit the scope of such arguments because, as Glover suggests<sup>24</sup>:

If someone with a handicap is conceived instead of a normal person, things turn out less well than they might have done. It would have been better if the normal person had been conceived. But things of this sort can be said about almost any of us. If my own conception was an alternative to the conception of someone just like me

except more intelligent, or more athletic or more musical, it would have been better if that person had been conceived.

This has troubling implications. The main one is that *if* a replacement argument is deemed sufficient to justify prohibiting saviour sibling selection then (other things being equal) parallel arguments should, for reasons of consistency, be deemed sufficient to justify (amongst other things) making compulsory the use of prenatal screening or PGD so as to reduce the amount of disease in the world, and making women impregnate themselves with enhanced donor sperm rather than the “normal” sperm of their partners. The replacement justification of these coercive state actions would be fundamentally the same as the one lying behind the prohibition of saviour sibling selection—that is, people’s procreative autonomy would be restricted on the grounds that it would be better if a “happier” group of future persons came into existence instead of a “less happy” group.<sup>25</sup>

Our contention is not that all of these practices are exactly the same; they are not. But we would argue that there is something troubling about allowing this style of reasoning to underpin restrictions on procreative liberty. We would be the first to admit that this argument needs much more fleshing out (not something there is space to do here). However, what is clear, even from this short version is that there is something problematic about using replacement arguments to justify coercive state action. Hence, this justificatory strategy is not one on which prohibitionists should rely.

## CONCLUSION

In this paper, we have critically assessed the three main arguments for prohibiting the use of PGD and tissue typing to select saviour siblings. These arguments are (a) that saviour siblings would be wrongfully treated as means rather than ends, (b) that they would cause or constitute a slide towards designer babies, and (c) that they would suffer physically and/or emotionally. We have found each of these arguments to be flawed and therefore conclude that the selection of saviour siblings should be permitted, especially given that prohibiting it would result in the preventable deaths of a number of existing children.

### Authors’ affiliations

S Sheldon, Department of Law, Keele University, UK

S Wilkinson, Centre for Professional Ethics, Keele University, UK

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- 14 Attributed to Josephine Quintavalle by BBC News. Pro-life challenge to embryo testing, 12 July 2002, <http://news.bbc.co.uk/1/hi/health/2125482.stm>.
- 15 This is partly because contesting this would take us too far from the issue at hand and into very complex territory, and partly because we don’t need to contest it to undermine the slippery slope argument.
- 16 Under s. 13, Human Fertilisation and Embryology Act 1990, we are directed that: “A woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for a father), and of any other child who may be affected by the birth.” It should be noted here that this section also explicitly invites us to consider the welfare of existing children. Whilst it is probable that the architects of the 1990 Act were thinking here of the prevention of harm rather than the according of benefits to existing children, the wording of the law is clearly broad enough also to include the latter. This was recognised by the Court of Appeal in its consideration of the Hashmi case, see the judgment of Mance LJ at 133.
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- 18 This possibility was specifically denied by both the Hashmis and the Whitakers, who claimed that they wanted another child in any case.
- 19 These kinds of arguments are routinely advanced by the courts in allowing parents to consent to allow one sibling to act as a donor to another. Such donation is held to be in the donor’s best interests, notwithstanding the pain and physical risks associated with the procedure, because of the donor’s interest in a continued relationship with his or her sibling. *Strunk v Strunk* (1969) 445 SW 2d 145 (Ky CA).
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