

Having One Child to Save Another: A Tale of Two Families

David Wasserman

An Insupportable Distinction

Zain Hashimi and Charlie Whitaker are two young boys afflicted with painful, life-threatening blood diseases. Zain has beta thalassemia; Charlie, Diamond-Blackfan anemia. Both conditions can be effectively treated only with compatible tissue from a donor who does not have the disease. Neither child could find a compatible donor; the only alternative source for such tissue was the umbilical (or other) blood of a newborn sibling. Zain's and Charlie's parents, who claimed to want larger families in any case, both sought to have another child right away to supply that blood. To be sure of bearing a child with compatible tissue, the mother would either have to endure a succession of pregnancies, testing each fetus until a compatible one was found, or do a single embryo screening, undergoing *in vitro* fertilization (IVF) and selecting, by pre-implantation genetic diagnosis (PGD), one or more compatible embryos for implantation. Because both

Whitaker—Diamond-Blackfan syndrome—is not genetically transmitted, so that his parents' embryos would require screening only for compatibility.

The question, of course, is why this difference should have dictated opposing results in the two cases. The explanation given by the HFEA's chair was that the child who developed from the embryo in the Hashimi case would benefit from the screening, while the child who developed from the embryo in the Whitaker case would not. And because the latter child would not benefit, the parents "would be creating a child to serve somebody else's needs." This distinction, I will argue, cannot bear the weight that was placed on it. But its collapse merely exposes the difficult question about what counts as an acceptable reason for having a child. I will not venture an answer to that question, but I will argue that its very difficulty weighs against any attempt to condition the state's provision of reproductive assistance on parental reasons or motives.

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families lived in the UK, they needed authorization for these procedures from the Human Fertilization and Embryology Authority (HFEA).

It is here that the families' stories diverged. The HFEA granted the Hashimis permission to proceed, and in a later decision denied permission to the Whitakers. A single difference between the two cases was adduced to justify these divergent results: the disease that afflicts Zain Hashimi—thalassemia—is genetically transmitted, so that his parents' embryos would have to be screened for the disease gene as well as for tissue compatibility. The disease that afflicts Charlie

Who Benefits from Pre-implantation Health Screening?

As a bit of reflection should make clear, the children sought by the Whitakers as well as the Hashimis would have benefited from PGD in one sense but not another. Those children would have received the benefit of gestation and birth; they would not have received any other benefit from the screening, such as better health. It is true that the Hashimis would be selecting a healthier as well as more compatible child, and health can be regarded as a benefit for the child who has it. But it is not a benefit that the future child would have received from the screening process. His health would not be improved by that screening, as it might have been, for example, by screening to assess the need for prenatal therapy. Screening for health benefits the future child only in causing the embryo from which he develops, rather than some other embryo, to be selected for implantation, precisely the same benefit

that the future child in the Whitaker case would have received from screening for compatibility alone. In terms of any benefit to the future child, then, it makes no difference if the screening were for health, compatibility, or both.

The HFEA was not alone in its confusion about benefit. An editorial in the *New Scientist* on the Whitaker case claimed that health screening “would benefit the unborn child”; it interpreted the UK’s Human Fertilization and Embryology Act as holding that “the unborn child itself must be at risk of inheriting the condition” to permit PGD. This language was also used in the *Guardian*, which stated that “the Hashimi baby would have been at risk of the condition that his brother could die from—thalassemia. . . .” But no child was “at risk”—a child would either have the disease gene or not. It was, rather, the parents who were at risk of having a child with that disease—a critical distinction in claiming a benefit for the child.

Widespread as it appears to have been, the claim that the child in the Hashimi case would benefit from the health screening overlooks what is known as the non-identity problem, raised by philosophers Robert Adams and Derek Parfit thirty years ago. The problem—paraphrased to avoid philosophical controversy about the identity conditions for a future child—is that a person with a worthwhile life appears to lack any ground for complaining about harms without which her existence or birth would have been impossible or, at least, unlikely. Parents who have a child with a genetic disease when they could instead have had a *different* child without that disease may act wrongly, but they do not appear to wrong the child they have, as long as she has a life worth living. Similarly, a child with genetic immunity to a given disease appears to have no reason to thank her parents for that “benefit,” as opposed to her mere existence or birth, if her existence or birth would have been impossible or unlikely without that benefit.

In the context of PGD, the problem of non-identity is stark. A child who develops from an embryo selected

because it lacks a disease gene has no obvious reason to thank her parents for her health, as opposed to her gestation and birth, since she would almost certainly not have been selected for gestation and birth if she had that gene. The “normal” gene she carries, and the better health prospects it yields, are not an additional benefit her parents conferred on her, but a benefit resulting solely from her parents’ decision to select a healthy embryo.

Admittedly, there are other differences between the two cases. The Hashimis would have had reason to utilize IVF and PGD regardless of the needs of an existing child. If they wanted to avoid the birth of another child with thalassemia, they might have been willing to incur the expense, discomfort, and uncertainty of IVF. The Whitakers, in contrast, had no reason apart from the needs of an existing child to choose IVF and PGD. But what can we make of this difference? Arguably, only the parents are made worse off by the utilization

of IVF—the embryos discarded, frozen, or miscarried are entities that almost certainly would not have existed *unless* IVF had been undertaken, and it is hard to claim that they would be harmed by their insensate existence.

Given the manifest inadequacy of the HFEA’s distinction between the two cases, it is tempting to conclude that it had adopted a pretextual rationale to reduce controversy, and to staunch the flow of requests for PGD from desperate parents seeking a compatible donor for an ailing child. Several commentators and politicians denounced the HFEA’s action in the Hashimi case, and the media described the children who resulted from compatibility-screening as “designer babies.” Yet within several months of the Hashimi decision, six other sets of parents applied for permission to use PGD to obtain compatible tissue. The Whitakers were one of those six, and in rejecting their request, the HFEA may well have been trying to limit the precedential and practical impact of its decision in the Hashimi case. The decision in the Whitaker



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case was circumvented when the Whitakers produced a compatible embryo at a private clinic in the United States, which does not require government approval for PGD. The decision in the Hashimi case was reversed by Britain's High Court for exceeding the HFEA's statutory authority, then reinstated on appeal. It remains to be seen if the Hashimis will be as successful in producing a compatible donor with HFEA approval as the Whitakers were without it.

"Good" Reasons to Have a Child?

Whether or not British law authorizes the use of PGD to save Zain Hashimi or Charlie Whitaker, the difficult question remains of whether it is morally acceptable to create a child to serve as a donor in *either* of these cases, or in any case. In all such cases, the timing of embryos' conception, as well as the criteria for selecting some of them for implantation, are dictated by the medical needs of another individual: an ailing sibling. Wouldn't the parents in all such cases therefore be seeking to create a child "to serve somebody else's needs," and isn't that objectionable?

This question is troubling in part because it is by no means clear what would count as a good or acceptable reason for having a child. One philosopher has asserted that, "we never have children for their own sake." He appears to assume that in order to do something for someone's sake, we must already have some attachment to, or at least acquaintance with, that individual of a sort that a prospective parent cannot have toward an unconceived child or an unimplanted embryo. But even if we cannot create a child for its own sake, we need not create children "to serve somebody else's needs"—at least if we understand "needs" in a restricted sense that excludes the mere *desire* to have a child. To act on that desire—to have a child to love and nurture—seems like a quintessentially good reason for having a child.

But perhaps we should resist the claim that it is wrong to have a child to serve, at least in part, someone else's needs. Just because it is difficult, if not impossible, to have a child for its own sake, there may be some needs that can legitimately motivate the creation of a child. Or perhaps almost any need will do. As Mr. Whitaker remarked, "people have children for all sorts of reasons . . . to look after them in old age, for passing on the family fortune. . . . Teenagers have babies in this country to get a subsidized flat. Why would they think we wouldn't love this child as much as any other?" A philosopher inclined to set a high standard for reproductive motivation could respond that good can often arise from a wrongful act, and that being a loving parent does not erase the wrong of having a child for a bad reason. But that would miss part of Mr. Whitaker's point. Just because love arises so

predictably and effortlessly from procreative acts done for the flimsiest of reasons, it is absurd to be so fastidious about those reasons.

So it may be simplistic to condemn the creation of a child to serve someone else's needs. But creating a child for certain reasons, or to serve certain needs, leaves a lot of people very queasy, and having a child to supply life-saving cells for an existing child is one such reason. Part of the queasiness may arise from a sense that if parents are permitted to create a child to "donate" life-saving umbilical blood or bone-marrow, they will be permitted to create a child to "donate" organs, perhaps even vital ones. But such misgivings are easily allayed. We can agree that it would be wrong to use an existing child, too young to consent, as a source of organs for others, and wrong to conceive a child for that purpose. The Hashimis and the Whitakers sought no such wholesale sacrifice from the new child for the old, however, and the sacrifices they did seek are ones that most of us would find acceptable to impose on an already-existing child to save a sibling. I suspect that few people who feel queasy about creating a child for its

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umbilical blood would object to the extraction of such blood from a newborn baby to save an older sibling, if that baby was conceived for other reasons. Conversely, most people would object to an organ "donation" from that baby, regardless of the reasons he was conceived. A number of lines can be drawn between acceptable and unacceptable sacrifices, and any such line can block a descent from the use of a child for a one-time blood donation to the use of a child as an organ bank. The same lines could be drawn to protect the future child from excessive sacrifices for his *parents' needs*—a concern raised by some commentators.

The Ethics of Imposed Sacrifice

The objection to having one child to save another may, however, go deeper than speculative anxieties about the exploitation of children conceived for that purpose. The source of these deeper misgivings is not the magnitude or duration of the sacrifice that may be required of the new arrival, but the fact that *that sacrifice is the sole or dominant reason* for having a child at that time. There are many chores, duties, and burdens which may be reasonably imposed on existing children, especially in exigent circumstances, but which would be unacceptable as the

exclusive reasons for creating a child. Thus, for example, an older single parent might expect her 10-year boy to help with her routine medical care, but the parent would have acted wrongly if the child had been conceived exclusively for that purpose. Similarly, the acceptability of taking umbilical blood from an existing child to save another does not imply the acceptability of having a child for that purpose.

Those opposed to having one child to save another could argue that even if we cannot create a child for his own sake, we must create him for reasons that include his own good. They could further claim that many of the reasons why children are typically created, such as

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those mentioned by Mr. Whitaker, *do* include the good of the future child. This is most obvious for parents who have a child “for passing on the family fortune.” Unless the parents’ desire is only to disinherit someone else, such as a hated brother, the stewardship of the family fortune is a good for the child they are creating, and may provide an adequate reason for creating him. Even the teenager who has a child “to get a subsidized flat” may be acting on a vision of the future, however unrealistic, that includes the good of the child she will raise in that flat. Something similar could be said for rural parents who have children in part to work their farms, or to look after them in old age. What motivates them is not simply the service the child would provide them, but a conception of family life in which successive generations till the same earth, with each generation caring for, then cared for by, the next.

But, the argument would continue, we do not need to look to urban teenagers or rural families to make the point. Take the familiar, not-at-all hypothetical case of parents who have a second child because they believe that it would be bad for the first child to be an only child—that his childhood and development will be impoverished without a sibling. This belief may be mistaken, but many parents seem to act on it, and we do not think that they act wrongly in doing so. Their action is informed by the vision of a larger family, in which the first child will be good for the second in much the same way that the second will be good for the first. Because of this inherent reciprocity, such parents can be said to create the younger child for reasons that include his own good.

In contrast, a child conceived to provide an older sibling with blood seems to be initially cast in a less

symmetrical, more servile role. The likelihood that he will play that role only briefly does not justify his conception to play that role. What is objectionable is not the kind of sacrifice demanded of the future child, but rather the preponderant role of that sacrifice in motivating his creation. It is the urgency of the ailing sibling’s needs, and the strength of the parents’ motivation to satisfy them, that distinguish such a case from more familiar ones where the good of an existing sibling motivates not only the decision to have an additional child but the decision to have it at a particular time. Parents who wait three or four years between children to mitigate sibling jealousy may be acting primarily for the good of existing children, but they also want the new arrival to have a more welcoming environment. The asymmetry between concern for the welfare of the existing and future child is much greater in the cases at hand. The good the latter will enjoy as a cherished member of the family looks like an afterthought, not a reason or motive for his creation, which seems to be based entirely on another’s needs. The principle that condemns his creation is not based on the extent of sacrifice involved or threatened, but rather on the degree to which his creation is subservient to the needs of another, and on the absence of his own good as part of the reason for his creation.

This is still not a clear standard for assessing parental motivation, because it invokes two concerns: 1) the degree of subservience to the needs of another, and 2) the absence of the child’s own good as part of the reason for his creation. The relationship between these two concerns, and their relative importance, need to be worked out. While I suspect that a fully-articulated standard along these lines would still be too demanding or fastidious, I am willing to accept it for argument’s sake, because I want to revisit the issue of whether it suggests a morally significant distinction between the two cases decided by the HFEA.

Hypothetical Cases and Actual Motivation

We can probe the role played by this sense of excessive subservience to the needs of another by varying the extent to which the future child is a creature (so to speak) of the existing child’s needs. Consider a case in which the parents of a child with a chronic, degenerative disease, aware the risk of genetic transmission but not the prospect of a life-saving transfusion, decide to have another child, and want to assure that it does not have the same disease as its older sibling. They want this second child for a variety of reasons, some of which include his own good more clearly than others: to love, cherish, and raise; but also to confer a partial sense of normality on the family, and perhaps to aid in the care of the ailing sibling as they grow older. The mother undergoes IVF, and screens the embryos for the disease gene, finding

five or six that lack it. At that point, the doctors tell the parents about the prospect of a transfusion for their existing child, and invite them to screen the “healthy” embryos for tissue compatibility. They do so.

Here, it could be said that while they did not choose to have a child merely to serve somebody else’s needs, they chose to have *this* child for that purpose. Is their course of action any less problematic than the Hashimis’? The child in this case would not have been conceived, but merely *selected* for implantation, solely “to serve somebody else’s needs.” (One can also imagine cases falling between the hypothetical and actual cases in this respect, e.g., the parents have decided to try having another child in a year, then, after an older child is diagnosed with the disease, start trying right away.) That may be enough to satisfy some, if not all, of those who opposed the parents’ actions in the Hashimi or Whitaker case.

Those cases look far more like each other than either does to the hypothetical case. It is only in the hypothetical case that the decision to have a child at present would not be dictated by the needs of another child, and the embryos would not be subject to health screening to serve the needs of that child. In contrast,

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the only relevant difference between the Hashimi and Whitaker cases is that the Hashimis intended to screen twice, first for health, then for compatibility, while the Whitakers intended to screen only once. Does this matter morally? As I argued earlier, it is difficult to claim that the Hashimis would have undergone the health screening out of concern for the welfare of the future child, since the screening could only select a healthy child, not make a child healthier. Nevertheless, that screening might not have been done solely to serve somebody else’s needs. Is the fact that health is a good for a child, and that it might well be part of the Hashimis’ reason for health screening to have a child that enjoys this good, enough to claim that the Hashimis but not the Whitakers would have selected a future child for reasons that include his own good?

The Hashimi’s own response to two unscreened pregnancies intended to produce a donor for Zain suggest that they were concerned with the good of their future as well as their existing child. When their first attempt yielded a healthy but incompatible fetus, they

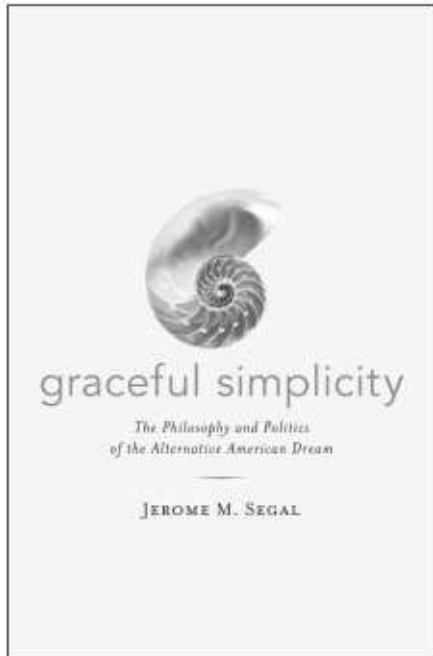
declined the doctor’s offer to “book a termination.” Ms. Hashimi later explained that “we love Harris for his own sake.” They did abort a second fetus, which, like Zain, had the gene for thalassemia, perhaps wishing to spare themselves, their family, and their future child the hardships associated with that disease. But these are decisions that the Whitakers could also have made if they had proceeded in the same way. More important, the Hashimis’ concern for the actual fetuses they produced do not resolve the uncertainty about their initial reasons for producing them.

We remain uncertain about those reasons, because of the mixed motives with which the Hashimis would have undertaken a health screening. We can tease apart those motives by imagining a case where the health of the future child is irrelevant to his adequacy as a donor—e.g., the parents are at risk of transmitting one disease, but the existing child suffers from another, non-transmissible one. Here, the health screening would clearly not be for the sake of the existing child, even if could not be said to be for the sake of the future one. We could even imagine that the healthier embryos would not make the best donors. If the parents were willing to sacrifice some compatibility for some health, their creation of a future child would not be entirely subservient to the needs of an existing child, though they could not be said to be acting for the sake of a future child. But could they be said to be acting for reasons that include the good of that future child, and if so, couldn’t this be true to a lesser extent in the Hashimi case?

An affirmative answer is suggested by considering a case where the parents are not willing to make any tradeoff between health and compatibility: they choose a highly compatible embryo likely to develop into a sickly child, with chronic, painful, but non-life threatening afflictions, instead of a marginally less compatible embryo likely to be very healthy. The sickly child resulting from their choice might well feel resentment (to use philosopher Joel Feinberg’s term), not because his parents made him sickly—they could not have made him any other way—but because they were indifferent to the health of their future child, a child who turned out to be him. The parents could not claim in their defense, as they could if they had declined to abort a child with the same genetic predisposition to ill-health, that they loved him despite those predispositions, and were unwilling to have a different child instead. At the time they made their decision, “he” was merely one candidate for implantation, and they chose him only for the compatibility of his tissue with that of an existing, ailing sibling. His good was no part of their reason for having him. In contrast, if the parents had been willing to choose the marginally less compatible embryo so that their next child would be healthy, it could be argued that their reasons for having that child included his own good.

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Even without the tradeoff between health and compatibility in this hypothetical case, it would seem that parents who chose a healthier embryo among equally compatible ones would be choosing that embryo for reasons that included the good of the child from whom it would develop. We can compare their choice to a choice among adult candidates for life-saving treatment. Those who believe that choosing an embryo on the basis of expected health is choosing for reasons that include the good of the future child could argue as follows: choosing an adult for life-extending treatment on the basis of expected health or longevity—as opposed, say, to expected productivity—would be choosing for

No one should be permitted to create a child to serve as an organ bank for existing siblings, or to sell to a laboratory for medical research. But the state should not deny a person the technological means to create a child, or to screen embryos, just because the dominant motive for doing so may be to preserve the life or health of an existing person.

reasons that included his own good. Like the healthiest adult candidate, the child who would develop from the embryo with the best health prospects would receive a greater benefit from being chosen than the other candidates would, so his selection would be made for reasons that included his own good.

Still, a critic might deny that in *any* case where the embryos were created to make a tissue donor for an ailing child, they were created for reasons that included the good of the future child. Inverting the description I gave of the first hypothetical, the critic might say that even though the parents would not choose to have *this* child merely to serve someone else's need—indeed, even if they would choose *this* child for reasons that included its own good—they would choose to have *a* child merely to serve someone else's needs, not for reasons that included the good of the child they created. Moreover, in the actual case, the Hashimis would have chosen *this* child partly, and maybe preponderantly, for reasons other than the good of that child, since an embryo with thalassemia would not make a suitable donor for their existing child, however compatible its tissue. As noted earlier, their motives for health screening would be inextricably mixed.

Conclusion

The difficulty of deciding what count as acceptable reasons or motives for having children compounds the difficulty of determining what parents' motives actu-

ally are. If parents themselves are often uncertain, confused, or self-deceived about their reasons for such critical decisions, how can the institutions that attempt to regulate their conduct hope to achieve a tolerable degree of certainty? These difficulties make clear that the state lacks both the knowledge and the moral authority to regulate the use of reproductive technology on the basis of parental motivation. For these reasons, the state should allow prospective parents the use of any safe reproductive technology so long as they have not established plans for their future children inconsistent with their responsibilities to protect, nurture and respect them. No one should be permitted to create a child to serve as an organ bank for existing siblings, or to sell to a laboratory for medical research. But the state should not deny a person the technological means to create a child, or to screen embryos, just because the dominant motive for doing so may be to preserve the life or health of an existing person.

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Sources: Aaron Zitner, "A Matter of Life, Ethics," *Los Angeles Times* (October 29, 2002); Human Fertilization and Embryology Authority, "HFEA to Allow Tissue Typing in Conjunction with Preimplantation Genetic Diagnosis," Press Release (December 13, 2001); Human Fertilization and Embryology Authority, "HFEA Confirms that HLA Tissue Typing May Only Take Place When Preimplantation Genetic Diagnosis Is Required to Avoid a Serious Genetic Disorder," Press Release (August 1, 2002); Tom Whitehead, "US Experts Question 'Designer Baby' Ban," *Press Association* (August 2, 2002); Editorial, "A Tale of Two Youngsters; Two Boys, Two Diseases. One Will Be Treated, One Won't. Why?" *New Scientist* (August 10, 2002); Sarah Boseley, "Women: A Matter of Life and Death," *Guardian* (September 6, 2002); Robert Adams, "Must God Create the Best?," *Philosophical Review*, vol. 81 (1972); Derek Parfit: *Reasons and Persons* (Clarendon Press, 1984); David Benatar, "Why It Is Better Never To Come Into Existence," *American Philosophical Quarterly*, vol. 34 (1997); Anthony Brown, "Six Couples Seek 'Ethical' Designer Babies," *Observer* (February 24, 2002); Margarette Driscoll, "Only Forbidden Science Can Save Our Son," *London Times* (April 6, 2003); Clare Dyer, "All We Wanted Was to Save Our Son: Zain Hashimi Could Be Cured by Blood from a New Sibling—But the Law Lags Behind Reproductive Technology," *Guardian* (January 14, 2003); Lois Terry, Anne Campbell, "Case Study: The Child that Might Be Born . . .," *Hastings Center Report* (May-June, 2002); Ethics Briefings, "Born to Be A Donor," *Journal of Medical Ethics*, vol. 27 (2002); Joel Feinberg, "Wrongful Life and the Counterfactual Element in Harming," *Social Philosophy & Policy*, vol. 4 (1982). Nancy Jecker, "Conceiving a Child to Save a Child: Reproductive and Filial Ethics," in *Morals, Marriage, and Parenthood: An Introduction to Family Ethics*, edited by Laurence D. Houlgate (Wadsworth, 1999).

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Robert K. Fullinwider, editor

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