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The Best Possible Child

Author(s): Michael Parker

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## REPRODUCTIVE ETHICS

## The best possible child

Michael Parker

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Julian Savulescu argues for two principles of reproductive ethics: reproductive autonomy and procreative beneficence, where the principle of procreative beneficence is conceptualised in terms of a duty to have the child, of the possible children that could be had, who will have the best opportunity of the best life. Were it to be accepted, this principle would have significant implications for the ethics of reproductive choice and, in particular, for the use of prenatal testing and other reproductive technologies for the avoidance of disability, and for enhancement. In this paper, it is argued that this principle should be rejected, and it is concluded that while potential parents do have important obligations in relation to the foreseeable lives of their future children, these obligations are not best captured in terms of a duty to have the child with the best opportunity of the best life.

The place where no harm can come is the place where nothing at all can come.<sup>1</sup>

In 2001, Sharon Duchesneau and Candy McCullough, a deaf lesbian couple living in Washington DC, had their second child, Gauvin.<sup>2</sup> Like their first, Jehanne, he was born deaf. The women, who wanted to have a deaf child, conceived Gauvin through artificial insemination by donor, using sperm from a friend they knew to have five generations of inherited deafness in his family.<sup>3</sup> Initially they had approached a local sperm bank but were told that congenital deafness was one of the conditions that ruled out would-be donors. In an extended interview in the *Washington Post*,<sup>1</sup> Sharon and Candy gave several reasons for their decision to have a deaf child. They argued that:

- deafness is an identity, not a medical affliction that needs to be fixed;
- the desire to have a deaf child is a natural outcome of the pride and self-acceptance many people have of being deaf;
- a hearing child would be a blessing, whereas a deaf child would be a special blessing;
- they would be able to be better parents to a deaf child than to one who could hear; and
- the child would grow up to be a valued member of a real and supportive deaf community.

The concept of “deaf culture” has been discussed extensively by deaf people and in the academic literature.<sup>4</sup> Notwithstanding the intricacies of this academic and political debate, however,

Sharon and Candy seem to have had a more everyday community in mind. For, both women live close to Gallaudet University in Washington (<http://www.Gallaudet.edu/>), the world’s first liberal arts university for the deaf where most of the staff are deaf and most staff and students and their families live nearby creating, according to the *Washington Post*, something that might be called a deaf community in the everyday sense of the word.

The reproductive choices made by Sharon and Candy raise a number of important moral questions: is there a moral duty to have a healthy child in situations where there is a choice?<sup>5</sup> If so, what is to count as healthy and/or disabled and who is to decide in any particular case?<sup>6</sup> What, if any, are the appropriate limits of reproductive freedom?<sup>7</sup> What are the appropriate relationships between personal morality, professional ethics and regulation in reproductive decision-making? In a paper discussing the ethical issues presented by this case and their implications for reproductive medicine more broadly, Julian Savulescu proposes two principles of reproductive ethics.<sup>8</sup> He calls these principles, reproductive autonomy and procreative beneficence. Following Robertson,<sup>9</sup> who uses the term liberty rather than autonomy, Savulescu argues that, in their reproductive decision making, people should be “free to do what others disapprove of or judge wrong, provided the exercise of freedom does not harm others” (see Savulescu,<sup>8</sup> p 771).<sup>10</sup> In this he also follows John Stuart Mill, who argues that

As it is useful that while mankind are imperfect there should be different opinions, so is it that there should be different experiments of living; that free scope should be given to varieties of character, short of injury to others; and that the worth of different modes of life should be proved practically, when anyone thinks fit to try them<sup>11</sup>

Savulescu’s second principle, procreative beneficence,<sup>12</sup> requires that potential parents choose, of the possible children available to them, those with the best opportunity of having the best life. In relation to genetic testing for example, he argues that,

Couples should employ genetic tests to have the child, of the possible children they could have, who will have the best opportunity of the best life. (see Savulescu,<sup>8</sup> p 771)

**Abbreviation:** PGD, preimplantation genetic diagnosis

Correspondence to:  
Professor M Parker, The  
Ethox Centre, Department  
of Public Health, University  
of Oxford, Gibson  
Building/Block 21, Radcliffe  
Infirmary, Woodstock  
Road, Oxford OX2 6HE,  
UK; michael.parker@ethox.  
ox.ac.uk

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It is important at this stage to point out that, like Parfit<sup>13</sup> and Robertson, Savulescu is not arguing that choosing to have a child other than the one with the best opportunity of the best life is to harm that child. A child who is born deaf is not harmed by his or her parents in cases such as the one above because no alternative, better, life is available to that child.<sup>1</sup> If Candy and Sharon had chosen to use sperm from a hearing donor, the resulting child would not have been the same child without the deafness. It would be a different child.

If the child has no way to be born or raised free of that harm, a person is not injuring the child by enabling her to be born in the circumstances of concern.”(see Robertson,<sup>9</sup> p 75)

This raises the question of what is meant by the term procreative beneficence and what work the principle can be said to be doing in reproductive ethics if it is not concerned with the avoidance of harm to people? Like Parfit and Robertson, Savulescu takes the view that even where there is no harm to the resulting child, there may be circumstances in which it would be reasonable to say that the parents would be wrong to have a particular child. Robertson captures this as follows:

...one may still morally condemn giving birth to offspring in such circumstances. Derek Parfit captures this point well in his example of a woman who is told by her physician that if she gets pregnant while on a certain medication she will give birth to a child with a mild deformity, such as a withered arm, but if she waits a month, she can conceive a perfectly normal child. If the woman refuses to wait and has the child with the withered arm, she has not harmed that child, because there is no way that this particular child could have been born normal. Still, many would say that she has acted wrongly because she has gratuitously chosen to bring a suffering child into the world when a brief wait would have enabled her to have a normal, though different, child. Now one could argue that her action is morally justified by the net good provided the child born with the withered arm. However, if one concludes that her actions are wrong, it is not because she has harmed the child born with the withered arm, but because she has violated a norm against offending persons who are troubled by gratuitous suffering. (see Robertson,<sup>9</sup> p 76)

For Savulescu, then, as for Robertson, potential parents have a duty to have the child with the best opportunity of the best life, not because to fail to do so would harm the child, but because they have a duty to bring about the best lives they can.

While the case of the deaf lesbian couple may seem rather unique, practical ethical questions about the limits of autonomy and beneficence arise frequently in the day-to-day practice of reproductive medicine and these questions are of significant ethical importance in practice and policy. Examples might include, situations in which women request prenatal testing and termination of pregnancy for what are sometimes called minor conditions, and situations in which decisions are being made about suitability for access to assisted reproduction<sup>10</sup> or about the use of preimplantation genetic diagnosis (PGD). Consider the following case:

<sup>1</sup>An exception is when the condition is so bad that it would be better not to have existed at all, but these situations will be rare.

“Rachel is going through in vitro fertilisation because she wants to have a child but is infertile. Unrelated to the cause of her infertility, Rachel is an unaffected carrier of x-linked spondyloepiphyseal dysplasia tarda (SED). As a carrier, and because the condition is x-linked, Rachel has equal 1 in 4 chances of: an affected son; an unaffected son; a carrier daughter, and a non-carrier daughter. She is considering whether she should use PGD to test the embryos for SEDT and only implant unaffected or non-carrier embryos. Does she, she wonders (having read Savulescu), have a moral duty to use PGD to choose the ‘best possible child’? Because it is x-linked, SEDT only affects males. At birth, affected boys are of normal length and proportions and reach normal motor and cognitive milestones. However, between 5 and 12 years of age their linear growth is retarded with the result that their final adult height is usually between 4’10” and 5’6”. They have a short trunk and barrel shaped chest. Affected men tend to get some back and joint pain, and some osteoarthritis and restricted joint movement. In some, but not all, cases, early hip replacement (eg in the 30s) and pain management, is required. In majority of cases, however, care is mostly ‘support’ and advice to avoid certain occupations—for example, those that involve stress on the spine. They have normal intelligence and life expectancy.<sup>14</sup>

To what extent should everyday reproductive decision making in cases such as this be guided by Savulescu’s principles? Is there a duty to have the child with the best opportunity of the best life and, if so, what does this mean in situations like the one facing Rachel? The cases above are both ones in which, at first glance, on a standard bioethical interpretation a conflict might be said to exist between reproductive autonomy and procreative beneficence—that is, while respect for autonomy requires Sharon’s choice to be respected, and for Rachel to be free to choose the embryo she wishes to implant, concerns about beneficence require the avoidance of deafness or short stature. The question raised by such cases on this interpretation is when, if ever, does procreative beneficence justify the overriding of autonomy—for example, by refusing Rachel access to PGD? On Savulescu’s account, however, the scope of application of the two principles means that there is no practical or theoretical conflict, for while reproductive autonomy is concerned with the limits of regulation and paternalism in professional practice, procreative beneficence, because no child is being harmed, is concerned solely with personal morality. This means that it is consistent for him to argue, as he does, that while reproductive autonomy means that it would be wrong for the women to be stopped from making the choices they wish to make, it would in fact (because of the principle of procreative beneficence) be morally wrong for them to choose to have a deaf or short-statured child when they could avoid this. They should choose, of the possible children available to them, the child who will start life with the best opportunity of having the best life, even if no one has the right to impose this choice on them. The choice to have a disabled child is wrong for Savulescu, as we have seen, not because it would harm the resulting child, but because it is to bring about a worse life than could have been the case. In what follows, I shall argue that while I agree with Savulescu that potential parents such as Sharon and Rachel have important obligations of beneficence when choosing between the bringing about of different possible lives, the concept of a duty to have the child with the best opportunity of the best life, combined with the separation of the personal from the social, is not a coherent way to capture such obligations. The principle of

procreative beneficence, where this is taken to imply a duty to have the child with the best opportunity of the best life, is underdetermining, paradoxical, self-defeating and overly individualistic.

### The principle of procreative beneficence is underdetermining

Moral principles require interpretation if they are to be applied in particular cases.<sup>15</sup> The minimum requirement for the meaningful application of Savulescu's principle of procreative beneficence is that it should be capable of ranking possible lives as better or worse,<sup>16</sup> not only in the sense that, say, a "hearing" embryo will be more likely to grow into a child who can hear better than one who is deaf, but also in relation to concepts involved in the understanding of a life as the best possible life. The key concepts requiring interpretation for the application of the principle in this second sense are, to say the least, highly complex. Not least complex among these is the concept of the best life itself, which can moreover have a meaningful use only in relation to other similarly rich and complex concepts such as those of the good life, human flourishing, well-being and of what it is that makes lives go well. This is not to suggest that the significance of these concepts would need to be established before that of the best life could be understood and used as the basis for interpretation, but rather to highlight the fact that any coherent use of the principle of procreative beneficence in ranking possible lives would unavoidably involve ranking the characteristics of, say, embryos, in relation to a cluster of complex, rich and interdependent moral concepts. This is not possible for two reasons. The first of these arises from the very fact that complex concepts, such as those of the good life, the best life, and human flourishing, are not reducible to simple elements or constituent parts which might be identified through the testing of embryos.

There are several inter-related reasons for doubting the possibility of reducing the good life to simple elements of this kind. Firstly, if we take a moment to consider our own lives, those of our friends and family, or perhaps those we have read about, such experience tells us that it is extremely difficult in advance, and perhaps also even in retrospect, to say with any precision what it is, or was, that makes (or made) a life go well. Is it true, for example, that a life free of troubled interpersonal relationships, free of suffering, loneliness or misunderstanding is a better life, or even, taken as a whole, a happier life, than one in which experience of these to at least some degree has played a part?<sup>17</sup> Is it true to say that the good life is the life free of any illness, disease or misfortune?<sup>17</sup> To ask these questions is not of course to suggest that nothing at all can be said about what makes a life go well or badly, nor is it to suggest that misfortune is a good thing. It is rather to reflect upon the fact that while it may be possible to delineate some conditions conducive to good lives, it is not going to be possible to relate the testable features of embryos in any useful or determinative sense to concepts as rich and complex as that of the "good life", thereby enabling the ranking of possible lives as better or worse. This means that the concept of the "opportunity of the best possible life" is inevitably underdetermining.

Part of the indeterminacy of such concepts in relation to reproductive choice arises out of the fact that their meanings are sustained by and transformed within complex and relatively fluid social practices and spaces. This means that, even if it was possible, the interpretation of the duty to have the best possible child would emerge within intersubjective and socially embedded discourses about human flourishing and about what it would mean for a life to go well, and there is good reason to think that in any, even moderately, diverse community, no single, agreed concept of the best possible life is going to be

possible or desirable. This leads to the second reason why it is not possible to rank embryos in terms of their relationships with the best possible life. This is because, even if it were possible, which I have argued it is not, to identify a number of key elements that might be said to be features of the best life, the diversity of preferences for, and beliefs about, the relative importance of what would inevitably be an extensive range of such elements, combined with the variety of their possible interactions means that it would not, even in theory, be possible to identify the rational choice with respect to any particular feature of an embryo or a possible child.<sup>18</sup>

What these two arguments mean, taken together, is that it is not possible to specify in any particular instance what would be involved in making a reproductive choice that respects the principle of procreative beneficence. This is not of course to suggest that nothing can meaningfully be said about the conditions under which a good life would be more or less likely,<sup>19</sup> or even to suggest that there could be no coherent concept of procreative beneficence. But it is to gesture towards a very different kind of principle of procreative beneficence, one which means that rather than having a duty to have the child with the best opportunity of the best possible life, those who are contemplating pregnancy have an obligation to consider carefully whether it is reasonable to expect that the child they are thinking of conceiving is going to be born under conditions conducive to the possibility of a "good life". What these arguments have also highlighted is the fact that the conditions conducive to the possibility of a good life are at least as much to do with the broader social, political, economic and environmental contexts in which people live as they are to do with their biological make-up, or the make-up of their family. This is an issue to which I return later in this paper.

### The concept of the best possible child is paradoxical

In *All's well that ends well*, Shakespeare has a minor character speak the following lines:

The web of our life is of mingled yarn, good and ill together;  
our virtues would be proud if our faults whipp'd them not,  
and our crimes would despair if they were not cherish'd by  
our virtues.<sup>20</sup>

In this, Shakespeare is not simply reminding us that human lives are by their very nature characterised by both good and ill, and that we must learn to live with these aspects of ourselves and of those around us. He makes the stronger and ultimately more interesting claim that both strengths and weaknesses of character, and of our lives more broadly, are essential and interdependent elements of the good life. Both aspects of our lives are interwoven, and indeed it is this interweaving and our struggles with it that make us what we are and constitutes in its interplay of light and dark much that is of value and significance in human existence. In these lines, as in so many others, Shakespeare captures something profound and, once again, complex about human existence and in particular about our relationships with ourselves. For he suggests that it is only through recognition of the fact that we are in our nature and in our particularity both light and dark that we come to feel both an appropriate humility and a sense of genuine self-worth. It is here too that we forge our identity.

What Shakespeare helps us to see then, is that in addition to being underdetermining, the concept of the best possible life is deeply paradoxical. The best possible life is not necessarily and indeed could not be one in which all goes well. The best possible life is not necessarily, indeed could not be, one lived by a person with no flaws of character or of biology. This is not to say that the best possible life would be one in which a certain

number of character flaws were thrown into the mix—for example, through PGD—but rather once again to highlight the complex, organic and profoundly paradoxical nature of the good life and of human flourishing.

The lesson to be learned from Shakespeare here is one that complements in significant ways the conclusion of the arguments above—that is, that the principle of procreative beneficence is underdetermining. For it suggests that while it may be possible to specify some conditions without which a life, any life, would be unlikely to go well, and while it may be possible in retrospect to say of a life that it was a good one, lived well, the good life is going inevitably in all cases, whatever else might be true about it, to be a mingled yarn of good and ill together.

### **The pursuit of the best possible life is self-defeating**

The arguments set out above have raised significant doubts about the possibility of specifying in advance, or even as a life progresses, in any objective way, whether it constitutes a good life, let alone the best possible life. Firstly, there will in most cases be legitimate disagreement and uncertainty about what constitutes the good or the best and, secondly, on any coherent account the good life will inevitably involve a complex of good and ill together. These two arguments hint also at a third. For they suggest that the active pursuit of the best possible life will be likely in practice to be disorienting. For, if we take seriously Shakespeare's evocation of the breadth, depth and paradoxical complexity of what it means to live a good life and also the inevitability of genuine uncertainty, the pursuit of the best possible will always be in important respects quixotic and unlikely therefore to be conducive to the good.

A different way of capturing this insight, in consequentialist terms, would be to argue that any consideration of the good life would need to factor in the effects of perfectionism itself, and it seems very likely that the active pursuit of the best possible in each and every aspect of one's life, including the selection of the characteristics of one's offspring, would not only make it less likely that the best possible would be achieved but might also make even the achievement of the good enough difficult. For, as none of us can be sure that we are living the best of all possible lives, the pursuit of the best possible, as opposed to the pursuit of the good, would be bound to lead to a life of dissatisfaction with any life as lived and to a constant drive for self-improvement which would inevitably be both exhausting and unlikely to lead to stable, satisfying or deep interpersonal relationships. From a consequentialist point of view, therefore, it is not impossible that the right thing to do would be to eschew the pursuit of the best possible.

### **The principle of procreative beneficence is overly individualistic**

The argument that there is a duty to select the child with the best opportunity of the best life should be rejected. Savulescu's account of procreative beneficence is underdetermining, paradoxical and self-defeating. This should not however be taken to imply that beneficence should be abandoned altogether as an important moral dimension of reproductive choice. For, while there is every good reason to reject the pursuit of the best possible life, this is, as I have indicated above, very far from arguing that nothing at all can be usefully said about the factors which contribute to the conditions under which it is possible for a life to go well. And, if it is possible to say something meaningful about the kinds of things that make this possible, beneficence will have a role to play in reproductive ethics and potential parents will have an obligation to ensure, insofar as this is possible, that any child they have has a reasonable chance of such a life. This is a useful reminder that what is being rejected in this paper is only the pursuit of the

best possible and not the obligation to ensure, insofar as this is possible, conditions for the possibility of a good life.

Mill, while calling for experiments in living, also argued that there ought to be limits to such experiments, drawn on the basis of our understanding of the kinds of things that make it possible for a life to go well.

*The fact itself, of causing the existence of a human being, is one of the most responsible actions in the range of human life. To undertake this responsibility- to bestow a life which may be either a curse or a blessing- unless the being upon whom it is to be bestowed will have at least the ordinary chances of a desirable existence, is a crime against that being. (see Mill,<sup>11</sup> p 177)*

Our understanding of what it means for a life to go well is related to our understanding and use of concepts such those of the good life, of "human flourishing" and of the things that make a life go well. These are complex and interdependent concepts in which meanings are sustained and transformed within the practices of social and linguistic communities, and this implies that the interpretation of the implications of beneficence—that is, the assessment of whether any particular possible child has a reasonable chance of a good life—will be inseparable from relatively complex intersubjective and social practices and values. It is an implication of this that, just as conceptions of the good vary between individuals, families, communities, etc, so too will legitimate beliefs about what it means to secure the conditions for the good in particular cases, and this implies that procreative beneficence will generate somewhat different obligations in different contexts.

This is not to suggest that the conditions for the possibility of the good life are, however, subjective. For while having subjective features, what counts as the good in a particular case, will be meaningful and reasonable only within the context of discursive rules, including rules of justification, of the communities within which it is being used as a justification.

In addition to being non-subjectivist, this is also a non-relativist position. The morally significant practices of communities, societies and individuals can themselves be criticised on the grounds of beneficence in at least some cases. For there are at least some respects in which the conditions into which a child would be born can be said objectively to be conducive to the possibility of a good life<sup>21</sup> and what this means is that a coherent account of procreative beneficence is, in addition to recognising the social aspects of procreative beneficence, going to be one that allows space for consideration of the objective conditions required for the possibility of flourishing of any human life.<sup>19</sup>

Related to this, any coherent and relatively comprehensive account of procreative beneficence must also be capable of taking seriously the fact that large numbers of women have no choice other than to bring children into a world of abject poverty, and the absence of anything approaching adequate healthcare. The fact that reproductive autonomy is a myth for many women is a reminder that, just as it is not possible to separate obligations of procreative beneficence from social context, neither is it possible for an adequate or coherent account of procreative beneficence to avoid issues of global inequity or politics. The obligation of procreative beneficence has intersubjective, social and political dimensions, which extend to beyond the family and the choices of individuals. A coherent, reproductive ethics will, as a consequence, be one that takes the social and the political extremely seriously.

### **CONCLUSIONS AND IMPLICATIONS FOR PRACTICE**

In response to the case of Sharon Duchesneau and Candy McCullough, Julian Savulescu argues for two principles of

reproductive ethics: reproductive autonomy and procreative beneficence, where the principle of procreative beneficence is conceptualised in terms of a duty to have the child, of the possible children that could be had, and of who will have the best opportunity of the best life. Savulescu goes on to argue on this basis that while Sharon should be free to make the choice she did—that is, to have a deaf child—and Rachel should be free to choose to implant any of her embryos—that is, to choose to have a child of short stature—both women have a duty to choose the child with the best opportunity of the best life—that is, the non-disabled child. In this paper, I have argued that this duty should be rejected. It is underdetermining: it is not possible to identify in particular cases which would be the best possible life. It is paradoxical: the good life will inevitably be a life involving struggles with the complexities of the human character and the human condition. It is likely to be self-defeating: to be exhausting and unlikely to lead to stable, satisfying or deep interpersonal relationships. And, finally, the principle of procreative beneficence, when defined as the duty to choose the child with the best opportunity of the best life, is overly individualistic: it does not consider the social embeddedness of the concept of the good life and related concepts, and ignores the political dimensions of reproductive choice and of reproductive ethics.

I have argued, however, that the concept of beneficence does have an important role to play in reproductive ethics. For, insofar as we have reason to believe that it is possible to say something meaningful about the conditions under which it is possible to live a good life, the concept of beneficence will have content and will require of us, where we have a choice and insofar as it is possible to discern, that we choose to reproduce in ways that make it possible for our children to grow up under such conditions. The morality of our reproductive choices can on occasion be legitimately called into question. In relation to choices such as those facing Sharon and Rachel, potential parents have an obligation to ensure, insofar as this is possible, that any child they have has a reasonable chance of a good life.

In some cases, such as the two described at the beginning of this paper, third parties will be involved in the process of bringing about a life. In the case of Sharon and Candy this was a friend who provided the sperm; in the case of Rachel it was the in vitro fertilisation clinic, which had the technology to carry out PGD. In such cases, the social location of the choice introduces another dimension and the third parties involved come to have relevant moral obligations. In most cases these will simply require, where resources permit and where there is a reasonable chance that any resulting child will have a good life, helping women to have a child they could not otherwise have. But, where health professionals have concerns about the quality of the life being created, such as for example in Rachel's case above, it will be incumbent upon them to help potential parents to think carefully about the life they are about to create. The health professionals involved will have obligations to encourage people to reflect on their choices, to give reasons, and to debate with them the moral dimensions of their choices. While it might be argued by some that this is an infringement of patient autonomy, this is not the case. It is more respectful of patient autonomy to discuss the reasons they have for making a choice and to challenge choices which seem unreflective than to simply accept such choices at face value. Such challenging is conducive to the patient's developing

understanding, and respectful of their ability to change their mind in light of good reasoning.

In some very rare cases it will be right for the health service to refuse to provide a service, whatever justification potential parents give. Examples will include cases in which potential parents choose to have children whose lives can be foreseen to be intolerable. It would for example, to take an extreme case, be morally required of a health service to refuse to provide treatment that would enable a woman to have a child with Edwards' syndrome, or Trisomy 13, given the current unavailability of effective interventions. In most cases of reproductive decision making however,—ie, those in which it might reasonably be argued that the conditions for the possibility of a good life have been met, these are choices that women should be free to make on the basis of their own values in the light of their own conceptions of what it means for a life to go well. In Sharon and Candy's case, this appears to be what they did. The case of deafness, within the context of a supportive deaf community, is nevertheless a very difficult and possibly limiting case, a case which brings into question the extent to which hearing is a necessary condition for the possibility of a good life. The case of short stature, in the choice facing Rachel, is in my view one in which, all other things being equal, it is possible that these conditions may have been met.

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