Better off Deaf?

by Robert Sparrow

Robert Sparrow investigates the ethics of a Deaf couple's decision to employ a sperm donor with a family history of deafness in order to maximise their chances of having a deaf child.

Should parents try to give their children the best lives possible? Yes. Do parents have an obligation to give their children the widest possible set of opportunities in the future? No. Understanding how both of these things may be true will allow us to go a long way towards understanding why a Deaf couple might wish their child to be born Deaf and why we might have reason to respect this desire.

Criticism of Sharon Duchesneau and Candy McCullough's decision, reported in the Washington Post, to seek out and employ a sperm donor with a family history of deafness in order to maximise their chances of having a deaf child, has concentrated on two aspects of this decision. The first is that they consciously sought the birth of a child that the vast majority of people would consider to be 'disabled'. The second argument, which may or may not presume the first, questions the decision they made to bring a child into the world who is likely to have greatly reduced opportunities by virtue of being deaf.

I want to concentrate on the second of these arguments here. The idea that deafness need not be a disability and can instead be an entry point to a minority culture coalesced around a signed language, and the foundation of a cultural identity as 'Deaf', is one that I am personally sympathetic to. But this argument has been well made elsewhere, by Deaf persons themselves, and for reasons of space I shall not repeat it here. In any case, settling the question as to whether D/deafness is a disability or a cultural identity—or perhaps both—does not in itself resolve the question of the ethics of deliberately seeking to bring about the birth of a D/deaf child. One may concede that deafness is a disability but hold that this is unimportant because deaf children can have sufficient opportunities in life to justify bringing them into the world. Alternatively, one may agree that deafness is a cultural identity, but still be concerned for the opportunities available to the child as a member of that culture. The question of the obligations of parents with regard to the opportunities available to the children they choose to bring into the world remains crucial.

Width or Worth of Opportunities?

In a society which fetishises individual choice and opportunity, it may seem obvious that these are goods. For parents to have a child with less of these than some other possible child they could have had may seem like them restricting their child's future liberty by imposing their projects and values on the child. Was Duchesneau and McCullough's decision to seek out a deaf sperm donor wrong because it was likely to lead to the birth of a child with less opportunities than if they had chosen a 'normal' donor? Do parents instead have an obligation only to have children who will have the widest possible range of opportunities?

The first thing we must do is to realise how strong a claim this is. It seems exceedingly unlikely that every child could have the *widest* possible range of opportunities. Presumably there is a limited number or class of children who have such. The remainder, the vast majority, have less than this. If parents have an obligation to ensure that their children have the widest possible opportunities then most parents will fail to meet it.

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Moreover, the class of children with the widest possible opportunities is likely to be an elitist one which reflects injustice more than any 'natural' distribution of opportunities. As minority rights and disability activists have argued, many sorts of restrictions of opportunity come about as a result of the relation between the characteristics of the child (race, sex, physical capacities, etc) and the social context into which they are born. In a sexist, racist and homophobic society (such as our own) the opportunities available at birth to women, non-whites and homosexuals are substantially less than those available to white, straight men. Parents concerned to maximise their child's life prospects would therefore do well to use sex selection technologies to give birth only to male children. Mixed race couples in racist societies should embrace the use of genetic screening to ensure that they only have children whose skin colour would allow them to escape the opportunity-reducing effects of institutionalised racism. In this way, an obligation only to

have children with the widest possible range of opportunities would make parents hostage to the social structure and bigotry of the society in which they live.

Already, then, it seems likely that parents' obligation in relation to their children is only to ensure that they will have some minimum threshold of opportunity rather than to maximise their opportunities. But, even this description of their obligations, I will argue, crucially under describes them. In fact what is important, when we consider the future of children, is that they should have a reasonable range of *valuable* or *important* opportunities. In order to see this we need to push a little bit harder on the idea that we should maximise our children's opportunities.

If we grant the existence of this obligation it seems extremely unlikely that it should be discharged with the choice of the sort of child that one brings into the world. Surely, our treatment of children after they are born is equally subject to it? Indeed our ordinary intuitions suggest that parents' treatment of their children after birth, in their early childhood and formative years, is *more* constrained by an obligation of this nature. Thus while most of us would not object to parents who allow themselves to have a girl child, who will have less opportunities than her brother because of the sexism of the society into which she is born, we are likely to object strongly if they then bring her up to believe that she should not aspire to anything because she is a girl. In the current controversy, Duchesneau and McCullough's decision not to fit their son with a hearing aid—in order to make the most of the residual hearing with which he was born—has incited nearly as much hostility as their decision to try to maximise their chances of having a deaf child in the first place.

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So, if we are concerned with the opportunities that children have at birth, this concern should extend to include their treatment in early childhood. In particular it should include the choices parents make about their child's education, especially early on, and the language they grow up speaking, as these are matters that may have a dramatic impact on the choices they have available to them in later life. These choices may have as much, if not more, impact as decisions about what sort of children we shall bring into the world.

Now we can begin to see just how demanding and counter-intuitive a concern to *maximise* the opportunities available to our children is.

Consider first the matter of what language(s) we should bring our children up speaking. This is a genuine and difficult question for parents who are members of minority language cultures surrounded by a larger culture which offers more economic opportunities. Insofar as they are concerned to maximise the opportunities available to their child, parents in such a situation should ensure that their child grows up fully fluent in a language other than their own. What makes this choice a difficult one is that doing so makes it much less likely that their children will grow up speaking their language in later life and much, much less likely that their grandchildren will.

Most commentators try to soften this dilemma by pointing out that parents in this situation can teach their children *both* languages (although in fact this is unlikely to avoid the outcome that concerns the parents). This resolution is revealed as less convenient than first appears when we realise that it is true for *all* of us that our children will have more opportunities the more languages they learn. They will be able to read more literatures, travel more widely, work in more countries, etc. If members of minority-language cultures have an obligation to maximise the opportunities available to their children, by teaching them another language as well as their own, then presumably so too do members of majority language cultures. Indeed, we should all teach our children as many languages as possible. Furthermore, given that there is a practical limit on how many languages our children can learn, it seems that we should teach them first that set of languages that will give them the *most* opportunities. At first approximation, this suggests that, in an increasingly international world, we all have an obligation to bring our children up speaking English, Spanish, Mandarin and Hindi, not necessarily in that order.

But while we might think that bringing children up speaking these languages is a good thing, we hardly feel that it is an obligation such that parents who have failed to meet it have thereby failed to be good parents. We certainly don't feel that parents are obligated to educate children in these languages at the expense of education in their own language, where this provides a reasonable modicum of opportunity. Again, it seems that parents are obligated to provide this modicum rather than to maximise the options available to their children.

However, it is when we move to consider the implications of a preoccupation with range of opportunities for education more generally that the real problems with it become clear. The desire to maximise opportunities will clash severely with other values that we feel strongly that it is the role of education to promote.

The first of these is the truth. There will be many cases

Dr Robert Sparrow is a Research Fellow at the Centre for Applied Philosophy and Public Ethics, University of Melbourne.
Email: rsparrow@unimelb.edu.au

when, for various pragmatic reasons, a child will have many more opportunities if he or she grows up believing things which are false and which his/her parents know to be false. These may be personal and idiosyncratic beliefs which it is advantageous to hold for various psychological reasons, or they may be falsehoods widely believed across society, the espousing of which is necessary to open various doors. Imagine a society (not too far-fetched) in which the public espousal of racism, or sincere devotion to a tyrant, was necessary in order to achieve any significant position in government or business. In such a society, a child would clearly have more opportunities if she grew up believing these falsehoods. But no one would, I take it, hold that a responsible parent should consciously inculcate ideas that she knows to be false in this situation. The role of a parental educator is to teach their children the truth as they see it. As I will discuss below, this obligation is especially pressing when the truths at issue concern moral questions that the parents believe bear critically on the question of how to live a good human life.

What we desire are not opportunities per se *but valuable or important opportunities.*

Before we turn to the question of the values we wish to imbue through early childhood education, it is worth noting that similarly counter-intuitive results arise from the desire to maximise opportunity in relation to the character traits we wish to inculcate in children, even where these are described with as little reference to our values as possible. To see this, imagine that there is a set of specific skills that are necessary in order to pursue a successful life of crime; brazen lying, ruthlessness, skills at shop lifting, knowledge of how to steal cars, burgle houses, etc. Possessing these skills opens up a veritable vista of opportunities for a life as a pickpocket, cat burglar, confidence trickster, and so forth. But even presuming that these could be taught without jeopardising the existence of other opportunities, we do not feel that an upbringing that includes them is a better upbringing than one which neglects them. We do not believe that, because we place no value on the opportunities or life paths they open up.

The role played by our judgements about the worth of opportunities becomes explicit when we consider what sort of moral education we should provide our children. There is no reason to believe that having a strong set of moral values, for instance, will lead to one having more opportunities in life. If anything it seems likely that having no strong moral beliefs will lead to one having a wider range of opportunities. One could then become a 'moral chameleon', adopting whatever moral code will facilitate our entry to various positions of power or opportunity. One need never be prevented from becoming a police officer by concern about the justice of the law, or a drug baron by scruples about the ethics of the trade. But this is hardly the result we seek from a good moral education. Instead, an important purpose of education in such values is to try to *prevent* us from pursuing certain life paths. Part of the nature of a good education is that it closes windows to people, by allowing them to realise why they are not worthwhile choices. When we consider the moral education of our children, we want them to develop values which reveal some choices as worthwhile and others as worthless. Our purpose in doing so is to encourage them to pursue certain life paths and to prevent them from pursuing others. We will count ourselves as successful in this, if they grow up making choices and adopting a lifestyle that we approve of and admire.

This is the real problem with a concern for the width of opportunities available to children when they are brought into the world; that it abstracts, and distracts us, from the question of *which* opportunities it is important that children should have. What we desire for ourselves (and others who we care about) are not opportunities *per se* but valuable or important opportunities. The mere multiplication of opportunities does not increase our chances of leading a meaningful or worthwhile life. It may even decrease our chances of doing so, if some of these options lead down paths to misery, confusion or delusion from which it is difficult to extricate ourselves. Parents should want their children to have the best life possible —this is internal to our idea of what it is to be a goo l parent—but the best life possible does not consist simply in the life with the widest range of opportunities. Our own judgements about what sorts of life are worth living inevitably come into the picture when we think about what sorts of opportunities children should have.

So does this mean that parents should educate and shape their children to live *the* best life possible? Should they force them into a mould determined by their most considered judgement about the nature of the good life? There are a number of pragmatic but nonetheless important reasons why this would be wrong. Firstly, to my knowledge no culture holds that there is only *one* way of living the good life. Even the strictest religious cultures typically hold that it is possible to live the good life as a farmer, or a builder, a physician, a man or a woman, or in any number of social roles. Conceptions of the good already have a range of options, through which they can be realised, built into them. Moreover, the character traits that suit a person to a particular social role or way of life, or even allow them to pursue it, are subject to a number of unavoidable contingencies. If we bring up our children with only one life path in mind, we are likely to be

disappointed if they turn out not to have the skills or inclination for it. The mere fact of our having such strong and determinate expectations may even make it less likely that they meet them, as the weight of parental expectation may be crippling for some children.

A person may believe that the best forms of life are those promoted by their own culture.

Thus while we may have strong intuitions that some life paths are, and some aren't, worth leading, we would be wise to ensure that our children have a *range* of opportunities in relation to the particular life they lead. Or, more accurately, that they have an adequate range of opportunities to live meaningful and worthwhile lives. But the extent and nature of this range will inevitably and properly be determined with reference to our own ideas about what makes a human life go well and which sorts of life are and are not worth living. This means that parents will inevitably disagree about these issues. To the extent that ideas about these questions are sustained and transmitted by cultures it also means that members of different cultures are likely to disagree about them systematically.

We may appear to have strayed a long way from the question of the ethics of a Deaf couple's desire to have a baby who is deaf. But the point of the preceding discussion was to establish that the judgement of what sort of child will have the best possible life is one that will inevitably refer to the values and beliefs of the person making it. This goes for education in general. It also goes for the decision about what sort of child to bring into the world in the first place.

Better off deaf?

The question remains, then, could parents ever have good grounds for believing that their child would be 'better off deaf'—where 'better off' is determined with reference to the worth of the range of opportunities they will have to lead a good human life? Yes. I think there are at least two different sorts of reasons that parents might have for holding this, one perhaps more plausible than the other.

The first set of reasons stem from a particular form of cultural identification that is more familiar in cases involving other minority language cultures. A person who strongly identifies as a member, and with the values, of their own culture may believe that the best forms of life are those promoted by and supported within that culture. For example, one can imagine a committed Francophile thinking that their child will have a better chance of leading a meaningful life if they have access to the wisdom contained in the French literary tradition. Or, a member of a religious culture, thinking that only life choices that acknowledge certain important religious truths have any worth. In both cases, these cultural loyalists may further feel that the majority of the ways of life promoted in other cultures are of little value. If parents have this sort of identification with their culture, they will believe that their child will have the most opportunities to pursue valuable life courses only if they grow up as a member of their culture.

Some Deaf parents *might* feel this way about Deaf culture. That is, they might value only the opportunities made available within Deaf culture and have little respect for the ways of life pursued by individuals in the wider hearing culture. In this case they will have good reason to desire that their child should grow up as a member of Deaf culture.

In fact, not having any allegiance to Deaf culture myself, I find this difficult to imagine. Deaf culture does not seem to support the distinctive forms of life that some indigenous cultures do, for instance. The basic sets of aspirations and role models seem pretty much coextensive with those of hearing culture. To the extent that this is the case, it will not be reasonable for Deaf parents to believe that their child will have a better chance of realising their values if they grow up Deaf. They will have a better chance if they grow up in a hearing culture which, simply because of its larger size, offers more opportunities to do so.

Nonetheless, I am reluctant to rule out the possibility of this sort of argument being made. Signed languages are not easily given a written form, and this means that some Deaf cultures have developed rich story telling traditions. One can perhaps imagine a parent thinking that these contained sufficient wisdom that access to them was an important precondition for living the best life possible. Alternatively, a Deaf parent might believe that being Deaf leads to a set of capacities and experiences that are superior to those of hearing persons and that these are essential to choosing wisely between life paths. This is analogous to the argument made by those who believe that deafness is a disability that prevents deaf children from having the full range of human experiences that would allow them to choose certain life paths, such as, for instance, that of a musician. The Deaf argument here is more plausible than first appears because Deafness may involve increases in certain capacities, such as visual acuity and spatial visualisation, beyond those of hearing persons. The claim of some Deaf persons that they would not have hearing even if it could be granted to them might be interpreted along these lines.

Because our cultural values shape our assessment of options so deeply, it is very difficult to make assessments about how members of other cultures might feel about the relative value of sets of options. So while I myself

find it hard to imagine making either of these judgements I would not like to rule them out entirely.

However, the second set of reasons why a Deaf parent might think that their child will have a better life if born deaf, measured in terms of access to a wide range of valuable opportunities, are more compelling. They might prefer a deaf child, not because they believe that the ways of life promoted in Deaf culture are more valuable than those promoted outside of it, but simply because they are capable of being much better parents to a child who belongs wholeheartedly to their own (Deaf) culture.

The range and nature of the opportunities available to a person is not solely a function of which culture they are a member of but also of how confident and secure they feel in that culture. The self-respect that comes from being secure in one's cultural identity allows a person to choose confidently between the opportunities available to them and to make the most of the opportunities they choose to pursue. Lack of confidence and insecurity about the opportunities available in a culture may be paralysing. An important role of parents is to foster and encourage their children to feel secure and confident in their cultural identity.

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If a couple's children are spending a large amount of time in a culture in which they (the parents) are unable to participate, then they may be justifiably concerned about their ability to guide, advise and support their children in relation to the choices they make in relation to that culture. They may be unable to fulfil their parental obligation to ensure that their children grow up with a secure cultural identity. This may be of especial concern if that culture is one in which the common opinion is that the parents are disabled, as this itself could constitute a serious threat to the children's confidence and self-esteem. Deaf parents may have good reason therefore to want their child to grow up in their own Deaf culture.

Conclusion

Duchesneau and McCullough's attempt to maximise their chances of having a Deaf child was made using only a knowledge of the family history of the donor concerned. But the controversy aroused by their decision resulted, at least in part, from an awareness that genetic technologies such as *in vitro* fertilisation, prenatal genetic analysis, 'gene therapy' and other techniques of genetic modification, and perhaps even cloning, are likely to play an increasing role in decisions about the sort of children we have in the future. I have suggested that Deaf parents may have two sorts of reasons for believing that their children would be 'better off deaf'. What do my conclusions imply for the right of Deaf parents to use genetic technologies to try to ensure that they have a Deaf child?

If we are to allow the conscious shaping of a child's genotype through new genetic technologies then we must allow all parents to use them to try to ensure the best life possible for their children, *as long* as their conception of what such a life consists in is a reasonable one. These are both important qualifications.

To discuss the second qualification first. There is a wide range of reasonable conceptions of what a good human life consists in. Different people, different cultures, different religions disagree about the nature and sources of happiness and about how a good person should live. Nonetheless every individual and society must also hold that some ideas about these matters are unreasonable. This commitment is internal to having any beliefs about them at all. We currently accept that parents have the right to make many significant decisions about the interests, education and upbringing of their children. But there are limits on these parental rights, and these limits are roughly delimited by the notion of the reasonableness of the decisions they make. If parents attempt to shape their children according to an idea about the best life for a person that is obviously unreasonable, then society may choose to step in. Children are also citizens, or future citizens, and so society also has an interest in their upbringing. This interest is, for instance, reflected in the restrictions that we currently recognise on the rights of parents to educate their children. Society insists that children should be educated in order to enjoy a particular range of opportunities, regardless of whether or not these are opportunities the value of which their parents affirm.

Furthermore, the decision to allow new reproductive technologies to be employed to shape the sort of children that are born is a public as much as a private one. The technologies which today make it possible to do this exist because of research which is, directly or indirectly, publicly funded. The consequences of their widespread use may be demographic changes (for instance, in sex ratios, or the number of children born with disabilities) which are clearly of a public nature and interest. The legal and regulatory context in which they are used is determined by public policy debates. If a child is born into the world with opportunities that could not reasonably be described as conducive to the best possible life then the public shares some responsibility for this. The public therefore has a legitimate interest in decisions being made about the sorts of children that are being born as a result of the use of these new technologies. We may properly restrict their use to cases where the parents' desire for a child of a certain sort is a reasonable one.

I have argued that the desire of Deaf parents for deaf

babies may be reasonable. But this judgement is problematised by the recognition that it rests on beliefs about which options and activities are valuable and central to living a worthwhile human life. Others may see the matter differently. That is, they may deny that the opportunities available to deaf children can reasonably be held to allow them the chance to have the best life possible. Given the existence of such disagreement we can only try to resolve the matter through public debate and dialogue and a process of democratic decision making.

Thus in order for Deaf parents to be granted access to genetic technologies for the purpose of having deaf babies, the majority of Australians must acknowledge that Deafness can be a source of pride rather that regret and that Deaf culture has within it the resources to offer people a wide range of opportunities, some of which might reasonably be held to be important enough to justify the belief that a Deaf child will have a better life than a hearing child. In particular, the popular misconception that deafness is a tragic disability that must inevitably blight a human life must be overcome. The strength of public hostility to the idea that Deaf parents might desire a deaf child suggests that we have a long way to go to reach this goal. However one may also hope that the publicity granted the Duchesneau and McCullough case has drawn attention to the fact that many Deaf people do not feel this way about their deafness, and to the existence of a rich and vital Deaf community and culture.

If we acknowledge the reasonableness of a cultural understanding of Deafness and an identification with Deaf culture, and if we allow the use of genetic technologies to parents wishing to have children of a certain sort, then we have no legitimate grounds to deny Deaf parents the right to use these technologies in order to have deaf babies, if they wish to do so. But the second of the qualifications raised above is much more important. It is far from clear to me that we should allow anyone at all to use the new genetic technologies to shape the genetics of their children. The impact of these choices on the demographics of future populations is likely to be significant and far reaching. Allowing parents to use these technologies to 'improve' their children risks subjecting the nature of the human species to a eugenics directed by market forces. Their use to ensure that children are not born with various 'disabilities' risks communicating a profound disrespect for people who have the genetic conditions that the parents are seeking to eliminate. Perhaps the most valuable lesson we can learn from the controversy surrounding this Deaf couple's attempt to have a Deaf child is that the idea of 'improving' our children is more complex and contestable than is generally recognised. This in turn might lead us to think again about whether this is a project that we, as a society, wish to embrace.

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