

## Berlin Conference contribution

# Choosing disabilities and enhancements in children: a choice too far?



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### Abstract

Some parents have taken steps to ensure that they have deaf children, a choice that contrasts with the interest that other parents have in enhancing the traits of their children. Julian Savulescu has argued that, morally speaking, parents have a duty to use assisted reproductive technologies to give their children the best opportunity of the best life. This view extends beyond that which is actually required of parents, which is only that they give children reasonable opportunities to form and act on a conception of a life that is good for them. Does the selection of deaf children violate that responsibility? Morally speaking, parents should refrain from using assisted reproductive treatments or prenatal interventions in order to have a child with a disability. Deafness and other disabilities represent intrinsic disadvantages that cannot be offset by other advantages that families and society can offer to people. By the same token, neither should parents seek enhancements of intelligence or physical traits that would undercut intrinsic goods of human life in similar ways. These moral arguments do not, however, sustain the judgment that the law should necessarily interfere with parents' decisions in these matters, even if those choices are morally unwise.

**Keywords:** *assisted reproductive treatments, children, deafness, disability, enhancement, ethics*

### Introduction

As they looked for help with having children, a same-sex couple living near Washington approached a fertility clinic with an unusual request. The two women were looking for spermatozoa that would help them have a deaf child (Mundy, 2002). The clinic turned these two deaf women away for the simple reason that they exclude deaf men from sperm donation. Sperm quality is usually a point of pride for fertility clinics. For example, one prominent US clinic (not associated with this case) describes its standards this way: 'A donor applicant is disqualified from participation in the donor program if there is a family history which indicates that the man's offspring may be at increased risk for a birth defect or known genetic condition' (www.cryobank.com, accessed 8 October 2008). Like others having congenital conditions, deaf sperm donors are not welcome. The couple eventually approached a deaf acquaintance with a history of deafness across multiple generations in his family. He agreed to donate spermatozoa, and the couple succeeded in having a deaf

child. In fact, they succeeded twice, first having a daughter and then a boy about 5 years later. At birth, the boy had a degree of hearing in one ear, and a physician recommended a hearing aid in order to capitalize on that capacity. The parents declined the recommendation, and they now have two functionally deaf children.

The choice to seek deaf children cuts across the grain of virtually all discussion in bioethics about prenatal interventions involving the traits of children. Most bioethicists spend their time worrying about the ethics of interventions to produce 'super kids', children that exceed their peers (and parents) in sight, hearing, intelligence, athletic skill, strength, resistance to disease, and so on down the list of desirable human traits (Sandel, 2007). If options to select enhanced traits were available, would parents not want them for their children? What moral reason is there, if any, to limit their choices? Should

parents be restrained against pursuing enhancements because of unforeseeable consequences or because the enhancements betray human nature in some fundamental way? What would it mean for justice that these techniques might be available only to people who already have the most advantages, namely the wealthy who could afford the extra steps involved? Bioethics forums are awash with these questions (Harris, 2007).

By contrast, parents wanting deaf children – children with a disability – take the debate in an entirely different direction. The couple mentioned above took pains to make clear that they would have accepted and loved a hearing child, but that's not what they really wanted. They wanted children like themselves, and they did not see this preference as a moral transgression: they wanted to see in their children the deafness that was central to their own identity, and they call their deaf children a special blessing (Mundy, 2002). They would be a deaf family, without apologies to anyone. (Apparently some deaf advocates have gone so far as to argue that the welfare of deaf children requires removing them from the homes of hearing parents who are not themselves part of deaf culture [Savulescu, 2002].)

While the decision of this couple to have deaf children grew out of their own moral intuitions, one commentator has offered a formal defence of the practice, so long as certain conditions are met. Teresa Blankmeyer Burke (2005) has argued that parents may attempt to have deaf children if they are themselves deaf and able to offer language immediately to the children, which is possible if the parents are fluent in American Sign Language. This moral analysis dovetails with the intuitions of this deaf couple but, because most parental preferences go in the opposite direction towards enhancement, parents who seek disabilities in their children are swimming against a very strong social and moral tide.

## Parents and their duties

Philosopher Julian Savulescu (2001) has explicitly argued that parents have an obligation to enhance the capacities of their children to the extent that doing so is within their power. In general, he says, 'couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information'. 'To fail to treat our children's diseases is to harm them. To fail to prevent them from getting depression is to harm them. To fail to improve their physical, musical, psychological and other capacities, is to harm them, just as it would be to harm them if we gave them a toxic substance that stunted or reduced these capacities'.

According to this argument, if parents are using IVF to have a child and they discover that some embryos are likely to develop genetic disorders or are otherwise susceptible to disease, they should pass over those embryos in favour of embryos that show no risk of disorders. Yet Savulescu's duty of 'procreative beneficence' extends further, beyond protecting children from disease and disorders: it also imposes an obligation to seek enhanced traits of intelligence and memory, for example, to the extent this might be possible. With this obligation, if it were possible to know that some embryos would go on to develop into children with stronger teeth and bones, sparkling intelligence, stunning good looks, resistance to disease, while others would grow up less endowed, parents

should select only the former embryos for implantation. Savulescu believes doing otherwise amounts to a moral lapse in parental responsibility. As a general rule, he says parents should work to ensure 'the best opportunity of the best life' (Savulescu, 2001).

From a perspective like this, it would seem that parents who take active steps to have a deaf child lapse in their duty as parents. Yet this conclusion follows only if Savulescu is right about his interpretation of parents' duties. I believe this analysis is overreaching, and this can be seen by a consideration of Savulescu's own summary of what's important for parents: he says that parents should not obstruct their children's capacities to form and act on their own conception of a good life, in which wisdom and pleasure are generously mixed (Savulescu, 2001). In fact, this overall goal does not require the overarching pursuit of the best possible life for the best possible children. There are many ways with which to frame and pursue a good life, not all of which – perhaps not even most of which – require that people have the greatest intelligence they can have, the greatest memory they can have, the greatest athletic ability they can have, and so on. People with disabilities are frequently as able as anyone else to identify a life that is good for them, to pursue it and to achieve it. Human life is meaningful in many ways, and it is simply not true that human life is meaningful only to the extent that people have physical or psychological capacities that set them head and shoulders above everyone else.

Deaf children are fully capable of identifying for themselves the conception of a good life – for example, what kind of work to pursue, what kind of relationships to form, how to spend leisure time, whether to have children or pets or both, what social injustices to protest, how much schooling to pursue and where – and deaf people are fully competent to work towards those goals. There is nothing about deafness by itself that undercuts the pursuit of meaningful human life in the way that extreme cognitive deficits, incapacitating diseases and disordering pain do. By itself, deafness does not necessarily interfere with people's abilities to frame and pursue a conception of a life that is good for them. Deaf people do learn, do form and maintain relationships, and do generally live and love in meaningful ways.

Moreover, some disadvantages that attend deafness are social artefacts. For example, in the past some deaf people faced discrimination because of the view that deafness indicated substandard intelligence or social worth. By contrast, at least one community – the island of Martha's Vineyard in Massachusetts – came to an accommodation of deafness without many parallels in history. Because of the high prevalence of deaf people there, many hearing islanders across the decades learned sign language with the result that deafness was not socially stigmatized or especially burdensome (Groce, 1985). In other words, the degree of social disadvantage that attaches to deafness depends on social factors rather than the anatomic or physiological facts of deafness.

Contrary to Savulescu's interpretation of the duty of procreative beneficence (2001), it does not follow that parents have the duty to ensure that their children be situated to have the best possible life. All that is required of parents is that they work to ensure that children are capable of identifying values and goods that are important to them and are, in some measure, capable of pursuing them. What is required of parents is only that they make choices that offer reasonable expectations of meaningful lives (Murphy, 2005).

Against this re-scaled set of parental responsibilities, a number of things can be said in favour of parents trying to have deaf children: deafness is compatible with the ability to pursue a meaningful and rewarding life. Its disadvantages can be offset by social circumstances. If a society neither stigmatizes nor ignores deaf people, deaf and hearing people can live alongside one another to mutual benefit. If this were the whole story, we would be at the end of the moral analysis, but there is more to the story.

## The case against choosing deaf children

Despite the fact that deafness does not disable the possibility of meaningful life and even though society can alleviate some of the disadvantages that attach to deafness, other moral considerations suggest that parents should not ordinarily take steps to have children with disabilities, including deaf children.

Whatever else it is, deafness is a disability in the sense that it represents an impediment in a major life function. Federal law in the USA affords deaf people certain protections in employment, among other things, precisely for that reason (US Equal Employment Opportunity Commission, 2006). Deafness is an impediment insofar as it represents the loss of a capacity that has intrinsic and extrinsic value in human life. Hearing has intrinsic value insofar as it is good simply to hear: soothing voices, a child's coo, words of love, a dog's bark, music that connects one to a time and place, and any sound, really, that interests and delights. Hearing has extrinsic value as well insofar as it opens doors to relationships and serves protective functions. Through hearing and speech, people build relationships, communities, cultures and cultural artefacts. In other words, hearing is a *prima facie* human good in itself and a good in its effects insofar as it opens up rich possibilities in human life and relationships.

There is virtual consensus that hearing is valuable to human beings, a consensus expressed first and foremost by the fact that human beings do not – as a virtually unbroken rule – deafen themselves, either as children, as adolescents or as adults. The desire to forgo the benefits of hearing is extremely rare in adults. According to a British psychologist, one woman did engage in a half-hearted attempt to deafen herself: she stifled her hearing through oiled cotton balls inserted into her ears and presented herself as deaf, although her hearing was never in fact impaired. The therapist concluded that the woman's behaviour was the consequence of certain psychological disorders rather than an actual wish to be deaf (Veale, 2006). Examples like this notwithstanding, most people simply do not want to lose the capacity to hear and go to great lengths to retain it, when disease and injury threaten it. (By comparison, a good number of people are willing to forgo sex in order to participate in celibate religious life, geographically isolated work assignments, and so on, which suggests that people are more willing to give up sex, either temporarily or permanently, than to give up one of their senses altogether.)

For the sake of the argument, let us consider the ethics of an adult who wished to become deaf: if that were an abiding interest and not a transient psychological symptom, would it be a morally defensible choice to deafen oneself? By appealing to Utilitarian logic, one could say that adults have the right to deafen themselves in the name of their personal happiness, so long as they are clear about the consequences of doing so and willingly assume the risks

of so drastic a change. This kind of choice does not inflict harm on anyone else; it is self-regarding within the meaning of John Stuart Mill's account of decisions which belong to oneself alone (Mill, 1989). In other words, so long as people knew what they were getting into, one could argue that from a Utilitarian point of view that society would have to abide by a rule of non-interference if competent adults really wished to deafen themselves.

This same conclusion might hold even if people who sought to deafen themselves were not fully competent. By way of explanation, consider that elsewhere in psychiatry, accommodations of mental disorders are made even though they do nothing to alleviate the underlying disorder. For example, US psychiatry defines persistent cross-sex identification as a disorder (gender identity disorder) (American Psychiatric Association, 1994). In the absence of any identifiable treatment for this disorder, some psychiatrists recommend that adults take steps to bring their bodies into conformity with the desired sex: they use various hormones and surgical techniques to do so, despite the fact that these interventions do not alleviate the very condition that is at issue, the cross-sex identification. The British therapist (Veale, 2006) who reported the case of the woman who wanted to be deaf expressed a similar approach: in discussing the case, he wondered whether it could be acceptable to help adults deafen themselves if therapists had no other tools available for treating the underlying disorder, no other way to bring comfort to a person deeply troubled by his or her own hearing. To be sure, there is some precedent in psychiatric medicine for taking that kind of approach, which is again supported by the willingness of the individual in question to assume the risks of the interventions.

When discussing the use of assisted reproductive treatments to effect deafness in children, however, we cannot use the individual's autonomy as a fulcrum of decision making. Neither can we ask the not-yet-existing child to balance risks and benefits. We can, however, ask whether a decision to elect a disability serves the child's better interests. The better-interest standard serves as a heuristic device, a method for evaluating different claims when trying to determine a course of action in contested situations, and that line of analysis has relevance here. Using the better-interest standard can illuminate whose interests are at stake in making a choice in favour of a disability and help determine whether the person most affected by that choice – the child – is its primary beneficiary. Can it be said that choosing deafness as a trait in a child serves the child's better interests?

First of all, asking how deafness serves a child's better interests is not the same as asking how deaf children benefit the parents or the deaf community at large. Taking steps to have deaf children can certainly benefit the parents: if parents very much want a deaf child, they will presumably be happier with a deaf child as against a hearing child. If deaf people are worried about the future of deaf culture, they might well wish to have children in order to help support that culture. After all, most deaf children are born to hearing parents. If hearing parents consistently resort to measures to initiate or restore hearing in their deaf children – and if those measures become more clinically successful through research – one can anticipate that there will be fewer deaf people in the future. Against this backdrop, some deaf parents might want deaf children in order to bolster deaf culture, deaf culture being the totality of social practices and accomplishments of deaf people. But both these motives, important as they may be, confer value on the deaf child only in an instrumental way. The children are

welcomed as instruments of other expectations, and motives like these do not demonstrate that choosing deafness is in the child's own better interests.

A more philosophical argument makes the same point in a different way: it is difficult to argue that deafness confers a benefit on a child that is both valuable in itself and in its effects. It is not clear in what way deafness could be considered intrinsically valuable. Not hearing any sound cannot be said to have any intrinsic value: deafness is a lack, a deficit, an incapacity. By contrast, hearing does have intrinsic values: hearing affords pleasures that are valuable as the experiences they are and require no further justification. Deafness may be extrinsically valuable for a child if non-hearing is the occasion of an introduction into a culture that it would not have otherwise entered, if deafness is also the occasion of more developed skills in sight, touch, and taste, for example. Those opportunities depend, of course, on the social circumstances of the child. In some times and places, deafness will be more damaging than not. A deaf child lucky enough to be born in a society that has a flourishing deaf culture will certainly experience far less deprivation than a deaf child born into a more rudimentary society. In other times, the social conditions for deaf people have been far more favourable. Even so, no matter what extrinsic values attach to deafness in a particular culture, deafness can never offer the intrinsic values attached to hearing.

To argue this way is not to say that the loss of hearing incapacitates meaningful human life or that the disabled deserve a reduced social standing, for both these views are surely not true. It is to say that hearing represents a richness in human life that, all things considered, is important to have and protect, and its loss amounts to an impediment in a major life function. It is to say that it is better that children have the intrinsic and extrinsic goods that flow from hearing available to them rather than to close off those benefits, even if it is done in a way that minimizes harm to children and even if there is some compensatory value to deafness. Depending on the extent to which they are affected, deaf people lack the capacities of hearing and its instrumentality in communication, relationships, self-protection and the arts. Those are not negligible losses, which is to say that choosing deafness in a child may be morally suspect especially if it is chosen for reasons that benefit the parents or deaf culture primarily.

This general analysis can be applied to all parents who may wish to have a child with any disability, and certainly some parents might wish to have children with disabilities other than deafness. In the course of discussing parents who might elect to have children with disabilities, Savulescu (2001) seems to assume that it is only parents with disabilities that would wish to have children with disabilities. But it is not clear that only deaf parents would want deaf children (e.g., some parents willingly adopt deaf children) or that only deaf parents should be entitled as a matter of moral right to use assisted reproductive treatments to have deaf children. Some hearing parents might wish to have deaf children for a variety of reasons, for instance, intentionally adding another deaf child to their family after a first unanticipated deaf child was born to them. In general, most parents are likely to not want children with disabilities, but that preference could change if people with disabilities become more socially visible and accommodated. Some parents without disabilities might well believe that a child with a disability could confer a benefit on them, their families or society at large. Some parents might wish to have children whose lives challenge assumptions that prevail in social policy and

practices, assumptions about what it is to have a meaningful life, how physicians should care for people with disabilities, and how buildings and cities should be designed in terms of accessibility. These parents might wish to blend ability and disability equally in their families. In short, there is no reason to expect that the question of disabilities in children is only a question for parents with disabilities. Yet the moral question for all would-be parents of children with disabilities remains the same, regardless of their motives: whether electing a disability in a child works to the benefit of the child, of the parent or of the society at large. For all the reasons there might be for wanting children with disabilities, still the most important question to be asked is whether that trait confers benefit on the child. Without a convincing account of how children themselves benefit by intrinsically valuable capacities being withheld (by the selection of deafness, blindness or any other disability), parents should ordinarily forgo taking steps to have children with disabilities.

## Should society stand in the way of parents taking steps to have deaf children?

What matters of law and policy follow from these observations? Should the law prohibit interventions that would foreseeably result in the birth of deaf children or children with other disabilities? Savulescu (2001, 2002, 2007) offers three arguments why the law should not intervene against parents wanting to select for that disability.

### Reproductive liberty

First, Savulescu (2001) invokes the general presumption of reproductive liberty: 'For purposes of public policy, there should be a presumption in favour of liberty in liberal democracies. So, ultimately, we should allow couples to make their own decisions about which child to have.'

In general, the law does not supervise people's motives for wanting to have children nor inspects the quality of their wish to become mothers and fathers. Parents have children for all kinds of reasons, many of them worthwhile and others more dubious. Some parents have children to express and deepen their commitments to one another, to take pleasure in the care and rearing of children and to enrich their families. Many people take joy from maturing into the roles of mother and father. By contrast, some parents may wish for children in order to hold failing relationships together, because of transient desire for companionship, because contraception fails, or for no really good reason at all. As far as the state is concerned, people may choose to have children for reasons that are important to them, not for reasons that must make sense to others or that meet a publicly defined standard of acceptability.

The philosophical question to be asked at this juncture is whether parents who take steps to have deaf children are doing something that is different enough in degree or kind from all other choices that people make in regard to children that would justify legal intervention against that action. One could say that what differentiates the issue of choosing children with disabilities is not the motive of the parents (which are not evaluated by the law except in adoption or foster care) but the effect of the motive on children. But to limit parents' choices for assisted reproduction



would be to ignore the fact that parents do choose to have children with disabilities elsewhere. This occurs when parents know by prenatal diagnosis that a fetus has a disease or disorder; some choose to continue the pregnancy and take the child into their families. In these cases, the law does not intervene to prevent the birth of these children even though, in a sense, these parents are choosing to have children with disabilities (in the sense that they take no steps to avoid the children). Despite the fact, for example, that Down syndrome is widely tested for in pregnancies in the USA, some parents choose to go forward with pregnancies even after learning that their child is affected. In one corner of the world, the majority of pregnancies identified as affected by Down syndrome are not terminated (Zlotogora *et al.*, 2007). Down syndrome affects children in varying ways but, in the most severe cases, children with Down syndrome are probably worse off than children born without hearing, yet society does not require women to bring pregnancies involving Down syndrome to an end. As a matter of consistency, it is therefore hard to make the case that the law should bar parents who take steps by insemination or other treatment to have children with disabilities but take no action against parents who take no steps to avoid having children with foreseeable diseases and disorders, some of which are far more grievous than deafness.

In looking to the law to limit the use of assisted reproductive treatment to select children with disabilities, an inconsistency appears because the law does not otherwise limit parents' wishes in other instances involving children with disabilities. Yet by itself, this inconsistency does not create an insurmountable defence of the right to have children with disabilities. It would be possible, after all, to argue that the law should intervene against people who knowingly let pregnancies involving diseases and disorders go forward. In other words, in the name of protecting children from disabilities, the law might, to be consistent, erect obstacles to all choices that end in children having disabilities. It is certainly not my view that the law should do this. This point is simply to show that if the law acted against all choices that ended in a child with a disability, it would not be possible to argue that the law fell prejudicially only on some parents (those using assisted reproductive treatment to have children with a disability) but not on others (those who choose not to terminate pregnancies when fetal diseases and disorders are prenatally diagnosed) even though the outcomes would be equivalent in terms of the effect of disabilities in children.

## Non-identity effects

Because of the limitations of the foregoing argument, it is perhaps no accident that Savulescu (2002) goes on to invoke non-identity arguments to help make the case against legal interference with parents' choices. According to this line of argument, children are not harmed when chosen as deaf because any such children – who are deaf in every moment of their existence – have not been deprived of anything they once had or expected to have. The alternative to being a deaf child, in a strict sense, is being no child at all, and being a non-hearing child is better than not existing at all. Generally speaking, a child has no prior claim to existence only under certain conditions, and Savulescu (2002) therefore concludes that 'Because reproductive choices to have a disabled child do not harm the child [in the sense just identified], couples who select disabled rather than non-disabled offspring should be allowed to make those choices, even though they may be having a child with worse life prospects.'

According to this kind of argument, which was original with that of Derek Parfit (1986), a child's existence is always presumptively better for the child than non-existence. If so, then even if born with deafness – through the use of gamete selection for example – a child is still better off that way than not existing at all. This line of analysis is superior to the previous one because its fulcrum is not consistency across parental decision makers but the value of the child's life as measured by the value of the life to the child. It is hard to argue that parents should be restrained by the law from having children whose lives are valuable to the children themselves, whether or not children have those lives because their parents relied on assisted reproductive treatment or prenatal diagnoses.

## Insufficient public knowledge

Third, Savulescu argues that the body politic does not have the kind of knowledge about the 'good life' for human beings that would legitimize it acting in ways to restrict choices in the name of protecting that good life (Savulescu, 2002). Imposing a conception of the good life on every parent, he says, is at best overconfidence and at worst arrogance (Savulescu, 2007).

This is an epistemological argument that governments (or legal bodies) do not have the knowledge that would justify their acting against parents in their decisions about children, and the argument is even stronger than Savulescu suggests. Not only do governments lack this knowledge, it is not clear that governments could ever have it. There is no one inherently desirable way for human beings to pursue a good life. If so, it follows that the pathways to good human lives are infinitely variable. Not only are governments large and lumbering institutions, when it comes to codifying acceptable conceptions of good human lives, they would be incapable of knowing in advance that certain lives are unacceptable and therefore not justified in taking steps to prevent them.

## Is there a case for legal constraint?

Taken collectively, these three arguments offer strong *prima facie* reasons why the law should not interfere with the choices of parents who take steps to have children with disabilities. But if these moral reasons are persuasive, we must also reconsider the strength of Savulescu's claim that choosing disabilities harms children and/or violates a parent's duties properly speaking. Let us recall that Savulescu (2007) says: 'A parent who intentionally inflicted deafness on his or her child, or failed to treat it, would be abusing the child.' He also specifically says: 'There is no difference, morally speaking, between causing a harm and deliberately and avoidably allowing it to occur.' But the law doesn't see it this way, which means that the harms done to children in each of these cases (intentional or by omission) are not equivalent. The law should certainly intervene against a parent who deafens an infant, but Savulescu (2005) himself has stated a strong case why the law should refrain from intervening against a parent whose gamete selection leads to a deaf child. It is therefore also not clear in what sense a parent has the duty to choose the best possible life for children, if they are, legally speaking, free to do otherwise. It seems that the status of the principle of procreative beneficence is more an aspiration than a duty properly speaking.

This conclusion shows once again the limitations of the idea that parents have a limited duty in regard to the lives of their children,

i.e. not to ensure that their child has the best possible chance of the best possible life. In fact, by pointing to the importance of reproductive liberty, it becomes clear that parents do not have that duty in any strong way. In other words, if parents may take steps to have a child with a disability – rather than otherwise taking steps to confer the advantages of robust physical and psychological health upon them – it is not clear in what sense parents have a duty to do any such thing.

As a side note, it can be mentioned that some advocates think the law should intervene and limit the choices of parents in regard to children with disabilities. In 2005, a United Nations committee debated a proposal to recommend the prohibition of all abortions of fetuses identified as having disabilities (Arieff, 2005). This proposal would have required the legal rollback of abortion (in jurisdictions where it is legal) for one of the most important reasons that parents terminate pregnancies: to avoid genetic and developmental diseases and disorders. Advocates of this view tend to believe that choosing among children on the basis of prenatal diagnostic tests works against the interests of the disabled by stigmatizing them and reducing the overall number of people with disabilities. Fortunately, this recommendation died in committee and for good reason.

The improvement of life for people with disabilities does not require that the law override reproductive liberty. It is entirely possible to improve the social circumstances of people with disabilities in education and employment without also curtailing the rights of parents to make decisions about their children. No one in society is more directly affected by children than their parents and, for almost this reason alone, parents should have a fundamental say about the children they have. Certainly, parents themselves are better situated than anyone else to decide the effect that children with disabilities would have on themselves and their families. The non-identity arguments do not apply here directly insofar as abortion involves a decision that does not fully predate the existence of the child, but it would be hard to argue in any case that a child has the right to be born with a disability. Even if we granted such a right for the sake of the argument, it is not obvious why that right would be absolute. Most rights are *prima facie* rights, which is to say that they may be set aside for important reasons so long as certain procedural protections are in place. Even if we granted that children had the right to be born with a disability, other rights could be invoked to override that right, such as the right of the parents to protect themselves against undue hardship or the right to decline responsibilities they cannot hope to meet. In any case, it would be a colossal act of overconfidence and arrogance for the law to intervene and say that – regardless of circumstance – all parents must go forward with pregnancies discovered to involve disabilities, regardless of the magnitude of those disabilities and regardless of the effect of those disabilities for children themselves and their families.

## A principled guide to enhancement

The principle of procreative beneficence has usually been discussed for its implications in regard to avoiding diseases and disorders. However, this same principle also has implications for identifying upward limits of ‘enhancement’ as well as transgenic human beings (who are also referred to as post-human).

If parents have a responsibility to protect their children’s

capacities to form a conception of a good life and to be able to pursue that life, they should – for that very reason – reject any enhancements that interfered with that prospect. This may sound paradoxical, but the advantages that parents seek for their children via enhancement could undermine their prospects for the best life possible for them. For instance, it might be possible to increase the range of human hearing, and in some circumstances that would be useful, for example, to musicians, spies and other people whose interests and work depend on acute hearing. Yet increasing the acuity of hearing (how sensitive one is to sound) and its range (to include sounds not heard by humans at present) could have damaging effects. Humans could well be disturbed to hear the sounds that are now only within the hearing of dogs, wolves and other animals. Increased hearing could lead to extreme hypersensitivity, especially in urban environments: noise can be extremely distracting to work, play, and sleep. The same could also be true of enhancements of the other senses, where increased capacity translated into hypersensitivity with disabling effects.

Suppose increased body strength took the form of a human having the arm strength of a chimpanzee. While this might be useful in some specific contexts, it could well prove a liability in the totality of a person’s life. Increased memory could perhaps interfere with the ability to form and maintain relationships if people with this enhanced capacity found themselves hypersensitive to interactions and relationships in one way or the other. Imagine if one could never forget all the real and imagined slights that pile up in life. Imagine not being able to forget a single moment of tension with parents, siblings, friends and others. Would the human capacity for familial bonds and friendships be enhanced under these circumstances or undercut? Some enhancements could very well carry unintended side effects that make the intrinsic and extrinsic rewards of human capacities more difficult to achieve.

The philosophers Alan Buchanan, Dan W Brock and Norman Daniels (2000) have argued that there are traits that are valuable to people as people, no matter who they are, where they live, how old they are, etc. They say these traits are intelligence, memory, self-discipline, impulse control, foresight, patience, sense of humour, cheery temperament, empathy and the ability to live peaceably and sociably with others. In many environments, these traits are genuinely rewarding for people and those around them. However, would enhancement of any of these traits necessarily improve people’s lives? People with enhanced impulse control might expose themselves to a lot less risk, but they might also be socially passive where more boundary-testing traits would be advantageous. People with enhanced humour might be highly entertaining to themselves and others, but they too might be excessively tolerant of hurtful relationships and social injustice: would it all be laughed away? People with enhanced patience might find themselves more easily victimized than others. The point being made here is that certain enhancements might be useful in particular circumstances but carry costs in other social contexts. It is also easy to imagine that an excess of any of these traits could inhibit other traits on the same list and undermine a person’s wellbeing that way.

Some human capacities and traits make human life valuable and meaningful: they carry rewards that are valuable in themselves and in their effects. Morally speaking, parents should not take steps that interfere with their children’s abilities to participate in these valuable human goods, to form intimate relationships, to understand themselves and the world around them, to appreciate

beauty and to live in community with others. Part of what it means to protect children, therefore, is to protect them from any disability that interferes with these capacities and to protect them from any enhancement that has the same effect.

## Conclusions

Overcoming infertility is hardly the last frontier of reproductive medicine. Biomedical research will continue to open options through which parents may choose traits of their children, traits they hope will have value for their children. Most parents employ assisted reproductive treatment to avoid diseases and disorders, but others hope for interventions that will confer enhancements on their children. By contrast, some parents have taken steps to have deaf children, and the door appears open to choosing children with other disabilities as well. Deafness is not an insuperable obstacle to human happiness, not by a long shot. Yet all things considered, it is better that people hear than not hear, just as it is better that they see, smell, touch, and taste, rather than be without those intrinsically rewarding capacities. In general, parents should not try to have children with disabilities, defined as impairments of major life functions, including deaf children, blind children, or neurologically diminished children. In general, parents should be guided by the standard of the child's better interests when making choices in the selection of traits, and they should work to protect the intrinsic values to be found in human capacities.

Deaf people will not disappear altogether even as biomedical research continues to make deep inroads against hearing loss. Some people will always become deaf through accident, disease and novel genetic mutations. Genetic counselling will, however, probably continue to decrease the numbers of people born deaf, at least in the parts of the world where this service is available, and advances in hearing technology will offer people more options to overcome deafness as well. These trends may work to diminish deaf culture, but that diminishment might paradoxically offer new opportunities for cohesion and strength: a smaller group may rally itself more readily for social and political reasons. In any case, it is not clear why the diminishment of deaf culture should serve as a justification for parents taking active steps in order to have deaf children, especially when hearing has intrinsic values that cannot by definition be compensated through immersion in deaf culture. In other words, it is philosophically unproven at this point how disability serves a child's better interests. Parental choice in favour of deafness in a to-be-born child is morally problematic, though not as wrong as inflicting deafness on an existing child.

Even as there is a place for deaf people in the human community, it is also important to protect the human capacities that are goods in themselves and their results, and hearing is exactly that kind of good. Because deafness and other incapacities fall short by comparison, parents really should not choose disabilities in children who do not otherwise have to have them, and clinicians should be wary about accommodating parental requests for help in using assisted reproductive treatment this way. For the same reasons, parents who want to tinker with their children's future by enhancing their traits should also be wary about the ways in which so-called enhancements could backfire and undermine the value of their children's lives to the children themselves.

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*Presented at Third International Conference on Science and Ethics of Assisted Human Reproduction and Stem Cell Research, 1–2 November 2007, Berlin.*

*Declaration: The author reports no financial or commercial conflicts of interest.*

*Received 8 April 2008; refereed 23 April 2008; accepted 10 November 2008.*

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