

Reproductive liberty, disease and disability



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Abstract

There are many arguments from many sides, which purport to give reasons for limiting access to reproductive technologies and to gene-based reproductive procedures. There is one reason to reject them all, and that is that they do not point to dangers or harms of sufficient seriousness, probability or proximity to justify the limitation on human freedom that they require. This paper shows why this is so and argues that reproductive liberty must also include the liberty to select against disability both for moral and for libertarian reasons.

Keywords: *democracy, disability, liberty, reproductive choice, screening*

Introduction

There are many arguments from many sides, which purport to give reasons for limiting access to reproductive technologies and to gene-based reproductive procedures. There is one reason to reject them all, and that is that they do not point to dangers or harms of sufficient seriousness, probability or proximity to justify the limitation on human freedom that they require. (Where of course they can point to such dangers we have reasons to consider them carefully.)

The democratic presumption

One of the presumptions of liberal democracies is that the freedom of citizens should not be interfered with unless good and sufficient justification can be produced for so doing (Harris, 2003, 2004). The presumption is that citizens should be free to make their own choices in the light of their own values, whether or not these choices and values are acceptable to the majority. Only serious danger either to other citizens or to society is sufficient to rebut this presumption, and the seriousness has of course at least two axes, one of the magnitude of the danger, the other concerning probability or proximity – how real and present it is. If anything less than this high standard is accepted, liberty is dead.

This presumption is sometimes expressed as saying that

citizens should enjoy the maximum liberty which is compatible with a like liberty for all. This way of putting the liberal presumption acknowledges that one legitimate limitation of the liberty of the individual is where its exercise limits the liberty of others, or threatens others with significant harm.

The alternative or, for the pedantic, ‘an alternative’ to a presumption of liberty is what John Stuart Mill called the ‘tyranny of the majority’ (Mill, 1859). To avoid this tyranny, the presumption in favour of liberty can only be rebutted by showing that the exercise of liberty for some either infringes the like liberty for others, or causes real and present dangers of significant harm to either individuals or society. It is not enough that others are made uncomfortable by its exercise, nor that they do not like it, nor that they find it repugnant.

Upholding liberty, safeguarding a free society, is not cost free. One of the costs is that citizens must be prepared to accept that others are free to do things that they themselves would not do and would not wish to do, and even things that make them uncomfortable or which they find abhorrent. The liberty to do only those things of which the majority approve is no liberty at all.

Freedom of religion and freedom of conscience are good litmus tests here. Since for all monotheistic religions there can

be only one true god it follows that all non-believers are not only mistaken but heretical. To protect their souls, or to protect the one true faith or to avoid offence to God, infidels should be suppressed. That we do not burn heretics signals our commitment to freedom and to democratic values. Equally if I judge you to be seriously morally wrong I must think you should not do what is wrong. But unless I can also show that what you propose, or are doing, is significantly harmful to others or society, then a commitment to democratic values means that I must leave you room to differ from me. What consenting adults do in private is (almost always) their own affair. Such exceptions as there may be to this are beyond the purview of this paper. The exceptions must establish serious harm to others or society.

Thus the burden of proof is not on those who defend liberty but on those who would deny it.

Those who would exercise reproductive liberty do not have to show what good it would do, rather those who would curtail freedom have to show not simply that it is unpopular, or undesirable, or undesired, but that it is seriously harmful to others, or to society, and that these harms are real and present, not future and speculative.

Freedom, disability and disease

It is important to emphasize that arguments in favour of choice and indeed of freedom are just that. It is a paradox that many of those who oppose reproductive choice do so partly out of fear that because some may wish to choose not to bring, for example, disability into the world, exercise of this choice may somehow lead to denying people the freedom to have children with disabilities if that is what they want to do. Those with disabilities want the freedom to have disabled children if that is their choice, but they seek to deny to others the freedom not to have such children if that is what they want. This is not only inconsistent but also distinctly illiberal.

For the remainder of my talk I want to concentrate on disability because this is the most plausible (this is not of course to say anything about the degree of plausibility) of the arguments adduced against reproductive liberty.

Is it better not to have a disability or not to be a person with disabilities?

Many people talk as if the disabled are simply differently abled and not harmed in any way. Deafness is often taken as a paradigm case here. In so far as it is plausible to believe that deafness is simply a different way of experiencing the world, but by no means a harm or disadvantage, then of course the deaf are not suffering from any disability. But is it plausible to believe any such thing? Would the following statement be plausible? 'I have just accidentally deafened your child, it was quite painless and no harm was done so you needn't be concerned or upset!' Or, suppose hospital staff were to say to a pregnant mother 'unless we give you a drug your fetus will become deaf, since the drug costs £5 and there is no harm in being deaf we see no reason to fund this treatment', they would be acting reasonably, unless of course it is in fact better not to be deaf (Harris, 2001).

Does an attempt to reduce or eradicate disability or disease imply that those with disability do not have a worthwhile life or have no right to life?

Choosing between existing people for whatever reason always involves the possibility of unfair discrimination because there will, inevitably, be people who are disadvantaged by the choice. Choosing which sorts of people to bring into existence or choosing which embryos or fetuses to allow to become persons can never have this effect because there is no one who suffers adversely from the choice, and it is easy to see why.

My parents were under no obligation to attempt to conceive in any particular month. If they had conceived in any month other than December 1944 I would not have existed. Not only are none of my possible siblings, who have been irrevocably harmed by this choice of my parents, complaining, I can assure you that had my parents chosen not to attempt to conceive that month (or had their attempt – if that is what it was, been unsuccessful) you would not have heard me complain.

Enhancements

Suppose some embryos had a genetic condition that conferred complete immunity to many major diseases – HIV/AIDS, cancer and heart disease for example – we would surely have moral reasons to prefer to implant such embryos given the opportunity of choice. But such a decision would not imply that normal embryos had lives that were not worth living or were of poor or problematic quality. If I would prefer to confer these advantages on any future children that I may have, I am not implying that people like me, constituted as they are, have lives that are not worth living or that are of poor quality.

Our commitment to intervene in the natural lottery of life

In one of the most famous and influential philosophical books on this subject, Allen Buchanan has argued that the motive we have for intervening to treat or cure disability, and the same would presumably go for the treatment of disease, is 'for the sake of equal opportunity'. He says '... some of our most basic social institutions reflect a commitment to intervening in the natural lottery for the sake of equal opportunity' (Buchanan *et al.*, 2000, p. 71). To be sure, Buchanan's main concern is to show how the concept of equality of opportunity requires extension to embrace what Scanlon and others have termed a 'brute bad luck' conception of equal opportunity – a conception which believes in intervening to mitigate disadvantaging factors that are beyond the control of the subject of those factors (Scanlon, 1989). This is a constantly repeated, but not universal, gloss on the moral reasons given for therapeutic or even enhancing interventions in Buchanan *et al.* (2000). Again: 'In other words, equal opportunity has to do with ensuring fair competition for those who are able to compete and with preventing or curing disease that hinders people from developing the abilities that would allow them to compete' (Buchanan *et al.*, 2000, p. 74). Buchanan and colleagues are self-consciously following Daniels and Rawls here. 'As Norman Daniels has argued, the case for a moral

right to health care relies, at least in part, on the fact that health care promotes equal opportunity' (Buchanan *et al.*, 2000, p. 73). Here the move from simply extending a conception of equality of opportunity to confirming that conception as an important part of the moral right to health care becomes clearer. It is this idea, the idea that the moral reasons we have for pursuing health or for enhancing the functioning of human beings, in short, our 'commitment to intervening in the natural lottery' of life, has much to do with equal opportunity or the 'ability to compete', that is genuinely bizarre.

Of course equality of opportunity is something we should try to maximize in the delivery of improvements in health or in functioning, but it seems only tenuously and contingently connected with our moral reasons for so doing. Suppose there was a painful condition which affected some people but not others. It did not however affect people's ability to compete or affect the pursuit of opportunities. I believe we would have exactly the same compassionate motive and moral reasons for intervening in the natural lottery to remove this condition as we would have if it was also 'competition affecting'. This latter factor seems to add nothing to our moral reasons for alleviating the condition.

The commitment to intervene in the so-called 'natural lottery' would (or should) surely be there quite independently of any contribution it makes to equal opportunity, although, as I have indicated, in pursuing health and/or enhancement for the good reasons we have for so doing, we should attempt to ensure equal opportunity to access such goods. So the claim that 'the case for a moral right to health care relies, at least in part, on the fact that health care promotes equal opportunity' seems false. Equal opportunity might in some circumstances be a further additional reason to support the moral right to health care, but to regard equal opportunity as an essential part of the moral basis for such a right or indeed the moral motivation for establishing such a right is doubtful. I have argued elsewhere (Harris, 1980, 1985) that where the provision of health care will prevent harm to human beings, the moral argument for delivering that care is as complete as it needs to be. Equal opportunity can say something about selecting who to help in conditions of scarcity, but it seems an inappropriate candidate for a factor that might explain or justify 'a commitment to intervening in the natural lottery'.

Suppose now all people were affected by a debilitating condition so that there was no inequality of opportunity, but, *inter alia*, the opportunities for all were reduced. The unnecessarily reduced opportunity would itself constitute sufficient moral reason for 'intervening in the natural lottery', not for the sake of equal opportunity (nor surely for the sake of competition), but for the sake of enhanced opportunity or enhanced functioning. Equally if, as we discussed when considering enhancement, a new protective treatment were to be developed, then even though before implementing it all would be equally disadvantaged by not having the treatment, the moral imperative to introduce it would not refer to equal opportunity at all and that case would not be enhanced by any such appeal.

Buchanan *et al.* (2000, p. 74) note that: 'It is possible, however, that some natural inequalities are not departures from normal species functioning but nonetheless so seriously limit

an individual's opportunities that he or she is precluded from reaching the threshold of normal competition. In such cases, genetic intervention might be required if it were necessary to remove this barrier to opportunity.' [This way of defining health and illness is derived from Boorse (1981) but is used also by Daniels (1996, p. 185) and many others.] Anticipating the question as to the precise circumstances in which this might be true Buchanan answers: 'Whether it does will depend on what the normal distribution of various characteristics is and how that relates to the most fundamental requirements for successful participation in social co-operation in a given society' (Buchanan *et al.*, 2000, p. 75). It seems implausible to think that either normal species functioning or successful social co-operation are the key ideas that license interference in the natural lottery of life, and it is not hard to see why.

We do not die of old age but of the diseases of old age. It is species-typical of us to die of these but it is not necessarily necessary that we do. If we could systematically treat these diseases in a way that enabled tissue to regenerate (stem cell therapy perhaps), this too would be enhancing, but would be another case of treating disease in particular ways that also constituted an enhancement therapy.

A number of the world's leading laboratories are working on radical therapies that would also constitute enhancements. For example, David Baltimore's lab at Caltech is working on the possibility of engineering resistance or possibly immunity to HIV/AIDS and cancer into cells (Baltimore, 2003). If this work were to be successful, the benefits would be incalculable. Whatever else they were, they would also constitute radical enhancement since, alas, immunity to HIV/AIDS or cancer is not part of 'normal species functioning' for our species. Equally other groups (Weinrich *et al.*, 1997; Bodnar *et al.*, 1998; McBrearty *et al.*, 1998) are working on life-extending therapies using a combination of stem cell research and other research into the ways that cells age both to regenerate ageing or diseased tissue and to switch off the ageing process in cells. Again to live several hundred years and perhaps eventually to become 'immortal' is not part of normal species functioning for our species.

These two sets of possibilities would be radically enhancing to the extent that if we manage to find ways to make such changes permanent, to insert them into the germline for example, 'we' might no longer be human, we would have evolved into a new distinct species. Whatever one thinks of these prospects, it is parochial in the extreme to imagine that our ethical response to them would depend on whether or not the failure to introduce these possibilities would 'so seriously limit an individual's opportunities that he or she is precluded from reaching the threshold of normal competition'. We have to ask what is the motive to introduce these and other new therapies in the first place? It cannot be to restore normal species functioning because immunity to cancer is not part of this. Nor would we plausibly want to make people immune to cancer in order to help people to reach 'the threshold of normal competition'. Normal competition and normal species functioning do not constitute reasons for considering the introduction of these and many other new therapies or enhancements. Nor could the idea of equal opportunity help us here, opportunity perhaps, but not equal opportunity.

Consider twin sisters, both of whom suffer from cancer. One is curable, the other not. We do not think that equal opportunity requires us to leave the curable twin untreated because we cannot treat both, and our moral motive and reason for treating the curable twin has nothing to do with equality. It has everything to do with saving a life that can be saved or alleviating pain, suffering and distress.

The moral imperative for David Baltimore's work, for example, is that it is required for what Hobbes (1651) referred to as 'the safety of the people' ['The office of the sovereign, be it a monarch or an assembly, consisteth in the end for which he was trusted with the sovereign power, namely the procuration of the safety of the people; to which he is obliged by the law of nature . . .'] (Hobbes, 1651, 30:1)] and for what others have called 'beneficence or non maleficence', or welfare. These are imperatives quite independently of their impact on or compatibility with equal opportunities or equal justice. A moment's reflection shows why this must be so. There is a vast shortfall in the availability of donor organs for transplantation in the world, certainly in the USA and UK. While we cannot treat all who need life-saving transplants, we treat as many as we can and we do so because to fail to do so would cost lives. We do not say we will perform no transplants at all unless and until we can secure equal access to transplants for all those who need them. Hopefully we allocate access to those organs that become available in ways that are consistent with equal opportunity; but the reason why we save lives in this way is not to secure equal opportunity or to secure access to 'normal competition'.

What is clear is that the moral motive for using technology to intervene in the natural lottery of life is for the sake of the goods that this will bring about. Equality of opportunity may sometimes be one of these goods. More usually it will be a constraint on the way the goods may legitimately be achieved. Saving lives or, what is the same thing, postponing death, removing or preventing disability or disease or enhancing human functioning are the more obvious and the more pressing reasons. These are the reasons we have to prevent or mitigate disability and to treat or cure disease.

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