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Ethics

The morality of screening for disability

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Abstract

Many people object to preimplantation or prenatal screening for disability on the grounds that it is discriminatory, has pernicious effects on the lives of existing disabled people, expresses a hurtful view of disabled people, and reduces human diversity. I argue that if these objections are held to be strong enough to show that screening is wrong, they must also imply the permissibility of causing oneself to have a disabled rather than an non-disabled child. Indeed, those who object to screening on these grounds and also claim that it is not worse to be disabled than not to be, seem to be committed to accepting the permissibility of deliberately causing disabling prenatal injury, even for frivolous reasons. If we cannot accept these implications, we cannot accept that the objections to screening show that it is wrong.

Keywords: *disability, ethics, prenatal injury, screening*

My topic is the morality of using screening technologies to enable potential parents to avoid having a disabled child. The relevant techniques include preconception genetic and non-genetic testing of potential parents, preimplantation genetic diagnosis (PGD), and prenatal screening with the option of abortion. Many people use these techniques and are grateful to have them. Others, however, object to their use, even when abortion is not an issue. The most common objections can be grouped into four basic types.

First, the opponents of screening and selection urge that these practices are perniciously discriminatory, in that their aim is to rid the world of people of a certain type, people who have increasingly come to share a sense of collective identity and solidarity. Some might even argue that for society to endorse and support screening for disability is analogous to promoting efforts to prevent the births of people of a particular racial group.

Second, the practices of screening and selection are not just detrimental to the disabled as a group but may also be harmful to individual disabled people in various ways. They may, for example, reinforce or seem to legitimize forms of discrimination against existing disabled people. And, if effective, they also reduce the *number* of disabled people, thereby making each disabled person a bit more unusual and a bit more isolated. The reduction in numbers may, in addition, diminish the visibility and political power of disabled people generally.

Third, it is often held that a reduction in the number of disabled people would have an adverse effect on human diversity. To eliminate the disabled would be to eliminate a type of human being who makes a unique contribution to the world. For the disabled themselves, and indeed their mere presence among the rest of us, teach valuable lessons about respect for difference, about the nobility of achievement in the face of grave obstacles, and even about the value of life and what makes a life worth living.

Fourth, it is often held that practices of screening and selection express a view of disabled people that is hurtful to existing disabled people. Efforts to prevent disabled people from existing are said to express such views as that disabled people ought not to exist, that it is bad if disabled people exist, or at least worse than if normal people exist, that disabled people are not worth the burdens they impose on their parents and on the wider society, and so on. Screening and selection, in other words, seem to say to existing disabled people: 'The rest of us are trying to prevent the existence of other people like you'.

One can respond to these objections to screening and selection, as some of the speakers at this conference have done, by appealing to rights of individual liberty. One could grant that

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the practices are objectionable for the reasons given but argue that those reasons are overridden by rights to reproductive freedom and by the benefits to those who are able to exercise those rights. But I want to advance a reason for scepticism about the force of the objections themselves.

The objections do of course express serious and legitimate concerns, concerns that must be addressed in appropriate ways. But I will argue that they're insufficiently strong to show that screening and selection are wrong or should be prohibited. For if they were taken to show that, they would also have implications beyond the practices of screening and selection. They would also imply the permissibility of certain types of action that most people believe are impermissible.

Consider this hypothetical example: Suppose there is a drug that has a complex set of effects. It is an aphrodisiac that enhances a woman's pleasure during sexual intercourse. But it also increases fertility by inducing ovulation. If ovulation has recently occurred naturally, this drug causes the destruction of the egg that is present in one of the fallopian tubes but also causes a new and different egg to be released from the ovaries. In addition, however, it has a very high probability of damaging the new egg in a way that will cause any child conceived through the fertilization of that egg to be disabled. The disability caused by the drug is, let us suppose, one that many potential parents seek to avoid through screening. But it is also, like virtually all disabilities, not so bad as to make life not worth living. Suppose that a woman takes this drug primarily to increase her pleasure but also with the thought that it may increase the probability of conception – for she wants to have a child. She is aware that the drug is likely to cause her to have a disabled child but she is eager for pleasure and reflects that it might be rather nice to have a child who might be more dependent than children usually are. Although she does not know it, she has in fact just ovulated naturally so the drug destroys and replaces the egg that was already present but also damages the new egg, thereby causing the child she conceives to be disabled.

Note that because the drug causes the woman's ovaries to release a new egg, the disabled child she conceives is a different individual from the child she would have had if she hadn't taken the drug.

Many people think that this woman's action is morally wrong. It is wrong to cause the existence of a disabled child rather than a child without a disability, just for the sake of one's own sexual pleasure. There are, of course, some who think that rights to reproductive freedom make it permissible to choose to have a disabled child just as they also make it permissible to try to avoid having a disabled child. But most of us do not share that view. Most of us think that if it would be wrong to cause an already born child to become disabled, and if it would be wrong to cause a future child to be disabled through the infliction of prenatal injury, it should also be wrong to cause a disabled child to exist rather than a child without a disability.

There are of course differences. Whether they are morally significant and if so to what extent, are matters to which I will return shortly. For the moment, the important point to notice is that if the arguments I cited earlier show that screening and selection are wrong, they should also show that the action of the woman who takes the aphrodisiac is permissible. This is because if it is morally mandatory to allow oneself to have a disabled child rather than to try, through screening, to have a child who would not be disabled, then it must be at least permissible to cause oneself to have a disabled rather than a non-disabled child.

Let me try to explain this in greater detail. If it is wrong for the woman to take the aphrodisiac, that must be because there is a moral objection to voluntarily having a disabled child – an objection that's strong enough to make it wrong to cause oneself, by otherwise permissible means, to have a disabled rather than a non-disabled child. But if there is such an objection, it must surely be strong enough to make it at least permissible for people to try, by morally acceptable means, to avoid having a disabled child and to have a non-disabled child instead, and to make it impermissible for others to prevent them from making this attempt.

Yet the critics of screening believe not only that it is wrong for people to try to avoid having a disabled child and to have a non-disabled child instead, but even that it is permissible for others to prevent them from having a non-disabled rather than a disabled child. It would be inconsistent for these critics to condemn the woman in this example for causing herself to have disabled rather than a non-disabled child and to condemn those who try to cause themselves *not* to have a disabled rather than a non-disabled child.

The crucial premise here is that if it would be morally objectionable to try to prevent a certain outcome, and permissible to deprive people of the means of preventing that outcome, then it ought to be permissible to cause that outcome, provided one does so by otherwise permissible means.

Note also that if we were to assert publicly that it would be wrong for this woman to do what would cause her to have a disabled child rather than a non-disabled child, or if we were to attempt to prevent her from taking the drug – for example, by making the drug illegal on the ground that it causes 'birth defects' – our action would be vulnerable to the same objections that opponents of screening and selection urge against those practices.

If, for example, we were publicly to state the reasons why it would be objectionable for the woman to take the drug – that the disabled child's life might be likely to contain more hardship and less good than the life of a non-disabled child, that provision for the disabled child's special needs would involve greater social costs, and so on – the evaluations of disability and of disabled people that might be thought to be implicit in these claims could be deeply hurtful to exiting disabled people, and if we were to prevent this woman and others from being able to take the drug, this would reduce the number of disabled people relative to the number there would otherwise have been, thereby threatening the collective identity and political power of existing disabled people.

In short, the arguments of the opponents of screening seem to imply not only that it would be permissible for the woman to take the aphrodisiac, thereby causing herself to have a disabled child, but also that it would be wrong even to voice objections to her action.

Some opponents of screening and selection may be willing to accept these implications. They might argue that there are relevant differences between causing oneself to have a disabled child rather than a different non-disabled child and causing an existing individual to be disabled. For example, in the latter case but not the former, there is a victim, someone for whom one's act is worse. So there are objections to causing an existing individual to be disabled that do not apply to merely causing a disabled person to exist, and to assert these objections merely expresses the view that it can be worse to be disabled than not to be, which seems unobjectionable, since it does not imply any view of disabled people themselves. Screening and selection, by contrast, are held to express a pernicious and degrading view of disabled people.

Thus, opponents of screening and selection typically think that they can draw the line between action by a woman that may cause her to conceive a child who will be disabled and, for example, action taken by a pregnant woman that injures her fetus, causing it to be disabled when it otherwise would not have been. But in fact many people, especially among the disabled themselves, contend that it is no worse to be disabled than not to be. They claim that disabilities are 'neutral' traits. So, for example, Harriet McBryde Johnson (2003), a disabled lawyer, emphatically repudiates the 'unexamined assumption that disabled people are inherently "worse off", that we "suffer", that we have lesser "prospects of a happy life" '.

The view that it is not bad to be disabled, apart from any ill effects caused by social discrimination, would be very difficult to sustain if it implied that to cause a person to become disabled would not harm that person, or that it is irrational to be averse to becoming disabled. But in fact those who claim that it is not bad in itself to *be* disabled can accept without inconsistency that it can be bad to *become* disabled. They can appeal to the transition *costs*. It is bad to become disabled because this can involve loss and discontinuity, requiring that one abandon certain goals and projects and adapt to the pursuit of different ones instead. It is these effects that make it rational to fear becoming disabled and they are a major part of the explanation of why it is wrong to cause someone to become disabled. The other major part is that the causation of disability involves a violation of the victim's autonomy.

But notice that these considerations do not count against causing disability through prenatal injury. For congenital disability does not have transition costs, and fetuses are not autonomous.

It seems, therefore, that opponents of screening and selection who also claim that it is not worse to be disabled have no basis for objecting to the infliction of prenatal injury that causes congenital disability. Moreover, to object to the infliction of disabling prenatal injury or to enact measures to prevent it would seem to express a negative view of disability and perhaps of the disabled themselves. At a minimum, it expresses the view that it is bad to be disabled, or at least worse than not to be disabled. And, if effective, efforts to prevent disabling prenatal injury would have other effects comparable to those of prohibiting or restricting screening for disability and selection, such as reducing the number of disabled people who would be born, thereby also threatening the sense of collective identity and solidarity among the disabled as well as diminishing their visibility and political power. Finally, prevention of prenatal injury would also threaten human diversity. It would deprive those who would have had contact with the person if he had been disabled, of the unique benefits that disabled people offer to others.

So for those opponents of selection who also hold that it is not a harm or misfortune to be disabled, it seems that there are not only no reasons to object to the infliction of disabling prenatal injury but even positive reasons not to object to it and not to try to prevent it.

Suppose there were an aphrodisiac that would greatly enhance a woman's pleasure during sex but would, if taken during pregnancy, injure the fetus in a way that would cause it to be congenitally severely disabled. Those who oppose screening and selection for the reasons I cited earlier and who also hold that it is not bad in itself to be disabled are logically committed by their own arguments to accept that it would be permissible for a pregnant woman to take this aphrodisiac just to increase her own pleasure, and they are further committed to accept that it would be wrong to try to prevent the woman from taking the aphrodisiac or even to criticize her for doing so.

If we think that these conclusions are mistaken, which they surely are, we must reject some part of the case against screening and selection.

I will conclude by briefly suggesting a more positive way of addressing the concerns of those who oppose screening and selection. My sense is that the chief worry of those opposed to screening and selection has to do with the expressive effects of these practices. The worry is, as I noted earlier, that these practices give social expression to a negative view of disabled people, thereby reinforcing other forms of discrimination against them.

But notice that it is usually only people who have not had a disabled child who are averse to doing so. Those people who actually have a disabled child tend overwhelmingly to be glad that they had the particular child they had. If any child they might have had would have been disabled, they tend to prefer having had their actual disabled child to having had no child at all. If they could have had a non-disabled child but it would have been a different child, they tend to prefer their actual disabled child. Of course, what they would most prefer is usually that their actual child had not been disabled. But it is almost invariably the case that any action that would have enabled them to avoid having a disabled child would have caused them to have a different child. When the parents appreciate this fact, they cease to wish that anything had been different in the past, and focus their hopes on the possibility of a cure.

In short, most people who currently have or have had a disabled child in the past do not regret having done so. They are, instead, glad to have had their actual child and frequently testify to the special joy and illumination afforded by being bound to a disabled child. This very different evaluation of having a disabled child by those who actually have experience of it is no less rational and no less authoritative than the evaluation that many people make prospectively that it would be bad or worse to have a disabled child.

We could therefore try to offset any negative expressive effects of screening and selection by giving public expression to these different and equally valid evaluations. I do not have any suggestions for how we might do this. That's a matter for specialists in public policy, not philosophers. But the crucial point is that it would be morally and strategically better for disabled people and their advocates to focus their efforts on positive proposals of this sort rather than to stigmatize and to seek to restrict or suppress practices such as screening and selection. By crusading against screening and selection, they risk making themselves appear to the wider public as fanatics bent on imposing harmful restrictions on others. That would certainly not serve the cause of obtaining justice for the disabled.

Reference

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