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Is there a coherent social conception of disability?

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Abstract

Is there such a thing as a social conception of disability? Recently two writers in this journal have suggested not only that there is a coherent social conception of disability but that all non-social conceptions, or "medical models" of disability are fatally flawed. One serious and worrying dimension of their claims is that once the social dimensions of disability have been resolved no seriously "disabling" features remain. This paper examines and rejects conceptions of disability based on social factors but notes that physical and mental conditions which disadvantage the individual have social dimensions.

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Is there such a thing as a social conception of disability? Recently two writers in this journal have suggested not only that there is a coherent social conception of disability but that all non-social conceptions, or "medical models" of disability are fatally flawed. One serious and worrying dimension of their claims is that once the social dimensions of disability have been resolved no seriously "disabling" features remain.[1]

What is meant by a social conception of disability? According to such a conception, disabilities are not mental or physical conditions of the organism which prevent or impair function, and therefore conditions a rational agent would wish to avoid or remedy, but rather, physical and mental impairments may be either positive, negative or neutral. On this view, the major disabling features of disability are social rather than physical or "mental" - "the basis of disability is located in social conditions"?[2] However, if disability could be identified simply in terms of social conditions, for example, social exclusion, or discrimination, then all victims of racial and gender discrimination would count as disabled and Jews, Blacks and Women would be people with disabilities.

If, on the other hand, we consider whether there is a social *dimension* to disability, it seems obvious that there is. Of course social conditions, including human attitudes, can be "disabling"; but it is somewhat confusing, both grammatically and logically, to think of them as "disabilities". The crucial question is whether, if all the social dimensions of disability could be resolved, there would be any other dimensions left and if so how important they would be? In particular would we have any reason to call these non-social, or "medical" dimensions, "disabilities" at all and would there be any reason left to alter these factors if we could?

In his discussion of these issues, Christopher Newell[3] quotes with approval a remark of Alison Davis:

> "If I lived in a society where being in a wheelchair was no more remarkable than wearing glasses and if the community was completely accepting and accessible, my disability would be an inconvenience and not much more than that. It is society which handicaps me, far more seriously and completely than the fact that I have spina bifida."[4]

Solveig Magnus Reindal focuses her advocacy of the social conception of disability on some thoughts of mine.[5] My response to the interesting and important ideas of Newell and Reindal will be in two parts; in the first part I shall discuss briefly Reindal's criticism of my own ideas and point out some unfortunate misunderstandings. In the second part I shall discuss the problems of giving a social account of disability and look again at the ethics of attempts to eliminate disabilities.

Part 1. Disability and discrimination

Reindal suggests: "Harris does not agree with disabled people who argue that gene therapy is a form or eugenics and that discrimination against them as a group is tantamount to devaluing them as persons". Neither part of Reindal's characterisation of my position is true. I don't disagree with people who argue that gene therapy to remove disability is a form of eugenics, I specifically adopt the Oxford English Dictionary definition of eugenics as "pertaining . . . to the production of fine offspring" and say that if this is what eugenics is everyone should favour eugenics. Moreover, I do not and have never denied that if the disabled are discriminated against as a group this is tantamount to devaluing them as persons. I just do not believe that attempts to remove or pre-empt dysfunction or disability constitute discrimination against the disabled as a group, anymore than medical treatment of disease discriminates against the sick as a group.

Although Reindal admits in a footnote that I am talking only ironically about the "genetically weak", echoing a phrase used by Ruth Chadwick, let me make clear that I do not believe there is such a thing as "people who are genetically weak", and that the term, as I use it, is an ironic reference to the chosen vocabulary of others.

Reproductive freedom

Reindal then suggests that I claim that "morally right eugenics does not deny the 'genetically weak' reproduction; it only prohibits or prevents the 'genetically weak' from giving birth naturally". I nowhere say any such thing, nor do I believe any such thing. On the contrary, I have always stoutly upheld the principle of reproductive freedom or reproductive autonomy. I do not believe that anyone should be prevented or prohibited from making his or her own choices about reproduction. However, and this is important, it does not follow from this that reproductive choices are not open to moral criticism and even moral condemnation. What I do say is that deliberately to make a reproductive choice knowing that the resulting child will be significantly disabled is morally problematic, and often morally wrong. Let me repeat here what I said in a more sustained study of this problem in my book *Wonderwoman and Superman*.[6] Speaking of a mother who deliberately brings a child with disabilities into the world I say:

> "It is difficult to believe that the mother has wronged her child. So far as her relations with the child she has engendered go, she has benefited that child. It has a life worth living because of her choice. The idea that she might have an obligation to compensate her child for benefiting him is nonsense. In such circumstances wrongful life cases are simply misconceived. Not because the life in question has not been impaired, not because the individuals are not suffering, not because they have not been harmed; it has, they are, and they have: rather because it is not plausible to regard them as having been wronged."[7]

It therefore could not be said that I suggest that people should be prohibited or prevented from having children with disabilities. On the contrary, as the above quotations show, I have argued consistently that they have this entitlement. What I have said and will now repeat is that "it is wrong to bring avoidable suffering into the world".[7] But that is a long way from saying that people should be *prohibited* or *prevented* from doing this sort of wrong. Reindal perpetuates a common fallacy, that it follows from the fact that something is wrong, that people should be prevented from doing it. It does not. It follows from that fact that something is morally wrong that they should not do it, but whether the doing of such things should be regulated, or prohibited by law, or punished are each, always further and separate questions.

Reindal then produces some interesting examples. In these Reindal seems to think that I might endorse a doctor's unilateral decision to override the wishes of a mother. For example, she discusses a case of parents who might plausibly wish to reproduce children with congenital deafness or achondroplasia and comments:

> "I suppose that he (Harris) would answer that it is morally wrong to implant the embryos with the impairments . . . and that the parents' decision is not morally justifiable. The right thing to do for the doctor (in these examples) would thus be to override the wishes of the two couples, if he or she were convinced that it is morally wrong to produce 'children who will be significantly harmed by their genetic constitution'."

There are two important points to make here. The first is, as I think I have now made clear, that I would not endorse the overriding of a parents' procreative choice in circumstances like this and the doctor would certainly be acting wrongfully as Reindal rightly suggests if she overrode the parents' choice. However, there is an important difference between achondroplasia, which is not plausibly regarded as a disability or indeed a handicap, and congenital deafness, which is.

Congenital deafness

Let's look at Reindal's example concerning congenital deafness in more detail. Reindal imagines a congenitally deaf couple who both use sign language as their first language and who speak and lip-read spoken language poorly. Reindal mentions that facilities in their house are adjusted to their situation and most of their friends also sign. This couple opts for in vitro fertilisation (IVF), and is supposedly fortunate in having, among their preimplantation embryos, two congenitally deaf embryos to implant. I believe in these circumstances that the parents are entitled to choose which embryos to implant. It does not follow from this, however, that they might not be acting wrongly if they implant the deaf embryos. It is important to be clear, however, about the nature of the wrong that they might do. In *Wonderwoman* *and Superman* I argued in some detail about cases like this, suggesting that whereas the parents would be harming their children, in that they brought children into the world in a harmed condition when they had the alternative of bringing healthy children into the world, they did not wrong those children because the children would clearly have a life worth living. In a case like this the parents have wronged no one, but have harmed some children unnecessarily, but those who were harmed had no complaint because for them the alternative was non-existence.

Reindal is, I think, suggesting not only that congenitally deaf parents are entitled to have their children, on which we both agree, but that they do no wrong in so doing. This seems less clear. Imagine the following two cases. All the facts are the same and the parents have had their congenitally deaf child. But now a cure for this congenital deafness is discovered, it is risk-free and there are no side effects. Would the parents, in this case, be right to withhold this cure for deafness from their child? Would the child have any legitimate complaint if they did not remove the deafness? Could this child say to its parents: "I could have enjoyed Mozart and Beethoven and dance music and the sound of the wind in the trees and the waves on the shore, I could have heard the beauty of the spoken word and in my turn spoken fluently but for your deliberate denial". Is it really plausible to say that all of these things that their child *could have done,* but for the parents' decision, are unimportant and the ability to do them and to experience them *counts for nothing*, such that its loss or absence is not a "disability"? Could not the child also say to its parents: "it might have inconvenienced you to have had to learn spoken language better, and to have had to learn to lip read better, and to widen your circle of friends; but this is surely nothing when compared with what you have denied me".

Perfect hearing

Now consider a fourth case. The same parents have chosen the embryo with the gene for congenital deafness which is duly implanted. By a terrible stroke of bad luck,[7] the preimplantation screening was faulty and when born the child has perfect hearing. Are the parents to be commiserated with? Is it really a terrible stroke of bad luck? Is it so unlucky and is deafness so clearly, simply a different ability rather than a disability that the parents would be entitled to deafen their child to restore their hopes and their (and the child's) good fortune?

I shall not argue for it here but I see these cases as morally on a par. I do not believe there is a difference between *choosing* a preimplantation deaf embryo and refusing a cure to a newborn. Nor do I see an important difference between refusing a cure and deliberately deafening a child. But even those who differ from me on these points will, I think, have some anxiety about these cases. Whether or not they are exactly the same, they are sufficiently morally similar to raise doubts in our minds. This brings me to the second part of what I have to say and to Reindal's positive account of disability.

Part 2. What is disability?

Reindal takes issue with the account that I give of disability. Parts of Reindal's account of my definition of disability, it is impossible for me to recognise. For example, she attributes to me the idea that disability is "a condition within the individual caused by earlier choices made by parents or professionals before, during or after pregnancy" and that it is "a function of people's choices caused by an action or refraining from action". I have never said any of these things. Although my account of disability is consistent with disabilities being caused by prior choices of the agent or of the agent's parents etc my account is not interested in the question of how or by whom or by what the condition is caused. However, Reindal is right to say that I do define disability as "a physical or mental condition we have a strong [rational] preference not to be in" and that it is more importantly a condition which is in some sense a "'harmed condition'". So for me the essential elements are that a disabling condition is harmful to the person in that condition and that consequently that person has a strong rational preference not to be in such a condition. Reindal describes this as the "medical model" within "disability studies". Reindal, on the other hand, endorses an alternative model which sees disability not as a problem that might be susceptible to cures but she says:

> "on the contrary it is mainly a cultural and sociopolitical problem. The medical notion of disability, seeing disability as a cause of a limitation within the individual, cannot account for the fact that not all people with losses, diseases, illnesses etc experience disablement".

This is a very interesting idea and it is worth discussing. However, we must immediately counter the second part of Reindal's claim. It is not true that the medical model of disability cannot account "for the fact that not all people with losses, diseases, illnesses etc experience disablement."

On Reindal's view a congenitally deaf individual in a supportive environment, or a paraplegic with a good wheelchair and an entirely wheelchairfriendly environment, might not be disabled, whereas for example, Blacks or Jews in a racist society would count as disabled. The danger is that Reindal equates disability with disadvantage and seems to want to say something like the following: "that disadvantage with impairment is disabling whereas impairment with minimal disadvantage is not". It is difficult at this stage not to get bogged down in rather sterile semantics. I agree with much of what Reindal says in her positive account. She is concerned, and rightly concerned, with the fact that where resources are directed exclusively into impairment-related research and intervention, insufficient attention and resources are channelled into social change for the inclusion of people with impairments. I agree with this and deplore it as much as Reindal does, but it seems absurd to move from this surely true premise to the conclusion that where people with impairments are not the victims of social exclusion they are not disabled. It seems to me that the correct approach is to say that disabilities are, as I have argued, physical or mental conditions that constitute a harm to the individual, which a rational person would wish to be without. It is also true that social exclusion, discrimination, ostracism and hostility are also conditions of life which a rational person would wish to be without. We need to concentrate on both.

It may even be true to say that for many disabled people (disabled as I would use the term) it is the social exclusion, discrimination, ostracism, hostility and so on which is worse than the physical or mental impairment. But these are separate sorts of harms although, of course, they are causally related. We surely need to be able to deplore these social, political, economic and cultural disadvantages independently of whether or not they are triggered by disability. Hence they are not a definition or conception of disability but part (for some the most important part) of what is *bad* about disability.

Core of the disagreement

However, we need to be clear that curing or preventing the disabilities of some does nothing to combat the social exclusion etc of others. On the other hand, with non-disability-caused social exclusion, there is nothing to cure. We do not want to *cure* people of being Jewish or Women or Black or White even though these factors may cause social exclusion. It is not that we couldn't in principle "cure" people of these things in some sense; change the skin colour, convert people from one religion to another and so on. It is just that such things are not illnesses or disabilities but they may be disadvantageous in some contexts. And this, it seems to me, is the core of the disagreement between Reindal and me. She wants to say that disabilities are not bad in themselves, like being Black or Jewish they are neutral features, disadvantageous only when they result in social exclusion. My response would be, where this is true they are not disabilities at all. Achondroplasia for example, is not on my view a disability, because it is not a harmed condition. Deafness is. The harm of deafness is not exhausted by the possible social exclusion. Its harm is the deprivation of worthwhile experience.

Social factors

At some points both Reindal and Newell talk as if the physical dimensions of disability do not exist in the absence of the social dimensions. Reindal says: "another example is research within gene therapy that strives to 'cure disability', while ignoring the social and cultural factors that make not walking, hearing, seeing etc into a problem" and Newell notes that the deaf "do not identify as having a disability". I don't believe that it is social factors that make blindness and lameness and deafness into a disability. Social factors may exacerbate the problem of having such disabilities but they are disabilities because there are important options and experiences that are foreclosed by lameness, blindness and deafness. There are things to be seen, heard and done, which cannot be seen, or heard, or done by the blind, the deaf and the lame *whatever the social conditions*. Some of these things are very worthwhile. That is not to say that people who are blind, or deaf or lame cannot find other and different worthwhile things to do and to experience. It is just that there are pleasures, sources of satisfaction, options and experiences that are closed to them. In this lies their disability. Their social exclusion, of course, given that it is added to these disabilities is simply gratuitous, in a way that the disabilities may not be, and it may indeed be worse than the disabilities. Nothing I have said denies that either of these things is possible.

One last claim that Reindal makes demands consideration. She suggests that people who, like me, continue to use what she calls the medical model, are involved in palpable discrimination and social exclusion. She says: "to continue . . . with individual models of disability, equating the problem of disability to impairments and individual conditions, is itself a discrimination against disabled people" and she says, seemingly by way of evidence for this, that "it is not a coincidence that the majority of non-disabled people use an individual model of disability, whereas disabled researchers use a social model of disability". I reject utterly the first claim, there is no reasonable sense in which defining disability in terms of harmed conditions discriminates against the disabled and it is no evidence to suggest that disabled people prefer a social model. People with irremediable disabilities of course prefer a "social model" because the medical model is of no further use to them. They want to operate on things that can be changed not on things that can't be changed. But they are not operating with a model of disability they are operating with a view about how to remedy some of the evil consequences of having a disability.

Let me conclude by saying I wholeheartedly endorse Reindal's concern that it is of no help to people with irremediable disabilities to prevent more disabled people coming into existence. Nor does it help them to look for cures for disabilities that will not be available to them. We must separate the question what is of use to existing disabled people from the question of what constitutes disability and the ethics of minimising its occurrence in the future. The bottom line is this: without what Reindal calls the medical model of disability and what I would prefer to call the "harmed condition" model of disability, it is impossible to give an account of the wrong that one might do in disabling someone or failing to cure disability.

Consider again the example of congenitally deaf parents who wish to deafen their hearing newborn. In the supportive circumstances that Reindal describes parents would, on her view, do nothing wrong in deafening their child, for they are not *disabling* that newborn by depriving it of one of its senses. Reindal must believe that hearing and not hearing are just different sorts of abilities rather like being indifferent between whether you teach a child French or Italian. This is, I believe, neither rational nor moral. Reindal concludes by saying:

> "If it is correct that Harris's definition of disability stems from an individual view . . . then his argument for claiming that gene therapy is not a form of eugenics and discrimination against the disabled as a group would also rest on this presupposition".

She goes on to conclude that disabled people "will experience these discussions as eugenics in disguise and hence as discrimination against them".

I have insisted that people should practise eugenics, if by that is understood the attempt to produce healthy, non-disabled children. I don't believe such an attempt is wrong or could conceivably be described as discrimination against the disabled, at least not more so than does any attempt to repair damage or to prevent or cure disability in normal medical practice.

A parallel would be the following: we do not describe broken legs as anything other than injuries simply because concentration on the medical treatment of broken limbs ignores the social exclusion that may result and moreover channels funds away from public health measures to reduce conditions which might result in broken limbs. A clearer example, perhaps, would be HIV/AIDS, which is characterised by social exclusion and stigma and yet must be defined in terms of viral load and resulting susceptibility to disease. We do not need to redefine HIV/AIDS in order to make sense of and tackle the huge social exclusion issues as well. And like many disabilities, HIV/AIDS is currently incurable. However, if there were to be an effective and unproblematic treatment the social exclusion dimensions would largely be resolved and that would be true of disabilities. It is just unfortunate that in many cases they can't be.

Conclusion

Reindal's own conclusion is that "the medical model of disability leads to value judgments by the unimpaired in so far as they view an impairment as meaning that a person has such poor quality of life that that life is judged, by the unimpaired, to be not worth living. These erroneous judgments will only be avoided if social models of disability are taken into account and the views of individuals with those impairments are sought and heard." Newell makes a similar point in milder form, quoting with approval Mary Johnson "an American disability activist":

> "A decision to abort based on the fact that the child is going to have specific individual characteristics such as mental retardation, or in the case of cystic fibrosis, a build up of mucus in the lungs, says that those characteristics take precedence over living itself. That they are so important and so negative, that they overpower any positive qualities there might be in being alive."[8]

Newell concludes that there "are obvious lessons here for all aspects of the debate to do with genetics, especially in terms of 'desirable' and 'undesirable' attributes".[8] Two important points must be made. The first is that it is difficult to understand what the lessons Newell refers to might be. Is it conceivable that anyone could think of cystic fibrosis as anything but undesirable? We are not talking here of a condition that could simply be described, in Johnson's language, as "a build up of mucus in the lungs". This is a genetic condition that destroys the lungs and will kill those who have it, on average by age 40. Evidence shows that most affected families wish both to avoid cystic fibrosis in their children and to have the option of terminating an affected pregnancy.[9]

The second point is that both Reindal and Newell are wrong to suggest that a decision to avoid bringing a child with a particular disabling or harmed condition into the world involves a judgment that such impairment involves "such poor quality of life that that life is judged . . . not worth living" or that such conditions are "so important and so negative, that they overpower any positive qualities there might be in being alive". This is a common fallacy, but fallacy it is. If we concentrate on preimplantation genetic diagnosis or embryo selection we can avoid clouding the main issue with attitudes to abortion. The decision not to implant or to choose between embryos need not be based on any decision that life in a particular condition is not worth living. This can be seen if we consider not the issue of disabilities or impairments but rather the issue of enhancements. Suppose some embryos had a genetic condition which conferred complete immunity to many major diseases—HIV/AIDS, cancer and heart disease for example, coupled with increased longevity. We would, it seems to me, 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.

It is quite clear to me that most disabilities fall far short of the high standard of awfulness required to judge a life to be not worth living. This is why I have consistently distinguished reasons for avoiding producing new disabled individuals from enforcement, regulation or prevention. This is why I have specifically and repeatedly said that for those who can only have disabled children, having such children may be morally better than having no children at all.[10] It is clear that these so-called erroneous judgments can be avoided, even by philosophers who Reindal takes as her principal target and even by philosophers who do not think much of social models of disability but who do think a great deal of social models of social exclusion.

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References and notes

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