
Equality and disability symposium

One principle and three fallacies of disability studies

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Abstract

My critics in this symposium illustrate one principle and three fallacies of disability studies. The principle, which we all share, is that all persons are equal and none are less equal than others. No disability, however slight, nor however severe, implies lesser moral, political or ethical status, worth or value. This is a version of the principle of equality. The three fallacies exhibited by some or all of my critics are the following: (1) Choosing to repair damage or dysfunction or to enhance function, implies either that the previous state is intolerable or that the person in that state is of lesser value or indicates that the individual in that state has a life that is not worthwhile or not thoroughly worth living. None of these implications hold. (2) Exercising choice in reproduction with the aim of producing children who will be either less damaged or diseased, or more healthy, or who will have enhanced capacities, violates the principle of equality. It does not. (3) Disability or impairment must be defined relative either to normalcy, "normal species functioning", or "species typical functioning". It is not necessarily so defined.

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My critics in this symposium illustrate one principle and three fallacies of disability studies. The principle, to which we all subscribe, is the following:

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The three fallacies exhibited by some or all of my critics are the following:

2. Choosing to repair damage or dysfunction or to enhance function, implies either that the previous state is intolerable or that the person in that state is of lesser value or indicates that the individual in that state has a life that is not worthwhile or not thoroughly worth living. None of these implications hold.

3. Exercising choice in reproduction with the aim of producing children who will be either less damaged or diseased, or more healthy, or who will have enhanced capacities, necessarily violates the principle of equality. It does not.

4. Disability or impairment must be defined relative either to normalcy, "normal species functioning", or "species typical functioning". It is not necessarily so defined.²

In what follows we will explore both the principle of equality and the three fallacies I have identified.

Is there any real disagreement between those who, like me, espouse the "harmed condition" model of disability and those who emphasise the social dimensions of disability? Some of my critics suggest we are simply using incompatible images of the same object (Koch)³ or different "models" (Jones).⁴ I believe it is important to understand what might be harmful about conditions variously described as disabilities, handicaps or impairments. I do not believe there are any generally agreed sharp distinctions between these three concepts as discussed by Jones, nor are they sharply distinguished in colloquial English, I shall therefore use "disability" to cover all three ideas. To be disabled in any sense is not the same as being differently abled. Being deaf for example is not simply a "dimension of human experience not available to hearing people" (Edwards)⁵ but a condition which harms the individual relative to freedom from deafness. Buchanan *et al*, for example, have stated recently that "Whether an impairment of the functioning that is normal for our species results in a disability depends on the social environment of the individual".⁶ This is clearly a slip since their definition of disability is in terms of inability "to perform functions that individuals of one's reference group (for example adults) are ordinarily able to do". The deaf are unable to hear whatever their social environment and are therefore disabled relative to those who can hear (whether or not hearing is species typical) and not relative to their environment.

Let's start, however, where we can all agree. Jones suggests we take a "truly holistic view of the problems encountered by people with disabilities, working together with them to ensure that they have equality of opportunity within the community".⁷ We all agree that people with disabilities, handicaps

or impairments are full, free and equal human beings and citizens with all the rights, entitlements and protections that implies. They must be free from discrimination of whatsoever kind and individuals and societies must take whatever steps are required to ensure that this free and equal status can be enjoyed with equal facility as any other person.

So where's the problem? Three important questions remain and on the answers to these questions I differ with some or all of my critics. These questions are:

1. What is disability?
2. Is it better not to have a disability or not to be a person with disabilities?
3. Is it better to avoid bringing people with disabilities into existence where possible?

What is disability?

The answer to the question: "what is disability?" is of more than semantic importance. I have defined disability as a condition that someone has a strong rational preference not to be in and one that is in some sense a harmed condition.⁸ For me then a harmed condition is defined relative both to one's rational preferences and to conditions which might be described as harmful, not relative to normal species functioning but relative to possible alternatives. This is very important because so many of those who write about disabilities not only persist in the fallacious view that disability, impairment or indeed illness must be defined relative to normal species functioning,⁹ but seem unable to contemplate clear alternative accounts.¹⁰ Normal species functioning cannot form part of the definition of disability because people might be normal and still disabled. Suppose due to further depletions to the ozone layer, all white skinned people were very vulnerable to skin cancers on even slight exposure to the sun, but brown and black skinned people were immune. We might then regard whites as suffering substantial disabilities relative to their darker skinned fellows. And if skin pigmentation could be easily altered, failure to make the alterations would be disabling. We will return to the issue of enhancements later. For the moment it is sufficient to note that in such circumstances whites might have disabilities relative to blacks even though their functioning was quite species typical or normal.

It is of course difficult to spell out exactly what one would and should call a "harmed condition". Harms can be quite slight but still be harms. I have suggested¹¹ that a harmed condition is one which if a patient was brought unconscious into the accident and emergency department of a hospital in such a condition and it could be reversed or removed the medical staff would be negligent if they failed to reverse or remove it. So although the loss of the bottom joint of the little finger would be a small harm to bear, if someone came into hospital with the little finger severed at the first joint and it could be sewn on again, the staff would be negligent not to do so: they would have harmed the patient by failing to restore the finger.

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

Many people critical of my position talk as if the disabled are simply differently abled and not harmed in any way. Deafness is often taken as a test 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? Both Koch and Edwards sometimes talk as though deafness were not a harm or a deficit. Would the following statement be plausible—would it be anything but a sick joke? "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 a hospital 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." But there is harm in being deaf and we can state what it is.

In my earlier paper in this journal I imagined a child whose deafness could have been successfully treated, saying the following to the parents who denied it the treatment: "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". In response Koch suggests that "one may acknowledge the joy that (these things) bring others without insisting that the inability to perceive them is a harm or a deficit. After all, many persons are 'deaf' to the pleasures of classical music (or jazz, or reggae, or rap, etc.) and yet none assume their limits of comprehension reflect a deficit or harm."¹² In similar vein Edwards suggests: "I suppose it may be said that a moderately intellectually disabled person misses out on those dimensions of experience which require considerable intellectual acumen And it may be said of those without musical ability that they miss out on *that* dimension of human experience."¹³

But to be "deaf" to the pleasures of classical musical is to be deaf in inverted commas, not really deaf. Musical taste can be educated, but not so hearing for the profoundly deaf.¹⁴ Edwards's point is rather different. The intellectually disabled do miss out on some dimensions of experience which are closed to them in the way that music is closed to the deaf. And this is a disability. It may be a moderate or even a slight disability. Life may well be not only tolerable but truly excellent with such a disability. Like the loss of the end joint of a little finger, the point is not that life is not worth living without such things but that we have reasons not to start out in life with any unnecessary disadvantages however slight. To understand what is and is not being claimed here we need to turn to our third question.

Is it better to avoid bringing people with disabilities into existence where possible?

Neither levels of impairment, nor suffering, nor normal functioning are the issue when it comes to reproductive choice. We are asking the wrong questions about disability if we think that the ethics of reproductive choice turn on degrees of disability or the subjective experience of disability. My critics tend to ask what would justify the prevention of this life or a life like this? What impairments or levels of impairment or deviation from the norm would justify abortion or selection of embryos? If we ask such questions, the loss of a little finger or even deafness seem doubtful candidates for reasons to prevent the existence of a person who will none the less have a good life. Discussions turn often on what sorts of features of existence or disabilities would justify abortion? And this is seen (wrongly) as the same question as asking what features of existence are so bad that it would be better never to have lived rather than live in such a condition.

Concentration on justifying abortion fogs the issue with irrelevant prejudices about what it takes to justify abortion. Instead we should concentrate on reproductive choices and in particular the least morally problematic of such choices. Let's start with preimplantation genetic diagnosis (PGD). Suppose a woman has six preimplantation embryos in vitro awaiting implantation. Preimplantation genetic diagnosis has revealed that three have various genetic disorders and three seem healthy. Which should she implant? Does she have any moral reasons to avoid implanting those with genetic disorders? Notice two features of this case. The woman is under no moral, nor any legal, obligation to implant any of the embryos. The decision to implant some or none is entirely within her unfettered discretion. She doesn't have to offer legal, moral or any other justifications to anyone if she decides to implant none of the embryos. Under English law she may only implant up to three without a special medical reason for implanting more. Which three should she implant? Can she say: "it is a matter of moral indifference whether or not my resulting child has a genetic disorder and therefore I have no reason to select the healthy embryos"? This seems implausible. Since none of the embryos has a right or an entitlement to be chosen rather than the others, since none is a person, nor yet a moral agent, and none has begun the sort of biographical life that would give it interests, her choice is relatively free. She has a reason to do what she can to ensure that the individual she chooses is as good an individual as she can make it. She has a reason therefore to choose the embryo that is not already harmed in any particular way and that will have the best possible chance of a long and healthy life and the best possible chance of contributing positively to the world it will inhabit.

If on the other hand she chooses to implant an individual destined to suffer an illness, she will have created that illness and any harm that it will do. This woman has the same reason to select against an embryo with a genetic disease as her sister who

is told that if she conceives immediately she will have a child with a genetic defect but that if she postpones pregnancy and takes a course of treatment she will have a healthy child.¹⁵

The question we should ask is: what reproductive choices would be legitimate and which, if any, reproductive choices would be wrongful? Before exploring further why this is the appropriate question we should look at what Koch says:

"Finally, the assumption of future harm as a basis for eugenic selection is difficult to justify and difficult to apply to conditions (like) ALS/MS (amyotrophic lateral sclerosis/multiple sclerosis), familial Alzheimer's Huntington's chorea etc. . . . To eliminate the person who might develop these conditions in midlife or later would be to deprive society at large of people like physicist Stephen Hawking, (ALS) former president Ronald Reagan (Alzheimer's) or singer Woody Guthrie (Huntington's)."

This is the famous "aborting Beethoven" fallacy.¹⁶ To choose not to have a child with inherited syphilis is not to decide that the world would be better off without Beethoven. It is as senseless to bemoan the fact that we have elected not to create "a Beethoven" as it would be to celebrate the fact that, by practising contraception, we have just prevented the birth of a Hitler.¹⁷

Consider the question: should John Harris have been born? (I am sure that a number of people, including some of my critics, have asked themselves this question.) Suppose my parents had been told in 1944 that that by postponing conception and taking a litre of orange juice every day for three months they would get a brighter, healthier, longer-lived child. Had they chosen this "optimising strategy", three obvious questions arise:

1. would they have done wrong?
2. would they have wronged me or people like me?
3. would I have had any grounds for complaint?

I cannot see that my parents would have done anything wrong had they made this choice. There is no one they would have wronged or harmed. And even if they had chosen to abort "me" rather than postpone conception with the result that "I" never existed, the same would have been true. Had they done so they would not have been depriving the world of anyone with particular features or skills or who lacked particular features or skills. Society would not have been "deprived of" John Harris nor would it have been "protected from" him—he, (I) simply would never have existed.¹⁸ Those people who, like me, defend abortion know that as a result both healthy fetuses and some with genetic diseases will never become persons.¹⁹ That does not mean that we deprive society of people like Einstein or Ghandi nor of people like Steven Hawking and Woody Guthrie. Nor does it mean that we discriminate against such people nor against people like them.

Choosing who shall exist

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.

My parents were under no obligation to attempt to conceive in any particular month.²⁰ 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.

Suppose IVF and PIGD had been available in December 1944 and I had existed in a petrie dish.²¹ Suppose my parents had chosen an embryo without my genetic disadvantages. Would I have had any ground for complaint? Would that have constituted discrimination against people with my genetic condition? I don't believe so. It is simply a fallacy to think that choosing between preimplantation embryos or choosing to terminate pregnancies of embryos because other embryos would have a better chance in life constitutes unfair discrimination.

Enhancements

This can be seen if we consider again 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.

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 having moral reasons for avoiding producing new disabled individuals from enforcement, regulation or prevention of the birth of such individuals. This is why I have specifically and repeatedly said, (and feel I must say it again now) that for those who can only have children with disabilities, having such children may well be morally better, for the parents and for the children, than having no children at all.²²

The moral reasons we have to avoid harm

I believe there is a continuum between harms and benefits such that the reasons we have to avoid harming others or creating others who will be unnecessarily harmed are continuous with the reasons we have for conferring benefits on others if we can. In short, to decide to withhold a benefit is in a sense to harm the individual we decline to benefit. We have reasons for declining to create or confer even trivial harms, and we have reasons to confer and not withhold even small benefits. But to say that it would, other things being equal, be better not to create an individual who will suffer an unnecessary harm is not to say that it would be better for that individual had he or she never been born, nor is it to say that the world would have been a better place had they never been born, nor is it to say that individuals with disabilities are somehow less valuable or lesser persons than others.

As I have just indicated in discussing enhancements, the opportunity to create healthier and longer-lived individuals than I am, or am likely to prove, is one that there are moral reasons to take. To say that is to say that my parents would have acted ethically had they attempted to achieve such an objective and that their doing so would not have implied either that my life was not worth living or not worthy to be lived, nor that the world would have been better off without me, nor that, since I am here, I am of lesser value than those better endowed in any of these respects, than I am.

“If I say, as indeed I would, that I would prefer not to lose, say, a hand, that it would be better for me if I did not lose one of my hands, that I would be better off with both hands and so on, I am not committing myself to the view that if I did in fact lose a hand that I would therefore, automatically become less morally important, less valuable in what I call the “existential sense”, more dispensable or disposable than you. I have a rational preference not to lose any of my limbs, I have a rational preference to remain non-disabled, and I have that preference for any children I may have. But to have a rational preference not to be disabled is not the same as having a rational preference for the non-disabled as persons.”²³

I would like to endorse Koch's humane and reasonable conclusion that “members of both oppositions generally share a commitment to social support for persons of difference who exist among us, and share, too, a desire for egalitarian over discriminatory practices.”²⁴ I do not believe there is any difference between any of us over responding to people “of difference” as Koch terms it.

Finally I would like to turn to Edwards's rather different critique. Edwards often attributes to me the claim that “in causing needless suffering one does a *moral wrong*” or that those who decline to terminate pregnancy “do a *moral wrong*.”⁵ There is a difference between “doing *what's wrong*” and “doing a *wrong*”, the latter implying that someone is wronged. So to be clear, I do not hold that “if it is possible for the mother to conceive a healthy

embryo at a later time, then it is *a moral wrong* to continue with the pregnancy". I do hold that it is *wrong* to continue with the pregnancy; but so long as the resulting child will have a life that is worth living that child is not thereby wronged and so it would not be doing "a wrong".²⁵

Edwards argues that I have assumed wrongly that "harm" necessarily and always entails "suffering" understood as a subjective unpleasant experience. Edwards is right to insist on this distinction and I don't believe I have ever denied it, but a certain sloppiness of expression to which I readily plead guilty, has not unreasonably lead him to believe otherwise. I was using "suffering" both as a term linked to harm in the sense that to suffer harm is to experience harm even if the subjective experience of harm does not always involve suffering in the other sense of unpleasant subjective experience and also to cover subjectively unpleasant experiences. I should have made clear that when I say that "a disabled person will inevitably suffer" I mean "suffer harm—experience harm, suffer from a disability" and not necessarily "feel agony or distress" although this will often also be true. My account of disability does not even mention the idea of "suffering".¹¹ Edwards is right in that he has shown that disability doesn't *necessarily and always* involve the subjective feelings of discomfort or distress, although it often will. However, if the word "harm" is substituted for the word "suffering" which was my main point (I have, after all, consistently called my conception of disability the "harmed condition conception of disability") then I believe my claim stands. I believe that "it is ethical to prevent the births of people with disabilities because it is right to prevent needless harm". This seems to me an equally if not more powerful claim than the claim expressed in terms of "suffering" and nothing in Edwards's arguments touches this claim.

Disabilities always involve a "harmed condition" of the individual and that being the case it is never wrong to prevent the births of people with disabilities and often right so to do. The moral obligation to prevent harm to others is at least as strong as the moral obligation to prevent suffering (noting that both "harm" and "suffering" admit of degrees). I stand by the claim that we always have a moral reason to prevent harm to others and where this is impossible, we have a moral reason to minimise the harm that we do. So that when Edwards says: "[t]he justification given in Harris's position for preventing such births is that in doing so one is inevitably reducing the incidence of suffering", the truth is that this will often be so, however, where there is no subjective suffering there will still be harm and the justification for reducing the incidence of harm to others is I believe equally strong.²⁶ Edwards has then achieved an advance in clarity for which I am grateful but has not diminished the force of the argument that we always have a moral reason to prevent disability. That does not imply that persons with disabilities are in any sense at all anything other than our full moral, political and social

equals, nor that they do not have lives that are thoroughly worth living.

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References and notes

- 1 "Persons" is here a term of art which excludes for example embryos and those in Permanent Vegetative State (PVS). However, no disabled persons, unless their mental functioning is strictly comparable to PVS or to that of a fetus, will fail to be embraced by this protective principle. See reference 19 below. My critics of course may not share this conception of personhood.
- 2 Disability or impairment must, I have argued, (see reference 8 below) be defined relative to some trait that confers advantage or to some feature that causes disadvantage.
- 3 Koch T. Disability and difference: balancing social and physical constructions. *Journal of Medical Ethics* 2001;27:370–6.
- 4 Jones B. Impairment, disability and handicap—old fashioned concepts? *Journal of Medical Ethics* 2001;27:377–9.
- 5 Edwards. Prevention of disability on grounds of suffering. *Journal of Medical Ethics* 2001;27:380–2.
- 6 Buchanan A, Brock D, Daniels N, et al. *From chance to choice*. Cambridge: Cambridge University Press, 2000: 286. If it was normal to be deaf or if deafness became species typical it would still be a disability relative to hearing. Just as species typical humans would be disabled relative to those whose endowments have been enhanced with Kryptonite, assuming such enhancements to be possible for normal humans.
- 7 See reference 4.
- 8 Harris J. *Wonderwoman and Superman*. Oxford: Oxford University Press, 1992 ch 4 and Harris J. Is gene therapy a form of eugenics? *Bioethics* 1993;7:179–89 at 180. It is important for the discussion of Edwards to note that "suffering" plays no part in this definition.
- 9 Boorse C. On the distinction between disease and illness. In: Cohen M, Nagel T, Scanlon T. *Medicine and moral philosophy*. Princeton, NJ: Princeton University Press, 1981 and Daniels N. *Just health care*. Cambridge: Cambridge University Press, 1985 and his *Justice and justification*. Cambridge: Cambridge University Press, 1996: 185.
- 10 Koch, for example, in his paper in this volume specifically attributes such a view to me on no basis whatsoever. See reference 3: reference 2.
- 11 See reference 8: Is gene therapy a form of eugenics?
- 12 See reference 3.
- 13 See reference 5.
- 14 Of course, if, like Beethoven, they have once been able to hear and can read music, they can talk about the quality of a musical composition, but not of course about the quality of a performance they have not heard.
- 15 This is the so-called "non-identity problem". See Parfit D. *Reasons and persons*. Oxford: Clarendon Press, 1984: part 4 especially page 358ff. I discuss this problem in the context of disability in *Wonderwoman and Superman* ch 3.
- 16 See reference 8: *Wonderwoman and Superman*: 179ff.
- 17 Since anything unpleasant may be attributed to Hitler we will assume it is also true of him.
- 18 The counterfactuals here are very problematic. Suppose Hitler had never been born—would that have necessarily meant that the world would have been saved from the holocaust?
- 19 Harris J. The concept of the person and the value of life. *Kennedy Institute of Ethics Journal* 1999;9:293–308, and Harris J. *The value of life*. London: Routledge & Kegan Paul, 1985.
- 20 I have been influenced by Julian Savulescu in my formulation of these points.
- 21 As previously I ignore problems about the scope of the personal pronoun here because in so far as they are problems they support my argument.
- 22 See reference 8: *Wonderwoman and Superman*: 72.
- 23 See reference 22: 72–3.
- 24 See reference 3.
- 25 I discuss the distinction between harming and wronging at some length in *Wonderwoman and Superman* ch 4: see reference 8.
- 26 See reference 5.