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Disability and Well-Being

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Abstract:

This entry discusses the relationship between disability and wellbeing. Disabilities are commonly thought to be unfortunate, but whether this is true is unclear, and if it is true, it is unclear why it is true. The entry first explains the disability paradox, which is the apparent discrepancy between the level of wellbeing that disabled people self-report, and the level of wellbeing that nondisabled people predict disabled people to have. It then turns to an argument that disabilities must be bad, because it is wrong to cause them in others. Sections 4 and 5 discuss whether disabilities might be intrinsically bad or even bad by definition. The final section turns to discuss the claim that to whatever extent disabilities are bad, this is not because disabilities themselves are harmful because only because society discriminates against people with disabilities.

1. Introduction

Disabilities such as blindness, quadriplegia, cerebral palsy, Down syndrome, arthritis, and dementia are commonly thought to reduce levels of well-being (which is to say, they are bad for us, are harmful, are costly; see also GOOD AND GOOD FOR; WELL-BEING). One obvious question to ask is whether this common view is right, and if so, about the degree to which disabilities reduce well-being. And if there is a harm associated with disability, a second obvious question to ask is *why* this is so: are disabilities themselves harmful, or should we think of the relevant costs as imposed by society's attitudes and choices (see also DISABILITIES, PEOPLE WITH)? We'll somewhat artificially take these questions separately, in turn.

Our attitudes about the potential harms of disability feed into our personal choices and feelings. For example, if you think disabilities are harmful, that might lead you to take steps to avoid becoming disabled, and lead you to feel unfortunate if you are. Or it might lead you to take certain decisions about reproduction, such as to screen for the presence of Down Syndrome (see also EUGENICS; GENETIC TESTING; PROCREATION ETHICS). Our views on the harms of disability also feed into our political choices. For example, a government might choose not to fund some health intervention based on its apparent cost/benefit ratio, but the benefits of certain health interventions might depend on whether disabilities make you worse off (see also ALLOCATING SCARCE MEDICAL RESOURCES; HEALTH CARE RESOURCES, DISTRIBUTION OF). Or, for another example, if you believe that the harms of disabilities are

predominantly caused by social attitudes, you might come to feel angry about this apparent injustice and decide to campaign for disability rights.

One complexity in all this is that different disabilities surely have *different* effects on well-being, or at least raise very different issues to one another. For example, a person who is blind, a person with sufficiently low IQ, and a person with depression, presumably all count as "disabled", and yet it is clear that the effects of these conditions on well-being might differ greatly. In what follows I shall talk about disabilities in general, as others often do, though it may well be true that what I say does not straightforwardly apply to every disability there is, but rather at best only to certain canonical disabilities such as missing or non-functional limbs and senses.

2. The Disability paradox

The first question above was about the extent to which disabilities are harmful. To answer this, we might consult the relevant empirical data. This data seems to show two things. First, that people with disabilities do tend to report lower levels of well-being than nondisabled people do. Second, that people with disabilities tend to report higher levels of well-being than nondisabled people predict they will. For example, in one representative classic study, on a scale from 0 to 1, patients on dialysis rate their quality of life at 0.52, whereas the general population estimates the quality of life of someone on dialysis to be 0.32 (Sackett and Torrance 1978; see also Albrecht and Devlieger 1999; Boyd et al. 1990).

Both of the above claims are worth emphasizing. First, there is clear evidence that disabled people typically report being worse off than nondisabled people. For example, in another classic study, "54.3% of the persons with serious disabilities in the study reported that they had an excellent or good quality of life. These numbers compare with 80±85% of persons with no disabilities who report they are satisfied or very satisfied" (Albrecht and Devlieger 1999: 981). Similar data can be found in numerous other sources: it is very clear that disabled people tend to report lower levels of well-being than nondisabled people.

The second claim above is that nondisabled people systematically disagree with disabled people about how bad it is to have a disability. Crudely, nondisabled people predict that disabilities are very bad, whereas those with disabilities report that they are only somewhat bad. This contrast, between the level of well-being that disabled people typically self-ascribe, and the level of well-being that nondisabled people predict they have, is known as the "disability paradox". The disability paradox is not a true philosophical paradox, in the strict sense of the term that requires logical inconsistency: it is instead just a notable piece of data.

How might we explain this discrepancy? Two obvious possibilities are that nondisabled people are simply ignorant about the costs of disability and overestimate them, or second, that disabled people psychologically adapt to disability so that they maintain relatively high levels of subjective satisfaction despite objectively worse circumstances (for more discussion of these possibilities and others, see Ubel, Loewenstein, and Jepson 2003; Ubel and Loewenstein 2008; Daniels, Rose,

and Zide 2011). I address these possibilities in turn, though note that they are consistent: you might think that each plays some role in explaining the disability paradox.

First, perhaps nondisabled people are simply ignorant about disability, so that they wrongly judge disabilities to be worse than they in fact are. For example, they might fail to understand what effects a disability actually has, or underestimate the extent to which one can work around various limitations. Nondisabled people who participate in these studies are asked to judge how bad certain disabilities are without any real first-hand experience of what life with those disabilities would be like. And even if they are given *some* information to consider, and some time to reflect, they are unlikely to *fully* grasp what a given disability would, or would not, change about their lives. To this extent we might expect them to come to mistaken conclusions about the impact of disability on well-being.

One further cause of ignorance could be the *focusing illusion* (Kahneman et al. 2006; Schkade and Kahneman 1998). If you are asked to imagine how your life would be if you had some disability, you will focus disproportionally on the *differences* that disability would make, rather than on the things that would stay the same. For example, on being asked to evaluate how life would be if you lost an arm, you might focus on the apparent costs this might impose, rather than on the numerous things – the conversations with friends, the books you read, walks in the sunshine – that would remain more or less the same. You will thereby overstate the difference the disability would make to your quality of life. One attraction of explaining the disability paradox by appeal not only to factual ignorance but also to the focusing illusion is that it explains why people who themselves used to be disabled also underestimate the well-being of disabled people (e.g. Ubel and Loewenstein 2008: S203-S204). People who used to have disabilities might have a better idea of what disabilities involve than other nondisabled people, but can still be subject to the focusing illusion and thereby overestimate the difference a disability would make to their life.

The thought above was that nondisabled people might be ignorant about the well-being of disabled people. A complementary line of thought is that if disabled people themselves report that their lives are going well, perhaps on general grounds we ought to defer to their expertise on the matter. In fact, it might seem positively *unjust* to disregard the testimony of disabled people (Barnes 2016: 119-142; Goering 2008, see also EPISTEMIC INJUSTICE). This line of thought further supports the idea that the disability paradox ought to be explained as a mistake on behalf of nondisabled people.

The second possibility is that disabled people psychologically adapt to their disabilities, so that they maintain relatively high levels of subjective satisfaction despite objectively worse circumstances. For example, we might think that your level of happiness is partly determined by your expectations, so that if you lower your expectations you can be happier with less. There is much independent evidence that this kind of hedonic adaptation can happen: in one classic study lottery winners were found to be barely any happier than non-winners within two months of winning (Brickman, Coates, and Janoff-Bulman 1978). The idea that people's levels of happiness

stay constant despite changes in external circumstances is sometimes known as the hedonic treadmill hypothesis or as the set point hypothesis (Brickman and Campbell 1971): the idea is that no matter how your external circumstances change, your level of happiness stays in roughly the same predetermined place. Obviously, if this were wholly true then we would expect disabled people to be *equally* happy as nondisabled people, and that is not what the relevant data shows. Still, if there is some incomplete hedonic adaptation, that would explain why people with disabilities are happier than predicted even if not as happy as nondisabled people.

If the disability paradox is to be explained (in part) by appeal to hedonic adaptation, what does that show about the relationship between disability and well-being? It is not clear. To understand the issues here, we should distinguish between *subjective* and *objective* theories of well-being. Very roughly, subjective theories say that well-being depends to a great extent on your psychological states, whereas objective theories allow that well-being might depend on other factors, such as your physical achievements (see also HEDONISM; SUBJECTIVE THEORIES OF WELL-BEING; OBJECTIVE THEORIES OF WELL-BEING). This disagreement may be relevant for evaluating the effects of disability on well-being. Subjective theories of well-being may entail that adaptation is a way of maintaining high levels of well-being: so long as you remain happy, that is all that counts. In contrast, objective theories of well-being may permit that disabled lives can be worse even if disabled people report that they are ok: perhaps such lives are worse off for lacking objective goods such as physical achievement (for some relevant discussion see Moller 2011).

Let me summarise. The empirical data suggests that disabled people typically have lower levels of well-being than nondisabled people, but also that disabled people typically rate their own levels of well-being higher than nondisabled people would predict. This discrepancy might be explained as reflecting mere ignorance or other irrationality on behalf of nondisabled people, or as reflecting hedonic adaptation by disabled people. Whether the last of those would show that disabled people *are* better off than they seem, or else that they *incorrectly* overestimate their own well-being, is unresolved, and depends on wider questions about wellbeing.

3. Causing and removing disability

Another line of reasoning on the harms of disability is that disabilities must be harmful, since it is wrong to cause them. There is some appeal to this line of thought: if I blind you, under normal circumstances you surely have a complaint against me. And if it is wrong to cause a disability, a natural explanation of that is precisely that by making someone disabled you thereby make them worse off: causing disability is wrong because it is harmful.

This argument has been influentially discussed, and rejected, by Elizabeth Barnes (Barnes 2014). She argues that we can explain the wrongness of causing disability in other ways. In particular, she claims that it is wrong to cause disability primarily because doing so involves meddling in someone else's life in an unjustifiable manner: we don't have the right to drastically interfere in

others' lives, and causing disability is wrong for that reason (Barnes 2014, 95). Moreover, Barnes argues that there are *transition costs* to becoming disabled: the state of being disabled isn't bad, but getting used to being disabled might nonetheless be bad (Barnes 2014, 96). This provides a further reason for thinking that it is wrong to cause disability without thinking that being disabled is itself unfortunate. To support these claims, it is helpful to consider an analogy: if I magically changed your sex, that would surely be wrong. It would be wrong not because your new sex would be intrinsically worse, but instead because (a) I don't have a right to interfere with your life in this kind of way, and (b) though neither sex is better than the other, changing between the two might be challenging at least in the short term.

One key worry for Barnes – and in turn, reason for thinking that the original argument might stand – is that the considerations she appeals to might not apply in every case. Most obviously, it is unclear whether it is wrong to interfere in the lives of our own children, and doubtful that they face sufficiently large transition costs when we do. So on Barnes view, it seems as though there may be nothing wrong about causing disability in young children. A second worry for Barnes is that it is not clear how she might account for the thought that it is *right* to *remove* disabilities when we can. On Barnes view, changing someone's disability status from nondisabled to disabled seems morally equivalent to changing it in the reverse direction. In this respect, Barnes' view may seem counterintuitive. Barnes is aware of both of these concerns, and embraces them, arguing that our intuitions to the contrary stem from prejudice (Barnes 2014, 97–106). Discussion of this issue – and in turn, of the broader question about the nature of the wrong of causing disability – is ongoing (Andric and Wundisch 2015; Bognar 2015; Kahane and Savulescu 2016; Barnes 2016a).

4. Disabilities as intrinsically bad

Assuming that there are harms to being disabled, are those harms intrinsic, or instrumental? The most obvious suggestion is that they are instrumental: to the extent that disabilities are harmful that seems to be because of the resulting discrimination, suffering, or absence of options. But might some of the harms be intrinsic? I shall briefly outline three possible routes to this conclusion.

First, perhaps at least some disabilities are intrinsically harmful because they essentially involve pain or other intrinsically harmful things. For example, if we are happy to count depression as a disability, we might think that disability is intrinsically harmful because it essentially involves sadness, and sadness is intrinsically harmful. Similar reasoning might show that other disabilities such as Complex regional pain syndrome are intrinsically harmful. This reasoning seems relatively unassailable, though it obviously shows something about some specific disabilities rather than about disability as such.

Second, perhaps *health* is an intrinsic good (e.g. Finnis 2011: 86), and if so, perhaps it follows that disabilities are intrinsically bad. But this reasoning is dubious: "health" can be understood in two

different ways, and neither offers an easy route to the conclusion that disabilities are intrinsically bad for us. First, we might define health in some evaluatively loaded manner (this view is sometimes known as "constructivism"). For example, the World Health Organisation famously defined health as "a state of complete physical, mental and social well-being" (World Health Organisation 1946). If we define health in this evaluative manner, though it becomes highly plausible that health is intrinsically good, it becomes to that very same extent less obvious whether disabilities are unhealthy at all: it is not obvious that disability is inconsistent with having such well-being (for related discussion, see Aas 2016; Wendell 2001). Second, we might define health in a less evaluative manner – as "normal" bodily functioning (this view is sometimes known as "naturalism"; see Boorse 1977, 1975, 1997). But if we define health in this more statistical manner, even if it becomes more plausible that disabilities are unhealthy, it becomes to that same extent less obvious that health is intrinsically good: there may be some instrumental benefit to having a typical body (e.g. because many objects are designed primarily with you in mind), but it is doubtful that there is anything *intrinsically* good about having a typical body.

A third line of thought appeals to the *perfectionist* idea that the fundamental contributors to well-being are (roughly) that you exercise your central human capacities well (e.g. Kraut 2007; see also PERFECTIONISM). We might think that if perfectionism were true, it would follow that some (all?) disabilities are intrinsically harmful because they necessarily involve limitations on some human capacities. Is this line of reasoning compelling? There are at least two unresolved issues here. First, most simply, perfectionism about well-being is highly contentious, and many reject it. Second, perfectionists must say something about which human capacities are the ones it is good to use (clearly, it is not good for you to exercise all of your capacities, including, say, your capacity to get appendicitis). And so whether perfectionism implies that disabilities are intrinsically bad will depend greatly on just which capacities they focus on. One common perfectionist thought is that it is good to exercise your capacity to be rational. If that were right, then perhaps perfectionism implies that physical disabilities are not intrinsically harmful, but that some intellectual disabilities are.

In short, we might be tempted to infer that disabilities are intrinsically bad because we think (a) that some disabilities involve pain or sadness by definition, (b) that health is intrinsically good, or (c) that it is good for us to exercise some central human capacities. The first of these lines of reasoning is compelling but only tells us something about *some* disabilities. The second line of reasoning is questionable. The third line of reasoning requires further examination.

5. Disability as bad by definition

Another line of thought is that disabilities are harmful by definition. The idea is that "disabled" is an evaluative term, like "weed", so that it is built into the meaning of the term that the relevant condition is undesirable (see also THICK CONCEPTS). On this view, if you try to show that some disability is harmless, the most you might show is that it wasn't really a disability after all.

Some deaf people, for example, might deny that deafness is a disability precisely because they think it is not bad.

This suggestion is distinct from the previous one. The previous suggestion was that if you have a disability, that is bad for you, independently of the effects of that disability (see also INTRINSIC VALUE; INSTRUMENTAL VALUE). The present suggestion is different. It says that if a condition is not harmful, and its effects are not harmful either, then that condition does not count as a disability in the first place.

Commitment to this idea unifies some otherwise very different writers (e.g. Kahane and Savulescu 2011; Harris 2001; Oliver 1996; cf. Silvers 2003). But the most popular way to develop this idea comes from *the social model of disability* (see also DISABILITIES, PEOPLE WITH). This theory has been extremely influential on the disability rights movement. The most influential statement of the social model appears in the "Union of the Physically Impaired Against Segregation" (UPIAS) document *Fundamental Principles of Disability*:

"In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called "disability", of people with such impairment [sic]. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (1974, reprinted in Oliver 1996: 22)

The idea is that we should distinguish disabilities and impairments, where "impairment" is an evaluatively neutral term for a certain kind of body, and "disability" refers to the *harmful* results ("disadvantage") of that impairment in your society (cf. "sex" vs. "gender"). On this view, to be "disabled" is to have certain costs imposed on you by society (because of your impairment).

(An aside: Adoption of the social model explains why some disabled people have a preference for the label "disabled people" rather than "people with disabilities". The social model suggests that the label "people with disabilities" is misleading in the same way that "people with oppression" is: it misleadingly presents something done to a person as a feature of that person.)

But although the social model tells us that disabilities are necessarily harmful, this relocates, rather than answers, our opening questions. The social model introduces the term "impairment" to label the bodily features we associate with disability. So although it tells us that disabilities are harmful by definition, it leaves open parallel questions about the extent to which impairments are harmful (or, in the terminology of the social model, about the extent to which impairments lead to disability). This is not a problem for the social model, but does suggest that to some extent

these terminological disputes – even if politically important – might ultimately make little difference to the substantive questions at hand about the relationship between (e.g.) being blind and well-being. Similar reasoning seems to apply to other attempts to show that disabilities are bad by definition: such claims would obviously show that disabilities *are* harmful, but only by making it an open question whether any given condition – even a paradigmatic disability such as quadriplegia or blindness – is really a disability. This is not obviously progress (cf. Barnes 2016: 11).

6. Disability as bad because of injustice

That said, defenders of the social model *do* also make claims about the extent to which impairments are harmful. In particular, some claim that impairments are themselves neutral, and are harmful *only* or *primarily* because of the resulting social oppression (see, for example, Amundson 1992; Amundsen 2005; Barnes 2016). On this view, being impaired is akin to being female or black: harmful, but only because of highly contingent and unjust social attitudes.

In what follows, to maintain consistency, I am going to switch back to using the word "disability", as I did at the start of this entry: defenders of the social model above can simply translate what I say into claims about impairment. We have thereby returned to the second question with which I began: to what extent are the harms of disability the result of choices made by others? Some defenders of the social model suggest that *all* of the harms of disability result from such choices, and indeed, from unjust choices. On this view, to the extent that disabled people are worse off, that is because of prejudice and not because of their disability.

Is it plausible that disabilities are harmful *only* because of injustice? It is very clear that disabilities are harmful at least partly because of what we might call *active prejudice*. For example, there is much evidence that disabilities are heavily stigmatised, and that this manifests itself in the decisions made regarding disabled people, such as in employment practices and dating choices (on the former, see e.g. Ren, Paetzold, and Colella 2008; on the latter, see e.g. Chen et al. 2002). Such stigmatisation is clearly unjust, and significantly harmful. To this extent, we might think that many of the major harms of disability result from unjust attitudes.

But that said, it is unclear whether *all* of the costs of disability should be explained in this way. In particular, even if some of the costs of disability arise from the way a disability affects your relationships with other people, some of the costs arise from the way a disability affects your relationship with your physical environment. For example, getting to work is potentially going to be more difficult if you cannot move your legs. For this reason, those who defend the claim that disabilities are harmful only because of injustice tend to focus not only on active prejudice, as above, but also on the *absence* of efforts to accommodate disability. For example, they might say that the difficulty of getting to work using a wheelchair reflects unjust failures to make public transport sufficiently wheelchair accessible. We might thereby maintain the view that disabilities are harmful only because of injustice, by allowing that such injustice can arise through negligent

failures to improve accessibility as well as active prejudice. With this qualification in hand, it is more plausible that disabilities are harmful only because of injustice.

This claim might still be doubted. Even though justice requires some effort to accommodate disability, it is not clear if it requires us to accommodate disabilities no matter the cost (see also EQUALITY; JUSTICE). To that extent, a disability might be harmful, and these might be harms that we could remove, but our failure to remove these harms might nonetheless be perfectly just, because the cost of removing them is too prohibitive. Of course, exactly how much we ought to pay to accommodate disability is open to argument, and plausibly we ought to spend more on accommodating disabilities than we do at present. Still, this is consistent with thinking that there is *some* limit to the amount that we ought to spend, and it might thereby be false that disabilities are harmful only because of injustice.

Let me summarise the last two sections. We might think that disabilities are bad by definition, since "disability" means "disadvantaged bodily state", or similar. Some defenders of the social model of disability make similar claims. Such claims may be interesting, but they seem to relocate, rather than answer, questions about whether it is bad to be blind, since they make it an open question whether blindness is a disability. Defenders of the social model make other claims as well, the most central of which is that being blind (say) is bad only because of injustice. To see that this is plausible, it helps to remember that injustice can occur due to negligence as well as active prejudice. But the resulting claim might still be doubted and deserves further investigation. Of course, even if this claim turns out to be false, we might yet maintain that many (most?) of the costs of disability are due to injustice (whether active prejudice, or negligence), and that might be all that matters for much real-world decision-making.

Cross-references

ALLOCATING SCARCE MEDICAL RESOURCES; DISABILITIES, PEOPLE WITH; EPISTEMIC INJUSTICE; EUGENICS; EQUALITY; GENETIC TESTING; GOOD AND GOOD FOR; HEALTH CARE RESOURCES, DISTRIBUTION OF; HEDONISM; INTRINSIC VALUE; INSTRUMENTAL VALUE; JUSTICE; OBJECTIVE THEORIES OF WELL-BEING; PERFECTIONISM; PROCREATION ETHICS; SUBJECTIVE THEORIES OF WELL-BEING; THICK CONCEPTS; WELL-BEING

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