Disability, Minority, and Difference¹

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[Disability is] the spectre haunting normality in our time. That spectre may be crippled, deaf, blind, spasming, or chronically ill – but it is clearly no longer willing to be relegated to the fringes of culture.
 Lennard J. Davis, 'Crips Strike Back: The Rise of Disability Studies'

Abstract: In this paper I develop a characterization of disability according to which disability is in no way a sub-optimal feature. I argue, however, that this conception of disability is compatible with the idea that having a disability is, at least in a restricted sense, a harm. I then go on to argue that construing disability in this way avoids many of the common objections levelled at accounts which claim that disability is not a negative feature.

Academic discussions of physical disability² present us with a striking

juxtaposition in accounts of its fundamental nature. On the one hand are those who want to treat disability as simply another way of being different; to have a disability is merely to have minority physicality in much the same way that, for example, to be African-American is to have minority race. In opposition to this view are those who argue that disability is something that makes a person worse off, so that to have a disability is to be different in a way that is *sub-optimal*; persons with disabilities have sub-optimal physicality in a way that African-Americans don't have sub-optimal race.

The most notable accounts of the former view³ have generally tended to defend their position by arguing that disability is a *social construct*. As Rosemarie Thomson writes, 'disability. . .is the attribution of corporeal deviance – not so much a

¹ Many thanks to Ross Cameron, Jamie Dow, Gerald Lang, Rob Lawlor, Daniel Nolan, Robbie Williams and audiences at the Leeds work-in-progress seminar and Ethics Reflectorium for very helpful comments.

² In everything that follows, I will for convenience take 'disability' to refer to physical, but not cognitive, disabilities. Similar arguments to those I'll put forward might apply to mental disabilities, but that would take some additional work to show. The two are, I think, very distinct phenomena and shouldn't be treated uniformly just because we can sometimes jointly refer to them with a single word. ³ Found largely within the emerging field of disability studies (see Barnes et al (1999) and Oliver (1990))

property of bodies as a product of cultural rules about what bodies should be or do'.⁴ Such a picture, it is argued, is needed in order to assure disabilities their 'separate but equal' status among other, more standard, physicalities.

The dominant characterization of disability in analytic philosophy is starkly different. The general consensus has tended to be that of *course* disability represents something sub-optimal. Many philosophers argue that disability must be considered a sub-optimal feature because otherwise, for example, it would be permissible to cause disability, when clearly it is not.⁵ Likewise, it's generally assumed that the life of a disabled person is clearly sub-optimal in the vigorous debates over whether and how it could ever be permissible to bring such a person into existence.⁶ Moreover, it's often taken for granted that someone should at the very least refrain from having a child with a disability if she might easily do so.⁷

The above contrast is illuminating, I think, if only insofar as to highlight how little either side seems to adequately represent the *experience* of disability. The former group have the advantage of giving voice and legitimacy to the growing number of persons with disability who report that they are fine, thank you very much – that they *enjoy* their experience of disability and anyone who tells them they're somehow sub-optimal simply doesn't know what it's like to have a disability.⁸ Yet in order to do so they argue that disability is nothing more than a social construction, which strikes many as highly implausible.⁹ If, for example, someone is in chronic

⁴ See Thomson (1996)

⁵ See especially McMahan (2005)

⁶ See Wasserman (2005), Brock (2005), Kamm (2002)

⁷ See especially the 'handicapped child case' from Parfit (1984); also Hanser (1990) and Parsons (1998)

⁸ See especially Johnson (2003) and Linton (2005). It's tempting to think this kind of testimony can't, under the circumstances, count as good evidence – but that's an objection I'll be addressing in subsequent sections.

⁹ See also Terzi (2004) for a systematic critique. This paper will be in part an attempt to give the sort of account of disability that Terzi's argues we need – one which salvages the corrective features of the social model of disability without buying into its counter-intuitive consequences.

pain, it seems that no amount of social awareness would be able to fully alleviate the ways in which they suffers from their disability.

Most philosophers who write on disability, in contrast, argue that we cannot construe disability as just one among many difference-making features because of the highly counter-intuitive results that would follow. Were having a disability just another way of being different, it would be permissible to cause disability, to withhold medical treatment for disability, to bring into existence a child with a disability rather than one without disability, etc. And since these actions are meant to be clearly *im*permissible, we conclude that disability must be in some robust sense *sub-optimal*.¹⁰ Fair enough for avoiding unpalatable conclusions, but it seems in tension with the actual first-person reports of many persons with disabilities, who often claim to have *benefited* from their experience of disability and to *like* being disabled.

In this paper, I will attempt to sketch out a way of understanding disability that represents something of a 'middle ground' between these two polar characterizations. It's important to note that, in what follows, I give arguments against the characterization of disability as a negative difference-maker, but say nothing substantial against the social-construct model. I am simply assuming, for the purposes here, that it would be good to have an alternative to that theory. At the very least, it's beneficial to further map out conceptual space by showing that you can think that disability is in no way suboptimal without resorting to anything like the social construct model (whereas the two are often seen to go hand in hand).

¹⁰ Standard philosophical discussions don't, in any way, take this notion of sub-optimality as reason to treat persons with disabilities any worse than any other group of persons; persons with disabilities in that sense *are* just another minority group. It's when it comes to how the minority feature itself (rather than the minority person) is viewed that the contrast becomes evident. The thought is that if no more persons were ever born with or developed disability, it would make the world a better place overall – the eventual eradication of disability is seen as a good, whereas the eradication of, e.g., gayness or blackness obviously wouldn't be.

The aim will be to provide an account of disability that allows us to maintain *both* that disability is just another way of being different (i.e., disability is in no way sub-optimal) *and* that disability can, in and of itself and even in ideal social conditions, be a harm.

Such a characterization of disability, if successful, would allow us to do justice to apparently contradictory claims of, for example, disability advocates and their caregivers. Many of the former claim that disability is not a negative, not something that automatically makes a person worse off. The latter want to grieve if a loved one develops a disability, and to eliminate that disability as far as they can. My account of disability will show how these positions can both be fully legitimate.

I will then argue, via a series of test cases, that the account is neither too strong nor too weak. It is not too strong because we cannot infer from it the permissibility of causing disability, withholding medical treatment for disability, etc. But neither is it too weak, because it gives us the standard results that disability advocates demand – namely, that persons with disabilities represent a legitimate minority group, and that practices such as selective abortion of foetuses with disabilities are, at the very least, morally blameworthy.

I. Disability as Difference-Maker

The central disagreement in modern discussions of disability concerns how we should view the presence of a disability. The fundamental question is whether disability is what I will call a *difference-maker* or a *negative difference-maker*. That is, whether having a disability is simply another way of being different or, more strongly, a way of being different which makes one worse off because of that very difference.¹¹

¹¹ And, more strongly: *automatically* worse off because of that very difference. The best way of explicating this is through the counterfactuals true of negative difference-makers. For any negative difference maker x, and any person a, a's welfare is counterfactually related to x such that: ceteris

The various sub-debates surrounding disability largely hinge on this. If disability is a difference-maker only, then persons with disabilities (hereafter, 'disabled people'¹²) are simply another minority group, deserving of all the rights and respect that we grant to any legitimate minority group. On the more traditional understanding, however, of disability as a *negative difference-maker*, disabled people can't be classed as simply one among many groups of minorities, for the crucial reason that they represent something sub-optimal. Disabled people have, on the negative difference-maker view, sub-optimal physicality, in a way that, e.g., African-Americans don't have sub-optimal race.

In what follows, I argue that we should construe disability as simply a difference-maker, not as a negative difference-maker. I maintain, in addition, that this construal of disability (i.e., disability as just another way of being different) is compatible with the notion that disability is, in some sense, a *harm*.

Why do we, intuitively, tend to think of disability as a negative differencemaker? That is, why do we think that disabled people are affected by their disabilities in such a way as to be worse off because of them, rather than merely non-standard because of them? In general it seems we're inclined to view disability as a negative difference-maker because of its effects, because of what it does. Disabilities are, in general, the kind of thing that makes life harder – they present limitations, they cause pain, they subject the bearer to social stigmas and discrimination. And because of this, we tend to think that any particular disabled person will have a lower quality of life than those in comparable circumstances without disabilities.¹³ Thus, because

paribus, had a not had x, she would have been better off and had a had x she would have been worse off.

¹² I know of know uncontroversial terminology here, so I will echo Linton (1998) in here choice of 'disabled people'.

¹³ Or perhaps the modal case is better: she will have a lower quality of life *than she would otherwise have had had she been able-bodied*. Alternatively, one might think this is best phrased in terms of probabilities: she will be less likely to have a high quality of life because of her disability. More on this in section II.1

disability impacts quality of life in this way, disability can be seen as a *negative difference-maker*.

In a nutshell, then, our reasoning about disability tends to be as follows:¹⁴

- (i) Having a disability is the kind of thing that makes life harder
- (ii) Because (i), disability has a negative impact on quality of life
- (iii) Because (ii) disability is a *negative difference-maker*

My dispute with this line of reasoning lies in (ii). (ii) is ambiguous between two notions of quality of life. To show why this is the case, we need to distinguish between *local* quality of life and *overall* quality of life.¹⁵ Local quality of life is simply quality of life in a given area, or quality of life with respect to a specific feature. Local quality of life can only ever be evaluated relative to a specific feature or state of affairs at a specific time – that is, we can only speak of local quality of life *with respect to* x at time t or *qua* x at time t. Overall quality of life, in contrast, is quality of life on the whole or 'total wellbeing'. Overall quality of life is thus never evaluated with respect to specific features or states of affairs, but rather can only be evaluated by considering *all* the features/states of affairs that have an impact on personal wellbeing (that is, all the aspects of local quality of life.¹⁶ The two metrics are, of course, not independent: a person's overall quality of life will be determined by the interaction of her varying levels of local quality of life.

¹⁴ There are, of course, other ways of arguing for the sub-optimality of disability. I deal with this one first both because I think it is the most common and the most basic. At the end of sec. II I show how my response can be generalized to deal with other forms of the negative difference-maker argument. ¹⁵ I'll be drawing on this distinction quite heavily in subsequent sections, and one could worry that it's artificial. I think, though, that it's actually both quite natural and quite commonplace. Here's a germane example: a person's overall quality of life is improved by the fact that she gets up at 6am to exercise, but there are certain restricted respects in which the practice represents a reduction in her quality of life. *On the whole* she's better off, because she's fit, has more energy, etc. But qua bleary-

eyed person who likes to be still in bed asleep at 6am, she's worse off.

¹⁶ An Aristotelian picture might also have overall quality of life understood *atemporally*, whereas local quality of life would always be indexed to a particular time. I want to remain neutral on that question (I think it might make perfect sense to talk of a person's overall quality of life *at t*), but I do see the appeal – for example, the painful but life-saving surgery detracts from your local (at surgery-time) quality of life but augments your overall (atemporal) quality of life.

Thus we can disambiguate (ii) as meaning either that disability will adversely affect a person's *local* quality of life, or that it will adversely affect a person's *overall* quality of life. On the former, weaker reading, (ii) is true but fails to substantiate the conclusion of (iii). On the latter, stronger reading, (ii) is simply false.

I take it that the stronger reading of (ii) – that disability will have a negative impact on a person's *overall* quality of life – is the one more generally intended, so I will first argue for its falsity before demonstrating why the weaker reading of (ii) fails to establish the intended conclusion.

My argument against the stronger reading of (ii) rests on parity of reasoning considerations. Concluding that disability is the sort of feature that automatically makes a negative impact on overall quality of life should, by analogy, license the same conclusion for various other features as well. If, as I think we should, we find this result untenable, then we should reject the notion that disability is a negative difference-maker.

As stated previously, disability is, quite obviously, the kind of thing that makes life *harder*. And so, because having a disability will make one's life harder, we infer that disabled people will have a lower quality of life than those (in comparable circumstances) without disabilities. But, of course, disability is far from the only feature that will make a person's life harder. Many other things – gayness, femaleness, etc – are, like disability, the sorts of things that can and do make one's life *harder*. Yet we do not infer from this – i.e., from the fact that gayness or femaleness will make one's life harder – that having such features will automatically make a person worse off. Indeed, we would find such inferences deeply morally questionable. And this is precisely because, in these cases, we are able to appropriately make the distinction between local and overall quality of life. Take, as a prime example, the case of homosexuality. If you are gay, you face a certain set of limitations (e.g., you cannot follow traditional societal models of procreation) and a world of social stigma and discrimination. It's fair to say, I think, that life is *harder* for gay people. But we'd be very reluctant to say that, in general, gay people have a lower quality of life than straight people.

We'd be averse to drawing such conclusions because many gay people greatly enjoy their experience of gayness. Others do not, of course – for some the disadvantages of homosexuality are so great that their sexuality is a burden to them, and if given a choice they would rather be straight than gay. But many find the experience of gayness to be a positive one. Yet it's not that those for whom gayness is a positive never experience any harms or disadvantages in virtue of being gay. Such harms could hardly be avoided in current society. Instead, they experience disadvantages because of their sexuality, but also experience benefits from it – benefits which can and in many cases do outweigh the disadvantages. What many gay people report, then, is that gayness has a negative impact on their *local* quality life in certain areas, but actually improves their *overall* quality of life.

The idea then, is that a feature (such as gayness) which makes life harder does so by negatively affecting local areas of quality of life. But that *very same feature* can positively impact other local areas of quality of life, to the extent that overall quality of life can be enhanced by the feature in question. If this is the case, then the feature is indeed a harm to the person that has it, in that it negatively impacts on certain aspects of quality of life. Crucially, however, the feature is a harm only in a very restricted sense: it is a *local* harm. Due to the enhancement of *overall* quality of life, however, the single feature can simultaneously be both a local harm and an overall benefit. The mere presence, in isolation, of the particular feature – gayness – in an individual doesn't tell us anything about that individual's *overall* quality of life. Some find the experience of gayness a burden and wish they could be rid of it, others find it a benefit and greatly enjoy it. How gayness affects a person's overall quality of life will depend on its interaction with countless other features and circumstances. But because it can be for some a positive, for others a negative, and for yet others probably not much of either, it is precisely the sort of feature I want to characterize as a *neutral* or *difference-making* feature. Being gay makes a person different, but not different in any way that somehow determines whether that person is better or worse off. And this is the case *despite the fact the being gay will make a person's life harder*.

And despite our tendency to view disability as a negative difference-maker, the above picture is precisely the phenomenon reported by many disabled people.¹⁷ Yes, disability is the sort of feature that makes life harder. And yes, some disabled people find this hardship to be a devastating one; that is, some disabled people report that their overall quality of life is (sometimes radically) adversely affected by disability. Yet for many others this is not the case. Many disabled people claim that, although disability detracts from local aspects of their quality of life, their experience of disability, on the whole, is positive.¹⁸ That is, they claim that their overall quality of life is in fact *improved* by their experience of disability.

¹⁷ See especially Thomson (2000) and Davis (2002) for discussion of the discrepancy between what the able-bodied assume when they see a disabled person and how many disabled people in fact feel about their lives.

¹⁸ See especially Linton (1998) for discussion of the emerging 'out and proud' disability culture and her (2005) for an autobiographical account of her own initiation into that culture.

Examples, at this stage, may help to clarify the phenomenon I have in mind.¹⁹

When confronted with the possibility of a cure for the disease that has slowly blinded

her, writer Rebecca Atkinson finds herself inclined not to take it. She describes the

experience of going blind as follows:

It is a unique perspective. It is a grand experiment that most don't get to try. . .

The loss is so gradual that as one sense dies others grow. Suddenly you can smell the world and sense when someone is standing out of your line of vision. Your brain grows on the inside and things on the outside start to matter less.²⁰

Disability rights lawyer Harriet McBryde Johnson writes, of the frequent comments

that she hears about her own disability to the effect of 'you must be so brave' or even

'if I was in your position, I think I'd kill myself':

I used to try to explain the fact that I enjoy my life, that it's a great sensual pleasure to zoom by power chair on these delicious muggy streets, that I have no more reason to kill myself than most people. . .But they don't want to know. They think they know everything there is to know just by looking at me. They don't know that they're confused.²¹

She goes on to write, of disability in general:

The presence or absence of disability doesn't predict quality of life. . .Are we [disabled people] 'worse off'? I don't think so. . .We take constraints no one would choose and build rich and satisfying lives within them. We enjoy pleasures other people enjoy, and pleasures peculiarly our own.²²

In a similar vein, disabled performance artist Mary Duffy, who was born without

arms, says the following in as part of an opening monologue:

How come I always feel ashamed when answering those big staring eyes and gaping mouths? 'Did you have an accident, or did your mother take them dreadful tablets?'. Those big words the doctors used, they didn't have any that fitted me properly. I felt, even in the face of such opposition, that my body

¹⁹ The examples I use are all contemporary, but it would be a mistake to think that accounts of disabled people who find their experience of disability beneficial are a recent phenomenon, or wholly contemporaneous with the disability rights movement. One can look, to name a single example, to Myshkin's description of the clarity and sheer euphoria experienced before an epileptic seizure in Dostoevsky's *The Idiot*, generally taken to be an autobiographical account of Dostoevsky's own experience of epilepsy.

²⁰ Atkinson (2007)

²¹ Johnson (2003)

²² Ibid.

was the way it was supposed to be. It was right for me, as well as being whole, complete, and functional.²³

The sentiments, expressed in varying ways above, are perhaps best summed up by Atkinson, when she writes:

If this experiment of going blind has taught me anything, it's that what you lose in one place you gain elsewhere, and while a blind life is different than a sighted life, it is not lesser.

Having a disability has made the lives of each of these women harder. But it has also enriched them, to the extent that they claim their experiences of disability are of overall benefit to them. That is, just like many other minority features, disability has negatively impacted various aspects of their local quality of life, but it has also positively impacted other areas, such that its overall impact on, as it were, 'total wellbeing' is beneficial.

It seems, then, that the inference in the stronger reading of (ii) is unsubstantiated. Yes, disability is the sort of thing that makes life harder, but from that we cannot conclude that it will have a negative impact on overall quality of life. Many features – gayness, femaleness, etc – make life harder, but we would be loath to conclude that the presence of such features entails that anyone who possesses them will have a lower quality of life than they would have had had they lacked them. We don't draw such conclusions because, though some find that such features inhibit their overall quality of life, many others with those very features find that they are an overall benefit, *despite the fact that they are a hardship*. And this is exactly the phenomenon reported by many persons with disabilities. Yes, disability will make a person's life harder; but that should tell us *nothing* about whether that person will have an overall high quality of life.

²³ Quoted in Thomson (2000)

What about the weaker reading of (ii)? On the picture of disability offered here, the weaker version of (ii) is true – disability will have a negative impact on local quality of life. But given the contrast between local and overall quality of life, the inference from a weaker reading of (ii) to (iii) is clearly unsubstantiated. That is, we cannot conclude, simply from the fact that disability will have negative impact on *local* quality of life, that disability is a negative difference-maker. A feature counts as a negative difference-maker only insofar as it will make a person non-standard in a way that they will be 'worse off' because of. But this notion seems clearly connected to *overall* quality of life. We cannot conclude from the weaker reading of (ii) that disability is a negative difference-maker because the mere fact that disability is detrimental to specific local areas of quality of life tells us nothing about how it will affect overall quality of life. This is simply due to the point, raised above, that *the very same feature which has a negative impact in one area can have positive impacts in other areas*, such that a person's *overall* quality of life is improved by the presence of that feature.

Thus if we use the weaker disambiguation of (ii) the reasoning outlined in (i)-(iii) is undermined. Having harmful impact on specific local areas of quality of life isn't enough to make a given feature a negative difference-maker. The very same feature could also have beneficial impact on other local areas of quality of life, such that, on balance, a person's overall quality of life²⁴ is in fact enhanced by the presence of that very feature.

Thus, neither disambiguation of (ii) manages to substantiate the claim that disability is a negative difference-maker. If (ii) refers to overall quality of life, then it is false. If it refers to local quality of life, then it doesn't license the inference to (iii).

II. Staving Off Objections

²⁴ As determined by the interaction of *all* the aspects of local quality of life

1. Probability

It may be tempting, at this point, to think that I have been attacking a strawman. Perhaps what we commonly think about disability is not that having a disability *will* make a person worse off than she would otherwise have been, but rather that having a disability will *likely* make a person worse off than she would otherwise have been. That is, a disabled person has a *lower chance* at a high quality of life than an able-bodied person in comparable circumstances.²⁵ I previously made the ambitious claim that the presence of a disability (by itself) can tell us nothing about a person's overall quality of life. But surely it can tell us at least this much.

I have two things to say in response to this point. The first is that I don't think it is true. That is, I think that if a given person has a disability that does not, in itself, make her less likely to have a high overall quality of life. But second, and perhaps more importantly, I think that the truth or falsity of the previous claim is largely independent of the question that concerns us here: namely, whether or not disability is a negative difference-maker.

For the first half of my response: note that what we should consider is *objective* chance at high quality of life. More specifically, the relevant notion is objective chance *for x* at high quality of life. That is, if x has a disability and we want to know whether x is less likely to have a high quality of life because of that disability, it's not enough to simply determine the average quality of life of persons in similar circumstances with similar disability and compare it to persons in similar circumstances without disability. Such a calculation (were it possible) would only tell us about *average* quality of life. But what we need to know is whether disability is objectively likely to be a detriment *for x*.

²⁵ Alternatively: than she would have had had she not had a disability.

Again, examine parity of reasoning considerations. Suppose that we wanted to know, for a particular person, whether being gay was likely to make her worse off. It wouldn't be enough to simply calculate the average quality of life (again, were this possible – I'm highly sceptical) of gay people and compare it to that of straight people. This just gives us averages, determined by what has happened to other people. We want to know what is likely to happen *to her*. What could provide such information? It would need to be something like intrinsic facts about her sexuality. Yet the relevant sort are not forthcoming unless we makes assumptions about the intrinsic value of her sexuality (which looks to beg the question).

Likewise for disability. We cannot tell what will happen to a particular person just by calculating averages. So unless we *assume* that disability is somehow intrinsically negative (which begs the question) we cannot make inferences about that person's chances at an overall high quality of life based solely on the presence of a disability.

Yet I think you could disagree with the above considerations, think that the relevant notion should be closer to subjective probability, or think averages should be more informative than I allow them to be while still not having an argument against the idea that disability is a neutral feature (a difference-maker). This is because, quite simply, *it could be the case that disability makes people less likely to have a high quality of life for reasons totally coincidental to disability itself*. So, for example, it could be the case that everyone with a disability is at least less likely to have a high overall quality of life than the able-bodied for, e.g., socio-cultural reasons (stigma, discrimination, etc). To make inferences about the nature of disability itself, you would need robust evidence that disability (and not other, contingently related factors) is what is causing the harmful effect on the chances of flourishing.

Again, consider the case of gayness. Suppose it turned out that *de facto* gay people are less likely to have a high quality of life than straight people (or that they have *on average* a lower quality of life). We would, I think, be inclined to take this much more as a reflection on society than as a reflection on the deep, *de jure* nature of gayness itself.

Thus my contention here is two-fold. Firstly, the presence of a disability does not license the inference that a person is less likely to have a high quality of life. Secondly, even if the presence of a disability did license such an inference, that fact alone would not allow us to draw substantial conclusions about the nature of disability itself. So even if I am wrong about the former claim, the latter should be enough to undermine the worry that probabilities pertaining to quality of life are sufficient for the conclusion that disability is a negative diference-maker.

2. Principles of Evidence

I should also note that I am, of course, taking disabled people at their word with respect to their own quality of life in the argument given in (I).²⁶ It's been suggested, however, that this is perhaps something we shouldn't do. Disabled people may report that they have a high quality of life and that their disabilities have, in fact, been of benefit to them; yet we can reasonably assume that such assertions represent a type of 'wishful thinking' on the part of disabled people. As part of managing a disability, it may be extremely psychologically advantageous to convince oneself that the disability is in fact an enhancement, and disabled people who manage to think this may very likely fare better with disability. But it would be a mistake to take these 'coping mechanism' beliefs as evidence that disability needn't impair overall quality

 $^{^{26}}$ NB: this does not at all entail that I'm assuming subjectivism about quality of life. I attend the arguments in this paper to be neutral, as far as they can be, with respect to specific theories of quality of life. The evidential principles I'm assuming, however, are fully compatible with objectivist theories of quality of life – personal testimony could simply be some evidence for what the objective criteria for quality of life are.

of life. Simply be reflecting on what disability *is*, we ought to be able to conclude that disability does, in fact, impinge on disabled people's chances at attaining a high quality of life.

I think that construing the testimony of disabled people as such is fundamentally misguided. I agree up to a point, though, in that I certainly think that the reports of disabled people represent fallible evidence as to their own quality of life. That is, I certainly think it's possible that disabled people could be fundamentally confused or deluded about their quality of life. However, I do think that the evidence their testimony gives us is much *better* evidence about their quality of life than the theoretical reflections of the able-bodied.

Basically, we're presented with two pieces of evidence about the quality of life of disabled people. The first is testimony of disabled people, some of whom claim that their overall quality of life is enhanced by disability. The second is arm-chair reflection of the able-bodied, who claim that disability is obviously an impairment to overall quality of life (and thus seek to explain away the reports of disabled people as 'wishful thinking'). The claim here is that both these pieces of evidence are fallible, but that the former is much less fallible. That is, disabled people are a much better source of evidence about their own quality of life than the preconceptions of those with no experience of disability.²⁷

Furthermore, I think the 'wishful thinking'-style explanation of the testimony of disabled people represents a deeply pernicious trend in the history of cultural prejudice. We have a particular 'obvious' assumption that we want to hold on to (in this case, that disability impairs overall quality of life) but evidence that prima-facie

²⁷ This point is strengthened, I think, by the fact that most disabilities are acquired, rather than congenital (i.e., most disabled people were born without disabilities). So many disabled people have robust experience of life both with *and* without disability, and yet still report that their experience of disability is of benefit to them.

contradicts this (e.g., many disabled people claim to have benefited from their experience of disability). Rather than considering the evidential datum on its own terms, though, we instead find a method, however convoluted, to explain away the apparently contradictory evidence and make it compatible with our original assumption.

Examples, of course, are plentiful. African-Americans certainly *seem* perfectly intelligent, but it's all just advanced mimicry. Gay people certainly *seem* to be happy, well-adjusted members of society, but it's only because their minds have been so poisoned by sin that they don't know what they should want out of life. And so on.

Thus while one can easily explain away the testimony of disabled people as some form of a 'wishful thinking', I would have grave reservations about doing so. Far better, I think, to attempt to construct a theory of disability which takes them at their word – and that is project of this paper.

There is, though, a more sophisticated version of the 'wishful thinking' response, that perhaps poses a more serious challenge to the idea that we should take disabled people's testimony as evidence of their quality of life. There is a notable psychological phenomenon called 'adaptive preferences', wherein persons in extraordinarily difficult circumstances, as a basic coping mechanism, change their goals and desires so that they no longer see their situation as bad or limiting. So, for example, women in repressive or abusive situations will sometimes identify themselves as happy, and not want their situation changed.²⁸ Why isn't it plausible to construe the first-person testimony of disabled people as exactly this sort of 'adaptive preference' coping mechanism?

²⁸ See especially the discussion in Nussbaum (2000), especially chapter 2, and chaper 1 section IV.

The dialectic here is very tricky, and we must tread carefully. An adaptive preference is characterized as changing ones desires to accommodate something *negative* or *sub-optimal*. So we should only count the given testimony of disabled people as examples of adaptive preference behaviour *if we have reason to think that disability is something negative or sub-optimal*. But that is precisely the question that is up for debate, so a simple diagnosis of adaptive preference runs the risk of question-begging.

One might argue, however, that the burden of proof lies with me, as the position I am defending (that disability is merely a difference maker), is a departure from 'common sense'. Moreover, it would be helpful if something could be said here to avoid a dialectical stalemate. With this in mind, I do think there is a disanology between standard cases of adaptive preferences and the case of disability.

In the hallmark cases of adaptive preferences, we do not take people at their word with respect to their own quality of life because we have *good reason* not to do so. And this good reason comes from the fact that the situations that tend to generate adaptive preferences (abuse, oppression, deprivation) are specific instances of what we consider *social wrongs* or inter-personal *moral badness*. That is, they are instances of one person or group exploiting another in order to gain power for itself.

The case of disability is not such a social or normative construction.²⁹ It is not the action of one person against another, it is not, at its most basic level, how one group of people control another. It is how one group of people are, intrinsically, much in the same way gender or sexuality is.

In the apparent absence of social or normative considerations to appeal to, I think we have less reason to consider the testimony of disabled people as an instance of adaptive preferences. Denying a person's own assessment of her quality of life is,

²⁹ Again, I am assuming that the social model of disability is false.

as argued above, a very serious matter, and I think we should do so extremely cautiously. Again, the idea here is not that the testimony of disabled people is infallible evidence – far from it – but rather that it is defeasible evidence which is still *much better* than the arm-chair reflection of the able-bodied.³⁰

3. Intrinsic and Extrinsic Harms

Finally, there is an obvious objection to the parity of reasoning considerations raised previously. The argument was that disability is not a negative differencemaker for the same reason that features like gayness are not negative differencemakers. Both are the sort of thing that makes life harder. But the fact that a feature makes life harder doesn't mean that it will negatively impact one's *overall* quality of life. A clear objection, though, to the analogy drawn between disability and, e.g., gayness, is that disability seems to make life harder largely in virtue of things intrinsic to the experience of disability itself, whereas gayness makes life harder largely in virtue of things extrinsic to the experience of gayness (social stigma, discrimination, etc). Were we to improve as a society, we could eliminate the hardship of gay people, but it seems that no amount of societal improvement could eliminate the hardship endured by, e.g., someone suffering from MS.

My response to this is that the disanalogy is insufficient to undermine the parity of reasoning considerations put forward. Both gayness and disability present difficulties that are a mixture of *both* intrinsic and extrinsic factors. Yes, the challenges faced by a gay person will be largely determined by social constructs, but they will not be entirely so. A gay man will not, for example, be able to have a biological child together with his partner – a factor intrinsic to gayness – and this may be a grief to him.³¹ So the difficulties faced by a particular gay person need not be

³⁰ For a much more detailed discussion of these issues, see Barnes (forthcoming).

³¹ Of course, such a limitation would only be perceived as disadvantage by some, but this is analogous with disability. Deaf persons cannot hear (an intrinsic feature of deafness) but many do not perceive

wholly imposed by society. Nor can we confidently assert that the majority of the difficulties faced by disabled people are intrinsic to disability; indeed, we tend to grossly underestimate the role that societal attitudes play in the experience of disability.³² Thus the difficulties of both features are a combination of intrinsic and extrinsic factors.

It could be protested here, though, that the *majority* of disability's difficulties come via intrinsic factors, whereas the majority of gayness's difficulties come via extrinsic factors. However, here we face a question of degrees, entangled in a perhaps unanswerable question of what the experience of such features would be like in a perfected society. Suffice it to say that such a slight disanalogy, if indeed it holds, doesn't look substantial enough to undermine the argument of the previous sections.

4. Other Ways of Arguing for Negative Difference-Making

Before leaving the intrinsic/extrinsic distinction, it's worth pointing out that this characterization of disability is entirely compatible even with the view that disability is, in itself, the absence of some intrinsic good or goods (such as health, a a sense modality, etc). Translating to that framework, the idea is just that it simply doesn't follow from the fact that some feature causes a person to lack an intrinsic good that the person is on the whole worse off because of that feature – the very same feature could cause that person to *gain* other intrinsic goods.

Likewise, the account of disability on offer can also, via similar reasoning, address the worry that disability must be a negative difference-maker because it is the absence of some *freedom* or the imposition of some *limitation* (either of which are taken to be intrinsically bad). Within this framework, the idea would be that just because disability takes away a freedom (creates a limitation) doesn't allow us to

this as any kind of disadvantage.

³² Barnes, et al (1999); Davis (2002)

conclude that it makes a person worse off. The same feature that takes away a freedom (creates a limitation) could create other freedoms (prevent other limitations) elsewhere.

III. Causing and Preventing Disability

In the above arguments I hope to have shown that we ought to construe disability, not as a *negative* difference-maker, but simply as a difference-maker. In the subsequent sections I will address concerns over what follows if we understand disability as such.

If we claim that disability is just another way of being different, rather than something obviously sub-optimal, we might worry that we will be forced into counter-intuitive conclusions. There are two main concerns here, which I will deal with in turn. The first is that this account of disability makes it morally permissible to withhold medical treatment of various serious illnesses, and thus allow persons with those illnesses to develop disability; the second is that it licenses us to cause someone to develop a disability.

Suppose that I have a child. I know the various medical risks associated with childhood illness, but I also have been convinced by arguments like those given above (so I think that having a disability is just another way of being different, and disabled people represent a legitimate minority group). I therefore decide not to inoculate my child against polio, because I think that if my child develops a polio-induced disability her overall quality of life will not obviously be harmed by it. My child subsequently catches polio and is permanently disabled from her illness. Intuitively, we want to say that I haven't just made my child 'different'. We want to say that I have acted wrongly – my actions have been those of gross negligence in failing to provide adequate medical care.

But does the characterization of disability given here do justice to that intuition? Can we simultaneously maintain that disability is just one of many ways of being different *and* that parents have a duty to prevent disability in their children where they can?

I think we can, and again I think the key to this lies in the distinction between local and overall quality of life. Crucially, according to the present characterization disability *is* a harm. Disability will (in all likelihood) have a negative impact on a person's (local) quality of life. That negative impact may, of course, be outweighed – the presence of a disability may have positive impact on a person's quality of life as well, such that the person's *overall* quality of life is enhanced by the presence of the disability. But the disability is still a harm to that person, in the restricted sense that it will have substantial negative impact on local areas of quality of life.

My contention here is that parents have a duty to prevent serious or substantial harms to their children, *even harms construed in this restricted sense*. That is, if parents have good reason to believe that something will cause serious harm to their child, they have a duty to prevent it where possible, even if they think that harm might be outweighed by other benefits. Thus for many cases of disability, parents will have a duty to prevent that disability simply because it will cause their child serious harm. Yes, that harm might be, on the whole, outweighed by other benefits of the disability, but that doesn't mean that the harm should therefore be allowed.

The basic point, then, is simply that parents shouldn't be actconsequentialists.³³ Their relationship to their children is one based on a duty of care, and a central provision of such a care relationship is the prevention, where possible, of

³³ This point is, of course, totally independent of whether act-consequentialism (or any other form of consequentialism, for that matter) is true. The idea is simply that act-consequentialism would be an improper way for parents to make decisions (perhaps just because it would not lead to the best consequences, parenting-wise).

serious harm (regardless of whether such harm might result in eventual benefit).³⁴ This is just a familiar point about role-morality, and the role-morality of parents (and doctors, for that matter, as they will face related issues) is decidedly juxtaposed to the act-consequentialist model.³⁵

Yet do such considerations in fact demand too much? The argument that disability is only a difference-maker and not a negative difference-maker rests on parity of reasoning considerations between disability and features like gayness. But if parents are obligated to prevent disability in their children, mightn't we then also conceive of a scenario where they are obligated to prevent gayness? Suppose, as we have reason to believe, that gayness is a genetic feature. Now further suppose that scientists managed to isolate the 'gay gene', and then developed a 'treatment' for gayness. Would, via the same considerations outlined above, parents be morally obligated to prevent their children from being gay?

The answer to this, I think, is that it depends on the situation. Importantly, the contention above is that parents have an obligation to prevent *serious* or *substantial* harm to their children. Obviously, parents aren't obligated to prevent *any* reduction in the local quality of life of their children; getting punished and having to eat your vegetables can represent reductions in local quality of life to children, but they're quite trivial ones. The idea here is that it's only substantial harms – ones that represent a great deal of suffering – that parents have a duty to prevent.³⁶ Is being gay such a harm? That, I think, depends on the cultural context. Arguably at least, in modern western society being gay does *not* represent a serious harm. In other social contexts, though – ones in which, e.g., gays are highly persecuted – it would represent

³⁴ The duty of care plays a complex role here, because it's at least reasonable to think that a child might be less likely to experience positive benefits of her disability if she knew that her parents caused it/could have prevented it.

³⁵ See Wasserman (2005) for further discussion in relation to disability

³⁶ Unless, of course, there's no reason to think the harm in question might be outweighed, in which case it must always be prevented.

such harm. So parents in an open and permissive society have no duty to prevent gayness, whereas those in an oppressive society might well have such a duty.

And, in symmetry of reasoning, the case seems similar for at least *some* disabilities – those that don't involve physical pain and illness, and seem to involve little suffering for those that have them, perhaps (deafness is a prime example here). In a society with extremely limited disability awareness and a high degree of prejudice, parents might be obligated to prevent such a disability. But I'd argue that in an accepting society fully aware of the access needs of those with non-standard physicality, the parents are under no obligation to do so.

It can, of course, be objected here that the notion of a *serious* or *substantial* harm is hopelessly vague. How are we to tell the difference between a serious and a non-serious harm, and what marks the distinction between the two? I have very little to say here that will be helpful; I don't know what the exact difference is between a serious and a non-serious harm. I suspect, though, that this may be a feature of the subject matter itself. If the criteria for quality of life are *themselves* vague (which I think we have some reason to believe) then we should expect exactly this phenomenon. We know various paradigm cases of either kind – childhood polio on the one hand, being forced to eat broccoli on the other – but we can't account for the exact locus or mechanism of the transition between the two. There will thus be a borderline area between the two poles, where things are, as it were, 'undecided'. But if we take it, as most standard theories of vagueness do, that if it is borderline whether p then no-one knows whether p, then we should expect exactly the sort of ignorance described above. We know the polar cases; we know the factors contributing to the transition between the two (i.e., amount of harm rendered); we know that the

transition will occur somewhere between the clusters of polar cases. If the case is one of genuine vagueness then that's about all we can know.

What about the case of causing disability? Jeff McMahan in his (2005) has argued that those who claim that 'it is not worse to [have a disability] have no basis for objecting to the infliction of prenatal injury that causes congenital disability'. Such prenatal injury, McMahan argues, would be free of any of the 'transition costs' associated with becoming disabled; and thus if disability is what he calls a 'neutral feature' (in the terms here, a *difference-maker* but not a *negative difference-maker*), it should be perfectly justifiable to create disability in an unborn child.

McMahan, however, rests his argument on the assumption that the only way to construe disability as a difference-maker involves the claim that 'it is not a harm or misfortune to [have a disability]' (98). The point of the characterization given here, though, is precisely that these two notions come apart. We can simultaneously claim that disability is just another way of being different (one which licenses no assumptions about the overall quality of life of disabled people) *and* that disability is, in a restricted sense, a harm. Thus it's impermissible to *cause* disability. It's impermissible because it's impermissible to cause a person (particularly one's own child) serious harm³⁷ – even if that harm stands a good chance of being outweighed by other benefits.

IV. Selecting Against Disability

So much for the worry that the account of disability on offer is too strong (leading to untenable conclusions). Unsurprisingly, as it's a very fine line being walked, there's an opposing worry that the characterization is in fact *too weak*, that it

 $^{^{37}}$ A notable exception to this would be a case wherein a serious harm to that person was deemed the 'lesser of two evils' – e.g., invasive surgery or chemotherapy.

doesn't manage to secure everything needed from a difference-maker understanding of disability.

A central goal in most any difference-maker theory of disability should ostensibly be to block practices such as *negative selection* against disability. Negative selection represents any systematic attempt to prevent a certain kind of individual (disabled people, in this case) from being born. For disability, negative selection takes various forms, but the most notable are the selective abortion of a foetus known to have a disability and (where a genetic risk factor is known in advance) the selective implantation of embryos that lack congenital disability.

Most disability advocates want to claim that negative selection is impermissible. If disability is merely a difference-maker, then the practice of negative selection, rather than being some sort of humanitarian endeavour, represents institutionalised stigma about disability and, in turn, prejudice against disabled people.

The worry, though, is that my account of disability cannot establish this. If we know that disability is a harm, even in a restricted sense, then why wouldn't it be permissible to negatively select? Negative selection would simply be the replacement of person x who has feature F with person y who does not have feature F. If feature F can sometimes be an overall benefit but is (at least almost) always a serious local harm, but the lack of F can also be a benefit and is (at least almost) never a harm, surely the replacement of x with y is justified.³⁸ Indeed, the replacement seems to simply be an instance of preventing harm, which previously was maintained to be obligatory.

³⁸ Similarly, Kamm (2002) argues for the permissibility to select against a child with a club-foot as being motivated "out of concern for the person who would come to exist. . . he [the child] would have an additional difficulty in life, and there is no-one who would lose anything by not being created."

Prevention of disability via negative selection, though, is clearly disanalogous to prevention of disability via medical treatment. Parents, I argued, have a duty to prevent serious harm (even if that harm is only local). But, crucially, this is a duty to prevent harm *to x*, on the assumption that x exists. The choice in the medical treatment case is over what will happen to a single individual; the choice in the negative selection case is either between the existence of two different individuals or between the existence/non-existence of a particular individual (if no further pregnancy will follow the abortion of a foetus with a disability).

I claimed above that parents are motivated by a duty of care to their children. But a duty of care can only be directed at specific (and persisting) individuals.³⁹ Thus a duty of care could never *mandate* negative selection.

That result, though, is still quite weak. Fair enough, the given model of disability doesn't *require* negative selection, but what we wanted to know was whether it could show that negative selection is *objectionable*.

I will not, in the space here, attempt to discuss whether negative selection is *impermissible*. Such a debate would take us far too deep into issues of personal identity, persistence, abortion ethics, etc. which, though interesting, are largely tangential to my purposes here. Nevertheless, I do want to argue that negative selection is at least *blameworthy*.

Let's assume the most lenient position for the sake of argument: that abortion itself is not a moral issue.⁴⁰ Any woman can abort any pregnancy for any reason and it is perfectly permissible for her to do so. If this is the case, then any particular instance of abortion – including negative selection – is perfectly *permissible*.

 $^{^{39}}$ Some – e.g., (Purdy 1996), Kamm (2003), Kumar (2002) – have argued that we can in fact be motivated to negatively select by something like a duty of care to those individuals we select against. For criticisms of this idea, see Wasserman (2005). Regardless, though, these arguments seem to require the assumption that disability is a negative difference-maker.

⁴⁰ In what follows I'm restricting discussion to the case of negative selection via abortion, for the sake of simplicity. The argument should generalize, though.

But in the case of negative selection, we have an instance of someone performing a permissible action – namely, having an abortion – for a very specific reason. The woman has the abortion *because* the foetus will have a disability. My contention is that the reason for the action makes negative selection blameworthy, even if the action itself is perfectly permissible.

The basic idea is that negative selection displays false and disparaging views of disability. Why choose negative selection? It can't be to prevent local harms, because it only makes sense to prevent local harms *to a specific individual*. But there is no individual that you are preventing harm to, because the pregnancy does not persist. Nor can it be to increase the welfare in the world, since disability can't be judged to decrease a person's chance at overall high quality of life.

Thus the only motivation for negative selection seems to be bound up in false views about disability – particularly, in the construal of disability as a negative difference-maker rather than just a difference-maker. The choice for negative selection relies on the notion that disability is somehow sub-optimal, and thus an ablebodied child is preferable to a child with a disability. But this view of disability is, I've argued, a profound misunderstanding. To make a decision of negative selection is thus to import disparaging views about disability (that it is something sub-optimal, rather than just something different) – and *that* is blameworthy, even if the action of abortion is perfectly permissible.

Again, parity of reasoning considerations are illuminating. Suppose that gayness is genetic and that doctors can tag the 'gay gene' in utero. Now suppose that someone, upon being told her child will be gay, elects to have an abortion. That is, suppose that someone practices negative selection against gayness. We would think this action was a blameworthy one, even if the act of abortion itself was permissible, precisely because it reveals and imports disparaging attitudes toward gayness. The person who negatively selects against gayness doesn't want a gay child – in their eyes, being gay is somehow sub-optimal. But gayness *isn't* something sub-optimal, and thus to treat it as such is discriminatory.

The crucial point, then, is just that *doing x per se* can be perfectly blameless, while *doing x because y* can still be blameworthy. Reasons for actions reveal attitudes and beliefs, and attitudes and beliefs can be blameworthy or otherwise.

Jeff McMahan, however, argues in his (2005) that we needn't construe cases of negative selection as such. A couple that decides to abort a foetus when told it will have a disability isn't claiming that disability is sub-optimal *per se*; they're simply claiming that having a child with a disability is sub-optimal *for them*. I don't see, however, how this helps with the criticism of negative selection levelled above. The couple may well only be demonstrating that having a child with a disability is suboptimal *for them* – but that isn't an appropriate attitude for them to have! It would be no better than a couple who claimed that having a gay child just wasn't optimal *for them*. The point is that no one is justified in taking such a view of these minority features.⁴¹

V. A Proof of the Negative Difference-Maker View?

The previous sections have outlined and defended a difference-maker account of disability. But might there be a much simpler argument to the effect that disability is clearly a negative difference-maker? McMahan (2005) offers such an argument, which runs as follows:

⁴¹ There may, of course, be extrinsic factors that could affect such a decision – e.g., a couple without health insurance in a society without universal healthcare learning that they will have a child that requires substantial medical care. But their choosing to negatively select wouldn't be any judgement against disability per se – it would simply be a manifestation of other (largely unrelated) social injustices. So that couple isn't claiming that having a child with a disability would be of less value to them; they might well love to have a child with a disability, but simply can't because of their economic circumstances.

A single disability may seem neutral because it can be compensated for by other abilities that develop to fulfil its function. . .But if disabilities were individually neutral, they ought to be neutral in combination; but they are not. If, to take the most extreme case, we consider all the abilities whose absence is regarded as a disability and imagine a human individual who lacks them all, it would be impossible to believe that the individual's life would not be worse than the lives of most others – or that it might be worse, but only because of social discrimination or lack of adequate social accommodation. It is true that some things have effects in combination that they do not have in isolation. But this is not the way disabilities work. If we consider why a number of different disabilities would in combination make a life worse, the explanation will appeal primarily to effects that each would have on its own but that cannot be adequately compensated for because of the presence of other

disabilities. . . In short, the bad effects of disabilities are largely additive (96). Can we infer from the fact that someone with every possible disability would seem to clearly be worse off that any of the disabilities are themselves, in isolation, negative difference-makers? The inference seems dubious, since, as McMahan himself rightly points out, features can jointly instantiate properties that none instantiate in isolation.

Take, as an example, the following list of features which seem perfectly 'neutral' in McMahan's sense and which are often thought of, in our society, as hallmarks of physical attractiveness in a woman: small waist, tallness, thinness, large breasts, small feet. A woman who had *all* of these features (in the right proportion) would be unable to walk without tipping over. None of the features are bad in isolation. Indeed, within modern cultural context many women find them desirable. But finding them each individually desirable doesn't mean you want to have them all. McMahan contends, however, that this 'is not the way disabilities work'. We can assume that disabilities are negative difference-makers because 'the bad effects of disability are largely additive'. But what are we meant to understand by 'the bad effects of disability'? If we construe it in an unrestricted sense – the *overall* bad effects of disability – then the argument begs the question. Whether, for any given instance of a disability, there *are* any overall bad effects is precisely what's up for debate. If, on the contrary, we understand 'the bad effects of disability' in a local sense, then the argument doesn't tell us anything new. If individual disabilities involve local harms, then those harms will naturally add up – having lots of disabilities will likely lead to lots of harm. But the crucial point here is just that this doesn't license the conclusion, *for any particular disability*, that it will make a person worse off on the whole.

VI. Conclusion

In the above sections I have argued for a way of understanding disability according to which we can't conclude that physical disability makes people worse off. This may strike many as highly counterintuitive – after all, disabilities are often used as prime examples of exactly the kind of thing that would make a person worse off. I hope to have shown, though, that all we can reasonably conclude about disability is that it's the sort of thing that makes life harder. Yet by parity of reasoning we shouldn't jump from this to the conclusion that disability makes one worse off. Many things make life harder; but they can also enhance and enrich it. Disability is just one of many such features – the sorts of things that create difficulty and hardship, but which make the world a more interesting and vibrant place in the process.

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