

Disabilities Are Also Legitimately Medically Interesting Constraints on Legitimate Interests

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What is it for something to be a disability? Elizabeth Barnes, focusing on physical disabilities, argues that disability is a social category. It depends on the rules undergirding the judgements of the disability rights movement. Barnes' account may strike many as implausible. I articulate the unease, in the form of three worries about Barnes' account. It does not fully explain why the disability rights movement is constituted in such a way that it only picks out paradigmatic disability traits, nor why only the traits identified by the movement as constituting experiences of social and political constraint count as disability. It also leaves out the contribution of people other than disability activists, to the definition of disability. I develop Barnes' account. On my account, a person is disabled if she is in some state which is constitutive of some constraint on her legitimate interests. This state must be the subject of legitimate medical interest and be picked out by the disability rights movement as among the traits for which they are seeking to promote progress and change. My account addresses the worries about Barnes' account. It is also able to include all disabilities, rather than only physical ones.

1. Introduction

What is it for something to be a disability? Specifically, what unifies the heterogeneous group of conditions we label 'disabilities'? This is a question about the definition of disability. On a common understanding, a disability is any abnormal condition of the body which causes a lack of, or constraint on, some ability. This view has received sustained criticism. Disability theorists and activists have argued that disability is not just about the body, but also its interaction with its surroundings – which may be more or less accommodating of atypical bodies. Disability instead is the disadvantage incurred by individuals with atypical bodies in unaccommodating environments.¹

¹ This is a broad-stroke representation of myriad views classed under the umbrella term, 'social model' of disability, each of which specifies this claim differently. See (Wasserman et al 2016) for a survey.

Elizabeth Barnes has recently provided a novel, though narrow, account of *physical* disability (Barnes 2016). Drawing from, and extending, the insights of feminist discussions about the definition of terms such as ‘gender’ and ‘woman’, Barnes rejects the view that there is something about disabled bodies that by itself explains what physical disability is. Instead, disability is a social category. Membership in this category is determined by the rules undergirding the judgements of the disability rights movement. An individual is physically disabled if, and only if, these rules classify her as disabled. The testimony of disabled individuals is central to the definition of physical disability.

Barnes’ specific proposal may strike many as implausible (as it has, in conversations). In this paper, I articulate the unease, in the form of three worries, about Barnes’ account. I then modify and extend the core social constructionist insight of Barnes’ account to address them.

In §2, I outline Barnes’ account. In §3, I identify three worries about it. It does not fully explain why the disability rights movement is constituted in such a way that it only picks out traits which we consider disabilities, nor why only the traits identified by the movement as constituting experiences of social and political constraint count as disabilities. It also leaves out the contribution of people other than disability activists to the definition of disability. In §4, I argue that these worries may be addressed by focusing on the legitimate constraints faced by individuals, and acknowledging the role played by legitimate medical interest in the definition of disability. Including medical interest as a constitutive element of the definition of disability is controversial, at least for proponents of social model or constructionist accounts. In §5, I clarify why my account does not smuggle in the medical model. It also does not posit the medical community as the gatekeeper of what counts as disability. Additionally, my account highlights several potential ways of resisting unjust or distorting influences on what counts as a disability. I conclude in §6.

2. Barnes’ account

In addition to common understanding, Barnes also distinguishes her social constructionist account from other accounts of disability. She observes that accounts which define disabilities as traits which depart from normal human functioning or the species norm, tend to over-generalise. They pick out atypical traits which are not disabilities – such as the traits of Michael Phelps the Olympic swimmer:

‘hypermobile joints, an arm span three inches longer than his height, unusually large feet, and muscles that produce a surprisingly small amount of lactic acid compared to normal ranges’ (Barnes 2016, p. 14). Not all atypicalities are disabilities. Against accounts which define disability as the lack of an ability that most people have, Barnes mentions disabilities, such as achondroplasia, for which there is no specific lack of ability, even though the exercise of certain abilities may be painful or take more time (p. 20). Finally, Barnes argues that social model accounts of disability – which define disability as ‘entirely constituted by social prejudice against persons with impairments’² (p. 25) – are not properly explanatory. They pass the difficulties of defining disabilities (such as those incurred by the above accounts) to the task of defining impairments. Neither do they plausibly account for the full spectrum of disabilities. There are disabilities, such as blindness, deafness, and chronic pain, which would still have bad effects without prejudice (p. 27). Disability is not entirely constituted by ableism.

Barnes’ discussion is guided by four criteria which she claims any account of disability must satisfy. One is central for my purposes. An account must deliver ‘correct verdicts for paradigm cases’ (p. 10) – include all clear cases of disability and exclude all clear cases of non-disability. My subsequent discussion will centre on this paradigmaticity criterion.³

On Barnes’ account,

A person, S, is physically disabled in context, C, iff:

- (i) S is in some bodily state x;
- (ii) the rules for making judgements about solidarity employed by the disability rights movement classify x in context C as among the physical conditions that they are seeking to promote justice for. (Barnes 2016, p. 46)

Let us unpack the essentials. By ‘bodily states’, Barnes refers to specific physical disability *traits*, ‘rather than family groupings of physical

² Whether Barnes has given us the most defensible or updated characterisation of social model accounts is tangential to my discussion.

³ The other criteria are that the account explains what unifies disparate cases of disability and does so non-circularly. Also, it must not stipulate that disability is bad or suboptimal. I shall not have much to say about the unity, non-circularity, and neutrality criteria.

traits, illnesses, etc' (p. 46 n.65).⁴ For instance, clause (i) ranges over the specific bodily states of someone with multiple sclerosis, rather than multiple sclerosis as a 'named' kind of disability constituted by multiple, different traits.⁵ Barnes does not defend this level of (fine) granularity. However, we may understand it as revealing similarities between different 'named' disabilities – which are, in any case, clusters or groups of different traits. This contributes to revealing similarities in people's experiences relating to those traits.⁶

Barnes describes the formulation of the rules as follows. A 'group of people with a variety of physical conditions got together' and observed commonalities in their experiences of their bodies, in virtue of those conditions (p. 44). These experiences include the following:

how those physical conditions were stigmatized, how people treated them because of those physical conditions, how those physical conditions made it difficult to access public spaces, to complete everyday tasks, to get adequate healthcare, get full-time employment and benefits, and so on. (p. 46)

While Barnes does not say so explicitly, we may see this as mirroring feminist or gay rights activists' 'consciousness-raising' meetings several decades ago. These meetings helped activists to identify common experiences of social and political constraints, around which they subsequently organised their political action. Indeed, Barnes describes disability activists as organising themselves in a civil rights struggle – thus constituting the disability rights movement – to promote justice for others with bodies and experiences they judge to be importantly similar (p. 44). These judgements, for Barnes, are of solidarity – about who counts as part of the group to whom the quest for justice is relevant (p. 44).

These judgements about which bodies and experiences are 'importantly similar' (p. 44) are not haphazard. Instead, they are 'rule-based' – specifically, involving 'something like cluster-concept reasoning' (p. 45). The disability rights movement judges a trait to be a disability,

⁴ Here, I follow Barnes' interchangeable usage of the terms 'traits', 'bodily states' and 'conditions'.

⁵ It may seem that multiple sclerosis is more appropriately described as a disease rather than a disability. Barnes does not discuss the distinction. While I do not discuss it here, I do so elsewhere.

⁶ The following is an upshot not discussed by Barnes: this also reveals similarities between disability traits, and 'normal' conditions at different stages of human life, such as the very young or old (Nussbaum 2007, p. 101). This may encourage people to take the task of addressing these traits more seriously, rather than dismissing it as politically unimportant.

if it has some sufficient number of features such as: being subject to social stigma and prejudice; being viewed as unusual or atypical; making ordinary daily tasks difficult or complicated; causing chronic pain; causing barriers to access of public spaces; causing barriers to employment; causing shame; requiring use of mobility aids or assistive technology; requiring medical care; and so on. (p. 45)

On Barnes' account, the testimony of activists within the disability rights movement⁷ is accorded central importance to the definition of 'disability'. It is *their* identification of the common experiences of living with their bodies and facing social and political constraints which is relevant; likewise their judgements about which traits and their corresponding experiences are importantly similar to those they have initially identified. This respects their privileged epistemic status concerning (the experience of) disability. Taken together, this serves as a corrective to a tendency of laypeople and philosophers to dismiss the testimony of disabled people (pp. 119-142), or to presume to speak for them without consulting them.⁸ This does not, however, mean that these activists are 'inviolable disability detectors' (p. 45). They could misunderstand or misapply the rules upon which their judgements are based. Thus Barnes describes disability as all and only that which the disability rights movement 'ought to consider' as disability (p. 46). Disability is picked out by the correct application of the rules.⁹

A final note: Barnes, drawing from and extending Sally Haslanger's discussion of gender and race (Haslanger 2000; 2005; 2006), characterises her account of disability as part of an ameliorative project. Ameliorative projects examine the point of having a particular concept (Haslanger 2006, pp. 95-96), and ask whether there is a legitimate purpose for having it (2000, p. 33; 2005, p. 11; 2006, p. 116). They aim to formulate concepts that help with unmasking and critiquing the hidden structures upon which our existing concepts rest (2005, p. 23; 2006, p. 116). To do so, it is necessary that the workings of such

⁷ Barnes acknowledges that the movement is not monolithic (Barnes 2016, p. 44). Multiple movements may render 'indeterminate' which movement and rules count – and have the result that in borderline cases 'it's indeterminate which physical conditions count as disabilities' (p. 50). I agree with Barnes that such indeterminacy is not a problem for her account in this sense. I revisit the issue of indeterminacy (§§ 3 and 4).

⁸ Barnes acknowledges that this constrains her account so that it covers only physical disabilities, due to complications arising from the testimony of individuals with mental disabilities (Barnes 2016, p. 3). I revisit this (§4).

⁹ Barnes does not discuss the possibility of error at other points – specifically, at the point of identifying experiences, and making judgements of solidarity. I revisit this (§3).

structures are included in the definition of the concept. For instance, Haslanger defines ‘woman’ as someone who is necessarily subject to systematic subordination, in virtue of being observed or presumed to have certain bodily features (2000, p. 42). This reveals that being a woman is not simply about having certain biological traits, but also about occupying subordinate social positions. This paves the way for political action to resist oppression and achieve gender justice (2000, p. 47). The counterintuitiveness of the concept is *expected* – a result of uncovering and foregrounding hidden (patriarchal) structures (2006, pp. 93-94). Barnes intends her account of disability to be understood similarly (Barnes 2016, pp. 40-42). Thus we may not dismiss it simply on the basis of its conspicuous counterintuitiveness. Instead, we should examine how and whether its constitutive elements satisfy the criteria listed above. To this we now turn.

3. Problems

Barnes under-specifies the mechanism through which the disability rights movement is constituted. On her description, the movement begins when ‘[a] group of people with a variety of physical conditions got together’ and observed commonalities in their experiences of their bodies, in virtue of those conditions (Barnes 2016, p. 44). The first worry is: *why* would any given group contain *only* disabled people? One way of understanding the worry is that Barnes’ account does not get to the heart of what disability is. Specifically, it seems that the activists may *already* be employing a concept of disability insofar as they are in a position to identify others as those with whom they may (or should) get together in order to struggle for justice.¹⁰ If so, Barnes’ account, which turns on the judgements of disability activists, may not give us a sufficiently thorough account of disability.

When the worry is put this way, I think Barnes has a ready response. Such groups contain only disabled people because these people *are involved in defining* the traits they possess *as disabilities* (p. 46). They are the ones who identify the commonalities in their experiences in virtue of their bodily traits, and judge whether other traits and experiences are importantly similar (by sharing a sufficient number of

¹⁰ Barnes discusses a related worry, namely, that her account violates the non-circularity criterion because it appeals to the practices of the disability rights movement in order to pick out disabilities. I agree with her contention that there is no circularity *in this sense*, because ‘[civil] rights movements are individuated by what they do, not by their names’ (Barnes 2016, p. 48). This response, however, is inapplicable to the worry I am pressing.

features with the identified traits). Individuals whom they judge not to have importantly similar traits or experiences are excluded as non-disabled. In sum, groups contain only disabled people, because the members define themselves as disabled and exclude those who are not.

We may, however, press the initial worry differently. Consider the following, hypothetical account of the constitution of a disability rights group. In addition to disabled individuals, there are also black and gay people.¹¹ They are included in virtue of the activists' judgements that their experiences of having these traits are importantly similar to those of other members. They are stigmatised or treated differently, have restricted access to public spaces, struggle to get adequate healthcare and employment, and so on (p. 46). Additionally, their traits are judged as sharing a sufficient number of relevant features. Barnes does not specify whether the judgement that a trait 'has some sufficient number of features' (p. 45) is purely quantitative, or whether some of the features are more crucial than others. But, looking simply at numbers, the trait of being black and the trait of being gay both share six of the nine features (preliminarily) identified by Barnes (p. 45). Solely on the basis of numbers, this appears to be sufficient. For instance, 'being myopic' is a disability, yet it also shares only six of the features – it is not subject to prejudice, and causes neither chronic pain nor shame. Since there is no appeal to a prior concept of disability which can do the differentiating work, 'being black' and 'being gay' appear to *count as disabled* on Barnes' account. If so, it violates the paradigmaticity criterion. It allows for traits to be picked out which we clearly *do not count* as disabilities (pp. 15, 18). Here, Barnes' claim that whatever is picked out by the disability movement is a disability, does not work as a response. The worry generalises, to include traits such as being ugly, lazy, talentless, stupid, socially awkward, boring, and so on (Anderson 1999).

In trying to resist this result – and thus meet the paradigmaticity criterion – it is explanatorily unsatisfactory to pass the buck on to activists. We cannot assert that the disabled individuals in the group *will exclude* being black and being gay as non-disabled. That is exactly what requires explanation. We now see that Barnes' account only explains *how* the traits we now consider disabilities are unified – they are picked out by the disability rights movement's judgements.

¹¹ Are racial and sexual traits *physical*? I take my cue from Barnes on this. She writes that it is 'a requirement of any successful theory of disability that it can distinguish between being disabled and being gay' (Barnes 2016, p. 15). It must also be able to distinguish disability 'from other social categories' such as being Black (p. 18).

Yet this allows, in principle, for more traits to count as disabilities than we are prepared to admit. This worry points to a gap in Barnes' account: it does not explain why the disability rights movement would be grouped or constituted in such a way that their judgements pick out only paradigmatic cases of disability and leave out traits such as being black or being gay.¹² Further explanation is needed.

Dismissing two unpromising responses clarifies the problem. We might think that the activists are making a mistake, because 'being black' and 'being gay' are not traits they *ought to* consider as disability. That is, if they truly understood, and correctly applied, the rules undergirding their judgements of which traits are importantly similar to disability traits, they would exclude black and gay people as non-disabled. However, on Barnes' account, the content of the rules is 'determined by social practice' (Barnes 2016, p. 45 n. 64). In the case of disability activism, the relevant social practice involves the identification of common experiences in virtue of having certain bodily traits, and judgements about whether other traits and experiences are importantly similar to those already identified. Where the set of initially-identified traits and experiences changes (to include 'being black' and 'being gay'), so will the judgements about which other traits and experiences are importantly similar, and *also* the rules underlying the judgements. Thus if black and gay people were included right *from the start*, then the correct understanding and application of the rules *would* indeed pick out 'being black' and 'being gay' as disabilities. There is no further sense of 'ought' beyond the rules determined by social practice. And there is no explanation (yet) for why and how black and gay people should be excluded from the start.

Alternatively, we might think that the fact that one group picks out 'being black' and 'being gay' as disabilities does not mean that the disability rights movement as a whole (or in general) ought to do so. However, this merely shifts the problem: ought the other groups within the movement to exclude such traits. It also leaves unaddressed the problem of why those other groups would not reach similar judgements. Again, explanation is needed.

I move now to the second worry. On Barnes' account, the initial identification of common experiences among disabled people

¹² Anita Silvers gestures to a worry in the opposite direction – that the rules may exclude individuals with traits that ought to be considered disability (Silvers 2016, p. 860). I elaborate on this as part of the second worry about Barnes' account.

contributes to their seeking justice. These experiences primarily refer to *social and political* constraints (p. 46). So does the set of features which are judged as constitutive of these experiences, and which are in turn referred to when judging whether other traits and experiences are importantly similar (p. 45). The second worry is: what about the disability status of other traits which are judged as (somewhat) similar, but not *importantly* so?

This worry is made vivid by referring to certain traits which do not present primarily, or even obviously, *social or political* constraints. Consider anosmia (loss of smell), or polycystic ovary syndrome (involving features such as irregular periods, difficulty getting pregnant, and increased risk of miscarriage).¹³ These traits are not *prima facie* constitutive of experiences that importantly resemble those initially identified by disability activists. It is not the case that someone is obviously stigmatised for possessing these traits, nor that possessing them makes it difficult to access public spaces, complete everyday tasks, get adequate healthcare or employment. (p. 46). Nor do they share a sufficient number of features to be judged importantly similar to disability traits. On Barnes' account, it appears that these do not count as disabilities. The worry is not simply that such a claim is counterintuitive. Rather, Barnes' account neglects the fact that these traits are nevertheless constitutive of experiences of some constraint – and *thus* may qualify as disability – *even if* they are not judged to be importantly similar to the traits and experiences identified by disability activists.

Barnes may respond by claiming that it is indeterminate whether these traits count as disabilities. These may just be the sort of expected vague and borderline cases that arise from the fact that the judgements involve cluster-concept reasoning (p. 45). She may acknowledge that these traits are constitutive of experiences of some constraints. That they do not count as disabilities, however, is simply due to the fact that they are at the margins – they share some, but not all (or not a sufficient number), of the features required to count as disabilities. The line which delineates disabilities from non-disabilities is coarse, and such borderline cases are to be expected. Indeed, Barnes claims that 'it would strike [her] as deeply implausible that any aspect of our multifaceted social reality had fully determinate boundaries' (p. 50). At the margins, we may find that severe manifestations of a certain

¹³ Barnes is unclear about whether an increased risk for a certain condition counts as disability. Discussing Michael Phelps, she writes that 'risk of heart problems notwithstanding, Michael Phelps is not disabled' (Barnes 2016, p. 15). Yet this is closely followed by the claim that 'having a predisposition to cancer does not make you disabled' (p. 16).

trait may count as a disability, while milder manifestations may not – as in the case of asthma (p. 47). In effect, Barnes may resolutely deny that it is a problem that borderline traits such as anosmia or polycystic ovary syndrome are not picked out as disabilities. It is not a drawback of her view (p. 50).

Barnes' response might be adequate if the worry were about indeterminacy. For any account, there are likely to be borderline cases. That the disability status of some traits is indeterminate should not worry us unduly – especially if a large number of (paradigm) cases are covered by the account. However, the worry is that being constitutive of certain experiences of primarily *social and political* constraints is a peculiar way of determining what counts as a disability. It may leave out traits which we regard as disabilities, even though they are not constitutive of such experiences. The risk here is of violating the paradigmaticity criterion. This worry points to another gap in Barnes' account: it does not explain why *only* the traits identified by disability activists as constituting social and political constraints count as disability. The connection between facing such constraints and being disabled is under-elaborated. Barnes' claim that the 'kinds of efforts made by the disability rights movement ... simply aren't for' others with such borderline traits (Barnes 2016, p. 47) may not be marshalled in her defence. We may grant this claim, while pressing for an explanation for why disability is defined in terms of being the appropriate beneficiaries of such effort. And recalling the earlier discussion, we may not pass the buck on to the disability rights activists.

A common thread runs through the two worries concerning the paradigmaticity criterion. On Barnes' account, the judgements of solidarity made by the disability rights movement appear to be – at least in some cases – untethered from what they are supposed to be tracking. Thus the disability rights movement may be constituted by judgements of solidarity that are overly accommodating, such that certain non-disability traits count as disabilities. The movement may also be constituted by judgements that are overly restrictive, such that many traits which we consider to be disabilities do not count as such. We need to explain how and why these judgements of solidarity do not actually lead us to these scenarios.

Finally, and this is the third worry, what about the testimony of people other than disability activists? The impression we get from Barnes' discussion is that only the testimony of disability activists matters. Barnes may argue that treating the testimony of disability activists in this way serves as a corrective to a tendency of laypeople and

philosophers to neglect or dismiss the testimony of disabled people (pp. 119-142), or to presume to speak for them without consulting them. It also corrects for the roots of such unfair practices – our inheritance of (naively) naturalistic accounts of disability (p. 47), according to which the testimony of disabled people has *no* role to play in the definition of disability. Moreover, this connects with Barnes' ameliorative project – to provide a definition of disability that we *should* employ to help with understanding, explaining, and addressing injustice (p. 41). Focusing on the testimony of disability activists foregrounds the nature of disability as a social, rather than natural, kind. We should use it to address the unfairness of our practices.

However, the fact that the testimony of disability activists plays this central role does not mean that *only* their testimony matters. What about the testimony of the parents, partners, care-givers, advocates, and so on, of disabled people? While Barnes does not rule out the potential contribution of their testimony, neither does she elaborate on how they feature in an account of disability. Yet we must consider these alternative testimonies, the roles they play in the definition of disability, and their status relative to that of disability activists – *even if* they are unfair or distorting. Learning from Haslanger's analyses, we must attempt to excavate and incorporate these elements into the definition of disability.

4. Legitimately medically interesting constraints on legitimate interests

On my account, which is a modification and extension of Barnes', a person, S, is disabled in context, C, if and only if:

- (I) S is in some state, x;
- (II) x is constitutive, in C, of some constraint on S's legitimate interests;
- (III) x is regarded, in C, as the subject of legitimate medical interest;
- (IV) the rules employed by the disability rights movement classify x in C as among the traits that they are seeking to promote progress and change for.¹⁴

¹⁴ My account draws from the analyses of Iris Marion Young (1990, 1994), Amartya Sen (1992), Avishai Margalit (1996), and Mari Mikkola (2016). Due to space constraints, however, I cannot outline my debt in great detail.

First, following Barnes, disability is understood as a particular state (of being) that an individual is in. Unlike Barnes' account, however, my account does not focus narrowly on physical disabilities. In condition (I), I drop the restriction that the states have to be physical. As we shall see, this does not run into problems arising from the testimony of individuals with mental or cognitive disabilities. This is because the testimony of disability activists features differently in my account.

Condition (II) of my account, which introduces the idea of constraints on legitimate interests, is a significant modification of Barnes' account. Constraints are to be understood broadly, as limits (of any kind and degree) on people's functionings – the ways they can be or can act (Sen 1992). Constraints may result from the arrangement of institutions and physical spaces, which restrict the ways in which individuals interact with one another and their environment (Young 1990; 1994). For example, a wheelchair user faces restrictions on her ability to move around in a society which does not have a reasonable number of access ramps. Constraints may also result from facts about disabled people's bodies. For example, someone with chronically degenerative or painful traits may regard herself as constrained in daily functionings. A clarification: constraints on functionings are not equivalent to a *lack* of functionings. As Barnes acknowledges, disabled people may complete certain tasks 'more slowly and with more pain', without being *unable* to complete them (Barnes 2016, p. 17).

The testimony of disabled people is very important, in helping us to identify what constraints there are, where they are located, and how they affect the lives of those who face them. We should take disabled people seriously when they say of any particular way in which our social world is organised, that it creates constraints on the functionings of people possessing the traits they do. However – and this is a specification of the third worry in §3 – their testimony cannot be all that we rely on to identify constraints. Parents of disabled people may identify constraints faced by the latter at a very young age. Partners may identify others concerning intimate and sustained cohabitation. Care-givers and advocates may also identify administrative or bureaucratic hurdles that contribute to constraints. Additionally, these people may identify constraints when those facing the constraints are unable to speak for themselves – as may be the case with individuals with severe mental or cognitive disabilities. Of course, these identifications (and judgements) of what counts as constraints are made against the backdrop of the prevalent attitudes, in C, towards disability traits. That is, they are not immune to the various forms of

prejudice about and against disability traits. The clarification of their contribution is, however, important. Drawing on Haslanger's insights, we want our account of disability to unmask the hidden structures upon which our existing concepts rest – even if those structures contribute to distortion and injustice.

More generally, highlighting the contribution of 'constraints' in the definition of disability also helps us to make sense of conditions such as factitious disorder.¹⁵ As Barnes notes, people with factitious disorder go to 'great lengths to fake the appearance of an illness or disability' (p. 32). However, despite the fact that they *do experience constraints* due to their pretending to have certain traits (and their commitment to keeping up the pretence), Barnes describes them as *not* disabled (pp. 33, 35). Barnes does not elaborate on her evaluation, beyond saying that it would be 'an odd result' to say that these people are disabled (p. 33). We may say more with our account. One reason why individuals with factitious disorder are not disabled is because they are not *actually* constrained. Their potential retort – that they *do experience constraints* – is insufficient, insofar as those experiences are not anchored to traits that constitute actual constraints. Later, I argue that another part of our rejection of factitious disorder as non-disability depends on the fact that it is not the subject of legitimate medical interest.

We may also turn to cases in another direction. Consider infertility. Barnes considers a woman who does not want children, but later discovers that she is infertile. Barnes claims that it 'would be strange to say that this person has just discovered that they are disabled' (p. 18). On my reading of Barnes' account, this is because a crucial aspect of disability is its being constitutive of experiences of constraint. The woman who does not want children *experiences* no such constraint, and thus is not disabled. This, however, seems unsatisfactory. We are still inclined to judge that the woman is disabled, *in some sense*, in virtue of her actually possessing the trait of 'being infertile'.¹⁶ This

¹⁵ My analyses apply similarly to Barnes' discussion of people with bodily integrity identity disorder, who identify as disabled *before* they make modifications to their bodies (Barnes 2016, p. 35).

¹⁶ I do not say of this judgement that it is correct. It is still open for Barnes to reiterate her claim that infertility is not a disability. As we shall see later, she may draw on the claims of Deaf activists and say that the relevant legitimate interest should not be fine-grained ('biological reproduction'), but coarse ('reproduction' or 'starting a family'). She may add that the level of granularity at which the initial interest was formulated is the result of our particular (heteronormative) historical trajectory. I find this strategy intuitively appealing, but regret that I cannot discuss it further here.

judgement appears to be stable, despite her not wanting to have children, and experiencing no constraints. On my account, the infertile woman is regarded as *actually* constrained with respect to biological reproduction, and thus is counted as disabled.¹⁷ Whether the accompanying constraint matters to her is taken to be a separate issue from how we may best describe the state she is in.

Next, what counts as S's legitimate interests is, importantly, left open. It would, among other things, depend on the context which S inhabits, and the range of available views about the interests of human beings. These views may come from individuals' conceptions of the good, which contain ideals about what is of value in human life (Rawls 1993, p. 13), and thus about what is of legitimate interest to human beings. Such views may be religious, or they may not. The views may also come from the legislative decisions and juridical statements in C. Individuals' conceptions of legitimate interests will be shaped by how existing laws determine which interests are legitimate (partly by deciding what kinds of claims are regarded as legitimate), and how those laws are interpreted by the courts. That is, they may depend on 'top-down' narratives about what count as legitimate interests in C.¹⁸ Thinking about what are regarded as our legitimate interests at any given time prompts us to consider how the boundaries of the social category of disability also depend on the contexts in which we are situated and contribute to the sustenance of.¹⁹

There will expectably be contestations about what count as legitimate interests. Consider Barnes' rejection of Deaf activists' claim that deafness is not a disability. She argues that such claims are 'often made out of ignorance of – and prejudice against – disabilities other than

¹⁷ There are complications here, arising from a lack of details about how this woman is infertile. Depending on which part of the body the condition affects – whether, for instance, it affects the ovaries, fallopian tubes, uterus, or more general hormonal issues – and depending on the context – such as the state of technological advancement and level of social welfare support – she *may not* actually be constrained with respect to biological reproduction. I discuss the relationship between constraints, wellbeing, and disability elsewhere (Lim 2017). There is also a further complication when we consider her social 'class' – wealth may mitigate low standards of available, state-provided accommodation. I am unable to tackle these complications here.

¹⁸ I sidestep an important complication – even within the same context, different institutions may specify legitimate interests differently. For instance, state welfare agencies and insurance companies may have different specifications of what counts as legitimate interests. Different traits would then be picked out as disabilities. I leave open how this heterogeneity may be addressed.

¹⁹ If so, we may need to rethink Barnes' claim that the social category of disability 'travels' across time and contexts (Barnes 2016, pp. 50–51).

deafness' (Barnes 2016, p. 34). They assume that disability is bad, judge that deafness is not bad, and conclude that deafness is not a disability. Barnes appears to be right. Being deaf is constitutive of certain constraints, the badness of which cannot be removed by the insistence that deafness is not a disability. However, I believe that their claims may be re-interpreted in a way which avoids the diagnoses of ignorance or prejudice. My account allows us a way of doing this. Instead of the naïve claim that being deaf is not constitutive of constraints, Deaf activists may be understood as challenging the prevalent understanding that we have a legitimate interest in *hearing*. Specifically, their claim challenges the fine-granularity of this interest. Rather than 'hearing', the relevant legitimate interest may instead be construed more generally, as 'social communication'. Since Deaf people have access to their own communicative practices – sign language – this interest of theirs is not constrained.²⁰ Accompanying this is their claim that the struggles they have communicating with hearing people is attributable to prejudice or lack of accommodation (Dolnick 1993). And a component of this prejudice is located in terms of the prevalent view – held by most hearing, and even many deaf, people – that hearing is the right way of understanding the legitimate interest. This view is expressed not just in ordinary interactions, but also in popular culture, art, and especially political decisions about how to address deafness in areas such as education, employment, or the physical environment. I take it as a virtue of my account that it creates a space in which we may situate the claims of disability activists and render them more plausible. I take it as a further virtue that it highlights the ways in which non-disabled people may participate in, and contribute to, the definition of disability.

At this point, my account already responds to the second worry that Barnes' account faces. It does so by acknowledging that not only the traits identified by disability activists as constitutive of social and political constraints count as disabilities. Disability is not only that which

²⁰ It may seem that Barnes might agree with me. Her discussion of Deaf activists is in the context of whether self-identifying as disabled is necessary or sufficient for being disabled. Since she does not consider the issue of legitimate interests, it appears more charitable to understand her as leaving open the possibility that Deaf activists are challenging our legitimate interests in the way I have suggested. However, Barnes links her discussion of Deaf activism to the ostensibly similar claim by high functioning disabled people, such as Paralympians, that they are not disabled (Barnes 2016, pp. 34-35). Yet the claim by the latter group appears to be more clearly in error – and cannot plausibly be reconceptualised as challenging our understandings of legitimate interests. Barnes' linking them together, thus, may be understood as revealing her evaluation of the claims of Deaf activists.

is constitutive of social and political constraints. Instead, it is constitutive of constraints more generally, without the narrower qualification. On my account, traits such as anosmia or polycystic ovary syndrome may be considered disabilities, even though they may not be constitutive of social or political constraints. My account also addresses the third worry. Those who are not in the disability rights movement contribute to the definition of disability – through the identification of constraints, through identifying how traits are constitutive of them, and through participating in or maintaining institutions and practices that determine what count as our legitimate interests.

Condition (III) of my account introduces the idea of legitimate medical interest. A trait is regarded as the subject of medical interest if its presentation and/or causal structures are regarded as being of interest to the community of medical professionals (which includes practitioners, researchers, theorists, and so on).²¹ Their work may identify a trait as a disability – even though it is not constitutive of any obvious constraints – by revealing that it shares the same causal structure as another trait which we regard as a disability. That traits with different presentations share the same causal structure underlies a strong intuition that both are disabilities. From the perspective of medical interest, one may say, contra Barnes, that even mild asthma is a disability, though its constraints are not as serious as those of severe asthma. In the case of factitious disorder, medical work may also reveal that the underlying physical causal structures do not constitute traits which count as disabilities (though attending to neurological structures may reveal that those with factitious disorder are disabled, but in a *different* way). In sum, medical interest and work also contribute to addressing the third worry about Barnes' account – there are other ways of identifying disabilities.²² Additionally, they allow my account to pick out traits as disabilities even when those

²¹ Of course, there are disputes within the community about whether some traits are the subject of medical interest. The disputes surrounding the Diagnostic and Statistical Manual of Mental Disorders (DSM) are examples of such internal disagreements.

²² It may appear that Barnes' account already accounts for this. Recall that the list of features which traits must sufficient share, include 'causing chronic pain ... requiring use of mobility aids or assistive technology; requiring medical care' (Barnes 2016, p. 45). The inclusion of these traits appears to indicate that Barnes may be amenable to the inclusion of the role of medical interest in determining what counts as disability. However, these are just three of the nine features she lists. She does not say *whether* and *how* these are crucial to the judgement that any given trait is importantly similar. I see my introduction of clause (III) as doing exactly this work.

possessing them are unable to speak for themselves (as in cases of severe mental or cognitive disabilities).

The medical interest has to be regarded as legitimate, and in two ways. An interest is regarded by medical professionals as legitimate if it conforms to the subject-specific norms regulating the domain of medicine generally. For instance, the interest concerns traits which have to do with issues such as health, disease, function, malfunction, fitness, and the like. Discussions about such issues must also adhere to reasoning norms accepted by the community. I shall not have much more to say about legitimacy in this sense. On this, I defer to medical professionals – noting that there may, in many cases, be internal disputes (Reiss and Ankeny 2016). The latter sense of legitimacy is normative, or moral. An interest is regarded as legitimate if it does not humiliate or denigrate the individuals who possess the trait(s) concerned. An interest is humiliating when it ‘constitutes a sound reason for a person to consider his or her self-respect injured’ (Margalit 1996, p. 9).

In general, the causes and forms of humiliation are myriad. But in the case of disability, they exhibit a certain pattern. Medical interest in a particular trait often expresses the view (explicitly or implicitly) that the trait is inherently dysfunctional, and that something *can be done by the medical community* to address it – often by *treating and eliminating* it. For some traits, however, the expression of such a view is humiliating to individuals who possess them. These traits are valued and are constitutive elements of their identity and even culture – they are constituents of these individuals’ self-respect. *To them* (and their allies), there is nothing dysfunctional about these traits, and nothing can (and should) be done by medicine to address them.²³ Examples are found by looking at traits which were historically subject to medical interest, but which we now do not regard as its legitimate subjects. For instance, being gay (Spitzer 1981; Bayer & Spitzer 1982), being black (Hogath 2017), being a woman (Williams 1993, p. 120), and even engaging in masturbation (Engelhardt 1974) were subject to such medical interest.

²³ This, I believe, bypasses the worries arising from medical interest in the predispositions of certain groups (be they racial or sexual) to certain medical conditions. The goal in those cases is not to treat or eliminate the trait itself, but, rather, accompanying traits. For instance, we may treat or eliminate the pain associated with a certain trait, but not the trait itself (Silvers 2003, p. 478). This is less likely to be regarded as humiliating by the people involved. I am, however, unable to pursue this complication.

In a different direction, there are also traits which were, until recently, systematically ignored by the medical community – such as chronic fatigue syndrome, or post-partum depression – despite the claims of those who had those traits. In these cases, the fact that those traits were not taken as medically interesting frequently meant that their manifestations were understood as character flaws. Those who possessed those traits were judged to be lazy, overly-sensitive, or not motherly. In these cases, it was important to the self-understanding and self-respect of these individuals that the traits they possessed were understood as legitimately medically interesting. At a general level, we may see these two types of cases as the result of successful challenges directed at the medical community (among others), about what counts as a subject of legitimate medical interest. And in these cases, it was *not insignificant* that activists succeeded in convincing the medical community (or society more generally) of the status of their traits – either that the traits in question were, or that they were not, disabilities. Only by highlighting the contribution of the medical community, can we leave room to make sense of the salience of such successes.

Highlighting the contribution of legitimate medical interest to the definition of disability helps us to avoid the first worry about Barnes' account. We can now see why the disability rights movement would be, and are in fact, constituted in such a way that they pick out only what we regard as paradigmatic disability traits, rather than traits such as 'being black' or 'being gay'. When disabled individuals group together, such traits would already have been excluded from the class of disabilities – they are already not regarded as the subject of legitimate medical interest. Crucially, this move is contingent on a certain context and historical trajectory. The disability groups here and now pick out the traits they do because of a certain history which we have inherited. Part of that history is that, because of civil rights movements other than those concerning disability rights, being black and being gay are no longer regarded as disabilities. Civil rights movements aimed at advancing gay rights put pressure on what counts as legitimate medical interest. The disability rights movement, then, contain only disabled people because of a background understanding of what is not the subject of legitimate medical interest.²⁴ This is not to

²⁴ Attending to the ways in which these movements unfolded gestures to the possibility that what qualifies, or is excluded, as the subject of legitimate medical interest is subject to political forces that resist unifying explanations. This may have implications for whether and how the unity condition may be met.

rely on a prior concept of disability to do the differentiating work. The challenges that other activists made to illegitimate medical interest do not necessarily rely on a concept of disability.

Three general lessons may be drawn from this acknowledgement of history. First, other civil rights groups *also* have a part to play in the definition of disability – through challenging the scope of legitimate medical interest. It is not simply the testimony of the medical community or disability activists which matter. Second, we should expect that if the disability rights movement were constituted in a different world, a different set of traits would be considered disabilities. In a world without, or prior to, the gay rights/pride movement, in which being gay is regarded by almost everyone to be the subject of legitimate medical interest, being gay may well be picked out as a disability by the disability rights movement.²⁵ Third, and again, even ordinary citizens may be implicated. Their individual and collective actions in response to such movements – of alliance, ambivalence, or antagonism – may significantly affect whether the latter succeeds or fails, and thus what counts (or continues to count) as a disability.

Condition (IV) of my account is a broader formulation of what is already present in Barnes' account. Even though Barnes' formal definition of disability refers narrowly to justice as the organising aim of disability activists, her initial, and more casual, explanation refers more broadly to moral progress and change (Barnes 2016, p. 42). I adopt the broader formulation. Promoting justice is only one of many political goals within the broader project of progress and change, and we want to leave room for disability activists to pursue such goals. Additionally, this helps us with addressing the second worry. My account will not just pick out those traits which are constitutive of social and political constraints.

It is important to resist understanding the terms narrowly. We should not adopt a naïve interpretation of the slogan that progress or change consists simply in changing the world, rather than disabled bodies. While this may be appropriate for a broad range of traits, not all traits that we count as disabilities may be accommodated in this way. Nor, in some cases, should we want them to be thus accommodated. For instance, for cases of extreme and debilitating allergies, chronic pain, or profound cognitive disabilities, we may decide that progress and change is to be understood as requiring their removal (or at least alleviation). This, I believe, helps my account avoid criticisms

²⁵ This is a separate point from (our evaluation of) whether they were right to do so.

that turn on identifying traits that cannot be accommodated, or be the subject of progress and change, in the narrow ways identified.

5. Worries about the medical model and community

Including medical interest as a constitutive element of the definition of disability is controversial, at least to proponents of social model or constructionist accounts. It raises the worry that I have smuggled the medical model of disability into an ostensibly social constructionist account. The medical model is often associated with three main problems. First, it takes there to be an intrinsic connection between disability traits and reduced wellbeing. Second, it explains disability solely or primarily in terms of the bodies of disabled people, and neglects social practices and the environment. Third, it takes medical treatment to be the only appropriate way of addressing disability (Wasserman et al. 2016). Taken together, these downplay the importance of disabled people's testimony, and shift attention away from social or political solutions to the constraints faced by disabled people, to solely medical ones.

I cannot fully tackle these worries here. However, I outline some salient differences between my account and the medical model.

First, I do not argue that there is an intrinsic connection between disability traits and wellbeing. Recall that my account understands a disability as a state, x , which is, in context C , constitutive of constraints on S 's legitimate interests. Even if we suppose that constraints intrinsically reduce the wellbeing of those who face them²⁶, my account does not claim that x is the sole constitutive component of S 's constraints, and thus the only component responsible for a reduction in wellbeing. Social practices and environmental factors, among others, are constitutive of the constraints S experiences. This is allowed by a broad reading of what counts as constraints, and also by the observation that x is constitutive of constraints *in C*. When the context (for example, practice or environment) changes, x may not constitute any constraint (Lim 2017).

Second, I allow that social practices and environmental factors, among others, may be constitutive of the constraints, which are in

²⁶ This reduction may be local – affecting some aspect of individuals' lives, or some aspect for some period of time – or it may be global – affecting most or all aspects, or affecting some aspects permanently. Local constraints may not have a significant impact on an individual's overall wellbeing. In some cases, local constraints in one area may even increase wellbeing in another.

turn constitutive of disability. Thus I do not explain disability solely or primarily in terms of the bodies of disabled people.

Third, I leave open what is to be done to address disability. Condition (III), concerning medical interest, simply expresses the view that medical professionals judge that something can be done by medical professionals to address the trait *x*. I do not say that we as a society therefore need to, or should, treat *x* in the way medical professionals propose. The possibility is left open that we may decide that the correct response to the constraints faced by disabled people is, in many cases, to make our society more accommodating – physically and socially – rather than to change their bodies to fit the existing world (Wolff 2009). Medical treatment is not the only appropriate way of addressing disability. And in some cases, it may not be an appropriate way at all. However, and crucially, I also do not wish to go too far in the opposite direction – to claim that the *only* appropriate way of addressing disability is through social and political action. I leave open the possibility that the correct solution may vary depending on the context (Francis and Silvers 2017).

There is also the worry that my account presents the medical community as the gatekeepers of what counts as a disability. That is, on my account, the medical community appears to have a disproportionate influence on what counts as a disability. As Barnes notes, this may well contribute to maintaining systematic epistemic injustice – of downgrading the testimony of disabled people about what disability is. The following considerations, I contend, may allay this worry.

First, the medical community is not the sole arbiter of what counts as subject to legitimate medical interest. The perspective of the medical community is just one of many others, which contribute to shaping what counts as a disability. Recalling our earlier discussions of condition (III), we see that it is open for activists to challenge the medical community's judgement that a particular trait is the subject of legitimate medical interest. The testimonies of others – especially, but not exclusively, disability activists – matter too. This partly diminishes the worry about gatekeeping.

Second, my account does not prioritise the testimony of medical professionals over those of activists (disability or otherwise). In fact, it allows for a plurality of positions about how they are related – especially when the testimonies come into conflict. Consider a trait that medical professionals regard as a disability, but activists do not. In these cases, we may very well decide to prioritise the claims of activists over those of medical professionals. This, we have seen, is what

happened for traits such as being gay. What about a trait that medical professionals *do not* regard as a disability, but activists do? Here, it may seem counterintuitive to prioritise the testimony of activists. In these cases, however, we should remember the struggles of those with ‘hidden’ disabilities – such as chronic fatigue syndrome – to convince people, including medical professionals, of the constraints they face, and of their eventual (though delayed) vindication. These lend plausibility to the thought that we should also prioritise the testimony of activists in these cases. Thus my account does not denigrate the testimony of disability activists. In fact, it is compatible with a general policy of prioritising their testimony. Of course, our judgements may, in some cases, go in a different direction, in favour of medical professionals – as in the case of factitious disorder. My account is able to accommodate these positions. This is because for a trait to count as a disability on my account, it needs to meet *both* conditions (III) and (IV). That is, both the medical community and the disability activists need to pick the trait out as a disability.²⁷

When these claims compete or conflict, the disability status of the relevant traits are unstable (or indeterminate). My account helps to explain our discomfort in some cases, especially where the conflict is ongoing. For instance, while many people find the claims of Deaf or autistic activists (that the respective traits are not disabilities) compelling, they nevertheless find it difficult to stop thinking of them as disabilities (Lim 2015). There is, then, a tension (if not outright conflict) in the attitudes we (must) hold about the same trait – for we (must) hold both that it is a dysfunction that medicine can help to treat or eliminate, and that it is not a trait that medicine should concern itself with. We are, now, of two minds about how we should think about these traits and relate to people who possess them. What we ultimately decide will depend crucially on the outcome of the contestation between the relevant groups. I take it as a virtue of my account that it can highlight the salience of such disputes (and their resolution) to the definition of disability.

For better or for worse, medical professionals, and even the general public, contribute to the definition of disability. Indeed, illegitimate historical medical interest in some traits (or lack of legitimate interest in others) has had distorting and lasting effects on our discourses and

²⁷ Of course, medical professionals may, in some cases, resolutely maintain their interest in a certain trait – disregarding activists – on the grounds that *from a medical perspective* the trait is counted as a disability. However – and assuming that the claims of activists are generally accepted as correct – they would then be using a different account of disability from us.

practices surrounding these traits. Even today, some portions of society still struggle to see some traits (for example, gayness) other than as dysfunctions to be treated or eliminated, and others (for example, chronic fatigue syndrome) as merely indicative of their possessors' character flaws. However, the fact that they contribute in these ways to the definition of disability, does not mean that they have the final word. Rather, we may see them as contributions which we must constantly monitor, to guard against overreach or even injustice. Incorporating their contribution into the account of disability, then, identifies targets against which activists (from the disability rights movement, or otherwise) may direct their collective political efforts.

More generally, my account also points to other potential sites for resistance. Activists, if they judge there to be an injustice in determining what counts as disability, may argue – against common or medical understandings – that a particular state (for example, being gay) is not constitutive of constraints, or that it is (as it may be, for example, in the case of chronic fatigue syndrome). They also may challenge what counts as our legitimate interests – to try to reconceptualise or re-specify them (as, for example, they may in the case of deafness/Deafness). They may also, learning from arguments in political liberalism, demand that we avoid letting any particular group's conception of the good strongly determine what counts as legitimate interests. Such challenges may be mounted on several fronts – tackling how constraints and legitimate interests are specified in religious (or, more generally, doctrinal), philosophical, legal, or social contexts. Of course, these challenges may not always succeed. My account makes room for us to understand this. Maintaining and changing what counts as disability does not depend on activists alone. Other contributors must be brought on to the project – through alliances forged, ambivalences treated, or antagonisms neutralised.

6. Concluding thoughts

Barnes' account represents a significant improvement to the ways we have been thinking about disability. It allows us to have fairly fine-grained discussions of whether and how a particular trait counts as a disability – rather than rely on the trade of intuitions or counterexamples. It is also an improvement that it accords central importance in defining disability to the testimony of disability

activists. My account improves on this by clarifying the relevance of constraints on legitimate interests, and the role that medical interest plays, to the definition of disability. What is important is not merely experiences of constraint, but the existence of constraints themselves. Additionally, the testimony of disability activists, even when given greater weight, is not (and has not been) taken as the sole determinant of what counts as a disability.

These clarifications feature as two additional conditions – (II) and (III) – in my account. The two additions capture the sense, which many people have, that Barnes' account has left something out. Including them in the account allows us to clarify and tackle these inchoate intuitions, in order that we may guard against, and hopefully overcome, the ways in which they may distort our definition of disability. Including them does not commit us to the assumptions of a naïve medical model of disability, nor does it commit us to thinking of the medical community as gatekeepers to the definition of disability. Moreover, these two clauses allow my account to broaden the scope of the two initial components of Barnes' account – now presented as conditions (I) and (IV) in my account. This renders my account able to account for all disabilities (rather than merely physical ones), and to acknowledge the fact that disability activists may have aims beyond that of promoting justice.

In sum, my account defines disabilities as traits which are picked out, in a given context, by the goal-oriented (progress-seeking) classificatory rules employed by the disability rights movement, and *also* as constitutive of legitimately medically interesting constraints on legitimate interests. In effect, it preserves the key insight of Barnes' account – concerning the testimony of disability activists – while addressing the worries about it. I believe it renders the social constructionist model more plausible, and also more amenable to activism (Saul 2006; Mikkola 2016).²⁸

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