

NLM Citation: Shepherd J. Disabilities and wellbeing: The bad and the neutral. In: Cureton A, Wasserman D, editors. Oxford Handbook of Philosophy and Disability [Select Chapters]. Oxford (UK): Oxford University Press; 2018.

Bookshelf URL: https://www.ncbi.nlm.nih.gov/books/



Disabilities and wellbeing: The bad and the neutral

Joshua Shepherd¹

ABSTRACT

This chapter argues for a normative distinction between disabilities that are inherently negative with respect to wellbeing and disabilities that are inherently neutral with respect to wellbeing. First, after clarifying terms I discuss recent arguments according to which possession of a disability is inherently neutral with respect to wellbeing. I note that though these arguments are compelling, they are only intended to cover certain disabilities, and in fact there exists a broad class regarding which they do not apply. In section three I discuss two such problem cases: Locked-in Syndrome and the Minimally Conscious State. In section four I explain why these are cases in which possession of the disability makes one worse off overall. I do so by explicating the notion of control over one's situation. I argue that disabilities that significantly impair control over one's own situation – e.g., Locked-in Syndrome and the Minimally Conscious State – strongly tend to be inherently negative with respect to wellbeing, while disabilities that do not strongly tend to be inherently neutral. The upshot is that we must draw an important normative distinction between disabilities that undermine this kind of control, and disabilities that do not.

Keywords: wellbeing, Minimally Conscious State, Locked-in Syndrome, control over one's situation

1. Introduction

I maintain that for a significant class of disabilities, possession of the disability itself does not make you significantly worse off overall, although social stigmatization, prejudice, and lack of proper care for the disability certainly may make you so. For this class, even if there are some negative effects connected to the disability itself, wellbeing is robust against the effects. I also maintain that for a significant class of disabilities, even if we remove factors connected to social stigmatization, prejudice, or lack of proper care, possession of the disability itself makes you worse off overall. What explains the asymmetry? I maintain that a key part of the explanation

Author Affiliation: 1 Oxford Uehiro Centre for Practical Ethics; Email: joshualshep@gmail.com.

This is a draft of a chapter that has been accepted for publication by Oxford University Press in the forthcoming book Oxford Handbook for Philosophy and Disability edited by Adam Cureton and David Wasserman (eds) due for publication in 2018.

© Joshua Shepherd 2018.

Monographs, or book chapters, which are outputs of Wellcome Trust funding have been made freely available as part of the Wellcome Trust's open access policy

revolves around the impact a disability has on those capacities that undergird and enable what I call *control over* one's situation.

First, after clarifying terms I discuss recent arguments according to which possession of a disability is inherently neutral with respect to wellbeing. I note that though these arguments are compelling, they are only intended to cover certain disabilities, and in fact there exists a broad class regarding which they do not apply. In section three I discuss two such problem cases: Locked-in Syndrome and the Minimally Conscious State. In section four I explain why these are cases in which possession of the disability makes one worse off overall. I do so by explicating the notion of control over one's situation. I argue that disabilities that significantly impair control over one's own situation – e.g., Locked-in Syndrome and the Minimally Conscious State – strongly tend to be inherently negative with respect to wellbeing, while disabilities that do not strongly tend to be inherently neutral. The upshot is that we must draw an important normative distinction between disabilities that undermine this kind of control, and disabilities that do not.

2. Disability and wellbeing

Our question concerns the relationship between disability and wellbeing. Any answer is complicated by the fact that the nature of disability as well as the nature of wellbeing is contested. Before beginning, then, I offer explications of both notions, aiming for as much agnosticism regarding contested theoretical issues as possible.

Some explicate 'disability' essentially in terms of detrimental effects on wellbeing (Harris 2000, Kahane and Savulescu 2009). To do so, however, rules out by definition the question I confront in this paper. Since I take it this question is posable, and interesting, we need a different explication of disability. One option here is to opt for a more substantive account that affords agnosticism regarding the relationship between disability and wellbeing (e.g., that of Barnes 2016). But my argument will find widest coverage if I remain as agnostic as possible. So I will understand disability in the medicalized sense of Wasserman and Asch (2013), on which a disability is an 'impairment, injury, or disease that involves or results in the absence, loss, or reduction of normal or species-typical function' (140). ¹

Wellbeing, as I understand it here, is a property that attaches to the lives of individuals, and that qualifies how things are going for them in terms of some valenced assessment. So, things can go well or poorly for someone, they can go better for one person than for another, and they can go worse for me at one time than another. Further, these assessments can apply to stretches of time that do not amount to a whole life, as well as to whole lives. Ultimately, of course, we need some sense of the kinds of things that ground or explain these assessments – the things in virtue of which one's life (or some stretch of it) goes well or poorly. As much as possible, I will try to appeal to shared territory here. For example, most views accept that positive experiences contribute positively, and negative experiences contribute negatively. And most views accept that other factors are (at least instrumentally) relevant to one's level of wellbeing. I have in mind here factors such as the ability to satisfy one's desires and intentions, the ability to enter into meaningful relationships, and the ability to appreciate and/or achieve highly valued items (e.g., personal accomplishments, aesthetic beauty, moral virtue, or whatever).

How does disability affect wellbeing? The assumption that disability is obviously and often severely negative with respect to wellbeing is prevalent in most western societies. But recently many theorists and disability rights advocates have argued that this assumption is indefensible – in fact disability is neutral with respect to wellbeing. What might it mean to say this? Often proponents of a neutrality view offer analogies and comparisons that give a good sense of the spirit of their view. Elizabeth Barnes (2016) outlines several claims characteristic of neutrality

¹ Notice that this makes the task of arguing that some disabilities are neutral with respect to wellbeing more difficult than if I adopted, e.g., a social constructionist account of disability. One reason I do not do so is that it seems dubious to me that we could explain all disabilities in terms of processes of social construction, even if some are well-explained by such a model.

proponents. Such proponents claim, for example, that in its neutrality 'disability is analogous to features like sexuality, gender, ethnicity, and race,' that 'disability is a valuable part of human diversity that should be celebrated and preserved,' and that much of the negativity associated with disability stems from 'society's treatment of disabled people, rather than disability itself' (69-70).

But it is possible to be more precise regarding claims of neutrality. Barnes offers one useful explication. According to Barnes, neutrality should be understood as holding overall, or with respect to one's level of wellbeing considered at some distance from individual events or experiences. Barnes concedes that a disability could be negative with respect to some aspects of a person's life. But she notes that the same is true of a range of aspects of a person's life, e.g., their race, gender, or sexuality. And most would find it difficult to defend the view that any of these are inherently negative with respect to wellbeing. With that said, Barnes explicates 'neutrality' in terms of sameness of wellbeing levels across nearby possible worlds: ' Φ has a neutral effect on x's wellbeing just in case the closest world(s) w in which x lacks Φ is a world in which x's level of wellbeing is the same as the level of wellbeing x has in the actual world' (80). While that is obviously a valid way to understand neutrality, in the present context it seems excessively precise. My own understanding of neutrality is one on which there exist differences in wellbeing levels small enough that it is not irrational to prefer one over the other. Spelling this out in full is beyond the present scope, but imagine being asked to care about or choose two very different life possibilities – a well-loved and very fulfilled fireman with seven interesting and healthy children living in 20th Century Chicago, or a well-loved, very fulfilled, wealthy and famous actress living in 19th Century Paris. Say, also, that one of these was marginally better than the other on whatever scale of measuring wellbeing that you prefer. Given the number of factors that enter into the calculation, it seems rational to prefer either of these scenarios. (Wellbeing levels are not like monetary levels.) My view of neutrality, then, maintains that if two wellbeing levels fall within some such range, they meet a neutrality requirement.²

This gives us a sense of what it means to claim that disability is neutral – a Mere Difference – with respect to wellbeing. But this neutrality claim faces a difficult objection. My formulation of it follows that of Guy Kahane and Julian Savulescu (2016), who call it the Unacceptable Implications Objection.

Unacceptable Implications Objection. If we accept the Mere Difference view of disability, then – in a society free of all the negative features associated with social stigmatization, lack of access to proper care, etc. – it would be morally permissible to intentionally cause a non-disabled person to become disabled (in a society free of all the negative features associated with social stigmatization, lack of access to proper care, etc.), and it would be morally permissible to intentionally omit to cause a disabled person to become non-disabled.

Many find these implications repugnant. As Kahane and Savulescu note, acceptance of these implications 'would mean that prospective parents have no reason to prefer to create an able-bodied . . . child rather than a disabled one. And it would also mean that it is misguided to exert so much effort to develop ways of preventing or removing disability' (2016: 775).

In response to considerations like these, Barnes argues that our intuitions that causing disability is bad do not track the causing of disability in isolation, but rather track ancillary factors. Barnes names three: the absence of consent, high transition costs, and a general principle of non-interference. According to Barnes, causing disability may be impermissible if it proceeds without consent, generates high transition costs, or violates a principle of non-interference. But none of these reasons identify causing disability in isolation as impermissible.

² Campbell and Stramondo (forthcoming) offer a different explication of neutrality, on which it is 'the space between prudential goodness (what is good for a person) and prudential badness (what is bad for a person).'

We can, however, ramp up the counter-intuitive nature of Barnes's position. Kahane and Savulescu point out that all three ancillary factors Barnes identifies are entirely symmetrical: the proponent of the Mere Difference view ought to apply the same reasoning to the causing of non-disability. So Barnes is committed to accepting that causing non-disability in the absence of consent is just as bad as causing disability in the absence of consent, that causing non-disability given transition costs is just as bad as causing disability given transition costs, and that, to quote Kahane and Savulescu, 'removing disability from a fetus is as wrong as causing a male fetus to become female, or causing a fetus' hair color to change from red to brown, let alone causing an abled fetus to become disabled' (2016: 779).

These implications are highly counterintuitive. What can the defender of a Mere Difference view say in response? One might double down on skepticism about intuitions here, claiming that our intuitions are stained by our participation in a society dominated by ableist thinking (Barnes 2016, 155-156). I think there is something to this skepticism, but it is not entirely satisfying in the present context. For it leaves us without a positive defense of a Mere Difference view.

I turn, then, to an argument Asch and Wasserman (2010) offer. The argument explicitly concerns what they call 'static' disabilities – disabilities that involve 'the simple absence of a sensory, motor or cognitive function, without the pain or progressive character of a disease' (2010, 202). Regarding at least these disabilities, Asch and Wasserman offer a package of related claims. First, a disability could qualify as neutral even if the disability represents the absence of an instrumental good for a subject. Second, a disability could qualify as neutral even if the disability is not compensated for in any direct way by a subject's existing capacities and functions. The reason why is that no single capacity or function should be regarded as 'an all-purpose good, essential for virtually any life plan' (208). Rather, the kinds of capacities and functions static disabilities concern should be understood as affording means to the realization of goods, values, achievements, positive experiences, and so on. And, according to Asch and Wasserman, 'human beings enjoy a fortunate redundancy in many of the capacities that are instrumental for, or constitutive of, valuable human goods and activities' (208).

The broader picture here is that a complex means-end structure connects instrumental access to the constituents of wellbeing with the constituents themselves. If this is right – and I think it highly plausible that it is – then human beings will have available to them a wide range of ways to access the core constituents of wellbeing (whatever they turn out to be). This picture is behind Wasserman and Asch's (2013) proposal regarding the asymmetry problem discussed above. The main claim is that we can have reasons to prevent loss of a capacity, or to restore a capacity, even if the capacity itself is neither intrinsically bad or good. The reason is of course that in preventing its loss or restoring it, we would be giving the agent something valuable – access to more means to the constituents of wellbeing – even if we do not give her something that in itself will positively impact her wellbeing compared to the case in which we do nothing. In explaining this point, Wasserman and Asch compare static disabilities to the absence of a capacity like literacy.

Like sight and hearing, literacy is a good thing to have. Indeed, it is often touted as opening up new worlds inaccessible to the unlettered . . . [But] despite the great value of literacy, lives can go as well without it as with it. There is little reason to doubt that the best lives of our illiterate forebears went just as well, or incommensurably well, on any plausible account of wellbeing, as the best lives of our literate contemporaries. (155)

I find this argument compelling, and I concur. There exists a significant class of disabilities – I think deafness, blindness, and some mobility impairments (e.g., loss of a limb or the ability to walk) clearly fall into this category – for which a Mere Difference view states an important truth about the relation between disability and wellbeing. We are left, however, with the pressing fact that, as least as Asch and Wasserman have it, this argument only covers some disabilities. Is there an argument that all disabilities are a Mere Difference? I think not, and I offer

reasons to agree in the next section. In section four I consider a further pressing question. What explains the distinction between Mere Difference and Bad Difference disabilities?

3. Two problem cases

3.1. Locked-in Syndrome

Locked-in syndrome (LIS) typically results from brainstem lesion that fully preserves consciousness and cognitive functioning, but results in almost complete paralysis – often, only eye movements are spared, and these are how patients communicate (although there are cases of total LIS that involve paralysis of eye motility).

Most people unfamiliar with LIS would, when given a brief description and asked, find the prospect of LIS horrifying – perhaps even worse than death. But this is not what many people with LIS say. A recent survey of LIS patients asked them to report on various aspects of their condition, including their perceived quality of life (Bruno et al. 2011). 91 out of 168 invited patients responded, a fact that the experimenters admit may have biased the sample towards higher quality of life ratings. 65 of the surveys could be used for statistical purposes. The results are interesting.

The experimenters asked participants to rate their quality of life on a scale from -5 to +5, with -5 indicating their current level is 'as bad as the worst period in my life,' +5 indicating 'as well as in the best period prior to LIS,' 0 indicating 'neither well nor bad,' and other numbers indicating something in between these options. For reporting purposes experimenters grouped participants into 'happy' if they reported in the 0 - 5 range, and 'unhappy' if they reported in the -1 - -5 range. According to this grouping, 47 reported happy and 18 unhappy. Moreover, participants were significantly more likely to report happy than unhappy if they were in LIS for longer, had recovered some speech production, reported positively to the prompt 'I move around my community as I feel necessary,' reported positively to the prompt 'I am able to participate in recreational activities (hobbies, crafts, sports, reading, television, games, computers, etc.) as I want to,' responded positively to the prompt 'I feel that I can deal with life events as they happen,' responded an absence of depression or anxiety, and a lower frequency of suicidal thoughts. Bruno et al. summarize these results as follows: 'Although most chronic locked-in patients self-report severe restrictions in community reintegration, the majority profess good subjective wellbeing . . .' (1)

In my view it is very important to take these kinds of reports seriously, and it is important to note that a majority reported that their quality of life was 'neither well nor bad' or better. But it is equally important to note that this grouping into happy and unhappy is somewhat artificial. A plausible interpretation of the scale given to participants is that many reports below a +5 indicate a reduction in wellbeing due to the injury. Only five participants reported +5, and many of those grouped in the 'happy' class reported 0 or +1 (16 by my count: the graph Bruno et al. offer is not clear). This should be coupled with the observation that 13% of participants reported depression, 67% reported moderate or extreme anxiety, 46% reported moderate or extreme pain, 58% did not want resuscitation in case of cardiac arrest (including 49% in the 'happy' group), and 32% reported having suicidal thoughts occasionally or often.

These numbers are comparable to another recent study on LIS wellbeing (Rousseau et al. 2015). In that study a cohort of 67 LIS patients was surveyed. 44% reported chronic pain. 55% reported anxiety or mood disorders. 27% reported suicidal thoughts. 67% wanted resuscitation if needed.

3.2. Minimally Conscious State

Minimally Conscious State (MCS) exists on a spectrum of similar conditions, usually due to traumatic brain injury, all of which severely impair consciousness and cognitive functioning. A rough ordering can be imposed in terms of preserved elements of consciousness and cognitive function, with Persistent Vegetative State (PVS) at

the low end of the scale, MCS in the middle (MCS is sometimes separated into MCS- and MCS+ (Bruno et al. 2011), and emergence from MCS (eMCS). It must be noted that behavioral differences between these conditions are often very slight: misdiagnosis rates are as high, with misdiagnosis of PVS instead of MCS often estimated at roughly 40%, and misdiagnosis of MCS instead of eMCS occurring frequently as well (though given low sample sizes, it is hard to offer a percentage, see Schnakers et al. 2009).

To give some indication of how the diagnosis is made, consider the deployment of the Coma Recovery Scale-Revised (CRS-R, see Giacino and Kalmar 2005). Administration of the CRS-R involves presenting a patient with stimuli of various sorts. The CRS-R divides the stimuli into an Auditory Function Scale, a Visual Function Scale, a Motor Function Scale, a Verbal Function Scale, a Communication Scale, and an Arousal Scale. Although a patient will be given an overall score from 0 to 23 depending on their individual scores on the subscales, most of the subscales offer sufficient conditions for a diagnosis of MCS: given the distributed and unpredictable effects of traumatic brain injury, the scale incorporates significant redundancy. Failure of all of these will lead to a diagnosis of VS, which is considered permanent if a patient shows or has shown no improvement for 30 days following injury.

Consider, for example, the Auditory Function Scale. It is insufficient for a diagnosis of MCS that the subject to orient head or eyes towards an auditory stimulus on the trials. It is sufficient if, on ¾ of the trials, the patient displays 'object-related eye or limb movement' to aurally delivered commands – that is, commands like 'stick out your tongue,' or 'look at [some object],' or 'look up at the ceiling.' On the Visual Function Scale, it is insufficient for a diagnosis of MCS if the patient fixates on a visually presented target for more than 2 seconds. It is sufficient if the patient follows a moving mirror for 45 degrees without loss of fixation for 2 seconds, on 2 out of 4 trials.

The Communication Scale of the CRS-R offers a way to distinguish MCS from eMCS. A patient is diagnosed as in MCS if they offer clearly discernible and accurate yes/no answers to at least 2 out of 6 visually or aurally based questions (e.g., 'Am I touching my ear right now?'). And a patient is diagnosed as eMCS if they clearly and discernibly answer 6 out of 6 such questions.

Both MCS and eMCS, then, preserve some elements of consciousness and cognitive functioning. But the amount preserved varies by case, and is often extremely limited – a patient can be diagnosed as in MCS even if they score 0 on many of the sub-scales. Neuroscientific studies including MCS and eMCS patients demonstrate that they lack many of the neurofunctional structures necessary for sophisticated information integration, such as the kind of connectivity between the thalamus and frontal cortex that could enable performance of 'top-down' cognitive control tasks such as, e.g., counting the number of times a target word is spoken over a 4-second period (Monti et al. 2015). In line with this, most MCS and eMCS patients lack the capacities required for legal competence (e.g., capacities for understanding their condition, appreciating its gravity, developing a view about how their own treatment should proceed, and communicating this view), a fact which often raises difficult questions that family members, doctors, surrogates and in some cases the courts have to answer.

Most patients in MCS and eMCS, then, often cannot report on their quality of life because they do not retain the mental capacities necessary for such reports. Thus, one important way to measure a subject's quality of life is missing. Nonetheless, it is the working assumption of many doctors and scientists and judges that there is something it is like to be in MCS, and that things can therefore go subjectively better or worse for them. Whether it is overall subjectively good or bad to be in such a condition is generally unknown, although one can find empirically informed speculation in the literature (Wilkinson and Savulescu 2012; Shepherd 2016a).

3.3. Implications for the Mere Difference view

What are the implications of these disabilities for how we understand the relation between disability and wellbeing? Regarding LIS, one has to acknowledge that these wellbeing-relevant reports are much lower than what one would find in the general populace. Indeed, by Bruno et al.'s (2011) own scale, it looks like a vast

majority of patients rated their current quality of life as lower than it was before the injury. Some of the wellbeing reduction – or alternatively, some of the reduction in quality of life reports – can certainly be attributed to social conditions, access to adequate care, and so on. But it is not at all clear that the entirety of the reduction is due to social factors. LIS patients often suffer from chronic pain, anxiety and depression, and suicidal thoughts. A high percentage of LIS patients do not want resuscitation. LIS gives many indications of qualifying as a Bad Difference.³

The case is, in my view, even clearer regarding MCS. One might resist this verdict by pointing out that, since MCS patients do not explicitly report on their quality of life, it is possible that at least some MCS patients enjoy a good quality of life. Perhaps their lack of knowledge regarding their own condition prevents them from conceptualizing it as bad, as seems to happen in some cases of LIS.

Even if this is true, however, I doubt one can plausibly maintain that MCS patients in general maintain a quality of life as good as LIS patients. Some of these reasons have to do with injuries and complications associated with the severe brain injury that causes the condition. But the chief reason is the absence of many so-called higher psychological capacities in MCS patients. To be in MCS is to lack normal capacities of attention, reasoning, imagination, memory and cognitive control, to lack access to the range of patterns of thought and streams of consciousness available before the injury, to lack access to the full, rich range of emotional and social experiences available before the injury. With proper care, much of this is available to LIS patients. On most plausible theories of wellbeing – hedonist views, objective list views, desire satisfaction views – access to a range of rich emotional experiences, and capacities to exercise sophisticated agency with respect to one's inner mental life and with respect to one's world-involving goals and desires, will be critical for higher levels of wellbeing. Whatever one's theory of wellbeing, then, it seems to me that in virtue of their disability, prima facie MCS patients are worse off overall than LIS patients.

Both LIS and MCS are Bad Difference disabilities: independently of the effects of social stigmatization they tend to make a person worse off overall. But they differ in important ways. Is there a unifying explanation regarding their relationship to wellbeing? And does it generalize to other disabilities? In the next section I argue in the affirmative. The upshot is a general and tractable normative distinction between classes of disabilities.

4. Control over one's situation

Here I argue that a central factor in an explanation of the difference between Mere Difference disabilities and Bad Difference disabilities is that the latter significantly undermine control over one's situation, while the former do not. Strictly speaking, I offer this control-based explanation as sufficient to explain the asymmetry in a wide range of cases. As features of complex biological beings, disabilities are diverse: we should not expect one factor to offer an exceptionless explanation. (Accordingly, I do not aim to explicate a necessary condition for some disability's qualifying as a Mere or Bad Difference.) Further, in many individual cases there will be other factors relevant to a full explanation of some singular disability's relationship to wellbeing. To take one example, a disability that causes chronic pain may be negative with respect to wellbeing both because it undermines control over one's situation, and because it causes chronic pain. To take another, a disability that significantly impairs one's memory may well undermine one's control (by impairing mid-range and long-term planning)

³ As Adam Cureton points out in comments on this chapter, for all I say LIS in an ideal society might qualify as a Mere Difference. This might be right – I confess I am not in an epistemic position that justifies dogmatism. If it is right, in my view this would be for reasons I outline in the next section.

⁴ I say significantly undermine because control comes in degrees, and because some disabilities undermine one's control only slightly. There will be a range of conditions for which it is unclear, and perhaps vague or indeterminate, whether they qualify as a Mere Difference or a Bad Difference. Those that clearly qualify as a Bad Difference will do so because the amount of control undermined passes a relevant threshold (the relevant threshold will likely differ depending on one's theory of wellbeing).

while at the same time undermining the significant richness that a fully functioning memory adds to one's ongoing stream of consciousness. On views of wellbeing that give weight to the value within one's stream of consciousness, memory impairment will undermine one's wellbeing in two distinct, though intertwined, ways.

Those qualifications aside, in this section I focus on *control over one's situation*. The terminology is my own. As such, I owe readers an explication of it. As an introduction, I note that the notion is similar to the more normatively loaded term *autonomy*. I choose not to use that term because I do not want to commit to any particular view of autonomy. It is worth mentioning, however, that on most plausible views of autonomy, central to the possession of autonomy will be possession of psychological capacities that enable processes of effective practical reasoning and decision-making. These are processes that include not only inference making, evidence weighing and intention formation, but general background capacities for knowledge acquisition, the integration of information with one's goals and values, and so on. Just what psychological capacities enable these kinds of processes will depend on how one decomposes the mind – plausibly some of the perceptual capacities, along with capacities for attention, memory, practical reasoning, imagination, cognitive control, emotional regulation, and perhaps metacognition will play important roles. When decomposed in terms of contributory mental capacities, then, autonomy is a wide-reaching condition. The same thing is true of control over one's situation.

Why do I refer to one's situation? I need a notion that is sufficiently general. While control of one's situation will include control over elements of one's stream of consciousness (e.g., one's imagination, one's ability to ruminate coherently and reason practically and theoretically), it is broader than this. Given the kinds of beings we are, control over one's situation for beings like us must include abilities to execute intentions, satisfy desires, and accomplish naturally arising goals in the world outside the mind. Roughly, then, possession of control over one's situation can be understood as possession of capacities – these capacities may not stop at the skull or body, since assistive technology and caregivers may significantly enhance one's control – that enable one to enhance good experiences and inhibit negative experiences (via, e.g., attention, reappraisal, imagination, targeted planning for the future, inhibitory control), to find and seek beneficial experiences and avoid negative ones, to shape one's conscious mental life, and to shape one's broader patterns of action in the world.

I have said control comes in degrees (see Shepherd 2014). Humans are in many ways fragile, and no matter how healthy or how well placed in society, no human adult possesses total control over her situation. Items hijack our attention, motivational levels fluctuate, the body can be difficult to work with, the environment can be uncooperative, and our desires are often wayward or regrettable. But adults display a significant amount of control in many ways. We exhibit significant degrees of freedom and control over what we attend to, over our trains of thought, over a life of imagination, over our responsivity to positive and negative events, over the ways we satisfy intentions, desires, curiosities, and so on.

Allow me to apply the key claim of this section – that in virtue of the fact that they significantly undermine control over one's situation, some disabilities are inherently negative with respect to wellbeing – to both MCS and LIS. It is clear that the brain injury that results in MCS significantly impairs many of the capacities that enable such control. The same thing is true of LIS, although the impact of LIS is more indirect. And it is here that a contrast between LIS and MCS affords an important insight. For, when given access to proper care – and perhaps in societies that do not stigmatize such a condition – LIS patients can enjoy high levels of wellbeing. Notice, in this connection, that 5 out of 65 patients surveyed by Bruno et al. (2011) reported that their wellbeing

⁵ In other work (Shepherd 2016) I have argued that cases of MCS – and cases that are structurally similar in relevant ways, such as advanced dementia – raise difficult moral problems because of a moral conflict that arises in these cases. The conflict concerns how we ought to weight two morally important factors: on one side, the patient's wellbeing, and on the other side, the patient's autonomy. In many cases we let autonomy trump wellbeing: agents have the right to autonomously act in ways that diminish their wellbeing. What is difficult about cases of MCS is that the patient's autonomy has been compromised by their injury. So, when deciding whether to, e.g., remove artificial nutrition and hydration, we not only have to determine what a patient's prior wishes might have been, we have to decide how their prior wishes ought to be weighed in their current condition, which includes some level of wellbeing but no autonomy.

was as high as it had been in the best period prior to LIS. That's a low number, but that any LIS patient could report such a number is important. Notice, as well, that the elements that correlated with higher reports of quality of life were in the main those that indicated the LIS patient possessed greater control over her situation. As I discussed above, surveyed LIS patients were significantly more likely to rate their quality of life as higher if they had recovered some speech production, reported positively to the prompt 'I move around my community as I feel necessary,' reported positively to the prompt 'I am able to participate in recreational activities (hobbies, crafts, sports, reading, television, games, computers, etc.) as I want to,' reported positively to the prompt 'I feel that I can deal with life events as they happen,' reported an absence of depression or anxiety, and reported a lower frequency of suicidal thoughts. In addition, Rousseau et al. (2015) report that access to good electronic communication devices and to powered electric wheelchairs made a positive difference. This is some evidence for the view that retention of control is a central factor in enabling a level of wellbeing robust against even severe perturbation.

LIS illustrates two important aspects of control over one's situation. First, one cannot control one's situation very well without *some* degree of control over one's body. That said, the amount of control over one's body required for a robust level of wellbeing may seem, to many, surprisingly low. This is because, second, control with respect to one's inner mental life appears to be weighted more heavily with respect to wellbeing than control with respect to one's body. The upshot is a graded spectrum on which control over one's situation can be impaired by bodily disability or psychological disability (however we wish to make that distinction). But bodily disabilities on their own rarely lead to significant impairments to control, while psychological disabilities more readily lead to such impairments given that many psychological disabilities target capacities central to the possession and exercise of this control.

The central claim of this section, then, enables an explanation of the difference between Bad Difference disabilities like LIS and MCS, and Mere Difference disabilities like deafness and blindness. As David Wasserman notes in comments on this chapter, the resultant typology is similar to that set up by Asch and Wasserman's (2010) discussion of static disabilities. But there will be important differences. In particular, control over one's situation may be significantly impaired when one suffers from various static psychological disabilities. Hopefully, then, my appeal to control affords a more illumination explanation of the relevant distinction. In this connection, consider the following list of potential disabilities.

Impairments to limbs due to congenital conditions or injury

Mobility impairments due to spinal cord injury or stroke

Loss of perceptual function, leading to, e.g., blindness, deafness, or deafferentation

Congenital insensitivity to pain

Language aphasias, e.g., Global, Anomic, Wernicke's, or Broca's aphasia

Attention Deficit Hyperactivity Disorder (ADHD)

Depression

Bipolar disorder

⁶ Of course the body and the mind are closely intertwined, and bodily factors can influence the control one has with respect to one's inner life. LIS patients suffer from depression, suicidal thoughts, anxiety, and chronic pain. Many of these may stem in part from their bodily condition. But these are all features that may impair control over one's own situation – it is difficult to cultivate a rich inner life, to enhance positive experiences and inhibit the impact of negative experiences, if one is constantly beset by (e.g.) chronic pain, or anxious thoughts. Some LIS patients do not recover speech production, cannot participate in recreational activities, and so on. In these cases, the bodily impairments associated with LIS seem to be overall negative with respect to wellbeing, even if much of the LIS person's mental capacity is preserved.

Personality disorders, e.g., Obsessive Compulsive Disorder, Scrupulosity, Narcissistic Personality Disorder

Learning disabilities, e.g., dyslexia, dyscalculia, or dysgraphia

So-called 'severe cognitive disabilities' associated with, e.g., traumatic brain injury, Down's Syndrome, or dementia

Impulse disorders, e.g., intermittent explosive disorder, kleptomania

Volitional disorders, e.g., abulia, or akinetic mutism

It is possible to organize this list in a rough fashion according to the degree to which items on it undermine control over one's situation. As already claimed, given adequate care and a non-ableist society, loss of perceptual function and certain mobility impairments undermine this control very little if at all. Other items are much worse, although given the complex interaction of capacities that enable control, various items will undermine control in various ways. That said, however, the notion of control over one's situation is helpful in assisting reflection on the relation between the items on this list and wellbeing.

Some items on this list fall in something of a gray area. These items might, in very idealized conditions, qualify as Mere Difference disabilities. Congenital insensitivity to pain is often a debilitating condition, and proper care is high-effort and difficult to find. The reason is that pain sensitivity is crucial for navigation of our world. But one could perhaps imagine circumstances in which this disability did not undermine wellbeing. Language aphasias are a very different kind of thing. Some are mild and undermine control very little if at all. Some – e.g., Wernicke's aphasia, which renders an agent unable to understand written or spoken language – seem to leave control over one's inner life largely intact, while undermining control over how one interacts with others in most imaginable human societies. Plausibly, this latter kind of aphasia is much worse with respect to wellbeing than the former kind.

Other items on this list seem clearly to be negative with respect to wellbeing, although there will be differences in degree. Intermittent explosive disorder undermines emotional regulation. It is possible to manage the condition such that it's impact on wellbeing is minimal, but in most cases the condition's impact seems decidedly negative. Those with intermittent explosive disorder sometimes lose control of their behavior, engaging in violent bouts of rage and aggressive behavior. It is difficult to consider these episodes as merely different ways of behaving. The behavior and the consequences are often very negative.

To take a different kind of case, one condition on this list – abulia, which in extreme form is classified as akinetic mutism – targets the ground floor of control over one's situation, namely, one's motivation to perform actions at all. Abulia in general is often classified as an absence of willpower, a lack of initiative, or the presence of apathy. With appropriate external prompting, some of those with akinetic mutism are capable of sophisticated actions, such as playing card games, going to and using the restroom, reading and remembering items read. But without external stimulation they tend to do nothing at all, lying unresponsive for hours on end. As Colin Klein comments, 'The primary deficit in AM patients seems to lie in forming intentions. AM patients present with a picture of profound apathy. It appears that they do not act because they do not want to act. That negation should be read with wide scope: the patients have no intentions whatsoever, rather than an intention not to act' (2017, 35). Such a disability may not lead to objectively negative experiences. But it seems clearly negative with respect to one's wellbeing insofar as it takes away all the normal patterns of thought and action that make one's life go well. Moreover, to reiterate, the way it does so is by undermining motivational capacities central to one's ability to control one's own situation.

At the extreme end we find conditions that target one's control to more significant degrees. Depression and bipolar disorder, for example, both in different ways target motivational, attentional, and volitional capacities, rendering stable patterns of thought and action difficult.

It appears, then, that a control-based explanation of the difference between negative and neutral disabilities can generalize to a diverse range of disabilities. Is significant control over one's situation sufficient to explain the difference in every case? I doubt it - as I said above, disabilities are multifaceted features of complex biological beings. I doubt that thinking in terms of necessary and sufficient conditions is fruitful in this context. But it is nonetheless worth noting how difficult it is to find cases that qualify as a Bad Difference in the presence of control (cases of long-standing chronic pain being the only obvious one), and cases that qualify as a Mere Difference in the absence of control. In comments on this chapter, David Wasserman offers an interesting proposal regarding this latter class. He asks us to imagine 'a condition that filled most waking moments with ecstatic but uncontrollable reveries, or a psychosis that, unlike schizophrenia, was characterized by warm, friendly, supportive voices - a kind of internal cheerleading squad.' Such conditions seem - on some views of wellbeing - to qualify as Mere Differences (or better) while undermining control over one's situation. But there are a few important observations we should make about such conditions. First, they only qualify as a Mere Difference on what I would regard as implausible views of wellbeing. It is a crude hedonism that cares about the tokening of ecstatic experiences to the exclusion of the wide range of rich, complex, positive experiences we typically undergo. If the ecstatic incidents were so frequent as to significantly undermine control, the subject would be blocked from many of these rich positive experiences. Second, in order to qualify as a Bad Difference, we only need a strong tendency in a disability to undermine wellbeing. This is consistent with some cases bucking the general trend. And it is plausible that any biologically plausible version of one of these conditions would, in many cases, present subjects with difficulties and problems, precisely because these conditions take control away from the subject, rendering her at the mercy of her condition. Some individuals could get lucky and find a good match between positive symptoms of the condition and an environment that allowed these symptoms to flourish in the absence of side effects, even as the disability on the whole qualifies as a Bad Difference. With that said, I do not wish to deny that counterexamples to my proposed explanation could be found. But given that I do not wish to frame my explanation in terms of necessary and sufficient conditions, it is important that these counterexamples run against a general and strong trend. It is the general and strong trend linking control over one's situation and wellbeing that indicates the kind of control's explanatory significance.

I would not claim that control over one's situation can by itself regiment the relationships between the very diverse class of all disabilities and wellbeing. Clearly control over one's situation is a high-level classificatory notion, and unhelpful in explaining many of the details that render specific disabilities and conditions what they are. But at a high level, the notion is fit for purpose. My aim here has been to render plausible, and worthy of further consideration, a view on which some disabilities are mere differences with respect to wellbeing, and other disabilities are bad differences. In order to do that, I needed to develop some explanation of the distinction. The discussion above indicates that control over one's situation is critically important for maintenance of the type and level of wellbeing human adults typically enjoy. People with control over their situations possess a level of wellbeing that is robust against the kind of perturbations these disabilities create. Thus, the notion forms a key part of an explanation for why wellbeing is robust against some disabilities, but not others.

References

Barnes, Elizabeth. The Minority Body: A Theory of Disability. New York: Oxford University Press, 2016.

Bruno Marie-Aurélie, Bernheim Jan L., Ledoux Didier, Pellas Frédéric, Demertzi Athena, Laureys Steven. A survey on self-assessed wellbeing in a cohort of chronic locked-in syndrome patients: happy majority, miserable minority. BMJ open. 2011;1(no. 1):e000039. PubMed PMID: 22021735.

Bruno Marie-Aurèlie, Vanhaudenhuyse Audrey, Thibaut Aurore, Moonen Gustave, Laureys Steven. From unresponsive wakefulness to minimally conscious PLUS and functional locked-in syndromes: recent advances in our understanding of disorders of consciousness. Journal of neurology. 2011;258(no. 7):1373–1384. PubMed PMID: 21674197.

- Campbell Stephen M., Stramondo Joseph A. The Complicated Relationship of Disability and Wellbeing. Kennedy Institute of Ethics Journal. forthcoming.
- Harris John. Is there a coherent social conception of disability? Journal of Medical Ethics. 2000;26:95–100. PubMed PMID: 10786318.
- Kalmar Kathleen, Giacino Joseph T. The JFK coma recovery scale—revised. Neuropsychological rehabilitation. 2005;15(no. 3-4):454–460. PubMed PMID: 16350986.
- Kahane, Guy, and Julian Savulescu, "The Welfarist Account of Disability." In *Disability and Disadvantage*, edited by Kimberlee Brownlee and Adam Cureton, 14-53. Oxford: Oxford University Press, 2009.
- Kahane Guy, Savulescu Julian. Disability and Mere Difference*. Ethics. 2016;126(no. 3):774–788.
- Klein Colin. Consciousness, intention, and command-following in the vegetative state. The British Journal for the Philosophy of Science. 2017;68:27–54.
- Rousseau Marie-Christine, Baumstarck Karine, Alessandrini Marine, Blandin Véronique, Billette de Villemeur Thierry, Auquier Pascal. Quality of life in patients with locked-in syndrome: Evolution over a 6-year period. Orphanet journal of rare diseases. 2015;10(no. 1):1. PubMed PMID: 25603901.
- Schnakers Caroline, Vanhaudenhuyse Audrey, Giacino Joseph, Ventura Manfredi, Boly Melanie, Majerus Steve, Moonen Gustave, Laureys Steven. Diagnostic accuracy of the vegetative and minimally conscious state: clinical consensus versus standardized neurobehavioral assessment. BMC neurology. 2009;9(no. 1):1. PubMed PMID: 19126193.
- Shepherd Joshua. The Contours of Control. Philosophical Studies. 2014;170(no. 3):395–411. PubMed PMID: 25653458.
- Shepherd, Joshua. "Moral Conflict in the Minimally Conscious State." In *Finding Consciousness: The Neuroscience, Ethics, and Law of Severe Brain Damage*, edited by Walter Sinnott-Armstrong, 160-179. New York: Oxford University Press, 2016.
- Wilkinson, Dominic, and Julian Savulescu. "Is it better to be minimally conscious than vegetative?" *Journal of medical ethics* (2012): medethics-2012.