Disability, Transition Costs, and the Things That Really Matter

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This article develops a detailed, empirically driven analysis of the nature of the transition costs incurred in becoming disabled. Our analysis of the complex nature of these costs supports the claim that it can be wrong to cause disability, even if disability is just one way of being different. We also argue that close attention to the nature of transition costs gives us reason to doubt that well-being, including transitory impacts on well-being, is the only thing that should determine the wrongness of causing or removing disability. Non-welfare considerations also defeat the claim that it is always wrong to cause disability. The upshot of these conclusions is that closer attention to the nature of transition costs supports disabled people who strenuously contest the assumption that their well-being is lower than nondisabled people. It also suggests that, in addition, disabled people should contest their opponents’ narrow account of how we should make ethical decisions regarding causing or failing to prevent disability.

KEYWORDS: causing disability, disability, transition costs

I. INTRODUCTION

Many people deny that their disabilities make them worse off than others, or worse off than they would themselves be without the disabilities. Elizabeth Barnes (2014) has suggested that there is nothing odd about these claims, because disability is a mere difference. Proponents of the mere difference view usually believe disability is just one way a person can be different, much like sexuality and gender, and argue that disability does not, in and of itself, make a person worse off. Instead, they maintain that if disabled people are actually worse off, it is because of social issues like stigma, discrimination, and exclusion.

Opponents of the mere difference view are often concerned about the unacceptable implications of the view. If it were true that disability is a mere difference, they suggest, then it would be permissible to cause disability, and permissible to refrain from preventing disability (McMahan, 2005; Kahane and Savulescu, 2016). These implications are absurd, or so we are invited to concur, and therefore disability cannot be a mere difference.

Barnes (2014) has argued at length that the unacceptable implications argument is a weak objection to the mere difference view. We agree with her assessment. Her main argument is that there are a number of reasons for why it may be wrong to cause disability, even if disability is a mere difference. One such reason is because of transition costs. According to this claim, causing a person who is non-disabled to become disabled is wrong because of the heavy transition costs associated with acquiring
disability, even if the person is not made worse off in the long run. Such transition costs are also highlighted by others (cf. Campbell and Stramondo, 2017).

In what follows, we discuss the nature of transition costs in much more detail than is found in the existing literature. Our detailed analysis of the nature of transition costs will then be used to argue for two main conclusions.

First, we provide considerable additional weight to Barnes’ argument that even if disability is a mere difference, transition costs entail that it can be wrong to cause disability. Furthermore, we strengthen Barnes’ argument by adding that transition costs entail that it can be wrong to remove disability (cause a disabled person to become nondisabled). We show that transition costs temporarily reduce well-being, sometimes very severely, so we often have compelling reasons to avoid inflicting them. By developing a more detailed analysis of the nature of transition costs, we are able to respond to objections to Barnes’ original account of the wrongness of causing disability, even if disability is a mere difference.

Second, our detailed analysis of the nature of transition costs provides reason to doubt that well-being, including transitory impacts on well-being, is the only thing that should determine the wrongness of causing or removing disability. Maximizing well-being is not the only thing we do or should care about. Our projects, relationships, careers, and so on are of paramount importance to us, and we often form special connections to these things. While these things almost always make up significant components of our total well-being, we often remain committed to those people or things to which we have a special connection, independently of well-being considerations, or, indeed, even when they (no longer) contribute positively to our well-being. The upshot of this analysis is that even if the mere difference view is too strong, even if it is true that some disabilities do make people somewhat worse off, non-welfare considerations still defeat the claim that it is always wrong to cause disability, because disability can be the basis for one’s special connections. While disabled people are right to strenuously contest the assumption that their well-being is lower than nondisabled people, they should also contest their opponents’ narrow focus on well-being in deciding how to make ethical decisions regarding causing or failing to prevent disability.

II. CASES INVOLVING ADULTS

Our discussion is focused, first and foremost, on cases involving adults (we turn briefly to infants in Section IV). Opponents of the mere difference view have argued that if disability is a mere difference, then it would be permissible to cause disability. But, of course, this does not follow. There are numerous reasons for why it may be wrong to cause persons to become disabled, even if disability is a mere difference, such as unjustly interfering with their lives, or acting without their consent (Barnes, 2014). We believe that a compelling reason for not causing someone to become disabled is due to the infliction of transition costs.

On our analysis of transition costs, such costs typically arise through the acquisition of a high-impact trait. High-impact traits are those that interact with many features of a person’s life and have a substantial causal impact on how that life unfolds (Campbell and Stramondo, 2017). To understand what is meant, it is perhaps easiest to consider first a trait that is not high impact. Stephen Campbell and Joseph Stramondo use “hitchhiker’s thumb” as an example (2017, 166). People with this trait can bend the top of their thumb back at an angle close to 90 degrees. It is a common enough trait that it brings no notoriety and it conveys no real advantages. Had persons with hitchhiker’s thumb lacked this trait, it is likely their life would have unfolded in almost exactly the same way. Their thumb almost certainly had no impact on who their friends are, what occupational areas they chose, how they navigate the world, or how to fill their lives with meaning.

Whether or not a trait is high impact is heavily dependent on personal and social circumstances. A barely perceptible quiver of the hand is unlikely to be a high-impact trait for most of us, but will be for a certain type of surgeon or concert pianist. Similarly, your accent is unlikely to have a high impact if it is shared by the majority of the population but can if you have a nonstandard accent. For example, people sometimes either mock certain accents or consider them attractive. Those with accents which reveal them to be non-native speakers are subject to various forms of implicit bias. Research has shown that non-native speakers are perceived as less credible (Lev-Ari and Keysar, 2010), less
intelligent, and competent (Fuertes et al., 2012), and are less likely to be considered suitable for higher-status jobs (Kalin, Rayko, and Love, 1980). Negative stereotypes can also be attached to regional accents. For instance, one study showed British people assumed those with Brummie accents are less intelligent (Workman, 2015). The impact of all high-impact traits are highly sensitive to personal and social circumstances in this regard.

Disability is most often a high-impact trait. Disability can play a crucial role in determining how persons navigate the world, what some of their significant preferences will be, what many of their social interactions will be like, with whom they will interact, what some of their major life projects and priorities will be, and so on (Campbell and Stramondo, 2017). Because high-impact traits have a strong influence over how one lives one’s life, when persons lose such a trait, they must adjust in ways that can substantially reshape significant aspects of how they live their lives and fill it with purpose and meaning. And, because new high-impact traits are usually acquired in this transition—for example, a person who acquires blindness—that person must also adjust to living with a new high-impact trait. It is this kind of necessary adaptation meant when referring to transition costs. Thus, two sources of transition costs have been identified: the very substantial adjustments associated with losing a high-impact trait and the very substantial adjustments associated with acquiring a new high-impact trait.

Consider the experiences of those who become deaf. They partly lose access to their native language, from which it follows that they have to change profoundly the way in which they interact with others; potentially have to change their careers; some may no longer be able to pursue cherished hobbies or pastimes, and they may undergo a change in their self-conception. Persons who become deaf then also have to adapt to the acquisition of a new language, which when acquired in adulthood is unlikely to be acquired fluently. Even once the new language is acquired, it is often not shared by their close relatives, friends, and perhaps even their partner. Despite these costs, such an individual may decide after a transitory period that their well-being is either as high or even better than when they were nondisabled. Even if this is true, most newly disabled people typically experience a lengthy, often painful and distressing transition period.2

It is worth elaborating on why the goods associated with new high-impact traits do not quickly cancel out the well-being losses involved in losing a high-impact trait. We have identified three potential reasons.

The first regards focusing effects and perception of the newly acquired trait. Studies indicate that nondisabled people often imagine disabled life being far worse than disabled people report (Ubel et al., 2005). It would not be surprising, then, if newly disabled people routinely anticipate that their future will be worse than it ends up being, or for this worry to detract from their well-being during the transition period. Similarly, people who have recently acquired a disability are likely to think about their disability several times a day. However, over time, the allocation of their attention changes and they begin to focus on everyday experiences like reading, listening to music, watching TV, or where they may go for breakfast (Kahneman et al., 2006). Often, particularly during the transition period, when people focus on their disability, their focus is on what they have lost. Lynley Adams, an ex-Head of Department at a secondary school, discusses this phenomenon in her blog. A spontaneous fracture in her pelvis left her with permanent chronic pain syndrome, stripping her of her ability to walk, drive, work, or dress by herself. The first 2 years following the fracture were spent trying to come to terms with this loss (Adams, 2017). Because feelings of loss often typify the initial experience of becoming disabled, it can be difficult for newly disabled people to enjoy the things other people living with the same disability value. The focus of the newly disabled is typically on the things they valued and can no longer access. Coming to accept and reap benefits from one’s disability, then, requires refocussing. As Adams (2017) writes, while her first 2 years being disabled were spent focused on what she could no longer do, she can now see and appreciate the positives: having time to catch up on the latest popular TV series, going shopping with her partner while everyone else is at work, enjoying time in her garden, and best of all, discovering a love of writing which inspired her to start her blog. Similarly, in her blog, “life of a blind girl,” Holly Tuke (2017) describes many reasons she likes being blind, such as being a member of the sightless community, never judging people based on their appearance, reading braille, and having the opportunity to use a guide dog. Even though being blind has these benefits, it is unlikely those who have recently lost their vision can immediately appreciate them. Refocussing takes
time, and this partly explains why well-being losses are not quickly canceled out by newly acquired goods.

Second, many goods associated with disability require cultivating new skills or enhancing old ones before the benefits can be experienced. Over time, those who acquire disability become more adept at using the sensory and physical capacities they have retained. While disability can prevent people from undertaking certain activities, disabled people often learn to complete activities in ways they could not have previously imagined (Menzel et al., 2002). For example, Gerry Kenny, a bilateral, below-elbow amputee, completes many of his daily activities using an elastic arm band that slides over his residual limb. This allows him to hold utensils like his toothbrush or cutlery (Edge, 2020). For many deaf people, sign language is of immense value, because it grants them access to an interesting and distinctive linguistic subculture not everyone is privileged to enjoy. As Deaf advocate Eileen O’Banion emphasizes, sign language and the Deaf community “allow individuals to be who they are and live in a way that is unique to them” (Clason, 2019). Braille is a unique way of reading in which many blind people take pleasure, and wheelchair sports likewise enrich the lives of many living with a mobility disability. However, because time must be allocated toward developing these skills before someone can experience the benefits, it takes time, also, for people to come to value and enjoy their disability.

Similarly, newly disabled people are often required to relearn skills they had before becoming disabled. Learning to walk using a prosthetic leg, for instance, has been described by users as a painful and arduous process (Murray, 2009). Walking suddenly becomes a deeply unnatural movement and mastering the use of a prosthesis requires extensive training, commitment, and stamina (Norlyk et al., 2016). Whether one navigates the world using bionic or biological legs may ultimately be a mere difference. For some, learning to use a prosthesis can even be a source of pride. But during the transition period, being a prosthesis user is often exceedingly difficult and frustrating, so much so that some users have expressed hating their prosthesis initially (Murray, 2009).

Third and finally, some benefits of disability appear to result from physiological changes that occur after a person has been disabled for some time. For instance, roughly one third of the cortical surface in primates is involved in visual functions. It was believed that, should someone lose their vision, this part of the brain would cease to have any function. However, a wealth of studies in both human beings and animals has shown that the visually deprived cortex not only structurally reorganizes but becomes involved in other non-visual tasks, such as tactile and auditory processing (Kupers and Ptito, 2011). The current view is that the brain maintains a high level of neuroplasticity well into adulthood; for example, some studies have reported that those with late onset blindness have enhanced auditory spatial abilities when compared with sighted controls (Merabet and Pascaul-Leone, 2009). Likewise, studies have found evidence of neuroplasticity in the auditory cortex of postlingually deaf adults (Lee et al., 2003). A separate study found adults with hearing loss have enhanced visual processing in the auditory cortex (Liang et al., 2020). Physiological changes such as these help compensate for the loss of a sense but may take considerable time for the newly disabled to acquire.

Several recent studies support the claim that a significant portion of the well-being lost after becoming disabled is indeed caused by transition costs. For instance, one study found that those who acquire a disability exhibit a 30%–50% recovery in mental well-being over time (Oswald and Powdthavee, 2008). In a separate study, 17 participants were interviewed over a four-and-a-half-year period examining personal adjustment to spinal cord injury. Of the 17, five reported consistently high quality of life, while six reported coping well after initially struggling. Two reported unstable quality of life and four reported consistently low quality of life. Lower reported quality of life was often related to suffering from severe pain or from difficulties adjusting, due to acquiring the disability at a later age (35 and above). The most difficult time following spinal cord injury was generally considered the first 7 months (Stensman, 1994). Another study found that wealth acted as a buffer against well-being loss following the onset of disability nearing retirement age. It revealed that those below median wealth suffer greater losses in well-being when becoming disabled. However, over time, the buffering effect of wealth fades, and those below median wealth recover some of their well-being (Smith et al., 2005).

As the above data suggest, well-being is often lowest when first becoming disabled and tends to increase after a transitory period. This indicates that transition costs can indeed have quite devastating effects on short-term well-being. While well-being does not always return to previous levels, this does not mean disability cannot be a mere difference. As stated, spinal cord injury is sometimes
accompanied by chronic pain, and we do not wish to deny that chronic pain can quite severely reduce
well-being. Most disabilities, however, are not like this at all. Another explanation which is perfectly
in line with the mere difference view is that those who become disabled are made into a minority and
will experience ableism first-hand. Ableism and issues related to poor levels of accommodation can
be expected to contribute to lower levels of well-being, even after a transitory period. Lastly, because
disability is a high-impact trait, one cannot always predict what impact disability will ultimately have
on well-being. Adjusting to such a monumental change in one’s lived experience is a difficult process;
not everyone will adjust fully. This is a final, powerful reason for why well-being might not always fully
be recovered, even if disability were a mere difference.

Because transition costs arise from the disruption associated with losing a high-impact trait, and
from the disruption associated with adjusting to a new high-impact trait, transition costs can occur
regardless of whether someone has transitioned to a high-impact trait that increases well-being,
reduces it, or is neutral. Irrespective of whether the trait is good, bad, or merely different, acquiring
a high-impact trait usually causes a drastic change in a person’s life, and any such change requires a
seriously demanding adjustment period. This is entirely compatible with recognizing that the person
might be better off after the process of transition. This point generalizes beyond traits associated with
disability. Changes to career direction or parental or relationship status can demand very significant
adjustments, as can leaving prison or moving to a different country.

Of course, we do not deny that sometimes the process of losing or acquiring a high-impact trait
can be more beneficial than burdensome (where this is distinguished from the benefit or burden of
having or not having the trait itself). Our arguments do not rely on denying that transition from or
to a high-impact trait can also be beneficial, as we hope is clear. Nonetheless, given that the loss or
acquisition of such high-impact traits is very disruptive, we think that many of the so-called transition
benefits associated with the loss or acquisition of a high-impact trait are simply the benefits of not
having, or having, the trait in question.

The imposition of transition costs is not the only reason it might be wrong to cause a person to
become disabled, even if disability is a mere difference. Barnes identifies two further reasons. The
first is that causing someone to become disabled often involves unjustly interfering in their lives
without consent. Most people believe we should respect another person’s autonomy. We believe this,
even if we change person in a way that does not make them worse off, or even makes them better off.
Therefore, even if disability is a mere difference, unjustified interference entails that it can be wrong to
cause disability (Barnes, 2014). The second reason is risk. As previously stated, because disability is a
high-impact trait, we cannot always predict the impact that disability will ultimately have on well-be-
ing. As such, considerations of risk do support the claim that it can be wrong to cause disability.

A number of authors have argued that unjustified interference and risk fail to provide reasons for
why it is wrong to cause disability that are sufficiently compelling to defend the mere difference view.
Our account of transition costs can successfully account for the wrong done in the disputed examples,
even if disability is a mere difference, as we now demonstrate.

For instance, consider the following counterexample to the relevance of risk presented by Guy
Kahane and Julian Savulescu. A person unknowingly puts themselves at great risk of becoming seri-
ously disabled. A bystander who recognizes the risk and could easily prevent this from happening
does nothing. While there is no unjustified interference (because there is no interference at all), most
would agree the bystander does something wrong by failing to act (Kahane and Savulescu, 2016,
780). Therefore, they argue that risk cannot explain the wrongness of failing to prevent disability;
appeals to risk cannot support the mere difference view.

While risk cannot explain the wrong done in this case, we believe transition costs can. It seems clear
that in their counterexample, Kahane and Savulescu are drawing on the belief that it is our duty to pre-
vent serious harm coming to others, especially when it is easily within our ability to do so. They have
incorrectly assumed that the serious harm we fail to prevent must be the disability itself. However, by
appealing to transition costs, advocates of the mere difference view can agree that allowing someone
to become disabled is to run the very real risk of permitting serious harm. By appealing to transition
costs, we argue that becoming disabled is the serious harm, not the disability itself.

Similarly, Greg Bognar has argued that unjustified interference cannot explain the wrong done
due to causing disability. He points out that in cases where someone consents to another’s disabling
them, most still hesitate to agree that causing disability is permissible, and “hesitation may reflect the fact that causing disability is to cause someone serious harm, and therefore requires further justification even in the presence of consent” (Bognar, 2016, 48). While we agree with Bognar that we should hesitate before causing a consenting adult to become disabled, we disagree with him that this demonstrates that disability cannot be a mere difference. People usually only choose to acquire a high-impact trait if they think the transition costs will be worth bearing: becoming a parent or changing career might be examples. Because proponents of the mere difference view believe that disability is typically a mere difference rather than a good difference, they, at least initially, should have genuine concern about a person's decision to bear such transition costs. All Bognar's example does is remind us that further justification is required beyond consent before causing someone serious harm. Like Kahane and Savulescu, Bognar incorrectly assumes that the serious harm must be the disability itself, rather than the transition costs a person bears when becoming disabled. While both unjustified interference and riskiness can certainly provide reasons for why it can be wrong to cause disability even if disability is a mere difference, transition costs provide more compelling reasons in most cases for why it is wrong to cause a person to become disabled.

What about a (purely) hypothetical case where a person consents to being made disabled, and together with them we consult a very powerful, magic crystal ball which tells us that they would suffer few if any transition costs? In such an example, it seems the mere difference view can have no objection to causing disability. We have two responses. First, we are always somewhat concerned that we should rely on intuitions about cases that are so radically removed from any actual cases with which we are familiar. Second, if we do try and focus on this case, we no longer have the intuition that it would be bad to cause disability. Put differently, if we could somehow know that there would be no unjustified interference, no transition costs, and no other risks involved in causing a particular consenting adult to become disabled, then our intuition is that causing disability in this case would not be morally impermissible.

Opponents of the mere difference view might respond to our argument as follows. If transition costs are what explain the wrongness of causing disability, and if transition costs occur when acquiring a high-impact trait, then it would be equally wrong to “cure” disability (or, as we would say, cause nondisability). As both disability and the corresponding ability are high-impact traits, then removing someone's disability and restoring the ability should also impose high transition costs. Yet, it is argued, we do not share the intuition that it is as bad to cause nondisability as it is to cause disability. Hence, the transition costs argument fails.

This objection does not succeed. There is good evidence that people who lose their disabilities do suffer significant and sometimes quite devastating transition costs. Consider the experiences of Mike May. May lost his sight at the age of 3. At 46, he underwent a procedure to have his sight restored. Because he had lacked visual input for most of his life, May reported experiencing "information overload" (Downie, 2014). This made the first few months after sight restoration very fatiguing. May would later learn that many who have their sight restored experience depression (Downie, 2014). Of course, one plausible reason people experience depression after sight restoration is that they usually still have very poor vision. If people who have their sight restored can only see rough patches of color, but had expected their vision to be better, then this could contribute to their depression. We would be wrong to think, however, that imperfect vision restoration accounted for all transition costs. For instance, if information overload is a serious worry, then perfect vision restoration could increase this cost, or at least would not diminish it. Similarly, it is typical for people to imagine all the beautiful things a person will be able to see after having their sight restored: the smile on a loved one's face, famous artwork, a sunset, and so on. We tend to forget (or had always denied) that blind people have distinct ways of navigating the world, of experiencing sensory input, and of interacting with others that become very disrupted with the acquisition of sight. These, too, are significant transition costs.

Nevertheless, we are prepared to concede for the sake of argument that the transition costs associated with losing a disability might often be less than those associated with acquiring a disability. However, there are perfectly adequate explanations for this asymmetry consistent with the mere difference view.

First, as by Stramondo and Campbell, transition costs are likely to be higher when becoming disabled than when becoming nondisabled, because society is favorably oriented toward the nondisabled
Disability, Transition Costs, and the Things That Really Matter

Because of this, newly disabled people will experience ableist prejudice first-hand and will often face issues caused by lackluster levels of accommodation. Those who remove their disability, however, alleviate themselves of the troubles caused by ableism.

Second, many disabled people have spent a significant portion of their life nondisabled. For these people, removing their disability could be a way of regaining access to old special connections, and thus transition costs might not be so high.

Third, it seems plausible that some of those people who have their disability removed will not be as violently, or completely, severed from the things to which they have special connections. For instance, many deaf people report enjoying being a part of the deaf community. If deaf persons have hearing restored, it does not become impossible for them to interact with their deaf friends through sign language. For hearing people who become deaf, however, accessing some hearing activities they enjoyed does become impossible, and their ability to communicate with their hearing friends and family becomes severely disrupted.

Finally, in the vast majority of cases where an adult becomes nondisabled, they have probably chosen to have their disability removed. This likely means they want to undergo the transition. Becoming disabled, on the other hand, is almost never something people choose to do. Therefore, because much deliberation is usually given before making a high-impact change, we can expect people who have their disability removed to be well-prepared for the transition, and to be aware that they will lose access to some disability-specific goods. They will have likely attempted to weigh up the potential positives and negatives of having their disability removed. Thus, if persons choose to have the disability removed, they probably expect this change to be a good difference for them personally, and the losses may feel more like a sacrifice towards what they hope will be a better life. While one can never be certain that a high-impact change will be as they imagined it, at the very least, because people who have their disability removed likely believe the transition costs will be worth bearing, it is reasonable to think that their focus will already be on the positives associated with the acquired trait, and therefore they may not have to undergo the process of refocussing, which those who acquire a disability nearly always do. This likely means those who remove their disability will have a more positive attitude toward the transition than those who acquire a disability. These considerations provide a final and compelling explanation for why causing nondisability is often not as harmful as causing disability. All of the reasons we have offered are consistent with disability being a mere difference.

If disability is a mere difference, we might wonder why many disabled people seek to become nondisabled, and why they expect removing their disability will be a good difference for them. Before addressing this question, we need to begin by recognizing that many disabled people vehemently deny that they need to be “cured.” Rosie Jones (2019), a stand-up comedian with cerebral palsy, writes “Don’t pity me. I love who I am. If there were a pill to make me able-bodied, I wouldn’t take it in a million years.” Paralympian and wheelchair tennis champion Dylan Alcott says, “I love having a disability and I wouldn’t change it for the world” (Cross, 2016). While deeply passionate about wheelchair tennis, he also articulates the importance the sport has in providing him “with a platform to do what I really want: which is to continue to change the perceptions around disability” (Pearce, 2018). A third example, which we have borrowed from Barnes, is the documentary, The Kids Are All Right. The documentary featured people with muscular dystrophy, with the focus being on finding a cure, and most of the money raised was put toward this end. However, those featured in the film claim that they would have much preferred the money be put toward better wheelchair technology, more accessible jobs, research on how to extend the lives of people with muscular dystrophy, and so on. Rather than helping them, those featured felt the focus on a cure increased the stigma around their condition (Barnes, 2014, 11).

Nevertheless, there are some disabled people who do wish to become nondisabled, and believe it would be good for them to do so. It does not seem implausible to suppose that, on average, resistance to removing disability is lower than resisting to acquiring disability. One potential reason for this difference is that some people who acquire disability have failed to adjust well. Again, because disability is a high-impact trait, the impact acquiring a disability will ultimately have on a person’s overall well-being is unpredictable. Moreover, as Barnes argues, when ableism is rife, it can be difficult for disabled people to accept their bodies the way they are, since ableism can shape how disabled people see themselves (2014, 11). When nondisabled people expect that the ultimate goal for any disabled
persons is to turn their disabled body into a nondisabled one, it can be hard for disabled people to accept and be happy with their body how it is, even though they might have been perfectly happy with their body in an ableism-free society. This is, of course, exacerbated by the fact that ableist societies tend to lack sufficient levels of accommodation. This lack of accommodation might lead some disabled people to believe that removing their disability will open further opportunities. They may well be correct about this, but this is compatible with the mere difference view.

We believe our discussion of high-impact traits and transition costs directs us to more carefully consider the well-being considerations that are at stake in causing or removing disability. No one denies that there can be many hassles associated with disability (Stoner, 2016). It might be hard for wheelchair users to reach things sometimes, or for deaf people to communicate with strangers. Some disabled people have to endure the tedium of physiotherapy or the irritations that are sometimes associated with personal care support. When the disabled say that they are not worse off in virtue of their disability, they are almost certainly focused first and foremost on the things that we care most about: our relationships, our significant projects and pursuits, our professional endeavors, our way of navigating through the world, our contentedness and lack of constant anguish, and so on (Stoner, 2016). Disabled people are saying that: they enjoy relationships as rich and rewarding as those of the nondisabled; that they enjoy art and culture; that they have projects and work as valuable and as rewarding as nondisabled people; that they quite like their atypical bodies, they sometimes find them interesting, and they are often proud of what they can do with them; that they do not suffer any more anguish or distress than the nondisabled. Sure, there are hassles too, but few of us choose the options with the least hassles or believe doing so will maximize our well-being. If that were the case, no one would choose to be a parent, or a manager, or a university bureaucrat. These things that we most care about can be severely disrupted by causing or removing disability, which is why it is often wrong to do so, even though disability is a mere difference.

III. OTHER GOODS

By developing a detailed account of the nature of transition costs associated with acquiring or losing a high-impact trait in adulthood, we have argued that the significant loss of well-being experienced in becoming disabled (or nondisabled) can explain why it would be wrong to cause disability, even if disability is a mere difference. However, what we learn from reflecting on high-impact traits is not only the significant role they play in understanding transition costs. We also learn, we believe, that maximizing well-being is not the only thing we care about. The loss of those goods we experience when becoming disabled (or nondisabled) is not only bad because of the transitory impact on our well-being. We often have good reason to want to retain access to these goods independent of well-being considerations.

As Dan Moller argues, people care about the specific means by which they derive their well-being, not just that they have high levels of well-being. We form special connections to people and activities which we do not wish to sever, even if doing so would (eventually) increase our well-being (Moller, 2011). The paradigm example is love. For each of us, there is a plethora of people who could make a compatible partner. Had we ended up with a different partner, then we would have had different children, too. And, had we grown up in a different country, we would have had an entirely different network of friends. With any of these changes, it is possible we would have been just as well off, or even better off, than we are currently. Recognizing this, however, does not mean we are indifferent to the way things went. This is because we form very strong attachments to the people we love. The value of these attachments to us goes beyond their contribution to our well-being (Moller, 2011). We would not swap out a loved partner if we believed a relationship with another person might make us better off. Indeed, we can rationally prefer to continue on with a relationship in which we can recognize that we would experience an eventual increase in well-being if the relationship were to end (Moller, 2011).

Moller argues we form the same kind of attachments to the activities we find meaningful and are passionate about. For instance, in virtue of having engaged enthusiastically with wheelchair basketball and disability activism for many years, and from embedding these activities in one’s life through interconnected memories and friendships, persons will wish to retain their connection to such activities. They do not bother thinking about whether their well-being might be greater in the long run if they were to become nondisabled. Even if they believed this would be the case, they can rationally wish
to retain their disability, if doing so is the basis for their valued connections. Similarly, a person who engages in hiking and bird watching, and has embedded his love for these activities into his self-understanding, his friendships, and his social activities, will resist their loss, even if he believed he might be better off without them. Even if such a person knew he would come to value even more wheelchair basketball and listening to music instead, that does not mean he is irrational in wishing to stick with what he has now. Wanting to maintain special connections is a reason we resist high-impact changes, not just becoming disabled: we often resist these changes irrespective of calculations about either transitory or long-term well-being, if we believe they will threaten our special connections.

If this is correct, then it follows that it can be wrong to cause disability independently of well-being considerations and transition costs. We do not say that it is always wrong to sever people’s attachments, or that it is always wrong irrespective of well-being impacts. Presumably, it is not difficult to imagine cases where someone’s current attachments have such detrimental impacts on well-being that severing them could possibly be justified. But most disability is not like that at all, and nor do we have any reason in the vast majority of cases for doubting the word of a disabled person who tells us of the importance of her special attachments and her commitment to retaining them.

Most of us do not spend our lives trying to maximize our well-being by reducing as much as possible all the hassles that we can confront. Rather, we secure our well-being by filling our lives with meaningful attachments and projects which, once secured, we honor without constantly calculating whether well-being gains could be made by ditching them. And for those attachments to other people, they presumably expect no less of us.

IV. DIFFICULT CASES

There is one rather prominent type of case that no appeal to transition costs can explain. Opponents of the mere difference view will argue that we have so far failed to confront the really difficult cases for our view, namely, selecting an embryo for disability or causing a fetus or newborn to be disabled. Certainly, most people believe that it would be wrong to cause a newborn infant to become disabled, or to fail to prevent disability in infancy. Given that fetuses and newborns have yet to develop significant attachments or express any high-impact traits, our transition cost argument has no purchase. Thus, these cases seem to undermine the mere difference view.

Moral issues that arise in the context of parenting are extremely complex and deserve more attention than we can provide here: we therefore confine ourselves to some brief suggestions. Firstly, others have recently argued that the mere difference view need not have unacceptable implications regarding selecting for or causing disability in infancy (see, e.g., Barnes, 2016; Schroeder, 2018). For example, it is noted that our judgments about the behavior of (would-be) parents are likely to be affected by numerous assumptions and intuitions about what good parents, particularly mothers, are like (Barnes, 2016). There are also many reasons why causing disability in newborns might be morally wrong, even if disability is a mere difference. The world is full of ableist prejudice, so a person born disabled is likely to have a harder life for this reason alone. Issues of interference with the “natural” course of events affects our intuitions, especially for high-impact traits where the deliberate intervention will profoundly affect what kind of life the eventual child has. Our strong intuitions concerning the moral difference between doing and allowing might be playing a role (Schroeder, 2018). We might especially question parents’ intentions and their understanding of what a virtuous parent is like when they interfere for what we take to be dubious or narcissist reasons (Stramondo, 2017), such as the belief that a disabled child would make them (the parents) more interesting or give their lives a bit more weight (Asch and Wasserman, 2005; Schroeder, 2018). Moreover, we have conceded it is possible that some disabled people might face many more hassles because of their disability (Stoner, 2016), and that there is a risk that a person with disability might have lower well-being than she would have had, had she not been disabled.

Second, our main response to the case of newborns is to simply disagree with opponents of the mere difference view that it would always be wrong for parents to cause disability or fail to remove it. As we argued in the previous section, disability advocates should question not only the widespread assumption that disability makes people worse off; they should also question the often excessive and
narrow focus on well-being in discussions about the ethics of parental choices in the context of disability. Parents are simply not required to always maximize their children’s well-being.

To show this, let us grant here for the sake of argument that disability is likely to make people somewhat worse off (than they would be without the disability or compared to the nondisabled). So what? Just as we do not always seek to maximize our own well-being, it is highly implausible to suppose that parents have a moral responsibility to maximize the well-being of their children. A more plausible view is that parents have a moral responsibility to ensure that their children have a range of rich and rewarding options with respect to relationships, projects and pursuits, which includes developing their capacity for autonomy (Lotz, 2006; Schroeder, 2018; Stramondo, 2020). Parents frequently choose to impose small to medium welfare costs on their children in pursuit of other ends, some of them quite trivial, such as the desire to move to a different town, or to use a nanny, or to save money on music lessons. Many of these decisions are not considered morally troublesome. If parents are under no obligation to maximize their children’s well-being at the cost of other opportunities or preferences, then this should apply equally to disability. What matters most of all is that parents act to ensure that their children can come to attain the important goods that are closely connected to significant well-being and a life of meaning: rich and rewarding relationships, engagement in meaningful projects and occupations, the ability to successfully navigate the world, a capacity to choose among the many options that exist, and so on. While there may be some disabilities and other high-impact traits that might jeopardize access to these goods, the vast majority of disabilities do not in any way do so.

It might be denied that parents have any reasons to choose or cause disability, in which case there is no justification for risking trading off any amount of the child’s well-being by selecting for or causing disability (again, assuming for the sake of argument that disability might make people somewhat worse off). But, this is just not true in most real-world cases. Most (would-be) parents who contemplate bringing into existence a disabled child are themselves disabled (Schroeder, 2018). Their lives have often been structured around their disability, and they wish to share these goods with their children. This might include sharing a language (sign), introducing a child to a valued community, or seeking to offer to the child their own valued way of navigating the world. These reasons for having a disabled child are not necessarily morally decisive. They might not be. Whether or not the goods of disability that parents want to share with their children might be outweighed by losses to the child’s well-being cannot be decided a priori, but would have to be considered on a case-by-case basis (Stramondo, 2017). We merely note that we give parents very wide latitude to sacrifice gains to their children’s well-being for all sorts of less than weighty reasons (Wasserman, 2017). As such, there is no good reason at all to suppose that well-being considerations will always outweigh the importance of sharing valuable ways of life.

V. CONCLUSION

To conclude, opponents of the mere difference view often argue that the view has unacceptable implications, namely, that it would be permissible to cause disability and permissible to refrain from preventing disability. As Barnes (2016) has argued, there are a number of reasons why the unacceptable implications argument is weak. The strongest reason, we believe, is that causing an adult to become disabled imposes often very severe transitory deficits in well-being. Our detailed analysis of the nature of the transition costs associated with losing or acquiring a high-impact trait demonstrates the plausibility of this argument. Moreover, focusing more specifically on the nature of transition costs confirms that well-being is not the only thing that matters. Some of the most significant aspects of our lives, such as our relationships and projects, have value beyond their contribution to our welfare. Just as we do not always seek to maximize our own well-being, it is highly unlikely that parents always have a duty to maximize the well-being of their children. A more plausible view is that parents have a moral responsibility to make parenting decisions for good reasons, and to ensure that their children have a wide range of valuable options with respect to rich relationships, and meaningful projects and pursuits, and the capacities to choose among those options. So, even if the mere difference view is too strong, even if disability does make people somewhat (but not very badly) worse off, it is not at all obvious that parents must never cause disability or fail to prevent it.
NOTES

1. Our discussion concerns physical and sensory disabilities only. We make no claims about the acceptability or otherwise of causing people to become seriously cognitively disabled. We are unconvinced that discussions about disability—ontological, epistemological, political, or moral—can feasibly treat all disabilities as on a par.

2. There are many different theories of well-being—happiness, preference satisfaction, objective lists, and so on. Our discussion is largely unaffected by differences in such theories as we attend to the pre-theoretical building blocks most commonly thought to contribute to a good life. Maintaining worthwhile relationships, engaging in projects we find meaningful, freedom from anguish or distress, et cetera, are almost always thought to contribute to our well-being, no matter what theory of well-being is assumed.

REFERENCES


