

Disability, Identity, and the Body as a Context of Choice:  
Making Space for the Mere Difference View in Healthcare Justice

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**Abstract**

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My dissertation seeks to defend the “mere difference” view of disability from the charge that it leads to objectionable implications in healthcare justice. The *mere difference view*, briefly put, conceptualizes disability as a morally neutral human trait, analogous to race, sex, gender, ethnicity, and sexual orientation, that ought to be treated in society as such. Its main claim is that disability is not a categorically or definitely bad state to be in but is instead simply another variation of human diversity. Disability as mere difference is a powerful counter to demeaning, pitiable depictions of disabilities as misfortunes and disabled lives as personal tragedies. It is meant to capture and validate the embodied experience and non-tragic identities of disabled people as represented in disability rights and pride movements. For numerous philosophers, this view raises the following worry: if disability were mere difference and not a bad or harmful state to be in, then there apparently would be no moral grounds to support medical research and interventions to prevent, reverse, or remove disability, such as maintaining or restoring the non-disability status of citizens who have become disabled due to some injury or physiological process. This objection is often raised to maintain the *bad difference* view of disability. In response, I argue that embodiment provides a *context of choice* that not only makes it possible for us pursue a certain range of life options, but also makes them meaningful in relation to how we understand ourselves and the good life. Abrupt or dramatic changes in a person’s embodiment, even though the new embodiment may not be intrinsically or definitely bad, can be inimical to the agency of the modified individual by upending their context of choice. If the state has a responsibility to secure the agency of its citizens and certain physiological states are important

conditions for agency—such as providing a stable context of choice—then the state has a moral obligation to secure the physiological conditions for agency through medical interventions. My goal is to provide a plausible account that both contributes to the destigmatization of disability while providing justification for a robust set of entitlements regarding the provision of healthcare resources.

In Chapter one, I argue for the mere difference view and elaborate the particular objection that it restricts what medical care and resources citizens are entitled to receive from the state. Chapter two presents the idea that embodiment is an important *context of choice* for autonomy. Building upon feminist insights on the relation of the body to autonomy and repurposing Will Kymlicka's notion of *context of choice*, I argue that specific embodied forms not only enable us to pursue a certain range of life options but make them meaningful to us. For this reason, treating or preventing disability through medical interventions may be justified as a practice of *identity-maintenance* and, in turn, *autonomy-maintenance*. Chapter three addresses a serious worry that subsidizing healthcare institutions to actively prevent, ameliorate, and eliminate disability expresses a negative social meaning that disability is a devalued embodied form of life, which reinforces the harms of attitudinal and structural ableism. This is an iteration of the expressivist argument that is often deployed in issues of selective reproduction and disability avoidance. I will defend the expressivist argument against prominent objections, recognizing that such devaluations are indeed sometimes expressed. Yet rather than rectifying this social harm by eliminating those practices, I recommend altering the broader social context that imbues disabled life with negative social meaning. This move helps to provide identity and agency maintenance across body types. Chapter four engages with hard cases for my position and offers a justification for providing citizens access to medical resources to alter or augment their bodies in ways that fit with their identity, like gender transition care for transgender people.

For Josefina, Apo, and Anita

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## Chapter 1: What Kind of Difference is Disability? On the ‘Mere Difference’ View and Taking It Seriously

*Disability is articulated as a struggle, an unnecessary burden that one must overcome to the soundtrack of a string crescendo. But disabled lives are multi-faceted – brimming with personality, pride, ambition, love, empathy, and wit.*

– Sinead Burke, “What It’s Like to Live in a World Not Designed for You” (Burke 2017)

### 1. Introduction

What does it mean to be disabled? How should the heterogeneous range of physical, sensory, motor, aesthetic, and psychosocial characteristics that are typically described as disability be comprehended, valued, and treated in society? These are important, complex philosophical questions. Historically, the meaning and value of disability have been taken for granted in philosophical discourses, presuming as given that disability is an undesirable and inherently disadvantageous condition. The notion of disability is often employed as a foil or limit in moral philosophy in thought experiments and counterexamples to test the plausibility of accounts of moral concepts like wellbeing<sup>1</sup>, moral responsibility<sup>2</sup>, and harm<sup>3</sup>. Any thesis that fails to be responsive to the supposed deficiencies that disability represents is typically deemed flawed. Prior to the recent surge in philosophical writing on disability, Susan Wendell pointed out that philosophical articles around the topic of disability were primarily limited to addressing two questions: “Under what conditions is it morally permissible/right to kill/let die a disabled person and how potentially disabled does a fetus have to be before it is permissible/right to prevent its being born?” (Wendell 1989, 104). In the past several decades, however, the disability rights and pride movements and disability culture have deeply unsettled the concept of

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<sup>1</sup> For example, Greg Bogner states that any theory of well-being that implies that disability is not a welfare-diminishing condition is a flaw to the theory, “In any case, the fact that a theory of well-being entails the mere difference view, arguably, constitutes an argument against it - unless of course an independent argument is available for the mere difference view” (Bogner 2016).

<sup>2</sup> Jared Smith criticizes moral philosophy discourse for presuming uncritically that obsessive compulsive disorder is a condition that automatically undermines moral responsibility, and that any account of moral responsibility that fails to account for this presumption is deemed implausible (Smith 2021).

<sup>3</sup> The most famous example is the non-identity problem as articulated by Derek Parfit. The non-identity problem refers to the problem of explaining the wrongness of bringing into existence people whose lives are inherently flawed when it was possible to bring into existence different people without those flaws. Disabled people are often represented as kinds of people with unavoidably flawed existences.

disability, turning it to a worthy object of philosophical inquiry, spurring an emerging subfield with metaphysical, epistemological, political, and moral dimensions.<sup>4</sup>

Beyond mere intellectual fancy, the question about the meaning and value of disability is important because disability is a social category that profoundly shapes our interpersonal interactions, structural arrangements and institutional practices, and the ways in which individuals with certain embodied properties are grouped together and characterized. It is, in the words of Åsta, a category we live by (Åsta 2018). Thus, the question carries deep political significance, rooted in a concern for justice for diverse, disabled publics. How we choose to conceive disability could create major political ramifications, especially in the sphere of medicine. This is the underlying motivation of this dissertation. I am especially interested in exploring the different understandings of disability and their normative implications in the realm of healthcare justice, that is, the justice of healthcare systems for developing and distributing medical goods for promoting certain embodiments.

This dissertation will center on a prominent account of disability called the ‘mere difference view.’ The *mere difference view*, briefly put, reconceptualizes disability as a morally neutral, though atypical, human trait (Barnes 2016). It refers to distinctive forms of embodiment, or what social model advocates call “impairments,” though in many ways the account acknowledges the manifold ways that society’s attitudes, practices, architecture, and so forth can create disadvantages for people who are atypically embodied. Its main claim is that disability is not a categorically or definitely bad state to embody, but simply another variation of human diversity, analogous to race, sex, gender, ethnicity, and sexual orientation. This contrasts with the *bad difference view*, which is the more prevalent view, that disability is a bad or harmful state due to its negative effects on those who embody its properties. Following the publication of Elizabeth Barnes’ book *The Minority Body* that articulates and defends the mere difference view, much philosophical energy has been devoted to critiquing her view and/or to bolstering her view. For my part, I am committed to the mere difference view as the most reasonable account of disability. What perhaps has not received enough attention yet is the question of how this understanding of disability might be reflected in our social relations and institutional practices, such as our healthcare institutions, in relation to requirements of justice. But to get us there, it is important to first introduce the mere difference view and understand why it ought to be taken seriously.

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<sup>4</sup> For example, at the time of this writing, there are seven entries related directly to disability in the Stanford Encyclopedia of Philosophy. Also, the Oxford Handbook of Philosophy series just released a volume on philosophy and disability, edited by Adam Cureton and David Wasserman (Cureton and Wasserman 2021).

I will begin by defending in section 2 why the discourse around the question, “What is disability?” is important, arguing that it is pertinent to justice. The political significance of this question is especially evident in the healthcare setting. In section 3, I will describe the mere difference view of disability, both its distinctive features and what makes it an appealing account in comparison to the prevailing interpretation of disability as bad difference. In section 4, I will defend the mere difference view from standard objections raised against it. Still, the mere difference view is not free of controversy and in section 5, I will elaborate a legitimate worry about this conception of disability, namely that it leads to troubling implications if health systems choose to adhere to it. My dissertation project, as a whole, aims to confront these difficulties, such as how to handle medical practices to treat and prevent disability and whether it is consistent for the state to subsidize such practices while at the same time having a commitment to the view that disability is mere difference.

## **2. The Meaning of Disability and its Political Significance**

Disability is a culturally messy, “essentially contested” concept that refers to a broad set of heterogeneous referents (Silvers 2003). The motivation to have a determinate account of disability, rather than resign as futile any attempts to fix what is continually fluid,<sup>5</sup> is that the concept of disability is live and socially operative. It is an established social label used to categorize people with diverse embodied properties, carrying connotations that shape how they are perceived, both by others and to themselves. Though the meaning of disability is erratic in many ways, it is an established group identity with stable significations and stigmas that are reproduced in social attitudes, interpersonal interactions, institutional practices, and self-conceptions. As disability rights scholar and activist Simi Linton points out, “As typically used, the term *disability* is a linchpin in a complex web of social ideals, institutional

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<sup>5</sup> Jonas-Sébastien Beaudry describes these accounts of disability as “radically open-ended accounts of disability” (Beaudry 2021, 14-16). The motivation behind these relatively indeterminate accounts is that any determinate account of disability will be unavoidably impoverished and exclude some important aspect of disability. One notable example of a radically open-ended of disability is Anita Silvers’ understanding of disability as a term of art, where the term “disability” has different specialized meanings, and it is used in different contexts to refer to different properties, such as identifying a collection of persons who should receive benefits from certain federal programs based on their embodied traits (Silvers 2016). I am deeply sympathetic to this account of disability and one of my future projects is to figure out how to adjudicate the different meanings of disability operating in social institutions and programs. Though I do not have the space to address adequately the question of whether Silvers’ account of disability as a term of art undermines the mere difference view thesis, I do believe that both accounts are compatible. The mere difference view revises the public meaning of disability in ways to serve a particular social purpose, which is to promote justice for disabled people. The account of disability as a term of art is to explicate the variety of ways that disability has been used in different contexts to refer to different groups of people. The approaches to defining disability are different, but not incompatible.

structures, and government policies” (Linton 1998, 10). Given the structural nature of oppression and the importance of recognizing certain forms of difference to ensure that people with certain properties are supported socially, it may be more beneficial to justice that the category of disability is preserved. Linton further argues, “I’m not willing or interested in erasing the line between disabled and nondisabled people, as long as disabled people are devalued and discriminated against, and as long as naming the category serves to call attention to that treatment” (Linton 1998, 13). For this reason, interrogating the meaning of disability is a matter of social justice.

### *2.1 Justice as Recognition*

The question of the public meaning and value of disability is relevant to justice in two ways. First, it is relevant to the recognition demands of justice. By this I mean the moral requirement of recognizing and representing publics in ways that exhibit respect, inclusiveness and responsiveness to the perspectives, experience, values, and characteristics of the represented. It is unjust to stereotype and otherize publics and render the perspectives of these publics invisible or invalid due to the imposition of prevailing social scripts, or what Hilde Lindemann calls “master narratives” (Nelson 2001, 6). Other justice theorists have identified this form of injustice with somewhat different terminology. Iris Marion Young calls it “cultural imperialism” and includes it as one of the five “faces” of oppression (Young 1990, 58-61). Nancy Fraser calls it “cultural injustice” which includes a litany of wrongs, like “cultural domination (being subjected to patterns of interpretation and communication that are associated with another culture and are alien and/or hostile to one’s own); nonrecognition (being rendered invisible by means of the authoritative representational, communicative, and interpretative practices of one’s culture); and disrespect (being routinely maligned or disparaged in stereotypic public cultural representations and/or in everyday life interactions) (Fraser 1997, 14). For both Young and Fraser, it is a problem of justice when subordinated publics are represented in ways that distort who they are, especially when they are associated unduly with negative traits. Furthermore, it is unjust when subordinated publics are excluded from shaping how they are perceived to other publics and to themselves, instead subjected to the interpretations of dominant groups.

How we conceptualize disability will have implications on how disabled people are publicly read by others as well as themselves. Therefore, getting the account of disability right is attached to the moral imperative of respecting disabled publics. It calls for properly recognizing disabled publics, holding them in ways that are responsive to their physical, social, and subjective realities.

## *2.2 Justice as Resource Distribution*

Second, the question, “What is disability?” is relevant to the equitable resource distribution demands of justice. I am construing “resource” here broadly to refer to the material goods and opportunities that are valuable to people as important means for developing and exercising their capacities and pursuing their specific conceptions of the good. Norms and beliefs underwrite the distribution of these resources, including how we understand certain social categories, like disability. How we choose to construe disability will have wide-ranging practical implications about what resources should be provided to or withheld from disabled publics. As Anita Silvers points out, “The disability label has been used to mark out classes of people whose exclusion from employment, educational, or recreational opportunity is permissible...The disability label has also been used to mark out kinds of people who are eligible for special compensations and protections, including protection against these aforementioned exclusions from work, education, and play” (Silvers 2003, 472). Yet how disability is used to justify the social treatment of certain people depends on how disability itself is conceptualized.

In practice, these two demands of justice—recognition and distribution—are interlinked with one another. Dominant representations of disabled publics justify the social and economic arrangements of the state, making disabled publics vulnerable to marginalization, exploitation, and deprivation. At the same time, the social and economic forces that shape disabled people’s lives may, in turn, reinforce the dominant meanings of disability as inescapably disadvantaged and how disabled publics are read publicly, making them vulnerable to misrecognition and disrespect. Furthermore, these dominant meanings may enable or constrain the participation of disabled publics to construct discursively the interpretative schemes that are applied to them, making disabled publics vulnerable to non-recognition and cultural domination. Therefore, the question of the meaning and value of disability has social consequences that affect the life prospects of disabled publics, imbuing the question with political significance that should be taken seriously as a matter of social justice.

## *2.3 Disability and Healthcare Justice*

The public meaning of disability and its practical implications are especially relevant in the healthcare realm. The concept of disability has played a critical and controversial role in healthcare

justice. One instance is in the problem of determining a just distribution of scarce healthcare resources. For some healthcare justice theorists, disability figures in as a morally relevant factor in prioritizing the medical needs of certain publics over others. For example, the conventional use of QALYs (or quality-adjusted life years) and DALYs (disability-adjusted life years) assessments to determine which lives should be prioritized when allocating scarce medical resources defines disability as a morally negative trait that diminishes a person's quality of life. In some instances, this justifies deprioritizing disabled publics from receiving critical medical care (Kamm 2009, Singer 1995, Silvers 1995). Another instance is in the problem of identifying which kinds of physiological and psychological states are proper objects of publicly subsidized medical care. The meaning of disability is often conflated with ill health. Thus, there is an assumed moral responsibility to diminish the manifestation of certain human differences, such as disability, because they are interpreted as pathologies or adverse biomedical conditions that the state is justified to prevent or ameliorate by means of developing and using medical technologies. Ani B. Satz argues that our contemporary healthcare system enacts a negative form of eugenics because it seeks to prevent, ameliorate, and eliminate disabled embodiments (Satz 2020). The goal of our healthcare system is to keep or make citizens nondisabled when possible. For Satz, the underlying motivation for treating and preventing disability is the idea that disability is by definition a harmful condition to embody. Furthermore, the representation of disability in medical institutions can have broader social effects since medical institutions have an authority over the construction of the meaning of disability. Emily Johnson points this out, stating, "[I]t is the medical community—by distinguishing 'normal' from 'abnormal'—that sets the foundation for broader social and cultural expressions of discrimination against people with disabilities" (Johnson 2016). Thus, reading disabled people as ill or deficient has social consequences that extend across different arenas of public life.

The relationship between disabled publics and the medical establishment is especially fraught, shaped by histories of medical abuse, neglect, and exploitation of disabled people (Johnson 2016). The contemporary medical institutions in the United States are linked to legacies of eugenic practices of forced sterilization of disabled adults and euthanasia of disabled babies, institutionalization and segregation of disabled people, and experimentation on the institutionalized, like the Willowbrook State School hepatitis experiments (Rothman and Rothman 2004). The painful past of medical maltreatment of disabled people has lingering effects, generating distrust in medical institutions, and raising concerns over whether the norms and beliefs that have underwritten these misconducts are still operational in our current medical practice.

It is important to reexamine critically the normative understandings of disability that operate implicitly and explicitly in the workings of medical care and research. Assumptions and judgments about disability are mediated through the various interactions with medical providers and staff, patient-physician relationships, policies and protocols, and built spaces, which, in turn, have negative effects on disabled publics. Adam Cureton elaborates how different aspects of medical practice could serve as mediums for expressions of disrespect toward disabled people (Cureton 2020). These disrespectful messages could come in the form of medical providers communicating disparagingly or treating disabled patients paternalistically. Physical structures like waiting rooms that are not wheelchair accessible or physical documents that are not formatted for other communicative modes express a lack of respect towards disabled people who rely on alternative modes of functioning to exercise their agency. Policies and protocols could express disability bias that discourage disabled patients from receiving important medical care and resources. For example, Emily A. Largent discusses how organ transplantation policies discriminate against people with disabilities, valuing them as prospective donors but devaluing them as prospective recipients (Largent 2020). The COVID-19 pandemic and the subsequent shortages of medical resources raised serious concerns, as well as legal challenges, that triage protocols are set up in ways that deprioritize the medical needs of disabled people (Savin and Guidry-Grimes 2020). Furthermore, the quality of clinical care may be compromised or unequal due to tacit disability assumptions and biases. Omar Sultan Haque and Michael Ashley Stein argue that the interplay of various disability biases shape patient-physician relationships and clinical decision-making, inspiring misplaced paternalism and low regard for disabled patients' competency or openness to certain treatment options (Haque and Stein 2020).

The ethical imperative to improve the medical care and equity of disabled publics calls for interventions at numerous levels, including medical education and training (Gallegos 2021, Campbell 2009, Goering 2015). Numerous proposals for educational reform have been made to rehabilitate the professional integrity of medical science and practice. They suggest promising ways of fostering perceptions and practices that are properly sensitive to the vulnerabilities and moral interests of disabled publics, demonstrating respect towards them and regarding their wellbeing as a central priority of the medical profession (Reynolds 2018). These include confronting social psychological biases that may negatively shape the diagnosis, treatment and prognosis of disabled patients or raising awareness of the variety of ways of how medical practice could express disrespectful messages to disabled publics and cultivate vigilance in avoiding these mishaps (Haque and Stein 2020, Cureton 2020).

We should also rethink the foundational ideas of disability that give normative content to disability bias and stigma and motivate actions and practices that discriminate against disabled people in healthcare settings and beyond. One account of disability that should be considered is the mere difference account of disability. In the next section, I will articulate this account and why we ought to take it seriously.

### 3. Disability as “Mere Difference”

The mere difference view of disability is an antithesis to the dominant contemporary understanding of what Barnes labels as the *bad difference view* of disability (Barnes 2016). The bad difference view holds that disability is a bad or harmful state to be in due to its negative effects on those who are disabled. Disability is standardly regarded as a welfare-diminishing trait such that its embodiment produces a nontrivial degree of suffering and deprivation of valuable experiences for those who are disabled (Kahane and Savulescu 2009; Singer 2005). Disability is also prevalently thought of as a trait that diminishes autonomy, because the negative atypical embodiment constrains its bearer from pursuing a broad range of life options and, in effect, limits the ways in which they could shape their own lives (Davis 2010, Daniels 2008, Buchanan et al 2000). Both accounts reflect and reinforce the conventional understanding of the bad-making features of disability. For these reasons, disability itself is understood as an adverse condition to important components of human life and therefore devalued. The bad-difference view of disability is so dominant, so prevalent and so infused throughout media representations, cultural beliefs, research, policy and institutional practices, even in our contemporary healthcare practices, that most people within the system assume it to be a basic fact, not in need of any justification or argument.

The mere difference view is a countervailing account to the bad difference view of disability. There have been many philosophers who have contributed to this counternarrative, such as Anita Silvers, Ron Amundson, and proponents of the “social model” of disability (Silvers 2003; Amundson 2005; Amundson and Tresky 2007). Here, I will mainly work with the account advanced by Elizabeth Barnes. I will articulate the mere difference account by describing what I take to be its two distinctive features: (1) disability is value neutral and (2) disability is rule-based solidarity. I will also differentiate it from another prominent conception of disability, which is standardly called the “social model,” and show why the mere difference view ought to be taken seriously.

### 3.1 Disability as Value-Neutral

The mere difference view of disability denies the bad difference thesis that disability is an overall bad or suboptimal state to be in, and that it is generally desirable to free people of its presence. Instead, the mere difference view presents a value neutral account of the class of properties that are designated as disability. Disability is neither essentially inferior nor tragic, but simply a different mode of being embodied with rich possibilities to flourish within that embodiment. The mere difference view reframes disability in neutral terms, drawing relevant similarities to other neutral forms of human difference, like race, sex and sexual orientation, where such embodiments may set certain biological limits in functioning or experiences<sup>6</sup> or have deleterious contingent consequences given the unjust social context<sup>7</sup>, but would not be deemed as categorically or definitively bad states to embody. It directly challenges the negative construal of disability by arguing that these representations are based on misunderstandings and the limited moral imaginations of nondisabled people, who misattribute or exaggerate the harms involved in being disabled (Mackenzie and Scully 2007). Disability as a mere difference is a powerful counter to demeaning, pitiable depictions of disability as misfortunes and disabled lives as personal tragedies in need of charity from nondisabled others (Stramondo 2010; Swain and French 2000). In response to the characterization that disability makes a person “worse off,” Harriet McBryde Johnson argues,

Are we ‘worse off?’ I don’t think so. Not in any meaningful sense. There are too many variables. For those of us with congenital conditions, disability shapes all we are. Those disabled later in life adapt. We take constraints that no one would choose and build rich and satisfying lives within them. We enjoy pleasures other people enjoy and pleasures peculiarly our own. We have something the world needs (Johnson 2020, 11).

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<sup>6</sup> Robert Sparrow points out that conventionally designated male bodies have notable opportunity limits, like the inability to experience gestation and childbirth and shorter life expectancies. If increasing welfare and opportunities are important moral ends, then we should ensure that people embody conventionally designated female bodies (Sparrow 2010). I do not accept Sparrow’s radical conclusion (indeed, it seems likely that he espouses it to be provocative), but it does highlight the normative implications of elevating moral ends, like open futures, to justify discriminating against atypical embodiments. Elizabeth Barnes also remarks that bodies with certain limited capacities, like the inability to have babies, do not necessarily mean that people in these bodies are automatically worse off (Barnes 2016, 58).

<sup>7</sup> Elizabeth Barnes remarks that being gay isn’t intrinsically bad even though it is a stigmatized embodiment that can bring about serious harm, “Most people hold a mere-difference view of gayness. And yet gay people tend to be at higher risk of depression, anxiety, self-harm, and suicide. It could well be the case that gay people have, *on average*, lower levels of well-being than straight people. But such discrepancy would not be remotely mysterious, nor would it in any way threaten a mere-difference view of gayness” (Barnes 2016, 56).

Since disability is not a state of extraordinary suffering, the mere difference view also pushes back against the representation of disabled people as inspirational. Disabled writer and activist Harilyn Rousso resists this label applied to herself, describing that her life is actually quite mundane, with the exception of living in an ableist context:

Well frankly, I'm not inspirational. I'm damn boring, if you ask me, which you rarely do. I worry about paying the rent, eating too much chocolate, and finding telltale wrinkles—sound inspirational yet?

I'm addicted to *Law and Order*, chardonnay with a nice bouquet, and—here's the biggest confession—McDonald's French fries. And yes, I talk with a disability accent that makes you wonder whether I've had too much of that chardonnay. My walk is less than graceful, not at all helped by those size twelves—I wish they were nines—but surely the *I* word requires more than that.

I know, I know, if you were me, you'd never leave your house and maybe even kill yourself. So I am inspirational because I haven't committed suicide—yet. Although it would appear that those laws are changing, at least for the likes of me. “Assisted suicide”—that's what they call it. “Murder,” “genocide”—that's what many of us with disabilities call it. Pressure to die to convenience others—people who can't imagine having a good life on a respirator or feeding tube (such lack of imagination), people who think such lives are too costly (is it better to invest dollars in wars and prisons?).

I'll tell you why I'm inspirational: I put up with the barriers, the barricades, the bullshit you put between us to avoid confronting something—probably yourself—and still pay the rent on time and savor dark chocolate. Now that takes real courage.

But most of the time, I'm dull, doing my thing and dreaming of the day when all shoe stores carry size twelve (Rousso 2013, 25)

The mere difference view makes room for the idea that disabled people can and do live enjoyable and fulfilling lives. Disability can be a positive individual and collective identity and offer a valued mode of being in the world. It can be a locus for community and culture, politics and activism for greater social inclusivity, and a source of value and meaning (Dunn and Burcaw 2013). As Rousso states, “I can't say I love [having cerebral palsy], but I don't hate it either. It's more a fact of my life that I live with comfortably and that, when the situation arises, I can speak about fairly openly without shame or apology. At times, particularly in recent years, I have come to view my disability as a positive source of identity and community” (Rousso 2013, 5). Crucially, the mere difference view makes it possible for disabled people to conceive themselves in affirmational ways. Disabled writer Eli Clare writes,

Pride is not an inessential thing. Without pride, disabled people are much more likely to accept unquestioningly the daily material conditions of ableism: unemployment, poverty, segregated and substandard education, years spent locked up in nursing homes, violence perpetrated by caregivers, lack of access. Without pride, individual and collective resistance to oppression becomes nearly impossible. But disability pride is no easy thing to come by. Disability has been soaked in shame, dressed in silence, rooted in isolation (Clare 2015, 107).

Although the mere difference view opposes the idea that disability is inherently or automatically bad, it does not entail that disability is always a positive trait.<sup>8</sup> Rather, the value of disability should be left open-ended and dependent on other contingent factors. The mere difference view recognizes that not all disabled people, such as those who acquire a disability later in life, will read their disability in non-tragic terms. Rather, it challenges the view that disability can only be read rationally as a personal tragedy. As a type of embodiment, there can be certain deficits in experiences and options attached to disability, but these losses do not justify the view that disability itself is a morally problematic type of embodiment. Barnes makes a useful distinction between *global bads* and *local bads* (Barnes 2016, 80). By *global bad*, Barnes refers to things or properties that are overall bad for an individual irrespective of context. But things or properties could also be *local bads* such that they are bad for an individual when considering additional contingent factors that make up their circumstance. The mere difference view could admit that disability can be a disvalued embodied form for an individual person, but not because disability *in se* is a detriment, but because that individual may be situated in ways that make disability an undesirable embodiment. My dissertation will take advantage of this subtle feature of the mere difference view when engaging with the justice of subsidizing medical care to treat and prevent disability. I will be addressing the following question: in what ways could disability be the kind of “local bad” that could generate demands of justice for the public funding of medical care and research for treating and preventing disability, while still accepting and promoting the mere difference view?

### 3.2 Defining Disability as ‘Rule-Based Solidarity’

The mere difference view is meant to capture and validate the embodied experience and non-tragic identities of disabled people as represented and amplified in disability rights and pride movements, where disability is not a trait that automatically compromises valued aspects of a person’s life but is rather a minority body that is unjustly marked for social discrimination and marginalization. This alludes to another distinctive feature of the mere difference account. It defines disability according to the perspectives of the disability community and the disability rights and pride movements, as opposed to the prevailing scripts in medical science and dominant culture as pathology or degenerate embodiments. The mere difference view appreciates disability as a social identity that organizes disabled publics. The term carries a social function among disabled publics, which is to

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<sup>8</sup> Barnes denies what she calls the “Magneto View” of disability, which is the view that “disability is the kind of thing that by itself or intrinsically makes you *better off*” (Barnes 2016, 69, author’s italics).

ground solidarity and mobilize collective actions of resistance against their shared oppression. As Barnes points out, “Although [disabled people] had a strikingly heterogenous range of physical conditions, they perceived a commonality in how those physical conditions were stigmatized” (Barnes 2016, 46). This follows Sally Haslanger’s ameliorative approach to defining social categories, which takes certain concepts to be tools to serve an important social purpose (Haslanger 2000; Barnes 2016, 39-43). The mere difference view embraces this pragmatic understanding of disability, redefining disability according to the underlying terms set by the disability rights and pride movements for the purpose of solidarity and social justice for disabled people.

Yet, the mere difference view, at least on Barnes’ account, is more nuanced than the simple definition that disability is whatever properties the disability community says is a disability. Such a definition would be susceptible to charges of arbitrariness and misguided infallibility of the disability community and movements (Campbell and Stramondo 2016). Rather, the mere difference view considers any property as a disability when such identifications adhere to the underlying rules that have, so far, shaped the judgments of solidarity and commonality among diversely embodied people that so far make up the disabled public. Barnes puts forward the following account of what it is to be (physically)<sup>9</sup> disabled:

S is physically disabled in context C iff

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

According to this account, the disability rights movement determines not necessarily which properties should be included as a disability but the norms that guide or govern its judgements. This leaves room for the disability community to make mistakes on who they choose to include or exclude because of

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<sup>9</sup> In her articulation of the mere difference view, Barnes explicitly restricts her analysis to physical disabilities, (Barnes 2016, 3-5). One reason is that much of her defense of the mere difference view rests on the first-person testimony of disabled people. Psychological and cognitive disabilities raise complications since these forms of disability are often considered to be the kinds of conditions that undermine the reliability of testimonies of those who embody such conditions. She leaves open the possibility of extending the mere difference view to psychological and cognitive disabilities. Philosophers, such as Chris Kaposy, extend the mere difference view to people with intellectual disabilities, like people with Down Syndrome, appealing to the testimonies of both them and their significant others (Kaposy 2018). In this dissertation, I am also inclined to extending the mere difference view to include people with psychological and cognitive disabilities, given first-person testimonies. Many people in those embodiments do speak clearly for themselves. Examples include Elyn Saks, *The Center Cannot Hold: My Journey Through Madness*; Esmé Weijun Wang, *The Collected Schizophrenias: Essays*; Jason Kingsley and Mitchell Levitz, *Count Us In: Growing Up with Down Syndrome*; and Michael Bèrubè, *Life as Jamie Knows It: An Exceptional Child Grows Up* (Saks 2008; Wang 2019; Kingsley and Levitz 2007; Bèrubè 2016).

their embodied traits, as well as avoid charges that their judgments are groundless. This is an important procedural constraint because like other socially defined publics, disabled publics are influenced by biases that ought to be checked.<sup>10</sup> Thus, disability is “all and only the things that the disability rights movement ought to consider as things they are promoting justice for—it is rule-based solidarity among people with certain kinds of bodies (Barnes 2016, 46).<sup>11</sup>

### *3.3 Mere Difference View versus the Social Model*

The mere difference view is what Barnes describes as a *moderate social constructionist* account of disability (Barnes 2016, 38). That is, disability is socially constructed in that the disability rights movement determines what *ought* to be the properties for the status of being disabled, as elaborated in section 3.2. To be disabled is to have an embodied property that the disability rights movement decides to destigmatize and promote justice for. Yet disability is also about objective embodied forms and experiences, comprehending the embodied properties designated as disability as a way of having a minority body and not as a deficient or inferior body, as elaborated in section 3.1.

The characterization of the mere difference view as a moderate social constructionist account of disability is made clearer when comparing it to another prominent account of disability: the *social model* of disability (Oliver 1996). The social model was developed in response to the medical model of disability, which interpreted disability as a biomedical disorder or pathology. It narrowly focused on the body as the locus of disadvantages experienced by disabled people, interpreting the social inequalities between disabled and non-disabled publics as fundamentally biological. The social model refocuses the concept of disability away from bodies and towards theorizing about social norms,

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<sup>10</sup> For example, Licia Carlson illuminates how the disability community also grapples with social hierarchical thinking, where certain persons are devalued or otherized on the basis of embodying certain kinds of disabilities, such as intellectual disabilities (Carlson 2010).

<sup>11</sup> There are still fair criticisms to grounding the meaning of disability in the authority of the disability community. For one, the move to appeal to the underlying norms that guide the collective decision-making of the disability rights and pride movements, and not the collective decisions themselves, as the standard for which to judge whether an embodied property should be regarded as a disability still does not avoid the circularity problem (Campbell and Stramondo 2016). I do not have the space to provide a robust defense to these worries, but the success of this criticism, I believe, depends on a variety of factors, including how one evaluates immanent, casuistic-style reasoning and deliberation. I take Barnes’ rationale as exemplifying casuistic-style reasoning, or reasoning that extend from shared norms and a battery of paradigmatic cases. Such communal forms of deliberations will always have the risk of who and what is being is being excluded from consideration, but this is unavoidable if we reject the idea that disability is a natural kind that can be discovered through transcendental reasoning. As Beaudry surmises, it may be “the best available way to counterbalance the testimonial injustice that paradigmatically ‘disabled people’ suffer from” (Beaudry 2021, 13).

relations, and structures that create inequalities of opportunity. In this way, the social model offers a social or structural concept of disability, where it conceptualizes the “disability problem” not as a medical problem as presented in the medical model, but rather as a social problem. The deleterious effects of disability are due to structural, environmental, and attitudinal barriers in a society organized around the undue valorization of nondisabled embodiments. Wheelchair users are incapacitated because architectural spaces are not designed in ways that support their mode of mobility, like lack of wheelchair ramps and elevators. Deaf people are substantially limited by what Neil Levy calls our “logocentric culture—one which is centred around the voice. The deaf will always be cut off from the buzz of conversation, always restricted to a narrower range of jobs, always slightly alienated from the mainstream of political, social, and cultural life” (Levy 2002, 284). Thus, the disadvantageous effects are not from a biologically defective embodiment, but from unjust marginalization and discrimination. The social model is predicated on the mere difference view in that atypical forms of embodiment that are typically described as disabilities are not necessarily bad, but it is primarily an understanding of disability that emphasizes the social conditions that enable and constrain the freedom and well-being of disabled persons.

The mere difference view, on the other hand, is mainly about disabled bodies themselves with respect to how they should be generally understood and valued. It focuses on the phenomenological dimensions of disability as lived embodiment, defining disability in terms of how it is experienced by disabled people and how it contributes to their sense of self and meaning to their lives in all their diversity.

The social model has often been criticized as invisibilizing disabled bodies, obscuring ableism from other types of injustices, like racism and misogyny, since disability is framed almost exclusively in terms of socially produced inequalities without any reference to the kinds of bodies that mark them for unjust social treatment (Barnes 2016, 27). Thus, the social model is sometimes described unattractively as a disembodied account of disability.<sup>12</sup> For example, Carol Thomas argues that the social model fails to recognize what she calls “impairment effects,” which refer to how disabled embodiments, in themselves, could lead to restrictions of activity (Thomas 1999). This is one of the motivations for developing the mere difference view: to refocus disability back to embodiments but

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<sup>12</sup> Liz Crow, for example, has been critical of the social model, even while recognizing how the social model has benefitted the disability community. She states, “I don’t think it is an exaggeration to say that the social model has saved lives” (Crow 1996).

not in ways that describe disability as deficiencies in the body. Although the social model is limited, I prefer to think of the social model as complementary to the mere difference view rather than a competing account. The social model is still a useful interpretative frame to understand the structural dimensions of disability by framing disability in terms of disabled people's relations to power, opportunity, and resource distribution. The mere difference view highlights a different sort of relation, between disabled people and their own embodiments. This is all to say that the nature of disability is a complex, multi-faceted phenomenon and the mere difference view and the social model articulate different facets of disability. Which account of disability should be used depends on the kind of analysis we would like to do for purposes of addressing a particular question related to disability—whether it is about social structures themselves and how they shape the freedom and flourishing of disabled people, or about the lived embodiments of disabled people while embedded in social settings that shape their opportunities and constraints on account of how they are embodied.

### *3.4 Mere Difference View as an Expression of Inclusion and Testimonial Justice*

The mere difference view should be taken seriously over conceptions of disability as bad difference because it exemplifies the diverse first-person accounts of members of disabled publics, especially narratives that affirm their disabled embodiments as valued modes of being and important components of their identity. The mere difference view appeals to the perspectives of disabled publics because it is important to include them in the participatory process of constructing the public meaning of disability, especially given that they will be subjected to such interpretations. Also, disabled publics are regarded as occupying an epistemically advantageous position to the question of what it is like to be disabled. Given their intimacy with disability, disabled people are better situated to evaluate disability as a lived embodiment. As Catriona Mackenzie and Jackie Leah Scully point out, our moral imagination and the assumptions and inferences we draw from them are constrained by our specific embodied experience. For this reason, disabled people should be taken as reliable and trustworthy sources about such matters, as opposed to the limited moral imagination and presumptions of nondisabled people (Mackenzie and Scully 2007). Thus, any conception of disability ought to integrate or be properly responsive to the testimonies of disabled publics. The mere difference view, in this sense, is an expression of upholding testimonial justice by recognizing disabled publics as valued contributors, if not privileged knowers, to the understanding of disability. The mere difference view incorporates the personal narratives of members of the disability community, the rich representations

of disability in disability culture, and the destigmatizing countervailing accounts of disability expressed forcefully in disability rights and pride movements. Many disabled people regard disability, not as a personal tragedy and deficient mode of existence, but as a positive identity and alternative way of being in the world that offers its own unique benefits (French and Swain 2000; Garland-Thomson 2012; Bauman and Murray 2014).<sup>13</sup> This, in turn, interprets the prevailing tragedy, bad-difference conceptions of disability as expressions of testimonial injustice since they discount testimonies of those who are stigmatized but whose perspectives ought to be most prioritized.

In this section, I summarized the mere difference view of disability, elaborating its distinctive features, and how it is distinct from other accounts of disability, like the bad difference view and the social model of disability. I also argued that the mere difference view ought to be taken seriously, especially over alternative bad difference accounts, since it takes seriously the perspectives of disabled publics and their broad-based efforts to destigmatize disability in the reconstruction of how disability should be understood. In the next section, I will consider common objections to the mere difference view and provide responses to them to defend the plausibility of this account of disability.

#### **4. Common Objections to the Mere Difference View**

Many philosophers want to deny the mere difference view, especially those who want to maintain the view that disability is a bad difference. In this section I briefly consider and reject four such arguments.

##### *4.1 Is Disability Really a Bad Difference?*

The mere difference thesis might be denied on the grounds that the properties typically described as disability are, in fact, detriments to valued aspects of human life. Guy Kahane and Julian Savulescu raise this objection, arguing that the plausibility of the mere difference view depends on

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<sup>13</sup> One example of how disabled embodiments could expand a bearer's range of opportunities and experiences is the phenomenon of "deaf gain". *Deaf gain* refers to the cognitive, creative, and cultural gains and opportunity benefits that result from deaf embodiment (Bauman and Murray 2014, xv). There is a growing literature on the phenomenon of deaf gain, documenting the ways in which being deaf generates advantages (Bauman and Murray 2014). This is closely related to Rosemarie Garland-Thomson's case for conserving disability, in which she argues that disability, including deafness, confers unexpected benefits not only to the individuals who embody them but society at large (Garland-Thomson 2012). Framing a disability trait, like deafness, as a gift that presents opportunities for flourishing to its bearers challenges the prevailing understanding of disability as an unfortunate, opportunity-diminishing condition that should be avoided.

whether the benefits of being disabled tends to balance its attendant losses (Kahane and Savulescu 2016, 776-777). For Kahane and Savulescu, the expected gains that may come with disabled embodiments do not outweigh the expected costs, such as lost experiences and opportunities. For this reason, Kahane and Savulescu think the bad difference view, or what they prefer to call the “detrimental difference view”,<sup>14</sup> is a more plausible account of disability (Kahane and Savulescu 2016, 776). They argue,

What is ultimately at issue between the Mere Difference View and the Detrimental Difference View is whether the overall loss of options and overall prospects associated with disability is entirely due to prejudice and, more generally, to injustice. We most certainly don't deny that some of this adverse effect on options is due to injustice and therefore that the prospects of disabled people could, and most certainly should, be better than they actually are. But a great deal of this loss of options cannot, we believe, be traced to prejudice or other forms of injustice (Kahane and Savulescu 2016, 777).

That is, disabled embodiments generally promise forms of life that are worriedly limited in terms of valuable experiences and life prospects, even in conditions of just social arrangements. In this regard, disabled embodiments are morally inferior, or in Kahane and Savulescu's words, morally harmful. This perspective is illustrated in their evaluation of deaf embodiments:

It is arguable that deafness is instrumentally bad in two senses. First, deafness reduces the goodness of a life by preventing access to the world of sound. A deaf person cannot hear music or the human voice. To be sure, in a world without sound, deafness would not be bad. It is the exercise of a capacity to hear that is valuable, not the capacity itself. But the capacity to hear is, obviously, a necessary condition for enjoying those intrinsic goods that are necessarily auditory. And in *our world*, there are plenty of such goods. Second, deafness also reduces the chances of realizing a good life because it makes it harder to live, to achieve one's goals, to engage with others in a world which is based on the spoken word...These difficulties are partly due to social circumstances, but...this needn't mean that they are all due to injustice (Kahane and Savulescu 2009, 49).

There are so many contentious presumptions operating in the background of Kahane and Savulescu's position. This includes their idea of what constitutes a just scheme of resource distribution among publics that are differently embodied<sup>15</sup>; or what kinds of gains and deficits matter or are significant in

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<sup>14</sup> Kahane and Savulescu prefer to call their understanding of disability the “detrimental difference view” as opposed to the “bad difference view” because the latter has the connotation that disability is inherently bad irrespective of context, which they do not accept. Rather, they argue that disability is only bad in relation to the kind of world we inhabit. They consider their view to be contextually responsive, arguing that “most of the conditions commonly described as disabilities are significantly likely to considerably reduce an individual's level of well-being *in the contingent physical and social environment that we actually inhabit*, and this would remain so *even if prejudice against disabled people were removed*” (Kahane and Savulescu 2016, 776, authors' italics). In some ways, their view is agreeable to the mere difference view in that the value of disability is not intrinsic but contingent on other additional factors. It is also, in some ways, agreeable to the social model in that many of the disadvantages of disabled people are socially produced. Kahane and Savulescu just have a more global perspective that disability is overall bad and disagree with the optimistic appraisal of disabled people's lives that is represented by the mere difference view, and they disagree with the idea that any socially produced inequalities are automatically unjust as represented by the social model.

<sup>15</sup> Kahane and Savulescu seem to conceive fair equality of opportunity for disabled people as so rigidly demanding as to be deemed “implausible” compared to aims for justice adopted for other historically marginalized social group,

evaluating the moral status of an embodied condition given that disability traits can create gains that are underappreciated and supposed neutral traits can involve substantial losses<sup>16</sup>; or what kind of world we live in since the one world Kahane and Savulescu refers to in the above quote seems to imply that our world is monolithic that caters to one specific body ideal instead of a more complicated context of richly diverse, overlapping social worlds, including diverse disability communities.

For now, I will simply raise two criticisms to the counterpoint that disability produces surplus badness. I argue that the counterpoint is unreasonably presumptuous, an outcome of misplaced a priori reasoning or limited moral imagination. Although the claim reflects the intuition of many nondisabled inquirers, the judgment that disabled embodiments are, in general, overall bad lacks justification. To make such a claim, especially when it goes against the widely shared perspectives of disabled people, one must provide an objective assessment of disability that legitimately trumps the phenomenology of disabled people. Such an evaluation depends on the ability to predict and take stock of all the experiential and opportunity benefits and costs resulting from disability, which is very dubious, to say the least. Rather, this counterpoint comes off as an expression of stigma of disability, and not as an honest appraisal of the objective consequences of disability. This is especially the case when such claims are propagated in the face of counternarratives by many members of disabled publics that disability is not a personal tragedy but a valued mode of being. It is objectionable to discount the testimonies of disabled people to measure the plausibility of the claim that disability is overall bad. Without independent evidence that outweighs the experience of disabled people, there is no valid reason to think that disability is a categorically or definitively bad state to embody.

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such as gender equality. But even today, the latter is even taken to be too demanding, since pregnant people are still discriminated against in the workplace and arguments are made that accommodating them would be too costly (Kitroeff and Silver-Greenberg 2019). Anita Silvers argues that justice for disabled people does not need to involve social accommodations that are unbearably costly, pointing out, “The UN Convention on the Rights of People with Disabilities (CRPD), and the Americans with Disabilities Act (ADA) that preceded it, are products of a participatory process that included many individuals with disabilities. Far from demanding radical leveling down, erasing all differences in prospects, and ignoring immense costs, the documents these processes produced express a standard for the pursuit of justice for disability in terms of reasonably achievable progress” (Silvers 2021, 37).

<sup>16</sup> All types of embodiments involve opportunity and experiential benefits and costs. But for many philosophers, like Kahane and Savulescu, it seems like certain kinds of benefits and costs are weighed more than others. This requires further argumentation for why a certain range of life options are more valuable than other kinds of ranges. Furthermore, such a perspective underappreciates, if not neglects, the ways in which disability could provide valued opportunities and experiences to those with such embodiments. Refer to footnote 13 for more details about deaf gain.

#### 4.2 *Are Disabled People Reliable Sources?*

A second objection relies on the notion of insincerity and adaptive preferences. As noted in section 3.2, the mere difference view defers authority to the disability community and its rights and pride movements in constructing the public meaning of disability. The mere difference view comprehends disability in neutral, non-tragic terms to reflect how many members of the disability community hold a positive view of their quality of life with disabilities and even regard their disability as a valued component of their identity for which society ought to be more inclusive to such embodied differences. But one could argue that our definition of disability does not need to be accountable to disabled publics since they are unreliable sources. Greg Bognar raises this point:

[I]t may be that it is the people with disabilities who do not consider their condition a harm that make the erroneous value judgment. On most plausible accounts of well-being, you can be mistaken about your own well-being. So even if every person with disability considered their disability no harm, that would still not get you to the mere difference view—unless you also assumed that their evaluations are to be trusted. In the parlance of the social sciences, it would have to be the case that their evaluations are both reliable and valid (Bognar 2018, 46).

There are two common but problematic reasons for thinking that disabled people are unreliable sources (Goering 2008). First, it is claimed that disabled people may simply be in denial about the unvarnished facts of being disabled when they express an affirmative attitude towards their own disability. Disabled editor Carroll Lisby expressed frustration with how disability pride advocates have characterized disability as a neutral or even positive trait, taking particularly umbrage to disability magazine publisher Cyndi Jones. Lisby writes in *The Tampa Bay Times*, “From a moral or ethical viewpoint, being Jewish, black or female is a neutral trait; it's not necessarily good or bad. But despite what Jones says, being disabled is bad. There is no virtue in being disabled. For anyone to suggest that someone's having to use braces and crutches to get around—rather than walking in a normal manner—is good is utter foolishness” (Lisby 1995). In the same article, Lisby also questions the sincerity of Jones’ claim that she would refuse a “magic pill” to cure her polio-induced paralysis if one was made available, “As for that magic pill, if you will let me know where and when it will be available, I promise you that there'll be a mass of humanity like you've never seen before waiting for an opportunity to take it. I'll certainly be there. And I won't be surprised if Jones is there, too” (Lisby 1995). Lisby strongly thinks that disability-positive testimonies are disingenuous and are simply expressions of unjustified optimism to compensate for disabled people’s low self-esteem resulting from longstanding societal mistreatment.

Second, it is claimed that disabled people may have adapted their preferences and expectations to accept their disabled embodiments. Yet these preferences are problematic because they have been adjusted in response to circumstances that are suboptimal or objectionable. In philosophical parlance, this is called adaptive preference, which refers to preferences for things that are morally inferior or unjust, developed in response to their morally objectionable circumstances. The idea of adaptive preferences is to capture the problem of enslaved persons whose preferences are adapted so that they approve their subjugation or abuse victims wanting to remain in their abusive relationships. The content of these preferences and the circumstances that shaped them are seriously problematic. Thus, the testimonies of people with adaptive preferences should be legitimately discounted. Many philosophers extend this reasoning to the positive testimonies of disabled people, arguing that such testimonies ought to be discounted because such preferences are adaptive to states of affairs that are themselves bad.

I have two responses to the charges of insincerity and adaptive preferences as rationales to doubt the credence of disabled people's positive testimonies. First, we should be immediately wary of such strategies to "gaslight" or undermine a person's credibility by offering armchair diagnoses of their purported psychology or motives. Sara Goering surveys the many reasons why disabled people have positive, or least relatively neutral or non-tragic, attitudes towards their disabilities, such as how such characteristics are important components to their identity and how they structure their social relations and their interactions with the world in ways that they deeply value (Goering 2008). In taking stock of these reasons, Goering states,

The main point here is that the experience of living with an impairment is not what many non-disabled people imagine it to be, and it does not leave most disabled people pining to have their bodies normalized. When they claim that living with an impairment is fine or would be if appropriate social and attitudinal changes were implemented, they aim to overcome the presumption about its inevitable badness, or the reasons for the associated disadvantages (Goering 2008, 129).

Without proper justification, rationales that disabled people are insincere or unknowing victims of adaptive preferences would be extremely patronizing to disabled publics and would count as instances of testimonial injustice (Goering 2008, 132-133; Barnes 2016, 135-142). These are dangerous rationales that lead to the nonrecognition of disabled publics. One could interpret disability-positive testimonies as expressions of insincerity or adaptive preferences, but the question is: should these interpretations be equally considered with or privileged over the first-person accounts of disabled people who have direct experience of their disability as a lived embodiment? It might be justified to discount the positive testimonies of disabled people if it is possible to argue that disability itself is bad or suboptimal without

any appeal to the experiences of disabled people. Disability-positive testimonies would then be understood as unresponsive to the objective and subjective realities of disability. But as shown in section 4.1, justifying the bad-difference view is not promising, especially if such arguments appeal to bare intuitions, limited moral imaginations, or exclusionary ideals<sup>17</sup> of nondisabled people, which we are even more warranted to discount as unreliable and untrustworthy (Mackenzie and Scully 2007). Thus, there is no overriding reason to think that disability-positive testimonies are invalid or less trustworthy and that we should instead appeal to other sources, like the intuitions of non-disabled inquirers. If one wants to uphold the charge that such testimonies are insincere or outcomes of adaptive preferences, then one must provide an independent argument for why disability is overall bad while not resorting to untrustworthy moral intuitions of nondisabled publics. I am quite skeptical that such an argument could be provided.<sup>18</sup>

Second, such arguments are morally risky. Jason Marsh argues that the kind of reasoning to discount the affirmational perspectives of disabled people towards their life with disability could also be used to discount the optimistic perspectives of nondisabled people towards their own lives when responding to radical pessimists, like David Benatar (Marsh 2021, 319-320). Benatar argues against the inherent goodness of human life, using similar lines of reasoning that nondisabled philosophers have used to characterize disabled life, claiming that people's self-assessments of their own well-being are

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<sup>17</sup> Here, I am thinking of how certain capabilities are deemed essential for the flourishing of human life, like sight, hearing, and bipedal mobility. Thus, the lack of these traits is interpreted as automatically diminishing a person's wellbeing or autonomy. These narrow, ableist understandings are often reflected in versions of the capabilities approach or objective list theories of well-being that take as given the importance of these sensory or motor capacities to have access to the possibility of living a flourishing existence. Martha Nussbaum, for instance, back pedals a bit on the necessity of the five senses as capabilities, opting instead for a more general claim about senses, imagination and thought (Nussbaum 2007). But Anita Silvers and Mark Stein expressed skepticism that capability theory could be as inclusive towards disabled people as its proponents hope (Silvers and Stein 2007).

<sup>18</sup> One example to illuminate the difficulty of constructing an argument that disability is an objectively negative embodiment even though disabled people subjectively judge their disabled embodiments in positive terms is Ron Amundson's "happy hick" example:

People who live in rural areas are called *hicks* by some urban people who feel themselves to have superior lives. (Why would anyone give up the symphony just to breathe clean air?) The happiness of hicks is regarded as merely subjective by the sophisticates who judge them. Some of the more reflective sophisticates (some college professors, for example) might realize that their feeling of [quality of life] superiority over hicks is not really an objective judgment trumping a subjective judgment. It is merely one person's subjective judgment clashing with another person's. The Happy Slave example illustrates the coherence of objective judgments on the quality of other peoples' lives, using a plausible case of a correct judgment. But it gives us no hints how to tell correct judgments from mere prejudices. The Happy Hick exemplifies mere prejudice in a logically similar judgment (Amundson 2005, 112).

Amundson's point is that it is extremely difficult to identify when a disagreement with a person's positive subjective judgement about their own circumstances is an expression of insincerity or adaptive preferences or undue bias.

unreliable and the negative aspects of human life overwhelm its positive aspects. For example, here is a partial description of Benatar's outlook on human life:

Even in good health, much of every day is spent in discomfort. Within hours we become thirsty and hungry. Many millions of people are chronically hungry. When we can access food and beverages and thus succeed in warding off hunger and thirst for a while we then come to feel the discomfort of distended bladders and bowels. Sometimes relief can be obtained relatively easily, but on other occasions the opportunity for (dignified) relief is not as forthcoming as we would like. We also spend much of our time in thermal discomfort—feeling either too hot or too cold. Unless one naps at the first sign of weariness, one spends quite a bit of the day tired. Indeed, many people wake up tired and spend the day in that state (Benatar 2015, 45-46).

Benatar sums up his characterization of human life in the following way, “Optimists will very likely suggest that this is a one-sided picture—that lives typically contain not only bad but also good. However, while it is true that lives are not usually unadulteratedly bad, there is much more bad than good even for the luckiest humans. Things are worse still for unluckier people, many of whom have almost nothing going in their favor” (Benatar 2015, 48). This sounds quite like how philosophers, like Singer, Kahane, and Savulescu, pessimistically describe life with a disability. If such skeptical reasoning is objectionable when it is applied to nondisabled life, then it should be objectionable when applied to disabled life.

Another moral risk that Marsh raises, which I take to be more serious, is that such reasoning could be easily patronizing and maintain the second-class status of a historically oppressed public by denying them the opportunity to shape their own public image. Claims that the judgments of disabled people are compromised in some way when they express an optimistic attitude about their disabled embodiments risk the continuation of silencing and gas-lighting disabled publics, which further stigmatize them. In the face of uncertainty and given the moral risks involved, we have strong reasons to trust the perspectives of disabled publics.

#### *4.3 Are All Disabilities Mere Differences?*

A third objection to the mere difference view is that it commits a faulty generalization. The mere difference view states that all embodied forms and characteristics in the category of disability are not intrinsically morally negative conditions. But for some philosophers, this seems false. Greg Bogner, for example, points out that there are bodily conditions that are described as disability that cause unbearable pain and hasten death such as like Tay-Sachs disease. These kinds of disabilities are “so bad that life with them is plainly not worth living” (Bogner 2016, 46). Thus, the mere difference view does not properly account for the qualitative differences among various physiological and

psychological states that are classified as disabilities. There are conditions that clearly lead to overwhelming harms to those embodying them and therefore, they should not be characterized as benign human variations (Campbell and Stramondo 2016).

I have two responses to this objection. First, even though there are harmful conditions that are widely regarded as disabilities, it does not mean that they should be regarded as disabilities if we are using the term to describe the atypical embodiments of people that are represented in the disability rights and pride movements. Again, the mere difference view reconceptualizes disability in ways that capture the embodied experiences and non-tragic identities of many disabled people. In the push to destigmatize disabled publics, the reconstruction of the meaning of disability as mere difference may lead to the exclusion of certain embodied properties from the category of disability from which they were once included. Even though an adequate account of disability needs to account for the paradigmatic cases, it does not need to match up exactly to our everyday, folk understanding of disability. It is unsurprising that certain conditions would no longer be deemed disabilities, since folk understandings of disability are entangled with notions of pathology. In response to Bognar, the undeniably tragic biomedical conditions that he considers to be disabilities and therefore counterexamples to the mere difference view may not actually belong in the class of disability at all. Tay-Sachs disease, for instance, might be better understood as an illness than a disability. There may be physiological and psychological conditions that many people outside the disability rights movement identify as disabilities, but if the disability rights movement is not pushing for such properties to be depathologized, then they do not qualify as disabilities.

Second, we must be wary of some of our pre-theoretic judgments of what we deem to be “undeniably” harmful embodiments, especially from the large group of people who are nondisabled. For many philosophers, the paradigmatic forms of disability are obviously bad. For example, Peter Singer argues:

In considering these issues, we need to avoid the facile retort that disability is a social construction. Of course there are ways in which society makes life needlessly difficult for people who are unable to hear or to walk. But no matter how much society changes, those with disabilities will often be unable to do things that many of us want to do. If you are deaf, you cannot listen to a thrush singing in the spring, to Mozart, or to the murmur of the waves on a distant beach. If you are paralyzed from the waist down, you cannot go backpacking in the wilderness or run barefoot across the beach into the sea. Maybe not everyone wants to do these things, maybe they don't add all that much to the quality of life, but don't we prefer to have the option? No matter how good society is at providing access for people in wheelchairs, how many of those now in wheelchairs would refuse a simple, inexpensive, no-side-effects cure for their condition? (Singer 2001, 56).

For Singer, disability as a morally undesirable property is a pre-theoretical given and thus, accounts of disability that do not accommodate these moral perceptions from non-disabled inquirers are immediately implausible. I am not necessarily disagreeing with Bognar and others who argue that there are some forms of embodiment that are morally tragic or pathological. I am simply rejecting types of reasoning that overly rely on bare intuitions, determining audaciously the moral dimensions of certain embodiments without engaging robustly with those with such embodiments. Such reasoning has a disturbing history, and as pointed out in section 3.3, the mere difference view is the product of philosophers and activists trying to be appropriately responsive to this history.

#### *4.4 Do All Disabled People Think Disability is a Mere Difference?*

A fourth objection to the mere difference view is the recognition that not all members of disabled publics regard their disability as a mere difference. Empirical studies show that many disabled people are subjectively satisfied with their disabled life, which has been popularly called the “disability paradox” (Albrect and Devlieger 1999). But there are disabled people who do perceive their disability in negative and tragic terms, such as the perspective of Carroll Lisby, whom I quoted earlier. For Lisby, being disabled is bad because such embodied circumstances involve significant losses in experiences and opportunities. Contrary to the feelings that many disabled people have about their disability, Lisby would take the magic pill to cure their disability if such a thing existed and surmises that there are many other disabled people who would do the same (Pulrang 2019; Lisby 1995). There is no reason to privilege the perspectives of disability rights and pride contingents in the disability community over other contingents, like disabled people who desire to be nondisabled. The variegated perspectives of disability among disabled publics could be used as a reason to challenge the broad construal of disability as mere difference.

I have two responses to this objection. First, it is worth noting that disabled people could be susceptible to internalized oppression as a result of concrete external oppression. This could explain why some disabled people devalue their own embodiments. There is a rich discourse on how members of oppressed publics, like disabled people, could suffer from false consciousness, accepting the master narratives of dominant publics that interpret certain types of embodiments as morally inferior. In important ways, this is an iteration of the adaptive preference argument, which would make this argument susceptible to the criticisms I put forth in section 4.2. For this reason, I do not put too much weight to this response, but I raise it as a possible consideration to temper the immediate appeal of

disability-negative testimonies from disabled people as positive reason to dismiss the mere difference view.

Second, the mere difference view builds in these variegated perspectives about disability from disabled people. As noted in section 3.1, the mere difference view leaves the value of disability open-ended and dependent on other contingent factors. What the view challenges fundamentally is the understanding of disability as an objectively detrimental form of embodiment. Thus, it validates the perspectives of disabled people who regard their disability as a valued mode of being and the perspectives of disabled people who disapprove of their disabled embodiment. Their differences are shaped by additional factors, such as their values and life plans. What motivates the mere difference view are the rich, diverse experiences of being disabled, with a large contingent of disabled people understanding their disability in positive or non-tragic terms. The validity of the mere difference view does not depend on a universal acceptance of disability as a neutral trait, but rather it is responsive to the diversity of perspectives and experiences among members of disabled publics. In other words, it is not a bug, but a feature.

In this section, I considered and responded to four prominent objections against the mere difference view. There are several other objections that are worth addressing, but I wanted to focus on the objections that are often employed to bolster the bad difference view. In the next section, I raise another prominent objection against the mere difference view, arguing that if the mere difference view is taken seriously, then it would lead to counterintuitive and troubling implications, including in the realm of healthcare justice.

## **5. Taking the Mere Difference View Seriously**

If the mere difference view of disability is correct, then this ought to be reflected in our institutional practices, such as our healthcare institutions, as a requirement of justice. This includes severing the conceptual linkage between disability and notions of pathology or moral tragedy. Although there are unique medical issues connected to disability, the holder of the mere difference view rejects disability itself as a proper object of medical care. Thus, the social disadvantages and distress that typify the experiences of disabled people should not be addressed as medical issues, where disabled embodiments would be interpreted as the source of the underlying problem that needs to be changed. Rather, the disadvantages associated with disability should be addressed as social issues,

where the underlying problem is a morally defective social environment, including institutional and attitudinal discrimination and maltreatment, that negatively impacts the life prospects of disabled people. Although it is inappropriate to draw a strict separation between the healthcare and social realms,<sup>19</sup> many of us think that certain social issues, such as unjust discrimination and lack of recognition respect, should not be addressed by resorting to medical interventions to ensure that people avoid having embodied properties that would make them targets of injustice. Indeed, when disability is treated as a medical issue, it is often because we are failing to listen to the testimonies of disabled people that it is not (Goering 2008). In respecting diversity and disabled publics, we want to avoid the medicalization of certain social problems, where we unreasonably rationalize the social inequality of certain social groups as being natural to their type of embodiment. Thus, we want to avoid addressing social disadvantages stemming from undue marginalization of certain populations based on their bodily characteristics by removing these characteristics via medical intervention, especially when such differences—in this case, atypical embodiments—are not only morally neutral from the standpoint of justice but integral to the identity of citizens. This is analogous to the ways in which we should address racism. We should not address such injustices by eliminating differences in skin color that mark out certain people for social maltreatment. Rather, such injustices should be addressed by altering the racist social context. As with racism, the target of rectification to alleviate the harms of ablesim should be societal change, not changing the atypical embodiments of disabled people.

One deep worry with the mere difference view of disability is that it seems to have objectionable implications in the realm of healthcare justice. For example, if we no longer associate disability with pathology, then the state seems to lack the moral justification to support medical interventions that maintain or restore the non-disability status of citizens who have suddenly become disabled due to some injury or exceptional physiological event or process. Proponents of the bad difference view argue that destigmatizing disability could be dangerous because social support for

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<sup>19</sup> It is worth noting that disability can be associated with a diminished health status due to disabled people being subjected to conditions of marginalization. This acknowledges the social determinants of health, or in the words of Paul Farmer, the “pathogenic role of inequity” (Farmer 2003, 20). I thank Carina Fourie for pointing out the problematic attempt to differentiate health-related issues from broader social issues. Health-related issues are entangled with broader social issues since basic social arrangements have a profound effect on the health of citizens. Returning to the issue of disability and its possible connection to ill health, it might be the case empirically-speaking that disability is associated with lower health outcomes. But the linkage would be merely contingent on the type of social environment that is impacting significantly the health of disabled people, and not a necessary property of disability itself. Also, in such cases, it seems inappropriate to treat the disability to relieve illnesses brought about from the undue social stressors of being disabled.

medical programs to prevent or cure disability is premised on the idea that disability is a condition that is rational to avoid (Harris 2001). The supposed implication of construing disability as normatively neutral is to restrict what forms of medical care are resources citizens are legitimately entitled to receive from the state. If disability is not a harmful condition, then there are apparently no moral grounds to support the research and provision of medical resources to prevent, reverse or remove disability. For numerous philosophers, the absurdity of this conclusion supports the notion that disability should not be regarded as a mere difference but a detrimental one (Harris 2001, Kahane and Savulescu 2016).

If one holds the position that it is permissible, if not obligatory, for the state to support medical programs to treat and prevent disability, then it raises the challenge to the proponents of the mere difference view of how to justify this position without appealing to the idea that disability is, in fact, a harm. Does the mere difference view of disability necessarily prevent the possibility of generating claims of justice against the state to provide its citizens with a robust set of medical care and resources to prevent them from acquiring a disability or remove disability when it is acquired, say, by some injury or physiological event or process?

I take up this challenge in the next chapter. I will argue that the mere difference view is still consistent with the position that non-disabled citizens have legitimate claims against the state to be provided with medical care and resources to maintain their non-disability status from the prospects of becoming disabled. My position will be built on my conceptualization of the body as an important *context of choice* for autonomy. That is, the body is not only crucial to autonomy in the sense that it enables embodied agents to act in the world, but also the body enables us to pursue a range of intelligible life options that are meaningful with respect to our identity, which is itself shaped and sustained by our embodiments. Dramatic and abrupt changes in a person's embodiment, even though the new embodiment may not be categorically bad, can be inimical to the autonomy of the modified individual by upending their context of choice. If the state has a responsibility to support the autonomy of its citizens and certain physiological states are important conditions for each individual's autonomy—such as providing a stable context of choice—then the state has a moral obligation to secure the physiological conditions for autonomy. For this reason, treating or preventing disability through medical interventions may be justified as a practice of *autonomy-maintenance*. I hope to show that this account both contributes to the destigmatization of disability while providing justification for a robust set of entitlements pertaining to the provision of healthcare resources and services grounded in the obligation of the state to help citizens remain as agents.

## 6. Conclusion

In this chapter, I summarized the mere difference view of disability and argued why we ought to take it seriously. The mere difference view is a re-conceptualization of disability from the prevailing account that disability is a class of properties that are harmful to those who embody them, an account that has been called the bad difference view. The mere difference view is a countervailing account that disability is a morally neutral expression of human diversity, motivated by the perspectives of disabled publics and disability rights and pride movements that disability is an atypical, non-tragic mode of being in the world in which people could derive a deep sense of meaning, community, and self from this embodied context. The mere difference view appreciates the conceptual work of disabled publics to reclaim the meaning of disability and revise it in ways that reflect their experience with disability as a lived embodiment and social marker. If this is the most reasonable conception of disability, then it ought to be reflected in our basic institutions, including our medical institutions, as a requirement of justice. In defending its reasonableness, I addressed four prominent objections against the mere difference view, focusing on the kinds of objections that are often raised to reinforce the bad difference view. But in thinking about the ways in which the mere difference view might reform structural arrangements and institutional practices, it raises a prominent worry that the mere difference view implies institutional reforms in the medical setting that are deeply troubling. One such worry is that if the mere difference view is the correct view, then it implies that the state is not obliged to, and maybe even be prohibited from, providing and subsidizing medical interventions to treat and prevent disability, such as non-disabled people acquiring a disability due to an accident or an exceptional physiological event or process. In the next chapter, I will address this objection.

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## Chapter 2: Autonomy and Embodiment as a Context of Choice: The Justice of Medical Interventions to Treat and Prevent Disability

### 1. Introduction

The nature and value of disability is a vexatious issue. Contemporary philosophical discourse on this topic is often approached in terms of whether disability ought to be regarded as a *bad difference* or a *mere difference*. These terms, introduced by Elizabeth Barnes in her influential book, *The Minority Body*, signify the normative status of disabled embodiments with respect to important dimensions of human life, such as well-being and autonomy.<sup>20</sup> The *mere difference view*, briefly put, reconceptualizes disability as a morally neutral, though atypical, human trait. As elaborated in the previous chapter, its main claim is that disability is not a categorically or definitely bad state to be in, but simply another variation of human diversity, analogous to race, sex, gender, ethnicity, and sexual orientation. Holders of the *bad difference view*—which is the more prevalent view that disability is a bad or harmful state due to its negative effects on those who are disabled—reject the mere difference view as implausible partly due to presumed normative implications that are not only counterintuitive but deeply troubling.

One key objection to the mere difference view is that if disability were mere difference as opposed to a negative condition, then there apparently would not be any legitimate moral claims against the state for citizens to receive medical care and resources to maintain or restore their non-disability status from conditions of disability that might have been acquired through injury or some exceptional physiological process (Buchanan et al 2000, 265). This view was succinctly stated at a biomedical ethics conference that I attended recently, in which an audience member asked in response my presentation that the mere difference view should shape medical practice and notions of health: “so instead of restoring a patient’s ability to walk, we should just build more wheelchair ramps?”<sup>21</sup>

I take up that question here. Does the mere difference view make it unnecessary, or even impermissible, for the state to prevent or remove disability? If disability is no longer associated with

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<sup>20</sup> It is worth noting that Barnes and others usually focus on the relation of disability to wellbeing. Some philosophers devalue disability on the basis of values like autonomy (Davis 2010). I am broadening the notion of “mere difference” to apply to disability’s relation to other moral values, like autonomy.

<sup>21</sup> This question was raised to me at the Biomedical Epistemology and Bioethics Graduate Conference at the University of Miami in 2014. At the conference, I was presenting a paper that proposed a social constructionist account of health that is both responsive to critical disability perspectives and political values central to John Rawls’ framework of justice.

harm or pathology, then, as the argument goes, the state is not obliged to support medical interventions that maintain or restore the non-disability status of citizens who have suddenly become disabled due to some injury or physiological process. For numerous philosophers, this implication is clearly objectionable, and then is taken to support the conclusion that disability should not be regarded as a mere difference but a bad or detrimental one (e.g., Harris 2001; Kahane and Savulescu 2016).

Philosophers of disability have responded directly to this worry (e.g., Barnes 2016; Amundson and Tresky 2008; Silvers 2003). Elizabeth Barnes has argued that there is a morally significant difference between *being disabled* and *becoming disabled* (Barnes 2016, 148). The latter involves transition costs, which are sufficient moral grounds to maintain or restore the non-disability status of citizens. I think Barnes is correct, but it is not immediately clear why avoiding the difficult process of adjusting to a newly acquired disability should rise to the level of being a legitimate concern of justice. There are many other kinds of difficult changes that people go through (e.g., loss of job, a breakup with a romantic partner, etc.), yet these are tolerated as being facts of life and we think state intervention is not justified or even desirable to prevent these changes from happening. Why is not coping, adaptation, and accommodation the most appropriate response to the prospects of becoming disabled?

In this paper, I take seriously the problem of “transition costs” of becoming disabled and take up the task of making sense of why avoiding them is a legitimate end of justice, according to which justice calls for providing medical care and resources to citizens to maintain their non-disability status without resorting to devaluing disability itself. My argument will be built on my conceptualization of embodiment as an important *context of choice* for the activity of self-determination. By *context of choice*, I mean the set of circumstances that pervasively shape our phenomenal world, architecture of choice, and sense of self, which in turn fundamentally shape not only the options and actions available to us, but also the values and beliefs that motivate our choices. In this sense, a style of embodiment is a “context of choice” that not only makes it possible for us to pursue a certain range of life options, but also makes them meaningful to us in relation to our self-conception and our conception of the good. Yet abrupt, dramatic changes in a person’s embodiment, even though the new embodiment may not be intrinsically or definitively bad, can disrupt the autonomy of the modified individual by upending their context of choice. If the state has a responsibility to support the autonomy of its citizens and certain physiological states are important conditions for autonomy—such as providing a stable context of choice—then the state has a moral obligation to secure the physiological conditions for autonomy

through the provision of medical care. Unlike a job or relationship, the immediacy of the body in the way we experience ourselves, as well as the personal ownership of our body, makes the preservation of the body more prior than coping and adaptation. My goal here is to provide a plausible account that contributes to the destigmatization of disability while providing justification for a robust set of entitlements pertaining to the provision of healthcare resources and services.

The paper proceeds as follows. In section 2, I briefly present the mere difference view of disability and how it stands in contrast to the bad difference view of disability. I also discuss the major objection that the mere difference view leads to troubling normative implications in the realm of healthcare justice. In section 3, I elaborate the concept of “context of choice” as a precondition for agency. In section 4, I describe the nature of embodiment, and in section 5, I use the context of choice notion to reconceptualize embodiment as an important context of choice, connecting the relevance of particular embodiments to autonomy. This provides the conceptual resource for justifying the medical treatment of disability, even though it is a mere difference. Maintaining or restoring citizens’ non-disability status is an effort to maintain citizens’ context of choice and, in turn, their autonomy. Then in section 6, I turn to the simple cases, like mobility loss, to put this account into action and illuminate its plausibility in addressing worries that the mere difference view limits our entitlements to certain healthcare resources. I conclude in section 7, by taking stock of the discussion in this chapter, pointing out some limits and worries introduced by my efforts to overcome the objection against the mere difference view, and raising some questions for further consideration.

## **2. Disability as Mere Difference and the Unacceptable Implications Objection**

As elaborated in chapter 1, the mere difference view of disability is an antithesis to the dominant contemporary understanding of what Barnes labels as the *bad difference view* of disability (Barnes 2016). The bad difference view holds that disability is a bad or harmful state to be in due to its negative effects on those who are disabled. The mere difference view of disability denies the bad difference thesis that disability is an overall bad or suboptimal state to be in, and that it is generally desirable to free people of its presence. Instead, the mere difference view presents a neutral conceptualization of disability’s differences. It is a form of embodiment that is neither inferior nor tragic, but simply another varied, affirmative type of human difference. The mere difference view reframes disability in neutral terms, drawing relevant similarities to other acceptable forms of human difference, like race, sex and sexual orientation, where such embodiments may set certain biological

limits in functioning or experiences<sup>22</sup> or have deleterious contingent consequences given the unjust social context<sup>23</sup>, but would not be deemed as categorically or definitively bad states to be in. It challenges negative conceptions of disability by arguing that these representations are inaccurate and unresponsive to the embodied experience and non-tragic identities of disabled people. Disability as a mere difference is a powerful counternarrative to dominant depictions of disability as misfortunes and disabled lives as personal tragedies.

Yet in reconceptualizing disability in ways that dissociate disability from notions of harm or pathology, the mere difference view invites a serious worry that is prominently raised by holders of the bad difference view. Interpreting disability as a harmful biological condition is what justifies subsidizing medical interventions to protect citizens from acquiring it and restoring the non-disability status of those who do become disabled. Yet if disability is no longer associated with harm or pathology, then the state seems to lack the moral justification to support medical interventions that maintain or restore the non-disability status of citizens who have suddenly become disabled due to some injury or exceptional physiological event or process.<sup>24</sup> Allen Buchanan et al argue:

What is striking about the radical disability advocates' critique, then is that...[it] condemns any effort to eliminate disabilities through medical interventions...For if taken literally, the slogan 'change society, not individuals' does not merely insist that we try to make the social world more accessible...it would require accommodating those with impairments rather than using medical science to prevent or correct impairments (Buchanan et al 2000, 265).

The supposed implication of ceasing to treat disability as a medical disorder is to restrict dramatically what medical care and resources citizens are legitimately entitled to receive from the state. If disability is not a bad state, then there are apparently no moral grounds to support the employment of medical technology to prevent, reverse or remove disability. This is an iteration of what Guy Kahane and Julian Savulescu call the *Unacceptable Implications Objection*. (Kahane and Savulescu 2016). Such an implication strikes our moral intuition as seriously problematic, which for Kahane and Savulescu is a strong reason for why the mere difference view is implausible. This very intuition is also built into John Harris'

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<sup>22</sup> Refer to note 6 in Chapter 1.

<sup>23</sup> Refer to note 7 in Chapter 1. Remember, this is what Barnes argues in relation to being gay: the fact that being gay is associated with higher rates of mental health issues does not mean it is intrinsically bad, but on that it is still stigmatized.

<sup>24</sup> Here, the interventions I am focusing on are "medical", which I take to be services and resources provided by healthcare institutions. But the maintenance and improvement of physical and mental health also involve the provision of non-medical resources, such as proper housing, sanitation system, or helmet laws. Although such goods are important to health, I do not consider them to be healthcare resources since they are not the kinds of goods that healthcare institutions are tasked to distribute. But the questions pertaining to the proper understanding of disability and how basic institutions ought to exemplify such an understanding in its practices are not only restricted to healthcare institutions.

conception of disability, defining disability as “a condition that someone has a strong rational preference not to be in and one that is in some sense a *harmed condition*” (Harris 2001, 384, my italics). A “harmed condition” is “one which if a patient was brought unconscious into the accident and emergency department of a hospital in such a condition and it could be reversed or removed the medical staff would be negligent if they failed to reverse or remove it” (Harris 2001, 384). In lieu of this objection, these philosophers conclude that disability ought to be recognized as an adverse condition since intuition and widely accepted medical practice<sup>25</sup> inform us that people generally want to avoid becoming disabled and believe that the state is obliged to remedy or discourage its occurrences, which seems to explain our medical practice and public safety laws.

The Unacceptable Implications Objection is provocative, given its appeal to a widely held intuition about treating disability. Yet I argue that accepting this intuition does not necessarily mean that the bad difference view is correct. Barnes alludes to other reasons that might explain why we find the idea unacceptable, arguing that becoming disabled involves “transition costs.” This refers to the difficult process of adjusting to an unfamiliar state of affairs, in this case, a new form of embodiment. Here, I argue that transition costs are worth avoiding and the state is obliged to help its citizens avoid them because they are costly to our sense of autonomy. To make this argument, I will turn to the notion of “context of choice” as a prerequisite of autonomy and conceptualize embodiment in these terms.

### **3. Context of Choice as a Precondition of Autonomy**

I turn to the notion of “context of choice” as an illuminating frame to conceptualize the nature of embodiment, why we might value our existing embodied forms, and why their stability might rise to the level of being a proper concern of justice. But what does “context of choice” mean and in what ways is it valuable? I draw this concept from Will Kymlicka’s work on the value of cultural membership within the liberal tradition of justice. The notion of context of choice comes into play in Kymlicka’s project to rehabilitate liberal political theory from its reputation of not properly recognizing and respecting distinct cultural communities as having direct moral importance. Liberalism has been prominently criticized by communitarian and feminist critics for developing a theory of justice around

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<sup>25</sup> Again, as argued by Ani B. Satz, our medical practices seem to be oriented around the idea that disability is a bad state to be in. For this reason, she characterizes prevailing medical institutions as practicing a form of negative eugenics (Satz 2020). For greater elaboration on Satz’s view, visit section 2.3 of Chapter 1.

the ideal of an autonomous individual abstracted from their interpersonal relations and social group membership (Wolgast 1987; Friedman 1989). This orientation may generate principles of justice of respect for individual freedom and equality but neglect the importance of existing minority cultures from which agents derive meaning, a sense of self, and the cultural resources to construct a life-affirming narrative. The idea of conserving minority cultures through limiting the freedoms of non-members whose actions might contribute to their deterioration seems to violate the central tenets of liberal individualism.

Kymlicka, who is expressly sympathetic to the claims of aboriginal peoples in North America that their culture be protected by the state, argues that cultural membership is indeed important in the liberal conception of justice. The value of what Kymlicka calls a *societal culture* is linked to the value of personal autonomy, such that a societal culture provides what he calls a *context of choice* that enables those ensconced in its ways to have a meaningful sense of autonomy. The key terms here need unpacking. Here, I will elaborate the meaning of “context of choice” through Kymlicka’s defense of minority rights, arguing that a societal culture enables agents entrenched in its ways to express their autonomy.

Culture is a complex, multifaceted concept whose connotations are rich and often highly contested and applied amply to various social organizations and phenomena. What Kymlicka is interested in is what he calls a *societal culture*, which refers to a “culture which provides its members with meaningful ways of life across the full range of human activities, including social, educational, religious, recreational, and economic life, encompassing both public and private spheres” (Kymlicka 1995, 76). For Kymlicka, a societal culture is not simply a distinctive set of shared beliefs, language, convention, and memories, but also common institutions and practices that shape social life. “And in the modern world,” Kymlicka states, “for a culture to be embodied in social life means that it must be institutionally embodied—in schools, media, government, etc.” (Kymlicka 1995, 76). What is important to emphasize about a societal culture is its institutional character, which enables and organizes specific patterns of living, shaping human life in more profound ways than if culture was only about a belief system. A societal culture constitutes institutions and practices that form, articulate and sustain the cultural beliefs and values, social identities, and distinctive forms of life of its members, which may not be found in other social contexts. This notion of culture is what Kymlicka describes as a context of choice that is necessary for autonomy.

The term “context of choice” refers to the set of background conditions that enables and deeply structures an individual’s autonomy. Individuals are autonomous in the sense that they are conscious, capable, and purposive agents who act in ways so as to accomplish certain aims. These activities, aims, and experiences are meaningful to the agent based on their beliefs and values about what constitutes the good life. To realize specific forms of life that we value is what motivates our choices and gives our lives meaning, making sense of who we are and why we do what we do. Based on this view of individuals, what are the ways in which a context of choice makes autonomy possible? I enumerate five characteristic features of a context of choice and how it supports autonomy. As we go through these features, it will be clear that they are deeply intertwined with one another, but these analytical distinctions are made to show how the notion of context of choice, though unassuming, is importantly related to autonomy.

(1) *Provides a range of available options.* One of the standard requirements for autonomy is the availability of options that an agent could choose from. A context of choice enables a certain range of experiences, activities, practices, and ways of living to be available to the agent. Different contexts of choice present different possibilities of life options, where certain forms of living may be possible or readily accessible in one context but hampered or dimly feasible in another. The possibility of living the spiritual traditions of the Aboriginal people is facilitated in a context where there are institutions and a community that support these patterns of living, such as the recognition of certain lands as sacred religious sites that are protected, with privileged access given to believers. More importantly, these life options may not, at all, be available in other contexts, which generate claims to preserve the contexts that make Aboriginal spirituality possible.

(2) *Makes options intelligible.* For an agent to be autonomous, the choices presented to them must be rendered intelligible. A context of choice is a repository of meaning such that it facilitates our background understanding. It encompasses scripts, narratives, and histories that make certain actions and practices not only cognizable to agents who are sufficiently acculturated in a given context, but also legible to them. This enables agents to be aware, make sense of, and be fluent in the variety of options open to them, which allows them to choose and act purposively. Kymlicka states, “Different ways of life are not simply different patterns of physical movements. The physical movements only have meaning to us because they are identified as having significance by our *culture*, because they fit into some pattern of activities which is culturally recognized as a way of leading one’s life” (Kymlicka 1989, 165). Without a familiar context of choice, agents would not be able to interpret and navigate

proficiently their physical and social world, hampering their ability to shape a coherent and meaningful pattern of living. This is what Kymlicka seems to mean when he states that a societal culture does not only present us with options but makes these options vivid so that we are able to intelligently examine them. This is achieved through language, history, and traditions, and we lead our lives by situating ourselves in this shared vocabulary and cultural scripts (Kymlicka 1995, 83). Returning to the example of Aboriginal spirituality, a life that inflects this mode of being is only made possible and vivid in a context where people can make sense of the practices and institutions that enable its expression. They are rendered intelligible through the scripts and narratives that are integrated and institutionally affirmed in social life.

(3) *Makes options normatively significant.* A context of choice does more than simply propose and make intelligible certain options to agents, but also makes them laden with value. A context of choice is coded with norms, ideals, expectations, and understandings that shape our behavior and how we perceive certain choices. As individuals, we value certain things, experiences, and ends. But these preferences are informed by our background understanding developed within a particular context of choice. This captures Kymlicka's point that we do not start "de novo" when deciding how to lead our lives (Kymlicka 1989, 164). The distribution of value across activities and forms of living is expectedly unequal in a given context of choice, where certain choices may be readily available, encouraged, celebrated, and supported while others are hampered, discouraged, obscured, trivialized, and erased. It is from this context that autonomy is enabled and enacted. As purposive beings in pursuit of certain ends, we need an interpretive schema of what choices are available and worth doing. Kymlicka, quoting Ronald Dworkin, states that our culture not only provides options, it also "provides the spectacles through which we identify experiences as valuable" (Kymlicka 1995, 83).

(4) *Furnishes and sustains a practical identity.* An action or end matters to an agent in relation to their own understanding of themselves. But this self-understanding is shaped from the ways in which we are situated. We make choices not as an undifferentiated beings, but as particular persons in relation to others, the world, and our personal histories. From our self-conceptions, we subscribe to ends that normatively resonate with us. In this way, autonomy is animated by and mediated through a person's identity. Having a practical identity is critical to directing and motivating our choices. Practical identities orient our values, plans, fundamental normative commitments, and the basic ways we perceive, experience, and interact with our world. It is from the particularities of who we are, including our value perspectives, that autonomy is expressed. Furthermore, it is critical that a person's practical

identity is supported in the context in which entrenched agents exercise their autonomy. From this understanding, a context of choice furnishes and sustains our practical identities. A societal culture helps shape the identities of its members, enables their expressions, and affirms them. An Aboriginal identity, where Aboriginal spirituality is at its core, can only be facilitated in a context where such identities could be formed and expressed, which are made possible by the institutions that govern everyday life. A context of choice furnishes, sanctions, and sustains particular identities through the types of activities, practices, roles, and forms of living that flourish within its normative bounds. If autonomy is expressed through an agent's practical identity and such expressions are only possible in a societal culture that acknowledges and supports such identities through its institutions, then autonomy is curtailed when this societal culture is deteriorating and where such identities cannot be expressed and sustained outside of it.

(5) *Grounds self-respect.* This feature is to qualify the previous one, pointing out that not all social identities facilitate autonomy. Autonomy requires that a person conceives themselves (as well as for others to conceive that person) as having “normative authority” over their decisions of practical importance in their life, which is an authority that is gained from having positive affective attitudes toward themselves, such as self-worth or self-confidence (Mackenzie 2008). For example, stigmatized identities, which envelope their bearers in meanings that demean their worth or generate stultifying self-doubt in their ability to achieve certain ends, may be imposed in a particular context and extinguish a person's motivation to exercise their autonomy. Incarcerated scholars John Bryant, James Davis, and others point out the dangers of assuming the identity of an ex-prisoner, since it is a status that is attached with negative social scripts delivered on federal, state, and social levels (Bryant et al. 2014). The denial of opportunities on account of their formerly incarcerated status can have a major impact on how formerly incarcerated persons value themselves, making them more susceptible to becoming “the monsters we are perceived to be” (Bryant et al. 2014, 109). Given the critical importance of self-respect to autonomy, John Rawls considers self-respect to be the most important primary good (Rawls 1971, 440). Rawls defines self-respect as having two components: (1) a person's sense of their own value in which their “secure conviction that [their] conception of [their] good, [their] plan of life, is worth carrying out;” and (2) a confidence in their ability to fulfill their intentions (Rawls 1971, 440). Without these two components, Rawls states, “When we feel that our plans are of little value, we cannot pursue them with pleasure or take delight in their execution. Nor plagued by failure and self-doubt can we continue in our endeavors. It is clear then why self-respect is a primary good. Without it nothing may seem worth doing, or if some things have value for us, we lack the will to strive for

them. All desire and activity become empty and vain, and we sink into apathy and cynicism” (Rawls 1971, 440). Thus, if we understand a context of choice as a prerequisite of autonomy, then it can only support practical identities that conceptualize their bearers in positive affective terms. A context of choice that facilitates autonomy must affirm entrenched agents as beings with value on the basis of their identities. Like other cultural communities, Aboriginal people derive their sense of value within the metaphysical and ethical frames of their Aboriginal identity. Preserving this societal culture is to preserve the source of value that support the autonomy of its members.

My construal of the meaning of context of choice is, in many ways, more elaborate than what Kymlicka actually presents in his work, but it does not go beyond what Kymlicka may have had in mind. I aim to map out what he says throughout his works, but elaborate his ideas in fuller, more precise terms of how a context of choice enables and deeply structures a person’s autonomy. Autonomy requires the ability of agents to make choices among a range of vivid and salient life options so that they are able to construct a life narrative that expresses who they are, that is, the “self” in self-determination. A context of choice enables this agential capacity, providing a context from which agents can effectuate their autonomy. A context of choice makes certain life options vivid and meaningful in relation to an agent’s positive self-conception, which itself is also shaped, affirmed, and sustained in this context. Furthermore, a context of choice enables agents to make choices that express their self-conception by both making these options accessible and supporting the agents’ normative authority to make the choices that they deem significant to their life narrative. In other words, autonomy involves the effective expression of an agent’s practical identity, which requires a set of circumstances that supports this expression by providing the options and the agential capacities to pursue them.

For Kymlicka, a societal culture provides a context of choice that makes autonomy possible. For this reason, he argues that preserving a societal culture, like Indigenous cultures that enable people to live and flourish in specific forms of life that accord with their Indigenous identity, is a requirement of justice. The deterioration of Indigenous cultures from the intrusive actions of non-Indigenous publics threatens the autonomy of cultural inhabitants by ruining their access to their range of meaningful options and the possibility to express their identity. The harm of losing a familiar cultural community that roots people’s identity is further exacerbated by the difficulty of integrating into another culture. As Kymlicka states, “We can’t just transplant people from one culture to another, even if we provide the opportunity to learn the other language and culture. Someone’s upbringing isn’t

something that can just be erased; it is, and will remain, a constitutive part of who that person is. Cultural membership affects our very sense of personal identity and capacity” (Kymlicka 1989, 175). This points to how our autonomy is intimately bounded to a particular context from which we make sense of ourselves and the world we’re in and act upon them to construct a meaningful form of life. The constitutive nature of our practical identity is what makes respecting people’s cultural membership morally prior to the option of facilitating their transition to another culture. As Kymlicka states, they are “not equally legitimate options. The affront minority groups feel at the latter proposal is grounded in the perception of real harm” (Kymlicka 1989, 176).

In this analysis, I want to emphasize how a context of choice affects pervasively our sense of self and capacity for autonomous agency. Kymlicka introduced this notion to describe societal cultures. Though the notion of context of choice is not without controversy, I believe it is a powerful concept that properly understands autonomy as dependent on context.<sup>26</sup> What I want to argue is that there are contexts other than societal culture that could be properly understood as a context of choice that is critical to autonomy, and when understood as such, the state ought to respect and protect these conditions from abrupt, dramatic, and unwanted changes. In the next section, I propose that we understand embodiment as an important context of choice. Although societal culture and embodiment are unlike each other in many obvious ways, embodiment is a context of choice in that it also enables and structures deeply our autonomy, shaping our phenomenal world and our sense of capacity and identity. Thus, any abrupt, dramatic, and unwanted changes of our embodiment can be understood as a serious harm to autonomy.

#### **4. The Meaning and Nature of Embodiment**

We are embodied beings, such that the ways in which we experience, think, feel, act, and engage with the world and with others are pervasively shaped by our bodies. The centrality of the body in structuring our inner lives is rooted in the philosophy of Merleau-Ponty and has been

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<sup>26</sup> Like any other concept in philosophy, the notion of “context of choice” has its detractors. For example, John Tomasi argues that a deteriorating context of choice, given the implied rigidness, may actually lead to a greater degree of personal autonomy since there are fewer constraints on what counts as an acceptable life plan (Tomasi 1995). It is beyond the scope of the paper to defend robustly the concept of context of choice as a critical feature of autonomy, but objections that the notion of context of choice is more at odds with autonomy is to misinterpret the background conditions of autonomy as demanding a kind of formless frontier for undifferentiated, fully autonomous moral beings. It does not appreciate the relational features of autonomy, which I believe are distilled in the notion of context of choice.

revitalized by feminist philosophers who challenge prevalent conceptions of the mind as entities or phenomena realized and organized independently of the body. To be embodied is to exist as a corporeally bounded being, in which the material facts of the body, complicated with cultural meanings, shape our experience of the world, our repertoire of actions, and our self-conceptions. As embodied beings, our freedom is both bounded and expressed in relation to the specific facticity of our individual bodies. (Young 2005a: 15-18).

The point of acknowledging the embodied nature of our being is to reconsider fundamental notions related to who we are as conscious and purposive moral agents. To bring attention to our embodiment is to prompt us to reconceive capacities, like autonomy, as embodied. Some philosophers have already connected autonomy to specific embodied forms to justify devaluing disability traits as impediments to autonomy (Davis 2010; Harris 2001). But I find such analyses as not fully appreciating the non-fungibility of our bodies, the situatedness of the body in a sociocultural context, as well as how our own embodiment shapes our own perceptions and imagination (Mackenzie and Scully 2007). Here, I want to deepen our understanding of the embodied nature of autonomy by illuminating how embodiment is a context of choice. To describe embodiment as a context of choice is to understand the body as a background condition that both enables and deeply structures a person's autonomy. It enables agents to pursue a specific range of intelligible, meaningful life options and fosters a complementary identity that motivates their choices. Before I develop this position, I want to foreground two aspects about embodiment that my thesis rests on: (1) our embodiment determines our first-person perspective and how we engage with the world; and (2) our embodiment is enculturated.

#### *4.1 Embodiment as First-Person Perspective*

Since we are integrally situated in our bodies, our first-person perspective of the world and ourselves, including the possible range of actions we are able to perform, is bounded by our particular embodiments. It is the implicit frame of reference from which we perceive the world and express our intentions. Catriona Mackenzie calls this our *bodily perspective*, which captures the idea that the body is typically felt not as an impersonal object but the point of view from which we perceive and engage intentionally with the world (Mackenzie 2009, 115). Though our subjectivity and intentionality are shaped along the terms of our embodiment—such as our bodily shape and frame, bodily knowledge, and bodily habits (posture, movement, and gesture) that are developed over time—the acclimated

body is, in many important ways, experienced as “transparent.”<sup>27</sup> This allows us to focus on more interesting things outside the body, like having coffee with friends or arguing about philosophy, even though the ways in which we perceive and interact with the world are mediated through our bodies. Mackenzie uses the ordinary example of making tea to illustrate the role and subtle experience of the body mediating our perceptions, actions, and interactions with the world:

[I]n getting up from my desk to make myself a cup of tea my attention is focused on certain features of the world—the kettle, the teapot, the cup, the milk in the fridge—that are necessary for realizing my intentions. In performing the actions involved in making a cup I not only undertake certain bodily movements, but I also negotiate my way through my environment—walking down the stairs, going through the doorway, moving around the kitchen benches, turning on the tap to fill up the kettle, reaching for the tea, and so on. In doing so I am not consciously aware of what my body is doing, of the movements I am making and of the way I am moving through the environment, but I undertake the actions involved seamlessly and effortlessly (Mackenzie 2009, 115).

Our bodily perspective arises from concrete features of our specific embodiment, like our bodily frame, our bodily habits, and bodily knowledge (Mackenzie 2009, 116). When a level of stability, familiarity, and fluency with our body is achieved, a familiar and meaningful phenomenal world is created. From this background context, we are able to construct a meaningful life narrative.

#### *4.2 Embodiment as Enculturated*

As embodied agents situated in historical and social settings, our physical and cognitive abilities are not fully predetermined biologically but are also enculturated by social norms and expectations. Particular bodies are laden with social meaning, shaping the ways in which a particular body is understood and experienced, nurtured and socialized to encompass certain bodily competencies, which in turn shapes how an agent acts with respect to norms inscribed to their body. This point is exemplified in Iris Marion Young’s influential work on female body experience. In “Throwing Like a Girl: A Phenomenology of Feminine Body Comportment, Motility, and Spatiality,” Young argues that the dominant ways that many women move, express, and orient themselves in the world are not due to some feminine essence, but to processes of socialization that condition the body to reflect feminine ideals (Young 2005b). Following Young’s lead, Sylvia Burrow points out that a person’s autonomy as

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<sup>27</sup> I borrow this description from Havi Carel, who describes a “healthy” body as “transparent” (Carel 2008, 26). Though, in many ways, I accept Carel’s description, I avoid using the term “healthy” in this paper. Unless “health” is understood in a less conventional way, acquiring a disability may make someone immediately conscious of their body as an object separate from their sense of being, but that does not necessarily mean disability itself is an “unhealthy” type of body. For me, what makes a body transparent is when the agent is so accustomed to it that it becomes integrated to their being. This will be further explored in section six.

an embodied capacity could be limited or expanded, depending on the kinds of norms that are encoded in the body (Burrow 2009). Situated in a sociocultural context, a lived body is enculturated with bodily habits, where the body is developed to realize certain capacities, competencies, and ways of behaving in the world. The major point I want to highlight is that our embodied perspective and felt capacities are not reducible to the physical facts of the body but are also shaped by social meanings and expectations imposed on people on the basis of their bodies. From this point, many feminist philosophers have argued forcefully that the autonomy of women is constrained by oppressive ideals internalized in their bodies, which is a critical point to keep in mind (Young 2005b; Burrow 2009). In the present context, I simply want to emphasize that bodily perspective is shaped by our bodies, but bodies themselves are socially encoded, which avoids simple accounts of biological reductionism.

In the next section, I want to build from the notion of bodily perspective to argue that embodiment could and should be conceptualized as a context of choice. To describe embodiment in this way is to indicate how our particular forms of embodiment are integral to enabling and structuring autonomy, not only in the range of possible actions but also their intelligibility, normative significance, and the formation, affirmation, and sustenance of a practical, self-affirming identity that motivates autonomous actions.

## **5. Embodiment as Context of Choice**

I argue that embodiment should be understood as a context of choice that is critically important for autonomy. My rationale is that a stable, familiar, and valued embodiment also enables and structures deeply a person's autonomy in ways that exemplify the five characteristic features that constitute a context of choice that is crucial for autonomy. A person's embodiment does this in the following ways:

*(1) Provides a range of available options.* One of the more obvious ways in which a body is essential to autonomy is that it provides an agent with a range of possible choices and actions. Particular forms of embodiment enable a certain breadth of experiences, activities, and ways of living to be available to the embodied agent. As noted earlier, different contexts of choice present different possibilities of life options, where certain forms of living may be possible or readily accessible in one context but hampered or dimly feasible in another. This is true for different embodiments. The world of experience and action of a Deaf person is expectedly different from that of a hearing person with

respect to how they are embodied. This is due to differential sensory capacities and their interplay with the larger physical and sociocultural context, which confer different opportunity and experiential benefits and costs. A deaf embodiment structures how the world is experienced, such as facilitating music to be listened to tactilely via vibration, and what opportunities could be effectively pursued on account of their abilities in relation to their specific physical and sociocultural world, which may be more or less accommodating to deaf bodies. Deaf gain, for example, refers to the cognitive, creative, and cultural gains and opportunity benefits that result from deaf embodiment, and there is a growing literature on the phenomenon of Deaf gain, documenting the ways in which being deaf generates peculiar advantages (Bauman and Murray 2014). An agent's opportunity range is also due to social meanings associated with certain embodiments and how they shape an agent's horizon of possibilities. Access to certain social spaces, roles, and positions are largely determined on the basis of embodiment. For example, a Deaf person is afforded or denied certain opportunities on the basis of their corporeality, possessing an opportunity range that may differ from the range presented to a hearing person (Mackenzie and Scully 2007 343-344; Schmidt 2007). In these ways, a lived body structures a range of possible life options that an embodied agent could choose from, making certain momentous choices and forms of living possible to them.

(2) *Makes options intelligible.* A lived body that is stable and familiar renders a world that is intelligible to the embodied agent, including their potentiality for action. As S. Kay Toombs notes, people come to “view the world through the medium of the limits and possibilities of their bodies” (Toombs 2001, 250). In this way, a body could be understood as a repository of meaning, encompassing a history, narrative, and social scripts accumulated over time as the body is lived and interacting with the world. This shapes diachronically an agent's capacities for action and their sense of what is possible in their given embodiment. In this process, the body, as well as the world in relation to it, becomes legible to the embodied agent (Silvers 1998). Our bodily perspective makes particular ranges of options vivid so that we are able to intelligently consider them. The choice to make coffee in the morning, to jog in the park, to grab a book from the top shelf, to be a doctor or a pilot, or pursue a philosophy degree, along with a full range of actions, activities, practices, and endeavors are more or less vivid to a person on the basis of their felt bodily capacities and competencies to realize their intentions in a specific physical and sociopolitical environment.<sup>28</sup> The sense that certain options

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<sup>28</sup> Again, the functional abilities of an individual agent are largely determined by the degree of fit between a person's embodiment and their physical and sociocultural context. A person may not be able to participate in a particular activity or pursue a valued opportunity, either due to a lack of a critical embodied capacity or that they live in a society

are open may not only be derived from the brute facts of our physical and mental capacities, but also the social expectations that shape the experience of particular embodiments, as well as the felt dimensions of our body's compatibility to their physical and sociopolitical world. A stable and familiar embodiment provides an agent with this interpretative schema to navigate proficiently their physical and social world, enabling their ability to build a coherent and meaningful life narrative.

(3) *Makes options normatively significant.* Concomitant with making certain options vivid to the agent, some of these options may come to have normative significance. As purposive beings in pursuit of certain ends, we need an interpretive schema of what choices are available and worth doing. A person's embodiment, given its corporeal features and physical capacities, can influence their outlook on the range of options presented to them. As individuals, we value certain things, experiences, and ends. But these values, life plans, and preferences are informed by our background understanding developed in our particular embodiment. For example, John Christman points out how a person's biological sex—that is, the anatomical, physiological, genetic, or physical attributes that help to determine if a person is a male, female, or intersex—influences pervasively their perspective and life plans, such as their “relation to the experience of having children, one's bodily comportment, styles of clothes, relation to sexual experience, and so on” (Christman 2001, 191). As Burrow, Young, and other feminist philosophers remind us, certain bodies are enculturated with norms and expectations through social patterns and institutions (Burrow 2009 and Young 2005b). Yet as Christman argues, “Nevertheless the way in which most people construct their life plans, preferences, dispositions, habits, and values is simply set *against the background* of [their] sex; choices are made *given that* one is male, female [or intersex], never in determination of it” (Christman 2001, 191). Christman illuminates how we come to value a spectrum of actions, activities, and various ways of living through the bodies we assume.

(4) *Furnishes and sustains a practical identity.* As noted earlier, an action or end matters to an agent in relation to their own conception of themselves, and this self-conception is shaped by the ways in which we are situated. This is clearly true regarding the particularities of our own corporeality. A person's embodiment helps shape and sustain their identities and enables their expressions. In this way, a person's embodiment is constitutive of, though not reducible to, a person's practical identity. For instance, a person's capacity to walk and run, and its interplay with other internal capacities, may

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arranged in ways that disadvantage people with certain types of embodiments. For this reason, Anita Silvers draws a distinction between a “mode” of functioning and a “level” of functioning (Silvers 1998).

stimulate interests in doing activities, like running in marathons, and enhancing their existing capabilities (increased lung capacity and muscular leg strength) via training to improve their performance. This may lead to a developed appreciation for this activity, where it becomes a major part of this person's life and an ethically salient feature of their identity. The ability to walk upright may also structure this person's life in other important ways that may be taken for granted, opening a horizon of life options and relations that become valuable to the person whereupon it becomes intimately tied to their identity. And this particular identity is significantly attributed to a particular embodiment, in which the latter allows the former to be facilitated, expressed, and sustained. Both diachronically and synchronically, a person's identity—comprised of value perspectives, plans of life, relations with others, and sense of place in the world—is pervasively and dynamically shaped by their lived body. This especially makes sense when we understand the relational aspects of identity and the lived body as the interface with the world. Our identity is responsive to the details of our embodiment, including what we are capable of doing and how we are regarded and treated by others and the broader community on the basis of our bodies. Thus, the interpersonal relations we form, the activities we do, and the world we know, which significantly shape our identities from which we are motivated to act, are defined significantly by what bodies we inhabit. A specific identity can only be facilitated in a context where such identities could be formed and expressed, which are made possible by the embodiments that shape our everyday life. A body can furnish, sanction, and sustain particular identities through the types of activities, practices, roles, and forms of living that flourish within its physical and normative bounds.

(5) *Grounds self-respect.* If a person's practical identity is connected to how they are embodied and this practical identity provides a level of self-respect to animate their autonomy, then a person's embodiment may also be a source of an agent's self-respect. An agent's normative authority over their judgments and actions may be grounded in their embodiment, such that they value themselves or feel confident in their abilities to fulfill their intentions as a particular embodied being. A person may derive a meaningful sense of self-worth from an identity that is tied or made possible by their corporeality, such as being an adventurous world traveler, a parent, or a doctor.<sup>29</sup> A person may also have a robust sense of self-trust in their physical abilities to put into effect a repertoire of actions that allow them to pursue a wide range of meaningful life options on the basis of their identity, given their

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<sup>29</sup> But like most identities, what kind of embodiment facilitates these identities are always in contestation. Also, there are manifold ways of how these identities could be expressed or manifested. But this doesn't negate the fact that many people's identities are inextricably tied or closely related to their embodiments.

experience of their body as the medium of their intentions. For example, a person's ability of walking bipedally and upright, which is enabled by their embodiment, may be one of their primary forms of locomotion to express their autonomy. It is the mode in which they go to coffeeshops and markets, navigate their home and workspace, explore new or beautiful terrains, exercise their dog daily, etc. A particular pattern of living, as well as an affirmative self-concept, may emerge and be sustained by this felt ability. In this way, this person's embodiment may be a source of self-respect by deriving from their body a sense of self-worth and self-confidence in their abilities to realize their aims.

The aim of this section is to show how an agent's sense of autonomy is profoundly shaped by the agent's embodiment. A person's embodiment makes possible a determinate range of options that are accessible, intelligible, and meaningful to an agent in relation to an identity and value commitments which are themselves negotiated and sustained by their particular body. In these respects, a person's embodiment is an important context of choice for the possibility of autonomy. Given that a person's autonomy emerges from and is bounded to their particular form of embodiment, dramatic bodily transformations that are abrupt and unwanted can be disruptive to the autonomy of the modified agent. For this reason, vulnerability to these changes ought to be diminished. In the next section, I will elaborate on the nature of dramatic bodily changes, such as acquiring a disability, and how these events could be understood as serious harms to our autonomy, even on a mere difference view.

## **6. Treating Disability and Bodily Change as Autonomy Harm**

Bodily change, like acquiring a disability, is a dramatic way of revealing the embodied nature of autonomy. The types of changes that I have in mind include paraplegia, sensory loss (ex. deafness, blindness), and major alterations of phenotypical traits (ex. amputation, paralysis). Given the body's role in organizing our abilities and experiences, mediating our relations with others and the world, and shaping our identity, which all constitutively shape our autonomy, it is understandable that an abrupt shift in embodied form is often experienced as a serious harm to our autonomy. An agent may be intimately attached and accustomed to their embodiment, valuing the particular pattern of living, identity, and life plan that are bounded intricately to a particular embodied form. When someone undergoes dramatic bodily change, it disrupts the bodily conditions that have shaped and sustained a particular way of being in the world from which they develop preferences and life plans and make decisions based upon them.

Consider the lived experience of loss of mobility from multiple sclerosis (MS). S. Kay Toombs and Havi Carel are two philosophers who have documented their experiences with MS, including the various ways in which their contexts of choice have altered significantly as a result of their change in ambulatory status (Toombs 2001, Carel 2008). They describe how different their world feels and appears to them as someone with mobility loss. Distances and tasks that were previously felt as short, unremarkable, or simple are now experienced as long, complicated, or laborious. Toombs, for example, shares how the meaning of objects, like her bookcase near her bedroom, is altered in relation to her diminishing capacity to walk, “The bookcase outside my bedroom was once intended by my body as a ‘repository for books,’ then as ‘that which is to be grasped for support on the way to the bathroom,’ and is now apprehended as ‘an obstacle to get around with my wheelchair’” (Toombs 2001, 254). These changes overall augment their sense of what they are capable of doing. Toombs writes,

The surrounding world appears (feels) different than it did prior to bodily dysfunction. In particular, the world is experienced as overtly obstructive, surprisingly non-accommodating. Actions are sensed as effortful, where hitherto they had been effortless. On occasion the world threatens even. And often it presents itself as questionable. The ‘knowing how’ of one’s engagement in the world is rendered circumspect. The effortful nature of worldly involvement that is characteristic of incapacitating disorders can engender a sense of fatigue that I shall call ‘existential fatigue.’ To organize and carry out projects requires not only physical ability but, as importantly, an exercise of will. When ceaseless and ongoing effort is required to perform the simplest of tasks (getting out of bed, dressing, taking a shower, going on a trip), there is a powerful impulse to withdraw, to cease doing what is required. The person with a disability is tempted severely to curtail involvement in the world (Toombs 2001, 253).

Though Toombs portrays disability as an autonomy-diminishing form of embodiment, her underlying point is that acquiring a disability can be deeply unsettling and disorienting to a person whose bodily perspective and ways of living have always been oriented around a particular type of embodiment, in this case the capacity to walk. Her aim is to detail the types of lived body disruptions that accompany mobility loss and loss of uprightness so that more effective therapy could be developed (Toombs 2001, 260). A person can have a precarious sense of what is possible in an embodied form that is not only estranged to them, including the phenomenal world that it brings about, but is exacerbated by social stigmas and expectations of what is possible in that given embodiment. Another notable example is Donald (or Dax) Cowart, whose body was seriously transfigured due to a propane gas explosion (he lost his vision and most of his fingers, and underwent multiple surgeries and skin grafts to reconstruct his face). After recovering from his injuries, Dax could not imagine a promising future for himself beyond selling pencils on a street corner (Wicker 1989). He eventually came to terms with his acquired disabilities and constructed a life narrative that he found deeply meaningful—happily married, becoming a lawyer and a patients’ rights activist—and admitted his error for thinking his life

lacked worthwhile prospects from his bodily context.<sup>30</sup> But this revelation and secured sense of being was preceded by a long, profound sense of loss for a particular way of being that presented a pattern of living and a range of futures that were intelligible and important to him. From these narratives, we can make sense of the autonomy harm involved when acquiring a disability as a rupture of a person's context of choice, without having to think of the disability in itself as a bad difference.

The significance of bodily change is also felt in its effects on how others respond to the modified individual. A person acquiring a disability may be engaged by others in ways that are deeply unsettling to them, where the differential treatment by others may not only be challenging to their particular identity but even be disrespectful to their basic value as a person, depending on the kind of changed body they assume. Toombs details how strangers treat her differently as a wheelchair user, neglecting the norms of respect of bodily space and control, such as strangers pushing her wheelchair or lifting her out of taxi cabs, all without her consent. As she notes, "While I have no doubt that these actions are taken with the best of intentions, imagine how you would feel if a taxi driver simply picked you up, lifted you out of the cab, and set you down on the curb (Toombs 2001, 256). Also, the subtle responses that characterize the interactions with others are different, like the "facial expressions, gestures, averted eyes, words directed away from me to my companion, irritation" (Toombs 2001, 256-257). Carel also discusses how acquiring a disability could strain, if not break, friendships. She notes that her loss of immediacy and spontaneity may compromise her familiar modes of forming new relationships or maintaining existing ones. Social activities, for example, may need to be modified or given up if a disabled person can no longer take part in them (Carel 2008, 52). This puts pressures on a relationship to accommodate to the new terms of someone's changed body, which makes the survival of these relationships more circumspect. Carel writes, "In the same way that distances increase, hills become impossible and simple tasks become titanic, the freedom to go out into the social world and improvise, to act and interact, is compromised. A new world is created, a world without spontaneity, a world of limitation and fear: a slow, encumbered world to which the ill person must adapt" (Carel 2008, 52). Again, what I aim to show through their accounts is that the effects of bodily change are expansive, altering not only our bodily perspective and the sense of what we are capable of doing in relation to the physical and normative structures of our broader community but

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<sup>30</sup> Though Cowart admitted his mistake about disabled life, he still thought that he should have been allowed to refuse treatment. In a public talk, Cowart argued, "Freedom, true freedom, not only gives us the right to make the correct choices; it also has to give us the right sometimes to make the wrong choices" (Cowart and Burt 1998).

also how others regard and treat us, which affects our sense of self, including our sense of self-worth and self-trust. Toombs discusses how shame becomes an “integral element to her disordered bodily style” (Toombs 2001: 256). In these ways, bodily change can threaten our identity and self-respect by altering the context that held us in a particular identity. Though an unwanted dramatic shift in embodiment can undermine a person’s self-respect, it does not necessarily mean that self-respect is impossible for that person with the new body, but only that it requires a reorienting of how they inhabit the world (as well as greater social inclusion) which can be a very difficult readjustment period.

Toombs and Carel’s accounts illuminate the pervasive effects of bodily change, like mobility loss, and how these effects could be translated to autonomy harms. Bodily change could compromise the effective expression of an agent’s practical identity if their newfound embodiment does not clearly support this expression. In Carel’s words, a “new world is created” when a person assumes a new embodiment. Yet this context may not provide the range of vivid and meaningful options, as well as their self-confidence in their abilities, to support the expression of a practical identity that emerged from and was entangled with their prior embodiment. This explains why we come to value certain bodily properties. They help manifest a particular context of choice from which we pursue possibilities and engage in projects on the basis of values and an identity that are dynamically shaped and sustained by that context. It enables us to become who we are. Anita Silvers makes this point, writing: “Eliminating such accustomed performance is likely to disrupt the core of how one lives one’s life, just as losing any other familiar life-plan component, a loved child or spouse, an important opportunity or possession, a respected community role, would do. These considerations reveal that badness lies in the dislocation of familiar patterns of living, disruptions that may but need not be occasioned by disability, rather than in disability itself” (Silvers 2003: 480). Thus, the autonomy harm in bodily change is in losing the particular context from which we made sense of ourselves and the world we’re in and how we act from them in our aim to construct a meaningful form of living.

Given that embodiment is an important context of choice for the possibility of autonomy, I argue that it is justified for a state to provide its citizens with medical interventions to protect or restore the non-disability status of citizens from the prospects of becoming disabled, on the condition that these citizens derived a robust sense of autonomy from their nondisabled embodiments. Dramatic bodily change is expectedly experienced as a serious autonomy harm because it ruins a person’s access to a range of intelligible, meaningful options and the means to express their identity. The harm of losing a familiar embodiment is further exacerbated by the difficulty of integrating into another

embodiment. Just as it is difficult for people to be displaced from one culture and transition into another, even if we provide the opportunity and resources to learn the culture, it is just as difficult for people to cope with a remarkably different embodied form, even if we provide the resources for them to adjust to it and understand it as a value-neutral alternative. Restating Kymlicka's words to serve this particular point, someone's upbringing in a particular embodiment isn't something that can just be erased; it is, and will remain, a constitutive part of who that person is. The constitutive nature of our practical identity is what makes respecting people's embodiment morally prior to the option of facilitating their transition to another embodiment. They are not equally legitimate options. For this reason, bodily change is regarded as a genuine harm.

In this section, I developed an account of dramatic bodily change as serious autonomy harm. It is a harm in that it involves the significant revision of an agent's context of choice. People are brought up in particular embodiments, tying and organizing their lives around its corporeal features and norms. In these ways, a person's autonomy is bounded to their particular embodiment. For this reason, dramatic changes in a person's embodiment are experienced as autonomy harms. This explains why acquiring a disability is interpreted as a serious harm, though the harm is often misattributed to the condition of disability itself rather than the bodily change. Reconceptualizing embodiment as a context of choice justifies the state's interest in maintaining the non-disability status of non-disabled citizens via medical interventions and research. In the next section, I will address the limited scope of my argument and the worries it might raise.

## **7. Some Worries**

The scope of my argument is admittedly limited. Its main aim is to address the persistent objection against the mere difference view that it makes it unnecessary or impermissible for the state to subsidize medical interventions to protect citizens from acquiring disability. I share the view that the state should provide medical resources to citizens to maintain or restore their non-disability status from the prospects of becoming disabled. But the justification is not that disability itself is a bad difference, but rather that dramatic and unwanted bodily change is the harm, more specifically an autonomy harm. Yet the limited scope of my paper and my conceptualization of embodiment and bodily change raise some foreseeable worries. I will consider two worries: (1) the everchanging nature of embodiment makes my position untenable; and (2) my position is uncomfortably silent on, and

may have worrisome implications to, circumstances where citizens seek medical interventions to change the original embodiments that they find distressing and inhospitable.

### *7.1 The Banality of Bodily Change*

In response to the account of embodiment and bodily change developed here, it might be objected that such an account fails to appreciate the fact that bodily change is commonplace. A prime example is aging. Many people dread the experience and the effects of growing old—such as the onset of gray or thinning hair, reduced muscle mass, wrinkles and dullness of skin, and deterioration of bodily and cognitive abilities—especially those whose way of living and identities are oriented around their youthful embodiments. Yet it may seem wrong to think that citizens are entitled to medical interventions to preserve, prolong, or restore their youthful embodiments from the aging process. Instead, aging citizens who cling to a stagnant identity of youth ought to let this identity go and instead revise their own self-conceptions that incorporate aging as an unavoidable consequence of their corporeal existence.<sup>31</sup> Also, much social and cultural work should be done to challenge ageism, which would help facilitate citizens to recognize and accept the biological reality of aging and incorporate it into their life narratives. If my position is prone to overdetermining supposedly benign bodily change, like aging, as problematic, then my position appears to be untenable.

I want to make four points in response to this objection. First, we have to be very careful in attributing which bodily change is a legitimate autonomy harm. Again, for a bodily change to be regarded as an autonomy harm, the bodily change has to result in the instability of the agent's context of choice. Though an agent may experience undesirable changes to certain properties of their embodiment, that does not necessarily mean we should think of these changes as upending a person's context of choice. A bad haircut, for example, should not be regarded, except in the most exceptional circumstances, as an autonomy harm. But how about an aging body? This is more complicated, but there are some reasons to think that growing old is usually not the kind of bodily change that is detrimental to autonomy. For one, the many changes involved in aging are gradual, expected, and occur piecemeal over time rather than the changes being sudden, strange, and comprehensive. This is significant because it allows people to respond to these changes more effectively without having to

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<sup>31</sup> Another way to frame this point is to say that valid identities ought to meet what Marya Schectman calls a reality constraint (Schectman 1996, 94).

radically rethink core understandings of who they are. This makes people less susceptible to feeling deeply alienated from their bodily perspective, such as the feeling that they are in the “wrong body”. We are more amenable to actively shaping our identities in response to bodily changes and their phenomenal and social consequences when the changes are slow and partial, whereas more dramatic changes seem to require a radical revisioning of identity. The changes that come with aging may be dissatisfying but they do not disrupt our existing order of our style of being. A subtle but important distinction is being drawn here. There are bodily changes that are more existential, involving changes to core corporeal features that deeply structure their context of choice and sense of self. And there are bodily changes to a valued property of an agent’s embodiment, but the change itself is not so exceptional to the extent that the agent’s bodily perspective is dramatically different in ways that make their autonomy precarious. Yet I am sensitive to the fact that people’s experiences with the aging body are different, depending on individual history, roles, positionality, and how sexist social norms valorizing youth are levied more harshly on women than men. As the actress Charlize Theron notes, “We live in a society where women wilt and men age like fine wine” (Dean 2016). These factors contribute to greater risks of feeling alienated and highly distressed in respect to the changes brought about by aging. My underlying point is to raise caution in describing too quickly certain bodily changes as legitimate autonomy harms. Whether or not aging poses a serious threat to the stability of a person’s context of choice depends on how the effects of aging are experienced by the person in relation to their practical identity, which is again the anchor from which their moral world and life plans are organized and a source of emotional security and self-respect. This is where phenomenological analysis is powerful and relevant.

Second, even if we concede that aging is the kind of bodily change that can upend a person’s context of choice, I do not think it necessarily challenges the tenability of my account. I may need to bite the bullet here. People may shape their entire identity around bodily properties attached to their youth. But we have to be reflective on why we think aging should be treated by the state with benign neglect (though this does not mean we treat ageism with benign neglect). Aging is often understood as natural, a biological reality for a temporally bounded corporeal being. But if this is the reason why we ought to accept or tolerate aging as an inextricable part of who we are, then this commits a kind of naturalistic fallacy. Furthermore, this line of reasoning could be used to tolerate and accept the onset of disability, which would be a problem for those who hold the position that treating disability is justified but not the effects of aging. A forceful refrain by disability advocates that ought to be taken more seriously is that disability is a natural feature of human life. Disability studies scholar Patty Berne

states in the documentary *Fixed*, “People with disabilities have always existed. People with disabilities will always exist. It is part of the natural biodiversity of humans to be young, to be old, to have a range of physical abilities, from people with limited physical mobility, to people with phenomenal physical mobility. We’re all expressions of humanity” (Brashear 2013). Dominka Bednarska, a performance artist and disability studies scholar, also notes in the same documentary, “Human beings by nature are all going to be limited. I mean, I really think it’s a fundamental aspect of the human condition...The fragility of the human body is not something that’s going to, I believe, anyway, completely go away ever” (Brashear 2013). Berne and Bednarska seek to demystify disability by arguing for its naturalness, challenging the characterization that disability is a biologically odd condition that deviates from species-typical normality. Thus, if disability is a natural phenomenon in human life and yet we find it justified to resort to medical interventions to treat or prevent its occurrences, then the fact that aging is natural is not a legitimate reason for disqualifying it as an object of medical care.

Third, in many respects, we already treat the effects of aging. For example, medical treatment is given to improve bone density, repair aging knees or hips, and fuse vertebrae that have disk damage that has accrued over time. Growing old often means being more vulnerable to acquiring a disability. Medical therapies are provided to maintain people’s functional abilities that are diminishing or threatened due to aging. We may disapprove of subsidizing medical interventions for anti-aging aesthetic ends, like restoring the skin’s plumpness or hair’s thickness and color, and yet we approve of interventions that maintain a person’s capacity to see or walk upright from the deteriorating effects of aging. Thus, aging is already medicalized, it is just that certain bodily conditions are prioritized over others. We just need to be more thoughtful in why we discriminate against the treatment of certain biological states, and aging proves to be a misplaced criterion for determining which states should not be treated via medical interventions. I argue that the bodily changes that should be open for treatment are the ones that alter our context of choice in ways that make it difficult for us to maintain our autonomy, and these can arise through aging. But not all biological outcomes that come about through aging should be treated, such as the more minimal ones that may not produce in the agent a global sense of disorder that permeates their everyday life.

Fourth, my position may be open to mitigating bodily changes associated with aging via medical interventions, but there may be other practical considerations for why certain interventions ought not to be subsidized. Limited resources, for example, may, for some reason, demand us to be more selective with what medical care is provided by the state. Given the resource-intensiveness of

keeping people looking and feeling young, a state may be justified in resorting to helping people accept and transition to their aging embodiment rather than expending resources to sustain a stereotypically youthful embodiment.

One serious worry that I will engage in the next chapter is that subsidizing anti-aging aesthetic treatments would reinforce attitudinal and institutional ageism. This might be one reason why a state ought to prioritize societal measures to help citizens accept aging as a bodily change that should be tolerated and incorporated to their identity, as opposed to resorting to medical interventions to resist or postpone such changes. I am deeply sympathetic to this worry. But this worry also extends to disability. Though there may be non-ableist reasons for treating disability, it may reinforce attitudinal and institutional ableism. I will return to this worry and seek to address it in the next chapter.

### *7.2 Body Discordance and Seeking a Different Embodiment*

My limited scope of defending the practice of maintaining existing embodiments from the prospects of dramatic and unwanted bodily change, such as protecting nondisabled people from becoming disabled via medical interventions, may be seriously wanting. What about people who are deeply distressed by the internal discord with their initial embodiments? For example, transgender people perceive themselves as not identifying with the sex typically assigned to their physical body. Given the distress of inhabiting a discordant body and the high attempted suicide rates driven by it, many people argue for gender transition care to be publicly funded (Go 2018). Also, people who identify as transabled feel intensely that a disabled embodied form expressly fits who they really are and desire to alleviate their alienation and transform their nondisabled embodiment to a disabled one that exemplifies their identities (Bayne and Levy 2005). Focusing only on the moral importance of upkeeping an existing embodiment and justifying it in terms of maintaining the stability of an agent's context of choice neglects, if not has objectionable ramifications on, the aforementioned cases. Does my account of embodiment and its relations to identity and autonomy help us to address other pressing circumstances where people are not looking to medical institutions to maintain their existing embodiment, but rather to actively augment it so that they can inhabit an embodied form that aligns with their self-conceptions?

I will address this issue more thoroughly in an upcoming chapter. For now, I acknowledge the worry and believe that my account of embodiment as an important context of choice can help inform

us on what justice requires of healthcare institutions pertaining to people experiencing discord with their embodiment. I argue that citizens deeply alienated from their embodiments experience a serious autonomy harm, and this chapter focused on dramatic bodily change as one of the pathways in which someone could be alienated from their current embodied form. But the experience of alienated embodiments can arise through other pathways as well. So, if healthcare institutions are oriented around the principle of promoting autonomy, then my account provides normative resources to defend subsidizing gender transition care or even elective amputations. But a robust defense also involves sensitivity to the content of the identities that motivate people to assume a certain embodied form. Not all identities ought to be equally respected, such as self-defeating identities that do not facilitate autonomy or proscribed identities that are, in themselves, objectionable because they undermine other considerations of justice. Consequently, there may be certain identities that ought not to be supported by our healthcare institutions (ex. pro-anorexia identities).

## **8. Conclusion**

In this chapter, I addressed one prominent objection against the mere difference view of disability, which argues that the mere difference view leads to objectionable implications in the realm of healthcare justice. That is, if the mere difference view is accepted, then non-disabled citizens do not have a legitimate claim against the state to be provided with medical care to maintain their non-disability status from the prospects of becoming disabled. To respond to this argument, I argued for two main conclusions. The first of these is characterizing embodiment as an important context of choice for autonomy. A person's body is a context of choice in that a person's autonomy is bounded to the ways in which they are embodied. A person's lived embodiment presents to them a range of options and patterns of living that are intelligible and meaningful to the person in relation to their practical identity, which is also shaped and sustained by their particular embodiment. The second main conclusion is that dramatic bodily change could be interpreted as a legitimate autonomy harm since it entails the disruption of a person's context of choice that they might have depended on to exercise efficaciously their autonomy. These two conclusions are then used as premises to overcome the objection against the mere difference view. The state is justified to subsidize medical interventions to treat and prevent disability not because disability itself is a definitely bad form of embodiment but that it is important for the state to help its citizens to remain as agents by maintaining their contexts of choice, which includes their specific embodiments that shape and bound their autonomy.

I defended my positions against two major worries, which I will further develop in the next chapters. But that does not mean there is no other persistent worries. One such worry is the permissibility of intentionally creating disabled children, either by selecting disabled embryos over nondisabled ones to implant in a person's uterus, so that disabled children are deliberately brought into existence, or intentionally disabling a non-disabled child while they are really young (on the condition that this bodily transformation can be done painlessly and without causing negative health effects). This is a legitimate concern and a number of philosophers have sought to address it (Barnes 2016; McMahan 2005). For future work, I would like to examine this issue more closely.

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## Chapter 3: Reinforcing Unjust Norms? On the Expressivity of Medical Interventions for Treating and Preventing Disability

*Taking up space as a disabled person is always revolutionary.*

– Sandy Ho, “Canfei to Canji: The Freedom of Being Loud”

*[W]e need neither a wholehearted acceptance nor an outright rejection of cure, but rather a broad-based grappling.*

– Eli Clare, *Brilliant Imperfections: Grappling with a Cure*

### 1. Introduction

In the previous chapter, I argued that, even if we accept a mere-difference account of disability, the state is justified in subsidizing medical interventions and research to prevent or treat acquired disability. The reason is not that disability itself is a categorically bad state to be in, but rather that dramatic and unwanted bodily change can be a serious detriment to the autonomy of the agent undergoing it. Thus, the account of disability as mere difference does not have to be incompatible with a publicly funded healthcare system that is committed to maintaining the non-disability status of able-bodied citizens through prevention and treatment. In other words, there may be justified, non-ableist reasons for supporting a healthcare system that seeks to mitigate the prospects of becoming disabled. Still, even if there are pro tanto reasons for the practice, it may have attendant harms to disabled people. One kind of harm, which will be the main issue of this chapter, is an expressive harm. That is, a subsidized practice to prevent or cure acquired disability may still express and reproduce negative stereotypical meanings about disability that are morally harmful to disabled people, either by offending disabled individuals’ sense of dignity or eroding the social standing and social bases of self-respect of members of the disability community.

The expressivity of an action or practice is an egalitarian concern when it challenges the social equality of citizens, especially those who have been historically excluded from “a society of equals.” State action and practices have been challenged on the basis of what they express. For example, racially segregated schools, as Charles R. Lawrence III noted, are objectionable under the equal protection clause because of the message conveyed, which is that “black children are an untouchable, caste, unfit to be educated with white children” (Lawrence III 1990, 439). Similar concerns are raised against practices pertaining to disabled people. The most prominent in the bioethics discourse is with prenatal

practices to avoid creating a disabled child, such as preimplantation genetic diagnosis (PGD) or prenatal screening followed by selective abortion. The objection is that such measures to prevent the birth of disabled children publicly transmit a message that disabled lives are less valuable and therefore such measures are morally unjustified. These sorts of arguments are often called “expressivist arguments.”

In this chapter, I use the term “expressivist argument” to refer to the argument that a subsidized healthcare system that seeks to discourage or mitigate the occurrence of disability through prevention and treatment (which I will put under the umbrella term, “medical practices for disability avoidance”) may be morally unjustified because of what it expresses to diverse publics, namely that disability is a morally disvalued form of embodiment and consequently, that the lives of disabled people are inferior or subordinate to those of non-disabled people.<sup>32</sup> This expression is objectionable because it violates the egalitarian commitment to promote the social equality of all citizens, including disabled people.

I consider the expressivist argument to be a powerful objection to medical practices and research that seek to protect the non-disability status of citizens from the prospects of acquiring a disability. If medical practices for disability avoidance contribute to injustices experienced by disabled people, then these practices ought to be seriously reconsidered. Although I have argued that the state has good reason to support medical practices for disability avoidance given the importance of bodily stability for individual agency – reasons that are not themselves ableist – I agree that such practices, at least in the current context, carry a public meaning that stigmatizes disability. Though there are serious moral costs to medical practices for disability avoidance, I want to argue that these practices are morally justified. Without them, citizens also face important losses that we should not reasonably ask people to accept, such as losing their context of choice that has oriented and sustained their sense of autonomy and identity. Thus, the price of rectifying the social harm of disability devaluation by ceasing medical practices for disability avoidance is too great. Instead, I recommend that we alter the broader

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<sup>32</sup> One may argue that negative expressions of disability would still be wrong even when there are not disabled publics present. Kristen Voigt, for example, argues that an expression could be problematic even if it does not negatively affect the demeaned public. What makes it problematic is the content of the expression. Voigt argues that a sign that indicates that a swimming pool is for white people only would have a problematic expressive meaning even if no one saw the sign (Voigt 2018, 447). This sounds right, but the swimming pool example seems unreasonably abstract, a case of a public expression without any publics or publics that do not interact with publics who are targets of such expressions. In most contexts, public expressions are not done in a social vacuum but in a deeply diverse social milieu. They can shape the social standings of certain publics that will likely be institutionalized in our social and economic arrangements and reified in our interpersonal interactions. It is difficult to imagine a subordinated public could only be subordinated in representation only and not be translated to their social treatment.

social context that imbues medical practices for disability avoidance and disabled life with negative social meanings. This move would help continue providing identity- and autonomy-maintenance across body types while challenging the suspect social norms of embodiment that lead to the harms of historically subordinated publics.

This chapter will proceed as follows. In Section 2, I will describe the standard expressivist argument and how it could be extended to medical practices for disability avoidance. In Section 3, I will elaborate skeptical arguments against the expressivist argument and respond to them, arguing that the expressivist argument presents a legitimate concern about the expressivity of medical practices for disability avoidance and that it needs to be recognized and addressed. In Section 4, I will consider possible ways of addressing the expressive harms of medical practices for disability avoidance and argue that the most justifiable response is to focus on broader structural change to reform the expressive meanings of medical practices for disability avoidance.

## **2. The Expressivist Argument and the Expressivity of Disability Avoidance**

What is the expressivist argument? In this context, it is an argument against an action or practice on the basis that it publicly expresses a message that is unduly harmful or disrespectful to a certain group of people, especially the historically vulnerable and stigmatized. A specific action or institutional practice may be attached with social meanings that go against egalitarian or anti-subordinate norms and thus, such actions or practices may be unjustified. One contemporary example is the public display of Confederate monuments. Many argue that they should be removed because of what they convey to diverse publics. It is argued that they express animus against Black people and affirmation of a racial hierarchy that disgraces egalitarian ideals (Szayna 2020, Shapiro 2017). Their expressions are therefore harmful to Black people. Note that the objectionable feature of displaying the statue is the expression, and it may hold even if the individual or group displaying the statue declares it merely to be a historical treasure.

The expressivist argument is a prominent line of argument against the use of reproductive selective technologies to prevent the birth of disabled children. These include prenatal testing for the purpose of aborting a fetus diagnosed with a marker for a disability trait or preimplantation genetic diagnosis for the purpose of deselecting an embryo with a marker for a disability trait. The general claim is that avoiding the creation of a disabled child sends a negative message about disabled lives

that they are morally inferior and not worth living, denying disabled people the recognition respect due to them as moral equals.

The expressivist argument can be extended, as Jaime Lindemann Nelson noted, to challenge the morality of medical practices that prevent or treat disability (Nelson 2000).<sup>33</sup> This argument is exemplified in disability rights protests against campaigns or telethons that seek to fund research for a cure for disability, like Christopher Reeve’s advocacy for spinal cord injury cure research.<sup>34</sup> The claim is that they reproduce the demeaning stereotype that disability itself is a personal tragedy and the solution is to cure it (Longmore 2016). As poet, disability rights activist, and former telethon poster child Laura Hershey put it,

“[T]his colossal begging festival, supposedly carried out on our behalf, is offensive to us and damaging to our efforts to become first-class citizens...It is an uncomfortable truth, in social work, in government activity, and in charitable endeavors, that actions which are intended to help a certain group of people may actually harm them. By harm, I mean—among other things—that these actions may reinforce the already devalued status of people with disabilities in this society.” (Hershey 1993).

Though telethons often operate egregiously as “dignity thieves” by explicitly portraying disabled people as tragedy stories to inspire donations, the broader worry is that efforts to prevent or cure disability through developing or using medical technologies send a negative message about disability and, in turn, disabled people, and that message is negatively consequential to disabled people.

The expressivist argument against medical practices for disability avoidance can be schematized as the following:

- (1) Any practice that imposes disproportionate harms on a historically vulnerable public is *prima facie* wrong.
- (2) Healthcare that aims at avoiding trait D from being acquired (through prevention and treatment) publicly expresses a negative valuation of D.

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<sup>33</sup> Nelson raises this point not to question the morality of healthcare practices that prevent or ameliorate disability, but as a *reductio ad absurdum* against the expressivist argument against selective abortion on the basis of disability. She argues, “If abortion on the basis of prenatal diagnosis sends a ‘we don’t want your kind here’ message, why would therapeutic interventions not do so as well—and the more successful the therapies are, the more effective the message? If abortion to avoid parenting a child with disabling conditions involves making a decision based on a single trait, would not efforts to cure or prevent disability also involve value assessments based on a single trait? If testing and abortion militate against social acceptance of disabilities as examples of human variation, why would testing and treating not do so as well?” (Nelson 2000, 220).

<sup>34</sup> In 1995, movie star Christopher Reeve sustained a high-level spinal cord injury following a horseback riding accident. He became a prominent spokesman for innovative research to cure and treat spinal cord injury. He helped found the Christopher & Dana Reeve Foundation dedicated to curing spinal cord injury, as well as improving the quality of life for individuals and families impacted by paralysis. In one interview, Reeve stated that he was drawn to the American Paralysis Association because “they were dedicated solely to finding a cure for paralysis, nothing less. I liked that ideal. They’re not into lower sidewalks and better wheelchairs” (Rosenblatt 1996).

- (3) Expressing publicly a negative valuation of D is, by implication, expressing publicly a negative valuation of people with D, which is a historically vulnerable public.
- (4) Expressing publicly a negative valuation of people with D imposes disproportionate harms on people with D.
- (5) Therefore, healthcare that aims at avoiding trait D from being acquired (through prevention and treatment) is *prima facie* wrong.

As premise 1 indicates, I interpret the expressivist argument in terms of harm as the wrong-making feature of an objectionable action or practice. Furthermore, I take the wrongness to be exacerbated when an especially vulnerable population that is subjected to structural injustice and cultural disrespect is made even more vulnerable. Though some proponents of the expressivist argument may be hesitant to use the moral language of harm to characterize the wrongness of expressions that emanate from certain actions or practices, preferring to derive its wrongness independently of its psychological or material effects on people<sup>35</sup>, I interpret the normativity of the expressivist argument within a harm-prevention framework for two reasons. First, it is a widely accepted normative framework that makes the expressivist argument less reliant on more controversial normative claims, like the idea that an expression could be wrong even when it is not interpreted as such and it has no adverse effect on the attitudes and life prospects of people. It seems quite unrealistic to think that a public expression that represents implicitly or explicitly a class of people in subordinating terms cannot have concrete subordinating consequences to that class, given that our institutional practices and interpersonal interactions are shaped by how we conceptualize the social standings of publics. Second, the language of harm captures the concerns expressed by many proponents of the expressivist argument, which I will elaborate in my explanation of premise 4.

Premise 2 claims that healthcare to help nondisabled people avoid acquiring a disability expresses the claim that disability is an undesirable property to embody. The background reasons may vary, including non-ableist reasons, such as the ones elaborated in the last chapter. Yet treating disability in our contemporary medical context adds thicker connotations to disability. These include invoking medicalized understandings of disability and the “cure narrative,” where disability is taken as a personal tragedy that requires individual fixing through medical interventions. These sorts of

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<sup>35</sup> Kristin Voigt, for example, thinks that there may be expressive harms from a law or practice that is not related to the psychological or material harms on people that result from the social meaning of the law or practice (Voigt 2018).

meanings are expectedly propagated when disability is placed in the purview of medicine, a practice defined prevalently in terms of promoting health and treating illness. Thus, medical practices for disability avoidance can reasonably leave the impression that disability is such an undesirable mode of being in the world that it calls for medical attention.

Premise 3 is the critical move of the expressivist argument. It claims that a practice that expressively devalues disability also, by implication, expressively devalues the lives of disabled people. Bjorn Hoffman calls this the *devaluing transfer* aspect of the expressivist argument (Hoffman 2017). Healthcare that aims at preventing people from becoming permanently disabled sends a negative message that a life characterized by disability is such a misfortune that it justifies medical intervention. This characterization of disability then reproduces the characterization of disabled people as inferior, pitiable beings, or unfortunate and brave. Disabled writers and activists raise serious concerns about the societal preoccupations with curing disability because it seems to promote the idea that a disabled life is less valuable than a nondisabled one (Clare 2017; Lu 2018; Klenke 2017). Practices that medicalize disability, in turn, propagate pathological images of disabled people as “sick”, “invalid”, or “cure-seekers.” For example, Jerry Lewis, who is famous for running telethons to raise money for developing cures for muscular dystrophy (MD), characterized people with MD as “half a person” (Lewis 1990). As queer and trans disabled writer Eli Clare puts it, “At the center of cure lies eradication.” The eradication he is referring to is the loss of the existence of disabled people through normalizing their body-minds (Clare 2017, 26). One of the reasons why Adrienne Asch finds prenatal testing for disability objectionable is that it communicates the message that the value and character of disabled people’s lives are reducible to their disability trait, given that certain types of lives are prevented on the basis of that individual characteristic (Asch 2000, Asch and Wasserman 2005). This worry can resonate with medical practices that target disability for prevention or mitigation, where discounting disability as a valued form of embodiment leads to discounting those who exist as disabled people. Writer Megan Klenke states on *The Mighty*, “Focusing on cure emphasizes the person’s physical being and overshadows them being viewed as a whole person” (Klenke 2017). When people express implicitly or explicitly that life would be better without a disability, it can also give the sense that they are rejecting disabled individuals as full persons (Clare 2017; Kent 2000).

There is an important question of who is responsible for this communicative act: is it the state for making the option and resources available to people who seek to avoid acquiring a disability, or is it the individual agents—the clinicians, researchers, and people who look to healthcare to maintain

their nondisabled embodiments—who actively participate in the practice for disability avoidance (Press 2000)? One of the reasons why this question is asked is to figure out who is morally liable and what is the appropriate response to the problem if the expressivist argument is correct. I will return to this issue in section 4. Though I cannot provide a sustained argument without sidetracking from the main point of this chapter, it seems reasonable to hold the view that both the state and individual agents are responsible for the communicative act. Individual agents make individual decisions that animate and sustain the medical practice for disability avoidance, and the state provides the background conditions that make the practice possible, even including the conditions under which desires for particular embodied forms are generated. Thus, it seems unreasonable to think that there is a strict dichotomy of who is the source of the expression of devaluing disability through the practice of disability avoidance. Instead, it seems more plausible to say that both the individual choices of individual agents, especially the patterns of choices that emerge across individuals, and state action can reproduce the message. Both are, in important ways, agents of the practice and purveyors of the message.

Premise 4 claims that publicly conveying the idea that disabled people are less valuable is expectedly harmful to disabled people. But what exactly is the nature of the expressive harm? There are at least two types of harms that are raised by proponents of the expressivist argument. One kind of harm is the psychological harm experienced by members of the disability community. Patterns of communication and representation that are disparaging to disabled people can be psychologically injurious to them. Philosophers like Charles Taylor and Axel Honneth, for example, describe the psychological harm of being misrecognized, including having a reduced sense of self-worth (Taylor 1994; Honneth 1992). Similarly, in his critique of racial profiling, Adam Hosein argues that a practice that gives members of a socially subordinated community a “reasonable sense of inferior political status” is unjust (Hosein 2018). These are political concerns because a diminished sense of self-respect and self-esteem has a negative impact on the autonomy of stigmatized agents (Rawls 1971, 440). If a politically and culturally backed practice is interpreted by disabled people as discounting their worth, then this could adversely affect the ways in which disabled people conceive and experience themselves. Disabled people may struggle with problems of depersonalization, objectification, and otherizing triggered by suspect practices that render certain individual traits as salient and determinative of a person’s social value and belonging. As Anita Silvers notes, “People’s vulnerability to being depersonalized derives not from themselves but from other individuals’ implicitly biased disinclination to give them the consideration due fully to real persons” (Silvers 2017). Sociologist Irving Kenneth

Zola describes the effects of the prevailing stereotype of disabled people as invalids, “As soon as I sat in a wheelchair [as a participant observer] I was no longer seen as a person who could fend for himself...Though [a colleague] had known me well for nine months and had never before done anything physical for me without asking, now he took over without permission. Suddenly in his eyes I was no longer able to carry things, reach for objects, or even push myself. Most frightening was my own compliance, my alienation from myself and the process” (quoted in Longmore 2016, 119). Thus, negative meanings about disabled people transmitted through actions and practices can be deeply offensive to disabled individuals’ sense of dignity.

Another type of harm is broadly social. Medical practices for disability avoidance may reproduce negative stereotypical meanings about disability that contribute to and sustain identity-based social hierarchies, in this case, attitudinal and institutional ableism. The harm here goes beyond the psychological harm experienced by individual members of the disability community. Rather, an inegalitarian social order is reinforced that further excludes disabled people from full consideration and participation in social life. This worry has been expressed by a number of authors, including Laura Hershey in her earlier quote. She claims that patterns of representation that malign the identities of disabled people as broken or inferior translate to social and cultural practices that treat disabled people like second-class citizens. Disabled people are vulnerable to exploitation, marginalization, powerlessness, and systematic violence, which are motivated by a dominant cultural schema that interprets disability and disabled people in inferior terms.<sup>36</sup> One example is how intensive care triage protocols during the COVID-19 pandemic harm disabled people by excluding or deprioritizing them from receiving care on account of their disability (Proulx, Anderson, and Sirotich 2020; Savin and Guidry-Grimes 2020). These triage protocol exclusion criteria are propped up by negative understandings of disability and disabled lives. Thus, a practice that reproduces negative meanings of disability and disabled people as “half a person” can justify denying them equal civic standing and reinforce unjust social relations and arrangements that lead to harms and inequities for disabled people.

Furthermore, focusing on efforts to cure disability seems to undermine the disability rights and pride struggle for a more inclusive society. Disabled people still face basic problems of accessibility, accommodations, political representation, and bigotry. And yet the worry with socially

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<sup>36</sup> I am using Iris Marion Young’s pluralistic account of oppression to describe the unjust social conditions of disabled people (Young 1990).

backed medical practices for disability avoidance is that they might compel individuals and society to avoid or deprioritize addressing broader social issues affecting the lives of disabled people. As Paul Longmore notes,

[C]ure would eliminate disability as a social problem by making disabled people virtually disappear. Such ‘success’ supposedly would relieve the financial burden of long-term personal assistance services. It would also turn aside the political demands of disabled people who were becoming increasingly activist. It would obviate the need for civil rights measures that ensured access and reasonable accommodations and barred discrimination in education, employment, and public services. If people with disabilities got better, non-disabled individuals would not have to grapple with their personal biases and society would not have to rectify its institutionalized exclusionary practices (Longmore 2016, 106).

The idea of treating disability to address disability injustices by making disabled people “virtually disappear” is parallel to the abhorrent idea of addressing racial injustices by medically augmenting the racial phenotypical traits of people of color, which thereby eliminate people of color.

Also, addressing the “disability problem” as a medical issue seems to be in serious tension with the civil rights approach, given that they invoke different meanings about disability and disabled people. Mary Johnson, the founder and editor of *The Disability Rag* and *Ragged Edge* magazine, makes this point, stating, “Reasonable accommodation, demedicalization, universal design, customization and integration are simple enough concepts to understand, but hard to implement when the society you live in continues to see people with disabilities as having something wrong with them, needing cure or charitable help, or as sly malcontents trying to get some special rights they don’t deserve, creating nothing but problems and extra costs for the rest of us” (Johnson, xvii). As Anita Silvers points out, an attraction to practices of normalizing embodiments can be “fatal” to disabled people by diverting attention and resources away from political and social aims to make society more inclusive and accommodating for disabled people (Silvers 1998).

I find the expressivist argument to be compelling. Expressing equal concern and respect for all citizens, especially historically subordinated publics, is important. If actions and practices can have a particular social meaning, then our moral analysis of actions and practices ought to take into serious consideration what they express or how they are reasonably perceived by others. The concern is that propagating certain messages could have adverse impacts on the life prospects of certain already marginalized publics, reinforcing negative scripts and stereotypes that either offend the dignity of members of a certain public or shape social relations and structural arrangements in ways that seriously disadvantage them. The expressivist argument against reproductive practices to prevent the birth of disabled children is a prominent argument that can be repurposed to challenge medical practices for disability avoidance, namely that targeting disability traits for prevention or removal via medical

interventions expresses implicitly, or even surreptitiously, ableist meanings to diverse publics that are likely harmful to disabled people.

The expressivist argument should be taken seriously. Given the historical, sociocultural context from which this practice takes place, I believe these practices reproduce social meanings about disability that complicate the struggles for broader social justice for disabled people. The difficulty then is to figure out what is the appropriate response to medical practices for disability avoidance if they do express a social meaning that contributes to significant harms against disabled people. Before we grapple with this issue, it is worth considering major challenges to the expressivist argument. After exploring two of them, I argue that, ultimately, they do not succeed.

### **3. Skeptical Challenges to the Expressivist Argument**

A number of challenges could be raised against the expressivist argument. Here, I will briefly consider and reject two such challenges, each raising skepticism about one of the major premises in the expressivist argument.

#### *3.1 Devaluing Disability, but Not Disabled People*

One challenge is against the third premise, that devaluing disability implies the devaluation of disabled people. According to the third premise, medical practices for disability prevention and treatment communicate the message that disabled life is less valuable than nondisabled life since devaluing disability (through its prevention and treatment) is also devaluing the kind of life shaped by it. But one could argue that no such message about disabled people is necessarily communicated. A number of philosophers have raised this objection, arguing that it would be a mistake to infer from a practice that selects against disability that it is vilifying disabled people. Preventing and treating disability does not necessarily send a demeaning message about the moral standing of disabled people for the same reasons why preventing and treating the flu does not necessarily send a demeaning message about the moral standing of flu sufferers (Edwards 2004). The expressivist argument incorrectly assumes that there is only one plausible reading of medical practices for disability avoidance. Mary Ann Baily makes this point regarding prenatal practices for disability avoidance by asking rhetorically, “Acceptance of prenatal diagnosis and abortion certainly can express rejection of people with disabilities. But *must* it? Or can one look at it another way?” (Baily 2000, 65). Choosing to

prevent or mitigate a disability could mean so many things that do not necessarily implicate the value of disabled lives.

There are two reasons for believing that there are plausible polysemic readings to medical practices for disability avoidance, which would undermine the claim that such practices clearly transmit disparaging public meanings about disabled people. First, there may be a variety of reasons for why people might want to avoid becoming disabled that aren't connected to how they regard disabled people. For example, certain persons may be situated in ways that make living personally with a disability more difficult, such as their socioeconomic circumstances or that their particular life plans depend on a non-disabled embodied form (Kittay and Kittay, 2000). Medical practices for disability avoidance may then have many meanings, some objectionable, some not. As Baily notes, people can choose to avoid living with a disability (or in her case, giving birth to a child with a disability) without disparaging disabled people. "Does my personal decision have an expressive character? It does not express my opinion on whether people with disabilities can have a worthwhile, fulfilling lives (they can), whether parenting a child with a disability can be rewarding (it can), whether other people should be pressured into aborting fetuses with disabilities (they shouldn't), or whether societal resources should be devoted to improving the lives of people with disabilities (they should)" (Baily 2000, 67). For Baily and others, the expression of an action is derived from the intentions of the agent and thus, it is unreasonably uncharitable, if not grossly inaccurate, to suppose that the decision of individual agents to avoid acquiring a disability through medical support, as well as state actions to provide such support, are expressions of animus towards disabled people (Buchanan 1996; Kittay and Kittay 2000).

I believe this criticism isn't successful. Though I am suspicious of the claim that the patterns of aversion towards disabled embodiments are not significantly influenced by some social prejudice, I will put this suspicion aside for now. Instead, I dispute the criticism's assumption that the expression of an act or practice is determined largely by the intention of the agent, whether it is the individual or the state. It seems erroneous to think that the public meaning of a particular action arises from the intentions or actual attitudes of the agents. Rather, it seems more plausible to think that the expressive meanings of an action are shaped by how the action is situated in a sociocultural context of formal institutions, social practices, and cultural scripts. In this way, an action's meanings are socially constructed. This makes much sense when we reflect on other communicative acts, such as using prejudicial language like the N-word or displaying the Confederate flag. Though an agent may perform these acts without intending to denigrate Black people—maybe they say the N-word as a term of

endearment or display the Confederate flag to demonstrate historic or regional pride—these acts can still have a denigrating expression since individual agents do not control what a particular act communicates to others. This reasoning can also apply to medical practices for disability avoidance. Individual agents and the state can still act in ways that invoke particular meanings of ableist ideologies even when they do not subscribe to such ideologies because these actions and practices are embedded in a sociocultural context that imbue them with such meanings. So, the expressivity of a practice, like medical practices for disability avoidance, is not necessarily determined largely by the intent of the individual participants or representatives of the state, but by the sociocultural context from which they operate in.

Yet the problem of the first challenge suggests a second one. It may be true that the expressive meaning of an individual action or general practice is not determined by the intentions or attitudes of agents but by the larger sociocultural and historical settings from which decisions are made and practices take place. But how are we to understand this setting? It could be argued that the background context does not imbue medical practices for disability avoidance with a specific, discernible meaning, especially one that devalues disabled people. Nelson makes this sort of argument. She believes that flying a Confederate flag over a state capitol is a contemptuous communicative act since the meaning of the Confederate flag “stems both from the conventional role of flags as symbols for collectivities and their aspirations, and from this particular flag’s place in America’s tragic history of slavery and the defense of slavery. It cannot, then, be used as a state symbol (as opposed, say, to a museum exhibit) without expressing contempt for African Americans...” (Nelson 2000, 209). The meaning of medical practices for disability avoidance, on the other hand, might be more ambiguous since they do not take place against a set of settled social practices that recognize them as expressing contempt towards disabled publics. If medical practices for disability avoidance are communicative acts, then they are, in important ways, “degraded” forms of communication.<sup>37</sup>

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<sup>37</sup> Eva Kittay describes selective abortion in these terms. Appealing to Roman Jakobson’s model of communication, Kittay argues that selective abortion does not clearly express a disregard for disabled people for three reasons: (1) there is no clear contact between addressee and addressor, (2) no established code by which to interpret the meaning of the act, and (3) understanding the context that largely determines the meaning of the act is contested (Kittay and Kittay 2000, 186-187). Though she does not believe that selective abortion clearly expresses antipathy towards disabled people, she makes the point that if context is giving selective abortion this social meaning, then the target of rectification is not the practice of selective abortion but the broader sociocultural context (Kittay and Kittay 2000, 188). I will argue for a similar position here but deny Kittay’s point that the communicative act doesn’t reinforce the context from which it is performed. She seems to neglect the ways in which ableist expressions and higher-level social processes and structures mutually reinforce each other.

This criticism, too, is unpersuasive. This challenge depends on how we appraise the broader social milieu that contextualizes medical practices for disability avoidance. One may argue that we live in a “mixed system,” made up of an array of complex social forces, which include de jure and de facto social relations that express identity-based prejudice against disabled people and those that countervail these identity-prejudicial elements, such as the Americans with Disabilities Act. Given the competing norms around disability, it is reasonable to infer that the meanings of medical practices for disability avoidance remain ambiguous and subject to multiple interpretations. Yet this strikes me as an unreasonably charitable description of our socio-historical circumstances, especially when we reflect on our medical system. People with disabilities have long experienced histories of discrimination in medicine and public health, such as forced sterilization, institutionalization, infanticide, de-prioritization to life-saving healthcare resources, and QALY assessments that deem disability as detriments to wellbeing. Practices of deselecting disability conjure up a legacy of eugenics programs that identify disabled people as unfit to breed or live on account of social characteristics that are considered undesirable (Sparrow 2011). And though there are institutional and social practices that challenge ableist norms, considerable work still needs to be done to counterbalance a context that has historically stigmatized disability and devalued disabled people. Our society is still coming to terms with attitudinal and structural ableism, as signified by enforcement problems with the ADA and continued disability discrimination in multiple arenas of social life. To consider oppositional readings to medical practices for disability avoidance as equally plausible is to be inappropriately unresponsive to the perspectives of disabled people, the patterns of aversion and discrimination against disabled people, and a living history marked by ableist ideologies.

Furthermore, given the conventional role of medicine as promoting health and how disability is conventionally symbolized as a pathology, pathological meanings of disability are expectedly reproduced in medical practices for preventing and treating disability. This, in turn, contributes to consigning disabled people to sick roles, which is an expression of disrespect towards disabled people. Contrary to Nelson, our publicly sharable symbolic system clearly includes understanding disability as pathology and disabled people as sick or biologically worse off. This also points to the incoherence of Edwards’ position on the possibility of devaluing disability but not disabled people. Though disabled people may relate to their disabilities differently, disability is a paradigmatic embodied difference that guides, if not determines, the ways in which people are perceived and judged. In this way, disability, like race and gender, is fundamental to the self, such that it not only orients the ways in which we engage with the world, but also shapes social relations that manifest either mutual respect or lack

thereof. This point is exemplified in the existence of disabled people as a distinct social group that emerged from socio-historical processes of exclusion and elimination on the basis of how they are atypically embodied and classified as abnormal, as well as a collective resistance against these forms of oppression. Disability is made salient, and becomes a salient part of who disabled people are.<sup>38</sup> Thus, medical practices for disability avoidance can be expressively problematic given the history of pathologizing disability, how it has been used to justify the subordinated status of disabled people, and how the disability community seeks to de-pathologize disability and reframe it as an affirmative group identity in their struggle for social justice.

Again, there may be many reasons why individuals choose to remain non-disabled through medical interventions but given the ways in which disability and disabled people have been historically stigmatized in the realm of medicine, it is more reasonable to think that medical practices for disability avoidance reproduce negative social meanings about disability and disabled people that are likely harmful to them.

### *3.2 Are They Really Harmful?*

Another challenge to the expressivist argument is against the fourth premise. The fourth premise claims that medical practices for disability avoidance harm disabled people by sending a negative message about disabled people that undermines their ability to securely believe they are equal members of society, or contributes to preserving identity-based social hierarchies. One may argue that even if medical practices for disability avoidance express publicly a demeaning message about disabled people, it is not too clear how potent that message is in either eroding the assurance of disabled people of their equal moral standing or creating or sustaining an inequalitarian social order. This isn't to deny that medical practices for disability avoidance do not reproduce negative meanings about disability that are liable to reinforce attitudinal and structural stigma of disabled people, but to question the degree of potency we can reasonably attribute to medical practices for disability avoidance in contributing to these wider injustices.

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<sup>38</sup> This reflects Elizabeth Barnes' moderate social constructionist account of disability. In a nutshell, disability is defined by the disability rights movement to promote justice for people represented in those movements. Its social function is to organize people to challenge systems that oppress them on the basis of certain properties (Barnes 2016, 43-48). For more details, refer to chapter 1.

The nature of this question is similar to questions raised in the climate change ethics debate on whether the CO<sub>2</sub> emissions from individuals or specific practices, like allowing people to drive gas-guzzling cars, contribute so significantly to the degradation of the ecosystem that they should bear some responsibility for exacerbating the risks of climate change (Sinnott-Armstrong 2006). Analogously, do medical practices for disability avoidance contribute significantly to a social climate that harms and disadvantages disabled people? As noted in the previous section, the expressive meaning of medical practices for disability avoidance are the product of broader social inequity. But I do want to go further and argue that they are also contributors to social inequity, which make their expressions harmful. Their expressive force resides in the authority we give to medical institutions. Emily Johnson surmises that “it is the medical community—by distinguishing ‘normal’ from ‘abnormal’—that sets the foundation for broader social and cultural expressions of discrimination against people with disabilities” (Johnson 2016). This idea is rooted in the understanding of the medical establishment as having an influential stature in shaping the broader social meanings of disability. Thus, the expressivity of medical practices for disability avoidance gets its potency from the fact that these practices are backed and performed by medical institutions. A parallel example is the medicalization of homosexuality. Until 1973, the American Psychiatric Association classified homosexuality in their Diagnostic and Statistical Manual (DSM) as a mental disorder. The classification of homosexuality as a pathology was used to rationalize the social treatment of gay people as sexual deviants that called for their institutionalization and marginalization from mainstream society. The removal of homosexuality from the DSM contributed to a greater social acceptance of gay people (Drescher 2015). Given medicine as a central institutional authority in society, it is reasonable to infer that the medicalization of disability through medical practices for disability avoidance impedes the kind of structural change for achieving the social equality of disabled people.

#### **4. Ethical Responses to the Expressivity of Disability Avoidance**

The prior sections argue that medical practices for disability avoidance, when operating in a problematic context, reproduce negative social meanings about disability that reaffirm a morally suspect value system that harms disabled people. If medical practices for disability avoidance have externalities that perpetuate suspect norms, then what does justice require us to do? Though justice may mandate different responses to different agents depending on their relations to the set of practices and their power to enact change, the concern of complicity must be confronted by those involved,

whether they be the state, medical institutions, the individual medical professionals, or the individual patients who seek medical assistance to avoid acquiring a disability.

#### *4.1 Abolition of Disability Avoidance and Individual Ethical Self-Reform*

One ethical strategy to avoid the expressive harms of medical practices for disability avoidance would be to abolish them altogether. At the institutional level, this may take the form of the state defunding measures to treat and prevent disability or medical institutions no longer providing them, focusing more so on helping people accept, transition, and live with their new embodied forms. At the individual level, people are exhorted to make peace with, rather than postpone or resist, the prospects of becoming disabled. This may involve developing certain dispositions to help individuals cope with the vulnerabilities of becoming disabled, such as what Michael Sandel calls being “open to the unbidden.”<sup>39</sup> This virtue was illustrated in an episode of the podcast, *Terrible, Thanks for Asking*. The host, Nora McInerny, interviewed Leah, an artist who became disabled after a forklift tipped over and fell on her, damaging her body and severing her spine. She became paralyzed from the armpits down and lost her right leg. McInerny describes Leah’s attitude to her acquired disability in awe-inspiring terms, stating, “There is no point in our conversation or the correspondence before our recorded conversation where Leah talks about her body or her life with anything other than awe and respect and curiosity. She speaks about herself and her body the same way before and after the accident. In our conversation there isn’t a version of her life that is better or worse, just different.” Leah’s own words soon followed afterwards, “If somebody offered you a once-in-a-lifetime experience, like you would get the front-row seat to this crazy thing that’s, you know, history-making, you just have to say yes...” (McInerny 2021).

This is undoubtedly a bold response to medical practices for disability avoidance, but is it the most reasonable one? There is good reason to be deeply wary of it. Though it is critically important for individuals and the state to express equal respect and consideration for disabled publics and avoid being complicit in perpetuating suspect norms that harm disabled people, it is also important to consider the serious moral costs that come with not providing or subsidizing medical practices to

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<sup>39</sup> Michael Sandel appeals to the disposition of openness to the unbidden to argue against idea of using genetic technology to design children. He argues that the idea of tailoring a child according to one’s preferences violates the parental virtue of openness to the unbidden, which is the virtue of treating one’s child as a gift rather than a product of parental design, and accepting their unexpected uniqueness (Sandel 2007).

prevent and ameliorate disability. Elizabeth Anderson notes, “Justice demands that the claims that people are entitled to make on others should be sensitive not only to the benefits expected on the part of the claimants but to the burdens these claims place on others” (Anderson 1999, 294). One of these burdens, as elaborated in the previous chapter, is the extreme precarity of people’s identity and autonomy that are tied intricately to their embodiments. Without these measures, people are vulnerable to dramatic bodily change that threaten their sense of self and autonomy. But does this outweigh the stigmatization and marginalization of disabled publics that come with medical practices for disability avoidance? This is a very difficult question, but I think it does. Given how our bodies are so deeply intimate to us and how they sustain, if not constitute, who we are, it is unreasonable to compel people to inhabit embodied forms that are estranged to them, bodies that may not support their valued forms of life or express who they are without having individuals reacclimate to new embodied forms and, in the process, reconceive themselves. There is a kind of forced acculturation following from proscriptions against medical practices for disability avoidance that is deeply unsettling. Proscribing medical interventions forces people who undergo dramatic bodily change to renounce their deep-seated self-conceptions and create for themselves a new identity. Though the kind of openness to the unbidden as exemplified by Leah is an admirable disposition, it is overly demanding to expect non-disabled publics to adopt this attitude towards the prospects of becoming disabled, given how people’s sense of autonomy and identity can be bounded so intimately to their embodiments.

Furthermore, it seems misplaced to address social injustice by regulating the individual decision-making of patients on what form of embodiment are they are allowed to assume. Julian Savulescu draws a similar conclusion regarding the ethical permissibility of using PGD to select an embryo with socially desirable traits in an unequal society (e.g., a female embryo in a deeply sexist society). Though permitting sex selective abortions may exacerbate inequalities, the appropriate response is social institutional reform, not interference in reproduction. He argues, “What is wrong in such a society is the treatment of women, which should be addressed separately to reproductive decision-making. Reproduction should not become an instrument of social change, at least not mediated or motivated at a social level (Savulescu 2001, 424). To be clear, I am at serious odds with Savulescu on the meaning and moral status of disability that motivates his position on what

reproductive choices follow from his principle of procreative beneficence.<sup>40</sup> But here, Savulescu reminds us of a line that we ought to take seriously: that certain aspects of our lives are much too intimate to be regulated or unsupported by the state. This includes what kinds of bodies we are allowed to embody or be in relations with.

#### *4.2 The Reconciliatory Approach*

Though it may be justified for the state to subsidize medical practices for disability avoidance, it doesn't necessarily mean we should accept the status quo. There is still a social responsibility to attend to the moral residue that such practices create. But what can be done to address it with the aim of fostering social equality? Margaret Little suggests a promising approach to this dilemma. In "Cosmetic Surgery, Suspect Norms, and the Ethics of Complicity," Little grapples with the ethics of cosmetic surgeries embedded in a complicated context of suspect norms of appearance. Though there is an obligation to help relieve the suffering of people, there is also an obligation to not be complicit in an unjust value system that is responsible for their suffering. Instead of choosing between two equally compelling but competing values, Little proposes a more reconciliatory approach:

If one must perform surgeries to help people meet suspect norms of appearance (out of concern for their suffering, say), then one must maintain an overall stance of fighting the norms. The only way to participate in the surgeries without de facto promoting the evil whose effects one decries is to locate the surgery in a broader context of naming and rejecting the evil norms. One's purpose and meaning—that of alleviating the extreme burdens the system places on some—can be expressed only if one's broader actions stand squarely against the norms (Little 2000, 173).

For Little, cosmetic surgeries should still be offered but accompanied with other actions and practices that countervail the vicious norms that motivate many people to change their appearances, such as providing prospective patients access to a range of stories of people who considered or underwent cosmetic surgery, pointing out the unfairness of the norms, and working against them. This counteracts social pressures that can limit people's imagination of what options are genuinely open to them. Little says most pithily, "[S]ometimes perform the surgery, and always fight the system" (Little 2000, 176). Furthermore, changing the context also changes the meaning of the practice, where

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<sup>40</sup> Savulescu argues that his principle of procreative beneficence calls for prospective parents to use reproductive and genetic technologies to avoid producing disabled children and ensuring the birth of nondisabled children. Procreative beneficence is a welfare-maximizing principle that prescribes prospective parents to create children that have the best prospects to live the best possible life. For Savulescu, disability is a welfare-diminishing trait and therefore prospective parents are proscribed from creating disabled children if they can create nondisabled children instead (Savulescu 2001).

cosmetic surgery would no longer be understood as a tool of injustice but rather as an ameliorative response to the suffering caused by it.

This reconciliatory approach could be applied to medical practices for disability avoidance. Instead of condemning an individual set of practices for its objectionable expressive character, we should concentrate on changing the context that imbues these practices with the kind of expressive meaning that sustains injustice experienced by disabled people. Kittay alludes to this response in her engagement with opponents of disability-selective abortion, saying, “If we are concerned with the devaluation of the life of the disabled...then we need to fix on, and fix, the context, not the utterance” (Kittay and Kittay 2000, 188). Reaping the benefits of medical practices for disability avoidance could be still done without having to sacrifice our egalitarian aims just as long as we reform our scheme of social and institutional practices in ways that overall promote the social equality of disabled people. This not only counteracts any disparaging expressions about disabled people that could be transmitted from medical practices for disability avoidance, but it makes room for the practice to be interpreted prevalently in non-ableist ways that do not reinforce ableist norms and hierarchies.

What kind of social reforms follow from this broad-based ethical strategy? The list of the needs of social reforms to achieve disability justice is extensive. Just to name a few: enforce robustly nondiscrimination laws, like the ADA; deinstitutionalization; universal design and radically inclusive public spaces; access to adaptive devices; authentic and dignified representations and greater visibility of disabled people in media; inclusion of disability perspectives in decision-making bodies.

There are also a number of practices that medical institutions should implement to help revise the meaning of medical practices for disability avoidance. For one, providing equal access to healthcare for disabled people is a critical first step. As noted earlier, disabled people are often deprioritized in triage protocols or given less optimal, if not positively harmful, care, the most recent example being their lack of meaningful access to COVID-19 treatments (Proulx, Anderson, and Sirotich 2020; Savin and Guidry-Grimes 2020). These institutional failings are related to QALY assessments used to form medical rationing policies and analyze the cost-effectiveness of certain healthcare provisions that define disability as a detriment to wellbeing, consequently assigning a lower value to disabled people (Gallegos 2021; Silvers 1995). Another positive step is to include disability competency curricula in medical education to combat biases and misperceptions that impact the quality of clinical care (Gallegos 2021; Haque and Stein 2020). Third, people who seek medical practices for disability avoidance should have access to the variety of perspectives and narratives of people living with an

acquired disability (through videos or peer mentors) before committing to such interventions. This not only helps prospective patients make more informed decisions by enriching their understanding of what it is like to be disabled, but it also helps destigmatize disability, legitimizing it as an acceptable form of embodiment.

The expressive character of medical practices for disability avoidance is tied closely to our systems of practice and a grim historical legacy of institutional and attitudinal ableism. For practices to prevent or cure disability to no longer reproduce and reinforce unjust attitudes and norms, broader social change must take place where disabled people are treated as moral equals. We ought to be concerned about what our actions and practices express to diversely located publics, especially historically subordinated publics who are struggling for equal recognition and respect, and we ought to act in ways that are deeply sensitive to expressive considerations. Medical practices for disability avoidance provide a critical good to nondisabled publics by providing them the means to sustain their particular autonomy, and for that reason, it is much too important to be sacrificed. But it is also important to address its expressive consequences. Thus, it calls for altering the broader context.

#### *4.3 Autonomy or Social Equality? A Moral Tragedy*

Yet there is still a moral unease with the reconciliatory approach. Though the expressive meanings of medical practices for disability avoidance are products of broader social inequality, they are, again, perpetrators of social inequality, which is one of the major points of the expressivist argument. As medical practices for disability avoidance continue to operate in our contemporary context, they will still reproduce ableist social meanings that harm disabled people and impede the kind of socio-structural change that is needed to reform the expressive character of medical practices for disability avoidance. The continued practice of preventing and curing disability hinders the promotion of broader disability justice. Thus, advocating for the reconciliatory approach could mean a longer and unsure road to social equality. In effect, it asks disabled publics to continue enduring the social burdens contributed by medical practices for disability avoidance so that nondisabled publics can still gain its benefits. There is an open question of whether extensive prohibition or nonsupport of medical practices for disability avoidance would likely encourage rapid progress towards a more inclusive society. But it seems just as unsettling for historically subordinated publics, like disabled publics, to assume the social costs of a set of practices that exclusively benefit nondisabled publics.

Though I still believe the reconciliatory approach is the most appropriate response to medical practices for disability avoidance because it tries to strike a reasonable balance between the dual values of autonomy and equality, there is still a morally tragic aspect to this approach that needs to be recognized. By moral tragedy, I mean a state of affairs where an unjust situation cannot be addressed without committing other forms of injustice. Preserving medical practices for disability avoidance comes at a cost of hampering social justice efforts by and for disabled people. Given its morally tragic element, the reconciliatory approach must be accompanied with a sense of urgency and expediency to relieve the harms of disabled publics.

## **5. Conclusion**

In this chapter, I grappled with the expressivist objection against medical practices for disability avoidance. In the first half, I defended the expressivist argument against various objections, supporting the position that medical practices for disability avoidance, in light of the background context, do reproduce negative social meanings about disability and disabled people that reinforce an inegalitarian social order that unduly harms disabled people. In the second half, I considered various responses to the expressivist problem. I argued that the appropriate response is to support medical practices for disability avoidance while, at the same time, make broader social reforms to revise the background context that imbue these practices with such negative expressive meanings. This response would help continue providing identity- and autonomy-maintenance across body types while challenging the suspect social norms of embodiment that lead to the undue harms of disabled publics.

In the next chapter, I will grapple with another objection against my thesis that the state is justified to support medical interventions to prevent and ameliorate disability even when disability is understood as a mere difference. The objection deals with the moral status of body-changing medical interventions, such as gender-transition medical care.

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## Chapter 4: Altering the Body (Un)Habitus: On the Justice of Gender-Transition Care and Other Body-Changing Interventions to Affirm Identity

*The something that was missing was me; the part that I kept running from all these years. I didn't begin to feel whole again until I started to validate me, the one I had stuffed so far down he was killing me for not letting him out. My soul was dying.*

— Anonymous trans man describing his life before transitioning (Mason-Schrock 1996, 187)

### 1. Introduction

In the previous chapters, I provided pro tanto reasons for why, even on a mere difference view of disability, the state should support medical interventions to treat and prevent disability in non-disabled people. Since an agent's particular embodiment is an important context of choice that enables and deeply structures their autonomy, and the value of autonomy generates obligations of the state to support people to remain as agents, the state is justified to support medical interventions to maintain the embodiment of individual agents from the prospects of dramatic bodily change that could disrupt their context of choice.

Yet characterizing dramatic bodily change as a threat to autonomy and understanding medicine's purpose as preventing or reversing the kinds of changes that could undermine an agent's autonomy seem to neglect, if not go against, the idea that some people's initial embodiments could be distressingly dissonant to their identity and that the state should also support medical interventions to change people's embodiments, and not simply be restricted to maintaining them, so that they align with their identity. The most prominent example is gender transition care for transgender people. This issue is especially resonant at the time of writing this chapter. Arkansas, for example, just banned the provision of gender-affirming medical care to trans young people as part of a current trend of U.S. states refusing to recognize the validity of transgender identities.<sup>41</sup> Other body-changing interventions to affirm a person's identity include deliberate disablement, like elective amputation of functioning

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<sup>41</sup> At the time of this writing, thirty-three states have introduced more than 100 bills that aim to curb the rights of transgender people. These include a number of states banning transgender athletes from participating in sports consistent with their gender identities and limiting the exposure of LGBTQ education in public schools (Krishnakumar 2021).

limbs, for transabled<sup>42</sup> people. I will use the catch-all term “body-changing interventions” to refer to medical interventions that seek to modify people’s natal embodiments so that they could support or exemplify their particular identities.

Should body-changing interventions be publicly funded as a requirement of justice? Or are they “cosmetic enhancements” that are extraneous to justice? One of the ways of addressing this question is to situate it with my argument for subsidizing medical interventions for disability avoidance as a form of medical care for maintaining the autonomy of agents whose autonomy is connected to their particular embodiments. Given my focus on maintaining embodiments, it may seem like my account has nothing to say about, or might even rule against, the public funding of medical interventions to change bodies. Thus, the central question of this chapter is: what is the moral status of body-changing interventions for affirming identity in relation to the understanding of the body as an important context of choice for autonomy?

I argue that my account of the body as an important context of choice for autonomy can help inform the question of justice of publicly funding body-changing interventions to affirm identity. If autonomy is the successful or efficacious expression of an agent’s practical identity and such expressions can only be facilitated through an embodiment that supports the agent’s identity, then autonomy is curtailed when an agent’s body is ill-suited to express or hold them in their identity, or it fails to make their self-expressions intelligible to others. This discord between embodiment and identity can be highly distressing.<sup>43</sup> A discordant embodiment that undermines autonomy may come about by dramatic bodily change, and for this reason the state should be interested in preventing such change from occurring. But there is no reason to think that this is the only way that someone could have a discordant embodiment. As trans people attest, people can and do experience an internal contradiction with their natal embodiment in ways that compromise their autonomy. Thus, the state should be interested in supporting body-changing interventions to promote the autonomy of agents by helping them attain the kind of embodiment that allows them to express who they are.

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<sup>42</sup> I will use “transabled” to refer to able-bodied people who identify as disabled and experience their nondisabled embodiment as an internal contradiction (Davis 2012). I will elaborate further this identity type in section 5.

<sup>43</sup> This type of distress is often called body dysmorphia. Body dysmorphia (or body dysmorphic disorder) is an overwhelming dissatisfaction with one’s body, perceiving it as flawed or defective. In a clinical setting, body dysmorphia is recognized as a mental health disorder, contrasting with gender dysphoria, which is not considered a mental health disorder. I will use this term sparingly given its connotation as a mental health problem. I want to generally avoid characterizing any distress arising from a deep sense of discord between a person’s embodiment and their identity as a pathology, reserving this term for more specific subjective experiences related to anorexia nervosa or bigorexia (a preoccupation with the idea that one’s body is too small or not muscular enough).

From this understanding, I argue that gender-transition interventions should be publicly funded. But this does not necessarily mean that all types of body-changing interventions to affirm avowed identity should be supported by the state. Not all identities generate legitimate claims against the state to provide its identity-bearers with medical resources to align their bodies with their identity. These include “peripheral” (as opposed to “core”) identities, “self-defeating” identities that do not facilitate autonomy, and “proscribed” identities that are, in themselves, seriously problematic in relation to other justice considerations. Thus, the justification of publicly funding body-changing medical interventions to affirm identity is conditioned on how the identity is related to autonomy and justice.

This chapter will proceed as follows. In section 2, I will begin my examination on the ethics of body-changing interventions by looking at gender-transition care. I will elaborate some of the procedures that fall under this type of care and key arguments against their subsidization. In section 3, I will defend gender transition care in virtue of promoting the autonomy of trans people. I argue that people could experience their natal embodiment as a kind of context that is unsupportive of their identity and, in turn, their autonomy. Building from my defense of gender-affirming medical care, I develop a general case for the state to subsidize identity-affirming medical care as required by justice. Yet I argue that this is conditional on the content of the identity, and in section 4, I will consider certain types of identities that should not be supported or respected by the state through its healthcare institutions. In section 5, I will consider transabled identities.

## **2. Gender-Transition Care and its Moral Standing**

To begin discussing the justice of subsidizing body-changing interventions for those experiencing discord with their embodiment, an apt place to start is to examine gender transition care for transgender people who desire to have a different embodiment. Given the contested meanings of terms used to denote diverse gender identities, it is important to make clear my language choices in this chapter. Following the GLAAD Media Reference Guide, I will use the language *transgender* (or shorthand *trans*-) in the inclusive sense to mean the following:

An umbrella term for people whose gender identity and/or gender expression differs from what is typically associated with the sex they were assigned at birth. People under the transgender umbrella may describe themselves using one or more of a wide variety of terms – including transgender...Many transgender people are prescribed hormones by their doctors to bring their bodies into alignment with their gender

identity. Some undergo surgery as well. But not all transgender people can or will take those steps, and a transgender identity is not dependent upon physical appearance or medical procedures (GLAAD).<sup>44</sup>

This is in contrast to *cisgender*, which is used to refer to people who are not transgender, that is, whose gender identity aligns with their sexed body designated at birth and their self-conception does not significantly transgress the traditional gender binary system.

*Gender transition care* refers to the set of medical interventions to help people reconfigure their embodied characteristics in ways that cohere with their gender identity. This can be accomplished through various methods. One method is providing puberty-suppressing treatments, or puberty blockers, to transgender young people to prevent or delay unwanted changes associated with their natal embodiments, such as periods in trans boys or an Adam's apple and deepening of the voice in trans girls. Puberty blockers are reversible and offer young people more time to decide how to proceed with their bodies. Another method is sex hormone therapy. This involves providing estrogen and antiandrogens to trans women and testosterone to trans men. These interventions can help a trans person attain embodied features that represent their gender identity, such as trans men achieving more stereotypically masculine characteristics like facial hair and a deeper voice and trans women achieving more stereotypically feminine characteristics like breasts. A third method is surgery – like hysterectomy, masculinizing chest surgery, feminizing augmentation mammoplasty, vaginoplasty, and phalloplasty – which are more invasive measures to reconstruct a person's embodiment (UCSF Transgender Care). Gender transition care is considered to be a part of a broader category of *gender-affirming* care, which describes not only a specialized species of medical services but also a general prescription of inclusiveness in healthcare settings. It is medical care that attends to the physical needs of transgender people in ways that respectfully affirm their gender identity, as opposed to pathologizing or mistreating them on account of their gender minority status. Though body-changing interventions should not be thought of as the end goal of all trans people, they are considered to be a

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<sup>44</sup> Another convention to denote maximal inclusivity is “trans\*”. In the end, I decided not to follow this convention because of the disagreement surrounding it. For example, the people behind Trans Student Educational Resources have opted to stop using “trans\*”, explaining, “There is nothing inherently problematic with the asterisk but it’s often applied in inaccessible, binarist, and transmisogynist ways. It is unnecessary and should not be used. Claiming the asterisk itself is fundamentally oppressive denies accountability and ignores the culture of binarism and transmisogyny that affects the community. People also often misattribute its history to cisgender and binarist people. . . . In the end, we decided to stop our use of the asterisk because of how unnecessary and inaccessible it is and its common application as a tool of binarism and silencing trans women. We encourage you to do the same. We are in the process of removing all asterisks from our web site, publications, and infographics” (Quoted in Garvin 2019).

critically important good that should be available to all trans people, whether or not they desire to undergo these interventions themselves.

The provision and public funding of gender transition care are still heatedly disputed. At the time of this writing, Arkansas recently passed a law that banned the provision of gender transition care to trans youths. A number of legal battles have been fought recently over the issue of whether Medicare and Medicaid should cover gender transition care. In 2019, the Iowa Supreme Court ruled that Medicaid should cover gender transition care, invalidating Iowa's ban on Medicaid coverage for those medical services. Gender-transition care, as deemed by the Court, should be regarded as an entitlement as derived from their laws that prohibit discrimination based on sexual orientation and gender identity in areas of housing, employment, education, credit practices and public accommodations (Aviles and the Associated Press 2019).

There are a number of arguments against publicly funding gender-transition care. I will not consider certain challenges, prominent though they may be, for purposes of brevity. One challenge is the legitimacy of transgender identities, arguing that such identities are objectionable since they defy biological or social realities and thus, states should not cater to these identities.<sup>45</sup> Another challenge is that gender-transition care is mutilation, arguing that these medical interventions actually cause harm to people who undergo them. I appeal to the testimonies of many trans individuals and take as my starting points the positions that (1) trans identities are legitimate identities and (2) gender transition care is not mutilation. Instead, I want to take seriously another standard challenge against gender transition care, which is that they are not medically necessary.

A prominent argument against subsidizing gender transition care services is that they are not medical necessities, but mere cosmetic enhancements. These terms have substantive value commitments built into them and what they mean have been the subject of much debate. They commonly function as a way to demarcate what kind of medical services should be covered in public and private insurance schemes, where medically necessary services are covered but cosmetic enhancements are not. The notion of medical necessity is related to the treatment/enhancement distinction. Its moral point in the context of healthcare justice is to identify which medical care should be excluded for coverage as extravagant and superfluous to justice since it is unreasonable to think

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<sup>45</sup> Prominent philosophers, such as Holly Lawford-Smith and Kathleen Stock, have argued against the legitimacy of transgender identities (Lawford-Smith 2020; Stock 2018). They represent a community of feminists often called “trans-exclusionary radical feminists”, or TERFs, who reject including transgender women in the social category “woman”.

that justice requires healthcare institutions to satisfy all preferences of people regarding how they would like their bodies to be altered (Daniels 1994, Resnik 2000, Davis 1998). Aesthetic enhancements, like botox injections, liposuction, and hair transplants, are widely considered to be unnecessary and are often taken to be paradigmatic cases of medical interventions that should not be publicly supported but can be made available for individual purchase. Why, as the argument goes, should we think of gender-transition care any differently?

This argument could be schematized as the following:

- (1) The state should not publicly fund medical interventions that do not promote the moral goal(s) of medicine.
- (2) Gender-transition care does not promote the moral goal(s) of medicine.
- (3) Therefore, the state should not publicly fund gender-transitioning care.

The crux of this argument is how we conceive the moral ends of medicine and how gender-transition care fail to promote them. But how should we understand medicine's moral purposes? One answer is treating and preventing diseases in human beings. Following from this, it could be argued that gender-transition care does not serve these goals. There are two serious problems with this response. First, this answer appeals to concepts, "health" and "disease", whose meanings are themselves seriously disputed. The definition of "health" and "disease" might seem straightforward as a description of biological states that could be assessed scientifically. However, the development of critical disability scholarship has called into question the conventional definitions of "health" and "disease" and how they are thoroughly value-laden (Aas 2016; Silvers 1998). More inclusive accounts of health could legitimate an expansive range of medical interventions, including gender-transition care, as medical necessities.<sup>46</sup> Also, even if a more conventional or narrow construal of health is used, it could still be argued that gender-transition care promotes health. Johann J. Go challenges the characterization of gender-transition care as a mere cosmetic procedure since gender dysphoria is recognized as a medical condition (Go 2018). Trans publics have a higher disease burden than cis publics. For example, trans people have higher rates of substance abuse, HIV seroprevalence, suicide ideation, and suicide attempts (Winter et al. 2016). On top of societal discrimination and stigma, a major contributor to poorer health outcomes in trans people is their experiences of psychological suffering of being in a

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<sup>46</sup> The World Health Organization defines the concept of "health" in broad terms of overall wellbeing. Health is "a state of complete physical, mental, and social well-being and not merely the absence of disease and infirmity" (WHO). This understanding of health would recognize gender transition care as a medical necessity, given the adverse physical, mental, and social effects of being in a discordant sexed embodiment.

body that conflicts with their gender identity. Gender-transition care is then an effective treatment for gender dysphoria.<sup>47</sup> Though I have reservations with approaches that seem to medicalize trans experiences, the underlying point here is that subsidizing gender-transition care could be justified as promoting the physical and mental health of trans people.<sup>48</sup>

The second problem is that even if a narrow construal of health and disease is accepted, there is still an open question of why public funding should only support medical practices that promote health. Aren't there other important objectives that medical institutions could help promote that are of interest to the state, such as well-being and autonomy? For example, breast reconstruction surgery for women who have undergone a mastectomy is covered by many public health systems, including the United States under the Women's Health and Cancer Rights Act (American Cancer Society 2019). And there are state-funded programs for removing anti-social or gang-related tattoos, such as swastikas, that people have gotten during their time in prison for purposes of survival or representing a previous, objectionable identity that they now renounce<sup>49</sup>, and tattoos of servitude or ownership of sex-trafficked women (Kogan 2020; Morin 2017). Yet these medical interventions do not really

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<sup>47</sup> A possible alternative is psychological treatment. By this, I mean ameliorating gender dysphoria by altering the self-conceptions of trans persons so that they reconceive themselves in ways that accord, or at least make peace with, with their current embodiment. This is analogous to conversion therapy. It seems quite appropriate in cases, such as bigorexia, since the alternative (giving them steroids and surgical muscle enhancements) is morally objectionable. Whether or not we ought to resort to this form of intervention depends on a number of considerations. One major consideration is the content of the identity. I will explain more in section 4. Given that trans-identity is understood here as a legitimate identity that ought to be recognized and supported by the state, resorting to psychological treatment would be *prima facie* morally objectionable. It is unlike bigorexia, but I do not have the space to develop a robust argument of how they are different.

<sup>48</sup> In the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), the American Psychiatric Association (APA) changed the diagnosis of gender identity disorder (GID) to gender dysphoria (GD) to foreground the distress often experienced with an incongruent sexed embodiment rather than pathologizing the identity itself (Davy and Toze 2018). Though renaming GID to gender dysphoria reflects the APA's attempt to be more respectful and responsive to the transgender community, its inclusion in the DSM still connotes to some trans-rights advocates as a psychiatric disease. Kayley Whelan, the board liaison of the National LGBTQ Task Force, states that the inclusion of GD may have a short-term of benefit of being a "stop-gap measure" to justify the reimbursement of trans people for gender transition-related medical expenses. But they argue,

"Yet, we must understand that as long as transgender identities are understood through a "disease" framework, transgender people will suffer from unnecessary abuse and discrimination from both inside and outside the medical profession. As long as gender variance is characterized by the medical field as a mental condition, transgender people will find their identities invalidated by claims that they are "mentally ill," and therefore not able to speak objectively about their own identities and lived experiences. This has even been used to justify discrimination against transgender people, such as in child custody cases, discrimination in hiring/workplace practices, or justifying them to be mentally unfit to serve in the military" (Whelan).

<sup>49</sup> For example, California is spending \$6.4 million to expand its pre-release tattoo removal program to serve 21 prisons and facilities across the state (San Quentin Contributor 2020). Also, Washington Hospital is funding a tattoo removal program to help teenagers and young adults who seek to make positive changes in their lives remove tattoos of negative symbols that represent their past (Washington Hospital).

promote health, narrowly construed, but are done for other legitimate reasons. In my previous chapters, I defended the public support of medical interventions to maintain the non-disability status of able-bodied persons on the basis not of health but of autonomy since disability is not a pathology. Thus, it is too quick to assume that healthcare institutions should only be concerned about health, narrowly construed. There are undoubtedly practical reasons for limiting what medical services are covered by the state with limited resources. Kathy Davis illustrates poignantly the struggle faced by the Netherlands with financing a national health insurance system that included “welfare surgery,” or cosmetic surgery to relieve psychosocial-related problems, in their national health insurance system (Davis 1998). Yet it is too presumptuous to dismiss uncritically gender-transition care as medically unnecessary on the grounds that it does not promote the health of persons undergoing the procedure. Such a response presumes a particular definition of health and a value system to govern healthcare institutions that require justification.

In the next section, I will consider the justice of subsidizing gender-transition care from the lens of autonomy and understanding of the body as a context of choice. I will argue that gender-transition care should be publicly funded because such interventions promote the autonomy of persons experiencing gender dysphoria, showing that the conceptual framework I have developed so far to defend body-maintaining interventions, like medical interventions for disability avoidance, as interventions to maintain agents’ autonomy can also support, in some circumstances, body-changing interventions, like gender-transition care.

### **3. Gender-Transition Care as Promoting Autonomy**

I see a number of ethical reasons that justify public funding of gender-transition care. Go develops a case from the consideration of health (Go 2018). Gender-transition care treats a medical condition, relieving and preventing the profound effects of gender dysphoria on the physical and mental health of trans persons experiencing it. Similarly, it could also be argued that gender-transition care is justified on humanitarian or welfare-based reasons. Gender dysphoria can be a source of psychosocial problems and can cause an unacceptable degree of damage to a person’s happiness and well-being. As noted earlier, the distress stemming from living in an embodiment that is in serious tension with their gender identity can lead to antisocial and suicidal behavior. Thus, it just seems cruel for the state not to provide the necessary care to alleviate the embodied conditions of persons that cause feelings of gender dysphoria.

Instead, I want to argue for the public funding of gender-transition care from the value of autonomy and the conceptualization of the body as an important context of choice. I want to orient the discussion around these ideas for two reasons. First, I want to dispel any worries that the conceptual resources used to defend subsidizing medical interventions for treating and preventing disability, in effect, prohibit subsidizing medical interventions to modify embodiments. This worry was initially raised at the end of Chapter 3 and I return to it here to address it. Second, arguing for the public funding of gender-transition care from the value of autonomy would provide another independent reason for this type of medical intervention, further supplementing the cumulative case for it. Autonomy-based arguments for subsidizing gender-transition care are not as readily available and such reasons would be more relevant to those who hold conceptions of justice that are oriented around the value of respecting and promoting autonomy.

### *3.1 The Body as a Context of Choice*

As argued in Chapter 2, the body is a critical prerequisite for autonomy, not only because we need a body to act in the world but that it can make our actions intelligible and meaningful to us, as well as to others, in relation to our practical identity, for which our embodiment may also provide meaning. This is what I mean when I describe the body as a context of choice. It enables and deeply structures our individual autonomy. We perceive, experience, and express ourselves in the world through our distinctive bodies, and our bodies help shape how others perceive and treat us. One of reasons why we may value our existing embodied forms is because they present us with forms of living that we value, enable us to act in ways that accord with who we are, and help to hold us in a particular valued identity. The connection I draw between the body, identity, and autonomy is that autonomy is achieved when the body supports the expression of an agent's identity. Thus, the moral importance of congruence between a person's lived body and their self-conception lies in the value of respecting and promoting autonomy.

### *3.2 Discordant Embodiments as Autonomy Harm*

It is a detriment to a person's autonomy when they assume a lived embodiment that is not compatible with their practical identity. A discordant embodiment undercuts an agent's ability to manifest their identity. As elaborated in Chapter 3, a discordant embodiment can come about through

dramatic bodily change, wherein the agent struggles with integrating their new embodied form to their former life and identity. But there is no reason think that dramatic bodily change is the only way that a person could be in a discordant embodiment. As trans people can attest, one can already experience an estranged, dissonant relation with their natal embodiment, where the body that a person was born with could feel thoroughly alien and contrary to their identity.

The autonomy harms of discordant embodiments could manifest in at least two ways. First, living in a discordant embodiment could be highly distressing. Again, this is tragically apparent in the high rates of attempted suicide and suicidal ideation among trans young people (Human Rights Campaign 2018). Studies have shown that trans young people, when living in an embodiment that is alien to them, are more susceptible to diminished levels of self-confidence because of (1) the incongruence of their gender identity with their sexed body and (2) the lack of social acceptance (Costa et al. 2015; McConnell, Birkett, and Mustanski 2016; McGruire, Doty Catalpa, & Ola 2016; Grossman and D’Augelli 2011). Thus, a discordant embodiment can negatively affect a person’s autonomy by damaging their sense of themselves as a capable and worthy source of action.

Second, living in a dissonant embodiment can undermine the intelligibility of one’s actions and choices. People are prone to being read in particular ways in particular social settings because of how they are embodied. This is especially true with sex and gender, as with other social categories (like race, ethnicity, and disability), where certain types of embodiments are socially inscribed with norms, expectations, and scripts, or what Robin Dembroff and Daniel Wodack call blueprints, that shape how people in those embodiments are interpreted (Dembroff and Wodak 2018, 378). When an agent is in a sexed embodiment that is dissonant to their gender identity, they are more vulnerable to being misgendered. For example, a trans woman going into spaces that are exclusive to women, like woman-designated restrooms, may not be interpreted by other people in ways that affirm their identity. Rather, they may be interpreted in nefarious terms as pretenders, or deceivers, or sexual predators (Bettcher 2007). Dembroff and Wodak elaborate this harm by way of examining the case of Catherine McGregor, a senior transgender military officer who has been misgendered by a prominent Australian politician. They state:

Consider gender-specific norms like *women shave their legs*. Misgendering McGregor would undermine the intelligibility of her actions and choices *vis-à-vis* this norm regardless of whether McGregor shaves her legs: she can only be recognized to conform to *or* violate the norm if the norm is recognized as applying to her. So if McGregor is misgendered as a *he*, the intelligibility of her actions and choices is undermined. She is stripped of certain forms of speech and self-expression. By this, we mean both that misgendering McGregor denies her *autonomy* over which blueprints apply to her, and leaves her with a range of blueprints that she can justifiably consider to be unsatisfactory. Setting aside the practical implications and dangers

of lacking this ability to communicate, there can be little doubt that this expressive stifling also does serious harm to an individual, especially given the social salience of gender norms (Dembroff and Wodak 2018, 378).

Dembroff and Wodak argue that misgendering can be an autonomy harm, not only because it violates the autonomy of trans people to choose how they are held and interpreted, but it also denies trans people the kind of social recognition from others that is required for their actions to be efficacious. As Sharon R. Krause points out, agency depends on a level of social uptake, where an agent's conduct is properly understood by other people in terms that reflect the agent's view of themselves (Krause 2013).<sup>50</sup> One problem with a discordant sexed embodiment is that it subjects a trans person to an interpretive schema that negates their identity and renders their actions as illegible or incredulous to other publics, or in other words, being misgendered. Instead, transphobic misinterpretations derived from prevailing systems of gender representation may shape the social perception and treatment of trans people, constraining trans people to affect the world in ways that affirm their practical identity. This is what Dembroff calls ontological oppression (Dembroff 2018).

These two harms reflect the identity (or subjective) and efficacy (or intersubjective) components of autonomy. A discordant embodiment can compromise any one of these components, which would then undermine autonomy.

### *3.3 Gender Transition Care as Making the Self Supported and Legible*

Given the autonomy harms that arise from a sexed embodiment in discord with one's gender identity, gender transition care can be reasonably conceived as a type of medical intervention that prevents or ameliorates these harms, and in turn, promotes the autonomy of trans people who feel thoroughly alienated from their sexed body. Again, not all trans people desire to undergo gender-transition care, but what I want to argue is that gender-transition care is an important good that the

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<sup>50</sup> Alisa Bierra challenges social conceptions of agency that depend significantly on the social legibility of an agent's actions. She raises concerns that such a conception would fail to recognize the possibility of resistant agency in contexts of oppression (Bierra 2014). Overall, I embrace Bierra's heterogeneous framework of agency. It rightfully appreciates the creative, improvised ways in which oppressed agents achieve ends in a social setting that distorts the meaning of their actions. These are instances of agents reclaiming their agency. This reclamation is also found in the narratives of many trans agents who express themselves in their discordant embodiments (Bornstein and Bergman 2010). But the level of creativity required to exercise a meaningful sense of agency within such contexts are made more difficult given the barriers and systems of interpretation that oppressed agents have to navigate and coopt to their advantage. It may be erroneous to characterize oppressed agents as always lacking agency, but I think it is reasonable to characterize oppressive circumstances as threatening the agency of oppressed agents without exercising a demanding level of creativity and resilience to transform, transcend, or coopt such circumstances.

state should fund publicly for the sake of promoting the autonomy of those of who do experience their sexed bodies in problematic, autonomy-constraining ways. In the previous section, I elaborated on how a discordant embodiment could be damaging to a person's autonomous agency. When a person's embodiment is in discord with their practical identity, their embodiment is unable to facilitate the effective expression of their identity or give meaning to their identity. Their sexed embodiment and the ways in which it shapes social interactions help form a moral world that is not conducive to who they are, conjuring experiences of estrangement and distress with their embodiment.

Gender transition care helps trans agents have a sexed embodiment that is more supportive of their practical identity, and in doing so, it promotes their autonomy. For one, a compatible sexed embodiment can mitigate the distressed sense of internal contradiction and misrecognition that could damage an agent's precarious sense of self as a valued source of actions. Second, a compatible sexed embodiment can make an agent's self and their self-grounded expressions legible to other publics, relieving trans agents from the systematic threats of being misgendered and any maltreatment following from it. With a sexed embodiment that is closely aligned with their gender identity, trans people's actions may be more receptive to broader social uptake.<sup>51</sup>

One may argue that the self-confidence of trans people and the intelligibility of their actions would assuredly improve if we undertook broader social change and removed transgender discrimination and stigma in society altogether, neutralizing the need to reconfigure people's sexed embodiments through medical means. I would like to respond to this argument in two ways: first, even in a more just and inclusive society, a trans person, though not all, may still experience suffering from having a discordant embodiment, though it may be true that an unequal, sexist, and transphobic society exacerbates feelings of insecurity in trans people (Bettcher 2014). Second, it is unreasonable to ask trans people to live in an unwelcoming moral world that fails to interpret their actions in ways that acknowledge and affirm their identity. It is a world that is existentially threatening to trans people and where it is frustratingly slow to change. Thus, it seems unreasonably burdensome to deny trans people the option to alter their embodiments in ways that make their conduct more legible to other publics, ameliorating their vulnerabilities to the maltreatments misgendering and transphobic violence.

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<sup>51</sup> Bettcher does point out even undergoing genital reconstruction surgery may not emancipate trans people from being socially interpreted as "pretenders" and "deceivers", given that mainstream view that a person's sex (or genitalia) is moral and invariant in nature and a person's reconstructed genitalia does not represent their actual genitalia (Bettcher 2007, 49).

In this section, I argued for the public funding of gender transition care from the value of autonomy and the conception of the body as a context of choice. A trans person may experience their given natal embodiment as immersed in a context that stifles rather than facilitates the expression of their gender identity, a core constituent of who they are. The principle of respect for autonomy generates the obligation on the part of the state and others, for example, healthcare providers and institutions, to promote the autonomy of trans agents whose autonomous agency may be impaired by an embodied context that undercuts the expression of their identity. Yet this raises the question of whether the reasoning for subsidizing gender transition care could be generalized to argue for the public support of any body-changing interventions for the sake of affirming a person's identity. I venture into this question in the next section.

#### **4. The Moral Limits of Body-Changing Interventions for Affirming Identity**

In the previous section, I argued that gender transition care is a species of body-changing medical interventions that can promote the autonomy of trans persons. It does so by augmenting the embodied characteristics of agents in ways that affirm their gender identity and enable its effective expression. Yet this raises the question of whether this reasoning could be extended capaciously to any kind of body-changing interventions for affirming any identity that agents might avow for themselves.

It is a worrisome implication if my argument can justify the public funding of any body-changing intervention for the sake of affirming any identity. From a practical standpoint, it seems unreasonable to think that justice demands that our healthcare institutions cater to any claims made by citizens to be provided with healthcare resources that help citizens realize their manifold self-conceptions, given that it would dangerously strain any healthcare system with limited resources. From a moral standpoint, it just seems erroneous to think that justice requires that any claimed identity-related need should be equally respected and supported by our healthcare institutions. If this is correct, then what kinds of identities do not generate obligations of the state to fund publicly body-changing interventions for the sake of affirming such identities?

I will explore this question here. It seems correct that not all identities generate legitimate claims against the state to provide bearers of such identities with medical resources to inhabit the kinds of embodiments that allow such identities to be expressed. I aim to provide a working account to this

position. What seems relevant in determining whether a medical intervention to align an agent's embodiment with their identity should be publicly funded depends on the content of the identity and how it is related to justice. Does the identity under consideration promote the autonomy of the agent seeking body-changing, identity-affirming medical intervention? Also, is the identity and its affirmation in medical institutional contexts consistent with other broader considerations of justice? If the answers are negative to one of these two queries—that is, the identity in question is irrelevant to the agent's autonomy or undermines it, or the promotion of the identity interferes with important political objectives, then these identities do not generate obligations of the state to support them through subsidizing body-changing medical interventions. It is not my intention to chart a detailed map of all possible identity types and tokens that fail to generate a political obligation to subsidize body-changing interventions in the name of affirming such identities. Instead, I would like to consider briefly a few prospects. I will use the following terms to typify these identities: peripheral identities, self-defeating identities, and proscribed identities. And I will raise another broader identity type—damaged identities—that is more difficult to pin down its normative status.

A brief aside: I want to raise a cautionary note about this discussion. Identity is a deeply complicated, sensitive topic, and understandably so. The question at hand is about the proper social recognition of people's identities, and whether they create a positive claim against the state to be provided with resources to exist as the kinds of beings prescribed by their identities through body-changing medical interventions. Thus, it invokes legitimate concerns about social invalidity and ontological erasure and for this reason this subject deserves to be treated with extreme care and epistemic humility. My account intends to be exploratory. It will be generally abstract, oriented around the values of autonomy and justice, to provide a standard by which to judge identities. What specific, lived identities fall under these categories is something that we cannot figure out in the abstract but through ongoing discourse and radical listening to people's testimonies about their phenomenological sense of self, especially regarding novel, socially unrecognizable ways of being. The concrete identities I do use to clarify the meaning of the proposed categories I take to be less contentious on the basis of present discourses – and where possible, my claims are based on readings from authors who have described their embodied experiences – but such claims should be taken as tentative, like most claims made in philosophy.

#### 4.1 *Peripheral Identities*

One kind of body-changing intervention that the state is not obliged to subsidize is an intervention that caters to what I call peripheral identities. By *peripheral identity*, I mean any components of a person's identity and value perspectives that are not critical for realizing their autonomy. These components may include ideals, aspirations, and embodied characteristics a person may value but whose sense of self and self-worth would not collapse if lost or not realized. For example, I strongly desire the property of being tall. I am a cisgender male who stands 5'4" tall situated in a "heightist" social world. At times, I feel self-conscious and insecure in my own embodiment when I enter particular social spaces, like a crowded concert venue, a bustling bar, or a social gathering of strangers, where I feel invisible or socially undesirable. Though I may value the property of being tall, the lack of this property does not lead to a compromise of my autonomy in a global sense. One major reason is that my robust sense of autonomy is not premised on having this particular characteristic. Rather, my autonomy is oriented and animated by other values, roles, life plans, patterns of living, and modes of being, which are regarded as critical constituents of my core or practical identity. In other words, the property of being tall is more so an object of desire than a critical identity need. For this reason, I should not be entitled to medical interventions, like the provision of growth hormones or limb-lengthening surgery (assuming that they are effective), for the sake of achieving a taller stature.

In important ways, the term, peripheral identity, is a contradiction in terms. Throughout this dissertation, I have been using "identity" in the deeper, existential sense to refer to the self in self-determination, where the self is defined by a person's critical interests that give their lives meaning and a sense purpose, as opposed to more trivial or mere experiential interests.<sup>52</sup> Thus, peripheral identity refers to aspects of a person that are not central to their practical identity and thus, they are not strongly relevant with respect to their autonomy. This reflects the general moral unease with cosmetic enhancements as not serving a medical necessity. One way to make ethical sense of this unease in terms that are relevant to justice is that bodily modifications to uphold peripheral identities are not crucial to helping people become or remain agents with particular practical identities.

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<sup>52</sup> Here I appeal to Ronald Dworkin's terminology of critical interests and experiential interests. Experiential interests are those that have to do with pleasures or satisfactions. Critical interests are those that give life its deeper or more lasting meaning and a sense of coherence (Dworkin 1993, 201-202). It is the latter that is often taken to be constituents of our core identity, or the moral tissue that makes up who we are (Lindemann 2014, 182).

## 4.2 *Self-Defeating Identities*

Another kind of identity that does not generate obligations of the state to provide medical resources to citizens who wish to modify their bodies in ways that allow them to express such identities is what I call a self-defeating identity. By a *self-defeating identity*, I mean an identity that undermines the autonomy of the identity-bearer due to the content of the identity. It may do this in two ways. First, an identity could be self-defeating when its physical manifestation is detrimentally harmful to their body, endangering the physical preconditions of autonomy, like curtailing life itself. Second, an identity could be self-defeating when it destroys the self-esteem or self-directedness of the identity-bearer, endangering the subjective or psychological precondition of autonomy. Catriona Mackenzie discusses how certain self-conceptions could undermine an agent's sense of self-worth or normative authority over their actions required for autonomy, such as having an entrenched, subordinated identity from internalizing oppressive social norms (Mackenzie 2008). There may be a case where an agent desires their body to be altered in ways that reify their morally degrading identity, wanting to live in an embodied form that symbolizes and upholds their devalued status. One example that offers some semblance of a self-defeating identity is pro-anorexic (or pro-ana) identities. Like other identities, the meaning of "ana" is contested and its multiplicity defies a unified, straightforward definition (Hammersley and Treseder, 2007; Giles 2006). But one throughline is that a pro-ana identity regards anorexia nervosa – and the extreme emaciation that typically accompanies it – as a valued or celebrated condition to embody. Suppose by way of an extreme example, that a person who identifies as pro-ana requests medical assistance to manifest an extremely thin body that is esteemed in pro-ana groups by way of a self-starvation program or medications to mitigate hunger pangs. This is objectionable, and uncontroversially so. If such assistance is dangerous to the life of the agent or further reinforces their devalued sense of self (with the assumption that a lack of self-worth underwrites or is constitutive of their identity), then such assistance ought not to be provided. Given the ways in which pro-ana identities could be self-destructive physically and psychologically, and thus undermine autonomy, it may be the case that the state should curtail the formation of such identities, not only by dismantling the social and digital spaces that encourage and support such identities (e.g. pro-ana websites and social media), but also the vicious standards of beauty reproduced on media and that govern social attitudes and institutional practices, exacerbating people's insecurities and moral scrutiny of their body size and shape (Morris and Katzman 2003).

### 4.3 Proscribed Identities

A third kind of identity that the state is not obligated to support through body-changing interventions is what I call proscribed identities. Proscribed identities are self-conceptions that are, in important ways, problematic because they undermine other political considerations of justice. Whether or not an identity is considered proscribed depends on the context from which we are making such judgments. Certain identity claims may be recognized and supported in certain contexts but not in others. The context I am interested in here is the ethics of body-changing interventions in a sociocultural and historical setting of multiple identity-based inequalities. From this background, do certain identity claims generate obligations of justice to provide agents with such identities access to body-changing interventions if these agents are deeply ill-at-ease in their current embodiment in relation to their identity? Is the state fulfilling such identity claims within this context consistent with other priorities of justice? There may be some practical identities that, if supported in the form of publicly funded body-changing interventions, would undermine the demands of justice.

One example is transracial identities. Transracial identity is an identity claim of membership to a racial group that is contrary to the individual's racialized and historicized embodiment. The paradigmatic example is Rachel Dolezal, the former president of the Spokane chapter of the NAACP, who stirred controversy for identifying and performing as Black even though her embodiment and heritage is stereotypically white. There are also other examples of transracial identity, like a white-presenting man in Florida causing headlines for identifying as a Filipino and creating a transracial support group (Flowers 2021).

Suppose a transracial person demands to be provided with medical resources to change their bodies in ways so as to embody racially signified characteristics that support or exemplify their racial identity. Though such interventions may be justified as promoting the autonomy of the transracial agent, body-changing care to affirm such identities may be trumped by other important political considerations of justice. For example, Dembroff and Dee Payton argue in *The Boston Review* that transracial identities, especially people with racialized white bodies identifying as Black, do not, in most circumstances, deserve social uptake. They argue,

“While it is important and good to value a person’s autonomy and respect their identifications, we also think this good must be weighed against the population-level effects of revising our classifications. In cases where revising a classification would have a negative sociopolitical impact that outweighs the good of respecting how an individual identifies, we think that the classification should not be revised. And we think that revising the rules of race classification to accommodate transracial identification into Blackness is a case like this” (Dembroff and Payton 2020).

For Dembroff and Payton, transracial identities obscure an important function of the social category of race, which is to track intergenerationally inherited inequalities. The ability of the state to correct and redress racial wrongs would be compromised if the state also recognized transracial persons as Black, who may not have been negatively impacted intergenerationally by institutional racist practices. This justice problem would be even more exacerbated if the state provided healthcare resources for transracial persons to assume stereotypically Black embodiments. It would socially erase the racial privilege of those who have not suffered from the downstream and long-lasting effects of racial oppression and yet they would be recipients of reparative policies, like affirmative action in employment and education and compensation for past economic exploitation.

The point here is not to dismiss a person's subjective sense of self but instead to note that its social uptake and accommodation in the form of body-changing, identity-affirming medical interventions must be balanced with other political considerations of justice, and it may be the case that the latter, in certain contexts, is weightier than relieving the internal dissonance and promoting the autonomy of individual agents.

#### *4.4 Damaged Identities*

So far, we considered three classes of identities that do not generate political obligations for their affirmation through subsidized body-changing medical interventions. These identities have trivial or adverse relations to the agent's autonomy, or they undermine weightier political considerations of justice. But I wanted to bring up a class of identities that are, in important ways, morally problematic but are less clear regarding whether they are the kinds of identities that the state is not obliged to support through the provision of body-changing interventions. What I have in mind are what Hilde Lindemann calls damaged identities (Nelson 2001). By *damaged identity*, I mean any identity that is shaped pervasively by oppressive master narratives, that is, dominating social scripts about what kinds of people are worthy of full moral respect. A person holds a damaged identity when they endorse these oppressive master narratives as part of their self-concept. Thus, their self-understanding and self-worth are built on such narratives. Master narratives also govern the distribution of valuable social roles and access to desirable relationships, which also help construct people's identities (Nelson 2001, xii).

Paradigmatic examples of a damaged identity include women who have internalized the dominant, fatphobic ideals of beauty, or disabled people whose self-conceptions are figured by ableist ideologies. In important ways, most cases of the three classes of identities discussed above—peripheral, self-defeating, and proscribed—are also damaged identities in that they are shaped by objectionable social scripts and affirming them would reinforce and reproduce unjust norms and social inequities. For example, a peripheral identity could be a damaged identity in the following way: the imposition of master narratives may foster in members of oppressed groups (e.g., women) an overwhelming desire to avoid the physical and social brunt of appearance oppression by transitioning to a body that allows them to escape them, but it may not necessarily be an expression of their deeply held values or wish to live according to who they are (Sherwin 2012).

Yet there is a question of whether the state should refrain from affirming identities through body-changing interventions on the sole basis that they are damaged. Though peripheral, self-defeating, and proscribed identities may be damaged, a damaged identity does not have to be any one of these classes. Take, for example, the case of a person whose self-concept is deeply ingrained with fatphobic values and yearn to have a form of embodiment and pattern of living oriented around this self-concept. They demand institutional support to embody a socially desirable thin body through medical interventions, like prescription medication or gastric bypass. Here, the case may not neatly fit into any one of the aforementioned classes. The distressed identity may not be a peripheral identity since their existential angst to be thin might not be peripheral at all but a reflection of their deeply held values. It may also not fit neatly as a self-defeating identity because the expression of the identity does not entail the destruction of the self, physically and subjectively. Rather, its efficacious expression requires an embodiment that aligns with oppressive social norms. The distressed identity could very well be a proscribed identity since catering to this aspiration would reinforce, or at least capitulate to, an oppressive value system that we should be actively resisting. This is why the question of complicity comes up in the ethics of cosmetic surgery (Little 1998; Amadio 2010). But there may be overriding reasons to support this identity through body-changing interventions, such as relieving the legitimate psychosocial strife of being conventionally unattractive (Little 1998; Davis 1998). I am not in the position to fully explore the moral intricacies of this case, but I want to make open the possibility that

the moral details of a case could justify supporting the autonomy of an individual agent even if it undercuts the moral imperative of challenging an oppressive value system.<sup>53</sup>

The aim here is modest. I simply want to show that it is not clear that damaged identities, in themselves, should be denied affirmation and accommodation through the public coverage of body-changing medical interventions for people with such identities to relieve their discordant embodiments. What makes this issue especially fraught is that most identities are not morally pristine but are, in varying degrees, touched by oppressive master narratives. This is understandable given that our identities are shaped by a complex of factors that include social norms that structure our society and, in turn, shape our own self-understandings. As said in Chapter 3, our selves aren't shaped *de novo*, but are formed significantly by the social scripts and counter-scripts in our society. Thus, it seems unreasonably quick to make blanket moral statements about the moral impermissibility of the state to subsidize any body-changing medical interventions to support the expression of agents' identities when such identities are, in themselves, damaged.

In this section, I argued that not all body-changing interventions for affirming identity should be subsidized by the state. It matters what kind of identity is being affirmed. I argue that certain types of identities, given their content, should not be affirmed through publicly funded body-changing interventions. These identities are those that are trivial or detrimental to an agent's autonomy or go against other important priorities of justice. I also wanted to raise a class of identities—damaged identities—that are problematic but cannot be readily dismissed as disqualifying of subsidized body-changing interventions. From this section, it is implied that transgender identities may not be peripheral<sup>54</sup> and are neither self-defeating nor proscribed. As mentioned earlier, I am committed to the position that transgender identity is legitimate. As mentioned earlier, it is beyond the scope of the paper to provide a robust defense of trans identity, but to take it as given to help launch the discussion on the justice of body-changing medical interventions for the sake of affirming identity.

In the next section, I want to reflect on a specific type of identity that is related to the broad themes of this dissertation and relate it back to this chapter's question of whether it generates

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<sup>53</sup> Chapter three grapples with this very tension. Like other identities, a person's embrace of their non-disabled identity is likely shaped by negative presumptions of disability. But the fact that an identity could be damaged may not disqualify an identity from being affirmed and supported by the state in its medical institutions.

<sup>54</sup> Transgender identity could be peripheral but it depends on how trans agents relate to that feature of their identity. As mentioned earlier, not all trans people feel the need to have a sexed embodiment that fits with their gender identity since they may not experience a distressing level of internal contradiction.

legitimate claims against the state to be provided with medical resources to alter agents' bodies in ways that fit with such identities. This identity is called transabled identity.

## 5. What about Transabled Identities?

*When I had finally woken up from surgery [caused by self-injury and resulting in an amputation], I recall a very deep relief. It was slow, but the more I came to realise the leg was finally gone I couldn't help but feel relaxed by the resolve.... It's been a little less than six months since the initial event, and I can only say that I am happy to see each new day with the sense of self worth and purpose I should have had from the day I was born. This wasn't about losing a leg; it was about gaining my own sense of self.*

- Woodie, a transabled person after acquiring a disabled embodiment (Davis 2012)

I would like to conclude this chapter by reflecting on an identity that is related to the major themes of this dissertation of disability, identity, and the pursuit of identity-affirming medical interventions. The identity I have in mind is transabled identity. *Transabled identity* refers to able-bodied persons who want or need to live in a disabled embodiment because it aligns with their self-conception as someone who was meant to be disabled.<sup>55</sup> The desire to become disabled is so strong that many transabled people seek to deliberately disable themselves through self-injury since there is no institutional medical support. One prominent case is Jewel Shuping who aspired to become blind. As a child, she would stare at the sun for hours, hoping to damage her eyes. Shuping eventually blinded herself with the help of a psychologist by putting drops of drain cleaner in each eye. Though she is now happy with her new embodiment, she does not approve of the way she had to attain it, "Don't go blind the way I did. I know there is a need but perhaps someday there will be treatment for it" (Midlane 2015). Shuping's efforts represent the emotional and existential need of many transabled people to have a disabled embodiment.

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<sup>55</sup> This phenomenon is also called body integrity identity disorder (BIID), but I will refrain from using this terminology to avoid its pathological connotations. Yet there is debate in the transabled community of whether it is socially desirable to pathologize their identity, such as including BIID in the DSM-5 (at the time of this writing, it is not). For some, its inclusion would mean that transabled identity does exist. Though it may be framed as a medical condition, its inclusion in the DSM-5 may open a path to legal corrective surgery since it may be construed as treatment. As one transabled person put it, "Why is it so bad to be labeled as having a mental illness? Could someone tell me what the F\*\*\* is so bad about it? As far as I'm concerned, I would much prefer to see BIID listed in the DSM, because it has to be listed \*somewhere\* before medical professionals take us seriously. I say, put it in the DSM, start studying it properly...I don't mind saying "yes, there's something wrong with me that can only be fixed through surgery" (Davis 2012, 335).

How should transabled identity be socially recognized and treated? Does this type of identity generate legitimate claims against the state to provide body-changing medical interventions for those who bear such identities and express the need to assume a disabled embodiment that coheres with their avowed identity? How should the state respond to requests from transabled people who seek “corrective” surgery to have an embodied form that accords with their disabled identity, such as amputating a functional appendage to live with an amputated embodiment or injuring the spine at a particular location to manifest a paraplegic body? On a mere difference view of disability, there’s no reason to think of deliberate and desired disablement as mutilation or even a harm for patients who value or identify positively with such embodied states. For this reason, Richard B. Gibson argues that surgical amputation of healthy body parts should be accessible to transabled patients who have identity-related needs to live with an amputated embodiment, given that those who are transabled simply “seek to move from a state of ‘mere-difference’ to another state of ‘mere-difference’ for therapeutic reasons” (Gibson 2020, 154).

At this time, I do not wish to draw a conclusion on whether body-changing medical interventions to help transabled patients assume a disabled embodiment should be publicly funded, or even permitted by the state and its medical institutions. Making that determination requires careful examination of the social meaning of transabled identity and their implications if given or denied social uptake in the medical setting. Instead, I want to raise some considerations for future research that is informed by the prior discussion. The question of whether a transabled identity should be given social uptake of the kind that secures its identity-bearers with the material resources to live in the embodiment that support their identity should not be taken as a metaphysical question of whether transabled identity is real. Rather, it should be approached as a political question. That is, does recognizing transabled people as disabled and supporting the efforts of some to embody the physical, sensory, motor, and aesthetic characteristics that exemplify their identity express a commitment to promoting autonomy and other political considerations of justice, such as social equality? One consideration I take to be important is the expectant consequence of not providing transabled people with the institutional support they need to live in an embodiment that accords with their identity. Based on the testimonies of transabled people, denying them this medical good will expectedly motivate many members of the transabled community to deliberately disable themselves, sometimes bringing undue risk to their life and wellbeing. Tim Bayne and Neil Levy appeal to this reason to argue that transabled people who seek amputations should be allowed to get them from qualified surgeons, “Given that many patients will go ahead with amputations in any case and risk extensive injury or

death in doing so, it might be argued that surgeons should accede to the requests, at least of those patients who they (or a competent authority) judge are likely to take matters into their own hands” (Bayne and Levy 2005, 79). The existential angst experienced by transabled people may generate obligations not only of beneficence but also justice if such internal strife undercuts their autonomy.

Another consideration is the expectant consequence to the disability community if the state provides institutional medical support to transabled people to transition to their disabled embodiments they so desire. Are there negative consequences to the disability community if such medical practices are subsidized? One place of examination is the historical and cultural significance of disability as a social identity. Like other socially salient identities, a disabled identity has a history and may connote a sociocultural meaning that ought to be respected. Thus, assuming a disabled embodiment through medical means may be an objectionable form of appropriation or fetishizing an embodied difference. Or given the social stigma of disability, it may be the case that transabled identity and its associated conceptualization of disabled embodiments as desirable and celebrated modes of being may further encourage the destigmatization of disability itself.

The normative status of transabled identity must be carefully assessed before we permit, require, or prohibit the subsidization of medical interventions to allow people with such identities to have embodiments that align with them. Its moral standing in relation to justice cannot be narrowly focused on what is best for the individual agent but also how it affects our broader visions and projects of justice.

## **6. Conclusion**

I have argued that my account of the body as an important context of choice for autonomy can be employed not only to justify medical interventions to maintain agents’ forms of embodiment but also to change their embodiments so that their body could facilitate the efficacious expression of their identity. This is in response to an objection raised in Chapter 2, where my argument for subsidizing medical interventions to help people avoid becoming disabled may have the normative implication of denying certain body-changing medical interventions, like gender-transition care, as requirements of healthcare justice. But I argue that not all identities should be supported by the state through the provision of medical resources to augment people’s embodiments in ways that support or exemplify their identities. Certain types of identities—peripheral, self-defeating, and proscribed—

are not identities that generate legitimate claims against the state to be provided with medical care to allow people to inhabit the kinds of embodiments that cohere with their identities. If such interventions do not promote their autonomy, then the state is not obligated to publicly fund these identity-affirming medical interventions.

One point worth noting is the practical difficulty of determining when an identity is peripheral, self-defeating, or proscribed, more so with the first type. This is again nicely illuminated by Kathy Davis, where she describes the challenges faced by the Netherlands to develop objective criteria to determine when the state should cater to the requests of its citizens to be provided with body-changing medical care (Davis 1998). My goal here is to provide a conceptual framework to develop policies and procedures.

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