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The ethics of selection: reproductive technologies, disabilities, and the quest for healthy children

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Dissertation

**THE ETHICS OF SELECTION:
REPRODUCTIVE TECHNOLOGIES, DISABILITIES,
AND THE QUEST FOR HEALTHY CHILDREN**

by

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DEDICATION

*I dedicate this work to my husband Leo
and the family we are building together.*

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ABSTRACT

In the face of recent and upcoming advances in reproductive technology, it is vital to determine what kinds of choices parents should make in the reproductive context with respect to using these technologies, and how medical professionals should advise their patients in the reproductive context with respect to these choices. This dissertation explores these issues by focusing on the ethical choices facing prospective parents and medical professionals with respect to screening and selection for or against disability traits. I argue that prospective parents should select against most if not all disability traits in their future children, because doing so is usually the best or ideal option for prospective parents to strive for as long as their situation allows for it. Regarding medical professionals, I argue that the most plausible account of how they should treat their patients in the reproductive context is not a monolithic, one-size-fits-all approach. Instead, I show that in reproductive contexts, genetic counselors should be directive about some things but not others.

Specifically, genetic counselors should actively encourage their patients to pursue testing and screening for disability traits, but should *refrain* from being directive in any way about selection against some trait or condition. To lay the groundwork for these arguments, I also demonstrate that the increasingly popular view that disability traits are mere differences rather than bad traits to have is implausible, at least for many if not all disability traits.

Chapter I offers a defense of the widely-held intuition that all things considered, it is better to be abled than to have some disability trait. I show that the three main strategies commonly employed to critique the intuition that it is overall bad to have some disability trait are not nearly as successful at dealing with the intuition that overall it is better to be abled with respect to some disability trait. I then show that since many of the key purported benefits of disability traits can be substituted for by similar or equivalent goods that are available to abled individuals, and the purported benefits of disability traits that cannot be adequately substituted for are likely outweighed by various costs of having those disability traits (costs abled individuals are not subject to), critics of this intuition lack a plausible response to it. I conclude that this casts doubt on the overall plausibility of the view that disability traits are mere differences.

Chapter II contends that with respect to most if not all disability traits, prospective parents *should* select against most if not all disability traits in their future children, because doing so is usually the best or ideal option for prospective parents to strive for as long as their situation allows for it, and is praiseworthy on that basis. To establish this, I draw upon both wellbeing-based and non-wellbeing-based considerations. I also address the most

prominent potential objections to the desirability and moral permissibility of selection against disability traits in one's future children.

Finally, the third chapter of my dissertation engages with practical implications of my arguments for medical best practices. I argue that medical professionals should adopt a directive attitude with respect to testing by actively recommending genetic testing to their patients, but a non-directive attitude regarding questions of selection. That is, medical professionals should not push their patients to take a certain course of action based on their genetic test results. This position stakes out a middle ground position between disability rights activists who oppose the use these technologies both to test and select, and those who want to promote directiveness with respect to testing and selection.

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INTRODUCTION

The field of reproductive technology has seen remarkable advancements in recent years, especially with the development of non-invasive prenatal testing (NIPT) and preimplantation genetic testing (PGT). These new technologies offer prospective parents an unprecedented level of control over the genetic make-up of their future children, enabling them to screen and select for or against certain traits. With the use of these technologies becoming more widespread and affordable, and with new tests being developed to screen for an increasing number of traits, including those not related to health, it is imperative to critically examine the ethical implications of using these technologies in the present and future. In particular, it is essential to determine what kinds of choices parents should make in the reproductive context with respect to using these technologies, and how medical professionals should advise their patients in the reproductive context with respect to these choices.

This dissertation explores these issues by conducting a rigorous analysis of the moral questions surrounding the use of new reproductive technologies. I focus particularly on questions surrounding the moral obligations of prospective parents and medical professionals with respect to screening and selection for or against disability traits, such as deafness, muscular dystrophy, and Down syndrome. By providing a thorough examination of these issues, I aim to contribute to the ongoing philosophical and political debates concerning the use of these technologies and their impact on society and individuals.

There are several reasons why I choose to focus on disability traits in my analysis. First, disability traits are currently the most prominent set of traits that can be screened and selected for or against, making them the first major frontier of genetic selection in the reproductive context. By focusing on disability traits, we can gain insight into the ethical implications of the broader trend towards genetic selection and modification in the reproductive context, including the potential for the creation of "designer babies". As such, disability traits serve as a crucial starting point in our exploration of the broader ethical and social implications of these new technologies. Second, the decision to screen and select against disability traits has the potential to significantly impact the lives of both disabled and non-disabled individuals, and so it is essential to determine whether this impact would be positive, neutral, or negative.

In my dissertation, I make several new contributions to the ongoing debates surrounding the ethics of these emerging reproductive technologies. I provide a novel argument showing that the increasingly popular Mere Difference View – the view that disability traits are mere differences rather than bad traits to have – is implausible.¹ Regarding prospective parents, I argue that prospective parents *should* select against most if not all disability traits in their future children, because doing so is usually the best or ideal option for prospective parents to strive for as long as their situation allows for it. As part of supporting this claim, I discuss and respond to various prominent objections to the

¹ Advocates of the Mere Difference View insist that having a disability is a *mere* difference rather than “something that by itself makes you worse off” (Barnes, 2016b, 78). They argue that the extent to which disabled people are worse off is primarily the result of ableism, that is, injustice against disabled people simply in virtue of their being disabled (cf. Miller et al., 2004, 9 and Oliver, 1996).

desirability and moral permissibility of such selection in the literature. Finally, regarding medical professionals, and particularly genetic counselors, I argue that the most plausible account of how they should treat their patients in the reproductive context is not a monolithic, one-size-fits-all approach. Instead, I show that in reproductive contexts, genetic counselors should be directive about some things but not others. Specifically, genetic counselors should actively encourage their patients to pursue testing and screening for disability traits, but should *refrain* from being directive in any way about selection against some trait or condition.

The structure of my dissertation is as follows. My first chapter offers a defense of the widely-held intuition that all things considered, it is better to be abled than to have some disability trait. I show that the three main strategies Mere Difference View advocates employ to critique the intuition that it is overall bad to have some disability trait are not nearly as successful at dealing with the intuition that overall it is better to be abled with respect to some disability trait. I then show that Mere Difference View advocates cannot respond by claiming that all the benefits of being abled which they cannot explain away are cancelled out by various purported benefits of having the relevant disability trait. This is because many of the key purported benefits of disability traits they would need to appeal to can be substituted for by similar or equivalent goods that are available to abled individuals. In turn, those purported benefits of disability traits that cannot be adequately substituted for are likely outweighed by various costs of having those disability traits, costs which abled individuals are not subject to. The result is that Mere Difference View advocates lack a plausible response to the intuition that for most if not all disability traits

it is better to be abled than to have that disability trait. This casts doubt on the overall plausibility of the Mere Difference View.

My second chapter contends that the only justifiable *general principle* about what prospective parents should do with respect to selection in the reproductive context is that with respect to most if not all disability traits, prospective parents *should* select against most if not all disability traits in their future children, because doing so is usually the best or ideal option for prospective parents to strive for as long as their situation allows for it, and is praiseworthy on that basis. To establish this, I propose what I take to be a defensible wellbeing-based argument I call the *Moderate Perfectionist* argument, namely, that with respect to some disability trait, prospective parents likely have some kind of reason to select against that trait in their future children, as long as and to whatever extent that trait negatively impacts wellbeing. I then provide additional arguments supporting the claim that prospective parents should select against disability traits which do not appeal directly to wellbeing. I also address potential objections to my claim that for most if not all disability traits, parents should select against the trait in question in their future children, focusing on the desirability and moral permissibility of such selection.

Finally, the third chapter of my dissertation engages with practical implications of my arguments for medical best practices. I argue that medical professionals, and in particular genetic counselors should adopt a directive attitude with respect to testing by actively recommending genetic testing to their patients. However, I also contend that medical professionals should adopt a non-directive attitude regarding questions of selection. That is, medical professionals should not push their patients to take a certain

course of action based on their genetic test results, and the patients' autonomy should be respected as much as possible. This position stakes out a middle ground position between disability rights activists who oppose the use these technologies both to test and select, and those who want to promote directiveness with respect to testing and selection.

CHAPTER I: Are Disability Traits Mere Differences?

In recent years, and especially since the publication of Elizabeth Barnes' book *The Minority Body*, a vibrant debate has emerged about the evaluative status of disability traits. Barnes and other supporters of what has come to be known as the Mere-Difference View (MDV) have offered sophisticated and increasingly influential critiques of the widespread assumption that most if not all disability traits are bad traits to have. Disability traits, they contend, are *mere* differences, that is, neutral features of human variation just like gender, sexuality, or race.

Mostly, the existing debate has concerned the intuition that it is bad to have a disability trait, and as a result has focused on the various costs of having disability traits. Defenders of MDV have offered several, often compelling arguments to explain away many of these costs as resulting from systemic ableism in society. As awareness of ableism in society has increased, so has the appeal of MDV. Barnes and others have also argued that at least some of the costs of disability traits which cannot be explained away as results of ableism can be explained away in other ways. For instance, they have argued that some of these costs are *transition costs*, which are costs of transitioning from lacking some disability trait to having it rather than costs of having the disability trait itself. They have also appealed to a supposed *fortunate redundancy* in the capacities human beings need to access various goods from which disability traits are supposed to cut one off.

Yet far less attention has been paid to the just as widespread intuition that all things considered it is better to be abled, such that a disabled person who becomes abled is

considered to have benefited.² In this chapter, my goal is to defend this intuition. My argument will proceed in two stages. First, I will show that the three main strategies MDV advocates employ to critique the intuition that it is overall bad to have some disability trait – appealing to the effects of systemic ableism, to the effects of transitions between being abled and being disabled, and to a purported fortunate redundancy in our capacities – are not nearly as successful at dealing with the intuition that overall it is better to be abled with respect to some disability trait.

The failure of these typical MDV strategies to deal with the intuition that overall it is better to be abled leaves MDV advocates in the following position: they must argue that all the benefits of being abled which they cannot explain away are cancelled out by various purported benefits of having the relevant disability trait. In the second stage of my argument, I will contend that such a move by MDV advocates would be unconvincing. First, many of the key purported benefits of disability traits appealed to by MDV advocates can be substituted for by similar or equivalent goods that are available to abled individuals. In turn, those purported benefits of disability traits which cannot be adequately substituted for are likely outweighed by various costs of having those disability traits, costs which abled individuals are not subject to. The result, I will argue, is that MDV advocates lack a plausible response to the intuition that for most if not all disability traits it is better to be abled than to have that disability trait. This casts doubt on the overall plausibility of MDV,

² Barnes is one of the only MDV advocates to engage with this intuition in detail. As we will see below, she argues that this intuition is a manifestation of ableist prejudice.

and makes starting from the intuition that it is better to be abled an especially promising avenue for critics of MDV.

The chapter will proceed as follows. In section I.1, I will make some preliminary remarks about terminology and methodology to frame the discussion. In section I.2, I will briefly summarize the existing debate concerning the evaluative status of disability traits. In section I.3, I will show that appeals to transitions, systemic ableism, and fortunate redundancy fail to undermine the basic intuition that overall it is better to be abled. As a result, MDV advocates must argue that all the benefits of being abled in some way which they cannot explain away are cancelled out by various purported benefits of having the relevant disability trait. In section I.4, I discuss some challenges such an argument would face, focusing on two key points: the substitutability of many purported benefits of disability traits, and the outweighing of the remaining non-substitutable purported benefits of disability traits by various costs of having those traits. I will conclude by discussing the broader implications of all this for the debate surrounding MDV.

I.1 – Preliminaries

I will begin with a note on terminology. In this dissertation I will not attempt to define the term ‘disability’ or provide a conceptual analysis of this notion.³ Instead, *for*

³ Broadly, I agree with Thomas Crawley that a plausible model of what counts as a disability should satisfy two desiderata: (1) the model must not preclude meaningful investigation into the relationship between disability and well-being, because that would beg the question in favor of BDV or MDV; (2) the model must be descriptively accurate, in the sense that it produces a concept that is recognizable as, or at least appropriately similar to, our ordinary, pre-theoretic concept of disability. The problem is that currently, there is no consensus on the best account of disability; all

present purposes I want to treat ‘disability’ as a term introduced by ostension which picks out certain traits and groups them together, just as Barnes, perhaps the most prominent defender of MDV, does in her 2014 (p. 89). Classic examples of traits referred to as disabilities include impairments to mobility such as paraplegia, impairments to one’s five senses such as deafness or blindness, cognitive impairments such as dyslexia, and emotional and psychological impairments such as depression and schizophrenia.⁴ For present purposes, ‘disabled’ people are individuals who have a disability trait.

Moreover, the list of traits commonly considered ‘disabilities’ is extremely heterogenous, and the ways each of these traits affect people vary accordingly. To determine whether some trait commonly considered a disability might be a bad trait to have (and how bad it is to have it), it seems more fruitful to focus on that trait individually rather than considering all such traits together as part of an unhelpfully monolithic category like ‘disability.’⁵

accounts of disability available seem open to counterexamples. In other words, no currently available account of disability uncontroversially identifies all the right conditions as disabilities, and no wrong ones. Notably, this is even true of what I consider the two most sophisticated attempts to define disability, Crawley’s Hybrid Model (see Crawley. 2021) and Barnes’ Moderate Social Constructionism (see Barnes, 2016b). I’m more sympathetic to Crawley’s view, but the key point for present purposes is that my arguments will be of interest as long as the reader endorses some account of disability which satisfies those two desiderata, because no specific definition of disability will play a major role in my arguments. My goal is to make arguments that work on most accounts of disability that would satisfy the two desiderata, including in particular those of Crawley *and* Barnes which are so different from each other.

⁴ Although the distinction between *disability* and *impairment* is widely used in the literature on disability, some philosophers, including Barnes, reject this distinction (see Barnes, 2016b). For further discussion of this distinction, see Barnes, 2018, Francis 2018, and Howard & Aas, 2018.

⁵ This is in contrast to a significant portion of the literature on both sides of the debate, which does make blanket assessments of the category of ‘disability’ as a whole (see, e.g., McMahan, 2005a and 2005b; Barnes, 2016b, 52; Crawley, 2021, 49).

Now, a few methodological notes. The ultimate goal of evaluating some disability trait is to arrive at an all-thing-considered judgment about whether the trait is good or bad to have. This sort of evaluation is *not* meant to establish that disability traits are inherently bad, or absolutely bad (i.e., bad in every context), or universally bad (i.e., bad for every person). The all-things-considered goodness or badness of a trait is at least to some extent context-dependent, because aspects of a trait that affect one negatively in some circumstances might affect one positively in others. For example, being blind might negatively affect one during a visit to the Louvre but positively affect one if one is in an extremely bright environment.⁶ Moreover, the various factors I will discuss are *pro tanto* reasons to think some trait is good or bad. Regarding general reasons to think some trait is good or bad that can apply to various traits, we need to check whether those reasons apply to the particular disability trait being evaluated. Finally, when I say that a disability trait might be a bad trait to have, I do *not* mean that someone with that trait is somehow morally bad or has less moral worth. I simply mean that having that trait would leave one worse off all else being equal, just as breaking your arm leaves you worse off all else being equal.

⁶ When making all-things-considered evaluations about some trait, we must do so with respect to those contexts that can reasonably be expected to actually matter for the person in question, and be relevant for them. In this chapter, the focus is on common-sense intuitions about what could reasonably happen to a person in their lives in today's world, in order to keep our focus on the actual world and nearby possible worlds, in the present and near future. So, when some specific disability trait is deemed a bad trait to have, or when some consideration is taken as a reason to think some trait is bad, it means that it is bad to have in the actual world and in those nearby possible worlds that represent possible situations in the near future which could reasonably be expected to occur and impact one's life.

I.2 – The Existing Debate

Most people assume that disability traits are bad traits to have. However, MDV advocates explain the extent to which disabled people are worse off as being primarily the result of systemic ableism, rather than some badness of disability traits themselves.⁷ A key observation motivating MDV is that those negative aspects of having a disability trait which are due to systemic ableism are caused by the prejudiced attitudes of other people and by the various social policies and lack of accommodations caused by those attitudes, not by the disability trait itself. This observation is a significant one – it is undeniable that at least some of the suffering of people with disability traits is a result of explicit and tacit choices that have been made by society, choices influenced by prejudice and which result in a lack of accommodations. Ableist attitudes and prejudices cause the needs and interests of disabled individuals to be systematically disregarded, especially in decisions about infrastructure design, resource distribution, and other issues in social and public health policy. For example, mobility-impaired disabled individuals are negatively impacted by the difficulty they face entering many buildings, but this is due to their interests being systematically disregarded in architectural and urban planning decisions, leading to a lack of accommodations such as ramps.

The core contention made by MDV advocates is that once negative effects due to systemic ableism are put aside, we can see that having a disability trait is not “something

⁷ Ableism consists in injustice against disabled people simply in virtue of their being disabled (cf. Miller et al., 2004, 9 and Oliver, 1996). *Systemic* ableism is injustice against disabled people that stems from broadly held (yet often unexamined) beliefs and norms, especially on the part of the non-disabled majority in society, and which especially manifests itself as a lack of accommodations for disabled people in our social arrangements (cf. Barnes, 2016b, 5).

that by itself makes you worse off’ (Barnes, 2016b, 78). They claim that on an overall weighing of the value of disability traits that disregards costs of those traits stemming from ableism, most if not all of those traits would have neutral rather than negative value, i.e., mere differences.

In recent years, the negative impact of ableism on the lives of people with disability traits has come to be widely recognized in the literature on disability, including by defenders of the view that disability traits are overall bad traits to have rather than neutral traits – the Bad Difference View (BDV). However, critics of MDV have argued that many if not all disability traits negatively impact people in ways that seem difficult to explain away as mere effects of systemic ableism, including pain, ill-health, reduced lifespan, and significant reduction of valuable options⁸ – something which even the staunchest MDV advocates have acknowledged at least to some extent (see, e.g. Barnes, 2016b, 57 and 76).⁹

Prominent defenders of MDV have responded by trying to explain away some of these costs as *transition costs*, that is, the costs of transitioning from lacking some disability trait to having it (see, e.g., Barnes, 2014, 96). Someone who comes to have a disability trait

⁸ See, e.g., Kahane and Savulescu (2016), McMahan (2005a, 2005b, 2006), and Crawley (2021)

⁹ Some BDV advocates also respond to MDV by attempting to show that MDV must be implausible because it leads to absurd or otherwise unacceptable implications. The alleged absurd implications include that if disabilities are neutral traits, then: (1) disabilities are neutral even in combination (such that a person with many disabilities is not worse off as a result), (2) it is permissible to cause disability, and (3) it is either impermissible to remove disabilities (because doing so would be ableist), or it is at least permissible to refuse to remove disabilities when one could (see McMahan, 2005a and 2005b; Singer, 2004; Harris, 2001; Kahane, 2009; and Buchanan et al., 2000). MDV defenders like Barnes respond that such arguments fail either because MDV doesn’t actually have the absurd implications alleged by its critics, or because the arguments of critics pursuing this strategy beg the question against MDV (see Barnes, 2014 and 2016b; for a response to Barnes’ argument, see Kahane & Savulescu, 2016). The debate surrounding these alleged implications of MDV is ongoing, and I will not discuss it in detail here.

without suffering transition costs (e.g., a person born with the trait) is not negatively impacted by such costs, which means those costs do not pertain to the disability trait itself. MDV advocates also argue that human beings have a *fortunate redundancy* of the capacities needed to access various goods from which disability traits are supposed to cut one off (see, e.g., Asch and Wasserman, 2010, 208). If so, then individuals with disability traits may not actually be subject to some of the costs critics of MDV have pointed out. MDV advocates further contend that any remaining costs which cannot be explained away by appealing to transition costs, the effects of ableism, or fortunate redundancy (which I will refer to as ‘*remainder costs*’) can be canceled out by various purported benefits of disability traits (see, e.g., Barnes, 2014, 90), with the result that on an overall weighing disability traits come out as neutral traits.¹⁰

In particular, MDV advocates point to two kinds of benefits of having a disability trait which can cancel out the remainder costs of having that trait. First, there are the general benefits of many disabilities, such as access to the distinct communities and cultures of disabled communities (e.g., Deaf culture), the way becoming disabled can give focus and direction to a previously aimless life (Barnes, 2009), and various benefits stemming from socially-adopted accommodations and policies, such as being able to avoid long lines and park conveniently (Campbell & Stramondo, 2017, 158). Second, there are disability-

¹⁰ MDV advocates must claim that the remainder costs of disability traits are cancelled out by the benefits of those traits, rather than outweighed by those benefits, because the claim that the benefits of disability traits outweigh the costs amounts to the view that disabilities are *good* differences to have – that all things considered one is *better off* if one has a disability trait. Although there is room in logical space for such a Good-Difference View about disability traits, it is radically unintuitive, and in any case I am not aware of anyone who defends such a view.

specific benefits, such as being able to work undisturbed in loud environments due to deafness, or having heightened hearing (as is the case for many blind individuals).¹¹

In sum, defenders of MDV appeal to ableism, transition costs, and fortunate redundancy to explain away as many negative aspects of specific disability traits as they can. The more costs of some trait MDV advocates are able to explain away with those three strategies, the more plausible their subsequent claim that the purported benefits of some disability trait cancel out its remainder costs becomes. So, these three strategies are key to MDV advocates' ability to cast doubt upon the widespread intuition that all things considered, it is bad to be disabled in some way.

1.3 – Transitions, Ableism, and Fortunate Redundancy

Whatever success these three MDV strategies might have against the claim that all things considered it is bad to be disabled in some way (which has been hotly contested), they are not nearly as successful at dealing with the intuition that overall it is better to be abled with respect to some disability trait. In this section, I will demonstrate this by defending the intuition that all things considered it is better to be abled against appeals to the effects of transitions, to systemic ableism and to fortunate redundancy.

¹¹ Cf. Barnes, 2014, 105 fn. 24 and Barnes, 2016b, 95.

1.3.1 – Transition Benefits

I will begin by addressing the MDV strategy of appealing to the effects of transitions. MDV advocates like Barnes have critiqued the intuition that it is bad to be disabled by trying to explain away some of the costs of having disability traits as costs of transitioning from lacking some disability trait to having it, i.e., as transition costs, rather than as costs pertaining to the disability trait. Transition costs are associated with the *process of change* to one's identity or situation, rather than with the new identity or situation itself. Examples of transition costs include the physical pain one feels while recovering from a car accident that leaves one paralyzed, or the psychological suffering one feels from not being able to do things one used to be able to do (see Barnes, 2014, 96).

Although we might not be convinced by such appeals to transition costs to explain away every negative aspect of specific disability traits, appealing to transition costs in general is not *prima facie* implausible. And of course, the more costs of some trait MDV advocates are able to explain away as being due to factors not inherent to simply having that trait, the more plausible their claim that the trait in question is a neutral trait becomes.

The problem for MDV advocates is that appealing to transitions does not help explain the intuition that it is better to be abled. Far fewer of the beneficial aspects of being abled can be explained away by appealing to the transition to becoming abled. Such a strategy would amount to appealing to the notion of a "transition benefit", i.e., some benefit associated with the process of change to one's identity or situation. Appealing to transition benefits in this way seems far less plausible than appealing to transition costs to explain some of the bad aspects of disability traits. This is because it is difficult to find a transition

process that would bring enough benefit to explain the intuition that one benefits from becoming abled. Processes like surgery, implant or prosthetic installation, or new gene therapies are unlikely to be pleasant, and in any case do not seem plausible as candidates for the source of our intuition that someone who becomes abled benefits thereby. Rather, it seems to be the *end state* of being abled in some way that people intuitively consider to be good. In other words, it is not the fact of change per se, but the fact that the change is *to a better state*, that explains the goodness of being abled. So, appealing to transitions is not a promising way for MDV advocates to critique the intuition that it is better to be abled. This means that starting from the intuition that it is better to be abled is more promising for critics of MDV, since MDV advocates will have more things they need to explain away than if critics of MDV start with the intuition that it is bad to be disabled (since some of the negative aspects of being disabled can be explained away by appealing to transition costs of becoming disabled).

1.3.2 – Ableism I

Another way MDV advocates can try to explain away the intuition that it is better to be abled is by appealing to concerns about ableism. One option could be to dismiss the intuition itself as ableist, on the basis that it is ableist to assume that the purported benefits of lacking some disability trait are actually benefits. For example, it might be ableist to assume that being able to see is inherently beneficial, because the benefits of being able to see might exist only because society is structured to privilege seeing over blind individuals

due to systemic ableism. In a truly non-ableist society, it might be the case that seeing individuals experience no benefits blind individuals lack access to.

To see why this view is unsatisfying, let's consider what a society in which there is no more systemic ableism would look like. In such a society, there would be no injustice against disabled people stemming from broadly held beliefs and norms related to disability. The needs and interests of disabled individuals would no longer be unjustly ignored due to prejudice or simple ignorance on the part of the abled majority in society. In particular, there would no longer be a lack of accommodations for disabled people in our social arrangements, including in resource distribution and urban design.

However, in such a non-ableist society, we would still consider someone who transitions from being blind to being able to see as benefitting from that transition. There are many benefits to being able to see for which there are no adequate substitutes. This lack of substitutes has nothing to do with systemic ableism, since the fact that blindness prevents one from experiencing the beauty of a masterpiece painting has nothing to do with unjust lack of accommodations, resource distribution, or prejudice. The same point holds for someone who somehow (perhaps due to some new medical treatment) transitions from having Down syndrome to not having Down syndrome. There are many benefits to having the kinds of cognitive capacities that humans without Down syndrome typically have, for which there are no adequate substitutes (but not due to systemic ableism). Such examples show that the widespread intuition that it is better to be abled cannot simply be dismissed as a symptom of ableism on the basis that it is ableist to assume that the purported benefits of lacking some disability trait are actually benefits. After all, this intuition can be

motivated by genuine concern for genuinely good things for which there are no substitutes. The goods that lacking some disability trait would give one access to cannot all be dismissed as existing only because society is systemically ableist, and the fact that many of those goods cannot be adequately substituted for cannot always be dismissed as obtaining only because society is systemically ableist either.

One potential objection to this line of argument is to contend that the description of a non-ableist society I have given is not radical enough. Some MDV advocates, especially those who support the social model of disability, have argued that a truly non-ableist society would require far-reaching changes to society, such that in the absence of ableism and its effects having a disability trait would have no negative aspects whatsoever.¹² If that is what a non-ableist society really looks like, then maybe the argument I have given depends on a flawed conception of a non-ableist society.

My response to this objection is to emphasize that achieving a non-ableist society – which is surely a worthy goal – is a matter of *justice*. We want a society in which individuals with disability traits do not suffer from injustice on account of having such traits. But eradicating injustice does not mean that individuals with disability traits will not suffer from any *misfortunes* on account of having such traits. Not all misfortunes are injustices. For instance, not being able to see a masterpiece painting because one is blind is a misfortune, but not an injustice. Yet avoiding such misfortunes is clearly a major benefit of being abled. The fact that only individuals who can see have access to the benefit

¹² For helpful discussion of such arguments and of the social model of disability, see Barnes, 2016b, 26-28 and 93-94; cf. Tremain, 2002, and Vehmas and Mäkelä, 2009.

of seeing a masterpiece painting is not an injustice. Likewise, the fact that there is no truly adequate substitute for actually seeing a masterpiece painting is not an injustice. If these were injustices, then it would be right to say that they could not occur in a non-ableist society. But these are not injustices, which means that even in a non-ableist society, the non-substitutable benefit of being able to see a masterpiece painting would constitute a genuine reason to think it is better to be abled rather than blind – a reason which has nothing to do with ableism.¹³

My contention is that even in a non-ableist society, there are many such reasons for most if not all disabilities. The burden is on MDV advocates to show that for each specific non-substitutable benefit of lacking a disability trait, either the existence of the benefit itself is an injustice, or the lack of adequate substitutes for that benefit is an injustice. However, the prospects of such a strategy seem doubtful, as there are numerous counterexamples of the sort I offered above. I agree with Rachel Cooper’s observation that “it is not the case that the problems faced by disabled people should always and necessarily be solved by changing society”, at least where the problems in question are misfortunes rather than injustices (Cooper, 2007, 579). In fact, it is precisely considerations such as these which drive even Barnes to acknowledge that the view that “all the bad effects of disability” are due to “social prejudice” is “incredible” because if you are disabled “there are good things you will miss out on [...] even in an idealized society” (Barnes, 2016b, 93-94).

¹³ I take this position on what a non-ableist society requires to be consistent with Barnes’ claim that “a world free of ableism is not simply a world where no individuals harbor prejudiced thoughts about the disabled, it’s also a world that doesn’t contain massive accessibility barriers for the disabled” (Barnes, 2016b, 5).

Another potential objection to the response I have offered to the charge of ableism is to question my claim that the good aspects of being abled I appeal to cannot be adequately substituted for. Asch and Wasserman, who endorse MDV, propose a “broad individuation of human goods that treats both the appreciation of paintings and the love of music as [interchangeable] types of aesthetic experience” (Asch and Wasserman, 2010, 208). In other words, whether we judge there to be adequate substitutes for some good depends on how we categorize that good with respect to other goods. If we accept the broad individuation of human goods Asch and Wasserman propose, thereby increasing the variety of goods which some particular good is deemed interchangeable with, then there might turn out to be adequate substitutes for many if not all of the benefits of being abled. In that case, it would no longer be true that there are significant benefits to being abled even in a non-ableist society, because in such a society people with disability traits would have access to adequate substitutes for those benefits.

However, the broad individuation of goods proposed by Asch and Wasserman strikes me as implausible. It ignores the immense, obvious differences between, for instance, the experience of hearing a beautiful symphony and the experience of seeing a beautiful painting, sculpture, or landscape. Sunsets and symphonies are not interchangeable aesthetic experiences. That is why it is difficult to imagine a music lover saying, “It’s alright if I never hear music again, because I can see paintings, sculptures, and landscapes”. The presence of significant differences between different kinds of aesthetic experiences, and more generally between various kinds of goods, means that at the very least, the burden is on proponents of broad individuation to make a positive case that such

differences do not matter for the purpose of how to group various goods. Yet Asch and Wasserman admit that they “have no general argument for broad individuation” (*ibid.*). So, until MDV proponents propose a plausible argument for broad individuation, this objection can be set aside.

So far, I hope to have established that the widespread intuition that it is better to be abled cannot simply be dismissed as a symptom of ableism on the basis that it is ableist to assume that the purported benefits of lacking some disability trait are actually benefits. As I have shown, this intuition can be motivated by genuine concern for genuinely good things for which there are no adequate substitutes.

1.3.3 – Fortunate Redundancy

Even if the appeals to ableism we have been considering so far are unconvincing, perhaps MDV advocates can explain away the intuition that it is better to be abled in some other way. For instance, Asch and Wasserman have contended that “human beings enjoy a fortunate redundancy in many of the capacities that are instrumental for, or constitutive of, valuable human goods and activities” (Asch and Wasserman, 2010, 208). If Asch and Wasserman are right about this “fortunate redundancy”, then perhaps we need not be concerned about losing access to good things due to having disability traits, because we have adequate substitutes for the *capacities* needed to access those goods. In that case, the intuition that it is better to be abled would lack adequate justification.

However, for Asch and Wasserman’s claim to be plausible, either (a) the substitute capacities giving one access to some good must be very similar in their functioning to the

capacities one lacks due to disability in order to grant access to the same good, or (b) the goods each capacity grants access to must be different but interchangeable. In many cases, (a) is implausible – for instance, sight and hearing are not interchangeable. Yet as I argued above, Asch and Wasserman have no general argument for the broad individuation of human goods needed to establish (b) in many of these cases as well. Moreover, in many cases (b) is intuitively implausible (consider, for instance, the difference between seeing the sculpture *Victory of Samothrace* or merely touching it). If in many cases neither (a) nor (b) are plausible, that suggests that in those cases (including for traits like blindness and deafness), Asch and Wasserman’s fortunate redundancy claim is not plausible either. This means we should be concerned about losing access to good things due to disabilities after all, which supports the intuition that it is better to be abled.¹⁴

1.3.4 – Ableism II (Barnes)

Having considered and rejected these various attempts to explain away the intuition that it is better to be abled, I will now turn to what I consider the strongest such attempt in the literature. Elizabeth Barnes offers the following critique of the intuition that it is better

¹⁴ This point is also important because it helps defend another important argument against MDV from the fortunate redundancy claim. As noted above, Jeff McMahan has argued against MDV on the basis that if MDV is true, disabilities are neutral in combination, such that a person with many disabilities is not worse off as a result (see McMahan, 2005b, 96). If the fortunate redundancy claim is true, then the effects of multiple disabilities on wellbeing are not necessarily additive; each additional disability does not necessarily make it harder to compensate for all the disabilities one has, because we are saturated with capacities that give us access to various goods (see Wasserman et al., 2016). Yet as I have argued here, the fortunate redundancy claim is not plausible in many cases, so McMahan’s anti-MDV argument does not face this difficulty in those cases.

to be abled. She compares two cases: one in which a parent chooses to make her baby disabled without transition costs (“Disabled Baby” – see Barnes, 2014, 97), and one in which a parent chooses to make her disabled baby abled without transition costs (“Reverse Disabled Baby” – see Barnes, 2014, 99). Critics of MDV see a discrepancy between these two cases – the parent’s interference in Disabled Baby is bad, while the parent’s interference in Reverse Disabled Baby is good. Barnes acknowledges that if there really is such a discrepancy, it would suggest that BDV is true and that MDV is false (*ibid.*). However, she denies that there is any such discrepancy.¹⁵

According to Barnes, Reverse Disabled Baby is analogous to performing binary-sex assignment operations on intersex infants. Some intersex individuals “argue that we should change society’s assumptions about sex binaries (and the relationship between sex and gender) rather than changing children who are born intersex” – a position which clashes with common intuitions and medical practices concerning such cases, but which does not seem problematic on that score, since those common intuitions and medical practices could well reflect the unreliable prejudices of a privileged majority (Barnes, 2014, 104). Similarly, Barnes claims we should change society’s assumptions about disabilities rather than changing people who are born disabled due to supposedly ableist intuitions. In

¹⁵ Barnes actually offers another response on behalf of MDV as well, namely, agreeing that such a discrepancy exists between Disabled Baby and Reverse Disabled Baby, but arguing that this discrepancy does not undermine MDV because MDV advocates can explain it by appealing to the increased risk of lowered wellbeing in Disabled Baby relative to Reverse Disabled Baby (see Barnes, 2014, 100-103). However, Barnes expresses worries about this argument, and claims that it is more promising for MDV advocates to deny the discrepancy and try to explain away the intuitions underlying the discrepancy claim. I agree with Barnes about this, so I will focus here on her discrepancy-denial response.

other words, Barnes holds that the intuition that it is better to be abled is analogous to the intuition that it is better for an intersex infant to undergo a binary-sex assignment operation – both intuitions are unjustified assumptions rooted in prejudice. Furthermore, if it is bad to interfere with intersex infants through binary-sex assignment operations, then given the analogy it is also bad to interfere with disabled infants to make them abled. This would eliminate the discrepancy between Reverse Disabled Baby and Disabled Baby – in both cases, interference would be bad.

Barnes also claims that it is not open to critics of MDV to deny her analogy on the simple grounds that unlike being intersex, having a disability trait is a bad difference, because that would beg the question against MDV. After all, whether or not disability traits are bad differences in the absence of ableism and transition costs is precisely what is at issue in the debate surrounding MDV – it cannot simply be assumed (Barnes, 2014, 106). Independent support must be provided for the claim that with respect to some disability trait, being abled is better than having that trait.¹⁶ Otherwise, the analogy between Reverse Disabled Baby and the case of intersex infants shows that the intuition that it is better to be abled is an ableist assumption.

Crucially, we can see from all this that Barnes' charge of ableism against the intuition that it is better to be abled turns on whether there is independent reason to think that for some disability trait, it is better to be abled than to have that trait. If it turns out

¹⁶ As Barnes puts it, “to support the claim that there’s an obvious cause/remove discrepancy, you’d need the further claim that the constraints imposed by disability are somehow worse than those imposed by nondisability” (Barnes, 2014, 106).

there is independent reason to think this, that would undermine Barnes' analogy between having a disability trait and being intersex, and with it her resulting claim that the intuition that it is better to become abled is an ableist intuition. So, Barnes is in the position of having to argue that on an overall weighing of some disability trait, it is no better to be abled than to have the disability trait. In the next section, I will cast doubt on the possibility of making such an argument convincingly.

1.4 – Weighing Ability and Disability

For Barnes to show that on an overall weighing of some disability trait, it is no better to be abled than to have the disability trait, she must claim that the benefits of disability traits will cancel out the remainder costs of not being abled.¹⁷ My goal in this section is to challenge this claim, and in the process to provide independent support for the intuition that it is better to be abled. I will first take stock of the typical kinds of remainder costs pertaining to most if not all disability traits which have been recognized in the existing literature. Then, I will discuss various kinds of purported benefits of disability traits that are supposed to cancel out those remainder costs, and show that for most if not all disability traits, many of the disability-specific benefits of those traits will have adequate substitutes, and the rest will be nowhere near sufficient to cancel out the remainder costs of those traits. I will show this by demonstrating that even in the case of deafness, which is perhaps the case friendliest to MDV, the remainder costs of not being abled likely outweigh the benefits

¹⁷ For Barnes' discussion of this point, see, e.g., Barnes, 2016b, 56-57.

of being deaf. Showing this would suggest that the same is true for other disability traits that are easier for critics of MDV to deal with. Contrary to the claim of MDV advocates that on an overall weighing of some disability trait, it will turn out that it is no better to be abled than to have that disability trait, it is likely that with respect to most if not all disability traits, it is better to be abled than to have the disability trait in question.

The negative effects of disability traits typically mentioned by critics of MDV include pain, ill-health, reduced lifespan, and significant reduction of valuable options due to impaired capacities (see, e.g., Singer, 2005, 56; Kahane & Savulescu, 2016, 777; Buchanan et al., 2000, 167-168 and 278; and Crawley, 2021, 155-169).¹⁸ These negative effects which make people with disability traits worse off are not always caused by ableist social arrangements or transition costs, nor are they mitigated by fortunate redundancies in our capacities. Rather, in many cases these negative effects seem to pertain to the traits themselves – they are remainder costs in virtue of which individuals with those traits would be worse off even in the absence of systemic ableism or transition costs.¹⁹ So, when MDV advocates claim that the benefits of disability traits cancel out the remainder costs of not being abled, we should take the remainder costs in question as including these negative effects of disability traits, though we have to determine which of these negative effects are caused by each particular trait, and to what extent.

¹⁸ For objections to the reduction of valuable options argument by MDV advocates, see, e.g., Asch and Wasserman, 2005, 2010, 2012 and 2014; Barnes, 2009 and 2016b; Campbell and Stramondo, 2017 and 2018; and Schroeder, 2018. For responses to these objections, see, e.g., Andric and Wundisch, 2015, and Crawley, 2021.

¹⁹ Barnes herself acknowledges this (see, e.g., Barnes, 2016b, 57 and 94).

One motivation for the claim that the benefits of disability traits cancel out the remainder costs of not being abled is that people who think it is better to be abled might ignore or downplay good aspects of having some disability trait. So, it is important to take into account these claims about good aspects of disability traits as far as is plausible, and show that even when the purportedly good aspects of having some disability trait are taken into account, it is doubtful that those benefits cancel out the remainder costs of having that trait.

To take stock of the purported benefits of disability traits, it is important to make two distinctions. The first distinction is between benefits of disability traits that *can* be adequately substituted for, and benefits of disability traits that *cannot* be adequately substituted for. For MDV advocates to be able to claim that on an overall weighing the benefits of disability traits will cancel out the remainder costs of not being abled, it is the benefits that *cannot* be adequately substituted for which will have to do all the work in their argument. After all, if some benefit of a disability trait can be adequately substituted for, then one could achieve the benefit in question through that substitute without having the disability trait, and thus without incurring the remainder costs associated with the disability trait. If the same benefit can be enjoyed both by an abled person and a person with a disability trait, that benefit cannot count as a benefit pertaining to the disability trait which could cancel out the remainder costs of not being abled.

The second distinction concerns two kinds of benefits of disability traits: general benefits common to many if not all disability traits, and disability-specific benefits. General benefits include access to the disabled community and cultural groups (see, e.g., Barnes,

2016b, 116 and Glover, 2006, 17), as well as the way becoming disabled can give focus and direction to a previously aimless life (Barnes, 2009), and various benefits stemming from socially-adopted accommodations and policies, such as being able to avoid long lines or park conveniently (see, e.g., Campbell & Stramondo, 2017, 158). In turn, disability-specific benefits will vary from trait to trait, often dramatically so. For a trait like deafness, there may be several disability-specific benefits (I will discuss these in detail below). But for traits like paraplegia and Down syndrome, there seem to be fewer such disability-specific benefits.²⁰

Finally, there is another important point to note besides these two distinctions. Given that we are trying to determine the evaluative status of disabilities themselves, even in a non-ableist society, our weighing will not take into account the actual socially-mediated costs of disability traits which are commonly attributed to ableism, and which would be absent in a non-ableist society.

With all this in mind, let's consider how a weighing of a disability trait's value might go. Notably, it seems relatively easy to find adequate substitutes for disability traits as ways of achieving the *general* benefits MDV advocates appeal to, which makes it less costly to lack those disabilities. For example, when it comes to the sense of belonging and inclusion one gets from membership in communities and cultures in general, we have a much more significant and obvious fortunate redundancy of communities and cultures to

²⁰ If my discussion of the purported benefits of disability traits does not seem exhaustive, note that the discussions of such benefits by *proponents* of MDV are not any more detailed (see, e.g., Barnes 2016a and 2016b, Campbell and Stramondo, 2017).

participate in than we do for the kinds of capacities disability traits deprive us of (such as movement, sensory modalities, and intellectual capacities). Likewise, in general there are many ways to give focus to an aimless life, and it is difficult to say whether such focus could be achieved only due to the presence of a disability trait (whether in advance or in hindsight), so this way of achieving the benefit looks like it could be substituted for as well. Even if we take the testimony of disability rights activists seriously, and grant that some of these general benefits are significant, it seems like there are other ways to get those benefits (or at least similar benefits) that do not require being disabled and suffering the costs of not being abled. Finally, in most cases the various social accommodations disabled individuals benefit from, like parking conveniently, seem clearly less significant than the remainder costs of their disability traits. So, most of these purported general benefits of disabilities, which are the ones typically mentioned by MDV advocates, seem substitutable, and the rest do not seem like they will be very weighty in an all-things-considered weighing of some disability trait. Appealing to general benefits of disability traits does not help the MDV advocate very much. It will have to be the disability-specific benefits doing the lion's share of the work of cancelling out the remainder costs of the relevant disability trait being evaluated.

My core claim is that for most if not all disability traits, many of the disability-specific benefits of those traits will also have adequate substitutes, and the rest will be nowhere near sufficient to cancel out the remainder costs of those traits, including pain, ill-health, reduced lifespan, and significant reduction of valuable options (among others). Since it is not possible to demonstrate this by exhaustively evaluating all disability traits

here, I will focus on demonstrating it in the case of deafness. Deafness is one of the disability traits regarding which MDV seems most plausible, and which MDV advocates appeal to as a paradigmatic case of a disability trait that is supposedly a mere difference. So, I focus on deafness because showing that my arguments have force even for that difficult case would suggest that my arguments will also have force for other disability traits that are easier for critics of MDV to deal with, such as paraplegia and Down syndrome. I will show that even for a trait like deafness, it is not very plausible that the benefits of disability traits which cannot be substituted for can, all on their own, cancel out the benefits of being abled.

In weighing the remainder costs and benefits of deafness, I will exclude substitutable general benefits of disabilities like membership in a cultural community of people with a shared identity, because in virtue of being substitutable these goods are available to abled individuals as well. I will also exclude certain substitutable disability-specific benefits. For example, I will exclude the benefits of avoiding harsh and unpleasant noises, together with the resulting capacity to work undisturbed in loud environments (Schroeder, 2018, 15), and the reported increased sense of peacefulness and capacity to focus (Campbell & Stramondo, 2017, 158), since these can be experienced by abled people through use of earplugs or earphones, among other means. I will also exclude the various benefits of learning and using sign-language, such as being able to communicate underwater and through transparent but soundproof walls and windows, since these benefits are available to abled individuals as well; nothing stops abled people from learning sign-language to enable communication in these scenarios. Finally, I will exclude the

benefits of having the capacity to lip-read, which abled individuals can develop as well through practice.

From among the benefits of deafness cited by MDV advocates, those which are not substitutable amount to enhanced peripheral vision and the enhanced ability to experience music through vibrations (see Barnes, 2016b, 57).²¹ In turn, the remainder costs of deafness include the inability to hear various kinds of sounds widely considered valuable to experience, such as music, natural sounds like birdsongs, the wind, and ocean waves, and the voices of our loved ones and friends; increased vulnerability in darkness and other situations with obstructed vision; and difficulty learning to speak (especially for congenitally deaf individuals).²²

Although it might be difficult, if not impossible, to precisely quantify the effect these various non-substitutable benefits and remainder costs have on the wellbeing of deaf people, intuitively it seems plausible that the remainder costs of deafness outweigh its non-substitutable benefits. The costs of lacking access to the various kinds of valuable sounds listed above seem to far outweigh the benefit of an enhanced ability to experience music through vibrations. In fact, there is especially strong reason to think lacking the ability to hear music is highly costly. Music is an enormous source of value for human beings. It is an intense source of pleasure for many people, and is also closely tied to other activities and artforms many people find pleasant and valuable, such as prayer, dancing, ballet,

²¹ My discussion of the purported benefits of deafness here is no less exhaustive than that of MDV advocates themselves.

²² Note that the difficulties learning to speak faced by many congenitally deaf individuals can be a huge disadvantage, as many deaf individuals desire, like most other people, to communicate effectively with hearing people and other communities besides the deaf community.

musical theater, and opera. Another reason music has such a central role in human life and culture is its capacity to move people emotionally – a role which is not only widely recognized all over the world, but which also has been emphasized by various philosophers throughout history, including Plato, Schopenhauer, and Nietzsche.²³ It is not clear that physically experiencing vibrations can be as pleasant as hearing music, nor is it clear that physically experiencing vibrations can move a person emotionally the way actually hearing music can.²⁴ Finally, it is tempting to say that the enhanced peripheral vision experienced by many deaf individuals does not outweigh the difficulties many of them face learning to speak and navigating situations of obstructed vision, and indeed may be outweighed by those difficulties.

So, although the degree to which it is better to be abled than deaf might not be overwhelming, it does exist.²⁵ Even if a deaf individual can live a life worth living, it remains the case that *ceteris paribus*, it is better to be able to hear, and that a deaf person who becomes able to hear benefits thereby (barring transition costs).²⁶

²³ See, e.g., Plato's various discussions of the relationship between music and politics in the *Republic* (Plato, 1968; cf. Valiquette Moreau, 2017), Schopenhauer's view of music as a representation of the Will itself in *The World as Will and Representation* (Schopenhauer, 2010 and 2018), and Nietzsche's various remarks on the relationship between music, physiology, and culture (which are scattered throughout his corpus – for interesting discussion, see Higgins, 1986).

²⁴ Of course, more empirical work can and should be done to fully vindicate these claims (including but not limited to collecting testimony from deaf individuals).

²⁵ For another evaluation of deafness that comes to a different conclusion, see Cooper, 2007. One shortcoming of Cooper's discussion is that she does not sufficiently distinguish between substitutable and non-substitutable benefits of deafness.

²⁶ There is plenty of evidence that many individuals who are part of or adjacent to the deaf community agree with this assessment. For instance, audiologists tend to think more research should be done to cure deafness (Cottrell et al., 2021), most parents of deaf children seriously consider cochlear implants for their children (Li et al., 2004), and deaf and hard of hearing adolescents tend to have positive attitudes towards cochlear implants (Most et al., 2007). As for the

Thus, even with respect to the disability trait that is perhaps most favorable to MDV, the claim that the benefits of that trait cancel out the remainder costs of not being abled is not very plausible. This suggests that in cases less friendly to MDV, such as paraplegia and Down syndrome, the claim that the benefits of those traits cancel out their remainder costs is dubious. It also suggests that Barnes' analogy between having a disability trait and being intersex, and her resulting claim that the intuition that it is better to be abled is an ableist intuition, is dubious as well. Having a disability trait is not analogous to being intersex because as we have seen, in the former case there is independent support for the claim that on an overall weighing of some disability trait, it is better to be abled than to have the disability trait.

If I am right, what should we make of the claims of disability rights activists that disability traits are mere differences, especially since concerns about epistemic and testimonial injustice against individuals with disabilities have been appealed to by proponents of MDV in response to criticism of their view? For example, Barnes claims that there is an “epistemic distinctness of discussing a marginalized social group like disabled people”, and that “philosophical discussions of the wellbeing of marginalized groups— including disabled people—have some unique epistemic features” (Barnes, 2016a, 295-299). For Barnes, when disability rights activists claim that their disabilities are not bad differences, we should take their claims seriously, something which she accuses critics of MDV of not doing sufficiently and thereby engaging in forms of epistemic and

public in general, we can take the large number of likes and positive comments on cochlear implant activation videos on social media as a rough indicator of typical attitudes (see Cooper, 2019).

testimonial injustice.²⁷ Addressing these issues of epistemic and testimonial injustice requires calling into question the claims of disability rights activists, and even potentially trying to psychologize about them in order to explain why they claim that their disabilities are not bad for them. We can see that in their debate with Barnes, Kahane and Savulescu do this: they claim that “disability activists have powerful reasons for wanting the Mere Difference View to be true. This view is psychologically reassuring and politically useful—a rallying point for activism” (Kahane and Savulescu, 2016, 785, fn. 24).

I am sympathetic to Kahane and Savulescu’s arguments about this and do not find those testimonial injustice arguments Barnes makes to be convincing. Barnes’ appeal to the testimony of disabled rights activists, and to claims about the history of epistemic injustice towards marginalized groups, in her reply to Kahane and Savulescu is unconvincing because, as I have argued in this chapter, there is a clear difference between disability and other identity categories that have been historically marginalized, such as skin color, sex and gender, sexual orientation, etc. In a world without racism, sexism, and homophobia, it would not be better to have any particular skin color, sex and gender, or sexual orientation. In contrast, for most if not all disability traits it *is* better to be abled rather than to have the disability trait in question. We have good reasons to be skeptical of the testimony of disability rights activists that there is nothing inherently bad about being disabled, or that disabilities provide benefits that equal or outweigh the badness of being

²⁷ Barnes emphasizes that “there is a long and very troubling history of ignoring what marginalized groups say about their own experiences and wellbeing”, and that “ignoring the claims of a marginalized group about their own lives is something that’s been a common source of error” (Barnes, 2016a, 299).

disabled, whereas we have no good reason to be skeptical in this way of the testimony of racial minorities, women, or LGBTQ people that, bracketing the effects of social prejudice, their experience would simply be different rather than worse. So, as Kahane and Savulescu note, “past mistakes [with respect to traits such as race, sex and gender, or sexual orientation] can’t show that intuitions about disability are prejudiced. They just give us reasons to give these intuitions extra careful scrutiny,” which is exactly what I hope to have done throughout this chapter (*ibid.*).

1.5 – Conclusion of Chapter I

In this chapter, I hope to have successfully defended the intuition that it is better to be abled against the critiques of MDV advocates. The first set of critiques I discussed appealed to transitions, to concerns about ableism, and to a supposed fortunate redundancy of human capacities, but these critiques proved unsuccessful. I subsequently showed that Barnes’ distinct argument that the intuition is ableist because it is analogous to the problematic claim that it is better not to be intersex, hinges on the further claim that the benefits of disability traits cancel out the remainder costs of not being abled. I then established that this further claim is not convincing, and that there is independent reason to believe the intuition that it is better to be abled, which we can see once we start weighing the value of disability traits. In particular, I demonstrated this in the case of one of the examples most frequently appealed to by MDV advocates, namely, deafness, which suggests that it is true for other disability traits as well, and thus that the MDV claim that

the benefits of disability traits cancel out the remainder costs of not being abled is also unconvincing in general. In light of all this, I submit that we should accept the common intuition that it is better to be abled.

Accepting the intuition that it is better to be abled puts significant pressure on MDV. Crucially, we have reason to consider any disability trait about which we have this intuition as bad to have, since it cuts one off from the benefits of being abled and is therefore bad to that extent, all else being equal.²⁸ More precisely, for any disability trait about which this kind of argument can be made, each benefit of being abled one is deprived of by the disability trait generates a remainder cost, which would constitute a *pro tanto* reason to consider that disability trait bad in itself, even in the absence of ableism and transition costs. These *pro tanto* reasons would have to be weighed against all the other relevant considerations, including the supposedly good aspects of having the disability trait in question that MDV advocates appeal to. But acknowledging these *pro tanto* reasons puts pressure on MDV by showing that for many disabilities there are considerable remainder costs which cannot be explained away as effects of ableism or transition costs, or by appealing to fortunate redundancy, thus casting doubt on the key MDV claim that the bad aspects of disability traits can be canceled out by the supposed benefits of those traits.

²⁸ This line of argument can also help explain the common intuition that someone born with a disability trait from the start (rather than developing that trait during one's life) is worse off as a result of having that trait, even in the absence of systemic ableism, and despite not experiencing any transition costs.

CHAPTER II: Prospective Parents, Disabilities, and the Reproductive Context

Recent advances in various medical and reproductive technologies have made it possible to screen and select for or against various traits that have a genetic component. Embryos or fetuses that are already growing *in utero* are often tested for certain traits using tests like chorionic villus sampling (CVS) or amniocentesis, at which point prospective parents can decide whether to maintain or terminate the pregnancy based on the test result. Such testing also often takes place as part of a broader IVF process that many prospective parents undergo: once embryos are successfully grown, a few cells from each embryo can be biopsied and tested, and prospective parents can decide whether they want to keep or discard embryos bearing the traits that were tested for.

Using such testing techniques to select against embryos and fetuses with disability traits has been a matter of intense controversy among bioethicists, moral philosophers, medical professionals, and disability rights activists. While some have argued that there is at least some kind of obligation for prospective parents to engage in such testing for this purpose (see, e.g., Savulescu, 2001 and 2008), others have claimed that conducting such selection is undesirable and even immoral, and demanded that testing for this purpose

be prohibited or at least discouraged (see. e.g., Watt, 2004, Perez Gomez, 2020, and Dietz & Reynolds, 2021).

Faced with this moral controversy, what, if anything, should prospective parents do? In this chapter, I will argue that the only justifiable *general* response to this question is that with respect to most if not all disability traits, prospective parents are praiseworthy for selecting against the trait in question. That is, considered in general we should take selecting against disability traits in the reproductive context to be supererogatory for prospective parents. This means prospective parents *should* select against most if not all disability traits in their future children – doing so is usually the best or ideal option for prospective parents to strive for as long as their situation allows for it.

My argument will proceed as follows. In section II.1, I will examine the most prominent argument in favor of selecting against disability traits that appeals to notions of wellbeing, namely, Julian Savulescu’s proposal that prospective parents should select the child they expect to have the best life from among the children they could have, and explain difficulties that Savulescu’s view faces. In section II.2, I will propose what I take to be a more defensible wellbeing-based argument I call the *Moderate Perfectionist* argument, namely, that with respect to some disability trait, prospective parents likely have some kind of reason to select against that trait in their future children, as long as and to whatever extent that trait negatively impacts wellbeing. In section II.3, I will provide additional arguments supporting the claim that prospective parents should select against disability traits which do not appeal directly to wellbeing. I will conclude that with respect to most if not all disability traits, prospective parents *should* select against the trait in question in their

future children, because doing so is usually the best or ideal option for prospective parents to strive for as long as their situation allows for it. In section II.4, I will address potential objections to my claim that for most if not all disability traits, parents should select against the trait in question in their future children. Finally, I will conclude by summarizing my argument and briefly discussing two other stances prospective parents can take with respect to the possibility of disability traits in their future offspring: avoiding selection against disability traits, and actively selecting *for* disability traits.

II.1 – Procreative Beneficence, Wellbeing, and Selecting the Best Children

Perhaps the most influential argument that prospective parents should select against disability traits in the reproductive context is based on Julian Savulescu’s principle of Procreative Beneficence. According to this principle, “couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information” (Savulescu, 2001, 415). For Savulescu, we should adopt this principle because it maximizes the potential wellbeing of one’s future offspring based on available information in the reproductive context (namely, genetic information obtained through screening). Savulescu claims that adhering to the principle of Procreative Beneficence in the reproductive context by engaging in selection is “*morally required*” (Savulescu, 2001, 425). Savulescu’s argument for Procreative Beneficence has been the subject of intense

controversy.²⁹ But if Savulescu is right that prospective parents should adopt the principle of Procreative Beneficence, that would mean parents should select against disability traits in the reproductive context. Savulescu, among others, draws precisely this conclusion: “if we have two embryos which in all respects appear to be the same, except B has a state which is a disability, then we have a strong reason to choose A” (Savulescu, 2008, 52; cf. Brock, 2005b, 73-74).

However, this conclusion has been called into question by Matthew Barker and Robert Wilson. Barker and Wilson contend that the principle of Procreative Beneficence does not license the claim that prospective parents have strong reason to select against disability traits, which they call *Disability-Free Procreation*. They show that there are two possible versions of the argument from Procreative Beneficence to Disability-Free Procreation: what I will call the *Substantial Harm* argument and the *Perfectionist* argument (“Version A” and “Version B” in Barker and Wilson, 2019, 311). On the Substantial Harm argument, we should accept Disability-Free Procreation “if most disabilities reduce well-being *substantially*” because this would give prospective parents “significant moral reason” to select against disabilities, and in fact most disabilities do reduce well-being substantially, so we should accept Disability-Free Procreation (*ibid.*, emphasis added). On the Perfectionist argument, we should accept Disability-Free Procreation “if most disabilities reduce well-being to *any* degree” because this would give prospect parents

²⁹ For further discussion, see, e.g., Herissone-Kelly 2006 and 2011, Parker 2007, Sparrow 2007, Savulescu 2007b, Stoller 2008, Bennett 2009 and 2013, Savulescu & Kahane 2009, Hotke 2012, Holland 2016.

“significant moral reason” to select against disabilities, and in fact most disabilities do “reduce well-being to some degree,” so we should accept Disability-Free Procreation (*ibid.*, emphasis added). According to Barker and Wilson, both of these arguments fail because they each contain a false premise. The Substantial Harm argument depends upon the false premise that most disability traits *substantially* reduce wellbeing, while the Perfectionist argument depends upon the false premise that prospective parents have a significant reason to select against disability traits if most disabilities reduce well-being to *any* degree (Barker and Wilson, 2019, 311).

Although I do not find some of the specific arguments offered by Barker and Wilson against these premises convincing (I will discuss their arguments in greater detail below), more generally I agree with them that these premises are false, and that the Substantial Harm and Perfectionist arguments from Procreative Beneficence to Disability-Free Procreation require adopting one or the other of these false premises. It is not clear that *most* (i.e. the vast majority of) disability traits *substantially* reduce wellbeing, whether wellbeing is understood as subjective wellbeing or as some form of objective wellbeing (see sections 3 and 4 of Barker and Wilson, 2019). Nor is it plausible that prospective parents have a *significant* reason to select against disability traits if most disabilities reduce well-being to *any* degree. As a result, Procreative Beneficence and the concern with wellbeing that motivates it likely cannot ground a *global duty* to select against disability traits in general (considered as a category of traits).

However, even if it is difficult to defend the notion of a global duty to select against disability traits in general, that does not rule out that there is some sense in which parents

should select against disability traits. In the next section, I will show that as long as we consider each disability trait on a case-by-case basis, we can arrive a weaker and more nuanced version of Disability-Free Procreation that appeals to considerations about wellbeing yet is defensible against Barker and Wilson’s arguments.

II.2 – The Moderate Perfectionist Argument for Selection Against Disability Traits

In this section, I will contend that with the right modifications, something like the Perfectionist argument can be defended against Barker and Wilson’s critiques, and thereby show that wellbeing-based considerations can justify at least some version of Disability-Free Procreation. More precisely, two changes need to be made to the Perfectionist argument as Barker and Wilson present it. The first is that, in line with my approach in Chapter I of this dissertation, the argument should be framed in a way that takes up disability traits individually on a case-by-case basis, rather than being cast in general terms and focusing on disability as a monolithic category. The list of traits commonly considered ‘disabilities’ is too heterogenous, and the ways each of these traits affect people is too variable, for us to make sweeping general claims about the effect of these traits upon wellbeing if they are taken collectively as a single category. So, instead of talking about “disabilities” or “most disabilities”, as Barker and Wilson do, I will talk about “some disability trait”. The second change to the argument is to add nuance to the argument’s claims about the *strength* of the reason to select against some disability trait that prospective parents are supposed to have due to the fact that the trait reduces well-being to some degree. I agree with Barker and Wilson’s observation that “the main factor that varies

directly with the significance of moral reasons [to select] ... is the *degree of expected reduction in well-being*: the greater that reduction, the more significant the reason” (Barker and Wilson, 2019, 321). This means that our modified version of the Perfectionist argument should avoid *assuming* that the reasons to select prospective parents have are “significant” for all or most disability traits, as is assumed in the version of the Perfectionist argument critiqued by Barker and Wilson.

The result of these changes is what I will call the *Moderate Perfectionist* argument:

- (1) If some disability trait reduces wellbeing to any degree, then prospective parents typically have some reason to select against creating a child who will probably develop that disability trait, provided they could instead create a child who probably will not develop that disability trait.
- (2) Most disability traits reduce wellbeing to at least some degree; the extent of the reduction in wellbeing can vary substantially depending on the disability trait in question.
- (3) The more the disability trait in question reduces wellbeing, the stronger the reason the prospective parents have to select against that trait.
Therefore,
- (4) *Moderate Disability-Free Procreation*: Prospective parents typically have a reason to select against creating a child who will probably develop a disability trait that reduces wellbeing, provided they could instead create a child who probably will not develop that disability. The strength of this reason depends on how severely the disability trait in question reduces wellbeing.

As we have seen, Barker and Wilson accept Premise (3), and they likely would not challenge Premise (2) either based on their claims in their 2019. Moreover, Barker and Wilson should accept Premise (1), given that they do not challenge the first premise of the Harm-Avoidance argument, namely, that “If most disabilities reduce well-being substantially, then prospective parents typically have a significant moral reason to select against creating a child who will probably develop a disability, provided they could instead

create a child who probably will not develop that disability” (Barker and Wilson, 2019, 311). In this premise from the Harm Avoidance argument, the strength of the reason to select reflects the severity of the reduction in wellbeing. Premise (1) in my Moderate Perfectionist argument does the same; such a premise seems like it would also be plausible to Barker and Wilson because the strength of the reason to select against some disability trait reflects the severity of the reduction in wellbeing brought about by having that trait. After all, Barker and Wilson themselves emphasize that the strength of the reason to select against some trait should vary in accordance with the degree of expected reduction in wellbeing caused by that trait (Barker and Wilson, 2019, 321). The key question, then, is whether Premise (1) is enough to establish Moderate Disability-Free Procreation once it is taken together with Premises (2) and (3). In order to answer this question, however, I must first say something about precisely whose wellbeing is impacted by the decision of prospective parents to either select against some disability trait in the reproductive context, or avoid doing so.

II.2.1 – Whose Wellbeing? The Non-Identity Problem

At first glance, one might think that one of the main reasons selection against some disability trait in the reproductive context would be desirable is that this practice would benefit the child one will have. However, when one selects against an embryo with some disability trait, this selection does not benefit that embryo (or the child that would have

resulted from successful implantation of that embryo), because that embryo is discarded.³⁰ Instead, it is another embryo which has been determined not to possess the disability trait in question which is implanted and which benefits from the selection. So, it's not that a particular child's life will be improved by screening and selecting; rather, prospective parents are choosing between two different lives.

In such cases, it seems we cannot appeal to some purported benefit to the particular child with the disability trait in order to explain the desirability of selecting against that trait. Yet the desirability of selecting against disability traits seems to depend on *someone* being made better off by this practice. Intuitively, it seems like such selection does create some kind of benefit. So, we must explain who benefits from selection against disability traits in the reproductive context in light of this non-identity problem. This will be relevant both to my response to Barker and Wilson, and to my overall argument in this chapter that prospective parents should select against disability traits in the reproductive context.

Dan Brock offers what I take to be an especially promising solution to the non-identity problem. Brock distinguishes between *same-person* and *same-number* choices (Brock, 1995, 272; cf. Parfit, 1984). A same-person choice is one in which the same person exists in each of the alternative courses of action one is choosing between, i.e., a choice between doing different things to the same person. In contrast, a same-number choice is one in which the same number of individuals exists in each of the alternative courses of

³⁰ As Dan Brock has noted, in cases where the child with the disability trait could still live what we would intuitively consider to be a worthwhile life, it would not be better for the child with the disability trait to have had it prevented since that can only be done by preventing that child from ever having existed at all (Brock, 1995, 271).

action one is choosing between, but the identities of at least some of those individuals are affected by the choice; same-number choices result in the same number of people existing, but not the same person. For Brock, the kinds of cases that run into the non-identity problem involve *same-number* choices.

In order to explain the wrongness of not selecting against disability traits in same-number choices, Brock argues that we should appeal to *non-person-affecting principles*. A non-person-affecting principle is a moral principle that does not appeal to harm or wrong (or benefit or doing right by) *to some particular person*. Instead, non-person-affecting principles appeal to an *impersonal* notion of harm or wrong. For instance, in order to explain the wrongness of not selecting against some disability trait, one could appeal to a non-person-affecting principle that seeks to avoid adding suffering to the world as a whole (Brock, 1995, 273). But one could also appeal to non-person-affecting principles that seek to avoid limiting opportunity in the world (*ibid.*), or to increase the overall level of flourishing in the world.

The plausibility of appeals to such non-person-affecting principles depends on the plausibility of the notion of *impersonal benefit*. An impersonal benefit is a benefit which does not pertain to a particular person. A non-person-affecting principle that seeks to maximize impersonal benefit, or minimize impersonal harm, could explain the wrongness of not selecting against some disability trait in same-number choices. In other words, appealing to a non-person-affecting principle of the kind we have been discussing would resolve the non-identity problem by rejecting one of the intuitions underlying it, namely,

that if something is good or bad, it must be good or bad *for* someone (see Parfit, 1987, 363).

One way to make the idea of impersonal benefits and harms easier to understand and accept in the specific context of selecting against disability traits in the reproductive context is to consider some implications of the distinction between *same-person* and *same-number* choices. I will begin with the observation that prospective parents who choose to select against disability traits in the reproductive context are making a *same-number* choice: either way, they are going to have one child, and they are choosing which particular child this one child they will have is going to be. More precisely, in such scenarios prospective parents are choosing to maximize the wellbeing, options, and chance to flourish of the child they are going to have (from this pregnancy or this round of IVF). Even if there is no identity of person here, such that it's not one particular child who benefits from the decision to screen and select, there is an *identity of number*: a single child will be brought into existence, and it is this single child, whose precise identity *qua* particular person is not established prior to the selection of embryo to implant, who benefits from the decision. The ethical rationale behind prospective parents' choice to select against some disability trait can thus include the following child-focused consideration: "given that we are bringing into existence one child, and we can choose which one it will be, let's maximize this one child's wellbeing, options, chance to flourish, etc." This rationale does not depend on some specific child personally benefiting in a way that would run into the non-identity problem. Instead, it involves impersonal benefit to the numerical child the prospective parents intend to have.

Notably, this is a common, familiar way people think ethically in these kinds of situations. Consider the case of a boss who is looking to hire a warehouse worker who will be engaging in heavy manual labor. When considering which specific human being from among several applicants will be the warehouse worker he is looking to hire, it would be natural, and even ethically laudable, for the boss to select for physical strength at least in part *for the sake of the warehouse worker whoever they will be*, because physical strength will help the warehouse worker avoid debilitating back injuries the work could otherwise cause over time. Here, the boss' decision to select according to this criterion of physical strength is done *for the sake of the numerical warehouse worker* he is looking for, not for the sake of a specific human being (e.g., specifically Applicant 1 Jane Doe, or Applicant 2 John Smith). In the same way, prospective parents who screen and select against disability traits in their embryos do so at least in part for the sake of whoever it is their child will turn out to be, the numerical child. Approaching the choice to select in this way is as familiar, common, and comprehensible a form of ethical thinking and decision-making as in the warehouse worker case, and is laudable for the same reasons.³¹ So, we can explain the benefit of selecting against disability traits as an impersonal benefit, and the harm of not doing so as an impersonal harm, to a numerical child the prospective parents intend to have,

³¹ Furthermore, it is to be expected that, at least in with respect to IVF with PGD, prospective parents who choose to select against disability traits are choosing for the sake of a numerical child, with a numerical child in mind, rather than for the sake of a specific particular child. After all, prior to the selection yielding the particular embryo that will be implanted, there simply is no particular child for whose sake they are making this choice. The only way the prospective parents could even approach thinking about this issue and making a choice is in these impersonal numerical terms, just like the boss in the warehouse example. Arguably, this point applies even to post-implantation cases involving amniocentesis or CVS testing and abortion.

and we can use that as a basis for making claims about the benefits of such selection despite the non-identity problem. This applies whether we think about the benefit in question in terms of wellbeing, or other considerations such as opportunity or flourishing.

II.2.2 – Defending Moderate Disability-Free Procreation

I will now return to the Moderate Perfectionist argument and its conclusion, Moderate Disability-Free Procreation. Barker and Wilson make several claims which, if true, threaten the Moderate Perfectionist argument by suggesting that its Premise (1) is not enough to establish Moderate Disability-Free Procreation. I will focus here on their claims concerning *dependent objective wellbeing* (DOW), and their claims concerning the potential significance of the reasons to select that something like the Moderate Perfectionist argument could yield.³² I will cast doubt on these claims, and show that Premise (1) is enough to establish Moderate Disability-Free Procreation.

Claim 1

³² Barker and Wilson also discuss subjective wellbeing and independent objective wellbeing, but I will not focus on these here. *Subjective* wellbeing refers to how well some person experiences their life to be going over some period of time (Barker and Wilson, 2019, 312; cf. Diener, 1984; Lawton, 1984; and Stock, Okun, and Benin, 1986). As I will argue in my response to Claim 1 from Barker and Wilson below, I do not think self-reports of subjective wellbeing by individuals with some disability trait are very useful for whether that trait actually makes those individuals worse off. In turn, *independent objective* wellbeing refers to those components of objective wellbeing that do not “typically cause or constitute subjective well-being” (Barker and Wilson, 2019, 318). I agree with Barker and Wilson that many of the capacities disability traits deprive one of are believed to be valuable “primarily because of their causal influence on subjective well-being in many cases, typically via their instrumental role in allowing people to achieve other goals” (Barker and Wilson, 2019, 319).

The first claim is that *disability traits do not significantly reduce DOW*, which consists in those “constitutive components of objective well-being” that “are the *main* causal factors of the subjective well-being of people, regardless of whether people are aware of (or confused about) those factors being the typical causes of subjective well-being” (Barker and Wilson, 2019, 315-316).³³ If that’s right, then there might not be significant reason to select against any particular disability trait, which would dramatically reduce the force of the Moderate Perfectionist argument. To support their claim, Barker and Wilson appeal to various studies purporting to measure the subjective wellbeing of individuals who have had disability traits from birth in order to establish that “most disabled people report only slightly lower QOL [quality of life] than most non-disabled people” (Barker and Wilson. 2019, 312).³⁴ Barker and Wilson then contend that “when the subjective QOL reports of *many* people with mobility-related disabilities suggest that low mobility typically does not cause large net reductions in their subjective well-being, this should be interpreted as strong evidence that low mobility is *not*, objectively, a large draw on subjective well-being, that is, it is not a component of DOW” (Barker and Wilson, 2019, 316); they extend this reasoning to disability traits in general (*ibid.*). Barker and Wilson hold that because not just a few, but many individuals with disabilities report similar QOL to non-disabled people, we should put aside the possibility that disabled individuals “over-

³³ Again, subjective wellbeing refers to how well some person experiences their life to be going over some period of time (Barker and Wilson, 2019, 312; cf. Diener, 1984; Lawton, 1984; and Stock, Okun, and Benin, 1986).

³⁴ See, e.g., Stensman, 1985, Mehnert et al., 1990, Fuhrer et al., 1992, Gow et al., 2005, and Endermann, 2013. The reason Barker and Wilson focus on studies involving individuals who have been disabled from birth is that this matches the situation an embryo with a disability would face if it were chosen to be carried to term in the reproductive context.

report their own subjective well-being,” for instance “by not accurately dwelling on how their low mobility really, objectively causes reduction in their subjective QOL” (Barker and Wilson, 2019, 316).

Defenders of *Moderate Disability-Free Procreation* can respond to this argument by questioning the key claim made by Barker and Wilson about how to interpret the various studies they cite showing that most disabled people report only slightly lower QOL than most non-disabled people. First, as Kahane and Savulescu point out, it can be “psychologically reassuring” for individuals with disabilities to see their disabilities as mere differences, which suggests that individuals with disability traits may have a psychological interest in believing, or making themselves believe, that their quality of life is similar to that of abled individuals (Kahane and Savulescu, 2016, 785, fn. 24). More generally, human beings can come to feel comfortable and satisfied with their quality of life in a wide variety of circumstances, including some that are uncontroversially bad, as in the example of the “hypothetical happy slave” cited by Barker and Wilson themselves (Barker and Wilson, 2019, 315). There is no reason to think these psychological dynamics do not influence the reported subjective wellbeing of individuals with disabilities in the studies cited by Barker and Wilson. If that’s right, it would give at least some reason to think many individuals with disability traits do over-report their subjective wellbeing, and therefore that the studies cited by Barker and Wilson do not license their conclusion that being abled in some way is not a component of DOW, and thus that disability traits do not significantly reduce DOW.

Finally, as Barker and Wilson themselves emphasize, individuals who are disabled from birth do not directly experience being abled barring medical interventions like cochlear implants (see, e.g., Barker and Wilson, 2019, 317). This suggests that *if* some ability is a component of objective wellbeing, individuals who lack that ability from birth due to being disabled in the relevant way may not know that they could be *even better off* if they were abled. That is, if individuals who have some disability trait from birth knew what they were missing, perhaps they would not rate their subjective QOL quite so highly, especially if the disability in question is one typically considered more severe.³⁵ The fact that most abled individuals would likely say that their subjective well-being would be reduced if they became disabled in some way, and perhaps significantly so depending on the disability (a type of counterfactual thinking that Barker and Wilson dismiss, about which more below) seems to provide at least some evidence for this.³⁶ And if that's right, that would provide further reason to think individuals who are disabled from birth might be over-reporting their subjective wellbeing. In that case, the studies cited by Barker and

³⁵ See, for instance, the short story *Flowers for Algernon* by Daniel Keyes (Keyes, 1959), in which an intellectually disabled man undergoes a medical procedure that dramatically increases his intelligence, but a flaw in the procedure eventually causes him to revert back to his previous state. Prior to undergoing the procedure, the protagonist is satisfied with his life. But after having his intelligence increased, experiencing the benefits of his new state, and then discovering the flaw in the procedure and coming to understand that he will revert back to his previous state, the protagonist is pained by his knowledge that he will revert, presumably because he now understands that he will be worse off in his former state than he would have been had the procedure's effects been permanent.

³⁶ Another potential source of evidence would be to ask individuals who have sought treatment for a disability trait they had from birth, such as individuals who were deaf from birth and got cochlear implants, how their QOL would be impacted if their cochlear implants were taken away. I think a study asking specific questions like this about a specific disability trait would be more relevant to the questions Barker and Wilson (and I) discuss than studies simply asking individuals with disabilities to rate their overall QOL.

Wilson would not license their conclusion that being abled in some way is not a component of DOW, and thus that disability traits do not significantly reduce DOW. This would mean that despite those studies, it could still well be the case that some disability trait does significantly reduce DOW and that prospective parents thus have a reason to select against that trait. So, given their reliance on these studies Barker and Wilson likely underestimate both how many disability traits reduce wellbeing, and the extent to which those traits do so.

Claim 2

The second claim made by Barker and Wilson is that because DOW is multiply realizable, a “well-lived life” is still possible for individuals with disability traits, so there is no strong reason to select against disability traits for the sake of DOW since those traits do not cut one off from all avenues of realizing DOW. However, this claim is not convincing. Proponents of *Moderate Disability-Free Procreation* need not, and do not, deny that with respect to most disability traits, life can still be worth living if one has one of those traits, and thus that one can be satisfied with one’s life even if one has such a trait. The view that prospective parents typically have a reason to select against creating a child who will probably develop a disability trait that reduces wellbeing, provided they could instead create a child who probably will not develop that disability, does not depend on the reduction in wellbeing being so severe that it would make the child’s life not worth living – especially given the qualification that the strength of the reason to select depends on how severely the disability trait in question reduces wellbeing. All proponents of *Moderate Disability-Free Procreation* need is the claim that if some disability trait negatively

impacts wellbeing, there is a corresponding reason to select against that trait whose strength depends on the extent of the negative impact upon wellbeing. This claim is can still be (and, in my view, is) true even if DOW is multiply realizable.³⁷

Moreover, Barker and Wilson ignore a consideration in virtue of which this point is especially significant. Prospective parents cannot know ahead of time whether their future child will be able to realize some alternative path to wellbeing if they have a disability trait. So, by selecting against a disability trait, prospective parents can avoid scenarios in which their future child ends up with reduced wellbeing because they fail to realize alternative paths to wellbeing to compensate for their disability trait. That is, the specific decision-making context in which prospective parents find themselves makes the reason to select against some disability trait stemming from that trait's negative impact upon wellbeing especially significant. Barker and Wilson fail to appreciate the specific, complex ethical situation of prospective parents.³⁸

Claim 3

The third claim made by Barker and Wilson is that the beliefs of abled individuals about reductions in dependent objective wellbeing due to having some disability trait turn on mistaken counterfactuals like the following: "If I, a very mobile non-disabled person, *became* disabled in a way that significantly reduced my mobility, this reduced mobility

³⁷ For further discussion of multiple realizability of goods in the context of debates about selection and disability traits, see Crawley, 2020 and Campbell et al., 2021.

³⁸ Moreover, Barker and Wilson cannot respond to this argument by appealing to the studies they cite concerning the subjective wellbeing of individuals with disability traits for the reasons mentioned in my response to their first claim above.

would probably significantly reduce my subjective well-being” (Barker and Wilson, 2019, 317). Such counterfactuals are supposedly mistaken because they “consider losing something” that abled individuals “have come to subjectively value through their experience, and then imagine *losing* that,” yet the context of selection focuses on “disabilities that are predictable (by methods such as PGD) prior to birth,” which are typically “early-onset, *lifelong* states of being” in which individuals with some disability trait never experience, and thus never lose access to, being abled in the relevant way (*ibid.*). However, Barker and Wilson fail to do justice to the full train of counterfactual reasoning prospective parents actually engage in. Prospective parents generally have reason to believe that, bracketing the disability being selected for, their future child will otherwise likely be similar enough to them that *if* that child were abled they would likely enjoy it and feel worse off if they became disabled in the relevant way.³⁹ This makes it natural for prospective parents to think their future child would be worse off if they became disabled in that way because the future child would be losing access to something valuable to them. But if that’s right, then it’s also natural for parents to think what would be lost due to the disability trait would be something valuable for their future child even if that child were disabled from birth – *whether or not that child would themselves think that or feel that way* due to having never experienced the valuable thing due to their lifelong disability. And as I argued above, this sort of thinking by prospective parents about the prospects of the future

³⁹ As argued above, the future child in question is the *numerical* child they intend to have in the future, who could be either abled or disabled in some way depending on which specific embryo the prospective parents choose to carry to term.

numerical child they intend to have is familiar and comprehensible, not mistaken as Barker and Wilson claim. The intuitions about losing access to valuable things underlying these common kinds of counterfactuals are not as easily dismissed as Barker and Wilson contend. Such intuitions do give us reason to think that some disability trait about which we have such an intuition does involve a reduction in DOW, and that prospective parents therefore have a reason to select against that trait.⁴⁰

Claim 4

The fourth claim made by Barker and Wilson is that since there are many reasons to select or not to select against some disability trait besides those yielded by the *Moderate Perfectionist* argument, the significance of any one reason to select against disability traits yielded by that argument would be diluted by the sheer number of other reasons. However, on its own this is not at all a decisive argument. If the reason to select against some disability trait yielded by the *Moderate Perfectionist* argument is a strong reason, as in cases where the disability trait in question significantly reduces wellbeing, then it could well remain a strong reason even if there are other reasons to select or not to select in play.⁴¹

Claim 5

⁴⁰ It is also worth mentioning that Barker and Wilson also contend that intuitions about loss of wellbeing due to late-onset conditions such as Huntington's disease or age-related dementia based on similar kinds of counterfactuals are mistaken as well (Barker and Wilson, 2019, 317-318). Rather surprisingly, they take this to be an interesting implication of their view rather than an absurd consequence indicating the implausibility of their view.

⁴¹ Note that, contrary to Barker and Wilson's claim on page 321 of their 2019, such cases have *not* been ruled out given the considerations I appealed to in my responses to Claims 1, 2, and 3.

The fifth claim made by Barker and Wilson is that the *actual* interests and wellbeing of prospective parents, who exist, are more significant than the levels of *expected* wellbeing in merely *possible* children the prospective parents could have (Barker and Wilson, 2019, 322; cf. Benatar and Wasserman 2015, 218). If that's right, it would suggest the reasons to select against some disability trait yielded by the *Moderate Perfectionist* argument might not be very significant. However, Barker and Wilson mostly ignore the radical and controversial implications of this line of argument – it is no coincidence that they cite the work of David Benatar, perhaps the most notorious anti-natalist philosopher. Most people think the expected wellbeing of possible children, whether their own or that of future generations in general, is *extremely* important, and at least as important as the wellbeing of actual people existing right now, if not more so. That is why debates about what prospective parents should do in the reproductive context are so charged, why so many people, institutions, and governments care so deeply about reducing their carbon footprint to help fight climate change, and so on. As such, I do not think this is an argument against *Moderate Disability-Free Procreation* that most people will find particularly compelling. In general, we should care about the wellbeing of future people. Moreover, we should especially want and expect *prospective parents* to care tremendously about their future children and their prospects, and privilege the interests of their future children rather than treat their own interests and wellbeing as more significant. Intuitively, this is a basic obligation prospective parents have insofar as they desire to be parents and see themselves that way. The failure of Barker and Wilson to consider this point (as well as their drawing upon anti-natalist arguments in making an argument about what prospective parents should

do with respect to future children they intend to have) again suggests that they do not appreciate the specific, complex ethical situation facing prospective parents in the reproductive context.

II.2.3 – Accepting the Moderate Perfectionist Argument

In sum, the considerations Barker and Wilson discuss that could threaten the *Moderate Perfectionist* argument are not convincing. Accepting the premises of this argument is enough to establish *Moderate Disability-Free Procreation*, and the premises are independently plausible, so we should accept *Moderate Disability-Free Procreation*. Moreover, as I have already suggested in my discussion of their Claim 1, Barker and Wilson likely underestimate both how many disability traits reduce wellbeing, and the extent to which those traits do so. This suggests that for many disability traits, prospective parents do have significant reason to select against those traits in their future children, although determining this definitively would require a thorough weighing and consideration of each trait individually to determine its impact on wellbeing. In the next section, I will provide additional arguments supporting the claim that prospective parents should select against disability traits in their future children.

II.3 – Moving Beyond Wellbeing

In this section, I will provide additional arguments supporting the view that prospective parents should select against disability traits in their future children. These

additional arguments need not be understood as appealing to considerations about wellbeing. They are simply arguments for the claim that it is desirable to select against disability traits in the reproductive context.

II.3.1 – It is Better to be Able

As I have argued in Chapter I, for most if not all disability traits, when we evaluate those traits individually on a case-by-case basis, it turns out that it is better to be able than to have the disability trait in question. With respect to most if not all disability traits we should accept the intuition that it is better to be able than to have that trait. On its own, this already gives us some reason to think selecting against disability traits in order to have able children would be desirable, and that prospective parents thus have at least some reason to do so.

II.3.2 – The Bad Difference View

Beyond the point that with respect to most if not all disability traits it is better to be able, there is also the further claim that disability traits are *bad differences*, or *bad traits to have*. This is known as the *Bad Difference View* (BDV). So far I have not argued directly for BDV in this dissertation. But if BDV is right, then insofar as some disability trait is a bad trait to have, there would be even more reason to think selecting against that trait would be desirable, and that prospective parents would have reason to do so.⁴²

⁴² For helpful recent discussion of BDV, see Crawley 2022.

As I contended in Chapter I, accepting the intuition that it is better to be abled with respect to most if not all disability traits also suggests that the Mere-Difference View (MDV) is implausible. In order to get from this intuition that it is better to be abled and the resulting implausibility of MDV to the further general claim that most if not all disability traits are bad traits to have and a resulting endorsement of BDV in general, we would have to also establish some threshold level of negative impact (on wellbeing, or flourishing, etc.) below which a trait would count as bad, and then show individually for each disability trait that it falls below that threshold and is therefore a bad trait to have. Establishing such a threshold, and therefore providing a full vindication of BDV is beyond the scope of my project in this dissertation.⁴³ However, we do not need to do so in order to see that intuitively, at least some disability traits for which it is clearly better to be abled, such as tetraplegia or Tay-Sachs, negatively impact wellbeing, available options, flourishing, etc. severely enough to be considered bad traits to have.⁴⁴ If that's right, then for any such disability trait it would be highly desirable not to have that trait, and prospective parents would have strong reason to select against it in reproductive contexts (all else being equal).

⁴³ In any case, between the arguments I make in this chapter and in Chapter I, the various problems facing MDV, and the various other arguments in support of MDV that have been offered in the literature and which I discuss in Chapter I as well, I think we have strong reason to accept BDV. However, my other arguments in this chapter do not depend on accepting this more ambitious claim.

⁴⁴ Even staunch defenders of MDV acknowledge that at least some disability traits are likely bad traits to have (see, e.g., Barnes 2016).

II.3.3 – Many Disability Traits Increase Vulnerability

Another reason to think prospective parents have reason to select against many disability traits in reproductive contexts, which has not been discussed at length in the literature, is that being abled is likely to make one less vulnerable and more resilient than one would be if one had the disability trait in question. For instance, being abled is likely to make one more resilient to nature, even in a non-ableist world. Not only is it better to be resilient to nature than not, but it is arguably bad to lack resilience to nature. Many disability traits decrease one's resilience to nature by making one more vulnerable to the significant and unpredictable threats that nature poses even today, and will continue to pose in the future.⁴⁵ Given these threats from nature, it is clearly better to be as resilient to nature as possible. That means it is better to be able to walk, see, hear, plan effectively, etc., than to lack these abilities in case you might face one of these threats from nature. Saying that it is better to be abled here has nothing to do with ableism. The increased vulnerability to nature caused by many disability traits is independent of any social prejudices that may exist. It is simply a fact that since greater vulnerability to harm is bad, and most if not all

⁴⁵ I must emphasize that despite the modern technologies and conveniences we live with, nature remains dangerous. We do not have full control over nature - we regularly hear about natural events putting people's lives in danger, such as wildfires in California, flash floods in Europe, earthquakes in Haiti, volcanic eruptions in the Canary Islands, powerful hurricanes and typhoons, and so on. These catastrophic events are not rare, and for many of them their recurrence and severity will only increase due to the effects of climate change. We do not have the technology to control these types of events, or to fully mitigate their effects, and there is no reason to believe that we will have such power in the near future, and even less that there will be no negative, unintended consequences from such technologies if we succeed in producing them; the same applies to proposed technological solutions to climate change (I have in mind here proposed technological solutions such as the SCoPEX geengineering project investigating whether seeding the atmosphere with aerosols could lessen the effects of climate change).

disabilities decrease one's resilience to nature's unpredictable threats, to that extent having these disability traits is bad, and prospective parents have reason to think they should select against those traits in the reproductive context.⁴⁶

Another underdiscussed reason to think prospective parents have reason to select against many disability traits in reproductive contexts is that being abled is likely to make one more resilient to coercion, malice, incompetence, and negligence by others, even in a non-ableist world; not only is it better to be resilient in these ways than not, but it is arguably bad to lack these kinds of resilience. Many disability traits decrease one's resilience to the bad actions of other people, especially the threat of coercion, violence, or their incompetent or negligent mistakes, whether on the level of society in general or on the level of particular individuals. With respect to society, having a disability trait can make one more reliant on society in general because depending on the trait one may need specific

⁴⁶ At this point, one might respond by saying that the chance of being affected by one of these natural disasters is so small that it is virtually irrelevant to the question of some disability trait's evaluative status. However, I must emphasize again that there are limits to how much control over nature humans can have, especially in times of climate change where the incidence and severity of natural disasters like floods, hurricanes, and wildfires keeps increasing, and will likely continue to increase to truly disastrous levels. For example, if you live in California, the threats posed by nature are a serious issue for you, in the form of wildfires, droughts, and earthquakes. It would be hubristic and delusional to believe that we can put all of nature under our sustained control, which is what would likely be required in order to eliminate the increased vulnerability of disabled people to nature. We do not have full control over nature now, and our entire history as a species is defined by this lack of control. Moreover, the dangers that I am discussing in the past, present, and future are real dangers. If we take climate change seriously, these dangers are going to be massively elevated and must be taken just as seriously as climate change itself. On top of that, human attempts to control nature can have unintended consequences that are harmful. A total transformation of society that would effectively and reliably insulate people with disabilities from the harms of nature at anything close to our level of technical development risks potentially generating these kinds of negative externalities. In any case we currently lack the capacity to implement such a transformation, and the prospects for gaining this capacity anytime soon appear slim.

goods and care for optimal functioning. Having a disability trait can even make one more reliant upon particular social systems or political regimes that provide one with the goods and care one needs due to one's disability. A person who is reliant on society, and especially upon particular social arrangements and political regimes, in these ways is more vulnerable to harm than someone who is not reliant in these ways. For example, whoever has political power, and therefore control over society's structure, resource distribution, and so on, can more easily coerce people who are highly reliant upon society into compliance with whatever they want. They can threaten to cut funding for whatever infrastructure is needed for people with certain disability traits to be able to live well, or even merely to survive. In turn, this means that people with those traits are more open to the threat of coercion than abled people, and this is a clear disadvantage as it is better to not be vulnerable to coercion and threats. This increased vulnerability to coercion is not caused by systemic ableism, which can be seen due to the fact that it would obtain even in a non-ableist world. In the same way that someone who threatens to kill your children to get your money is not prejudiced against children, someone who threatens to make life more difficult for people with disabilities to get what they want is not necessarily prejudiced against people with disabilities - they just use whatever leverage they have to get what they want. This sort of coercion and violence could just as easily exist in a totally non-ableist as in our actual world. So, the increased vulnerability to coercion caused by many disability traits that I am discussing here has nothing to do with structural ableism, which suggests that it is instead something bad about having those traits in virtue of which

prospective parents have reason to think they should select against those traits in the reproductive context.

In addition to increased vulnerability to coercion and violence, many disability traits increase the extent to which one is reliant upon other individuals, for instance, those who provide one with needed healthcare, or who help buy one's groceries, or even help one go up the stairs or cross the street. If these helping individuals are incompetent or negligent and make a mistake, those who are reliant upon them will be harmed. In this way, many disability traits open up those who have them to additional occasions of being harmed by others that one would not be vulnerable to were one not disabled in the relevant way. In general, the less self-reliant one is, the more vulnerable one is to people's mistakes, incompetence, negligence, and malice, as well as to technological glitches and malfunctions. With respect to many disability traits, a disabled person's safety is often in other people's hands or in the hands of some technology to a greater extent than for people who lack that disability. For example, a blind person must rely upon the proper functioning of audible traffic signals in order to not get hit by a car as they cross the street. Likewise, one must hope that the person administering medical treatment one requires for one's disability trait does not make a mistake. Such increased vulnerability to the mistakes, incompetence, negligence, and malice of others due to decreased independence and self-reliance is yet another negative aspect of many disability traits in virtue of which

prospective parents have reason to think they should select against those traits in the reproductive context.⁴⁷

II.3.4 – Many Disabilities Interfere with the Capacity to Play Valuable Roles for Others

Yet another reason to think prospective parents should select against disability traits in the reproductive context, at least in most cases, has to do with the valuable roles we can play for others. For example, especially for family and friends, it's important to be someone they can rely on physically and psychologically. Being someone who can be relied upon physically can involve things like the capacity to take care of daily chores around the house, to lend a helping hand with physical tasks, to be able to physically protect one's family, and so on. Being someone who can be relied upon psychologically includes being able to give loved ones good advice and help them with their problems, being able to support loved ones emotionally in difficult times while controlling one's own emotions, and so on. Since such roles are valuable, the capacity to fulfill them is also valuable, particularly but not only because of how these roles impact wellbeing.⁴⁸ Life is difficult, and being able to rely

⁴⁷ Notably, concerns about independence and self-reliance need not be motivated exclusively by concerns about wellbeing. Various philosophers have offered additional reasons for valuing independence and self-reliance, including Ralph Waldo Emerson (see his essay "Self-Reliance" in Emerson, 2000) and Nietzsche (see, e.g., Nietzsche's remarks praising the self-reliant Sophist Hippias in *The Wanderer and his Shadow*, §318). Emerson holds that self-reliance is vital for personal growth and a flourishing society. In turn, Nietzsche claims that self-reliance is "the road to freedom of spirit and person" (WS 318).

⁴⁸ There are many reasons to think being able to fulfill such roles is valuable besides the impact of fulfilling those roles on wellbeing, stemming from diverse traditions in moral philosophy, including virtue ethics, Christine Korsgaard's Kantian constructivism (see Korsgaard 1996), and the ethics of care. So, I take the claim that the ability to fulfill various roles for others is valuable to be relatively uncontroversial in contemporary ethics.

on others who play these kinds of important roles in our life can make us better off. Moreover, helping others and being relied upon can increase our own wellbeing by making us feel useful and giving us a sense of purpose. In turn, having the various capacities needed to help others in meaningful and diverse ways can allow one to contribute significantly to overall wellbeing by playing such roles, and “participate effectively in the dominant cooperative framework,” a point which holds even in a non-ableist society (Buchanan et al., 2000, 260). But many disability traits can impede one from being able to fulfill at least some of these valuable roles (which specific roles one is impeded from fulfilling depends on the disability trait in question). Any disability trait that deprives one of the capacities to play such helpful roles reduces wellbeing to that extent. For any such disability trait, prospective parents have additional reason to think they should select against that trait in the reproductive context, to whatever extent it impedes the fulfillment of such valuable roles.⁴⁹

II.3.4 – How Strong is Prospective Parents’ Reason to Select Against A Disability Trait?

In light of the various considerations I have examined so far, with respect to some disability trait prospective parents have some kind of reason to select against that trait in their future children:

1. insofar as that trait negatively impacts wellbeing;

⁴⁹ Moreover, at least some disability traits can put a burden on the loved ones of the person with the trait, because those loved ones are moved to play difficult, taxing roles for the person with the trait. Although I will not focus on this point, it also generates a reason to think it is desirable to screen and select disability traits that have such an effect.

2. insofar as that trait makes one less resilient, less independent, and more vulnerable;
3. insofar as that trait reduces one's capacity to play valuable roles for others;
4. more generally, insofar as that trait is a bad trait to have, or at least it is better to be abled than to have that trait.

The reason prospective parents have to select against the disability trait in question is a pro tanto reason. The strength of this reason can differ significantly depending on the trait in question, because *how much better* it is to be abled than to have some disability trait can vary dramatically depending on the disability trait in question. Some disability traits have a strong negative impact on wellbeing, or are even clearly intuitively bad to have (e.g., Tay-Sachs, tetraplegia), while other traits have a less significant negative impact on wellbeing (e.g., dyslexia). The more strongly some disability traits negatively impact wellbeing, the stronger the reason prospective parents have to select against that trait, all else being equal. But given the various considerations I have examined so far in this chapter, as well as my argument in Chapter I that for most if not all disability traits it is better to be abled, it seems likely that prospective parents *do in fact have at least some reason to select against most disability traits*, and that for many of these traits the reason to select may be significant.

II.3.5 – Costs of Selection

Prospective parents can face various kinds of costs associated with selecting, these costs can be significant, and they can weaken or on occasion even completely outweigh the reasons prospective parents might have to select against some disability trait. The impact

of these costs can depend on whether the selection method is pre-pregnancy or post-pregnancy.

Pre-pregnancy selection involves the use of IVF with PGD to determine which embryos created through IVF have the disability trait, and then selection of an embryo without the trait prior to the implantation of that embryo. The main costs of pre-pregnancy selection are the money and time spent to undergo IVF with PGD, the physical and psychological discomfort of the IVF process, and the potential psychological discomfort of selection. In turn, post-pregnancy selection involves the use of amniocentesis or CVS to test a fetus the mother is already pregnant with for the disability trait, and then potentially an abortion to terminate the pregnancy if the fetus is found to have the disability trait so that a new pregnancy can be attempted. The main costs of post-pregnancy selection are the physical and psychological discomfort of undergoing amniocentesis or CVS, and then the physical discomfort and psychological burden of undergoing an abortion. The severity of these costs, whether of pre-pregnancy or post-pregnancy selection, can vary significantly depending on the prospective parents in question and their situation. Some prospective parents may be able to easily handle the financial, physical, or psychological costs of these medical interventions, while others may not. Some might find the costs associated with post-pregnancy selection harder to bear, while others might feel that way about pre-pregnancy selection. In cases where the costs of selection are significant for the prospective parents, they may in some cases outweigh the reasons prospective parents have to select against some disability trait, although in many other cases the reasons to select against the disability trait may outweigh the costs of post-pregnancy selection.

It is important to note that in many if not most cases, the reason *not* to select provided by the costs of selection should not be considered very significant *even if* the costs are significant. This is because the reason in question is supposed to be a reason *for prospective parents*. Intuitively, prospective parents have an obligation to care about the prospects of their future child and sacrifice at least to some extent in order to increase the chances that those prospects will be good.⁵⁰ For instance, if prospective parents put little or no effort into preparing a welcoming, safe, and healthy home for their future child to whatever extent they are able to do so, they are typically considered to be falling short as parents and to be blameworthy for that reason. So, even if selecting against disability traits (whether pre-pregnancy or post-pregnancy) would be costly for prospective parents, in many if not most cases we would expect them to bear those costs for the sake of their future children. That is, in virtue of being prospective parents the costs of selection would not yield *significant* reasons against selection. This would apply to cases in which the costs seem *bearable*, even if they may be difficult or unpleasant. It may not apply to cases in which the long-term health of the prospective parents would be put at serious risk by the medical interventions associated with selection, or in cases where the prospective parents would face legal penalties for selecting or cannot afford to pay for such treatments and have exhausted all possibilities of financial assistance (especially if we assume that ‘ought’ implies ‘can’).

⁵⁰ See also my remarks above critiquing the anti-natalist train of thought in Barker and Wilson, 2019.

II.3.6 – *Superogatory vs. Duty*

So far, we have seen that the strength of prospective parents' reason to select against some disability trait can differ significantly depending on the trait in question; the more severely some disability traits negatively impact well-being, the stronger the reason prospective parents have to select against that trait, all else being equal. We have also seen that for most disability traits there likely is some reason for prospective parents to select against that trait, and moreover that for many of these traits this reason may be significant. Finally, we have seen that there are financial, physical, and psychological costs to engaging in such selection, and that the strength of the reason *not* to select against disability traits provided by these costs can also vary depending on who the prospective parents are and what their situation is. However, this reason not to select will usually not be a very significant reason given that prospective parents have an obligation to sacrifice at least to some extent for their future child given that they are prospective parents.⁵¹

I cannot, of course, undertake to examine each disability trait individually here in order to determine the precise strength of the overall reason prospective parents have to select (or refrain from selecting) against that trait. However, the various considerations I have discussed suggest that with respect to most disability traits and most situations prospective parents might be in, the overall reason prospective parents will have is to select against the trait in question, so they should do so. In other contexts, we praise parents for

⁵¹ If prospective parents *cannot* engage in selection, whether for health reasons or due to their financial situation, then as long as we accept that 'ought' implies 'can', then it's not that prospective parents in such a situation have a strong reason not to select, but rather that they cannot do so. My claim here is that as long as prospective parents *can* engage in selection, their reasons not to do so due to the various costs in play will likely not be very strong given the reason mentioned here.

making efforts they should make insofar as they are parents in order to improve their children's prospects. The reproductive context is no different: with respect to most disability traits, it is praiseworthy for prospective parents to select against the trait in question in their future (numerical) child, even if doing so involves some level of sacrifice on the part of the prospective parents.

Are prospective parents *blameworthy* if they do not select against disability traits in the reproductive context, such that they have a duty to select against those traits? Intuitively, certain disability traits (e.g. Tay-Sachs) are so bad to have that prospective parents may be blameworthy for not selecting against those traits as long doing so would not involve significant health risks and is possible legally and financially. In such situations and with respect to such disability traits, prospective parents may have a duty to select against those traits. However, given how dependent this claim is on the disability in question and the situation of the specific prospective parents in question, it seems difficult to formulate a plausible general principle that could clearly identify in which cases prospective parents would have a duty to select against some disability trait which they would be blameworthy for violating. For this reason, it seems to me that only the claim that with respect to most disability traits, prospective parents are *praiseworthy* for selecting against the trait in question, is justified. Considered in general, we should consider selecting against disability traits in the reproductive context to be supererogatory for prospective parents. This is the sense in which we can say that with respect to most disability traits, prospective parents *should* select against the trait in question in their future

children – it is usually the best or ideal option for prospective parents to strive for as long as their situation allows for it.

II.4 – Potential Objections

I will now address potential objections to the claim for most if not all disability traits, parents should select against the trait in question in their future children, focusing on some of the most prominent and widely discussed arguments in the literature. I will start by discussing objections to the desirability of selection, and then turn to objections to the permissibility of selection. If it turns out that selection is either undesirable or impermissible, that would threaten the claim that prospective parents have reason to select against most if not all disability traits in the reproductive context.

II.4.1 – Objections to the Desirability of Selection Against Disability Traits

The claim that it is desirable to select against disability traits in the reproductive context has been the subject of intense debate in the literature, and several kinds of objections have been leveled against it. By discussing and responding to these objections, I will defend the notion that selecting against disability traits in reproductive contexts is desirable, and that prospective parents have reason to engage in such selection. First, I will respond to a set of objections to the desirability of selecting against disability traits that appeal to concerns about openness to the unbidden. Next, I will discuss a set of objections that appeal to certain purported parental duties. Then, I will address a series of objections

that appeal to various purported negative consequences of screening and selecting against disability traits in order to challenge the desirability of this practice.

Openness to the Unbidden: Sandel

One set of objections to the desirability of selecting against disability traits in the reproductive context appeals to a supposed tension between such interventions and some kind of *openness* which prospective parents should desire to manifest. That is, selecting against disability traits is supposedly undesirable because it impedes prospective parents from manifesting openness, which is desirable to manifest.

In his 2007 book, Michael Sandel characterizes the attempt to enhance human beings through biomedical interventions as undesirable because it represents a hubristic attempt to master nature driven by a boundless desire for mastery and dominion. Sandel argues that in general, it is more desirable to be open to the unbidden and accept our imperfections instead of trying to endlessly control and extirpate them. Being open in this way is desirable because it would help us remain humble in a virtuous way, and avoid becoming overly ambitious, controlling, hubristic, and power-hungry people (Sandel, 2007, 46).

Selecting against disability traits in the reproductive context is exactly the kind of undesirable intervention Sandel has in mind. He claims that “to appreciate children as gifts is to accept them as they come, not as objects of our design or products of our will or instruments of our ambition [...] parenthood, more than any other human relationship teaches [...] an ‘openness to the unbidden’” (Sandel, 2007, 45). So, if we apply Sandel’s

general argument against biomedical enhancement of human beings to the specific case of selecting against disability traits, it seems that this practice would manifest a lack of acceptance of one's children as they come, and constitute a hubristic attempt to design or will one's children to be a certain way in line with one's own ambitions. This could cause prospective parents to become overly ambitious, controlling, etc., which would be undesirable both in general and especially insofar as they will be *parents* to their future children. If Sandel is right that such concerns about openness and hubris are important, they may give us reason to think that screening and selecting against disability traits in reproductive contexts is undesirable.

Yet Sandel's argument is problematic for several reasons. To begin with, at first glance it is not clear what distinguishes the sorts of interventions Sandel would deem hubristic from interventions to cure diseases. Severe, often fatal disability-causing diseases like Tay-Sachs are just as 'given' and 'unbidden' as disability traits like deafness are.⁵² More generally, conditions like cancer and Alzheimer's disease are given by nature and unbidden as well. Yet for these severe conditions, it is almost universally accepted that it would be desirable to medically intervene to prevent and cure them if we could; intuitively, it does not seem undesirably hubristic to want to avoid Tay-Sachs, cancer, or Alzheimer's. But without a way to draw a distinction between such conditions and those it supposedly would be hubristic to try to avoid, proponents of Sandel's view would run the risk of implausibly suggesting that we should be open to the prospect of having conditions like

⁵² As Leon Kass notes, the giftedness of nature "also includes smallpox and malaria, cancer and Alzheimer's disease, decline and decay" (Kass, 2003).

Tay-Sachs, cancer, or Alzheimer's, and that there would be something bad about trying to cure these conditions once we suffer from them. This implausible implication would cast doubt upon the overall Sandelian view.

To avoid this problem, Sandel himself tries to draw precisely such a distinction between interventions that enable us to achieve our natural potential, such as a treatment for COVID-19, and interventions that modify our natural potential. The latter are supposedly hubristic in a way the former are not, because only the former are "governed, or at least guided, by the norm of restoring and preserving the natural human functions that constitute health" (Sandel, 2007, 47). Sandel claims that "although medical treatment intervenes in nature, it does so for the sake of health, and so does not represent a boundless bid for mastery and dominion. Even strenuous attempts to treat or cure disease do not constitute a Promethean assault on the given" (Sandel, 2007, 46-47). So, to return to the case of selecting for disability traits in the reproductive context, perhaps selecting against conditions like deafness or Down syndrome constitutes a "Promethean assault on the given" in a way that selecting against Tay-Sachs does not.

However, this distinction between therapeutic treatments allowing our natural potential to flourish, and enhancements altering our natural potential, faces serious problems. Most significantly, such a distinction is "metaphysically and normatively problematic" and runs "afoul of contemporary developmental biological theory" (Powell, 2015a, 29; cf. Powell, 2015b and Holtug, 2011). Presumably, if some aspect of our potential is considered natural, that is because it pertains to our nature as human beings, rather than to some cause stemming from outside that nature. Such a claim seems to require

appealing to some kind of essentialist account of human nature, on which whatever traits Sandel-inspired opponents of selection would consider ‘natural potential’ would count as part of the set of properties that all human beings share (in virtue of which they count as members of the species). Yet the many problems of such essentialist accounts have been well-documented, and it is notoriously difficult to articulate a coherent conception of human biological nature (see Buchanan 2009, 6-8). In fact, contemporary developmental biology tells us that species do not have normal traits that are independent of local, contingent developmental environments (Powell, 2015b, 672; cf. Hull, 1996 and Lewens, 2012). This complicates the effort to distinguish between a human being’s natural potential, and unnatural alterations to that natural potential. And if that distinction is not tenable, then Sandel’s argument does implausibly imply that we should be open to diseases after all.⁵³

Moreover, even if we grant that we have a given biological nature as human beings, it is not clear whether that nature has intrinsic value, nor how weighty that value is if it exists (Powell 2015b). ‘Normal’ functioning for a species (if that can even be clearly specified) is a result of the highly contingent selection pressure a species happens to have been under over the course of its history. According to Darwinian evolutionary theory, these selection pressures select for reproductive fitness, but reproductive fitness is by no means exhaustive of what is good for human beings. So, even if there is a human nature, that nature might significantly fall short with respect to important goods, because it will

⁵³ Michael Hauskeller attempts to defend Sandel by distinguishing between mere ‘givenness’ by nature, which applies to diseases, and ‘giftedness’ which applies only to talents and capacities deemed good (see Hauskeller, 2011). However, this distinction seems to lack rigorous philosophical basis and is rather mystical; it’s not clear why we should think nature ‘gifts’ us capacities any differently than it ‘gives’ us diseases.

not have been selected for in terms of those goods. In that case, it is not clear why the status quo of our given human nature should be privileged over potential improvements that could be made to it in order to help achieve those important goods (Buchanan, 2009, 3-4).⁵⁴ This makes Sandel's distinction between therapeutic treatment allowing our natural potential to flourish, and enhancement altering our natural potential, not very helpful, because it does not clarify why the former are desirable in a way the latter are not.⁵⁵

More generally, Sandel's view has been strongly criticized in various other ways. For instance, as Lewens has noted, at best Sandel's argument only succeeds in showing that some cases of enhancement (rather than enhancement in general) are problematic, namely those in which parents are actually trying to satisfy their own hubristic desires rather than acting in the interest of the child (whether a specific child or a future numerical child they intend to have). Since "efforts to enhance need not go against the interests of the child," Sandel's argument does not "support a generic case against all forms of

⁵⁴ In addition, even if we grant that given human nature does have some intrinsic value, it is not clear how far this human nature can be changed before causing the loss of intrinsic value associated with remaining fundamental human, because there may be many aspects of our nature that we could change without changing whether we are still fundamentally human (Powell, 2015b).

⁵⁵ As Powell has also noted, even if there is some kind of human nature, the increasing mutational load in the human population that will likely result from the relaxation of selection pressures due to increased effectiveness and availability of conventional medicine is likely to change that human nature for the worse anyway, so genetic interventions may be necessary merely to *preserve* the human nature Sandel privileges (Powell, 2015b). In general, as Powell and Buchanan have persuasively argued, far from being a hubristic attempt to meddle with nature, genetic enhancement technologies (including those far more radical than screening and selecting against disability traits in embryos) are morally desirable methods we ought to employ because the unintentional genetic modification of natural selection (as opposed to intentional genetic modification by human beings) "is wantonly destructive of life, often involves suffering on a massive scale, and is utterly insensitive to the requirement that the costs of improvement ought to be fairly distributed" (Powell and Buchanan, 2011, 8).

enhancement” (Lewens, 2009, 356). Similarly, Buchanan points out that Sandel provides no evidence that those who pursue enhancement are motivated by a desire for total mastery over the conditions of human existence or an obsessive aim for perfection. Given that there is a significant difference between the desire for improvement in a certain respect, and a desire for total perfection, it certainly seems possible to pursue enhancement because one desires improvement in a certain respect - which does not seem hubristic - rather than out of a hubristic drive for total perfection (Buchanan, 2009, 8-10). So, at best a Sandelian critique of selecting against disability traits is significantly limited only to those cases that can actually be shown to be motivated by some problematic desire or character vice. It is not obvious that prospective parents who want to select against disability traits in particular are motivated by satisfaction of their own desires without considering their child’s interests, or by a hubristic drive for total perfection and mastery. The burden is on critics of such selection to provide evidence of these problematic motivations, rather than simply assuming from the armchair that these motivations obtain.

Yet even if such motivations were demonstrated to exist in specific cases where prospective parents decide to select against disability traits, it is not clear that the sort of humility Sandel appeals to as a virtue is worth pursuing to the extent that those parents should not select against disability traits. There are many important considerations that go into deliberations about whether to screen and select in reproductive contexts, and considerations about avoiding hubris and maintaining a certain kind of character are only some among these many considerations. Late in his book, Sandel himself retreats from framing his openness argument as a full-blown critique of the sorts of interventions we are

considering. Instead, he moves to the weaker claim that the considerations about character he appeals to merely should not be ignored when deciding whether or not to enhance (Sandel, 2007, 96). Yet it is perfectly possible for these considerations regarding openness and character to be taken into account *and outweighed* in deliberation concerning whether to select against disability traits.⁵⁶ If all the openness argument amounts to is offering some additional considerations to take into account in deliberations about selection against disability traits, then it is not actually a full-blown argument against such selection.⁵⁷ Proponents of the openness argument have the additional burden of showing that the considerations they appeal to will always (or at least often) outweigh the reasons favoring selection against disability traits, and it is unlikely that they will be able to meet this challenge.

For all these reasons, Sandel's openness argument does not seem convincing as a critique of selecting against disability traits by prospective parents. The problems facing Sandel's distinction between therapeutic treatments allowing our natural potential to flourish, and enhancements which alter our natural potential, mean that it is difficult for proponents of the openness objection to avoid the implausible suggestion that we should be open not only to disability traits like blindness and deafness, but also to extremely severe and costly ones like Tay-Sachs. In turn, the basic contention underlying the openness

⁵⁶ In fact, this seems not only possible but likely, not only because there is reason to think the sort of humility Sandel appeals to is not worth pursuing to the extent that we should not screen and select against disability traits, but also given my argument in Chapter I that with respect to most if not all disability traits it is better to be abled. See Harris, 2007, 113, and Nietzsche, *Beyond Good and Evil*, 260 for additional reasons to think the sort of humility Sandel appeals to is not worth pursuing to the extent that prospective parents should not select against disability traits.

⁵⁷ For helpful discussion of this point, see Buchanan, 2009, 8-11.

objection that the desire to select against disability traits is driven by problematic desires and character traits lacks evidence to support it. Moreover, even if that basic contention were true in some specific cases of prospective parents deciding to select against some disability trait, proponents of the openness objection face the difficult challenge of showing that this would be enough to make selection against disability traits undesirable *overall*.

Openness to the Unbidden: Garland-Thomson

A more radical version of this sort of general openness argument comes from Rosemarie Garland-Thomson. Unlike Sandel, Garland-Thomson bites the bullet and argues that we ought to preserve disease-causing disabilities, including conditions like Tay-Sachs (Garland-Thomson, 2012, 349). This is because she holds that “disability generates circuits of meaning-making in the world” in various ways, a function she takes to be valuable (Garland-Thomson, 2012, 344). For example, the presence of people with disabilities offers us not only the ethical opportunity to be open to the unbidden (Garland-Thomson, 2012, 347), but also generates “inherently interesting” and “singularly vivid” narratives and experiences with the potential to “provide theatrical, edifying encounters” for “ordinary folk dulled by the ordinary” (Garland-Thomson, 2012, 344). Garland-Thomson also claims that the presence of disabled people “can act as an epistemic resource” by sharing their distinctive life experience (Garland-Thomson, 2012, 345). These considerations Garland-Thomson discusses are supposed to explain why it’s unproblematic to bite the bullet and be open even to disease-causing genetic conditions, including those commonly considered disabilities. Because the presence of people with disabilities

provides these sorts of ethical, narrative, and epistemic opportunities for society, it would be undesirable to select against the genetic variations causing those disabilities. Instead, we should remain open to those genetic variations, and they should be preserved.

However, Garland-Thomson's argument is implausible for several reasons. First, the narrative, ethical and epistemic considerations she appeals to seem insufficient to justify her radically unintuitive conclusion that we ought to preserve disease-causing genetic variation. Even if we grant that those considerations can be beneficial to an extent, those benefits are far outweighed by the immense costs of the conditions she argues should be preserved in terms of pain and suffering, reduced lifespan, reduction of valuable options, and the various other factors I have discussed in this dissertation. In addition, there may even be something morally problematic about insisting on bringing a child with a disability trait, including severe conditions like Tay-Sachs, into the world so that others can have certain narrative, ethical, and epistemic experiences. The considerations Garland-Thomson appeals to involve certain purported benefits to others besides the person with the disability trait. Yet when deciding whether to select against disability traits, it seems far more important to emphasize considerations directly bearing on the welfare and flourishing of the one who will have the disability-causing genetic variations in question, whether they are conceived of as a specific person or impersonally as a future numerical child.

Second, Garland-Thomson's argument also seems unable to deal with the reversal test proposed by Bostrom and Ord (2006; cf. Powell, 2015a). The reversal test is a test to see whether one has an unreflective, unjustified preference for the status quo with respect to any attempt to change or modify a human trait. If someone claims that we should not

attempt to select *against* some human trait, we can ask whether they also think we should not attempt to select *for* that trait. If they respond that they would favor selecting for that trait, they would need to explain why that trait should be selected for. Alternatively, if they respond that they would be against both selecting against and selecting for that trait, then they need to explain why the current state of affairs with respect to the distribution of that trait is optimal. If such an explanation cannot be provided, then that person's preference for the status quo with respect to the trait in question is an arbitrary, unsupported *bias* for the status quo.

Applying this reversal test to Garland-Thomson's argument reveals that it faces a difficult dilemma. On one hand, Garland-Thomson would fall into a *reductio ad absurdum* if she opts for the claim that we should have *more* disease-causing genetic variation, since it is implausible that we should increase the amount of disease in the world. On the other hand, Garland-Thomson would fall into a status quo bias if she opts for claiming that we are currently at the optimal level of disease-causing genetic variation, since there seems to be no justification for that claim. As a result, Garland-Thomson's argument is unconvincing, and does not help proponents of Sandelian openness arguments resolve the significant challenges to that view I have discussed.

Parental Duties

A different sort of potential objection to selection against disability traits appeals to certain purported parental duties that would be violated by this practice. Helen Watt (2004) has argued that parents in particular ought to adopt an attitude of unconditional

acceptance toward their future offspring, such that a prospective parent who selects and screens for or against specific traits, including disability traits, would be falling short of their duties as a parent, making that practice undesirable. According to Watt, “*unconditional acceptance*” is “central to the notion of good parenthood which many of us share” (Watt, 2004, 52). Crucially, Watt extends these claims to fetuses and embryos: she claims that selecting against embryos manifesting certain screened-for traits (including disability traits) would undermine parents’ psychological capacity to manifest unconditional acceptance of their children (Watt, 2004, 53-56; cf. Watt, 2000, 45-65).

There are several problems with Watt’s argument. First of all, it is not clear that unconditional acceptance really is central to good parenthood. Certainly, it seems that there are many aspects of a child’s life of which parents should be accepting. But the notion that good parents should unconditionally accept everything about their child, no matter what that child is like, is implausible. If as a child grows up it becomes clear that they exhibit signs of sadism or psychopathy, or even less extreme traits like a tendency to cruelly bully their peers, many of us would say that their parents should not be accepting of these characteristics, and should do what they can to change them. So, instead of appealing to the value of unconditional acceptance, it seems that Watt must explain how to distinguish between traits that should be accepted, and traits that should not be accepted. Since this explanation will inevitably appeal to other aspects of the to-be-accepted traits beyond the intrinsic value of acceptance itself, this would mean the argument Watt actually provides does not do any work on its own against screening and selecting.

However, even if we grant to Watt that in general, acceptance is central to good parenthood, there is another problem. Watt's claim that selecting against embryos with certain traits would undermine parents' capacity to manifest acceptance is dubious and lacks evidential support. It is perfectly possible to, for instance, screen against embryos with Down syndrome, have children without Down syndrome, and then be a good, accepting parent toward those children. Indeed, it seems implausibly harsh to brand the millions of parents who actually have screened against Down syndrome as bad parents simply for having done that, without taking into account how they treat the children they actually do have. And in any case, Watt does not present any evidence that parents who engage in this kind of screening and selection are bad parents towards the children they actually end up having. For all these reasons, Watt's argument is unconvincing.

In turn, Adrienne Asch and David Wasserman (2005) contend that prospective parents who screen and select against disability traits in their offspring display some kind of moral weakness in their intentions and attitudes towards their children. Such prospective parents might be motivated by a "consumerist" desire for a child compatible with the parents' projects, ambitions, or lifestyle", by a "perfectionist desire for 'the perfect baby'", or by an attitude they call *synecdoche*, in which "the part [i.e. the disability trait] obscures or effaces the whole" (which Asch and Wasserman deem to be a "characteristic response to a stigmatized trait"), all of which are morally problematic in distinctive ways (Asch and Wasserman, 2005, 173-175). In other words, it is undesirable for prospective parents to select against disability traits because to do so is to act upon morally problematic intentions and attitudes. Asch and Wasserman further contend that parents should aspire to a posture

of “unconditional love” towards their offspring, and that this requires a posture of “unconditional welcome” (Asch and Wasserman, 2012; cf. Asch and Wasserman, 2005 and Asch and Wasserman, 2014).

In my response to Watt above, I already provided some reasons to question whether a posture of unconditional acceptance or welcome really is central to good parenthood. Yet even if we grant that claim to Asch and Wasserman, other responses to their argument can be made. In particular, as I argued in Chapter I, prospective parents who screen and select against some disability trait can be motivated by genuine concern for genuinely good things for which there are no substitutes to which a child with that trait might lack access, as well as by genuine concern with avoiding genuinely bad things for their child. After all, with respect to most if not all disability traits it is better to be abled, and most if not all disability traits might even be bad traits to have. If so, then Asch and Wasserman’s condemnation of prospective parents who select against disability traits in their offspring is implausible because it is overly uncharitable to them in its assessment of their intentions, and morally condemns them without sufficient justification. It is also worth repeating Buchanan’s point that sweeping psychological claims about the attitudes of those who engage in screening and selection must be backed by evidence (see Buchanan, 2009, 8-10). Yet Asch and Wasserman do not provide convincing evidence that prospective parents who choose to screen and select against disability traits are actually driven by the consumerist, perfectionist, or synecdoche-committing attitudes they criticize.

Moreover, even if it is granted that parents have some kind of duty to avoid the risk of falling into the attitudes Asch and Wasserman describe, that is not enough on its own to

license the conclusion that selecting against disability traits is undesirable overall. For if it also turns out that prospective parents have some kind of strong reason or even a duty to select against certain disability traits, or a broader duty to engage in procreative beneficence (as Savulescu has argued), these would provide strong reason in favor of selecting against the disability trait in question, and prospective parents would be in a position where they must weigh and balance these various reasons and duties against one another in order to determine whether to screen and select. The duties cited by critics of screening and selection like Watt, Asch, and Wasserman would have to be shown to trump the reason or duty to select against the trait in question or the duty to engage in procreative beneficence, as well as any other relevant parental duties that give prospective parents reasons to select against the trait in question. On an overall weighing of the various reasons for and against selection that is as exhaustive as reasonably possible, it seems unlikely that the duties cited by Watt, Asch, and Wasserman would outweigh the sorts of duties proponents of selection appeal to. That's because the latter sorts of duties directly concern the wellbeing, options, and flourishing of the future numerical child prospective parents plan to have, rather than avoiding moral weakness or character flaw in the parents. Intuitively, maximizing the wellbeing, options, and flourishing of one's child seems far more central to a plausible notion of good parenting than worrying about the purity of one's own character.

Negative Consequence 1: Deprivation of Future Wellbeing

Perhaps the most widespread type of objection to the claim that selecting against disability traits in the reproductive context is desirable appeals to the purported negative consequences of doing so. I will respond to several versions of this negative consequences objection (NC), which differ based on what the negative consequences are supposed to be.

The first version of NC I will consider (henceforth NC1) claims that such selection is undesirable (except with respect to traits that make the lives of those who have them not worth living) because it would deprive some future person of the wellbeing they could have experienced in the future (see, e.g., Watt, 2004; cf. Marquis, 1989). In other words, most if not all embryos produced during IVF can have at least some wellbeing in the future, so they have lives worth living, so they should not be selected against and discarded just because they have a disability trait; the same applies to fetuses in the womb that are found to have a disability trait. This objection is rooted in a line of argument critiquing abortion that has been the subject of much controversy, according to which most abortions are morally wrong because they share the same wrong-making feature as killing someone.⁵⁸ Several responses to this argument have been offered by philosophers defending abortion rights.⁵⁹

Although it is beyond the scope of my project to address the broader debate about abortion in detail, I contend that for anyone who finds those responses compelling and

⁵⁸ On this view, what makes killing wrong is that it deprives the killed person of their future, and thereby deprives them of everything they value and would have come to value (see Marquis, 1989).

⁵⁹ For more on this debate see, e.g., Marquis, 1989 and 2011; Norcross, 1990; Boonin, 2002; Wilson, 2007; Strong, 2008 and 2009; Di Nucci, 2009; Nichols, 2012; Christensen, 2019; Burkhardt, 2021; and Ekendahl & Johansson, 2022.

rejects the anti-abortion line of argument at the heart of this objection, and thinks that it *can* be desirable to abort and thus deprive an embryo or fetus of future wellbeing for various reasons (e.g., for the sake of the mother's career), considerations about future wellbeing do not give them reason to also think it could never be desirable to abort a fetus or discard an embryo for the sake of having a child without some disability trait. In other words, if the broader anti-abortion line of argument underlying NC1 does not threaten the claim that it can be desirable for a mother to abort for the sake of her career, then there is no reason to think NC1 threatens my claim that it can be desirable to select against an embryo or fetus for the sake of avoiding disability traits either. After all, in both cases, the act of selection deprives a future person of future wellbeing, which on this line of argument is the supposedly undesirable feature of the act of selection. So, for anyone who does not consider this consequence of the act of selection to be enough to render abortion undesirable in general, they should not consider this consequence to be enough to render abortions that select against disability traits, or selecting against embryos who have some disability trait, undesirable either.

Negative Consequence 2: The Expressivist Objection

The second version of NC (henceforth NC2) is the so-called 'Expressivist' objection, according to which screening and selecting against disability traits is undesirable because it negatively impacts existing disabled people by reflecting or embodying "a conviction that children with impairments are a burden to themselves, their parents, and society" (Asch and Wasserman, 2005, 172). This is supposed to harm disabled people by

disrespecting them, making them feel bad, causing an increase in stigmatization of existing disabled people, or by reinforcing attitudes that lead to fewer disabled people being born due to widespread screening and selection reducing the presence, visibility, and representation of existing disabled people in society and culture.⁶⁰

In response, I contend that these Expressivist arguments fail to establish that screening and selecting against disability traits is undesirable. First of all, the Expressivist claims about what this practice ‘expresses’ are implausible. Screening and selecting against disabilities might express a “wide variety of messages – many of which need not devalue extant disabled people,” such as a mere personal preference (Perez Gomez, 2020, 74). Moreover, screening and selecting against disability traits is a nonverbal action, which means that more interpretation is needed to establish precisely what its meaning is than would normally be needed for verbal expressions. Yet this is complicated by the fact that screening and selecting against disability traits is not an action that has an undisputed, widely-acknowledged “rule-governed role in a publicly sharable system of symbols”, such as flying a Nazi or Confederate flag on a public building; the meaning of screening and selecting can and is disputed, and does not necessarily express disrespect for people with disability traits or a denial that their lives have value (Nelson, 2000; cf. Perez Gomez 2020, 76).

⁶⁰ This general Expressivist argument has been advanced by Asch 2000, 2003; Asch and Wasserman 2015; Parens and Asch 1999 and 2000; Kukla and Wayne 2018; Wendell 1996; Saxton 1997; Scott 2005; Nelson 1998; Holm 2008, and Perez Gomez 2020 among others.

Proponents of the Expressivist objection might respond that even if a decision to screen and select against some disability trait is not intended to express a devaluing message about existing people with that trait, and does not necessarily express such a message, some existing people with that trait might still receive such a message (see, e.g., Hofmann, 2017 and Edwards, 2014). The problem with such a response is that, as Perez Gomez acknowledges, “if all that’s required for an action to express a message of disvalue to and about a certain group of people is the judgment of a member of the relevant group, then *any* action could in theory meet this criterion” (Perez Gomez, 2020, 77). For example, an expecting mother’s decision to take folic acid in order to avoid her child having spina bifida could be perceived by someone suffering from spina bifida as expressing disrespect or disvalue about people with spina bifida. Similarly, one’s decision not to smoke in order to avoid lung cancer could be perceived by someone suffering from lung cancer as expressing disrespect or disvalue about people with lung cancer. Yet we do not consider taking folic acid to avoid spina bifida in one’s child, or avoiding smoking to avoid lung cancer, as expressing any kind of disrespectful or negative message about those who suffer from those conditions.

This means that in order to justify their claim that screening and selecting against disability traits expresses messages of disrespect and disvalue towards existing individuals with those traits, proponents of the Expressivist objection must appeal to other factors beyond the mere fact that some people with the trait being selected against perceive screening and selecting as expressing those messages. However, if we look at other potential factors such as the intentions of prospective parents who screen and select, or how

this practice is typically understood in the culture, we find little if any evidential support for the claim that this practice expresses disrespect or disvalue of disabled people. In light of all this, even philosophers sympathetic to the Expressivist objection have noted that it “lacks a semantic framework to support the idea that using or promoting prenatal testing [...] actually expresses precise devaluing messages” (Perez Gomez 81).⁶¹

We can also see that the Expressivist claim that screening and selecting expresses disrespect and disvalue of disabled people is implausible by considering analogous cases. As Savulescu points out, “to attempt to prevent accidents which cause paraplegia is not to say that paraplegics are less deserving of respect” (Savulescu, 2001, 423). There is nothing about accident prevention and mitigation measures which expresses disrespect toward existing paraplegic people. Similarly, attempting to help recent college graduates find jobs is not to say that unemployed people in general are less deserving of respect. The case of selecting against disability traits is analogous to these examples. Savulescu is correct when he states that just like paraplegia-prevention measures like seatbelts in cars, or attempts to help people find jobs, attempts to avoid disability traits in one’s children do not disrespect existing populations with those traits: “It is important to distinguish between disability and persons with disability. Selection reduces the former, but is silent on the value of the latter” (*ibid.*). That is, even if selecting against a specific trait is a product of a judgment about the value of that trait, this judgment is *not* a judgment about the overall value of existing people

⁶¹ For arguments providing similar critiques of the Expressivist objection, see, e.g., Buchanan 1996; Nelson 1998, 2000; Baily 2000; and DeGrazia 2012

who have that trait, and on its own does not suggest anything about how much respect they are owed or how they should be treated.

So, although it is true that some disability rights activists do claim to feel disrespected by such selection, if the analogies I am discussing work, then their claims seem as unreasonable as feeling disrespected by accident-prevention measures if one is paraplegic, or by employment programs if one is unemployed, or by expectant mothers taking folic acid if one has spina bifida. Not all feelings of offense are reasonable, and unreasonable feelings of offense felt by some people should have no bearing upon the high-stakes deliberation of prospective parents about whether to screen and select against disability traits.

In turn, the Expressivist claims about the causal impact of what screening and selection against disability traits supposedly expresses are also implausible. Even if it were granted that screening and selecting against a disability trait did express some kind of negative stance concerning the quality of life of people with that trait, expressing such a stance does not necessarily imply anything in particular about how existing individuals with that trait should be treated. As Perez Gomez notes, negative attitudes about the quality of life of someone with a certain trait are conceptually distinct from negative attitudes about how someone with that trait should be treated (Perez Gomez, 2020, 79; cf. Shakespeare, 2014; Glover, 2008; Buchanan 1996). For example, it is perfectly possible to hold negative attitudes about the quality of life of someone suffering from heroin addiction and homelessness, without also having negative attitudes about how they should be treated; in fact, one common motivation for treating people suffering from substance abuse problems

and homelessness *positively* by helping them is likely to be precisely one's negative attitude about their quality of life. Similarly, one's negative attitude about the quality of life of individuals with a particular disability trait does not mean one will also have a negative attitude about how they should be treated, and might even cause one to have a positive attitude about how they should be treated (e.g., by causing one to support accommodations for existing individuals with the disability trait in question). If so, then the fact of having negative attitudes about the quality of life of individuals with some disability trait need not cause harm to individuals with that disability trait by affecting how they are treated by those with the negative attitude in question.

Moreover, as Perez Gomez acknowledges, the Expressivist objection “lacks evidence that using [...] prenatal testing for selective abortion actually bring about wrongs or harms for extant disabled people *in virtue of what* [such selection] *express[es]*” (81). The burden is on proponents of the Expressivist objection to provide evidence that prospective parents choosing to screen and select against disability traits actually causes harmful treatment of existing disabled people. Absent such evidence, the claim that existing disabled people are harmed by prospective parents choosing to screen and select lacks sufficient support. It is not clear that any existing disabled person is actually harmed by this practice in the way these arguments contend. This is another way in which the case of screening and selecting against disability traits is analogous to the examples provided above. There is nothing about accident prevention and mitigation measures which harms existing paraplegic people, nothing about attempting to help recent college graduates find jobs that harms the overall population of unemployed people, and nothing about expectant

mothers taking folic acid that harms existing people with spina bifida. Just like in these cases, there is no evidence that prospective parents choosing to screen and select against some disability trait actually harms existing individuals with that trait.

For all these reasons, the Expressivist objection to screening and selecting against disability traits is unconvincing. As far as the actual decision by prospective parents to screen and select against disability traits goes, the Expressivist objection fails to give us reason to consider this decision undesirable.

Negative Consequence 3: Reduced Diversity Due to Screening and Selecting

The third version of NC (henceforth NC3) I will consider appeals to a negative *social* consequence of prospective parents choosing to select against disability traits in the reproductive context. Selecting against disability traits in the reproductive context might be undesirable because if the practice becomes widespread it could reduce a valuable form of diversity (see Gyngell, 2015). In particular, the considerations proposed by Garland-Thomson that I discussed above suggest that selecting against disability traits could deprive us of the distinctive cultural and material contributions that individuals with the traits being selected against can offer the world (Garland-Thomson, 2012). If that's right, these negative consequences for society would give us at least some reason to think that selecting against disability traits would be undesirable.

I am happy to grant that individuals with disability traits can and do make distinctive cultural and material contributions to society, whether individually – for instance if they are motivated and inspired by their life experiences – or as a community,

as in the case of deaf culture. However, the value of the *potential* for such contributions from one's future children if they have the disability trait in question at best constitutes merely a pro tanto reason to think selection against that trait is undesirable. Such a pro tanto reason would have to be weighed against the various reasons to think selection against that disability trait is desirable, including the various reasons to think the trait in question is a bad trait to have. It seems likely that the latter reasons would heavily outweigh any reason against selection based on the potential value of the distinctive contributions one's future children could make to society if they had the disability trait in question.

II.4.2 – Is It Permissible to Screen and Select Against Disability Traits?

Even if selecting against disability traits is desirable, it could still be objected that prospective parents should not do so because this practice is morally *impermissible*. At first glance, considerations of autonomy provide the strongest reasons in favor of thinking it is permissible for prospective parents to select against disability traits in their future children. A plausible and comprehensive account of reproductive freedom likely includes the freedom of prospective parents to choose not to have an unhealthy child, and thus to select against disability traits in their embryos or in their fetus.⁶² More generally, a commitment to liberal values calls for allowing individuals to decide what to do for themselves in cases

⁶² This basic point has been acknowledged even by those wary of superficial appeals to autonomy to legitimate screening and selection – see, e.g., Elisabeth Hildt's point that "personal autonomy and individual choice are important aspects in the legitimation of PGD. It goes without saying that issues concerning individual family-planning belong to the sphere of private life, and that it is clearly the individual couple involved that is entitled to make its own decisions in this very private field" (Hildt, 2002, 70).

where there is no strong rationale for prohibiting a particular practice, which as I will now argue is exactly the case when it comes to selecting against disability traits.⁶³ I will show that the strongest purported reasons to think this practice is impermissible (even if it is desirable) are implausible. That is, I will consider and respond to purported reasons to think this practice is impermissible that are independent of its desirability.

Parental Openness and Permissibility

Above, I responded to arguments from Watt and Asch & Wasserman that because parents have certain duties toward their offspring, selecting against disability traits would be undesirable because it would involve or encourage violation of those duties. However, their arguments can be reframed as challenges to the permissibility of this practice rather than its desirability. So, perhaps we shouldn't *permit* selection against disability traits, even if doing so would be desirable overall, because doing so can foster attitudes that run counter to certain duties towards their children that parents have, and risk making those who select *bad parents*.

However, this argument is not plausible. Large numbers of prospective parents have already selected against Down syndrome. There is no evidence that (and more generally it's not plausible that) because they did this, all those people, or even a portion of them,

⁶³ This is especially so given that not only is selecting against disability traits desirable, but many prospective parents *actually already do desire to engage in this practice*, and it is plausible that as the cost of such testing decreases and as accessibility improves, an even greater proportion of prospective parents will come to share this desire, especially if governments start to subsidize this practice.

developed attitudes that caused them to be less open towards, and be worse parents to, other children they had. This lack of evidence should not surprise us. Prospective parents who select against disability traits likely do so from an impersonal same-number perspective that involves intense concern for the future (numerical) child they intend to have. This intense concern then carries over to the specific person that future child turns out to be once the selection has been made and the embryo is carried to term. There is no reason to think prospective parents who select against disability traits feel any differently than parents who do not engage in selection towards the specific children they end up having.

Dignity, Respect, and Permissibility

Some who deny that selecting against disability traits is permissible contend that it is wrong to discard or abort a fetus or embryo for the sake of some benefit to another embryo that is selected for implantation, or for the sake of the parents or of society. This is because doing so would violate some inherent dignity the fetus or embryo is supposed to have, and would constitute a lack of respect for the value of humanity. For example, in her critique of screening and selecting against disability traits, Watt claims it would be wrong to treat one's child merely as a means (Watt, 2004, 52), and extends this point to screening and selecting during IVF or pregnancy because embryos supposedly have "the same moral status as the older human being" (Watt, 2000, 64).⁶⁴

⁶⁴ Recently, these sorts of arguments have been employed in legal contexts, as in the ruling by the Alabama Supreme Court in *LePage v. Center for Reproductive Medicine*.

Of course, such appeals to the inherent dignity or humanity of an embryo or fetus have implications that go much farther than the debate surrounding selecting against disability traits – in fact, they form the backbone of many arguments against abortion and IVF in general. Again, it is beyond the scope of my project to address the broader debate about abortion or IVF in detail. However, I will note that such appeals to inherent dignity and the inherent value of humanity are not easy to ground. Moreover, for anyone who rejects the anti-abortion and anti-IVF line of argument at the heart of this objection, and thinks it can be morally permissible to abort or engage in IVF for various reasons (e.g., to abort for the sake of the mother’s career, or to engage in IVF due to difficulty conceiving a child), absent some other argument they would have no reason to think it could never be permissible to abort or engage in IVF specifically for the sake of having a child without some disability trait either.

Expressivist Objection to Permissibility

The Expressivist objection to screening and selecting against disability traits can also be framed as an objection specifically to the permissibility of this practice, even if it is granted that this practice is desirable. The objection would run as follows: even if, as argued above, it’s not clear that existing disabled people are *harmed* by prospective parents screening and selecting against disability traits in their offspring, disabled people might still be *wronged* in other, non-harm-related ways. Here, critics of such screening and selecting could draw upon arguments by Rima Basu in her recent work on moral

encroachment.⁶⁵ Basu contends that a hermit who believes something prejudiced or racist about another person who will never be causally affected by the hermit's thought (and thus is not harmed by it in any way,) still wrongs that other person by having that thought, because he violates some kind of relational norm (Basu, 2019b; cf. Basu, 2019a). Applying this to the cases we are interested in, a proponent of Expressivist objections to screening and selection could contend that if prospective parents choose to screen and select against disability traits, they would do something impermissible to existing disabled people in precisely this sense. By reflecting or embodying the conviction that it's bad to have a disability trait, prospective parents would wrong existing disabled people even if the expression of this conviction through their choice to screen and select would not harm or even causally affect existing disabled people in any way.

However, I do not think this line of argument is promising. Crucially, Basu never specifies what relational norm the racist hermit violates in virtue of which he wrongs the other person. In the absence of a plausible, non-harm-based relational norm that would explain how the hermit wrongs the other person, Basu's position about that case is unsupported. This means that, when it comes to Expressivist objections to the moral permissibility of screening and selecting against disability traits, the claim that prospective parents who engage in this practice do something impermissible (i.e., wrong) to disabled people is equally unsupported.

⁶⁵ For an example of such a move, see, e.g., Perez Gomez, 2020.

Negative Social Consequences and Permissibility

Some critics of selecting against disability traits have argued that we should not permit this practice because of its potential negative social consequences. For example, some worry about a potential slippery slope from this sort of practice to widely condemned, immoral state eugenics programs like those of Nazi Germany and the United States for much of the twentieth century (see, e.g., Garland-Thomson, 2012). However, it is important to consider the key distinction between the state eugenics of the past and what has been called the *liberal eugenics* of today, in which emphasis is placed on the individual free choices of prospective parents regarding what traits their children will have, rather than upon the role of the state. Allowing prospective parents to individually choose to undergo certain medical interventions need not lead to the revival of state-run eugenics, and there is little if any reason to think this is a credible danger (see, e.g., Agar, 2008, Anomaly, 2018, and Anomaly, 2021).

A stronger version of this worry focuses on the argument that if we permit selection against disability traits in the reproductive context (including through selective abortion), we will also have to allow selection (including through selective abortion) on the basis of sex (see, e.g., Watt, 2004, and Williams, 2012). Although it is controversial whether selecting on the basis of sex is morally problematic in individual cases, it's not controversial that there is a social interest in banning selection on the basis of sex, for instance because such selection could lead to severe negative consequences like a significant numerical imbalance in society between the sexes that could cause social unrest. So, if screening and selecting against disability traits would open the door to screening and

selection on the basis of sex, then perhaps we should consider screening and selecting against disability traits to be impermissible.

However, I contend that there is a key difference between selecting on the basis of sex and selecting against disability traits: although there are no good reasons for the former, which is typically motivated by sexist beliefs and prejudices, there are good reasons for the latter. For example, as I argued in Chapter I, selecting against disability traits can be motivated by genuine concern for genuinely good things for which there are no substitutes which a child with some disability trait might lack access to, as well as genuine concern with avoiding genuinely bad things. I also discussed some additional reasons to think it might be desirable to select against disability traits in this chapter. Such considerations give us strong reason to think that selecting against disability traits is not analogous to selecting on the basis of sex.

II.5 – Conclusion of Chapter II

In this chapter, I have contended that parents *should* screen and select against most if not all disability traits, because doing so is good and praiseworthy, usually in a supererogatory sense, but sometimes as a duty. In support of this claim, I proposed the *Moderate Perfectionist* argument according to which, with respect to some disability trait, prospective parents likely have some reason to select against that trait in their future children, as long as and to the extent that the trait negatively impacts wellbeing. Given the significant negative impact on wellbeing many disability traits have, the reason to select yielded by the *Moderate Perfectionist* argument can in many cases be quite significant. I

also provided additional reasons supporting the claim that prospective parents should select against disability traits which do not appeal directly to wellbeing, by drawing upon my defense of the intuition that for most if not all disability traits it is better to be abled (in Chapter I of this dissertation), extending that argument to support the *Bad Difference View* for many disability traits, and appealing to considerations concerning vulnerability and valuable roles we can play for others. I then showed that the most prominent objections to the desirability and permissibility of selecting against disability traits in the reproductive context are not convincing. For all these reasons, we should hold that with respect to most if not all disability traits, prospective parents *should* select against the trait in question in their future children.

I will conclude by briefly discussing two other stances prospective parents could take with respect to disability traits and the issue of selection in the reproductive context. The first stance is “rolling the dice” by avoiding selection altogether, such that the chance of having a child with some disability trait would be higher than if that trait were selected against. The second stance is to actively select *for* disability traits.⁶⁶ Given the arguments I have made in this chapter, the blameworthiness of adopting either of these stances would depend on the specific disability trait in question, and how strong a reason the prospective parents have to select against that trait (which includes taking into account the costs of selection, as discussed above). In cases where there is strong enough reason to select against some disability trait that it is supererogatory for prospective parents to do so, both

⁶⁶ For discussion of a famous example of such a case, see Savulescu, 2002.

of these alternative stances are not problematic enough to be blameworthy, especially given considerations of reproductive freedom, although both stances could still be considered suboptimal. This would likely be the case with respect to disability traits like deafness. However, in cases in which the reason to select against some disability trait is so strong that prospective parents have some kind of duty to do so, prospective parents who adopt either of these alternative stances would be blameworthy. This would likely be the case with respect to disability traits like Tay-Sachs. With respect to the first stance of avoiding selection altogether, the wrong in question would be a wrong of negligence, while with respect to the second stance of actively selecting *for* some disability trait the wrong in question would be an active harming.

CHAPTER III: Striking a Balance in Reproductive Genetic Counseling

In recent years, the field of genetics and reproductive technology has developed rapidly, especially with the introduction of new technologies such as non-invasive prenatal testing (NIPT) and preimplantation genetic testing (PGT). These technologies offer prospective parents an unprecedented level of control over the genetic makeup of their future children, enabling them to screen and select for or against certain traits. Currently, one of the most widespread uses of these technologies is to select against disability traits such as Down syndrome, and such uses are likely to remain common in the future. As the use of reproductive technologies becomes more widespread and affordable, and new tests are developed to screen for an increasing number of disability traits, the importance of re-examining the current non-directive approach taken by genetic counselors towards the patients they advise in the reproductive context grows.

The non-directive standard has come under attack by various philosophers who contend that genetic counselors should actively direct patients towards specific choices. In particular, some philosophers have challenged the desirability of the non-directive approach by suggesting that the non-directive approach fails to address issues of ableism in reproductive decision-making; if people are left to make their own reproductive decisions, they will likely make ableist choices, so genetic counselors should encourage patients to make non-ableist choices. (see e.g., Dietz and Reynolds, Forthcoming; cf. Parens & Asch, 2003). Others have criticized the non-directive approach because prospective parents may make suboptimal reproductive choices that would fail to maximize

the potential well-being of their future children, (see e.g., Savulescu, 1995 and 2001) so genetic counselors should encourage patients to pursue liberal eugenics through selection of the “best” potential offspring. The growing influence of both anti-ableism and liberal eugenics has increasingly brought these debates to the forefront in the literature on genetic counseling.

In this chapter, I will argue that the most plausible account of how genetic counselors should treat their patients in the reproductive context is not a monolithic, one-size-fits-all approach. Instead, I will contend that in reproductive contexts, genetic counselors should be directive about some things but not others. Specifically, genetic counselors should actively encourage their patients to pursue testing and screening for disability traits, but should *refrain* from being directive in any way about selection against some trait or condition.

The chapter will proceed as follows. In section III.1, I make some preliminary remarks framing the discussion. In section III.2, I provide background information about genetic counseling, testing and screening, and selection. In section III.3, I provide an overview of relevant ethical considerations I will appeal to in weighing the merits of non-directive and various forms of directive counseling. In section III.4, I defend directiveness in favor of testing and screening. In section III.5, I defend the current non-directive standard of practice for selection. Finally, in section III.6, I explain why these two claims are not in tension.

III.1 – Framing the Discussion

Before I begin, I will make a few preliminary remarks framing the discussion. First, I will assume that the individual seeking genetic counseling about reproduction-related issues intends to parent their future child, unless they choose to terminate the pregnancy. I will not consider cases involving surrogacy cases, as they introduce significant complexities to the question of reproductive autonomy and are beyond the scope of my project here. In other words, I will focus on the typical scenario where a prospective parent, and their partner when applicable, seek genetic counseling within the reproductive context.

Second, in this chapter I will assume that a non-directive approach to genetic counseling is possible to implement, and is a live option. Some have questioned whether non-directive counseling is even possible in principle, because it is difficult or even impossible to avoid expressing some value judgments to patients.⁶⁷ However, medicine is a normative field, so it is unrealistic to expect non-directive genetic counseling to be completely nonevaluative. I think it is appropriate to call an approach to genetic counseling non-directive as long as it strives to minimize evaluative judgment in consultations and to maximize the communication of factual information, with any evaluative judgments that are made merely expressing widely accepted norms of medicine as a field, such as “pain is generally bad”, “longer life is generally good”, and so on. As long as a standard of practice follows these basic guidelines, I think it is plausible to consider it genuinely non-directive.

⁶⁷ See, e.g., Savulescu’s discussion of framing effects (1995, 328-329); cf. Chańska 2022a, 384-385.

I will have more to say more about non-directiveness and how it can admit of degrees in the following section.

III.2 – Background

Genetic counseling consists in helping patients understand and respond to information about their genetic makeup or that of their future offspring, especially genetic contributions to disease. It centrally involves “interpretation of family and medical histories to assess the chance of disease occurrence or recurrence. Education about inheritance, testing, management, prevention, resources and re-search. Counseling to promote informed choices and adaptation to the risk or condition.”⁶⁸ The term ‘genetic counseling’ was coined in 1947, but genetic counseling *as a profession* emerged in the early 1970s (see Resta, 1997; see also Baty, 2018, 55).⁶⁹

In the reproductive context, genetic counselors focus on advising or informing patients in two main areas. The first area has to do with genetic screening and testing. Patients with an increased risk of having or passing down some trait or condition, or of being carriers of the associated mutation, are identified by assessing their family history,

⁶⁸ See Resta et al. 2006.

⁶⁹ A distinction between genetic counseling *as a clinical practice* and genetic counseling *as a profession* can be made. Biesecker, for example, explains that genetic counseling as a profession came several decades after genetic counseling as a clinical activity, and that genetic counseling as a profession does not have its roots in eugenics, whereas genetic counseling as a clinical practice does. She also explains that some of the key historical moments of the development of genetic counseling as a profession include the creation of a specialized master program in the late 60s, as well as the formation of the National Society of Genetic Counselors (a professional society for genetic counselors). For more: see Biesecker, *et al.* 2019, especially Chapter II.

background, and other risk factors to determine whether they should undergo genetic testing, and then administering the relevant tests.⁷⁰ The testing itself consists in analyzing the patient's genetic code, or that of a fetus or embryo, to identify mutations associated with specific traits or conditions.

Genetic testing can serve various purposes in the reproductive context. First, it can determine whether a patient is a carrier of a gene associated with an autosomal recessive condition, such as cystic fibrosis or sickle cell anemia, which they can pass on to their children if their partner is also a carrier. In such cases, the patient does not show symptoms

⁷⁰ In the reproductive context, there are several types of testing available, namely, carrier screening, diagnostic testing, prenatal testing (non-invasive prenatal testing, chorionic villus sampling and amniocentesis), and preimplantation genetic testing (PGT-A, PGT-M, and PGT-SR). Prenatal testing, which includes NIPT, CVS and amniocentesis, helps determine if a fetus has a genetic abnormality likely to cause mental or physical impairments. Preimplantation genetic testing takes place in the context of IVF, and involves the testing of embryos created through the IVF process. PGT helps determine whether an embryo has a genetic abnormality likely to cause mental or physical impairment. The difference between PGT-A, PGT-M and PGT-SR simply concerns the genetic abnormality that are being tested: PGT-A tests for aneuploidy, PGT-M tests for monogenic/single-gene diseases, while PGT-SR tests for structural chromosome rearrangements. Both prenatal and preimplantation genetic testing are focused on testing the DNA of the embryo or fetus alone. These tests are typically done when the parents are carriers of or affected by a genetic disorder, or when the parents are at higher risks of having a child with some genetic abnormality (for example, there is a higher risk of having a child with Down syndrome with advanced maternal age). That being said, some of these tests are becoming more and more routine, and people who are not necessarily at high risk of having a child with a genetic abnormality are still being proposed some types of prenatal testing -- in particular, NIPT which only requires a blood draw is now proposed to most patients, irrespective of their age and risk factors. Other types of testing include carrier screening and diagnostic testing. Carrier screening detects autosomal recessive disorders, such as Tay-Sachs or cystic fibrosis, whereas diagnostic testing is used to determine whether someone has a genetic disorder that they either suffer from, or will likely suffer from in the future, such as Huntington's disease or FSHD. As I discuss later in this chapter, receiving a positive diagnostic in the case of diagnostic testing is typically much more difficult psychologically and emotionally than it is to receive a positive finding in the case of carrier screening, and the right not to know needs to be considered carefully.

of the condition they are at risk of passing on.⁷¹ Second, genetic testing can diagnose the presence of an autosomal dominant disorder, such as FSHD or Huntington's disease, in a patient who can pass it on to their children regardless of their partner's genetic profile. In these cases, the patient might already show symptoms, or will likely show symptoms at some points in their lives. Finally, genetic testing can diagnose whether a fetus the patient is pregnant with, or an embryo created through IVF, carries some genetic mutation associated with certain traits or conditions (whether recessive or dominant).

The second area in which genetic counselors advise or inform their patients has to do with using genetic test results for various purposes, which genetic counselors can describe or even recommend to their patients depending on whether the standard of care is directive or non-directive. For example, some patients might use genetic test results to be better informed about a condition their child may inherit (or has inherited if the patient is already pregnant), and more generally to be better prepared for the arrival of their child. Other patients may use genetic testing to avoid having a child with certain genetic mutations, whether by terminating their pregnancy, by choosing to undergo IVF with PGT, or by refraining from reproducing and eventually opting to adopt.

There are two basic approaches to best practices in genetic counseling, namely, directive and non-directive.⁷² Directive genetic counseling has been described as aiming to influence patients' behavior in a specific way (Kessler, 1997a and 1997b), or to help

⁷¹ A genetic carrier is an individual who has the relevant mutation but does not manifest the trait or condition itself.

⁷² For more details on the distinction between directive and non-directive genetic counseling, see Jamal, Leila et al, "An ethical framework for genetic counseling in the genomic era", *Journal of Genetic Counseling*, 2020, Vol. 29 (5), p.718-727

patients reach a specific wise decision (as opposed to reach a decision wisely) (Shiloh, 1996). Directive genetic counseling can pursue various values, such as anti-ableism or liberal eugenics in the name of procreative beneficence.

In contrast, non-directive genetic counseling has been generally understood as a counseling method designed to be value neutral (Caplan, 1993), as a commitment not to impose one's own values on patients (Fine, 1993), as a counseling strategy that supports autonomous decision-making by patients (Bartels, LeRoy, McCarthy, & Caplan, 1997), or as the prevention of coercion or persuasion in genetic counseling (Biesecker and Hamby, 2000).⁷³ Non-directiveness has historically been the guiding principle of genetic counseling and taken as an ideal and aspirational target.⁷⁴ One reason for this principle of non-directiveness has been to differentiate genetic counseling from the history of misguided, overreaching paternalism in the medical profession (especially the coercive state eugenics movement), by emphasizing informed, voluntary decision-making by individuals and families, rather than pursuing specific genetic outcomes for the population

⁷³ Non-directive counseling can be understood in several ways: as (1) *fact-giving education*, as (2) *rational counseling*, and as (3) *therapeutic self-finding* (Chańska 2022a). However, I do not think options (2) and (3) are plausible. The worry with (2) is that it's easy to blur the line between trying to evaluate the rationality of the patient's decision process and the rationality of their values, at which point the guidance being given would no longer be non-directive. The worry with (3) is that it may ask too much of genetic counselors professionally, namely, to "create conditions that would enable the [patient] to reach his own emotions" which "reflect the true 'self' of the client" (Chańska 2022a, 390). It's too much to ask genetic counselors to also be fully-trained psychotherapists. For these reasons, in this chapter I will be focusing on (1), and treat non-directive genetic counseling as fact-giving education for present purposes.

⁷⁴ "The longstanding approach to counseling about genetic testing has been based largely on the model of nondirective pre-test counseling with follow-up counseling of those patients who elect to proceed with genetic testing (Kessler 2001; Weil et al. 2006)" (Biesecker, et al. 2019, Chapter 11, p. 188).

(see Resta, 1997 and Fine, 1993). To this end, at present one of the main goals of reproductive genetic counseling is to “promote the client's self-determination in exercising choices” by providing them with as much relevant information as possible for the sake of making the most informed choice (Biesecker, 2001; cf. Rantanen et al., 2008, and Johnston, 2017).⁷⁵

It is urgent to settle which approach genetic counselors should adopt for several reasons. In general, genetic counselors play an important role: people care about their genetic information and that of their offspring, and there is already strong interest in genetic testing in the reproductive context.⁷⁶ It is not easy for patients alone to decide which if any of the many available genetic tests are right for them, to interpret their test results, and to make choices on the basis of those results. The type of counseling a patient receives can significantly impact what they decide to do with respect to their future offspring and their own reproduction, which brings to the fore not only concerns about patient autonomy, but also the prospect of dramatically affecting the wellbeing of patients and their offspring.⁷⁷ Moreover, because the type of counseling a patient receives affects which children will be born, it also has significant implications for the composition of future society, especially

⁷⁵ Notably, non-directiveness admits of degrees; it is scalar rather than binary. The degree to which a genetic counselor's practice is non-directive depends on factors such as the content of the counselor's communications to their patient (both explicit and implicit), the manner in which this content is communicated (tone, gestures, etc.), and the broader context of the communication.

⁷⁶ A few examples: it is estimated that in the United States 25-50% of pregnant people opt for NIPT testing, Medicaid and nearly all commercial insurance companies cover NIPT for high-risk patients in most states; in the Netherlands, around 42% of pregnant people opt for NIPT, and in Belgium it is over 75% (Kasper Gadsbøll et al., 2020).

⁷⁷ It is estimated that there are over 6000 single gene disorders (the type that it is easiest to develop testing for), and many more resulting from abnormalities in several genes, and 1 in 300 births is affected by one of these disorders (see A Guide to Genetic Health, p. 19).

since much of the currently available and soon-to-be available technology, as well as much of the current focus from the public and the medical profession, centers on disability traits, and the kind of testing we are considering is already quite common in many countries.⁷⁸ In light of these high stakes, it is crucial to determine whether some kind of directive approach might be preferable to the current non-directive standard of care with respect to testing and screening, and with respect to selection.

III.3 – Relevant Ethical Considerations

In this section, I will provide an overview of the kinds of ethical considerations relevant for weighing the merits of non-directive and various forms of directive counseling. I will focus on the widely accepted four principles of bioethics first proposed by Tom Beauchamp and James Childress in 1977, namely, autonomy, non-maleficence, beneficence, and justice, as well as the additional principle of reproductive freedom.⁷⁹

The four principles of bioethics are defined by Beauchamp and Childress as follows:⁸⁰

⁷⁸ For example, the data shows that the spread of such testing has coincided with a large increase in elective terminations of pregnancies where the fetus has Down syndrome (de Graaf G, Buckley F, Skotko B., 2017).

⁷⁹ Some people may argue that the notion of reproductive freedom falls under the notion of autonomy. After all, being autonomous not only means having the capacity to decide for yourself, but also having the capacity to act on your decision. So, having the freedom to act on one's own reproductive choices – e.g., with whom, how, and when they reproduce, or which traits one's children will have – may be considered being autonomous. However, it is also important to discuss reproductive freedom as its own ethical consideration, because the basic idea that people should be free to reproduce how they like, with whom they want, and so on, is distinct from the idea that people should be free to decide for themselves what happens to them medically. Although in medical reproductive context, respect for reproductive freedom and respect for patient autonomy often overlap, these are distinctive considerations that can come apart and which offer two distinctive kinds of reasons.

⁸⁰ See Beauchamp T., Childress, J. *Principles of Biomedical Ethics*. New York: Oxford University Press. 1994. In this book, Beauchamp and Childress argue that bioethical decisions making should

“(1) respect for autonomy (a principle requiring respect for the decision-making capacities of autonomous persons); (2) nonmaleficence (a principle requiring not causing harm to others); (3) beneficence (a group of principles requiring that we prevent harm, provide benefits and balance benefits against risks and costs); and (4) justice (a group of principles requiring appropriate distribution of benefits, risks and costs fairly).”⁸¹

Along with reproductive freedom, each of these principles express distinct values that can sometimes be in tension with one another in particular cases. As none of them are consistently overriding, it is necessary to weigh them against one another when considering the approach and practices genetic counselors should adopt toward their patients in the reproductive context.⁸²

III.3.1 – Autonomy

In biomedical ethics, autonomy is a patient’s capacity for self-determination or self-governance. More precisely, autonomy refers to the patient’s ability to consider various alternatives, make a free choice among those possibilities, and take action in line with that decision. Patients exercise autonomy when their decisions and actions are genuinely theirs, unencumbered by pressure or influence from others, including the medical professionals treating them. Autonomy can thus be understood as freedom from external influence when

use principles that are common to various system of ethics, rather than trying to conform to a single theory of ethics, such as utilitarianism or Kantian ethics. This approach, called principlism, has become widely adopted in research policy and clinical practice.

⁸¹ Beauchamp and Childress, 1994, 18. *The Principles of Biomedical Ethics*.

⁸² There has been much debate in the literature about how precisely the various core values of biomedical ethics. Settling this debate is beyond the scope of my project; for helpful discussion, see, e.g., Beauchamp and Childress, 1994.

making medical decisions, or as the right to have one's medical care be determined in accordance with one's own values and aims. Some generally accepted components of autonomy include: (1) the capacity for rational decision-making, (2) independence from external influences, (3) the ability act on your decision (agency), and (4) having the skills and knowledge necessary to make informed decisions (see, e.g. Biesecker *et al.* 2019, Chapter 6, 98).⁸³

The principle of autonomy in bioethics calls for respecting the decision-making capacities of autonomous patients. Medical professionals should allow patients to exercise their capacity for self-determination with respect to their own medical care. In practice, this principle limits what medical professionals can do to patients. For example, a doctor cannot treat a patient against their will, because doing so would violate their decisions, values and preferences, and hence violate their autonomy.

One important thing to note is that the principle of autonomy plays a significant role in protecting patients against paternalistic overreach and abuses by medical professionals, especially when compared to the other principles of bioethics (non-maleficence, beneficence, and justice).⁸⁴ For example, the principles of beneficence and

⁸³ Note that autonomy is not a binary concept, it is a matter of degree. A person may be more or less autonomous. For instance, external factors such as social, cultural, or economic conditions may limit a person's autonomy in certain ways, notably by limiting their range of available options. Someone can also have the capacity to be autonomous but be under the influence of some substance that impacts their decision-making capacity.

⁸⁴ It is important to note that some philosophers argue that paternalistic actions, which infringe upon an individual's autonomy, may occasionally be morally permissible or even good. One common argument is that such paternalistic acts are morally acceptable (or good) because individuals *would* consent to them *if* they were thinking more rationally or were better informed. Others contend that certain paternalistic actions that infringe on personal autonomy are permissible (or good) not because individuals would consent to them if they were more rational or better

non-maleficence, which require healthcare providers to promote the wellbeing of their patients and avoid harming them, can lead medical professionals to override their patients' preferences in pursuit of what they consider to be best for the patients or avoiding harm to the patients.⁸⁵ Likewise, the principle of justice, with its focus on distributive, procedural, and compensatory fairness (see below) can lead medical professionals to override their patients' preferences in pursuit of promoting these values in society. In contrast, respect for autonomy helps protect patients from paternalistic overreach and abuses by centering the patient's own values, preferences, and decision-making power. As Fine helpfully puts it, "in bioethics, recognition of an individual's right to define one's own conception of what is good (for oneself) is a response to a long history of medical paternalism" (Fine, 1993).

Moreover, in contemporary medical ethics it is widely accepted that concern for autonomy provides the ethical foundation for the practice of seeking informed consent (see e.g., Beauchamp and James F. Childress, 1994; see also Faden and Beauchamp, 1986; or

informed, but because these actions promote the well-being of the individual. This is especially true in cases where the violation of autonomy is minimal, and the resulting improvement in well-being is substantial.

⁸⁵ The principle of non-maleficence obliges healthcare providers to avoid causing harm to patients, but what is considered harmful is subjective, and a doctor acting according to this principle may end up violating his patient's autonomy. For example, a Jehovah's Witness patient requires a blood transfusion to treat severe anemia, but they refuse the treatment due to their religious beliefs. The doctor believes that not providing the transfusion would cause harm, but by insisting on the transfusion, the doctor would violate the patient's autonomy. To avoid paternalistic overreach, it is then crucial to also respect the principle of autonomy, and here upholding autonomy requires medical professionals to consider the patient's perspective on what constitutes harm, ensuring that non-maleficence is aligned with the patient's values and preferences, rather than solely based on the provider's judgement. The principle of justice may lead to some paternalistic overreach as well. For example, a patient who does not wish to receive a transplant due to personal or cultural reasons may be pressured to accept the transplant, as the system deems them to be the most eligible candidate based on the objective criteria. In this case, prioritizing justice (fair allocation of resources) may violate the patient's autonomy (their right to make decisions based on their values and preferences).

Appelbaum, Lidz and Meisel, 1987).⁸⁶ Informed consent results from providing patients with sufficient information about the risks, benefits, and alternatives of a proposed medical intervention. This information empowers individuals to decide what happens to their own bodies based on their personal values and preferences, which is why obtaining informed consent is a key aspect of respecting autonomy. So for instance, in order to maintain a patient's autonomy regarding medical decisions, healthcare professionals should present them with information on alternative treatment options, along with their respective advantages and disadvantages. That way, the patient can make an informed choice based on their own values and preferences. The relationship between informed consent and autonomy thus revolves around the idea of empowering patients to make their own healthcare decisions by providing them with the necessary information to weigh their options. This ensures that their autonomy is not compromised and that their right to self-determination is respected.

III.3.2 – Non-Maleficence

Non-maleficence is the obligation not to harm patients, whether intentionally or unintentionally.⁸⁷ In the medical context, intentional harm may occur if, for example, a

⁸⁶ For instance, we can read in the work of Beauchamp and Childress that the “the primary justification advanced for requirements of informed consent has been to protect autonomous choice” (Beauchamp and James F. Childress, 77). This can also be seen in the work of Faden and Beauchamp who maintain that an “analysis of the nature of autonomy provides the essential foundation for our analysis of the nature of informed consent” (Faden and Beauchamp, 235). It is important to note that this view has also been challenge, see e.g., Taylor (2004).

⁸⁷ Of course, it is unrealistic to demand of medical professionals never to harm their patients in any way, as caring for patients inherently carries the potential for inflicting some pain, suffering, or

healthcare provider administers a medication to a patient knowing it will trigger an adverse reaction. Conversely, unintentional harm can occur when a healthcare professional acts negligently or recklessly, or from an inexcusable lack of knowledge. For instance, a surgeon who neglects to follow appropriate sterilization practices before surgery might inadvertently cause a post-operative infection in the patient, thereby harming their patient.

In the context of reproductive genetic counseling, the primary concerns regarding non-maleficence tend to focus on psychological and social harms rather than physical harms (see Biesecker *et al.* 2019. Chapter 6, p. 98). This is because the risks of psychological and social harms are much greater than the physical one in this context. After all, genetic testing to identify potential mutations usually involves minimal physical discomfort, as it often requires just a simple blood draw.⁸⁸ However, getting tested can sometimes lead to psychological distress, such as stress about the test results, sadness, despair, anxiety, or even guilt in the case of positive findings. In addition, these emotions may affect not only the individual tested but also their family members, as they may share similar genetic risks. There can also be some significant social harm involved. If a patient tests positive for a condition, they may suffer stigmatization and discrimination as a result, such as having trouble securing employment or obtaining insurance coverage, among other

injury -- for example, a necessary surgical procedure may cause temporary pain or discomfort. However, we can expect medical professionals to exercise “due care”, that is, to act in a way that minimizes the harm (or the likelihood of causing harm) to their patient when caring for them.

⁸⁸ Some tests, such as chorionic villus sampling (CVS) or amniocentesis, are more invasive than a simple blood draw; however, in these cases too the physical discomfort experienced is usually less significant than the potential psychological and social harm these procedures might inflict.

things.⁸⁹ For example, certain insurance companies have imposed higher premiums or refused coverage for African Americans with sickle cell trait (see Hudson et al. 1995; see also Biesecker *et al.* 2019. Chapter 6, p. 98). So, in the context of reproductive genetic counseling, upholding the principle of non-maleficence requires striving to provide accurate, clear and empathetic guidance to help individuals and families navigate the complexities of genetic information, understand and process the potential consequences of that knowledge for themselves and their family members (existing and future), and help them make informed decision about their ownhealth and well-being, and that of their potential future children. All of this must be done by genetic counselors while striving as much as possible to avoid psychological and social harm to the patient, whether by attending to the way information is delivered to patients, general manner with patients, always remaining kind and empathetic, keeping patient information private, and so on.

III.3.3 – Beneficence

Beneficence goes beyond merely avoiding the infliction of pain and suffering, as emphasized by the principle of non-maleficence. Instead, beneficence calls for proactive efforts to promote the wellbeing of patients. In the medical context, assisting patients and promoting their wellbeing are fundamental obligations; for medical practitioners, providing benefits to patients is not merely commendable but essential and mandatory. For

⁸⁹ The Genetic Information Nondiscrimination Act of 2008 now protects against some of these discriminatory practices, however, the potential for social harms remains a concern in genetic counseling.

example, when a patient visits a doctor with symptoms of the flu, the doctor has an obligation to diagnose the illness accurately and prescribe the proper medication or treatment, thereby actively promoting the patient's wellbeing as part of their professional duty.

In the context of reproductive genetic counseling, adhering to the principle of beneficence involves cultivating a relationship between the genetic counselor and client in which the counselor serves as a “trustee” of the client's welfare (Schmerler 1998). Acting as a trustee of the client's welfare means that the genetic counselor has a responsibility to prioritize the client's best interests, provide accurate and relevant information, and offer guidance that supports the client's physical and emotional wellbeing. For example, this can involve recommending genetic tests that have the highest reliability and safety, or encouraging a patient to participate in support groups and connect with genetic disease networks (Biesecker *et al.* 2019. Chapter 6, p. 99).

III.3.4 – Justice

In the medical context, questions of justice focus on fostering fairness and giving people what they are owed, notably including issues concerning distributive justice, procedural justice, and compensatory justice. Questions of *distributive justice* include whether everyone should get healthcare or not, and if so to what extent. Questions of procedural justice include whether patients have the right to informed consent and shared decision-making in their medical care. Finally, questions of compensatory justice concern whether patients should be compensated for any harm they may have suffered due to

medical treatment. In the context of genetic counseling, the principle of justice demands that genetic counselors demonstrate consistent behavior and impartiality towards all patients, and that differences in the practice of the genetic counselor need to be justified by relevant differences in the cases in question (Biesecker *et al.* 2019. Chapter 6, p. 100). As we will soon see, one version of a directive approach to genetic counseling is motivated primarily by justice-based concerns specifically having to do with injustices associated with ableism in society.

III.3.5 – Reproductive Freedom

Reproductive freedom is the freedom to decide whether or not to have children, how many children to have, when to have them, with whom, and arguably to a certain extent the freedom to decide which traits the children will have, which includes the freedom to use selecting or enhancing technologies (see e.g., Buchanan et al. 2001; Brock 2005; Harris 1998; Robertson 1994, Savulescu 2002 and 2007a).⁹⁰ Having your reproductive freedom respected can involve not being impeded from having access to birth control methods, being free to decide with whom you have sex, being able to get an abortion, or even having access to new reproductive technologies, such as IVF and PGT. In the context of reproductive genetic counseling, respecting a patient’s reproductive freedom means that

⁹⁰ Savulescu maintains that reproductive freedom (or procreative liberty) should be extended to enhancement for two reasons. First, because “bearing and raising children is a very private matter. Parents must bear much of the burden of having children, and they have a legitimate stake in the nature of the child they must invest so much of their lives raising” (Savulescu, 2007a, 527). Second, because reproduction should be about having children with the best prospects, and that “to discover what are the best prospects, we must give individual couples the freedom to act on their own value judgement of what constitutes a life with good prospects” (*ibid.*).

the genetic counselor should strive not to impede the patient from considering her full range of options concerning reproduction. This can be achieved by minimizing pressure on patients to achieve some particular goals through procreation that would be deemed “objectively good” which might be incompatible with certain options.

III.4 – Argument for Directiveness in Favor of Testing and Screening

There are two general approaches genetic counselors can take in the reproductive context specifically with respect to testing and screening: directive, and non-directive. Non-directive counseling with respect to testing and screening involves providing information about available tests, but leaves the decision about whether to undergo testing up to the patient. Under a non-directive approach, genetic counselors would simply act as fact-givers, and educate prospective patients about available testing and screening options, and the benefits and costs of each option.⁹¹ Directive counseling, on the other hand, involves encouraging the patient to take a certain course of action. This can involve either encouraging the patient to undergo testing, or discouraging them from doing so. Under a directive approach in favor of testing and screening, genetic counselors would actively recommend to their patients that they should engage in testing and screening. Under a directive approach against testing and screening, genetic counselors would actively recommend to their patients that they should *avoid* testing and screening.

⁹¹ With respect to the reproductive context, some have defended a global non-directiveness: genetic counselors should leave it up to patients as much as possible whether to undertake testing and screening, and should at most offer, but not recommend, testing (see, e.g., Ravitsky, 2017, and Chen and Wasserman, 2017).

In this section, I will argue that genetic counselors should adopt a *directive attitude in favor of testing and screening* in the reproductive context. To defend this claim, I will compare the degree to which each of the possible views promotes or threatens the various values I discussed in the previous section, and show that on balance directiveness in favor of testing and screening in the reproductive context is the most attractive position.⁹²

III.4.1 – Justice

At first glance, considerations having to do with justice seem to pose the toughest challenge for directiveness in favor of testing, and to provide the strongest source of support for directiveness against testing. Proponents of directiveness against testing argue that non-directiveness and especially directiveness in favor of testing promote ableist injustice in society. Only directiveness against testing avoids these injustices – in fact, it is primarily motivated by these concerns about injustice – so that approach is the most just. However, as I will now show, the case that testing itself and encouraging testing actually promotes these ableist injustices is quite weak. As a result, directiveness against testing has no special advantage over the other approaches when it comes to promoting justice.

Concerns about potential injustice due to testing for disability traits, and especially due to actively encouraging such testing, is rooted in what has been called the *Expressivist*

⁹² Again, my goal here is not to determine or present an account of how to weigh the core values of biomedical ethics against one another in general. Rather, my goal is to provide ethical guidelines for genetic counselors specifically with respect to testing and selecting against disability traits in the reproductive context, with the present section focusing on the issue of testing. So, the position I will be defending concerns how to weigh the various core values of biomedical ethics specifically with respect to the various approaches genetic counselors advising prospective parents about testing and selecting against disability traits in the reproductive context might take.

argument. According to the Expressivist argument, screening and selecting against disability traits is undesirable because it negatively impacts existing disabled people by reflecting or embodying “a conviction that children with impairments are a burden to themselves, their parents, and society” (Asch and Wasserman, 2005, 172). This is supposed to harm individuals with disability traits by disrespecting them, making them feel bad, causing an increase in stigmatization of existing disabled people, or by reinforcing attitudes that lead to fewer disabled people being born due to widespread screening and selection and thereby reducing the presence, visibility, and representation of existing disabled people in society and culture. In light of this last point, proponents of directiveness against testing and screening might even contend that encouraging or even just refraining from discouraging testing and screening would amount to complicity with ableist eradication of future people with disability traits. In all these ways, being non-directive or especially directive in favor of testing is supposed promote injustice.

Proponents of directiveness in favor of testing and screening can respond that these practices are not necessarily ableist or (liberal) eugenicist, because testing and screening need not be done for selection purposes. Prospective parents who engage in testing and screening in order to better be able to prepare for a disabled child certainly do not express anything negative about disabled people – if anything, they express something neutral or even positive – nor are they complicit with ableist eradication of future people with disability traits, since they are committed to having a disabled child if their child turns out to have a disability trait. For these reasons, it is simply not true that testing and screening

necessarily involve these negative aspects. There is nothing about testing and screening on their own that necessarily harms individuals with disabilities.

Proponents of directiveness against testing and screening can push back on this last argument as follows. They can claim that it is not enough to point to possibility of patients using testing to prepare for a child with a certain trait or condition, because society is ableist, and this influences patients. If genetic counselors encourage testing and screening, then de facto most patients will end up testing and screening in order to select against disability traits in their offspring, not in order to prepare for having a child with a disability trait. This can be seen most clearly in the case of Down syndrome. Since testing and screening for Down syndrome became available, the vast majority of embryos and fetuses with Down syndrome have been selected against.⁹³ So, even if some prospective parents might use test results to prepare for having a disabled child, if the vast majority of those who undergo testing do so in order to select against disability traits, perhaps testing does express an ableist message after all.

However, there are several potential responses to this line of argument, First, the plausibility of the expressivist argument itself has been called into question, and faces serious challenges.⁹⁴ First of all, as even those sympathetic to the anti-ableist concerns motivating directiveness against testing have acknowledged, testing for disability traits might express a “wide variety of messages – many of which need not devalue extant

⁹³ See Zhang, 2020.

⁹⁴ See, e.g., Savulescu, 2001, 23 and Perez Gomez, 2020. For extended discussion of the various issues facing the expressivist argument, see Chapter II of this dissertation.

disabled people,” such as a mere personal preference, or a desire to prepare for having a child (Perez Gomez, 2020, 74). So in the first place, it is not necessarily the case that testing expresses the sorts of harmful messages under consideration. Moreover, proponents of the Expressivist argument offer little if any actual evidence that genetic testing in the reproductive context is widely understood as expressing disrespect or disvalue of disabled people in the culture. As Perez Gomez points out, even philosophers sympathetic to the Expressivist Objection have noted that it “lacks a semantic framework to support the idea that using or promoting prenatal testing [...] actually expresses precise devaluing messages” (Perez Gomez, 2020, 81). At most, the only evidence they offer seems to be the claims to offense of a relatively small number of radical disability rights activists. But the Expressivist Objection as formulated by its proponents requires more than that - it requires that the practice being objected to, in this case genetic testing, be commonly understood in society as expressing the disrespectful message. And this is clearly not the case. It does not help resolve this issue to reply that some individuals with disability traits nonetheless insist that testing expresses a negative message about them. This is because “if all that’s required for an action to express a message of disvalue to and about a certain group of people is the judgment of a member of the relevant group, then any action could in theory meet this criterion” (Perez Gomez, 2020, 77).⁹⁵

⁹⁵ Perez Gomez herself offers what she takes to be a stronger version of the Expressivist objection specifically with respect to the practice of medical professionals in the reproductive context. She makes two main claims. First, she argues that when medical professionals promote prenatal testing for selective abortion, “they sometimes express implied messages or meanings that can be about extant disabled people. When these expressed messages or meanings are inaccurate or misleading, medical professionals act wrongly, as they violate a duty to obtain informed consent to do prenatal, disability-related testing on their expecting patients” (Perez Gomez, 2020, 89). I am perfectly happy

Besides the fact that testing can express a variety of messages, and the lack of evidence that genetic testing in the reproductive context is widely understood as expressing disrespect of disabled people in the culture, it is also more generally implausible that testing for disability traits or encouraging patients to test expresses such disrespect. We can see this by considering analogous cases. The CDC “supports screening for breast, cervical, colorectal (colon), and lung cancers as recommended by the U.S. Preventive Services Task Force (USPSTF)”.⁹⁶ Yet this does not express any disrespect towards existing individuals suffering from these forms of cancer. Similarly, there is nothing about testing for disability traits, or recommending such testing, that expresses disrespect towards existing individuals with disability traits. Such testing, and the recommendation to test from a genetic counselor, do not take a stance about the value of existing individuals with disability traits one way or the other.

to accept this point, as I agree that it is wrong for medical professionals to express *inaccurate* or *misleading* information of *any kind* to patients, precisely for the reason Perez-Gomez identifies: doing so violates the duty of medical professionals to obtain informed consent from patients. And as Perez-Gomez herself acknowledges, this concern does not have to do with harms or wrongs to existing individuals with disability traits due to something being expressed, so my accepting it does not concede much at all to proponents of the Expressivist objection itself (Perez Gomez, 2020, 90). The second claim offered by Perez-Gomez is that proponents of the Expressivist objection can appeal to the account of doxastic wrongdoing given by Rima Basu and Mark Schroeder to claim that existing disabled people might still be wronged in other, non-harm-related ways by the promotion of prenatal testing for selective abortion by medical professionals (Perez Gomez, 2020, 93-99). However, I address why appealing to doxastic wrongdoing in this way is implausible and unconvincing in Chapter II of this dissertation, in my discussion of the Expressivist Objection to Permissibility. In any case, I am also sympathetic to the potential objection to her argument that Perez Gomez briefly discusses, namely, that it is unlikely that “given the training that medical professionals in general and genetic counselors in particular receive”, they will promote prenatal testing for selective abortion in the morally objectionable ways Perez Gomez describes.

⁹⁶ Source:

<https://www.cdc.gov/cancer/dcpc/prevention/screening.htm#:~:text=CDC%20supports%20screening%20for%20breast,cancer%20before%20you%20have%20symptoms.>

Absent solutions to those challenges, the Expressivist argument is not very convincing, whether in general or as a point in favor of directiveness against testing and screening. But there is yet another point to consider that further blunts the threat posed by the Expressivist argument to the ability of nondirectiveness and directiveness in favor of testing to do well with respect to justice. Even if there are cases where testing usually leads to selection, it is not clear that there is anything ethically suspect or unjust about patients individually deciding to select against disability traits in their offspring on the basis of genetic test results. After all, if it turns out that disability traits are actually bad traits to have rather than neutral traits (which would track widely held, common-sense intuitions), then it might be morally permissible and even desirable, if not obligatory, to engage in such selection. The claim that there is something morally wrong about engaging in such selection depends upon the further claim that disability traits are mere differences rather than bad differences, which is a controversial claim that is not accepted by many bioethicists, let alone the broader society. Absent this controversial claim being vindicated, there might not actually be anything wrong about genetic counselors encouraging testing even in cases where most patients choose to test and screen in order to select against disability traits in their offspring.

The result of all this is that directiveness against testing likely has no special advantage over non-directiveness or directiveness in favor of testing when it comes to promoting justice. And as we will see throughout the rest of this section, directiveness against testing has significant *disadvantages* with respect to the other core values of biomedical ethics.

III.4.2 – Autonomy and Reproductive Freedom

Directiveness in favor of testing and screening strongly fosters patient autonomy. This is because testing and screening increases the information available to patients about potential genetic conditions they or their future offspring might have. By encouraging patients to obtain the most information possible, directiveness in favor of testing and screening fosters informed consent (or as close to informed consent as is realistically possible to achieve). For the same reason, directiveness in favor of testing and screening promotes reproductive freedom as well, since patients can be prompted by test results to consider their full range of options with respect to reproduction. This is because if patients have more information about their genetic risks and status, and that of their future children, they have greater power over their reproductive choices, and have more options available to them than if they did not have any information. That is, patients can use the information they get through testing and screening to make decisions about reproduction about issues like whether or not to have children at all, which embryos to implant, which pregnancies to carry to term, and so on. In that way, directiveness in favor of testing and screening increases reproductive freedom.

Despite the fact that non-directiveness about testing and screening is motivated primarily by concern for patient autonomy, it is actually inferior to directiveness in favor of testing and screening when it comes to fostering autonomy, for several reasons. First, when it comes specifically to the decision whether to engage in testing and screening, a patient's autonomy would actually be more effectively fostered by genetic counselors

being directive in favor of screening and selection, rather than by a non-directive approach. This is because directiveness about testing and screening basically amounts to encouraging patients to seek out more information about their own health and that of their future offspring. More information leads to more autonomous choices because the more information a patient has, the easier it is for them to choose options that genuinely reflect their own values. Moreover, directiveness in favor of testing and screening helps bring patients closer to the ideal of informed consent than the non-directive view. So, in the specific case of directiveness about testing and screening, the concerns about patient autonomy and medical paternalism that typically motivate non-directiveness actually lend more support to directiveness in favor of testing. By encouraging patients to seek out information they can use to make their own decisions, directiveness about testing and screening fosters greater patient autonomy.

In contrast to both directiveness in favor of testing and non-directiveness, directiveness against testing and screening significantly threatens patient autonomy in several ways. First, directiveness against testing works to limit access to information that patients can use to make their own informed decisions, thereby directly interfering with patient autonomy. Moreover, unlike directiveness in favor of testing, which need not be motivated by any specific set of values beyond the basic values of medicine (such as pain reduction and life extension) since test results can be used to prepare or to select, directiveness against testing imposes a certain set of moral and political values – those of

radical anti-ableist activism – on patients.⁹⁷ In addition, directiveness against testing and screening inhibits reproductive freedom by pressuring prospective parents to avoid obtaining information that can prompt them to consider options they may not have considered in the absence of that information, or to make choices that are not consistent with their own reproductive values.

III.4.3 – Non-Maleficence

Directiveness in favor of testing presents only a slight risk of harming patients (whether intentionally or unintentionally), and this small risk can be mitigated to a great extent. One of the main risks of directiveness in favor of testing is that undergoing testing can cause psychological distress to some patients, even when knowing the results is ultimately useful and beneficial. On this basis, critics of directiveness in favor of testing might suggest that if genetic counselors encourage testing and screening for all their patients, in some cases patients would be harmed. However, there is evidence that most patients have favorable attitudes towards undergoing testing and screening in the reproductive context, indicating that these concerns about psychological distress may be overblown because most patients themselves deem testing worth the risk of psychological distress.⁹⁸ More generally, most patients prefer clear recommendations about which

⁹⁷ See, e.g., the “actively anti-ableist” approach advocated by Dietz and Reynolds (Forthcoming, 12). I discuss their view in greater detail below.

⁹⁸ <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0156088>

<https://www.nature.com/articles/jp201430>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6299338/>

prenatal genome sequencing results to receive (Sullivan et al., 2019), and explicit encouragement and support from a counselor for a specific choice, such as the choice to test, can actually reduce the psychological distress patients might feel (Salema, Townsend, & Austin, 2019).

Moreover, genetic counselors can and should take certain precautions to mitigate concerns about potential harm to patients due to psychological distress caused by testing. For instance, they can engage in basic mental health screening of their patients prior to appointments through questionnaires and obtaining medical history in order to identify patients who might be at particular risk of psychological distress due to testing. They can also be trained to deliver and discuss test results in a sympathetic manner that fosters trust and makes the patient feel as comfortable as possible. And of course, even on a directive approach in favor of testing, patients would still be free to refuse testing if they fear the distress they might suffer from the test results. Once all these points are taken into account, it is clear that the potential harm to patients due to psychological distress from being encouraged to undergo testing and screening is minimal.

The other main potential source of harm from directiveness in favor of testing has to do with emotional or psychological harm caused by the supposed anti-ableist message communicated by encouragement to undergo testing. Here, I am focusing on potential harm to the patient, not to the broader community of individuals with disability traits (I will

<https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-018-2077-6#:~:text=48.1%25%20of%20the%20women%20have,to%20accept%20or%20decline%20prenatal>

address that distinct point below). This concern is rooted in the *Expressivist* argument I discussed above, which as we saw faces various problems. With respect to non-maleficence, what matters is that due to these problems, concerns about potential emotional or psychological harm to patients caused by the supposed anti-ableist message communicated by encouragement to undergo testing are implausible.

Non-directiveness about testing also does well with respect to non-maleficence, though perhaps not quite as well as directiveness in favor of testing. Non-directiveness avoids the aforementioned minor concerns facing directiveness in favor of testing, while increasing the risk of negative outcomes for certain patients, namely those patients who do not undergo testing but would have had they been encouraged to do so. The two most prominent potential negative outcomes in such cases are that because such patients would lack the information from testing, they would be less prepared for a child with a disability trait and suffer difficulties as a result, or would be less likely to engage in selection and thus at risk of being subject to various difficulties and negative consequences from having a child with a disability trait. Moreover, we must also consider the reduction in overall wellbeing due to the suffering which, all else being equal, the disabled child themselves would suffer that a non-disabled child who would have resulted from selection would not have suffered. Arguably, these potential harms are more serious than those discussed above with respect to directiveness in favor of testing. Even if we grant that some existing individuals may feel offended by directiveness in favor of testing being the standard of care and that this would lower overall wellbeing to some degree (although as we have seen such claims are not very convincing), the reduction in overall wellbeing that would result from

non-directiveness being implemented and causing children with disability traits to be born instead of children without those disability traits would be far more significant. Intuitively it seems far worse to not be able to walk, or to have reduced cognitive capacities, or to have a sensory modality impaired, for example, than it is to feel offended by a medical policy.

In turn, directiveness against testing risks the same harms to patients and their potential offspring as non-directiveness, but with much higher risk and for all patients rather than the subset mentioned above. After all, under directiveness against testing there would be even more children with disabilities born instead of children without those disabilities than there would be under non-directiveness. As a result, directiveness against testing would likely generate even more of the significant reductions in overall wellbeing associated with disability traits than non-directiveness, and intuitively these reductions in overall wellbeing would also far outweigh whatever reduction in overall wellbeing would be caused by feelings of offense on the part of some existing disabled people regarding a policy like directiveness in favor of testing.

III.4.4 – Beneficence

Directiveness in favor of testing and screening in the reproductive context directly increases overall wellbeing.⁹⁹ It can do so in several ways. For some prospective parents who undergo testing and screening as a result of encouragement from their genetic counselor, the information they obtain is very useful because it allows them to undertake

⁹⁹ Throughout this chapter, when I discuss overall wellbeing, I am referring to an impersonal notion of wellbeing, which I discuss in detail in Chapter II.

specific preparations for raising a child with a particular trait or condition and helping that child flourish, preparations which they may not have known to undertake had they not been encouraged to undergo testing and screening. Such preparations are likely to increase the wellbeing of both the child and the child's family. For example, prospective parents who already have children, and who decide to carry a pregnancy of a fetus with Down syndrome to term, can use the knowledge they can gain from testing their future child to prepare their existing children for life with a sibling who has Down syndrome. For other prospective parents who undergo testing and screening as a result of encouragement from their genetic counselor, the information they obtain can be used to select against embryos or fetuses with certain traits that can significantly reduce wellbeing.¹⁰⁰ Of course, only a relatively small portion of people who undergo testing will receive useful information that might prompt a decision or action, such as deciding to engage in IVF with PGD, terminating or continuing a pregnancy, or preparing for the arrival of a baby with special needs. However, for those parents who do receive useful information, there are significant, concrete benefits which directiveness in favor of testing helps make available, namely, enabling those prospective parents to prepare for having a child with a certain trait or condition, or to engage in selection to avoid having a child with that trait.

Non-directiveness about testing does not do as well with respect to beneficence as directiveness in favor of testing. If genetic counselors remain non-directive with respect to

¹⁰⁰ Finally, if as I have argued in Chapter II, it is desirable for prospective parents to undergo genetic testing and screening to prevent harm to their future children, that could support the idea that genetic counselors should actively encourage their patients to undergo testing.

testing, there will likely be patients who do not undergo testing but would have had they been encouraged to do so by their genetic counselor. At least some portion of this subset of patients, namely, those who stand to receive useful information from the testing, will therefore miss out on the significant benefits of having this information mentioned above. Non-directiveness about testing thus does not go as far as directiveness in favor of testing when it comes to proactively promoting the wellbeing of patients.

In turn, directiveness against screening would likely *reduce* overall wellbeing by causing patients who might otherwise have engaged in testing and screening not to do so. This would result in those patients remaining ignorant about potential conditions their children might inherit, and for that reason failing to prepare adequately for having such a child by seeking various kinds of support, or avoiding selecting an embryo without the condition who all else being equal would be better off – in both cases leading to a reduction in overall wellbeing.

III.4.5 – Taking Stock

We have seen that once we evaluate the various approaches genetic counselors might take with respect to testing for disability traits in the reproductive context, directiveness in favor of testing is the best option. Crucially, when compared to the other approaches, directiveness in favor of testing is most effective at fostering not only patient autonomy, but also patient wellbeing considered both in terms of beneficence and in terms of non-maleficence, while faring as well as the other approaches in terms of justice.

This result is unsurprising given the weakness of the main arguments against directiveness in favor of testing. We have seen that concerns about potential psychological distress to some patients experienced in reaction to their test results are easily dealt with. Various steps can be taken to mitigate the risk of causing such distress, and the remaining risk is outweighed by the significant potential benefits to wellbeing for patients. That is, concerns about causing psychological distress to their patients do not outweigh the benefits of testing, and the potential benefits of encouraging testing outweigh the potential harms of causing psychological distress in patients that would not have undergone testing had they not been encouraged by their genetic counselor.

Likewise, we have seen that anti-ableist worries about directiveness in favor of testing, both with respect to potential injustice and potential harm to existing disabled individuals, are unconvincing because they rest upon the dubious Expressivist argument. More generally, although it is true that fighting against ableism in society is important, there are many ways to do so. Instead of having genetic counselors significantly interfere with the autonomous decision-making of their patients by discouraging testing for the sake of pushing them towards suboptimal choices with respect to wellbeing, we should choose those methods of combatting ableism that do not threaten patient autonomy and wellbeing. Such methods can include promoting accommodations and combatting social stigma for existing individuals with disability traits. Given the existence of such alternatives, as well as the problems with the Expressivist argument, considerations of justice offer little if any reason to reject directiveness in favor of testing.

In sum, a directive approach in which genetic counselors encourage patients to test and screen has several advantages. Such an approach most effectively increases patient autonomy and contributes to overall wellbeing, without necessarily leading to unjust outcomes on the social level, especially as there are alternative ways to combat ableism that are less threatening to patient autonomy than discouraging testing and screening. So, genetic counselors should be directive *in favor of* genetic testing for their patients in the reproductive context.

III.5 – Argument for Non-Directiveness about Selection

Reproductive genetic counseling can take a directive or non-directive approach to selection as well. Non-directive genetic counseling concerning selection entails providing the patient with descriptive information about some genetic mutation present in either the parents or potential offspring and explaining available reproductive choices, but ultimately defers the decision-making process regarding pregnancy continuation, termination, the use of preimplantation embryo selection, or continuing to attempt to reproduce at all, to the patient without the genetic counselor making any value judgments or recommendations. Directive counseling, in contrast, encourages the patient to take a particular course of action. This can involve either encouraging patients to adopt or maintain anti-ableist ways of thinking about the condition associated with the genetic mutation they or their offspring carry (anti-ableist approach), or encouraging patients to avoid having a child with the mutation by terminating the pregnancy, foregoing reproduction, or using preimplantation

genetic testing to select an unaffected embryo (liberal eugenics approach).¹⁰¹ I will focus on two prominent accounts of directiveness with respect to selection, one defending directiveness against selection from Elizabeth Dietz and Joel Reynolds, and another defending directiveness in favor of selection from Julian Savulescu.

In this section, I argue that genetic counselors should maintain the current standard of *non-directiveness about selection against disability traits* on the basis of genetic test results in the reproductive context. To defend this claim, I will again compare the degree to which each of the possible views promotes or threatens the various core values of biomedical ethics, and show that on balance non-directiveness about selection against disability traits in the reproductive context is the most attractive position. This comparison will be more complicated when it comes to the issue of selection than it was for the issue of testing, because at first glance each of the three possible views seems to have one of the core values on its side: justice for directiveness against selection, autonomy for non-directiveness, and beneficence for directiveness in favor of selection. I will argue that non-directiveness is the best position because in addition to maximizing patient autonomy, it also does better than the other views with respect to non-maleficence and even arguably justice, while doing only slightly worse than directiveness in favor of selection with respect to beneficence. But before making this argument, I will describe the positions of Dietz and Reynolds, and Savulescu, in greater detail.

¹⁰¹ In the contemporary clinical setting, the latter eugenicist approach is *liberal* because it is based on free individual choice by patients rather than state coercion.

III.5.1 – The Other Views

Dietz and Reynolds claim that society is saturated by ableism, so if prospective parents are left to their own devices they will make unjust choices based in “epistemic frameworks rooted in ableism” (Dietz and Reynolds, Forthcoming, 1). In response, genetic counselors should be “actively anti-ableist” and try to influence prospective parents to stop seeing disability traits as bad differences, and start seeing them as mere differences (Dietz and Reynolds, Forthcoming, 4); Dietz and Reynolds contend that the entire field of “genetic counseling as a practice must become actively anti-ableist” (Dietz and Reynolds, Forthcoming, 12).

In turn, Savulescu contends that medical professionals should try to rationally convince their patients to screen and select against disability traits (Savulescu, 1995). Savulescu offers an argument against non-directive approaches and for a certain kind of directive approach. He claims it is undesirable for medical practitioners to avoid making and communicating value judgments, because medicine is committed to certain values that should be pursued (e.g. pain is bad, longer life is usually better than shorter life). The moral stakes of medical choices are high, and patients can fail to make correct judgments about what is most valuable, so medical professionals should be directive to help patients arrive at correct judgments. In addition to being fact-providers, medical providers should be argument-providers. Medical providers should make value judgments about what would be best for their patients, and argue rationally but non-coercively with patients to convince them to choose what is best (Savulescu, 1995, 330). Crucially, Savulescu means here judgments about what would be best for patients *all-things-considered*, not merely what

would be best in terms of the basic, uncontroversial values of medicine qua field such as pain reduction and prolongation of life (*ibid.*). In other words, Savulescu thinks medical professionals should take on the role of making judgments about a patient's entire life and values.

The view Savulescu settles on is Rational Non-Interventional Paternalism. On this approach, medical providers would make judgments about what would be best for their patients, all things considered, and then attempt to rationally convince patients to do what would be best for them (Savulescu, 1995, 330). Elsewhere, Savulescu defends the view that the best thing to do in the reproductive context, all things considered, is to test and select the best embryos through IVF in the name of a principle he calls *procreative beneficence* (Savulescu 2001). So, if Savulescu's model of Rational Non-Interventional Paternalism is applied to the practices of genetic counselors in the reproductive context, it will amount to directiveness in favor of testing and selection.

Before I begin comparing how the various views do with respect to the core values of biomedical ethics, I will first say something about Savulescu's argument against non-directiveness about selection and why I do not find it convincing. There is an important difference between basic values widely held as fundamental to the medical profession such as "in general, pain is bad" and "in general, longer life is better than shorter life", on one hand, and on the other hand values an individual medical practitioner might conclude are important for her patient to pursue all-things-considered, such as having as many capacities and talents as possible. One cannot point to the fact that the former values are uncontroversial values that all agree are central to the medical profession, in order to argue

that the latter kinds of values are unproblematic and merely an expression of medicine's basic normativity, because the latter values clearly go beyond medicine's basic normativity.

III.5.2 – Autonomy and Reproductive Freedom

Autonomy-based considerations provide some of the strongest reasons favoring the non-directive approach to selection. Non-directiveness about selection fosters most effectively patient autonomy for the simple reason that under this standard of care the patient does not have value judgments communicated to them, or specific courses of action recommended, by a medical provider with at least some authority over them (whether for or against selection). Instead, the patient is left free to make her own choice based on her own values. By maintaining a non-directive approach with respect to selection, counselors support patients in making decisions that align with their own beliefs and values.

In contrast, directiveness against selection actively threatens patient autonomy. The shift in the standard of practice of genetic counselors and other medical professionals towards anti-ableism proposed by Dietz and Reynolds centrally involves a radical revision of what patient autonomy amounts to. Currently, it is considered ideal for patients to give informed consent to medical interventions. In contrast, Dietz and Reynolds want to move to a new conception they call “critically informed consent”. Critically informed consent is consent given by patients whose “background organization” of “knowing, judging, and valuing in general” avoids ableist prejudice and bias (whether conscious or unconscious) (Dietz and Reynolds, Forthcoming, 11). As an ideal informing best practices for genetic

counselors, critically informed consent “acknowledges that the provision of information is not without bias and understood as a goal of the practice of genetic counseling, it argues that such biases must be deployed in the service of epistemic transformation” (Dietz and Reynolds, Forthcoming, 6). The result would be an actively “*anti-ableist genetic counseling*” committed to the “*epistemic transformation*” of patients in the name of justice (Dietz and Reynolds, Forthcoming, 1).

Dietz and Reynolds are explicit that such a standard of practice “requires being directive” (Dietz and Reynolds, Forthcoming, 10). This would be done “not merely by providing more information (though that is certainly important), but also by helping clients to think differently about disability” (Dietz and Reynolds, Forthcoming, 9). Given that disability rights activists and scholars have criticized both prenatal genetic testing and selection for manifesting ableism in various ways (see, e.g., Parens and Asch, 2003 and Hodgson and Weil, 2012), the anti-ableist genetic counseling Dietz and Reynolds envision would be directive against both practices in most cases.¹⁰²

Crucially, such directiveness against selection threatens patient autonomy in a problematic way. Genetic counsellors expressing highly morally and politically charged anti-ableist views which are explicitly intended to reform society and common sense, often in radical and even revolutionary ways, will put a lot of pressure on patients, especially given the position of authority genetic counsellors are in with respect to their patients. The pressure this would put patients under would clearly undermine patient autonomy by

¹⁰² Dietz and Reynolds acknowledge that for certain uncontroversially terrible conditions there may be exceptions (Dietz and Reynolds, Forthcoming, 3; cf. Shakespeare 2014 and Wendell 1996).

imposing the genetic counselor's own values and beliefs on the patient. For the same reason, directiveness against selection poses a threat to reproductive freedom. Such directiveness would give genetic counselors the role of pressuring patients to adhere to a specific set of radical moral and political values. This would make it difficult for patients to freely choose from the full range of options available to them. For example, a pregnant patient who might not want to carry a fetus that has tested positive for Down syndrome to term would be pressured under such a directive approach to have this child she otherwise would not want to have. Respecting reproductive freedom means letting the patient decide whether or not to have a particular child without pressuring her, and allowing her to freely consider her full range of reproductive options. The same applies to a patient who is trying to choose which embryo to implant during IVF with PGD, and who on her own would choose an embryo with a typical number of chromosomes. Respecting such a patient's reproductive freedom means letting her freely consider her full range of options, including her favored option, without pressuring her.

Turning to Savulescu's directiveness in favor of selection, we can see that a genetic counselor trying to rationally convince patients about values she might conclude are important for her patient to pursue all-things-considered threatens patient autonomy as well. Directive counseling of this sort risks depriving patients of their autonomy to make their own informed decisions about selection in the reproductive context, because it risks the counselor imposing her own values and beliefs on the patient. This issue is especially worrisome because medical professionals are commonly seen as having authority, a view which has been encouraged in the context of the Covid-19 pandemic and which is vital

given the negative impact of misinformation about vaccines, etc. Yet the fact that medical professionals are seen as having authority means that there is a power imbalance in the sort of rational dialogue with patients Savulescu envisions. Given the authority of genetic counselors, patients may feel pressured to reach a certain conclusion or fearful of reaching a different conclusion than those of their genetic counselor. In this way, directiveness in favor of selection threatens patient autonomy.¹⁰³

III.5.3 – Justice

At first glance, justice-based considerations seem to provide some of the strongest reasons favoring directiveness against selection. Proponents of directiveness against selection argue that non-directiveness and especially directiveness in favor of selection promote ableist injustice in society. Only directiveness against selection avoids these injustices – in fact, it is primarily motivated by these concerns about injustice – so that approach is the most just. However, as I will now show, these concerns with ableist injustice are based on highly controversial assumptions, absent which they do not pose a threat to non-directiveness or directiveness in favor of selection. Then, I will show that both forms of directiveness regarding selection carry the risk of contributing to other forms

¹⁰³ Savulescu's directiveness in favor of selection stands in tension with reproductive freedom as well. However, this is complicated in a way that does not apply to the tension between directiveness against selection and reproductive freedom, because it is actually controversial that parents should have the freedom to choose a 'suboptimal' embryo (see, e.g. Savulescu's arguments for the principle of procreative beneficence in his 2001), especially in the most radical cases such as the famous case of a deaf couple that wanted to have a deaf child (for discussion of this case see Savulescu, 2002). As it is beyond the scope of my project to evaluate the plausibility of the principle of procreative beneficence, I will put aside this matter.

of injustice, risks which only non-directiveness does not carry. For this reason, it is at least arguable that non-directiveness about selection actually does best in terms of justice as well.

I will begin by saying more about the way directiveness against selection is motivated by concerns about injustice. Dietz and Reynolds are motivated by the view that disability traits are mere differences rather than bad differences, which they assume for the purposes of their argument.¹⁰⁴ On the mere difference view, a disability is a neutral trait that does not make you worse or better off by itself, just like gender or skin color.¹⁰⁵ If that is true, then prospective parents selecting against disability traits would be similar to selecting against a certain gender or skin color – at best, an arbitrary whim likely motivated by unconscious bias absorbed from society, and at worst an explicit expression of prejudice. For the sake of avoiding injustice, genetic counselors would need to actively discourage their patients from engaging in such selection.

However, the mere difference view’s plausibility has been called into question by various philosophers, including Kahane and Savulescu (2016), McMahan (2005a, 2005b, 2006), and Crawley (2021). Broadly, these thinkers argue that disability traits are bad traits

¹⁰⁴ Dietz and Reynolds claim that the bad-difference paradigm embedded in the “medical model” of disability and “the larger socio-cultural dynamics of our current epoch” is “not simply empirically dubious—it is also morally problematic” (Dietz and Reynolds, Forthcoming, 11). They do claim that they offer arguments against this paradigm, but their arguments focus on the uncritical “‘common sense’” assumption of the bad-difference view (*ibid.*); they do not engage with more sophisticated philosophical defenses of the bad-difference view in their article. That is why I state here that Dietz and Reynolds assume that the mere-difference view is true for the purposes of their argument.

¹⁰⁵ Perhaps the main reason supporting the mere difference view is that ableism is indeed a big problem in society, and explains at least some of the negative aspects of having some disability trait. For more on the mere-difference view, see, e.g., Barnes (2016) and Kaposy (2013).

to have because they are associated with negative effects such as pain, reduced lifespan, significant reduction of valuable options, and ill-health, which cannot be explained away simply as effects of ableism or as transition costs of becoming disabled after having been abled for some portion of one's life.¹⁰⁶ In addition, the case against the mere difference view can be bolstered with the following argument. Typically, a disabled person who becomes abled is considered to have benefited. This claim cannot be dismissed as a result of ableism because it can be motivated by genuine concern for genuinely good things for which there are no substitutes, even in a non-ableist society.¹⁰⁷ Nor can this claim be explained away as a result of the transition to becoming abled. So, if becoming abled is good because it grants one non-substitutable benefits, then being (as well as becoming) disabled in the relevant way is bad because it deprives one of these benefits of being abled. The benefits one is deprived of by disability traits constitute significant costs of being disabled which have nothing to do with systemic ableism in society.¹⁰⁸

¹⁰⁶ Transition costs are costs associated with the *process* of change to one's identity or situation, such as psychological suffering from not being able to do things one used to be able to do which one feels before one gets used to being disabled, or physical discomfort as one's body adapts and gets used to spending large amounts of time in a wheelchair. For detailed discussion of transition costs, see Chapter 1.

¹⁰⁷ For example, there are many benefits to being able to see for which there are no adequate substitutes for reasons having nothing to do with ableism. The fact that blindness prevents one from experiencing the beauty of a masterpiece painting has nothing to do with unjust lack of accommodations, resource distribution, or prejudice. The same point holds for someone who somehow (perhaps due to some new medical treatment) transitions from having Down syndrome to not having Down syndrome. There are many benefits to having the kinds of cognitive capacities that humans without Down syndrome typically have, for which there are no adequate substitutes (but not due to systemic ableism). For further discussion of this point, see Chapter 1.

¹⁰⁸ A detailed discussion of all these arguments against the mere difference view can be found in Chapter 1.

If we do not accept the mere difference view, then the justice-based anti-ableist argument for directive counseling against selection is not very convincing. For if disability traits are bad traits to have, then parents should be allowed to, and probably should actively strive to, ensure that their children do not have disability traits. There is nothing inherently unjust about trying to avoid having a bad trait in one's offspring.

Moreover, directiveness against selection faces the additional problem of potentially contributing to additional significant injustices through a slippery slope of paternalism. The prospect of medical professionals advancing radical moral and political projects through their practice – and the anti-ableist approach advocated by Dietz and Reynolds is such a radical project – is worrisome given the moral disasters that have ensued in the past as a direct result of medical professionals engaging in these kinds of projects. For example, in the past many medical professionals collaborated with governments in order to pressure patients in the name of coercive state eugenics programs. There is no guarantee that this time, the medical professionals advancing radical moral and political projects through directiveness against selection are getting things right – and as I have suggested above, there are several reasons to think they are not getting things right (e.g., with respect to the mere difference view). Crucially, this is not just an abstract, hypothetical slippery slope – these sorts of errors and abuses have actually happened in history on a massive scale, so we have strong reason to be suspicious of any attempt to use the position of authority medical professionals occupy to advance radical moral and political projects. The moral and political pressure patients could face from medical professionals advancing such radical projects could lead to life-altering injustices, such as

families essentially being forced through such pressure to have disabled children they otherwise would not have had. In addition, even if we put aside worries about this specific directive approach, its adoption would set a precedent and make the adoption of other such moral and political projects by medical providers more likely, thereby increasing the risk of catastrophic medical misconduct on a large scale in the future.

Savulescu's directiveness in favor of selection also faces the problem of the slippery slope of paternalism, for the same reasons as those given above concerning directiveness against selection. Directiveness in favor of selection can lead to injustice on a massive scale by normalizing eugenics in the reproductive context, eventually opening the door to more explicitly coercive forms of eugenics. Given that many atrocities have already been committed throughout the world in the name of eugenics, often with complicity and even active participation from medical practitioners, we should be especially wary of the problem of the slippery slope of paternalism in the case of Savulescu's directiveness in favor of selection in the name of liberal eugenics.

In contrast to both forms of directiveness about selection, non-directiveness about selection avoids the problem of the slippery slope of paternalism. By leaving patients free to make their own choices about selection based on their own values without pressure from their genetic counselor, the non-directive approach avoids both the risk of encouraging moral error and the risk of setting a precedent that would make the adoption of other moral and political projects by medical providers more likely (thereby increasing the risk of catastrophic medical misconduct in the future). The non-directive approach is expressly designed to avoid the sorts of catastrophic moral errors and abuses of authority and trust

by the medical profession that have resulted from medical professionals advancing their own moral and political projects through their practice and imposing them onto patients. Moreover, as long as the mere-difference view about disability traits turns out to be false (and also given the aforementioned problems with the Expressivist argument), there would be little if any reason to think that non-directiveness would cause injustices to existing individuals with disability traits. After all, if disability traits are bad traits to have, it is difficult to see what would be unjust about prospective parents choosing to avoid their future offspring having such traits. If anything, the injustice would be to impede prospective parents from freely choosing what is best for their future children.

Finally, it is worth noting that both directive approaches face an additional injustice-related concern that non-directiveness arguably does not. Because it does not seek to impose certain moral and political values on patients, a non-directive approach is likely to be much more sensitive than directive approaches to the particular cultural and religious considerations some patients use as the basis for their decision-making about selection. In this way, a non-directive approach avoids the illiberal imposition of dominant values or a particular conception of the good upon vulnerable minority groups (including immigrants and refugees), and thereby respects cultural diversity.

III.5.4 – Beneficence

Directiveness in favor of selection likely does best from among the three views with respect to beneficence. Prospective parents can significantly improve the wellbeing of their future offspring by selecting against embryos or fetuses with traits that can significantly

reduce wellbeing, including disability traits.¹⁰⁹ In particular, selection against disability traits can increase wellbeing by mitigating negative effects of those traits, which in many cases would mean less pain, increased lifespan, access to more valuable options, and access to various non-substitutable benefits of being abled in the relevant way. Being encouraged to engage in selection by genetic counselors following a directive approach in favor of selection would make the most number of patients better off.

Under a non-directive approach, fewer patients would engage in selection. In particular, those patients who would only undergo selection had they been encouraged to do so by their genetic counselor would forego selection under non-directiveness. As a result, under non-directiveness fewer patients would be made better off through selection than under directiveness in favor of selection. However, it seems likely that at least for at least some disability traits, the difference in number of patients benefitted between the two approaches would be very small or even negligible. Consider the case of Down syndrome. In the United States, even under the current non-directive standard of care, at least two-thirds of all pregnancies with definitive prenatal diagnosis of Down syndrome result in selective termination.¹¹⁰ The rate of selective termination in the case of Down syndrome is

¹⁰⁹ Here I have in mind the fact that prospective parents who engage in selection are choosing to maximize the wellbeing, options, and chance to flourish of the child they are going to have (from this pregnancy or this round of IVF). Even if there is no identity of person here, such that it's not one particular child who benefits from the decision to screen and select, there is an *identity of number*: a single child will be brought into existence, and it is this single child, whose precise identity *qua* particular person is not established prior to the selection of embryo to implant, who benefits from the decision. I discuss the impact of the non-identity problem on claims about the wellbeing of future children resulting from the kinds of reproductive decisions under consideration in this dissertation in greater detail in Chapter 2.

¹¹⁰ <https://obgyn.onlinelibrary.wiley.com/doi/full/10.1002/pd.2910>

even higher in countries like Iceland (close to 100%), Denmark (98%) and France (77%).¹¹¹ This suggests that when it comes to selecting against at least some disability traits, directiveness in favor of selection does not enjoy a tremendous advantage over non-directiveness in terms of beneficence.

Directiveness against selection would likely *reduce* overall wellbeing by causing patients who might otherwise have engaged in selection not to do so. The future children of prospective parents who do not engage in selection against disability traits because they are actively discouraged from doing so by genetic counselors would in some cases end up having disability traits that could have been detected and selected against. As a result, those children would in at least some cases lose access to valuable options and to various non-substitutable benefits of being abled (with no relation to ableism), thereby reducing overall wellbeing.

III.5.5 – Non-Maleficence

From among the three views we have been considering, non-directiveness about selection is most effective at promoting non-maleficence. This is because are several kinds of harms that one or both forms of directiveness about selection make likelier, but which non-maleficence helps avoid. These potential harms include psychological distress in the patient, negative medical outcomes for patients and their future children due to mistrust of

¹¹¹ <https://www.cbsnews.com/news/down-syndrome-iceland/>

medical professionals, and the harm of one's future child having a disability trait that could have been selected against.

One potential source of harm that both forms of directiveness about selection make likelier is potential psychological distress to patients stemming from the imposition of the genetic counselor's values under a directive approach. Such psychological distress can stem from several sources. For some patients, it can take the form of feelings of being disrespected and even indignation at being pressured to abandon their own values in favor of those the genetic counselor seeks to impose. For others, the distress could take the form of feelings of guilt and shame as a result of feeling judged by their genetic counselor. And for others, the distress could take the form of feelings of offense due specifically to having their specific cultural values disrespected – a point which is especially salient as societies around the world become more diverse.

Non-directiveness about selection is much less likely to cause these kinds of distress in patients because it helps foster trusting and collaborative provider-patient relationships between the genetic counselor and the patient. Patients may be more likely to engage in open and honest discussions about their concerns and preferences when they feel that their autonomy is respected and their decisions will not be judged. In particular, a non-directive approach is likely to foster trust between patients and genetic counselors because it is sensitive to the emotional difficulty many patients find themselves in when trying to decide whether to screen and select, and gives patients space to deal with this by not imposing additional pressure, stress or guilt on patients to conform with specific values. In this way, genetic counselors can avoid causing distress to patients trying to make decisions

about selection. A non-directive approach can also foster trust because it is more likely to be sensitive to the particular cultural and religious considerations some patients use as the basis for their decision-making about selection. Patients may have diverse cultural and religious backgrounds that inform their values and decisions about reproduction. Genetic counselors can gain their patients' confidence by respecting their beliefs and avoiding advocating for specific reproductive choices that may conflict with patients' cultural or religious values.

Non-directiveness about selection is also far less likely than both directive approaches to contribute to negative medical outcomes for patients and their future children by fomenting mistrust of medical professionals. The adoption of a directive approach would threaten to generate widespread mistrust of genetic counselors and medical professionals more generally. Now more than ever, it is important to combat mistrust of medical professionals.¹¹² If medical professionals enter the business of making judgments not only about medicine but also about value, morality, and the structure of society, that can call the objectivity and even political neutrality of medical professionals into question in the minds of many patients and undermine trust in the medical profession. It is important for medicine not to appear politically polarized in order to avoid negative consequences that can result from patients refusing to seek medical treatment or refusing to follow medical advice from trained professionals due to mistrust. Patients may be more likely to seek treatment and advice from medical professionals, and engage in open and honest

¹¹² This is especially so given the rise of medical misinformation and anti-vaccine sentiment in response to the Covid-19 pandemic. For more on this, see, e.g., Hsu, 2022.

discussions about their concerns and preferences, when they feel that their decisions will not be judged.

Finally, it must also be noted that for any disability trait that is a bad difference rather than a mere difference, directiveness against selection also risks additional harm stemming from one's future child having a disability trait that could have been selected against had selection not been discouraged, unlike both non-directiveness and directiveness in favor about selection. After all, for any disability trait that is a bad difference, it would be harmful for one's future child to have such a trait when the child might not have had it. In particular, at least some disability traits might cause a patient's future child to suffer from additional pain, have their lifespan shortened, or have certain health problems. In addition, in at least some cases the patient themselves might be better off from avoiding the various difficulties and costs that sometimes come with having a child with certain disability traits. Selecting against disability traits (whether or not one is encouraged to do so) would avoid these potential harms and thereby increase overall wellbeing. In contrast, assuming that it is implemented effectively directiveness against selection would likely result in more of these harms being suffered by patients and their offspring than under the other approaches.

III.5.6 – Taking Stock

We have seen that once we evaluate the various approaches genetic counselors might take with respect to selecting against disability traits in the reproductive context, non-directiveness about selection is the best option. When compared to the other

approaches, non-directiveness about selection is most effective at fostering not only patient autonomy, but also patient wellbeing considered in terms of non-maleficence, and is arguably the most effective at avoiding injustice as well. Although directiveness in favor of selection does best when it comes to beneficence, its advantage over non-directiveness in this respect is likely to be relatively small in many cases. So, we can see that on balance the basket of reasons rooted in the core values of bioethics which favor non-directiveness about selection are likely to outweigh the reasons favoring the two directive approaches.

In sum, a non-directive approach in which genetic counselors merely provide descriptive information to patients about some genetic mutation present in either them or their potential offspring, and explain available reproductive choices without making value judgments or recommendations, has several advantages. Unlike directive approaches, a non-directive approach fully respects patient autonomy, and fosters trusting relationships between patients and medical professionals which can lead to better care and support for the patient throughout the decision-making process in the reproductive context, and better medical and life outcomes overall. While directiveness against and in favor of selection are both motivated by concerns about core values of bioethics (justice and beneficence, respectively), both views face several significant problems: they pose grave threats to patient autonomy, risk undermining trust between patients and medical providers and thereby causing suboptimal medical outcomes, risk being culturally insensitive and disrespectful to vulnerable minorities in a diverse society, and open the door to catastrophic paternalist abuses of medical authority. For these reasons, genetic counselors should remain non-directive about selection in the reproductive context.

III.5.7 – Implications for Testing

Endorsing non-directiveness about selection also has implications for certain special cases related to testing. Consider the following case. Based on her family history, Alice is at risk of having an autosomal dominant disorder like Huntington's disease. Alice does not want to know whether she herself has the mutation such that she may manifest symptoms in the future (which is an exercise of her right not to know, violation of which would be a violation of her patient autonomy).¹¹³ In such a scenario, a genetic counselor should not be directive, and should avoid actively recommending testing even for her future offspring, whether a fetus she is pregnant with or embryos created through IVF. This is because if the genetic testing revealed that her future offspring have the mutation for Huntington's, that would necessarily mean that Alice has the mutation (assuming that the father does not have it) given that it is autosomal dominant. Given that Alice does not want to know, the information this test would reveal could not be used to help her prepare for a child with the disorder, nor could it be used for her to choose to abort a fetus with the disorder, since in both cases she would be made aware that she herself has the disorder as well. The only possible use for the information this test would reveal that would not involve Alice herself knowing the results would be to conduct non-disclosure testing for the

¹¹³ The right not to know consists in a patient's right to choose not to receive information about their own genetic risks or predispositions for certain diseases or conditions; it is grounded in the value of patient autonomy.

purpose of selecting those embryos free from the genetic mutation causing Huntington's.¹¹⁴ So, in a scenario like this where the patient does not want to know the results, and only the medical professionals treating her would know them, the only purpose of running the test at all would be to conduct non-disclosure testing for purposes of selection. However, if a genetic counselor were to actively recommend testing for the specific purpose of non-disclosure testing, they would de facto be directive in favor of selection. Given the arguments we have made in favor of non-directiveness about selection, it follows that in these kinds of scenarios genetic counselors should remain non-directive about testing as well.

III.6 – Directiveness about Testing and Screening, Non-Directiveness about Selection

In this section I will show that even given the arguments I presented in the previous section in favor of non-directiveness about selection, this position is not in tension with my defense of a directive attitude for testing. There are a number of key dissimilarities between the case of testing and the case of selection in virtue of which directiveness is unproblematic with regard to the former but not with the regard to the latter.

One dissimilarity is that the values motivating directiveness about testing and screening are less controversial than the values motivating directiveness about selection. Directiveness about testing and screening is, as I have argued, the best way to increase the

¹¹⁴ Non-disclosure preimplantation genetic testing is a method used by individuals at risk for late-onset disorders, such as Huntington's Disease or Spinocerebellar Ataxia, who want to ensure their children don't inherit the disease without finding out their own genetic status.

information available to patients so that they can make their own choices, which promotes the widely accepted core value of patient autonomy in medicine. Directive encouragement of testing and screening simply responds to the unproblematic fact that most people want to know about what genetic mutations they or their potential offspring might have in order to make more informed medical and reproductive choices that better reflect their own values. Moreover, both the patient and the genetic counselor typically share a common goal in the testing phase – obtaining accurate and comprehensive information about potential genetic risks. This shared objective fosters collaboration and trust between the patient and counselor, as both parties work together to gather the necessary data to inform decision-making. In contrast, the values motivating directiveness about selection (whether anti-ableist or liberal eugenicist) are much more controversial, for the reasons described above. Directiveness about selection is thus far more likely to put undue pressure on patients than directiveness about testing.

Another dissimilarity between the case of testing and screening and the case of selection is that with respect to the former the moral stakes are much lower. If a patient decides to undergo genetic testing and screening, the result of this process will merely be that they will come to possess more information than before, along with whatever emotions they may experience in response to this information. The decision to undergo testing and screening does not commit the patient to any further course of action regarding themselves or their future offspring. In contrast, the decision to engage in selection can involve fraught ethical questions and dilemmas about controversial issues such as abortion, embryo selection, potential ableism, and so on. This dissimilarity is reinforced by the fact that the

psychological impact of testing and screening compared to selection can differ significantly. While testing may cause some anxiety or distress, selection often involves much more profound emotional and psychological challenges, in part due to the higher moral stakes. So, because there is less at stake morally and psychologically in the case of genetic testing and screening, genetic counselors who actively recommend it are at far less risk of causing their patients distress than counselors who would be directive about selection.

A third dissimilarity is that despite the fact that in both cases the genetic counselor is in a position of authority relative to their patient, directiveness about testing and screening fosters patient autonomy by increasing the likelihood that more information is available to patients so they can make whatever choice they want in the reproductive context in line with their own values, rather than advocating for a particular outcome based on judging the patient's values. In contrast, directiveness about selection arguably infringes upon patient autonomy. For the same reason, there is a much greater risk of a slippery slope towards radical medical paternalism with directiveness in favor of selection, as opposed to directiveness in favor of testing and screening.

A fourth dissimilarity has to do with the effect on trust and rapport between the genetic counselor and the patient. A directive approach in favor of testing does not threaten trust in the provider-patient relationship in the same way a directive approach to selection does, because in the former case the focus is on providing information, enhancing understanding, and promoting informed decision-making rather than making value judgments about the patient's personal values and choices. A directive approach to testing

is less threatening to the provider-patient relationship at least in part due to the objective nature of testing. Genetic testing involves assessing specific genetic markers or conditions based on scientific evidence. The results of these tests are objective, factual pieces of information that can be clearly communicated in a descriptive manner by the genetic counselor. In contrast, selection decisions involve more personal, subjective, and value-laden choices. By being directive only in favor of testing, the genetic counselor can avoid intruding on the patient's personal values and decisions, and show sensitivity towards the particular cultural and religious considerations some patients use as the basis for their decision-making about selection, thereby fostering trust.

III.7 – Conclusion of Chapter III

In this chapter, I hope to have shown that genetic counselors should be directive with respect to genetic testing and screening in the reproductive context, but remain non-directive with respect to decisions about selection, such as to pursuing or terminate a pregnancy, ceasing attempts at reproduction, or using IVF with PGD for purposes of embryo selection. Directiveness about testing and screening would increase patient autonomy and reproductive freedom and contribute to overall wellbeing, without necessarily leading to unjust outcomes on the social level. In turn, the current non-directive standard remains plausible with respect to selection, because it alone fully respects patient autonomy, while also fostering trust between patients and genetic counselors and avoiding the various significant problems facing both forms of directiveness about selection.

CONCLUSION

In this dissertation, I have argued that it is in fact desirable and morally permissible for parents to use reproductive technologies to screen and select against disability traits in their future offspring. I have also contended that the most plausible account of how genetic counselors should treat their patients in the reproductive context is not a monolithic, one-

size-fits-all approach. Instead, in reproductive contexts, genetic counselors should be directive about some things but not others. Specifically, genetic counselors should actively encourage their patients to pursue testing and screening for disability traits, but should *refrain* from being directive in any way about selection against (or for) some trait or condition. In the process of defending these claims, I also demonstrated that the increasingly popular view that disability traits are mere differences rather than bad traits to have is implausible, at least for many if not all disability traits – a crucial point which underlies my further claims about what prospective parents and medical professionals ought to do.

I argued for these claims by first showing in Chapter I that advocates of the Mere Difference View lack a plausible response to the intuition that for most if not all disability traits it is better to be abled than to have that disability trait, which threatens that view's overall plausibility. In particular, I demonstrated that appeals to transitions, systemic ableism, and fortunate redundancy fail to undermine the basic intuition that overall it is better to be abled. I then showed that it is also implausible to claim that the benefits of being abled in some way that cannot be explained away by those strategies are cancelled out by various purported benefits of having the relevant disability trait. I discussed two key challenges such an argument would face: the substitutability of many purported benefits of disability traits, and the outweighing of the remaining non-substitutable purported benefits of disability traits by various costs of having those traits.

Next, in Chapter II I argued that with respect to most if not all disability traits, prospective parents are praiseworthy for selecting against the trait in question. So,

prospective parents *should* select against most if not all disability traits in their future children in the sense that doing so is usually the best or ideal option for prospective parents to strive for as long as their situation allows for it. To show that selecting against disability traits is desirable, I proposed the *Moderate Perfectionist* argument based on wellbeing, namely, that with respect to some disability trait, prospective parents likely have some kind of reason to select against that trait in their future children, as long as and to whatever extent that trait negatively impacts wellbeing. I also discussed additional arguments supporting the claim that prospective parents should select against disability traits which do not appeal directly to wellbeing, including concerns about vulnerability and the capacity to play valuable roles for others, as well as the claim from Chapter I that it is better to be abled and the further claim that most if not all disability traits are bad traits to have. I then addressed various potential objections to my claim that for most if not all disability traits, parents should select against the trait in question in their future children, and defended both the desirability and moral permissibility of such selection.

Finally, in Chapter III I argued that medical professionals should be directive in favor of testing and screening in their interactions with patients, but defended the current non-directive standard of practice with respect to selection. I did this by focusing on the widely accepted four principles of bioethics of autonomy, non-maleficence, beneficence, and justice, and showing that directiveness in favor of testing and screening, and non-directiveness about selection, do better than other approaches in terms of these principles. I also explained why these two claims are not in tension.

By doing all this, I particularly hope to have contributed debates concerns issues surrounding selection in the reproductive context. As existing reproductive technologies continue to be refined and new technologies are introduced, the use of these technologies for purposes of selection becomes easier, less costly, and more accessible and available. The disastrous ethical track record of state involvement in decisions about selection mean that the ethical burden of deciding what to do should fall to prospective parents themselves and the medical professionals guiding them. My hope is that the arguments I have presented in this dissertation shed light on how prospective parents should approach these decisions, and how medical professionals can effectively collaborate with prospective parents to help guide their decision-making in an ethical way.

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