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A Feminist Contestation of Ableist Assumptions: Implications for Biomedical Ethics, Disability Theory, and Phenomenology

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A Feminist Contestation of Ableist Assumptions: Implications for Biomedical Ethics, Disability
Theory, and Phenomenology

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
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DEDICATION

To my mom, grandma, and Ray, who have always supported and believed in me.

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ABSTRACT

This dissertation contributes to the development of philosophy of disability by drawing on disability studies, feminist philosophy, phenomenology, and philosophy of biology in order to contest epistemic and ontological assumptions about disability within biomedical ethics as well as within philosophical work on the body, demonstrating how philosophical inquiry is radically transformed when experiences of disability are taken seriously.

In the first two chapters, I focus on epistemological and ontological concerns surrounding disability within biomedical ethics. Although disabled people and their advocates have been quite vocal regarding their views on disability and in critiquing bioethicists' approaches to issues that affect them, the interests, knowledge, and experiences of disabled people have had minimal impact on discussions within biomedical ethics textbooks. The risks of making problematic assumptions about disability are high within this subfield insofar as bioethicists impact practices within medical facilities, public policy, and, through student engagement with their texts in biomedical ethics courses, the views of potential health care professionals. All of these, in turn, affect the care provided to disabled people and potential/actual parents of disabled children.

Chapter three raises ontological issues related to disability theory, examining the role of the impairment/disability distinction in framing discussions of the body as well as the status of experience. I discuss two approaches to incorporating subjective experiences of the body in disability, arguing that neither is sufficient. I examine debates within feminist theory on questions related to experience. I argue that a feminist phenomenological approach that builds on Merleau-Ponty's work offers the best way to address bodily experiences in disability theory. The

assumptions that disability theorists and Merleau-Ponty make about disability are often at odds. Chapter four points out the ableism in Merleau-Ponty's use of a case study and considers some of the oversights within *Phenomenology of Perception*. In spite of my critique, I argue that his approach to phenomenology—with appropriate modifications—is useful not only for theorizing the experiences of disabled people but also for addressing other types of marginalized embodiment. Chapter five applies this method to body integrity identity disorder (BIID), arguing that combining Merleau-Ponty's insights with those of disability theory allows us to address lived experiences of BIID and to identify assumptions about disability within research on this condition.

INTRODUCTION

Over the last couple of decades, philosophers such as Ron Amundson, Adrienne Asch, Eva Kittay, Martha Nussbaum, Anita Silvers, Shelley Tremain, and Susan Wendell have been philosophically examining numerous issues concerning disability, including such things as perceptions of and attitudes toward disability, the implications of disability for ethics of care, and questions of justice and disability. Nonetheless, philosophy of disability is only now showing signs of emerging as a recognized area of philosophical inquiry. With few exceptions, historically, disability has not been considered to be of philosophical interest or importance. One of the reasons for this is that disability, like other types of marginalization associated with particular bodily features, has often been conceived of in terms of lack—in regard to bodily abilities as well as moral status—rather than as a way of being that can contribute to a greater understanding of what it means to be human and to live a good life.

Within philosophy, there is a tendency to ignore or discount the richness of experiences of disability and the knowledge that can be gained from them. One might expect to find considerations of experiences of disability within philosophical treatments of embodiment. However, much of the philosophical work on embodiment assumes that privileged types of bodies can represent human bodies in general. In addition to assuming maleness, whiteness, and heterosexuality, such accounts are ableist in the sense of being able-centric, i.e., presuming able-bodiedness to be universal or at least the only kind of embodiment with which philosophers need to be concerned. If experiences of disability are cited, it is typically in order to clarify nondisabled experiences: to tell us what is normal. In addition, the attempt to account for

disability within existing frameworks describing embodiment demonstrates their inadequacy insofar as these frameworks often do not cohere with lived experiences of disability.

Dominant discussions of disability within and beyond the discipline of philosophy are filled with dichotomies and determinisms. The medical model of disability focuses on the body as it can be analyzed and measured in scientific terms, while the social model of disability largely excludes the body in favor of attending to disabling social influences.¹ Biological, and often, specifically, genetic determinism as well as various forms of cultural determinism are cited as unidirectional causes of disability. In the case of genetic determinism as applied to pre-implantation genetic diagnosis and prenatal genetic testing, genetic material serves as a stand-in thought to predict the lived experience of an embryo or fetus if allowed to develop into a child. In the case of cultural determinism, biological characteristics of bodies become largely irrelevant because they have a secondary ontological status; they are not only interpreted but also produced by social practices such as diagnosis and other types of cultural impositions upon bodies. Genetic determinism gives too much explanatory weight to particular aspects of the body, while cultural determinism gives too little. Both miss the negotiation between the embodied subject and her social milieu and fail to account for the role of the individual in making sense of her situation. Thus, I will argue that these approaches are inadequate for theorizing experiences of disability because they cannot begin to capture the complexity of embodied subjectivity.

Chapter one is divided into two sections. In the first section, I describe three epistemic and ontological assumptions that bioethicists uncritically adhere to in their discussions of disability: the medical model of disability, bad-difference views of impairment, and biological reductionism and determinism—especially genetic determinism. The *medical model of disability*

¹ As Ron Amundson states, “[t]he reader may consider the Social and Medical Models to present a false

conceives of disability as an individual, biomedical condition that disadvantages those it affects. The focus remains on the individual and ways that she might be cured, rehabilitated, or otherwise assisted to live with her limitations. While social factors affecting disabled people may be given cursory mention, most bioethicists endorse *bad-difference views of impairment* insofar as they assume that functional limitations always greatly reduce the quality of one's life and the corresponding assumption that *not* having functional limitations guarantees that an individual will have more opportunities, better health, and a higher quality of life (QOL) than a person with an impairment. Bioethicists provide inadequate conceptions of human bodies and lives when they rely on simplified and suspect scientific accounts used to support ableist ideologies. In doing so, they provide a great disservice to the field of biomedical ethics and to disabled people. I discuss ways that these assumptions are epistemically problematic and largely antithetical to the interests of disabled people. I also introduce concepts that are useful for understanding how the inferior social position of disabled people is perpetuated and for conceiving of alternatives.

With this context in place, section two examines articles on genetic and other types of prenatal testing and selective abortion within six biomedical ethics anthologies published between 2010-2014 in order to show how models of disability, views on impairment and QOL, and genetic determinism influence authors' approaches and conclusions about what moral principles such as beneficence and justice require of parents and/or society. The majority of these articles adopt the view that living with impairment is a harm that limits opportunity and results in a low QOL. Given this starting point, these bioethicists tend to focus on the responsibility of parents and society to prevent impairment through genetic intervention. However, a few of the articles that endorse the social model of disability contend that impairment is compatible in many cases with satisfactory levels of opportunity and a high QOL, if society enables people with

impairments rather than disabling them. Instead of focusing merely on ways of altering the bodies of individuals, these authors consider what changes would expand the reproductive choices of women and opportunities for disabled people. Assumptions about what disability is have a tremendous impact on conclusions regarding what types of intervention move us toward beneficence and justice for disabled people.

Conceptual disagreements about disability are one of the reasons there is tension between biomedical ethicists and disability advocates. The experience and knowledge of disabled people and their advocates ought to be central for making judgments about medical and social interventions, yet they are often excluded in favor of less-informed perspectives. In chapter two, I examine the ways that the dominant assumptions regarding disability, which I have developed in chapter one, impact epistemic practices in biomedical ethics. I argue that appeals to conceptual neutrality regarding disability, which Anita Silvers—a philosopher of disability—recommends, are counterproductive. Objectivity as neutrality serves to obscure the social values and interests that inform epistemic practices. Drawing on feminist standpoint theory and epistemologies of ignorance, I examine ways that appeals to objectivity as neutrality serve to maintain the status quo and ignorance regarding disability. Bioethicists commonly dismiss the reports of disabled people regarding their QOL as biased. This chapter clarifies ways that “wrongful requests to understand” and calls for “neutrality” contribute to epistemic harms of disabled people within biomedical ethics. Gaile Pohlhaus explains that what she calls “wrongful requests to understand” protect the privileged from the type of epistemic openness that undergirds just knowledge practices while rendering members of marginalized groups vulnerable to a number of harms. I will show that this is especially apparent within biomedical ethics. Sandra Harding’s notion of strong objectivity is useful for thinking about ways that examination of values and interests

informing epistemic practices related to disability in biomedical ethics could create better knowledge practices by taking the standpoint of disabled people seriously.

In chapter three, I argue for the importance of incorporating bodily experience into disability theory as an epistemic resource. I examine the role of the social model of disability's impairment/disability distinction in making exclusion of the body more likely within disability theory. I also show that when the body is included in disability theory, this tends to be in terms of impairment. For instance, Liz Crow suggests that impairment as a value-free description of bodies should be theorized in order to address disabled people's lived experiences. Judith Butler's work on gender has been especially influential for calling into question the naturalness of impairment and the impairment/disability distinction within disability theory. I focus on Shelley Tremain's application of Butler's notion of "performativity" for thinking about ways that impairment is produced through discourse. While I agree with Crow and Tremain that embodied experiences of disabled people should be included in disability theory, neither the conception of impairment as value-free description nor a performative notion of impairment is adequate for this task.

Like disability theorists, feminist theorists have struggled with how and whether to include bodily experiences. They have important insights that are relevant to disability theory. I discuss the influential position of feminist historian Joan Scott on this question as well as the responses of feminist philosopher Linda Martín Alcoff and disability theorist Tobin Siebers. Scott considers social identity and experience to be produced by ideology, and therefore, she holds that drawing on either can only be counterproductive for challenging dominant narratives. Like Alcoff and Siebers, I contend that although social identities can be limiting and experience is fallible, both can be important resources for understanding and changing oppressive social

practices. Merleau-Ponty's approach to phenomenology can be used to address these concerns, while maintaining the centrality of embodiment for being in the world.

Merleau-Ponty's phenomenology has been the starting point for numerous theorists concerned with marginalized embodiment. Yet, in chapter four, I argue that the primary aim and effect of *Phenomenology of Perception* was to clarify "normal" (read non-disabled heterosexual white male) being in the world, rather than to consider the richness of other ways of being. Disability theorists often cite Merleau-Ponty but seldom engage in sustained discussion of the relationship between his approach to phenomenology and his assumptions about disability. Philosophers who are beginning to consider the usefulness of Merleau-Ponty for theorizing disability likewise tend to spend little time analyzing his approach in favor of developing constructive phenomenological accounts of various types of impairments and illnesses. While I think this is an important contribution to philosophy of disability, there is little discussion of the role of disability in Merleau-Ponty's own project. I address this gap in the literature through careful examination of his treatment of a case study of a person with an impairment and his remarks on impairment in *Phenomenology of Perception*.

I show that disability theorist Rosemarie Garland-Thomson's notions of material anonymity, fitting, and misfitting are useful for drawing attention to oversights within Merleau-Ponty's description of the normal subject. These oversights are also present in the works of his successors, who assume that the normal subject's body recedes from awareness (attains material anonymity, in Garland-Thomson's terms). This stance fails to consider ways that the material environment and social expectations facilitate the smooth functioning of some bodies while hindering others. Experiences related to marginalized social identities are connected (and overlap) insofar as they often require that one attend to one's bodily comportment to an extent

that is not required of those in privileged positions. In spite of my critique, I contend that Merleau-Ponty's notion of *one's own body* is very useful for theorizing disability because it moves beyond descriptions of impairment in order to address experiences of embodied subjectivity. For example, this approach can make sense of the fact that individuals alter their bodies, sometimes drastically, in order to enact an identity.

In chapter five, I apply a phenomenological approach informed by insights from disability theory to body integrity identity disorder (BIID), a condition that entails a strong desire to acquire an impairment, in part, in order to obtain social recognition as a disabled person. Neither psychological nor neurological accounts are able to fully address lived experiences of people with BIID. Many theorists who hold bad-differences views of impairment have thought about this condition as an incomprehensible desire to trade normal function for pain, limited function, and reduced social status. Mere-difference and good-differences views of impairment provide alternative perspectives from which to think about BIID. I argue that the dominant way of thinking about BIID is unnecessarily narrow and suggest that future empirical research will be able to provide a more complete account of BIID by thinking about living with limb loss as a way of being.

CHAPTER ONE: PERSPECTIVES ON DISABILITY WITHIN BIOMEDICAL ETHICS²

Within philosophy, disability is most often discussed in the context of biomedical ethics.

Textbooks in this area commonly contain philosophical debates regarding issues that disproportionately affect disabled people. Discussions surrounding topics such as euthanasia, physician-assisted suicide, pre-implantation genetic diagnosis (PGD), prenatal testing, selective abortion, and health care rationing all tend to be premised on shared assumptions regarding disability, biology, and quality of life (QOL), with little recognition that even the term “disability” is contested. Bioethicists often share three types of unacknowledged and unexamined epistemic and ontological assumptions about disability. First, their positions tend to be in line with the medical model of disability, which conceptualizes disability at the level of the individual as a biomedical condition that creates disadvantages. Second, bioethicists are likely to endorse what Elizabeth Barnes terms *bad-difference* views of impairment, which hold that impairment inherently and inevitably reduces QOL, and would do so even apart from social factors such as stigmatization, poverty, and inaccessibility (2014, 91). Third, bioethicists’ arguments often rely on biological determinism and biological reductionism. Bioethicists provide inadequate conceptions of human bodies and lives when they rely on these types of suspect scientific accounts, which are informed by and support ableist ideologies.³ Furthermore, the ways in which

² Portions of this chapter have been previously published in 2015, “Thinking Critically about Disability in Biomedical Ethics Courses,” *American Association of Philosophy Teachers Studies in Pedagogy* 1: 83-98 and, per the author agreement, do not require permission to be reproduced here.

³ Some authors make a distinction between *ableism* and *disablism*. In a previous paper, I characterized these terms in the following way:

most bioethicists discuss disability are often in conflict with the lived experiences, perspectives, and interests of disabled people. Compounding the issue is the reality that the perspectives of disability rights advocates and disabled people remain marginal within biomedical ethics textbooks.⁴ This is a problematic state of affairs because it makes it seem as though there is only one possible perspective from which discussions within biomedical ethics can emerge; disability is presented as an apolitical issue, and philosophical debates about disability are unnecessarily limited.

I focus on biomedical ethics textbooks here on the basis of my assumption that these readings are likely to have the greatest readership beyond bioethicists and other philosophers. In addition, many of the students in biomedical ethics courses plan to become healthcare professionals. A number of studies have suggested that nondisabled people are likely to estimate the QOL of disabled people to be much lower, on average, than disabled people themselves report, and several studies have provided evidence that there is an even greater disparity between the judgments of nondisabled healthcare professionals and disabled people's rankings of QOL.⁵ Thus, assumptions about disability and QOL in biomedical ethics textbooks are especially

I adopt Veronica Chouinard's definition of *ableism*: "ideas, practices, institutions, and social relations that presume ablebodiedness, and by so doing, construct persons with disabilities as marginalised" (Chouinard 1997, 380). *Disablism* consists of beliefs and practices that inferiorize and/or discriminate against people with impairments or who are thought to have impairments. Practices informed by ableism privilege able-bodied people by centering their needs and experiences (Wieseler, 2013, 16).

However, I have since decided to follow the more standard practice of using the term "ableism" to refer to this set of phenomena because they are so intertwined as to be almost indistinguishable. The presumption of able-bodiedness as an ideal—with the corresponding view that impairment is something to be avoided at all costs—is used to argue that discrimination is not unjust.

⁴ Significantly, there are disabled people and disability advocates who are also bioethicists. Indeed, this seems to be the primary reason that the perspectives of disabled people and their advocates have been included within the biomedical ethics literature.

⁵ See Gerhart and Corbet 1995; Amundson 2010.

important to evaluate because they have the potential to either reinforce or challenge dominant narratives of disability among students, including future healthcare professionals.

This chapter highlights ways that uncritical reliance on the medical model of disability, endorsement of bad-difference views of impairment, biological reductionism, and biological determinism shape how disability tends to be treated within biomedical ethics. In the first section, I discuss these three prevalent assumptions and their alternatives as well as concepts that are central for the textbook analysis undertaken in the second section. These include: oppression, ideology, and ableism. The second section examines articles from six biomedical ethics anthologies in order to illustrate how these assumptions frame issues surrounding PGD, prenatal testing, and selective abortion. While I want to emphasize that not all bioethicists engage in the practices I critique here, these practices are widespread enough—especially within biomedical ethics textbooks—and sufficiently influential to warrant critical scrutiny. Although there are a number of bioethicists and disability theorists who adopt the social model of disability and mere-difference view of impairment and reject biological determinism, the medical model of disability, bad-difference views of impairment, and biological determinism—specifically, genetic determinism—maintain dominance within the biomedical ethics textbooks surveyed.

1.1 Three Types of Assumptions and Some Concepts Related to Disability

1.1.1 Assumption one and an alternative: The medical model of disability and the social model of disability

Much of the time, bioethicists uncritically adhere to the medical model of disability. This model conceives of disability as a biomedical condition that disadvantages the individuals it affects.

“Biomedical condition” is to be understood as inclusive of a wide range of functional and

morphological variations considered to be species atypical for humans (e.g. congenital disorders, mental illnesses, and consequences of traumatic injuries). Since this model focuses on bodies as the sole origin of any disadvantages individuals may face, those who subscribe to this model recommend development of medical cures, treatments, and methods for normalization of bodies with functional limitations. Examples include medication, psychiatric treatment, surgical intervention, prosthetics, speech, occupational, and physical therapy. This model has also been referred to as an individual model of disability because it conceives of disability as a problem that inheres within an individual rather than as a relational phenomenon; individuals' bodies (and sometimes their attitudes) need to be changed in order to alleviate or learn to live with the disadvantages of disability (Kafer 2013, 5). Despite the name "medical model," it is not the only model medical professionals adopt and its influence extends well beyond the theory and practice of medicine.⁶ Disability activists coined the name "medical model of disability" for this view, since those endorsing it did not perceive a need for a label for the view. As Ron Amundson points out, those who adopt this perspective, "typically do not see it as a model at all, but rather as simple truth" (2005, 123n2). While social factors may be given cursory mention in discussions of the QOL of disabled people, many bioethicists make the reductionist assumption that functional variations themselves *always* greatly reduce opportunities and QOL as well as the corresponding assumption that *not* having functional variations guarantees that an individual will have more opportunities, better health, and a higher QOL than a person with an impairment. The medical model is currently the dominant way of understanding disability within and beyond the field of biomedical ethics (Amundson 2005).

Some have claimed that the medical model entails the view that disabled people ought to be pitied and thought of as victims of their biomedical conditions, but there is disagreement on

⁶ See Bricout et al. 2004; Swain and French 2010.

the question of whether or not this is a necessary component of the model.⁷ While those who explicitly or implicitly endorse the medical model may espouse these views, for the purposes of this dissertation, I will not assume that the medical model necessarily implies them. My critique of unreflective endorsement of the medical model by bioethicists does not require that this model entail these views.

The social model of disability, which has been hugely influential within disability theory and activism, makes a distinction between the biomedical condition of an individual and disadvantages created by social obstacles such as unjust discrimination, lack of accessibility, and limited options for health care and education. Michael Oliver coined the phrase “social model of disability” in 1983 to describe the views articulated by the Union of the Physically Impaired Against Segregation (UPIAS), a disability rights organization created in the United Kingdom in 1974 (Barnes 2012, 13; Roulstone, Thomas, and Watson 2012, 3). Within this model, species atypical morphology and functionality are termed “impairment,” and social factors that systematically disadvantage people with impairments are collectively termed “disability.” UPIAS states, “Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from society” (1976, 4). Though there are some important exceptions, disability theorists and activists tend to focus on disability rather than impairment.⁸ This is because the goal activists had in creating this model was to shift attention from differences or limitations resulting from biomedical conditions to disadvantages caused by the

⁷ For example, Amundson claims that pity for disabled people is a component of the medical model (2005, 102). Anita Silvers views the medical model as dealing with “biological conditions that disadvantage individuals” and advocates bringing the medical and social models together in order to address both disadvantages resulting from bodies and social arrangements (Silvers 2003, 485). The view that disability is inherently a misfortune that warrants pity is, on the other hand, constitutive of what has alternately been termed the “personal tragedy” or “charity” model of disability (Oliver 1996, 34).

⁸ See Crow 1996; Wendell 1997; Thomas 2007. For example, disability activists have drawn on the social model of disability in order to influence legislators to enact laws such as the Americans with Disabilities Act of 1990.

oppression of disabled people, which cannot be accounted for if the focus remains on isolated individuals. To understand why, it will be helpful to expand on how “oppression” is being used within the social model of disability.

According to Iris Marion Young, the term “oppression” took on a new meaning when social movements in the 1960s and 1970s adopted the term to designate, “systematic constraints on groups that are not necessarily the result of the intentions of a tyrant. Oppression in this sense is structural, rather than the result of a few people’s choices or policies” (1990, 41). Though Young wants to move away from the notion that there must always be an individual or group that is intentionally constraining members of another social group, she contends that for every social group that is oppressed, there is a corresponding group that experiences benefits.⁹ Young notes that tyranny is also considered oppression; the new meaning of oppression broadened the term’s definition rather than superseding the previous one. Because the types of oppression social movements such as the disability rights movement are concerned with are structural, identifying whether or not a particular harm or set of disadvantages an individual faces is due to oppression requires examination of that person’s social context.¹⁰

In seeking to articulate a concept of oppression that is comprehensive and applicable to all oppressed groups, Young explains five “faces” or aspects of oppression: exploitation, marginalization, powerlessness, cultural imperialism, and violence. While I would argue that, as a social group, disabled people experience all of these aspects of oppression in particular

⁹ Recently, my claim that disabled people are oppressed was challenged on the basis that there is not a dominant group that intentionally limits opportunities of disabled people in order to benefit economically or politically. Young’s definition of oppression does not require this. In addition, it might be argued that a great deal of profit is generated through unnecessary institutionalization of disabled people and through prenatal testing made to seem necessary, in part, through stigmatization of impairment. See Saxton 2013.

¹⁰ I will return to Young’s conceptualization of oppression later in this chapter in connection with my discussion of the term “ableism.”

circumstances, I will limit my discussion here to cultural imperialism¹¹ because it is most relevant for understanding how disability is conceptualized within biomedical ethics textbooks and, more generally, how ideology becomes naturalized.

Young explains that within cultural imperialism the dominant group's perspectives are widely circulated and become "the unremarkable," and "the dominant group constructs the differences which some group exhibits as lack and negation" (1990, 59). Disabled people tend not to be thought of as having their own positive characteristics or communities but rather as being people who lack abilities. Young goes on to assert that:

The culturally dominated undergo a paradoxical oppression, in that they are both marked out by stereotypes and at the same time rendered invisible. As remarkable, deviant beings, the culturally imperialized are stamped with an essence. The stereotypes confine them to a nature which is often attached in some way to their bodies, and which thus cannot easily be denied. These stereotypes so permeate society that they are not easily noticed as contestable (1990, 59).

The systematic disadvantages faced by members of some social groups evade identification as oppression when they are conceived of as justified on the basis of bodily "abnormality."

Although legislation such as the 1990 Americans with Disabilities Act rejects the view that impairment invalidates claims of unjust discrimination because it necessitates a reduction in opportunities, the opposite perspective remains pervasive. Because impairment does itself often entail functional limitations, it is especially difficult to keep the focus on ways that society sustains unjust practices that limit opportunities. At the same time, cultural imperialism results in disabled people's perspectives being delegitimized when they challenge the dominant narratives that construe living with impairment as the experience of suffering and lack (e.g., of ability, dignity, opportunity, autonomy, and QOL).

¹¹ Young adopts this term from Lugones and Spelman 1983.

In focusing on disadvantages created by society rather than bodily limitations, the social model seeks to challenge the authority of medical professionals and other experts to define disability. It should be noted that the medical and social models of disability are not the only frameworks for thinking about disability. I have chosen to focus on these models because the medical model is dominant and the social model is the most influential opposing model. Although I will later argue that the social model has its own shortcomings, it does show that there are important omissions in the medical model's description of disability.

1.1.2 Assumption two and alternatives: Bad-difference, mere-difference, and good-difference views of impairment

In “Valuing Disability, Causing Disability” (2014) Barnes discusses three ways of thinking about impairment:¹² as a *bad difference*, *mere-difference*, or *good-difference*. Bad-difference and mere-difference views of impairment involve opposing perspectives on the relationship between impairment and QOL, while good-difference views of impairment are compatible with mere-difference views. I will discuss these views and how they relate to judgments about QOL.

Barnes states that the claims in figure 1 in column 1 are examples of ways that a person may hold a bad-difference view of impairment. None of these claims is necessary for a bad-difference view of impairment, but each is sufficient (92). These claims are often taken to be commonsense understandings that do not need to be interrogated or even made explicit (93). As will be demonstrated in section two of this chapter, bioethicists are among those who take bad-difference views to be obvious.

¹² She uses the term “disability,” but notes that those who make a distinction between impairment and disability should substitute “impairment” where she uses this term. For the sake of clarity and consistency, I will do so when discussing her work.

Table 1: Barnes' Three Types of Views of Impairment

1. Bad-difference Views of Impairment	2. Mere-difference Views of Impairment	3. Good-difference Views of Impairment
(i) "Disability [impairment] is something that is an automatic or intrinsic cost to your well-being" (Barnes 2014, 91).	(i') Impairment is <i>not</i> something that is an automatic or intrinsic cost to your well-being.	(i'') Impairment is something that is an automatic or intrinsic benefit to your well-being.
(ii) "Were society fully accepting of disabled people, it would still be the case that for any given disabled person x and arbitrary nondisabled person y , such that x and y are in relevantly similar personal and socioeconomic circumstances, it is likely that y has a higher level of well-being than x " (91).	(ii') Were society fully accepting of disabled people, it would <i>not</i> be the case that for any given disabled person x and arbitrary nondisabled person y , such that x and y are in relevantly similar personal and socioeconomic circumstances, it is unlikely that y has a higher level of well-being than x .	(ii'') Were society fully accepting of disabled people, it would be the case that for any given disabled person x and arbitrarily nondisabled person y , such that x and y are in relevantly similar personal and socioeconomic circumstances, it is likely that x has a higher level of well-being than y .
(iii) "For any arbitrarily disabled person x , if you could hold x 's personal and socioeconomic circumstances fixed but remove their disability [impairment], you would thereby improve their well-being" (92)	(iii') For any arbitrarily disabled person x , if you could hold x 's personal and socioeconomic circumstances fixed but remove their impairment, you would <i>not necessarily</i> thereby improve their well-being.	(iii'') For any arbitrarily disabled person x , if you could hold x 's personal and socioeconomic circumstances fixed but remove their impairment, you would reduce their well-being.

According to Barnes, those who hold a mere-difference view of impairment reject all three of the claims that fall under the bad-difference view. She notes that it is compatible with a mere-difference view of impairment to acknowledge that impairment "involves the loss of intrinsic goods or basic capabilities (and, *mutatis mutandis*, needn't deny that disability [impairment] is, in a restricted sense, a harm—a harm with respect to particular features or aspects of life)" (2014, 90). Unlike a bad-difference view, a mere-difference view does not conceive of impairment as "merely a loss or a lack;" for example, it can include the claim that

impairment may cause an individual to lose out on some goods while enabling one to participate in others (90).

Good-difference is the third type of view of impairment Barnes describes. She claims that expressions of this view, such as those listed below, are compatible with mere-difference views. To be clear, not everyone who holds a mere-difference view of impairment maintains that impairment is a good-difference.

To illustrate the claim that the absence of an ability need not reduce well-being even if it is not “compensated for,” Barnes provides a different kind of example:

We might think that the ability to be pregnant and give birth—to grow a new person in your own body—is an intrinsic good, at least insofar as any ability is an intrinsic good. Nor is there any obvious man-specific ability we can point to which compensates men for this lack. But we don’t tend to think that people who are biologically male are automatically worse off than people who are biologically female, simply because they lack an ability we might count as an intrinsic good (90n30).

It seems correct that most people do not assume that the inability of males to be pregnant and give birth automatically reduces their level of well-being in comparison to females who have this ability. In fact, in contexts with high mortality rates during childbirth and/or where contraception and abortion are illegal or difficult to obtain, we may expect that this inability among males is likely to increase QOL by comparison. It might be objected that the male inability to be pregnant is disanalogous to impairment insofar as the latter tends to involve limitations on major life activities while the former does not. This is a fair observation, but I do not think it detracts from Barnes’ point. In fact, her example likely needed to be at least somewhat disanalogous to make it clear that there are cases in which lacking an ability tends to not be thought to automatically reduce QOL. Barnes’ use of this example serves to challenge the necessity of the connection between impairment and reduced QOL.

Amundson discusses two opposing views on the relationship between disability and QOL, which map on to Barnes' distinction between bad-difference and mere-difference views of impairment. The *standard view* is that "disabilities [impairments] have very strong negative impacts on the quality of life of the individuals who have them" (2005, 103). In other words, this view assumes that impairments themselves greatly reduce QOL. Amundson notes that this is the view most nondisabled people hold, and that it "is well integrated within the literature of biomedical ethics" (2005, 104). Those who hold the standard view are likely to at least implicitly endorse one or all of the claims that Barnes lists to describe a bad-difference view of impairment. The *anomaly* of the standard view is that when disabled people are asked about their QOL, they report, on average, that it is only slightly lower than the QOL nondisabled people report (103). Amundson points out that many factors that tend to reduce QOL such as poverty, unemployment, and lack of transportation are "*contingently associated* with impairment [emphasis in original]" (2005, 118). Even if a particular impairment creates limitations, it does not follow that an individual with this impairment has a lower—much less significantly lower—than average QOL. Impairment itself does not automatically greatly reduce QOL, though social factors contingently related to impairment may (2005, 118-119). The anomaly is in alignment with mere-difference and good-difference views of impairment, which track the perspectives of many disabled people and disability rights advocates. While the standard view and its anomaly are useful as a starting point for considering opposing positions on the relationship between disability and QOL among bioethicists, Barnes' description of bad-difference, mere-difference, and good-difference views of impairment contains more elaboration on the nuances within these categories.

1.1.3 Assumption three: Biological reductionism and biological determinism

As R.C. Lewontin, Steven Rose, and Leon Kamin state in *Not in Our Genes: Biology, Ideology, and Human Nature*, “reductionists try to explain the properties of complex wholes—molecules, say, or societies—in terms of the units of which those molecules or societies are composed” (1984, 5). In regard to characterizing a society, one form of reductionism sets out from an individualist ontology. Lewontin et al. suggest that biological determinism might be considered a type of biological reductionism insofar as it conceives of human lives as determined by components of human bodies. In response to the questions of why individuals are how they are and why they act as they do, the authors explain that, “they [biological determinists] answer that human lives and actions are inevitable consequences of the biochemical properties of the cells that make up the individual; and these characteristics are in turn uniquely determined by the constituents of the genes possessed by each individual” (1984, 6). Of course, genetic determinism does not exhaust the category of biological determinism. For example, biological determinists also focus on finding and assigning social significance to other biological features such as differences in brain characteristics, reproductive organs, and hormone levels (Fausto-Sterling 2000). Biological determinists may consider environmental factors, but they are typically framed in terms of how they inhibit or facilitate the development of genetically pre-programmed capacities or propensities within individuals and groups. In addition, this approach entails a “spurious dichotomization of nature and nurture” (Lewontin et al. 1984, 56). Scientists and others have adopted biological determinism in the attempt to explain sexual inequality, violence, class, homosexuality, and a long list of other phenomena (Lewontin et al. 1984).

1.1.3.1 Biological reductionism, biological determinism, and ideology

Lewontin et al. forcefully argue that biological reductionism and biological determinism are used in order to express ideologies, which they define as “the ruling ideas of a particular society at a particular time. They are ideas that express the ‘naturalness’ of any existing social order and help maintain it” (1984, 3-4). Young states that ideology “systematically distorts people’s understanding of their social conditions in ways that reinforce unjust relations of economic and social power, at the same time that it inhibits imagining alternatives” (2002, 42). Lewontin et al. critically examine ways that biological determinism has been used in the service of patriarchy and white supremacy. Regarding the former, they state, “ ‘facts’ about differences between men and women in society—*gender* differences—are seemingly naturalized as manifestations of essentially biological *sex* differences, so apparently obvious as to be beyond question” (1984, 132). If women have subordinate positions in society in comparison to men, this is said to be the outcome of biological traits such as biological differences in the brain, hormones, or role in reproduction (1984, 135). Women and men are considered to have diverging capacities, with men possessing those abilities that ensure they will occupy the most powerful positions in any society. The implication is that women and men are suited for different roles both in the household as well as in the public sphere.

Biological determinism serves to naturalize the *status quo*. Attempts to make society more just by remedying disparities in status, wealth, and influence are said to “go against nature” (Lewontin et al. 1984, 7). In the words of Lewontin et al., “What is not always realized is that if one accepts biological determinism, nothing need be changed, for what falls in the realm of necessity falls outside the realm of justice” (1984, 236). The authors’ argument that biological reductionism and determinism are used to naturalize patriarchy, white supremacy, and

differences in socioeconomic status also applies *a fortiori* to the case of ableism. If disability is conceptualized as the inevitable result of genetic or other types of biological variation, and disabled people are thought to be oppressed by nature, then it doesn't make sense to talk about injustice faced by disabled people, other than the injustice imposed when impairment is not prevented.

In order to clarify oppression on the basis of impairment, it will be helpful to spend a moment considering both the function of the term *ableism* and ways that this type of injustice has been legitimated as natural. In *Claiming Disability: Knowledge and Identity*, Simi Linton asserts that an important purpose of the term *ableism* is to draw attention to and challenge the “domination of the nondisabled experience and point of view,” a central aspect of cultural imperialism (1998, 9). Ableism, as the term is commonly used, refers to two sets of mutually supportive beliefs and practices: first, able-bodiedness is presumed and privileged, and, secondly, people with impairments are inferiorized and/or unjustly discriminated against.¹³ Importantly, ableism does not require that individuals *intentionally* contribute to marginalization or inferiorization of disabled people; many acts that accomplish this end are intended to be beneficent. Since ableism is a type of oppression, it is structural. As Anita Ho states: “Historically, frameworks impoverished by the omission of disabled people’s own standpoints have supported systems and practices that patronize and thereby further oppress disabled people, even while intended to serve their supposed good” (2007, 413). Within biomedical ethics, ableism is often couched in the language of beneficence, choice, and rights. Indeed, as I will show in this and the following chapter, arguments in favor of practices that prevent the birth of children with impairments make use of these terms.

¹³ To compare these beliefs and practices to terminology related to oppression on the basis of gender: the first is analogous to androcentricism, while the second is analogous to sexism.

Nirmala Everelles' "In Search of the Disabled Subject," argues that adopting a historical materialist perspective can elucidate ways that the ideology of ableism works to create and maintain inequalities within capitalist societies. Inequalities along the lines of race, gender, class, and disability have all been purportedly explained through scientific claims that members of subordinated groups are characterized by biological defect or deviance that inevitably causes them to occupy an inferior social position (Everelles 2001, 100-105). At this point, there is much more recognition (still far from universal) that this is a problematic attempt to justify racism, sexism, and classism than is the case with ableism.¹⁴ Indeed, ableism is often not identified as a prejudice but rather a common-sense understanding of or response to disability.

Genetic reductionism and determinism are commonly assumed within discussions of pre-implantation genetic diagnosis (PGD) and prenatal testing in biomedical ethics. Thus, it is important to understand what these approaches entail and the problems inherent in them. As molecular biologist Jackie Scully puts it in *Disability Bioethics: Moral Bodies, Moral Difference*:

Genetic reductionism uses the popular but oversimplified picture of gene action in which DNA sequences (molecular biologists call this the genotype) encode instructions for proteins that ultimately determine people's bodily characteristics (or phenotype), from hair color to their sexual preferences, and especially their health. According to this model, genes provide the most fundamental (and therefore, in reductionist terms, the best) account of human embodiment (2008, 5).

Within this conception, inheritance is narrowly discussed in terms of genetics, and knowledge of genes is privileged and often isolated as a means for understanding the capacities of individuals as well as group differences. According to geneticist Eva Jablonka, this is problematic insofar as it fails to consider epigenetic, behavioral, and symbolical inheritance systems as well as "the

¹⁴ Bioethicists sometimes suggest that unjust treatment of disabled people is analogous or disanalogous to the effects of racism and/or sexism in order to support their positions on genetic testing and quality of life of disabled people. See Amundson 2005; Asch 2013; Davis 2013, 560; McMahan 2005, 167-168; and Singer 2006.

whole dynamics of an inheritance, which is an aspect of the development process” (Jablonka 2001, 114). Another shortcoming of genetic reductionism is that it can be used to support the notion that there is one standard human genome, when there is actually a great deal of variation that may be considered typical. Scully claims, “the main problem with genetic reductionism as popularly practiced is its tendency toward essentialism, and the reification of one genotype as species typical” (2008, 6). This tendency aligns with use of the categories “normal” and “abnormal.” However, it is not legitimate to claim that this distinction is necessarily grounded in genetic models. In Scully’s words: “Although medical practice is structured by a normal/pathological dichotomy, genetic models of human variation can be used without necessarily supporting such binary oppositions between normal and abnormal” (24).

Biological reductionism and biological determinism are so ingrained in the literature of biomedical ethics as well as everyday conversation that it can be difficult to conceive of an alternative. Some have suggested that the alternative to biological determinism must be environmental or cultural determinism, but this is not a viable, much less the only, alternative (Lewontin et al. 1984, 10). Lewontin et al. suggest that cultural determinism is just as flawed as biological determinism insofar as it underestimates the importance of biology in placing the emphasis of causation on culture. Some versions of social construction developed by the “post-1968 New Left in Britain and the United States” go too far, according to the authors, who state:

The helplessness of childhood, the existential pain of madness, the frailties of old age were all transmuted to mere labels reflecting disparities in power. But this denial of biology is so contrary to actual lived experience that it has rendered people the more ideologically vulnerable to the “commonsense” appeal of reemerging biological determinism (Lewontin et al. 1984, 10).

In considering nature to be radically malleable and susceptible to the influence of society’s force, cultural determinism obscures understanding and departs from lived experience. Ironically, as

the authors note, the attempt to oppose biological determinism with its antithesis made biological determinism seem more palatable.

Rather than endorsing either of these determinisms, Lewontin et al. advocate dialectical explanations, for which, “the phenomena we see at any instant are parts of processes, processes with histories and futures whose paths are not uniquely determined by their constituent units” (1984, 11). They state, “[d]ialectical explanations, on the contrary, do not abstract properties of parts in isolation from their associations in wholes but see the properties of parts arising out of their associations. That is, according to the dialectical view, the properties of parts and wholes codetermine each other” (11).

Susan Oyama, Paul Griffiths, and Russell Gray also reject the false dichotomization of biological determinism and cultural determinism, in favor of what has come to be called developmental systems theory (DST). In *Cycles of Contingency: Developmental Systems as Evolution*, they discuss DST in terms of the following “major themes”:

1. Joint determination by multiple causes—every trait is produced by the interaction of many developmental resources. The gene/environment dichotomy is only one of many ways to divide up these interactants.
2. Context sensitivity and contingency—the significance of any one cause is contingent upon the state of the rest of the system.
3. Extended inheritance—an organism inherits a wide range of resources that interact to construct that organism’s life cycle.
4. Development as construction—neither traits nor representation of traits is transmitted to offspring. Traits are made—reconstructed—in development.
5. Distributed control—no one type of interactant controls development.
6. Evolution as construction—evolution is not a matter of organisms or populations being molded by their environments, but of organism-environmental systems changing over time (Oyama, Griffiths, and Gray 2001, 2).

If these claims are adopted in place of the “program model of gene action,” which privileges the causal role of genes in development, there are significant implications for what conclusions it is possible to draw on the basis of knowledge of genetic variation (Scully 2008, 32). As Scully notes:

if the systems theories of gene action are correct, the outcome of the DNA sequence changes at the level of the organism may be inherently unpredictable. The identification of a person as disabled *on the basis of* his or her genotype is a radical shift in the meaning of both disability and impairment. It takes chemically encoded information as a suitable marker for phenotypic change, and then for impaired structure and function, and then for the lived experience of disadvantage (Scully 2008, 32).

As Scully makes clear, the practice of conflating genetic variation with disability involves the assumption of the program model of gene action and a number of unjustified inferences. The rejection of genetic determinism requires instead an account that can capture the contingency and complexity of these phenomena in place of simplistic accounts that assume a linear relationship from genotype to phenotype to impairment and lived experience of disability. Developmental systems theory is such an approach.

In sum, biological determinism is informed by and used to support ideologies and it is an inadequate “way of explaining the world;” indeed these aspects of biological determinism are intertwined (Lewontin et al. 1984, 8). Yet, biological determinism is often uncritically assumed to be an objective scientific approach in discussions of disability within biomedical ethics.

1.1.3.2 The medical model, bad-difference views of impairment, and genetic determinism: A perfect storm?

Because the assumptions of the medical and social models of disability as well as the bad-difference and mere-difference views of impairment differ both in how they conceptualize disability and its relation to QOL, they entail not only very different conclusions regarding issues central within biomedical ethics but also contrasting approaches to formulating the issues

themselves. Assumptions about QOL tend to be made explicit in relation to PGD, prenatal testing, selective abortion, the right to refuse treatment, euthanasia, physician-assisted suicide, and health care rationing. I will focus on topics related to reproduction in order to illustrate how the medical and social models along with the bad-difference and mere-difference views of impairment shape discussions within biomedical ethics.

In the context of discussions of PGD, prenatal genetic testing, and selective abortion, theorists whose positions are in line with the medical model often engage in genetic determinism. There are numerous problems with thinking about disability through this lens. I will begin by focusing on two problems related to pre-implantation and prenatal genetic testing. First, genetic testing yields only degrees of likelihood, not certainty, regarding whether or not an embryo or fetus will go on to develop a disease or condition. Evelyn Fox Keller notes that while single-gene disorders such as Tay-Sachs, Huntington's disease, cystic fibrosis, thalassemia, and phenylketonuria are better understood than conditions involving multiple genes, "even in these clear-cut cases much remains to be understood about the processes that link the defective gene to the onset of disease" (2000, 68). Likewise, the degree of severity of a possible condition of a potential child cannot typically be known in advance. One of the reasons that genetic testing cannot provide these answers is that knowledge of genotype is insufficient for predicting phenotype.

Second, in the context of discussions of prenatal genetic testing, PGD, and selective abortion, bioethicists often conceive of limited opportunities and low QOL as necessary consequences of genetic variations. Insofar as this view engages in genetic determinism, it fails to account for phenotypes as interactively constructed by genetic, environmental, and other factors. In *Evolution's Eye: A Systems View of the Biology-Culture Divide*, Oyama states:

Everyone “knows” that *any* phenotype, normal or anomalous, depends on a given set of interactions between a specific set of genes and specific environments. Yet such knowledge does not prevent people from believing that some special executive or formative power resides in the guide of a plan, program, or code. In this view, the genetic potential of the organism is defined by the cellular code (2000, 38).

The formulation of phenotype as a product of interaction between genes and environments may leave out epigenetic factors (Oyama, Griffiths, and Gray 2001, 4; Jablonka 2001, 99-116).

Bioethicists are prone to exhibiting this pattern in their discussions of genetic testing. For example, while it is not uncommon for bioethicists to acknowledge that the environment is relevant for development in the context of discussing selective abortion, they often revert back to speaking about genes as determining not only the phenotype but also the level of QOL and opportunities available to humans with a particular genotype. In sum, claims that posit a direct causal connection from genotype to phenotype to level of opportunities and QOL assume a greatly simplified and misleading account of molecular biology and fail to consider social context.

If one accepts the medical model as an adequate description of disability, de-contextualization of issues related to disability makes sense because this view suggests that all relevant information can be read at the level of an individual body, genotype, or other bodily component. Within discussions of genetic testing and selective abortion, bioethicists who accept this model commonly make claims about opportunities and QOL solely on the basis of genotype. Scully clearly articulates the limitations of extrapolating out from components of a body, such as genes, to the experience of living as a particular embodied subject, in the following:

Its [molecular biology’s] power to provide *descriptions* of the human body in terms of constituent genes and cells is also an inappropriate place to find an account of living *with* or *as* or *in* a particular kind of body. This is an important distinction to keep in mind: since ethics is about living and not chemistry, it is surely accounts of lived experience, and not biomedical description, that should form the basis for morally evaluating types of embodiment (2008, 6).

In discussing the value of life with an atypical genotype, bioethicists are clearly concerned with projected future lived experiences of potential people. They often assume that they can predict what the lived experiences of an individual will be on the basis of the particular genotype or other characteristics of an embryo or fetus. On this basis, bioethicists have found it fitting to make claims about the morality of reproducing when there is a chance that potential offspring may develop in ways that are not species-typical.

The notion that parents have the choice to avoid having children with genetic and other variations challenges the view that impairment is unavoidable in such cases (Denier 2014). Indeed, it has been argued that justice *requires* “genetic interventions” to prevent disability (Buchanan et al. 2013, 287). Because the medical model locates the disadvantages of disability at the level of individuals’ bodies, approaches informed by this model typically endorse use of technology to prevent conception or birth or, failing that, medical interventions to eliminate or reduce the limitations of impairment. The bad-difference view of impairment serves to bolster the case. Bioethicists such as Peter Singer do occasionally suggest that a just society should prohibit discrimination on the basis of disability (impairment), but they tend to fall back into thinking about disabled people as naturally inferior to nondisabled people and to characterize their lives as filled with suffering and lack of opportunities (Singer 1993, 188-189; Brock 2013, 570; Buchanan et al. 2013, 604).

Oyama uses phenylketonuria (PKU) as an example to demonstrate the limitations of genetic reductionism. Those with PKU are unable to process phenylalanine, and the buildup of this amino acid can cause intellectual impairment as well as a number of other symptoms. However, if a child consumes a diet without phenylalanine, he will not develop these symptoms. Oyama notes that the genotype and the diet are both essential in determining the phenotype of a

child with PKU (2000, 37). For this reason, Oyama endorses constructivist interaction, which conceives of ontogeny—the development of individuals—as wholly genetic and wholly environmental; both “cause” the phenotype to develop in a particular way. Thus, it does not make sense to say that a biomedical condition (including those considered “normal” or species-typical) is genetic *or* environmental because it is always inextricably both. As Keller points out, “a cell’s DNA is always and necessarily embedded in an immensely complex and entangled system of interacting resources that are, collectively, what give rise to the development of traits” (2005, 51). Even if certainty regarding the severity of a so-called genetic disease could be ascertained in advance, the environment within and beyond an individual’s body—including social context—is an essential aspect of an individual’s level of opportunities and QOL.

Since it is not possible to predict, prior to birth, the phenotype, much less the quality of an individual’s life, solely on the basis of genetic or other information obtained through PGD and prenatal testing, it seems clear that it is a mistake to frame ethical debates on PGD, prenatal testing, and selective abortion as if this is possible. Yet, as I will show, this is the approach many bioethicists take. In addition, the question of the subjective experience of living with a particular condition is an empirical rather than a conceptual question. It would seem that, in many cases, the best way to develop knowledge regarding the lived experiences of people with a particular condition would be to *ask* those living with that condition, when possible. However, bioethicists are much more likely to advocate relying on moral imagination, in which the reader is asked to imaginatively take on the perspective of a disabled person (or even a fetus likely to develop into a child with an impairment) than this approach (Singer 2006; Hare 2006).¹⁵

If disabled people’s lives are imaginatively reduced to limitation and suffering, it is easy to understand why genetic testing and selective abortion have been seen as averting unnecessary

¹⁵ The problems inherent in this approach will be developed in chapter two.

pain by preventing the existence of individuals with impairments and serving the interest of societal progress. A particular misguided interpretation of evolution may be perceived as providing support for this position. As Oyama states, “Evolution, or natural selection, with which evolution is too often identified, is frequently depicted as an agent that continuously scrutinizes organisms in order to identify those best suited to life” (Oyama 2000, 10). Indeed, this is the understanding of evolution that seems to inform some bioethicists’ and others’ thinking about genetic testing and selective abortion, in spite of efforts to distance themselves from eugenics through emphasis on personal choice and inclusion¹⁶ (Savulescu 2001, 424; Davis 2013, Buchanan et al. 2014). It is not accidental that “selective abortion” has resonance with “natural selection,” and many assume that we are able to and should use technology to “optimize” reproductive outcomes through identification of “those best suited to life” and selecting against those “at risk” of developing a congenital illness or impairment (Oyama 2000, 10). This approach is also framed as a preventative measure to ensure that children whose lives, it is imagined, will be filled with suffering and lack of opportunities are not brought into the world. The view that there is a parental responsibility to select “those best suited to life,” formulated in a variety of ways, undergirds the positions articulated in several of the articles that will be considered in the following section.

Section one has detailed three types of unacknowledged and unexamined assumptions that tend to be adopted by bioethicists in their discussions of disability as well as problems with and alternatives to these assumptions. I have also engaged in a preliminary exposition of how the

¹⁶ In “Genetic Intervention and the Morality of Inclusion,” Buchanan et al. state:

Surely the difference between the old eugenics and the new genetics is unmistakable: The former was particularistic and exclusionary, condemning as defective all those who failed to meet supposed criteria of racial purity or human perfection; the latter is universalistic and inclusive, seeking to prevent suffering for all of humanity through eradication of genetic disease (2014, 281).

medical model, bad-difference views of impairment, and genetic determinism coincide within discussions of genetic testing and selective abortion. In the following section, I will examine several articles within biomedical ethics textbooks in order to elucidate ways that these and opposing assumptions shape the authors' positions on the relationship between genotype, level of opportunities, and QOL, which frames their discussions of both selective abortion and genetic testing (Savulescu 2001; Brock 2013; Buchanan et al. 2013; Davis 2013; McMahan 2013; Purdy 2013; Buchanan et al. 2014). Those whose positions are in line with the medical model need not adopt the bad-difference view of impairment or engage in genetic determinism, but, in the context of discussions about PGD, prenatal testing, and selective abortion, they often do.

1.2 Survey of Articles on PGD, Prenatal Testing, and Selective Abortion in Biomedical Ethics Anthologies

Anita Ho's 2007 article "Disability in the Bioethics Curriculum" surveys seven biomedical ethics textbooks in order to examine how the authors approach disability in the context of the topics of genetic testing, euthanasia, and physician-assisted suicide. While noting that philosophy anthologies generally are slowly beginning to include the voices of women and ethnic minorities, Ho contends that perspectives of disabled people still tend to be excluded, even when disability is central to the discussion. Regarding the articles in the biomedical ethics textbooks she examined, she states that they "all represent a particular viewpoint—one that sees disability as inherently and unrelentingly barring attainment of a good life" (2007, 406). She concludes that, "They continue to adopt the ableist presumption that life with impairment is inherently inferior to one without impairment" (2007, 405). Ho characterizes an ableist society as assigning "lower value or worth to people based on their bio-physical and mental impairments" (2007, 405). Although there is a growing body of literature related to biomedical ethics challenging ableist

narratives,¹⁷ the biomedical ethics textbooks Ho examined seldom provided resources for thinking critically about disability.

Given the frequency with which new editions of biomedical ethics textbooks are issued and the increasing presence of disability rights perspectives within journal articles and monographs, it is worth finding out if there has been a change in representation of perspectives on disability since Ho's article was published in 2007. In the remainder of this chapter, I examine articles on PGD, genetic and other types of prenatal testing, and selective abortion reprinted in six biomedical ethics textbooks published between 2010-2014.¹⁸ This survey is limited in scope, and I do not claim that it is necessarily a representative sample; these texts were chosen from a number of textbooks that I had considered adopting for my biomedical ethics courses. Textbooks were excluded from this survey if they did not cover the topics under consideration or if they had a single author. Seventeen articles focused on these topics; four of these articles were reprinted twice (Asch 2013, 2014; Davis 2010, 2013; Kass 2011, 2013; Purdy 2011, 2013). Ten of the articles are clearly in line with the medical model, three adopt the social model, and four contain elements of both. Some of the authors who assume the correctness of the medical model engage with disability rights critiques; however, they tend to focus on extreme versions of the social model rather than more commonly held views and to equate mere-difference and good difference views of impairment (McMahan 2013; Steinbock 2013; Buchanan et al. 2014).

Although prenatal genetic testing is not the only type of prenatal testing available, it is the main focus in the articles discussed here. Ten of the seventeen articles focused solely on

¹⁷ Here are a few examples of authors who have published on these topics who adopt a disability rights perspective: Amundson 2005; Asch 2005; Barnes 2014; Barnes 2016; Bickenbach, Felder, and Schmitz 2014; Kittay 2002; 2010; 2011; Ouellette 2013; Parens 1998; Silvers 1998; 2005, Scully 2008; Stramondo 2011; and Wendell 1997.

¹⁸ Beauchamp, Walters, Kahn, and Mastroianni 2014; DeGrazia, Mappes, and Brand-Ballard 2011; Holland 2012; Pierce and Randels 2010; Steinbock, London, and Arras 2013; Vaughn 2013.

preconception, pre-implantation, and/or prenatal genetic testing (Robertson 2010; Savulescu 2012; Brock 2013; Buchanan et al. 2013; Davis 2013; Purdy 2013; Buchanan et al. 2014; Denier 2014).¹⁹ In a number of the articles, implicit or explicit endorsement of genetic determinism, the bad-difference view of impairment, and the medical model underlie the claim that there is a moral obligation to prevent the birth of children with impairments. In contrast, the articles that reject genetic determinism and subscribe to the mere-difference view of impairment and the social model are concerned with ways that the stigmatization of impairment and mistaken assumptions about disability influence decisions regarding prenatal testing and selective abortion. The following sub-sections will clarify the assumptions made in these articles and provide critical analysis.

1.2.1 Theme One: The parental obligation to maximize opportunity and QOL

The authors I will discuss in this section assume that it is possible to know ahead of time what level of opportunities will be available to potential children on the basis of genetic testing. They further assume that the number of opportunities available to a person determine quality of life. Since the authors considered here combine these assumptions with the view that parents have a moral obligation to provide their children with a certain QOL, this informs their positions on how preconception and prenatal genetic testing ought to be employed.

In “Procreative Beneficence: Why We Should Select the Best Children” (originally published in 2001, reprinted in Holland 2012) Julian Savulescu contends that there is a parental

¹⁹ As Lippman observes, “Though it is only one conceptual model, ‘genetics’ is increasingly identified as *the* way to reveal and explain health and disease, normality and abnormality” (1991, 18). Asch’s “Prenatal Diagnosis and Selective Abortion” is one of the exceptions. She notes that a number of fetuses have been surgically operated on to repair atypical neural tube development in order to prevent the development of myelomeningoceles (2012, 59-60). This is a condition that is diagnosed through the use of one or a combination of: a maternal serum alpha-fetoprotein test, ultrasound, and amniocentesis, rather than genetic testing, since it does not have a genetic basis.

responsibility to have offspring with the “best genes.” His argument clearly exhibits genetic determinism. Savulescu primarily focuses on pre-implantation genetic diagnosis (PGD), a type of genetic testing women using in vitro fertilization (IVF) may employ in order to find out the genotype of embryos prior to implantation. He summarizes his argument as follows:

(1) some non-disease genes affect the likelihood of us living the best life; (2) we have a reason to use information which is available about such genes in our reproductive decision-making; (3) couples should select the embryos or fetuses which are most likely to have the best life, based on available genetic information, including information about non-disease genes [italics in original] (2001, 413).

As the quotation makes clear, Savulescu contends that genetic testing should not be limited to identifying what he calls “disease genes” because, on his account, other types of genes have a significant influence on an individual’s level of well-being. He assumes that “disease genes” or genes related to impairment, reduce QOL—the medical model, a bad-difference view of impairment, and genetic determinism are all at play here. As a result, Savulescu considers it to be an obvious moral imperative that if a woman uses IVF, she (perhaps in consultation with a partner) should select embryos without genes that may contribute to disease or impairment. Here his approach is to show that the moral imperative should be expanded beyond selecting against embryos with “disease genes” to selecting embryos with the “best” genotype (i.e., genes he supposes will contribute to desired behaviors, characteristics, and abilities such as an above average level of memory and intelligence). Enhancement is construed as unequivocally good insofar as Savulescu assumes that it contributes to well-being. He thinks it is only a matter of time before behavioral genetics will be able to identify genes that predispose individuals to “criminal behaviour,” “maternal behaviour,” and homosexuality as well as those that impact memory and intelligence (2001, 417).²⁰ Regarding intelligence, Savulescu acknowledges that it may turn out that there is only a “weak probabilistic relation between genes and intelligence”

²⁰ Savulescu claims, “a gene has been identified for criminal behaviour in one family” (2001, 413).

(414). Nonetheless, he contends that there is a parental moral responsibility to obtain information from whatever genetic tests are available in order to have offspring likely to have the “best life.”

Savulescu assumes that it is possible to know which potential child is likely to have the “best life” solely on the basis of genotype. There is slippage from “expected to have the best life” to the “best children,” in the title of the article. He characterizes the “best life” as the one “with the most well-being,” noting that he does not want to restrict his conception to health-related well-being (2001, 419). He provides some clues as to what he has in mind through his examples of intelligence and memory. He claims that whether a hedonistic, desire-fulfillment, or objective list account is adopted, intelligence is necessary for evaluating and making choices that will enable one to have the best life (421). In regard to memory, he points out that, “Failing to remember can have disastrous consequences. Indeed, forgetting the compass on a long bush walk can be fatal” (420). Thus, he concludes that there is an obligation to select embryos *ceteris paribus* with the “best” genotype in regard to intelligence and memory when (if) this becomes possible.

Like Savulescu, John Robertson is primarily concerned with the moral status of using PGD to select for particular traits rather than against potential disease and impairment in “Extending Preimplantation Genetic Diagnosis: Medical and Non-Medical Uses” (in Pierce and Randels 2010). Both articles have implications for thinking about impairment. Though they have similar concerns, their assumptions and approaches differ. For example, unlike Savulescu, Robertson claims that it is unlikely that it will be possible to use PGD to select for traits such as intelligence, sexual orientation, and memory. He states, “Because the genetic basis of those traits is unknown, and in any case is likely to involve many different genes, they may not be subject to easy mutational analysis, as Mendelian disease or susceptibility conditions are” (2010, 648).

Robertson adds, “Aside from gender [chromosome type], which is identifiable through karyotyping, it is unrealistic to think that non-medical screening for other traits, with the possible exception of perfect pitch, will occur anytime soon” (648-649). He lays out five types of concerns that must be addressed in order to evaluate the permissibility of using PGD to select for or against a trait and then uses selection for sex and perfect pitch as test cases.

1. How important is “the reproductive choice being asserted”? (649)
2. Is it justified to create and to destroy embryos in order to serve this choice?
3. Will resulting offspring be harmed as a result? (649)
4. Will selecting for/against a trait contribute to the stigmatization of existing persons? (649)
5. What are the potential implications for society? (650)

In Robertson’s discussion of the use of PGD for sex selection, he notes that it is controversial “because of the bias against females which it usually reflects or expresses, and the resulting social disruptions which it might cause” (649). He states that it “may reinforce entrenched sexism toward women” (649). This is a problem in regard to questions 1, 4, and 5. However, Robertson asserts that the motivations and effects of selecting for male offspring differs in the case of first born children in contrast to selecting for a particular sex in later children in order to have a “balance” of male and female children (649). In the first case, he thinks it is more likely to express and reinforce sexism as well as to create disparities in the sex ratio within the population, which is already a problem as a result of selective abortion in India and China (649). In the second case, Robertson thinks there are motivations and effects other than sexism. For him, the remaining question is whether or not a desire for a child of a particular sex is a strong enough justification to create and to destroy embryos.

Robertson then turns to examining the case of selecting for perfect pitch, “the ability to identify and recall musical notes from memory” (2010, 650). While the genes or gene coding have not yet been mapped or sequenced for this trait, he thinks it is feasible that they could be.

Robertson suggests that the desire for children with perfect pitch could be strong within “highly musical families,” especially if other family members have perfect pitch. Regarding question 1, he states, “Parents clearly have the right to instill or develop a child’s musical ability after birth. They might reasonably argue that they should have that right before birth as well” (650). On question 2, Robertson asserts that the judgment of whether or not the desire for offspring with perfect pitch justifies creating and destroying embryos rests with the couple [or individual]. On the question of potential harm to children resulting from selection, he contends that as long as the child is not prevented from developing interests and abilities other than music, the parental investment in having a child with perfect pitch is unlikely to cause harm. Since not having perfect pitch is not stigmatized, Robertson thinks that this case fares well on question 4. He raises a concern regarding question 5 that using PGD to select for perfect pitch would set a problematic precedent, making it more likely that screening for other traits would be seen as acceptable and “moving us toward a future in which children are primarily valued according to the attractiveness of their expected characteristics” (651). Robertson concludes that this worry is too hypothetical to justify limiting parental choice.

Although Robertson focuses on the use of PGD for sex selection and potential use to select for perfect pitch, the questions he raises are relevant for considering the use of PGD to decrease or increase the likelihood of the birth of children with impairments. He is concerned about the possibility that selecting for/against a trait may contribute to the stigmatization of existing persons as well as broader implications for society as a whole. He does not assume that genetic information is sufficient to predict the opportunity of QOL of potential children. In these ways, his approach differs from Savulescu as well as many of the other authors that will be discussed here.

Like Savulescu, Laura Purdy emphasizes parental responsibility to avoid the birth of children who may develop impairments or diseases, and she assumes that it is possible to predict the QOL of potential children on the basis of genetic information. In “Genetic and Reproductive Risk: Can Having Children Be Immoral?” (reprinted in DeGrazia, Mappes, and Brand-Ballard 2011; Vaughn 2013) Purdy contends that, “it is morally wrong to reproduce when we know there is a high risk of transmitting a serious disease or defect (2013, 544).”

Purdy uses Huntington’s disease (HD) as an example, but her argument has much broader application. Thus, it is important to go beyond this example in order to consider her overall argument, which is as follows:

Premise 1: Parents ought to try to provide their children with a minimally satisfying life.

Premise 2: A minimally satisfying life requires normal health.

Implicit: Parents ought to ensure that their children have normal health.

Implicit: Lack of normal health entails that one is unable to have a minimally satisfying life.

Implicit: It is better not to exist than to lack a minimally satisfying life.

Implicit sub-conclusion: It is better not to exist than to be born without normal health.

Therefore, it is immoral to have children who will lack normal health (2013, 546).

For the sake of argument, let us assume that premise 1 is true. Should premise 2 be accepted?

Dominant narratives regarding health and disability would suggest that it should, but this premise is actually highly controversial.²¹ Of course, if this premise is called into question or rejected, then the implicit premises and sub-conclusion as well as the conclusion lack sufficient support.

In assuming that normal health is required for a minimally satisfying life, she conceives of health, which can purportedly be predicted through genetic testing, as determinative of QOL.

Throughout most of the essay, Purdy uses *lack of normal health* and *serious disease or defect* interchangeably. However, she does assert that, in spite of substantial agreement to the

²¹ Though the categories of disease, disability (“impairment” in the terms of the social model), and lack of normal health are not necessarily equivalent, there is overlap between these categories. Some diseases themselves are classified as impairments, while others can lead to or increase functional limitations. For further discussion see Michael Oliver, *The Politics of Disablement*; Susan Wendell, “Unhealthy Disabled: Treating Chronic Illnesses as Disabilities,” 161-176.

contrary, abortion may be justified even in cases of “relatively trivial problems” because “lesser defects can cause great suffering,” (2013, 544; 548n6). This statement implies that physical “defects” themselves, including cosmetic ones, cause great suffering. She further suggests that aborting a fetus in favor of conceiving and carrying to term a normal fetus in such cases is warranted because the goal is to “bring those with better prospects into existence, instead of those with worse ones” (2013, 546). The assumption that genetic testing can predict the prospects of potential children is central within the majority of the articles discussed here that align with the medical model, a bad-difference view of impairment, and genetic determinism. In this particular case, lack of normal health or typical appearance is thought to be sufficient to reduce opportunities and preclude a minimally satisfying life.

Taking a similar approach, in “Genetic Dilemmas and the Child’s Right to an Open Future” Dena Davis considers whether or not it is a harm to intentionally increase the likelihood of having D/deaf children (reprinted in Pierce and Randels 2010; Vaughn 2013).²² She is primarily concerned with the question of whether or not it would be moral for genetic counselors to assist D/deaf clients in having D/deaf children.²³ She contends that genetic counselors should not help clients to have D/deaf children because it is a harm to be D/deaf. She bases this conclusion on the claim that being D/deaf limits one’s possibilities. Davis considers the preference for a D/deaf child to be irresponsible and based on self-serving motives such as having a child that is able to fully be a part of the family and the Deaf community.

Davis proposes that we should adopt Joel Feinberg’s notion of “the child’s right to an open future” to assess the moral status of genetic counselors in assisting women in having D/deaf

²² I use “D/deaf” here as a way to indicate the contested status of deafness as an impairment versus Deafness as a culture.

²³ The widely publicized case of Sharon Duchesneau and Candace McCullough, a D/deaf lesbian couple that used sperm from a donor with a heritable form of deafness to increase the likelihood of having D/deaf children did not involve a genetic counselor (Scully 2008, 60).

children (2013, 556). This right is comprised of what Feinberg calls “rights-in-trust,” which are to be preserved for children to exercise when they are older. Davis provides the example of the right to reproduce; although this right cannot be robustly asserted until adulthood, it would be wrong for parents to have their children sterilized on this account. In sum, rights-in-trust “can be violated by adults now, in ways that cut off the possibility that the child, when it achieves adulthood, can exercise them” (2013, 555). Although she states that it is a fraught approach to oppose parental autonomy to concerns about the QOL of their potential children, her use of the right to an open future does, ultimately, pit these against each other. Though Davis frames her argument in terms of the future autonomy of potential children, her application of the notion of the right to an open future entails the assumption that a high quantity of options is a necessary condition for children to develop into adults with a high QOL. She claims that parental action taken in the attempt to have a particular kind of child puts limits on that child’s future by reducing the number of options open to him or her.²⁴ This, in turn, results in a low QOL. That is why she considers it to be morally wrong for genetic counselors to assist clients in having D/deaf children.

In “The Non-Identity Problem and Genetic Harms” Dan Brock notes that most genetic risks that can be detected through preconception and prenatal screening are “compatible with having a life worth living” (2013, 568). His concern is to be able to articulate the wrong that is done by bringing disabled children into existence in spite of the fact that most are better off than if they had not been born. Brock posits what he terms a “non person-affecting principle” that, “It

²⁴ Purdy contends that use of PGD for sex selection to achieve “balance” in family composition ought to be discouraged because parents are likely to have expectations that are likely to allow for the child to pursue his or her own interests (2013, 562). Her position differs from that of Robertson on this matter. He does not think that potential parents’ willingness to use PDG in the attempt to have a child with perfect pitch is significantly different from other ways they could play a role in a child’s development. He suggests that parents who are heavily invested in having a child with perfect pitch may still encourage their child to be well-rounded.

is morally good to act in a way that results in less suffering and less limited opportunity in the world” (2013, 570). When applied to the question of genetic testing in order to avoid having a disabled child, he claims, “a couple acts in a morally good way by taking steps not to have a child *whom they learn from genetic screening will experience suffering and limited opportunity* that another child they could have instead would not experience [emphasis added]” (570). Like most of the previous authors discussed here, Brock explicitly assumes the medical model, a bad-difference view of impairment, and that it is possible to know on the basis of genetic screening whether or not a potential child will experience suffering and limited opportunity.

On the same basis as Purdy, Davis, and Brock, Buchanan et al. state in “Genetic Intervention and the Morality of Inclusion” (reprinted in Beauchamp et al. 2014):

[We] have argued [elsewhere] that there can be obligations of justice, as well as obligations to prevent harm, that require genetic interventions. From this perspective, we are committed to the judgment that in the future the world should not include so many disabilities and hence so many individuals with disabilities. But it is not the people with disabilities that we disvalue; it is the disabilities themselves (Buchanan et al. 2014, 287).

The distinction between impairments and people with impairments can be a very useful one, which makes it possible to distinguish between effects of impairment that may be undesirable and the overall life of the person with that impairment, which may be highly satisfying. However, Buchanan et al. are not consistent in making this distinction when discussing potential children, as evidenced in the following remark regarding “wrongful life cases”: “[a]borting a fetus found during the first two trimesters to have a disease that *would make life a burden to the child* prevents the creation of a person with a life not worth living [emphasis added]” (2013, 603).²⁵ If the goal is to reduce the number of impairments, in the context of discussing genetic prenatal testing and selective this distinction may lose its force when the only means suggested for

²⁵ Though they were reprinted in different textbooks in different years, these quotations are both excerpted from Buchanan et al. 2000.

preventing impairment is through preventing the birth of people who might develop impairments.²⁶²⁷

In addition, Buchanan et al. focus on genetic interventions alone, rather than including what Lippman terms “low technology” approaches to reducing the incidence of impairment and infant mortality such as “providing essential nutritional, social, and other supportive services” (1991, 25). While it may, *prima facie*, seem feasible and praiseworthy to attempt to reduce the number of impairments in the world, this discussion ignores non-genetic causes of impairment as well as the fact that medical technology including ventilators and antibiotics have made it possible for people with impairments to live much longer lives than were previously possible, increasing, in a sense, the number of impairments rather than reducing it.²⁸

Buchanan et al. do not think there is a moral distinction between forms of genetic intervention including gene therapy that might be developed in the future, avoiding conception if genetic testing indicates a risk of having a child with an atypical genetic make-up, and selective

²⁶ They add:

We hope that our analysis so far makes it clear why we believe that there are some cases, albeit very few, in which it would be clearly and seriously morally wrong for individuals to risk conceiving and having such a child. However, use of government power to force an abortion on an unwilling woman would be so deeply invasive of her reproductive freedom, bodily integrity, and right to decide about her own health care as to be *virtually never morally justified*. Allowing the child to be born and then withholding life support even over its parents’ objections would probably be morally preferable. The government’s doing this forcibly and over the parents’ objections would be extraordinarily controversial, both morally and legally, but in true cases of wrongful life, the wrong done is sufficiently serious as to possibly justify doing so in an individual case [emphasis added] (Buchanan et al 2013, 603).

²⁷ In “Implications of Prenatal Diagnosis for the Human Right to Life” Leon Kass pointedly asks in regard to selective abortion, “in the case of what other disease does preventative medicine consist in the elimination of the patient-at-risk?” (2013, 541). Of course, in calling a fetus a “patient,” Kass introduces language that is likely to be controversial, but, setting that aside, it is still possible to appreciate the point that in some cases the only “preventative measure” currently available is abortion.

²⁸ As Kass puts it, “The existence of ‘defectives’ cannot be fully prevented, not even by totalitarian breeding and weeding programs” (2013, 541). Lennard Davis observes, “medical advances have kept people alive who otherwise would have died from their disabilities. This increase in the numbers of the disabled is particularly notable in the case of premature babies, those with spinal cord injuries, and older people with debilitating conditions” (1995, 8).

abortion. They claim that the same motivation is likely to inform these interventions: “the desire not to bring into the world an individual with seriously limited opportunities” even if that individual’s life would be worth living (2014, 287). Buchanan et al. assume that impairments greatly limit opportunities, even if they do not necessarily reduce QOL to the point that a person’s life is not worth living. Since their approach is informed by genetic determinism, and they do not adequately consider the impact of the social context, these authors remain fixated on genetic interventions to prevent impairment and limited opportunity. Because, on their account, disabilities reduce opportunities, “justice—and more specifically, equal opportunity as one component of justice—sometimes requires genetic intervention to prevent disabilities” (2014, 284). This claim seems sensible if we assume that impairments inevitably seriously limit opportunities, that this situation is unjust, and that genetic intervention, including selective abortion, is the only way to prevent limitations of opportunities.

So far, I have discussed the assumptions of Savulescu, Purdy, Davis, Brock, and Buchanan et al. that it is possible to predict opportunities and QOL on the basis of genetic testing and that there is a parental responsibility to ensure that their children have a high level of opportunities and QOL. This responsibility means that potential parents should prevent the birth of children likely to have less than the best genes (Savulescu), normal health and appearance (Purdy), and ability to hear (Davis) in order to make sure that they don’t have children with limited opportunities or reduced QOL in comparison to nondisabled children. However, each of these authors notes, to an extent, the possibility that social factors can also limit opportunities. I now turn to a discussion of their perspectives on the relationship (or lack thereof) between limitations assumed to result from genetic variation and reductions in opportunities as a consequence of social arrangements.

1.2.2 Theme two: Bad-difference views of impairment decontextualize “genetic-choices”

Some of these authors whose assumptions are in line with the medical model note that unjust discrimination against disabled people is a problem but suggest this is all but irrelevant for discussing genetic testing and selective abortion because they endorse a bad-difference view of impairment. Thus, the disadvantages of impairment itself are thought to be sufficient reason to prevent the birth of children likely to develop impairments, regardless of the social context (Savulescu 2001; Brock 2013; Buchanan et al. 2013, 2014; Davis 2013; McMahan 2013). On this view, changing discriminatory social institutions is a separate issue from that of potential parents making reproductive choices on the basis of genotype. While the issue of social pressure to obtain genetic testing and select against embryos or fetuses that may develop into children with impairments is not addressed, Buchanan et al. do mention that public funding may be required so that all women have access to these prenatal testing and selective abortion (2013, 603).

In regard to the question of the impact of discrimination on the opportunities of members of marginalized social groups, Savulescu contends that even if it serves to reinforce inequality, couples or individuals should use PGD to select embryos with the “best” genetic profile. He states that, “there are other avenues to correct inequality than encouraging or forcing people to have children with disabilities or lives of restricted genetic opportunity” (2001, 424). While he acknowledges that social inequality may limit opportunities, Savulescu implies that genes themselves limit opportunities, and he claims that it is wrong even to encourage people to have children with less than the “best” genes. In sum, for Savulescu, the “best” genes produce the “best” children and the highest QOL, and the context is irrelevant to the parental imperative to choose to have these children.

Purdy notes that, “There are many causes of misery in this world, and most of them are unrelated to genetic disease. In the general scheme of things, human misery is most efficiently reduced by concentrating on noxious social and political arrangements” (2013, 543). This may seem like a statement informed by the social model of disability. However, Purdy does not consider how noxious social and political arrangements may create disadvantages for those with genetic diseases. Her position is in line with the medical model insofar as her focus is on the individual, and she assumes that lack of normal health itself is the sole cause of disadvantages and suffering. She does not consider ways that societal attitudes toward those with atypical features may contribute to or even be the sole cause of any suffering associated with these features. It is clear that she thinks there is a divide between misery caused by genetic diseases in contrast to misery caused by social and political arrangements and that there is a moral duty to avoid having children at risk for genetic diseases. Purdy assumes that it is possible to predict QOL on the basis of genetic variation, and she does not consider social context, except to contrast social and political arrangements with genetic diseases as sources of misery.²⁹

Davis demonstrates awareness of the social factors that impact D/deaf people. After stating that, “deafness is a very serious disability,” she cites a dismal statistic on the income disparity between D/deaf and hearing people³⁰ and the insufficient education most D/deaf people receive (2013, 560). While not being able to hear in the context of living in a social environment that assumes the ability to hear and does not encourage hearing people to learn sign language may lead to disadvantages, Davis does not explain how it is that deafness itself leads to low wages and inadequate educational opportunities. She notes that hearing parents typically do not

²⁹ In her claim that selective abortion may be warranted in cases in which the fetus is likely to develop relatively trivial problems due to the suffering and reduction of prospects they cause, Purdy endorses and even extends the standard view that impairment greatly reduces QOL (2013, 544; 548n6).

³⁰ She cites the statistic that, “Deaf people have incomes thirty to forty percent below the national average” (Davis 2013, 560). This figure is attributed to Groce 1985, 85.

expect to have a child who cannot hear and may not obtain the correct diagnosis for months or even years. Subsequently, they may be unprepared to raise and educate their child (2013, 560). Of course, these are not the circumstances of hypothetical D/deaf children who could be selected for with the assistance of genetic counselors because, to date, the potential parents have themselves been D/deaf. Yet, Davis' argument assumes that D/deaf people inevitably have much more limited opportunities than hearing people. In this way, her position assumes the correctness of the medical model of disability. In response to the question of whether D/deafness constitutes harm, Davis replies:

If deafness is considered a disability, one that substantially narrows a child's career, marriage, and cultural options in the future, then deliberately creating a deaf child counts as a moral harm. If Deafness is considered a culture, as Deaf activists would have us agree, then deliberately creating a Deaf child who will have only very limited options to move outside of that culture, also counts as a moral harm (2013, 561).

Clearly, she is correct that there are some careers and ways of participating in culture that require the ability to hear. Interestingly, few of these assumed limitations are a direct effect of not being able to hear.

In spite of her acknowledgement that selecting for D/deafness is a "same number choice" rather than a "same person choice," Davis maintains that parents harm their children if they do so (2013, 559). To clarify this point: a single child would be (or not be) brought into existence in contrast to a child with different possible characteristics. In this case, a D/deaf child brought into existence with the assistance of a genetic counselor is a child that would not otherwise have been born (same number) rather than a child that would otherwise be able to hear (same person). Davis focuses on instances in which potential parents seek to have a D/deaf child; she does not address whether or not women or couples have a moral obligation to use PGD, prenatal testing, and selective abortion in the attempt to prevent the birth of D/deaf children.

Thus far, the authors discussed have focused on the choices and responsibilities of individuals—potential parents and genetic counselors—in relation to genetic testing and selective abortion. Though these authors acknowledge that unjust discrimination sometimes limits opportunities, they continue to focus on the reduced opportunities and QOL thought to result from impairment itself.

1.2.3 Theme three: Social context and responsibility, informed choices, and QOL

In the following, I will discuss the articles that unequivocally adopt the social model of disability and a mere-difference view of impairment. They are “The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations” by Erik Parens and Adrienne Asch (reprinted in Holland 2012) and “Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy” (reprinted in Steinbock, London, and Arras 2013; Beauchamp, Walters, Kahn and Mastroianni 2014).

Rather than focusing on genetic interventions, social theorists of disability point to social constraints on potential and actual parents of disabled children such as the lack of resources available to parents raising disabled children, stigmatization of impairment, and the pressure women face to abort fetuses likely to develop into children with impairments. The authors I have discussed whose positions are in line with the medical model and a bad-difference view of impairment do not consider the perspectives of pregnant women, much less engage with the views of disabled people or disability rights advocates.

In her discussion of prenatal testing—including ultrasound, maternal serum α -feto-protein screening, chorionic villus sampling, and amniocentesis—Asch notes:

These tests, which are widely accepted in the field of bioethics and by clinicians, public health professionals, and the general public, have nonetheless occasioned some apprehension and concern among students of women’s reproductive experiences, who

find that women do not uniformly welcome the expectation that they will undergo prenatal testing or the prospect of making decisions depending on the test results. Less often discussed by clinicians is the view, expressed by a growing number of individuals, that the technology is itself based on erroneous assumptions about the adverse impact of disability on life (2013, 610).

Asch claims that public health should consider the ways that social and economic factors “pose obstacles to health and health care” for disabled people as it does when considering disadvantages on the basis of race, sex, and sexual orientation rather than narrowly focusing on medical interventions (2013, 610). She states that it is due to this focus that “it appears natural to use prenatal testing and abortion as one more means of minimizing the incidence of disability” (2013, 610). Asch suggests that the difference between race, sex, and sexual orientation and disability is that the former characteristics are generally thought to be compatible with a rewarding life, while the latter is not (2013, 610).

Asch asserts that it makes sense that healthcare professionals are “especially attuned to the problems and hardships that affect the lives of their patients” (2013, 611). Healthcare professionals encounter patients while they are experiencing the effects of “acute illness or sudden injury” as well as those who have congenital conditions or acquired ones to which they have adjusted (2013, 611). Asch claims that it is easy for healthcare professionals as well as bioethicists to mistakenly assume that “the life of a person with a chronic illness or disability is forever disrupted, as one’s life might be temporarily disrupted as a result of a back spasm, an episode of pneumonia, or a broken leg” (2013, 611). However, the experiences of many disabled people and people affected by chronic illnesses belie this view. While Asch maintains that the fields of medicine and bioethics tend to show adequate concern regarding the physical and psychological effects of medical crises on patients and their families, she finds it highly

problematic to think of all impairments and illnesses in this way. Once again, we encounter a clash between bad-difference and mere-difference views of impairment.

Like Asch, Yvonne Denier is concerned with the context in which potential parents use prenatal testing and make decisions regarding whether or not to have children with impairments. In “From Brute Luck to Option Luck? On Genetics, Justice, and Moral Responsibility” (reprinted in Beauchamp et al, 2014) she argues that use of prenatal genetic diagnosis as an example demonstrates that the luck egalitarian approach is disrespectful of individual choice and that what it posits as justice is actually unjust. To illustrate, she notes that Buchanan et al. claim that through genetic interventions, what was formerly a matter of good or bad fortune is now possible to control, which brings “genetic endowments” into the realm of justice (Denier 2014, 175).

Denier seems to assume the bad-difference view of impairment and vacillates between the medical and social model of disability. For example, she refers to “genetically based disadvantage,” but she also claims that justice requires society to provide support for disabled people in the form of accessibility and basic goods such as education (175, 181).³¹ Denier is attentive to the pressure potential parents may feel to avoid having children with impairments due to the societal view that disabled people are a “drain on social resources” (175). She suggests that “genetically responsible parenthood” conceptualizes responsibility in a flawed way insofar as it incorporates a hegemonic view of the good life and moral convictions (176). This application of option luck, whereby potential parents “willingly take a risk in the full knowledge

³¹ She also states, “Our genetic identity—who we and our children are—has long been a paradigm of nature’s responsibility and not ours, and a substantial shift of that determination to the sphere of our own responsibility destabilizes much of our conventional morality” (Denier 2014, 179-180). The assumption here seems to be that nature previously determined who we are and our children were, but through genetic interventions we are able to subvert nature’s ability to determine this.

of its possible consequences” demands parents expend their own resources to raise a disabled child as a penalty if they refuse to obtain prenatal genetic testing and/or refuse to abort based on the results (173; 176). In this case, caring for a disabled child may be characterized under “the class of *voluntary expensive tastes* for which people are supposed to take full individual responsibility” (179).

Denier suggests an alternative way of thinking about responsibility whereby prenatal genetic testing is used to help parents to prepare for a child with a disease or impairment in line with their own view of the good life and moral convictions with the knowledge that they can depend on society to fulfill its responsibility to provide necessary resources (178). She contends that is only when this is realized that prospective parents will be able to make a “free and responsible choice” about whether or not to give birth to a disabled child (178).

Though there are differences in their views of impairment and level of commitment to the social model, Denier and Asch agree that practices surrounding genetic testing and selective abortion can be done in ways that limit or enable informed choices. Asch states, “this article assumes a pro-choice perspective but suggests that unreflective uses of testing could diminish, rather than expand, women’s choices” (2013, 610). Her primary focus is on advocating that, if we as a society insist on the practices of prenatal genetic testing and selective abortion, then health care professionals need to improve on how they provide information about “predictable difficulties, supports, and life events associated with a disabling condition to consider how a child’s disability would fit into their own hopes for parenthood” (2013, 616). More specifically, she suggests that to engage in responsible practice, health care professionals should provide potential parents:

information about the services to benefit children with specific disabilities in a particular area, and about which of these a child and family are likely to need immediately after

birth; contact information for a parent-group representative; and contact information for a member of a disability rights group or independent living center (617).

To be clear, Asch herself opposes prenatal testing and selective abortion, but she thinks it is possible to provide such options in ways that allow potential parents to make informed decisions.

Parens and Asch explain that some disability rights critics are concerned that “[r]ather than improving the medical or social situation of today’s or tomorrow’s disabled citizens, prenatal diagnosis reinforces the medical model’s view that disability itself, not societal discrimination against people with disabilities, is the problem to be solved” (2012, 60). Parens and Asch state, “living with disabling traits need not be detrimental either to an individual’s prospects of leading a worthwhile life, or to families as they grow up, or to society at large” (2012, 60). While acknowledging that impairments themselves *may* cause pain and disadvantages, Parens and Asch think it is wrongheaded to attempt to prevent the birth of children that may have impairments on the assumption that they are unlikely to have worthwhile lives.

In section two, I surveyed a number of articles reprinted in six biomedical ethics anthologies in order to show how influential the medical model remains within discussions of QOL in the context of PGD, prenatal testing, and selective abortion. I have highlighted the tendency of these authors to adopt genetic determinism in their assessments of the implications of genetic variation for potential children’s opportunities and QOL. Conversely, those who endorse the social model deny that genetic variation and impairment necessarily reduce opportunities or QOL, while drawing attention to ways that social obstacles do.

1.3 Conclusion

In this chapter, I have focused on ways that bioethicists characterize disability. I detailed three types of epistemic and ontological assumptions that bioethicists tend to make that relate to disability: the medical model of disability, bad-difference views of impairment, and biological determinism—often, genetic determinism, specifically, in discussions of so-called reproductive choices. I also discussed alternatives to these assumptions, which are often adopted by disability theorists. After detailing these assumptions and a few other key terms, I surveyed articles in biomedical ethics anthologies in order to examine which assumptions these articles endorsed and the effect this had on their recommendations related to preconception, pre-implantation, and prenatal testing and selective abortion. One of the clear distinctions between authors whose positions are in line with the medical model and a bad-difference view of impairment in contrast to those who endorse the social model and a mere-difference view of impairment is the type of responsibility they emphasized (parental and societal, respectively). As shown in Table 2, one of the significant divides between these perspectives is located in their responses to the following questions:

Whose responsibility is it to respond to potential and actual children with impairments?
What constitutes an appropriate response?

In addition, positions informed by genetic determinism tended to narrowly focus on genetic interventions to prevent suffering and limited opportunities rather than considering social changes. These trends point to the limitations of the medical/social model distinction: namely, they may be seen as supporting a spurious dichotomy between medical and social interventions, which implies that disabled people must choose one or the other rather than leaving open the possibility that both may be desirable.

Table 2 Models of Disability and Roles and Responsibilities

Model of Disability	Medical Model of Disability Bad-difference Views of Impairment	Social Model of Disability Mere-difference Views of Impairment
Role of Potential Parents	Potential parents should use genetic testing to make responsible choices (i.e. prevent the birth of children likely to develop impairments) or they should be responsible for bearing the costs of raising such children.	Potential parents may find genetic and other types of prenatal testing to be useful in preparation to raise a child that may develop an impairment or disease. However, they should not be pressured to use this testing.
Role of Healthcare professionals	Healthcare professionals should provide genetic and other prenatal testing on demand and provide medical interventions to prevent/reduce impairment.	Healthcare professionals should provide information about possible outcomes to help potential parents to have an understanding of what it is like to live with the particular impairment or disease the potential child may develop.
Role of Society	Society should fund genetic and other prenatal testing as well as research to cure impairments and diseases.	Society should provide resources so that potential parents feel as though they have a choice about whether or not to raise a child that may develop a congenital impairment or disease.
Primary Focus	The primary focus is on parental responsibility. The responsible choice is for potential parents to prevent the birth of children with impairments and congenital diseases.	The primary focus is on societal responsibility. Disability should be prevented, but it cannot be uniformly assumed that preventing impairment is good.

All of the authors considered here are concerned to prevent suffering, to the extent that is possible, and envision a world in which children have worthwhile lives filled with opportunities. Indeed, several authors state that justice requires interventions to ensure that this is the case. However, their perspectives differ on whether or not impairment inevitably causes suffering and limited opportunities. Accordingly, they differ on the necessity and appropriateness of genetic

and other types of social intervention. In chapter two, I will examine the epistemic dimensions of the divide between these positions.

CHAPTER TWO: EPISTEMIC ISSUES IN BIOMEDICAL ETHICS: IGNORANCE, KNOWLEDGE, OBJECTIVITY, AND DISABILITY

“With the right kind of philosophical account, empirical evidence can appear irrelevant” (Amundson 2005, 109).

[P]erhaps even more important than ideologies at the explicit and articulated level (for example, libertarianism, biological determinism) are ideologies in the more primeval sense of underlying patterns and matrices of belief, or ideology as “common sense.” The former are at least visible as ideologies, specific demarcated bodies of thought in contestation for people’s belief, whereas the latter may seem to be mere neutral background, an ideational framework to be accepted by all, without political implications. Thus the latter may well be more influential and efficacious than the former simply by virtue of their ability to set the terms of the debate, to limit the options deemed worthy of consideration (Mills 1988, 253).

In this chapter, I argue that objectivity as neutrality in biomedical ethics sustains ignorance and makes the perspectives of disabled people and their advocates seem superfluous or even antithetical to knowledge production. As a result of the exclusion of these perspectives, bioethicists do not know as well or as much as they could, and they are considered untrustworthy among many members of the disability rights community. I argue that strong objectivity, which makes social interests and values affecting research explicit rather than denying their existence, provides an approach that is superior both epistemically and ethically.

In 2001, *The American Journal of Bioethics* published an essay by Mark Kuczewski entitled “Disability: An Agenda for Bioethics” along with fifteen commentaries.³² Kuczewski argues that, “bioethics needs to be more concerned with issues related to disability and to engage

³² See *The American Journal of Bioethics* 3(1).

the disability perspective” (43). In spite of the time that has passed since he wrote this article, it raises concerns that are just as relevant today. For example, as I have shown in chapter one, the perspectives of disabled people are still marginalized within a number of biomedical ethics textbooks published between 2010-2014. In addition, there is continued tension between prominent bioethicists and disability advocates. Bioethics as a field generally fails to consider the disabled people’s experiences and knowledge to be central for issues that affect disabled people’s lives.

Later in this chapter, I will discuss Kuczewski’s position in more depth as well as the responses of Anita Silvers and Peter Singer, which both call for neutrality. Concepts developed throughout the chapter serve to clarify why objectivity as neutrality is epistemically counterproductive. In an expanded version of her response to Kuczewski, Silvers argues that “bioethicists and disability advocates need to construct a conceptually neutral space around disability” (2003, 474). She contends that it is possible and desirable for both communities to set aside their differing political values in order to develop “conceptual neutrality” regarding disability (2003, 475). For Silvers, “neutral” means value-free (2003, 473). Yet, her description of how bioethicists and disability advocates ought to proceed does not entail the absence of values and interests. Nonetheless, I contend that Silver’s approach shows promise if it is reframed as a means for making values and interests explicit and beginning to distinguish between liberatory and anti-liberatory values rather than achieving neutrality. There are a number of persuasive arguments within philosophy of science and feminist standpoint theory that challenge her overall claim that conceptual *neutrality* in regard to the concept of disability is possible or desirable. Given that I reject the possibility of a neutral conception of disability, my

aim here is to develop an alternative way of framing the desire I share with Silvers to facilitate respectful dialogue between bioethicists and disability advocates.

Feminist standpoint theory and epistemologies of ignorance provide conceptual tools that are useful for clarifying the obstacles to the sort of reconciliation between bioethicists and disability advocates that Silvers endorses. In this chapter, I will provide an overview of the key insights of feminist standpoint theory and epistemologies of ignorance prior to developing the ways in which they are beneficial for mapping out the epistemological terrain regarding conceptualizations of disability within biomedical ethics.

I will begin with a discussion of feminist standpoint theory in section one. I will then turn to considerations related to objectivity in light of feminist standpoint theory. Because I am concerned with the question of how it is possible to conceptualize disability without the ideal of objectivity as neutrality, I will develop Sandra Harding's claim that it is possible to create stronger standards for objectivity by recognizing the ways that values are integral to knowledge production rather than purporting that they are not. I will also discuss Naomi Scheman's examination of the purpose of objectivity.

In section two, I will describe epistemologies of ignorance, drawing on the work of Charles Mills. Epistemologies of ignorance might be thought of as an extension of feminist standpoint theory. Epistemologies of ignorance contend that ignorance, like knowledge, is produced and sustained through power relations and serves particular interests and values (Tuana 2006, 3). While there is a precedent for drawing on epistemologies of ignorance within scholarship on disability,³³ I have not found work on biomedical ethics that takes this approach. I

³³ See Gilson 2011 and Hall 2012. In "Vulnerability, Ignorance, and Oppression," Gilson argues that epistemic vulnerability among members of dominant groups can mitigate the harms of oppressive forms of ignorance. In "'Not Much to Praise in Such Seeking and Finding': Evolutionary Psychology, the Biological Turn in the Humanities, and the Epistemology of Ignorance" Kim Hall argues that what she

will draw on Gaile Pohlhaus Jr.'s discussion of the ways in which being asked to understand from dominant perspectives can curtail individual epistemic agency and reinforce oppression. I use her notion of “wrongful requests to understand” in order to explore the epistemic harms imposed upon disabled people as well as to provide suggestions for moving toward more just epistemic practices (Pohlhaus 2011). The section elaborates on ways that appeals to neutrality obstruct efforts to know and harm those who seek to challenge dominant perspectives.

In section three, I will argue that the ignorance among bioethicists regarding the perspectives and claims of disabled people and disability rights advocates is not a simple lack of knowledge; epistemologies of ignorance can help to elucidate the ways in which dominant beliefs regarding disability are reified while non-ableist beliefs tend either not to be taken into consideration or to be quickly dismissed. In light of the insights of feminist standpoint theory and epistemologies of ignorance, it is not tenable to appeal to objectivity as neutrality in discussions of disability and quality of life (QOL). I will also discuss claims regarding the QOL of disabled people made in the name of objectivity by some bioethicists in order to show how objectivity as neutrality can work against the interests of disabled people. I will focus on the ableist view that impairments necessarily greatly reduce QOL, which is widely endorsed within the literature of biomedical ethics in spite of the protests of people who live with impairments. Pohlhaus explains that “wrongful requests to understand” protect the privileged from the type of epistemic openness that undergirds just knowledge practices while rendering the marginalized vulnerable to a number of harms (2011). I will show that this is especially apparent within biomedical ethics and medical practice.

terms the “biological turn” in the humanities is “an epistemology of ignorance that contributes to a climate of hostility and intolerance regarding feminist approaches to gender, identity, and the body” (2012, 30).

Finally, in section four, I will develop Silvers' recommendations for developing conceptual neutrality regarding disability. I will demonstrate that her approach is not actually value-free and that rather than constituting a weakness, this is a strength. I conclude by arguing that strong objectivity and objectivity as trustworthiness provide both a more accurate description and a better prescription of just epistemic practices within biomedical ethics in regard to disability than approaches that appeal to objectivity as neutrality.

2.1 Feminist Standpoint Theory and Objectivity

Although there are a number of feminist standpoint theorists worthy of discussion,³⁴ I will limit my focus to three of these theorists who have been influential within philosophy and are most relevant for the concerns of the current project: Sandra Harding, Nancy Hartsock, and Alison Jaggar. After discussing the notion of a feminist standpoint, I will draw on the work of Harding and Scheman in order to examine the relationship between feminist standpoint theory, objectivity, and trustworthiness.

2.1.1 Feminist standpoint theory

In her ground-breaking 1983 essay "The Feminist Standpoint: Developing the Ground for a Specifically Feminist Historical Materialism," Hartsock draws on Marxian theory in order to consider the potential for applying Karl Marx's insights to feminist concerns. She is primarily interested in the epistemological usefulness of a feminist historical materialism. Before we can discuss Hartsock's suggestion, it is necessary to understand the epistemic consequences of non-feminist historical materialism.

³⁴ See, for example, Patricia Hill Collins 2000; Donna Haraway 1988; Sandra Harding 1986, 1991, 1992, 1993; Nancy Hartsock 1983; Alison Jaggar 1983; Hilary Rose 1987; and Dorothy Smith 1974, 1987.

According to Marx, class is the primary social structure within capitalist society, and this has significant epistemic consequences. Marx considers the differences between the perspectives of the capitalist (at the level of commodity exchange) and the worker (at the level of production) to be epistemically telling. While the capitalist is likely to believe that his relation to the worker is one of equality, the worker has a greater possibility of recognizing the exploitative nature of their relationship (Hartsock 1983, 286-287). According to Hartsock, “a Marxian account of exchange vs. production indicates that the epistemology growing from exchange not only inverts that present in the process of production but in addition is both partial and fundamentally perverse” (287). On Hartsock’s account, the proletariat is able to develop a more comprehensive understanding of social reality in being able to take on the perspectives of both the capitalist and the proletarian, whereas the capitalist’s version is *partial*—often confined to a single perspective. She claims that the capitalist’s perspective is *perverse* insofar as it wrongly privileges exchange rather than use, which is essential for preserving and reproducing the human race. In Charles Mills’ words, “Marx believes that the illusory appearances of capitalism—though admittedly exerting a certain doxastic pull on everybody—can be at least partially ‘seen through’ from a certain perspective, that of course being the perspective of the working class” (1988, 242). While being a member of the working class does not *guarantee* that one will identify the illusory appearances of capitalism, such as the fable that workers freely sell their labor, Marx posits that members of the working class—proletarians—have the best chance of recognizing and attempting to change the causes of their exploitation. Proletarians have less investment in maintaining the *status quo* than capitalists, who benefit from the system and stand to lose a great deal if it is overturned.

Marx has been widely critiqued for failing to adequately attend to the relevance of gender and race for understanding exploitation (Young 1980; Hartsock 1983; Mills 1988). Due to his focus on wage labor, for example, his approach is unable to problematize the domestic labor performed by women. Hartsock claims that Marx and Engels' theorizing is, in fact, premised on it. She states, "It is no surprise to feminists that Engels, for example, simply asks how women can continue to do the work in the home and also work in production outside the home. Marx too takes for granted women's responsibility for household labor" (Hartsock 1983, 291).

Nonetheless, feminist Marxists and materialist feminists have sought to adapt Marxist theory, claiming that women's lives differ greatly from men's and "that the position of women is structurally different from that of men" (Hartsock 1983, 284). Hartsock seeks to develop the epistemic resources implicated by this claim. She suggests that, "like the lives of proletarians according to Marxist theory, women's lives make available a particular and privileged vantage point on male supremacy, a vantage point which can ground a powerful critique of the phallocratic institutions and ideology which constitute the capitalist form of patriarchy" (284). While, like the proletariat, women are prone to colluding in our domination, we also have less material interest in maintaining the current social structure than men do.

Hartsock describes the characteristics of the proletarian standpoint in order to consider the possibility of a feminist standpoint. Before discussing the notion of a specifically *feminist standpoint*, it will be helpful to clarify the nature of a *standpoint*. Hartsock states:

A standpoint is not simply an interested position (interpreted as bias) but is interested in the sense of being engaged...A standpoint, however, carries with it the contention that there are some perspectives on society from which, however well-intentioned one may be, the real relations of humans with each other and with the natural world are not visible (1983, 285).

A standpoint is not a given; one must work to attain it. While it is possible for those in privileged positions to take on a proletarian standpoint, it involves difficulties beyond their desire to maintain the *status quo*. For example, aspects of social relations that are readily apparent from the perspectives of some workers are not salient to capitalists in most cases. Attaining a standpoint involves the insights of others, and this is especially true for those in privileged positions because they are at an epistemic disadvantage. Developing a standpoint is a social endeavor.

Marx contends that the proletarian standpoint originates in practical activity (Hartsock 1983, 285). While Hartsock's notion of a feminist standpoint builds on his insights, she disagrees with Marx on a fundamental point. She says that Marx "dismisses the sexual division of labor as of no analytic importance," whereas Hartsock argues that the sexual division of labor has profound effects for differences in the experiences of men and women, making it a logical starting point for a feminist standpoint (290). She uses the term "sexual" rather than "gender" for two reasons. First, insofar as women and not men bear children, the division of labor is not reducible to social determinations. Second, Hartsock wants to emphasize "the bodily aspect of existence—perhaps to grasp it over-firmly in an effort to keep it from evaporating altogether" (289). She examines ways that practical activity can contribute to the development of a feminist standpoint.

Hartsock's discussion of practical activity focuses on the institution of motherhood, gender socialization, female bodily experiences, and the nature of work undertaken by women — indeed, it becomes clear that these foci are all intertwined. In regard to the institution of motherhood, she asserts that the socialization of almost all girls includes preparation for motherhood (1983, 294). Mothering and other domestic work is tied to necessity and

embodiment, making it difficult for women to reside in the abstract realm of masculinity (296). Hartsock states, “the female experience in bearing and rearing children involves a unity of mind and body more profound than is possible in the worker’s instrumental activity” (294). Women’s labor is also more likely than men’s to be central to self-definition insofar as women, on average, work much more when wage labor and work to sustain the family and home are considered.

Hartsock concludes “These different (psychic) experiences both structure and are reinforced by the differing patterns of male and female activity required by the sexual division of labor, and are thereby replicated as epistemology and ontology” (1984, 296). She suggests that the domination of ways of thinking stemming from male activity has led to dualist oppositions and radical individualism, whereas unity and the dialectic ways of thinking that originate in women’s activity are marginalized (298-299). Because the former abstract modes of thinking are in accord with other patterns of male activity, Hartsock contends that it is more difficult for men to notice that there are alternatives or that these ways of thinking are particular rather than universal. This is one aspect of the epistemic disadvantage she thinks characterizes the male social position that gives rise to abstract masculinity, which provides a partial and perverse perspective. Conversely, women are more likely to recognize the inadequacy and contingency of these ways of thinking.

According to Jaggar, feminist critiques of existing knowledge “reveal how prevailing systems of conceptualization are biased because they invalidate women’s interests and promote the interests and values of the men who created them” (1983, 371). The impact of systems of conceptualization is not confined to theory; it plays an important role in structuring societal practices more generally. A feminist standpoint allows for identification of the values and

interests being served within systems of conceptualization and allow for the provision of alternative possibilities.

It cannot be emphasized too strongly that a standpoint is not something one simply has in virtue of being in a marginalized social position. Members of marginalized groups do not automatically recognize that there are alternatives to the dominant narratives. Hartsock maintains that both science and the education gained through working to change social relations are needed in order to achieve a standpoint (1983, 285). This is what distinguishes a perspective from a standpoint. Harding reminds us that, “the dominant ideology restricts what everyone, including marginalized people, are permitted to see and shapes everyone’s consciousness” (Harding 1992, 582-583). She elaborates on Hartsock’s contention that activism contributes to one’s ability to think in opposition to the dominant ideology in the following:

Only through such struggles [political activism by and on behalf of oppressed, exploited, and dominated groups] can we begin to see beneath the appearances created by an unjust social order to the reality of how this social order is in fact constructed and maintained. This need for struggle emphasizes the fact that a feminist standpoint is not something that anyone can have simply by claiming it. It is an achievement. A standpoint differs in this respect from a perspective... (Harding 1991, 127).

This quotation refers to multiple dominated groups. Although Hartsock’s essay seeks commonalities between women in different social locations, she calls a feminist standpoint “an important epistemological tool for understanding and opposing all forms of domination” (1983, 283). Other feminist theorists attend to differences within the category “women” related to race, sexuality, class, and, most recently, disability status in order to develop in greater detail how a feminist standpoint might be used to address all forms of domination (Mairs 1990, 1996; Morris 1995; Collins 2000; Garland-Thomson 2005; Mahowald 2005; Wendell 2008).

2.1.2 Feminist standpoint theory and disability

Feminist disability theorists have recognized the significance of feminist standpoint theory for both disability activism and theory. In “Personal and Political: A Feminist Perspective on Researching Physical Disability” feminist disability theorist Jenny Morris claims that one of the obstacles entailed in the oppression disabled people face is a difficulty in developing a standpoint and having our knowledge and experiences included in cultural representations of disability. Morris asserts, “Making our standpoint known to both ourselves and to others is a central part of the feminist research agenda, as it must also be of a disability rights agenda” (1995, 263). As this remark makes clear, she considers this work to be vital not only for disability advocates but also for feminist theory. Morris challenges nondisabled feminists to recognize the concerns of disabled women as feminist concerns.

As the title of her essay suggests, Mary Briody Mahowald asserts in “Our Bodies Ourselves: Disability and Standpoint Theory” that her defense of a human-flourishing based definition of disability is premised on feminist standpoint theory. Central to her position is the claim that false universalization of the perspectives of privileged people leads to injustice based on unnecessarily limited epistemic practices. She states, “Ethicists commit this epistemological error when they claim that impartiality is indispensable to ethical judgments and consider their own ethical positions as exemplars of such impartiality” (Mahowald 2005, 241). Mahowald contends that inclusion of the standpoints of disadvantaged groups such as disabled people serves as a corrective to this epistemological error. Though there is slippage in her discussion between the *perspectives* and *standpoints* of disabled people, she is clear on this point: it is a necessary condition of just policy and health care decisions impacting disabled people to take their experiences and knowledge into account.

Like Morris and Mahowald, Susan Wendell contends that feminist theory needs to include disabled women. She suggests that feminists ought to be suspicious of the claim that when disabled people face social disadvantages such as unemployment, poverty, and lack of access to appropriate education it is because they are “victims of nature or accident” (2008, 829). Wendell thinks that feminists are likely to be able to identify parallels between this claim and the claim that women are disadvantaged by nature. However, she maintains that disabled people are in a better position than able-bodied people to develop a critical consciousness regarding disability in the following: “From the standpoint³⁵ of a disabled person, one can see how society could minimize the disadvantages of most disabilities, and, in some instances, turn them into advantages” (829). Wendell discusses reasons she thinks the knowledge of disabled people is “silenced” as well ways that this knowledge could benefit society as a whole (837).

Like Hartsock, Wendell conceives of a critical standpoint as something that is achieved through dialogue. She states: “[b]ecause I do not want simply to describe my own experience but to understand it in a much larger context, I must venture beyond what I know first-hand. I rely on others to correct my mistakes and fill in those parts of the picture I cannot see” (2008, 827). Significantly, Wendell suggesting that experience is fallible and should not be uncritically accepted. She also notes the limitations on any one person’s experience and knowledge.

Although Nancy Mairs does not explicitly cite feminist standpoint theory in *Waist-High in the World: A Life Among the Nondisabled*, she reflects on her experiences as a disabled women and the disability community’s awareness of the political nature of disability. Rosemarie Garland-Thomson suggests that Mairs articulates a “feminist disability sitpoint theory,” regarding which she states, “my use of *sitpoint* particularizes standpoint theory to disabled

³⁵ Here Wendell uses “standpoint” in the way that Hartsock uses “viewpoint.” For example, Wendell asserts, “[I]ike everyone who is disabled, I have a particular standpoint determined in part by both my physical condition and my social situation” (2008, 827).

women by calling attention to the normative assumption that one perceives the world from a standing rather than sitting position” (2005, 1570). While I appreciate Garland-Thomson’s effort to prompt feminists to be wary of ableist assumptions, I worry that she may be taking “standpoint” a bit too literally. In addition, she verges on conflating being a disabled woman with having a feminist disability “sitpoint,” which is problematic in at least two ways. First, it seems to exclude the possibility that disabled men might develop this critical consciousness. Secondly, I think it is important to preserve the distinction between a perspective stemming from being disabled from a standpoint in order to recognize that insights regarding social relations are not automatic but require sustained effort.

While feminist theorists have long recognized the applicability of feminist standpoint theory for thinking about disability, this approach remains marginal within epistemic practices within biomedical ethics as well as research on disability. The notion that feminist standpoint theory entails social values and interests and is thus antithetical to objectivity—the proper approach to research—is central for understanding why the impact of feminist standpoint theory has not been greater.

2.1.3 Feminist standpoint theory and objectivity

The epistemological insights that emerge from Marxian theory and its feminist adaptations have significant consequences for thinking about objectivity, particularly for problematizing the conception of objectivity as neutrality. Jaggar remarks:

Since knowledge is one aspect of human productive activity and since this activity is necessarily purposive, the basic categories of knowledge will always be shaped by human purposes and the values on which they are based. For this reason, Marxists conclude that even so-called empirical knowledge is never entirely value-free. The conceptual framework by which we make sense of ourselves and our world is shaped and limited by the interests and values of the society that we inhabit (Jaggar 1983, 358).

On this account, when epistemic practices are contextualized it becomes clear that they are motivated by societal interests and values, which may not be shared or even recognized. This understanding of knowledge and feminist standpoint theory undergirds Harding's discussion of two notions of objectivity.

2.1.3.1 Objectivity as neutrality

Within feminist as well as mainstream epistemology, science has often been taken to be the paradigm for examining knowledge practices. One might think that if objectivity as neutrality is possible within any human domain, it is within science. While there is no consensus among feminist theorists about whether or not to maintain objectivity as an epistemic ideal, there is widespread criticism of claims that science *is* objective in the sense of being disinterested and value free (Amundson 2013; Haraway 1988; Harding 1991; Harding 1992; Harding 1993; Lewontin, Kamin, and Rose 1984; Tuana 2006). Later in the chapter (section 5), I will show that Harding's discussion of objectivity is especially useful for considering how best to conceptualize disability without appealing to neutrality as an ideal (Harding 1991; Harding 1992; Harding 1993). I will recount her explanation of ways that politics influence scientific practices in order to set the stage for clarification of the limitations of objectivity as neutrality as well as the benefits of what she terms "strong objectivity."

Harding distinguishes between two types of politics related to science. The first conceives of politics "as the overt actions and policies intended to advance the interests and agendas of 'special interest groups'" (1992, 567). As the quotation makes clear, this understanding of the politicization of science involves intentional manipulation. Politics impacts scientific practices *from the outside*, so to speak, influencing the research questions that are pursued and how results of research are framed (567). Examples of this type of politics

impacting research include corporations and organizations commissioning scientists to obscure findings regarding the harms of smoking cigarettes or being exposed to environmental tobacco smoke (i.e. secondhand smoke) or to create doubt about the existence of or causes of climate change (Proctor 2008; Oreskes and Conway 2008; Christensen 2008). Another example is when pharmaceutical companies engage in public relations campaigns to promote awareness of conditions that they produce medications to treat. Sprout Pharmaceuticals, manufacturer of flibanserin—a medication currently under review by the Federal Drug Administration (FDA) to treat female hypoactive sexual desire disorder (HSDD)—provides funding to the “Even the Score” campaign, which claims that gender equality requires safe and effective treatments for HSDD, often referred to as “female sexual dysfunction” on the website (even though this is not consistent with the terminology adopted in the DSM-V), apparently to emphasize the purported similarities to “male sexual dysfunction.”³⁶ In all of these cases, there is a clear attempt to distort or reframe scientific evidence in order to shape policy and public opinion in a way that benefits corporations and actually or potentially harms members of the public. Harding contends that the idea of objectivity as neutrality is most apt for addressing this type of involvement of politics in science.

³⁶ Their website states:

As supporters of the Even the Score campaign, we believe that women have the right to make their own informed choices concerning their sexual health; that gender equality should be the standard when it comes to access to treatments for sexual dysfunction; and that the approval of safe and effective treatments for women’s sexual dysfunction should be a priority for action by the FDA (<http://eventhescore.org/about-us/>).

Even the Score claims that the problem is as follows:

There are 26 FDA approved drugs to treat various sexual dysfunctions for men (41 if you count generics!), but still not a single one for women's most common sexual complaint. You can see a list of all 26 individually evaluated and approved drugs for men right here, compiled from the [FDA's own website](#). 26 v 0. That just doesn't make sense all these decades and scientific publications later (<http://eventhescore.org/about-us/>).

Although there is no mention of flibanserin by name, it is easy to infer that these claims are meant to bolster support for flibanserin insofar as it is the first drug to be reviewed by the FDA for treatment of HSDD.

The second type of politics works *within* science rather than from the outside. Harding states, “power is exercised less visibly, less consciously, and *not on but through* the dominant institutional structures, priorities, practices, and languages of the sciences” (1992, 567). Rather than acting on the structures of science, this type of politics structures science. The politics of male dominance, racism, classism, and imperialism are examples she cites that function in this way (568). The ideal of objectivity as neutrality is unable to detect such structural biases. Worse yet, according to Harding this ideal “certifies as value-neutral, normal, natural, and therefore not political at all the existing scientific policies and practices through which powerful groups can gain the information and explanations that they need to advance their priorities” (568-569). As a corollary, Harding notes that objections to these claims are silenced through definition as “agitation by special interests that threaten to damage the neutrality of science” (569). Scientific claims are legitimated through appeals to neutrality even as they are thoroughly political in this second sense.

Harding explains that one of the differences between what she terms “spontaneous feminist empiricists”—feminist biologists attempting to correct for sexism and androcentricism—and feminist standpoint theorists is that the former think that these biases can be eliminated by adhering to objectivist methods more carefully in order to attain objectivity as neutrality, while the latter think that new methods are necessary for systematic identification of the values and agendas that shape scientific practices (1993, 51). On Harding’s account, feminist empiricists—with the notable exceptions of Helen Longino and Lynn Hankinson Nelson—are concerned with the first rather than the second type of politics. Spontaneous feminist empiricists think social values and interests only guide ideologically tainted science, while feminist standpoint theorists hold that social values and interests are ineliminable from science. Harding

contends that the conservatism of feminist empiricism is both its strength and weakness; it is more widely accepted than feminist standpoint theory but also less effective in identifying the impact of widely held social values and interests due to its adherence to objectivity as neutrality (1993, 52-53).

The ideal of objectivity as neutrality is used to reify dominant narratives and to serve the interests of privileged groups. Chapter one referred to the claim of Lewontin, Rose, and Kamin that biological determinism and reductionism are appealed to in order to buttress ideologies, defined as “the ruling ideas of a particular society at a particular time” (1984, 3-4). Biological determinism and reductionism, it is claimed, are simply “objective” descriptions. Harding argues that one problem with objectivity as neutrality is that, “Objectivist methods are designed to identify and eliminate those social and political values and interests that *differ* between the *individuals* who constitute a scientific community [emphasis added]” (1992, 577). What these methods are not designed to do is to locate and eliminate the values and interests that are *shared* among members of a scientific or other type of epistemic community.

According to Harding, objectivism conceives of objectivity too narrowly, in one sense, and too broadly, in another, to be able to achieve its goals (1991, 144).³⁷ Objectivity is too narrow insofar as it concerns differences in values and interests between individuals, as noted above, and limits its scope to the context of justification, which deals with gathering and interpreting evidence. Objectivist methods do nothing to address the context of discovery, which clearly incorporates interests and values in prioritization and formulation of research questions.³⁸

This leads to Harding’s next criticism, which is that objectivity is too broad in seeking to

³⁷ Harding reports that “the conventional notion of a value-free, impartial, dispassionate objectivity” is “sometimes referred to as ‘objectivism’” (1991, 138-139). She uses these terms interchangeably.

³⁸ Harding states, “it is in the context of discovery that culture-wide assumptions which subsequently are among the most difficult to identify make their way into the research process and shape the claims that result” (1992, 577-578).

eliminate “all social values and interests from the research process and the results of research” (1991, 144). She finds this problematic not only because she thinks it is impossible to prevent values and interests from influencing research, but also due to her position that it is unnecessary to do so. In her words “not all social values and interests have the same bad effects upon the results of research” (Harding 1993, 71). In sum, methods for meeting the standard of objectivity as neutrality cannot be entirely effective, but, fortunately, it is not requisite to rid science of all values and interests, on Harding’s view.

Objectivity as neutrality, which Harding refers to as “weak objectivity,” leads to another significant problem: “It offers hope that scientists and science institutions, themselves admittedly historically located, can produce claims that will be regarded as objectively valid without their having to examine critically their own historical commitments, from which—intentionally or not—they actively construct their scientific research” (1991, 147). Harding contends that this hope is in vain. Here she reiterates that scientists need not purposely, much less malevolently, incorporate shared commitments into their work for it to reflect these commitments. The presence of interests and values within science is not an issue in itself; however, denial of this presence may serve to mask the actual influences and functions of scientific research.

Harding notes that “antilibertarian interests and values” can insulate knowers from looking for or taking into account evidence against their claims (1991, 149). Conversely, she holds that, “Democracy-advancing values have systematically generated less partial and distorted beliefs than others” (1993, 71). The former are informed by ideologies that serve to sustain privilege and oppression while the latter oppose these ideologies. The task, then, is to sort out antilibertarian interests and values from democracy-advancing ones. On Harding’s account, the traditional notion of objectivity as neutrality is woefully inadequate for this task insofar as it

cannot detect values and interests shared within a scientific or broader community, and it is incongruous with the possibility that a standpoint could provide epistemic resources.

2.1.3.2 Strong objectivity

Harding argues that objectivity needs to be reconceptualized as what she terms “strong objectivity” in order to make it possible to systematically identify the values and interests that shape scientific and other epistemic practices. Strong objectivity incorporates the insights of feminist standpoint theory, which entails rejection of central tenets of conventional approaches to Western science and epistemology. Rather than assuming a subject/object dichotomy, strong objectivity recognizes that socially situated individuals play a role in constituting objects of knowledge. Harding states, “Strong objectivity requires that the subjects of knowledge be placed on the same critical, causal plane as the objects of knowledge. Thus, strong objectivity requires what we can think of as ‘strong reflexivity’” (1993, 69). This entails broadening science’s scope of inquiry to consider subjects as objects of knowledge. Rather than limiting the focus to identification of idiosyncratic beliefs of individuals, strong objectivity locates the beliefs of individuals within a broader social context.

Western science and epistemology have traditionally judged that the social identities of knowers are irrelevant, as long as individuals are able to prevent their particular characteristics from affecting their work (Jaggar 1983, 357). Within strong objectivity, by contrast, involvement of participants with heterogeneous social identities is conducive to making science more critical and reflexive than it would be if the default were to prevail. On this matter, Harding states:

[K]nowledge-seeking requires democratic, participatory politics. Otherwise, only the gender, race, sexuality, and class elites who now predominate in institutions of knowledge-seeking will have the chance to decide how to start asking their research questions, and we are entitled to be suspicious about the historical location from which those questions will in fact be asked (1991, 124).

Harding is skeptical regarding the likelihood of scientists who are privileged across all axes identifying ways in which androcentricism, sexism, and racism impact their research. In addition, the questions that members of a homogenous, privileged epistemic community raise may only be of concern to a small fraction of the population or may be formulated in such a way as to contribute to ignorance regarding those outside of this group. Furthermore, in contrast to the perspective informing traditional Western science and epistemology, Harding contends that social identities of knowers have always mattered for epistemic practices.

The difference between mainstream Western science and epistemology and feminist approaches, according to Harding, is that feminist standpoint theorists are more aware of the ways that the social positions of members of an epistemic community may facilitate or hinder knowledge production. She states:

[T]he fact that feminist knowledge claims are socially situated does not in practice distinguish them from any other knowledge claims that have ever been made inside or outside the history of Western thought and the disciplines today; all bear the fingerprints of the communities that produce them (Harding 1993, 57).

The reflexivity of feminist knowers is the reason that strong objectivity values pluralism.

The notion of a feminist standpoint, which informs Harding's concept of strong objectivity, should not be understood as implying either that women's perspectives provide unmediated access to reality that should be accepted uncritically or that men ought to be excluded. On the first point, Harding asserts, "To start thought from marginal lives is not to take as incorrigible—as the irrefutable ground for knowledge—what marginal people say or interpretations of their experiences" (1992, 583). Although she advocates beginning research with the concerns of marginalized people, she does not think this is sufficient for attaining strong objectivity. On the second point, Harding says that men have not only the ability but also an

imperative to develop “distinctive forms of specifically feminist knowledge from their particular social situation” (1993, 67).³⁹ She points out that John Stuart Mill, Marx, and Engels contributed to understanding of the social situations of marginalized groups of which they were not themselves members (1992, 583).

In response to the concern that members of dominant groups may take her recommendation as providing one more means for silencing members of marginalized groups, Harding clarifies:

Far from licensing European-Americans to appropriate African-American thought or men to appropriate women’s thought, this approach challenges members of dominant groups to make themselves “fit” to engage in collaborative, democratic, community enterprises with marginalized peoples. Such a project requires listening attentively to marginalized people; it requires educating oneself about their histories, achievements, preferred social relations, and hopes for the future; it requires putting one’s body on the line for “their” causes until they feel like “our” causes; it requires critical examination of the dominant institutional beliefs and practices that systematically disadvantage them; it requires critical self-examination to discover how one unwittingly participates in generating disadvantage to them...and more [ellipses in original] (1993, 68).

Because it is informed by a concern for just epistemic practices, strong objectivity is much more demanding than objectivity as neutrality. Members of dominant groups cannot simply claim to speak for others; rather they must transform themselves in order to have a greater understanding of the ways that they are implicated in sustaining oppression as well as of marginalized people’s lives. In this way, knowers move toward the ideal of strong objectivity and become deserving of trust.

2.1.3.3 Objectivity as trustworthiness

In *Shifting Ground: Knowledge and Reality, Transgression and Trustworthiness* Naomi

Scheman explores the question “what does objectivity do?” She contends that if we call

³⁹ See Harding (1998). See also Larry May (1998) for additional arguments in favor of this position and practical suggestions for how men might go about this task.

something “objective” we are suggesting that it should be regarded as credible by the wider community, regardless of differences in perspectives and interests from those who produced the claim under consideration (2011, 209-21). She maintains, “If objectivity is an instrumental good, then it has actually to function so as to produce the good it promises; what we label ‘objective’ has actually to be worthy of our trust and the trust of a diverse range of others” (2011, 210). Scheman notes that her concern with trust as a central epistemological issue is aligned with social epistemology (214). Knowledge production and its accompanying attempt to attain objectivity is not a solipsistic activity.

In line with Harding’s call for democratization of epistemic practices, Scheman states:

liberatory politics such as feminism are intrinsically related to objectivity in their commitment to struggling for social institutions that are worthy of trust on the part of all those whose lives are affected by them: A “bias” in favor of such struggles is a bias in favor of the conditions that would make objectivity a real possibility, rather than a merely theoretical gesture (2011, 211).

Although Scheman does not define objectivity, her characterization of how it might be achieved is very much in line with the methods required by Harding’s strong objectivity. Rather than detracting from the possibility of objectivity, epistemic practices that are informed by liberatory politics enhance their trustworthiness.

Scheman says that trustworthiness is characterized by “competence and integrity” (2011, 219). Her concern with trustworthiness is not restricted to individuals; rather, she focuses on “the systematically trust-eroding effects of various forms of social, political, and economic injustice” (219). Given that scientific and other epistemic practices are conducted within a socio-historical context, it is essential to guard against incorporating values and interests that reinforce these types of injustice. This is what makes the results of research trustworthy. Scheman suggests that it is important that those without expert status have the possibility of being recognized as

competent knowers who may be able to offer critiques and supplement the accounts of “authoritative knowledge producers” (210).

Scheman thinks that the disagreement between what she calls “feminist objectivity theorists” and their critics hinges on whether they endorse an internalist or externalist account of objectivity (2011, 219). These accounts are in line with Harding’s distinction between objectivity as neutrality versus strong objectivity, respectively. In other words, an internalist account assumes it is possible to prevent social values and interests from impacting epistemic practices, while an externalist account rejects this stance and instead advocates careful identification and evaluation of the impact of social values and interests. Scheman states that, “the question is whether the norms that are meant to yield objectivity are narrowly epistemic or also broadly moral and political” (220). Critics of feminist objectivity theorists accuse them of “endangering” objectivity, while feminist objectivity theorists contend that objectivity needs to be strengthened through consideration of context, not abandoned (207).

According to Scheman, who endorses an externalist account, objectivity is something that we achieve in degrees. She asserts: “Objectivity on an externalist account is not an all or nothing matter, settled by rules laid down in advance; it is, rather, a rolling horizon we move toward as we increasingly democratize our epistemic practices” (2011, 230). Here again, Scheman’s characterization of the type of objectivity we ought to work toward is very much in line with Harding’s description of strong objectivity. Both recognize objectivity as an ongoing process requiring conscientious participation and pluralism; it is not something that can be attained once and for all.

Appeals to objectivity as neutrality within biomedical ethics often serve to legitimate ableist ideologies. According to Scheman’s consideration of the function objectivity should have,

this use of objectivity is illegitimate because such claims are not “worthy of our trust and the trust of a diverse range of others” (2011, 214). She states, “Charges of irrationality are oddly directed at those who point out—correctly, from their perspective—that they do not have good reason to believe what experts say” (2011, 230). Some disability advocates have expressed distrust of bioethicists. As a result, bioethicists have sometimes dismissed them as irrational or biased, though this distrust has often been warranted.

Objectivity as neutrality works against the interests of disabled people and maintains ignorance under the guise of knowledge. Epistemologies of ignorance are useful for considering how this occurs. In section 2, I will explain the framework of epistemologies of ignorance, focusing on Mills’ notion of white ignorance. I will also recount Pohlhaus’ notions of wrongful requests to understand and strategic refusals to understand. In section 3, I will demonstrate the usefulness of epistemologies of ignorance as well as wrongful requests and strategic refusals to understand for examining epistemic practices within biomedical ethics. In particular, I will clarify the ways that appeals to objectivity as neutrality make it more difficult to identify and challenge the ableist assumptions underlying discussions of QOL.

2.2 Epistemologies of Ignorance and Wrongful Requests to Understand

Linda Martín Alcoff explains the novelty of epistemologies of ignorance in the following: “Even in mainstream epistemology, the topic of ignorance as a species of bad epistemic practice is not new, but what is new is the idea of explaining ignorance not as a feature of *neglectful* epistemic practice but as a *substantive* epistemic practice in itself” (2007, 39). In contrast to prior

approaches within mainstream epistemology, epistemologies of ignorance consider the ways ignorance is produced and the values and interests it serves.⁴⁰

2.2.1 Against “race-neutral” social epistemology

In his 2007 essay “White Ignorance,” Mills forcefully demonstrates ways that systematic production of ignorance has been used to create and maintain inequality on the basis of race.⁴¹ Colonization, racism, and white domination produce epistemic injustices including denial of epistemic authority and hermeneutic resources to racialized others. The first results in people of color not being taken seriously as knowers and the second means that they have limited conceptual tools for understanding their own experiences outside of dominant narratives. Thus, the experiences of people of color are marginalized as sources of knowledge.

As Mills notes, epistemology has traditionally been concerned with the individual knower and has assumed that particularities of the knower do not (or at least, should not) matter for knowledge. However, Quine’s call to naturalize epistemology was one factor that made it possible to theorize actual knowledge formation of embodied, socially and historically located subjects. According to Mills, regardless of his own intentions and commitments regarding the possibility of apolitical knowledge, Quine’s work “opened Pandora’s box” (2007, 14). In spite of

⁴⁰ A note on terminology is warranted. Theorists interested in the systematic production of ignorance use the terms “epistemology of ignorance” and “agnotology” as a label for their work. For an excellent discussion of the coining of the term “agnotology” see Robert Proctor’s 2008 “Agnotology: A Missing Term to Describe the Cultural Production of Ignorance (and Its Study).” Groundbreaking anthologies in these areas include *Race and Epistemologies of Ignorance* (2007) edited by Nancy Tuana and Shannon Sullivan and *Agnotology: The Making and Unmaking of Ignorance* (2008) edited by Robert Proctor and Londa Schiebinger. The terms “epistemology of ignorance” and “agnotology” are roughly interchangeable; indeed, a couple of essays are included in both of these texts. I will use the term “epistemology of ignorance” in order to be consistent with the authors I am drawing on here.

⁴¹ This is an idea Mills begins to cultivate in *The Racial Contract* (1997) where he states:

One could say then, as a general rule, that *white misunderstanding, misrepresentation, evasion, and self-deception on matters related to race* are among the most pervasive mental phenomena of the past few hundred years, a cognitive and moral economy psychically required for conquest, colonization, and enslavement (19).

the increasing philosophical acceptance of work on social epistemology, Mills expresses the concern that mainstream epistemology has not been transformed to the extent he believes is desirable. In particular, he highlights the lack of consideration of Marxist, feminist, and especially racial critiques within mainstream epistemology (2007, 15).

Mills begins his essay by asking the reader to imagine an ignorance “*presenting itself unblushingly as knowledge* [italics in original]” (2007, 13). As this quotation makes clear, the ignorance with which he is concerned is not a simple lack of knowledge. Mills conceptualizes ignorance as “both false belief and absence of true belief” (2007, 16). He focuses on ignorance that is produced systematically, often accepted as the default, and typically overcome with difficulty.⁴² Mills contends that this type of [social] ignorance is implied by standpoint theory. The basic idea is that if members of oppressed groups have a privileged standpoint in regard to knowledge about how things are, in virtue of social location, then members of privileged groups are at an epistemic disadvantage. The former are more likely than the latter to be able to identify ignorance as ignorance rather than mistaking it for knowledge.

Mills maintains that social epistemology has not addressed oppression. He reports that authors such as Alvin Goldman have not considered racism and sexism to be fundamental considerations because they view them as exceptions. Conversely, Mills claims that, “Sexism and racism, patriarchy and white supremacy, have not been the *exception* but the *norm*” (2007, 17). White racial domination has given rise to and sustains a type of social ignorance Mills terms *white ignorance*. He makes ten points to clarify this concept. Though all of these aspects are

⁴² Here I have in mind Lu-in Wang’s notion of discrimination by default. Though her project is not specifically focused on epistemology, I think her claim that the systematic nature of unjust discrimination makes it possible for us to participate in problematic practices without intending to do so is how white ignorance functions. See *Discrimination by Default: How Racism becomes Routine* (2008).

important, due to space limitations within the current project, I will discuss a few of these assertions. Mills states:

racialized causality can give rise to what I am calling white ignorance, straightforwardly for a racist cognizer, but also indirectly for a nonracist cognizer who may form mistaken beliefs (e.g., that after the abolition of slavery in the United States, blacks generally had opportunities equal to whites) because of the social suppression of the pertinent knowledge, though without prejudice himself (2007, 21).

Here Mills notes that the cognitive phenomenon of white ignorance is not limited to those who have racist intentions or would identify themselves as racists; rather it can affect anyone in virtue of being located within a racist society. Thus, he takes the issue of racism to be central for social epistemology.

In spite of the name *white* ignorance, Mills is not claiming either that all white people fall prey to this phenomenon or that people of color (his focus is on black people, specifically) are immune to it. He contends “speaking generally about white ignorance does not commit one to the claim that it is uniform across the white population” (2007, 22). Mills suggests that we think of white ignorance as a “cognitive tendency” that whites and blacks alike must overcome in order to have knowledge. While any member of an oppressive society may be ignorant in ways that are caused by racism, those in marginalized positions are more likely as a result of their lived experiences to recognize that dominant narratives are distorted.

Finally, Mills suggests that just as traditional epistemology has been normative in the sense of seeking to understand and ultimately avoid “cognitive processes that typically produce false belief,” so too, the point of understanding white ignorance through social epistemology is in order to elucidate how it is sustained and how it might be avoided (2007, 23). In his words:

For a social epistemology, where the focus is on supra-individual processes, and the individual’s interaction with them, the aim is to understand how certain social structures tend to promote these crucially flawed processes, how to extricate oneself from them (insofar as that is possible), and to do one’s part in undermining them in the broader

cognitive sphere. So the idea is that there are typical ways of going wrong that need to be adverted to in light of the social structure and specific group characteristics, and one has a better chance of getting things right through a self-conscious recognition of their existence, and corresponding self-distancing from them (2007, 23).

For Mills, we should stop behaving as if our epistemological practices are neutral in regard to race. Indeed, doing so has prevented mainstream and social epistemology from recognizing white ignorance. Failure to acknowledge the relevance of social position in epistemic practices also allows other types of social ignorance to go unnoticed. In addition, there is little impetus to know, and one may even have social incentives to maintain ignorance because, as Mills puts the point, it is “functional.” Yet, when we examine the concrete effects that systematic forms of ignorance such as white ignorance have on oppressed people, it is clear that people in privileged positions have not only an epistemic but also an ethical imperative to resist the allure of ignorant complacency in favor of pursuing knowledge.

2.2.2 Wrongful requests and strategic refusals to understand

In “Wrongful Requests and Strategic Refusals to Understand” Gaile Pohlhaus Jr. argues that there are cases in which it is wrong to expect people in marginalized social positions to take on the dominant perspective. After explaining her position, I will demonstrate in section 3 that she provides concepts that are useful for clarifying ways that the status of disabled people as knowers is diminished through claims of neutrality within biomedical ethics and as well as in clinical encounters between disabled people and medical professionals.

Pohlhaus notes that in most instances it is “ethically and epistemically virtuous” to understand others (2011, 224). She states, “[b]y ‘understanding others’ I mean attending to the sense of another’s reasoning so that one is able to follow and to feel the possible force of that reasoning” (224). This also requires taking on their starting assumptions. In the majority of cases,

we *should* attempt to understand others and rightly expect them to do the same. However, Pohlhaus argues that there are situations in which it is wrong to ask a person in a marginalized social position to understand from the dominant perspective. Doing so may compromise that individual's agency, both as a knower and more generally. To be clear, Pohlhaus is not finding fault with members of marginalized groups who do understand from dominant perspectives; she points out that it may be necessary to do in order to ensure one's safety. Her focus is on those who request "that type of understanding from others" (237).

Pohlhaus uses an example from legal scholar Patricia Williams' 1992 *The Alchemy of Race and Rights* to illustrate how requests to understand may cause harm. Williams shares her experience of being denied entry to a Benetton clothing store in New York City in the 1980s due to a judgment based on her racialized appearance as black when buzzer systems were in effect to allow employees to decide whether or not individuals should be allowed to enter stores. She notes that there were "repeated public urgings that blacks understand the buzzer system by putting themselves in the shoes of white storeowners—that, in effect, blacks look into the mirror of frightened white faces for the reality of their undesirability" (Williams 1992, 46; quoted in Pohlhaus 2011, 224). The assumption was that black people should take on the perspectives of white storeowners and then they would affirm that the buzzer system was a rational response to the threat of blacks suspected of having criminal intentions. Furthermore, it is claimed that (presumably white) employees will be able to distinguish between potential customers and criminals based upon appearance alone. Thus, Williams is implored to accept the reasonableness of racial profiling, and the act of assuming this as well as the actual racial profiling both unjustifiably limit her agency.

Context and social position are very important for considering whether a request to understand is problematic or not. In the previous example, the request to understand is wrongful because it undermines the agency of Williams and other black people, but there are other cases in which requests to understand should be honored. Pohlhaus clarifies “my argument does not imply a condemnation of requests for understanding others who have something to say that we simply do not want to hear” (2011, 236). In the case of the buzzer system at the Benetton store, she contends that the white storeowner has a responsibility to understand why others hold that his actions are unjust, even though understanding this may be difficult or painful for him (236). This understanding may contribute to a change in his self-perception, but it does not unfairly constrict his agency. To ask the white storeowner to understand is not a wrongful request. Indeed, it seems that there is a moral obligation for him to understand the harm his actions and the underlying reasoning cause, regardless of his intention.

When Williams attempts to have an essay published that recounts her experience at the Benetton store and resists the dominant perspective blacks are implored to adopt, she is met with resistance from a law review journal because she insists on discussing race. The journal had a “‘race neutral’ policy that forbade reference to one’s race” (Pohlhaus 2011, 235). Williams wants to articulate and disrupt the narrative that gives sense to use of the buzzer system, but she is rendered unable to do so, given this requirement. Pohlhaus remarks:

As William’s essay reveals, in the case she describes, persons are being called to understand something that only makes sense from within patterns and practices that hold oppressive power relations firmly in place and that actively prevent those asked to understand from calling attention to this fact (231).

While black people are expected to understand a perspective sustained by asymmetrical power relations, Williams is prevented from presenting her perspective in a way that might instead lead

readers to understand that the practice of using the buzzer system contributes to the oppression of people of color.

Pohlhaus points out that the epistemic harm that may result from practices of institutions and individuals in dominant social locations need not be *intended* to harm (2011, 236). Indeed, these practices may be intended to be inclusive. She states, “[s]pecifically, one of the main insights conveyed by the [Williams’] essay is that the call for neutrality and for ‘understanding all sides’ in our communication with one another is anything but neutral and can make certain ‘sides’ of the situation invisible without appearing to do so” (Pohlhaus 2011, 232).⁴³ In this case, the demand for neutrality regarding race precludes identification and examination of racist practices. Claims to be neutral do not solve the problem at hand; worse, they obscure the power relations at play and create obstacles to addressing the problem.

There is nothing neutral about the assumptions made about people on the basis of race. While whiteness is generally treated as being neutral or normative, meaning it tends not to hinder perception of white people as individuals, blackness is homogenized, which leads to perception of black individuals through racist stereotypes.⁴⁴ In the context of thinking about the racism informing buzzer systems, Pohlhaus asserts, “Williams reveals the public debate to be grounded

⁴³ James Hamblin provides another type of example in which calling for “understanding all sides” functions as a barrier to productive discussion of an issue in the following:

The serious structural problems that most conceptions of rape culture describe—under-persecution of rapists, limited education and understanding with regard to what constitutes consent, lacking resources for victims, male entitlement, female objectification, social power dynamics, misinformation among both men and women about what constitutes rape, traditions of looking the other way, etc.—are productive to address. When the media makes an effort to “present both sides” and one of the sides involves denying the importance of these factors in sexual assault, it undermines productive discourse (2014).

⁴⁴ As Alcoff states, “A fear of African Americans or a condescension toward Latinos is seen as simple perception of the real, justified by the nature of things in themselves without need of an interpretive intermediary of historico-cultural schemas of meaning” (2006, 188).

in white privilege in ways that reduce Black persons to types of bodies considered nothing more than potential criminals” (2011, 234). She goes on to say:

Within a world that is oriented in this way, those whose bodies are identified as Black cannot simply move through the world as those whose bodies remain unmarked (in their whiteness) can, but must anticipate and negotiate within a context that already finds them suspect. Moreover, because these assumptions are built into the sense of the debate, it curtails the ability of people of color to convey this fact from within the debate (Pohlhaus 2011, 234).

Williams and other people of color are forced to deal with being interpreted through negative stereotypes, and they are prevented from pointing out the injustice of this situation because the terms of the dominant narrative do not allow for this. Neither the assumptions of the dominant narrative nor the effects are neutral.

Williams draws attention to the ways in which the terms of the debate about buzzer systems attempt to diffuse the concrete effects of this practice on individuals by focusing on abstract individuals. She notes that those who support buzzer systems go so far as to deny that they would prevent *her* from entering a store; the practice purportedly has nothing to do with Williams (2011, 233). Pohlhaus adds, “[o]f course, *every* person barred from entry to a store is a ‘*me*,’ but this point is actively discounted in the public debate by figuring the one profiled as an abstract individual whose defining characteristic is to be either a purchaser or a criminal” (233). Even the suggestion that William is an exception to the norm insofar as she is not who those who support the buzzer system have in mind is quite problematic. The move toward abstract individuals ignores the fact that Williams was denied entry to a store on the basis of being categorized as a member of an oppressed group based on her appearance.

Pohlhaus suggests that “strategic refusals to understand” may be a useful response to mitigate, if not prevent, these harms (2011, 224).⁴⁵ She cites Susan Brison’s experience of telling people that a man attempted to murder her. When pressed for more information about what happened, she added that he sexually assaulted her prior to strangling her. Upon learning this detail, Brison says that, “most inquirers were satisfied with that as an explanation” (2001, 3 as quoted in Pohlhaus 2011, 224). She expresses confusion, suggesting that it seems to her that the combination of attempted murder and sexual assault should require more of an explanation, rather than making sense. Pohlhaus notes that Brison’s confusion may be “feigned or unfeigned” (238). For this reason, I am not sure it is accurate to call Brison’s response a “strategic” refusal to understand, as she may simply not have understood. Regardless, her confusion stems from a divergence with how others are making sense of what was done to her and thus, it has the potential to invite others to question their own understanding.

Strategic refusals to understand and even moments of not understanding call into question the sense of a way of reasoning, by refusing to accept it as the neutral default. According to Pohlhaus:

a strategic refusal to understand can help us to illuminate how those institutions and practices work by bringing them out of the background and to the fore. Moreover, such refusals affirm that oppression is not necessary, but actively maintained by our interactions with each other, even at the most basic level of how we approach the world (238).

⁴⁵ In “Vulnerability, Ignorance, and Oppression,” Erinn Gilson makes a similar point. Where Pohlhaus refers to “understanding others,” Gilson uses the term “epistemic vulnerability.” Becoming epistemically vulnerable requires recognition that one does not know as well as recognition of one’s epistemic dependence on others. Gilson suggests that avoiding epistemic vulnerability—being closed off to being affected and altered—may be an act of resistance among members of oppressed groups. On this point, she states, “we must distinguish between invulnerability as a constitutive attitude that is practiced as willful ignorance—as it is for those aspiring to the position of ‘master’ subject—and a knowingly undertaken refusal of vulnerability through which one seeks to protect the self” (2011, 321).

These responses refuse to accept oppressive practices as unremarkable and present their effects on concrete individuals' lives. They invite others not only to recognize that what is treated as neutral is not but also to consider alternatives.

When people in dominant positions are closed off to being affected and altered by members of oppressed groups through refusing to understand their claims, this is ethically and epistemologically problematic. However, when members of oppressed groups refuse to understand dominant perspectives, there are cases in which this is a defense against epistemic harm. Thus, both understanding and refusing to understand can serve oppressive or liberatory aims, depending on the purpose and social situation of the person adopting them.

In the past two sections, I have shown that Harding, Scheman, Mills, and Pohlhaus all argue that assertions of neutrality serve as a screen for the interests and values of dominant groups—whether this is intentional or not. This hinders accountability and can lead to distrust among members of oppressed groups who are cognizant of the ways that purportedly neutral assumptions undermine their interests and epistemic standing. In contrast, strong objectivity, which requires transparency about the values and interests that inform our epistemic and other practices, has the potential to recognize members of oppressed groups as having cognitive authority and to increase the trustworthiness of experts.

In the following section, I will begin by examining the role that objectivity as neutrality plays in biomedical ethics. I will apply insights from epistemologies of ignorance as well as Pohlhaus' notions of wrongful requests and strategic refusals to understand in order to clarify the problematic epistemic effects of appeals to objectivity as neutrality. While there are many sorts of harm that may result from dismissal of disabled people's perspectives, I will attend specifically to *epistemic harms* occurring when disabled people are denied epistemic authority

and expected to make sense of others' claims through the lens of dominant narratives regarding disability.

2.3 Objectivity as Neutrality, Nondisabled Ignorance, and Wrongful Requests and Strategic Refusals to Understand in Biomedical Ethics

Much of the literature within biomedical ethics is premised on the ideal of objectivity as neutrality. This purported objectivity is derived explicitly or implicitly from two sources: biology/biomedicine and ethical theory—especially those influenced by ideal theory in the vein of John Rawls. I will highlight the latter here. In this section, I will begin by examining how objectivity as neutrality functions within biomedical ethics, including ways that objectivity as neutrality and ignorance are mutually sustaining. I argue that this ideal disadvantages disabled people by normalizing ableism as apolitical, which allows the concerns of disabled people and advocates to be dismissed as unreasonable and/or political. I will focus on the problem of bioethicists dismissing the claims of disabled people regarding their own reports on their QOL in favor of the projections of nondisabled people and suggest that this is best described through the framework of epistemologies of ignorance. What might be termed *nondisabled ignorance* contributes to the continuing divide between a number of bioethicists and disability advocates.⁴⁶ I use this phrase with the understanding that everyone in an ableist society—not just nondisabled people and not even uniformly among members of this group—is susceptible to it as a cognitive tendency. The problems with objectivity as neutrality that Harding identifies in scientific practices are present within biomedical ethics as well. I contend that strong objectivity is necessary in order to first make explicit which values and interests shape the epistemic and

⁴⁶ While there are ways that race and disability are disanalogous and the categories intersect within experience, I hope to show that there are parallels in the epistemic effects of racism and ableism.

ethical practices within biomedical ethics and then to shift to incorporation of values and interests arising from a critical disability standpoint.

3.3.1 Objectivity as neutrality in biomedical ethics

Mimicking appeals to objectivity as neutrality within the sciences, political theorists and ethicists have sought to prevent localized interests and values from impacting their theories. As Jaggar states:

John Rawls has tried to guarantee objectivity in a somewhat similar way [to science] by stipulating that the imaginary individuals who formulate his principles of justice should be ignorant of their own particular interests and their place in society to be regulated by those principles. By concealing their particular interests behind a “veil of ignorance,” Rawls believes himself to have guaranteed the impartiality of his imaginary political theorists and to have established an “Archimedean point,” outside the society, from which the justice of that society’s basic institutions can be evaluated objectively (Jaggar 1983, 357).

Rawls’ approach remains widely influential within normative ethics, and this is especially apparent within mainstream biomedical ethics.⁴⁷ For instance, Singer claims that reflective equilibrium is central not only to contract theory but also to ethics *tout court*. He states, “Ethics requires us to go beyond ‘I’ and ‘you’ to the universal law, the universalisable judgment, the standpoint of the impartial spectator or ideal observer, or whatever we choose to call it” (1993, 12). By moving from the viewpoints, concerns, and interests of concrete individuals to those of an abstract “impartial spectator,” Singer thinks it is possible to achieve objectivity as neutrality within ethics.⁴⁸

As discussed earlier in this chapter, feminist philosophers have called into question the ideal of objectivity as neutrality and the method of reflective equilibrium because theorists have tended to unreflectively generalize their own perspectives, including their interests, values, and

⁴⁷ It is beyond the scope of my project to delve into the relationship between Rawlsian theories of justice and the rights of disabled people. See Silvers and Francis 2005.

⁴⁸ Here he is specifically concerned with practical ethics, of which biomedical ethics is one area.

prejudices. Furthermore, there is much evidence that epistemic credibility is not strictly determined by reliability or competence. Nancy Tuana eloquently captures this critique in the following:

What feminist epistemologists and social studies theorists have carefully demonstrated is that our theories of knowledge and knowledge practices are far from democratic, maintaining criteria of credibility that favor members of privileged groups. Cognitive authority is determined by many factors, including the character of a speaker, her or his intellectual capacity, his or her reasonableness, and so on—criteria that feminists have demonstrated to be imbued with the prejudices of sexism, androcentricism, racism, classism, ageism, and ableism (Tuana 2006, 13).

Social identities impact how credible knowers are perceived to be.⁴⁹ The claim that epistemic practices are neutral makes it difficult to draw attention to this as a pervasive phenomenon rather than an episodic failure.

Kuczewski highlights the lack of democracy in knowledge production within biomedical ethics. He claims that concerns related to disability have been peripheral within the literature of biomedical ethics and, in part, this is due to bioethicists' "overidentification with the medical profession" (2001, 37). On his account, this has resulted in a disproportionate amount of attention being focused on acute care and issues that are likely to receive funding and media attention. As a corrective, he maintains that, "the field of bioethics must itself develop a conscience and dedicate itself to advocacy for those who have no money or power to offer this new profession" (37). He concentrates specifically on disabled people as a group without money or power to offer bioethics, and he contends that bioethicists should engage with and learn about their lives. Kuczewski does not think that disabled people will be the sole beneficiaries of this shift; he conceives of engagement between bioethicists and disabled people as being mutually beneficial. For example, he suggests that such engagement will lead bioethicists to more

⁴⁹ See Addelson 1983; Alcoff 2000; Fricker 2007; Medina, 2013.

carefully examine the values related to disability and visions of the good life that influence their claims (42).

In his “Response to Mark Kuczewski” Singer asserts:

Bioethics, as a field or discipline, should not dedicate itself to advocacy for anyone. Its only commitment, as a field, is to pursue knowledge and understanding with integrity and respect for the views of other scholars in the field... Individual bioethicists who come across something that they regard as wrong may choose to dedicate themselves to advocacy for the cause of those who they see as wronged, but if they become mere partisans, dismissing without adequate consideration the views of others who are not advocates for the same group, they risk becoming propagandists rather than scholars. The difference lies in the readiness to consider and perhaps even be moved by good arguments that count against a position one has previously held (2001, 55).

When the prospect of including critical disability standpoints is considered, bioethicists such as Singer are quick to point out the dangers of introducing politics into bioethics and engaging in propaganda.⁵⁰ However, they fail to notice that bioethics already serves particular agendas and is thoroughly political. They also lack the reflexivity to identify their own failure to “consider and perhaps even be moved by good arguments” and evidence (Singer 2001, 55). By claiming to be neutral while dismissing the claims of disabled people regarding their experiences, Singer and other bioethicists risk becoming propagandists rather than scholars. The guise of objectivity as neutrality prevents reflexivity about the impact of social values and interests on knowledge production within biomedical ethics and allows for continued nondisabled ignorance.

Although the factors Kuczewski identifies may have a role in shaping bioethicists’ epistemic practices (especially what areas are worth knowing about), he does not develop ways that bioethicists’ social positions and nondisabled ignorance are relevant. Kuczewski does note

⁵⁰ In response to the Washington Protection and Advocacy System’s recommendation that disability advocates be included in ethics committees at Seattle Children’s Hospital, physician Douglas Diekema states, “ethics committees are not for people with political agendas” (Kafer 2013, 60). Kafer suggests that Diekema “positions people living with disability—family members, disability advocates, and disabled people...as political actors in ways that doctors and bioethicists are not” (Ibid.).

that the failure of bioethicists to engage with disabled people is akin to a research community composed of white males that only does research on white males (2001, 42). However, his account neither explores the reasons that bioethicists have had minimal engagement with disabled people (other than those noted above) nor the failure of this engagement to substantially impact most bioethicists' claims about disability. While Kuczewski's recognition of some of the ways that social values and interests impact research within biomedical ethics is an important contribution, these additional factors also need to be examined.

3.3.2 Nondisabled ignorance and quality of life

Because bioethicists such as Dan Brock, Norman Daniels, Jeff McMahan, and Peter Singer are so certain that they know the relationship between disability and quality of life (QOL), not only do they think of empirical research as unnecessary, they dismiss the credibility of such research in various ways when they are forced to contend with it. Amundson critiques bioethicists who take this approach, maintaining that their judgments about disability are shaped by social stigma and ignorance rather than objectivity (2005, 110-113). He asks, when the topic is the QOL of disabled people, "Why should the opinions of nondisabled people be epistemologically privileged over those of disabled people?" (2005, 112) In the following, I will build on Amundson's work in order to further develop an understanding of the influence of ableism and ways that ignorance about disabled people's experiences is sustained and treated as knowledge within biomedical ethics.

Nondisabled ignorance is manifested in bioethicists' discussions of the QOL of disabled people. As discussed in chapter 1, bioethicists are likely to endorse what Amundson terms the *standard view*, "that disabilities [impairments] have very strong impacts on the quality of life of

the individuals who have them” (Amundson 2005, 103).⁵¹ The idea is that the biomedical conditions of individuals necessarily reduce QOL, apart from social factors. In fact, nondisabled people estimate that the QOL of disabled people is significantly lower than disabled people themselves report (Amundson 2005, 103; Silvers 2005, 58). On average, disabled people rate their QOL as only slightly lower than nondisabled people rate their own QOL (Amundson 2005, 103; Amundson 2010a). Yet, bioethicists commonly characterize impairments as inevitably significantly reducing opportunities and QOL.

The assumptions that bioethicists tend to make regarding disability conflict with the perspectives and interests of disability rights advocates and disabled people. The problem is not that bioethicists are unfamiliar with these perspectives; i.e., a simple lack of knowledge that could be corrected once they are provided with testimonies of disabled people. Some bioethicists who hold the standard view explicitly engage with perspectives that *ought* to lead them to question this view. Instead, countervailing evidence is typically mischaracterized or dismissed altogether. Evidence contrary to the standard view is abundant in narratives of disabled people and in psychological studies on the effect of impairments such as spinal cord injuries on QOL (Albrecht and Devlieger 1999; Amundson 2010; Gerhart et al. 1994). Yet, many bioethicists ignore or dismiss this evidence in two ways: 1) by calling into question the credibility of disabled people and 2) by continuing to equate an impairment with a person with an impairment’s life as a whole. Bioethicists sometimes attempt to justify the former approach by claiming that disabled people lack the ability to be objective about the quality of their own lives, while nondisabled people are able to perceive the quality of disabled people’s lives objectively (Amundson 2005). As Silvers puts it, “It is, further, epistemologically aberrant to grant precedence about anomalous

⁵¹ As discussed in chapter one, the standard view is in line with what Elizabeth Barnes terms the “bad-difference view of impairment” (2014).

health states made by species-typical people over those made by individuals actually experiencing those health states. Ordinarily we defer to first-person reports of subjective states” (2005, 60). The phenomenon with which I am concerned is the practice of privileging the dominant narrative of the standard view and refusing to grant epistemic authority to disabled people. The pervasiveness of bad epistemological practices among bioethicists, whom we expect to know better, demands explanation.

Amundson provides examples of bioethicists’ claims to objectivity in regard to disabled people’s QOL. Dan Brock claims that serious disabilities usually lower a person’s QOL and cites the Americans with Disabilities Act’s (ADA) definition of disability as limiting at least one major life activity. Amundson notes that, “It might be argued that it is a matter of empirical fact that limitations in walking and seeing [examples of major life activities] are associated with lower QOL. This would require empirical data about the correlation. Brock offers no data of this sort” (2005, 108). Sometimes Brock attempts to narrow the scope of this claim by saying that he is referring to health-related aspects of QOL (Amundson 2005, 108). Regarding the concept of health-related quality of life (HRQOL) as opposed to QOL, Amundson suggests that it can be used for “gerrymandering of social problems into medical ones” (2005, 117). He argues that the Health Status Index (HSI)—an instrument designed to measure HRQOL and endorsed by Brock—demonstrates how this occurs. Even the supposedly objective (in the sense of being neutral) measures for “physical activity” and “mobility” privilege typical modes of function rather than attending to level of function and evaluating the accessibility of the built environment rather than bodily capacities (2013, 484; 2005, 109-110). In addition, there is a conceptual jump from biomedical limitations to judgments about QOL.

Brock demonstrates awareness that disabled people, on average, report an only slightly lower QOL than nondisabled people and a much higher QOL than nondisabled people estimate they have (2005, 108). Rather than questioning the correctness of the standard view, Brock makes a distinction between subjective and objective QOL. Amundson states, “Subjective QOL is how happy or satisfied one is with one’s life. Objective QOL is how well one’s life is *really* going” (2005, 109). Brock’s move to discredit the reports of disabled people fits into a larger pattern of epistemic practices in which the perspectives of nondisabled people are taken to be objective, while disabled people’s perspectives are thought to be deluded or merely subjective.

Singer goes so far as to claim that the lives of disabled people are less worth living than the lives of nondisabled people, stating:

It may still be objected that to replace either a fetus or a newborn infant is wrong because it suggests to disabled people living today that their lives are *less worth living* than the lives of people who are not disabled. *Yet it is surely flying in the face of reality to deny that, on average, this is so.* That is the *only way* to make sense of actions that we all take for granted [my emphasis] (1993, 188-189).

Singer fails to recognize that endorsement of the ableist *assumption* that the lives of disabled people are less worth living is sufficient for social practices such as selective abortion to make sense. He contends that when disabled people report a QOL that is comparable to that reported by nondisabled people, we should not take this “at face value” (2009, 207). He agrees with the suggestion that people with severe impairments “‘adjust their expectations’ or ‘lower their expectations in life’” (Cowen 2009, 208). For Singer, if disabled people report similar levels of QOL to nondisabled people, the definition of QOL must differ *and* not measure up to that of nondisabled people.

Similarly, Norman Daniels states that, “‘people with long-standing disabilities will often rank their welfare higher than would other people who are merely imagining life with such

disabilities' and he speculates that 'perhaps people with disabilities accommodate by adjusting their goals and expectations'" (Silvers 2005, 58). Daniels contends that disabled people "lack the objectively fair share of opportunity that normal or species-typical functioning would provide" (2005, 58). Apparently, nondisabled people are the only ones capable of noticing that disabled people lack the opportunities that species-typical function provides. Daniels grants the imaginations of nondisabled people about what it is like to live as a disabled people more credibility than the reports of disabled people.⁵²⁵³ Silvers compares this approach to a Chinese woman reporting being satisfied with Chinese haute cuisine. In this analogy, she may be telling the truth, but the researcher who views French cuisine as the gold standard thinks she is wrong not to be upset that French cuisine is unavailable to her. Silvers asserts, "It would, of course, be odd to say that the subject has adapted because she reports being eminently satisfied by Chinese haute cuisine, and odd as well to say that she is mistaken in being so satisfied" (Silvers 2005, 59). So, too, Silvers thinks it is problematic to take normal health and species-typical functioning to be the objective standard that everyone should desire.

Even while claiming to have the interests of disabled people in mind, many bioethicists undermine the claims of disabled people and dismiss disability rights perspectives. Buchanan et al. state, "disabilities as such diminish opportunities and welfare" (2001, 278). In *From Chance*

⁵² Singer advocates "empathetic imagination" as a method for figuring out the interests of disabled people rather than engaging with actual disabled people (1993, 53). I discuss and critique this approach in "A Philosophical Investigation: Interrogating Practices and Beliefs about Disability" (2012). In short, I claim that when a nondisabled person tries to imagine the interests and what it is like to live as a disabled person without consulting disabled people, "her main 'resources' for doing so will likely be stereotypes of disability and her own fears. Iris Marion Young warns, 'The perspective of the other can too easily be represented as the self's other represented to itself-fantasies, desires, and fears' (1997, 347)" (2012, 38).

⁵³ Larry May notes, "as one gets further and further removed from the actual experience, and as the pool of experiences upon which one draws is less and less analogous to the actual experience, the powers of imagination are more and more strained" (1998, 341). His position is that while it is not impossible to gain understanding based upon other people's experiences, this requires engagement with those who have had the relevant experience as well as examination of one's own biases (338).

to Choice, Buchanan et al. appeal to the notion of fair share of opportunities in order to provide justification for their position that there is a moral duty to provide health care in order to maintain, restore, or achieve the normal functioning of individuals when possible. *Prima facie*, this may seem unproblematic. After all, disability advocates argue that disabled people have a right to appropriate health care. However, in addition to premising their argument on a necessary causal relationship between impairment and reduced opportunities, Buchanan et al. imply that disabled people have a responsibility to avail themselves of normalizing medical interventions.

In regard to research on QOL, Silvers notes that there is a difference between discussing the “burden of blindness” versus the “burden of life with blindness” (2005, 54). This way of discussing blindness acknowledges that blindness can pose a burden without necessitating that life with blindness itself is a burden.⁵⁴ She states, “It is consistent to think that being blind is a burden, an obstacle that one must constantly work to overcome, but that being alive while blind is not a burden, regardless of the challenges associated with being blind” (2005, 54). The distinction between the effects of an impairment and the overall life of a person with an impairment is elided in much of the literature within biomedical ethics.⁵⁵ Adrienne Asch’s term “synecdoche” provides a useful descriptor for this trend. She states that her use of this term refers not to “the literary device, in which the part stands in for the whole, but the characteristic response to a stigmatized trait, in which the part obscures or effaces the whole” (Asch and Wasserman 2005, 173). Bioethicists often engage in synecdoche in the context of discussing

⁵⁴ It should be noted that not everyone thinks that blindness is a burden at all. At the very least, it must be acknowledged that there is likely to be a tremendous difference in the experience of a person who lives with blindness from birth in contrast to a person who acquires this impairment.

⁵⁵ For example, Singer claims that it is not bias that leads nondisabled people to assume that the lives of disabled people are worse than their own. “He hypothesizes that most people who use wheelchairs would prefer to ‘have full use of their legs’ and cites this as evidence that the claim that the lives of people with disabilities are inferior to the lives of those without disabilities is not a mere prejudice” (Wieseler 2012, 39).

genetic and prenatal testing, selective abortion, healthcare rationing, physician-assisted suicide, and euthanasia. Acknowledging that there is a distinction between an impairment and a person with an impairment's life as a whole is necessary for understanding how it is that a person can have atypical function or morphology and a high QOL.

Bioethicists who endorse the standard view often misunderstand or dismiss the claims of disabled people because of this tendency to engage in synecdoche. For example, McMahan seems to conflate Harriet McBryde Johnson's claim that the assumption that disabled people have a lower QOL than nondisabled people with the claim that impairments are neutral traits in the following:

many people, especially among the disabled themselves, contend that it is no worse to be disabled than not to be. They claim that disabilities are "neutral" traits. So, for example, Harriet McBryde Johnson (2003), a disabled lawyer, emphatically repudiates the "unexamined assumption that disabled people are inherently 'worse off,' that we 'suffer,' that we have lesser 'prospects of a happy life'" (McMahan 2013, 551).

Although disability rights advocates *do* sometimes make the claim that impairments are neutral, it seems clear that this is *not* the claim Johnson is making here. Rather, she is suggesting that ableist assumptions often remain unexamined and that it is false that "disabled people are inherently 'worse off'" than nondisabled people (2013, 551). Elsewhere, McMahan seems to comprehend that it is possible to maintain both that impairments may cause difficulties in themselves and that people with impairments need not have a lower QOL than nondisabled people.⁵⁶ Yet, he defends the preference for a nondisabled child to a disabled child on the assumption that "her quality of life would be higher than that of a disabled child" (2005, 148). McMahan seems to assume that parental acceptance of their disabled child means that rather than wishing they had a different non-disabled child, they "focus their hopes on the possibility of a

⁵⁶ McMahan even concedes, "Some disabled people, indeed, have lives that go conspicuously better than the lives of most people without disabilities" (2005, 143-144).

cure” (2013, 552). Many bioethicists have a difficult time taking disabled people’s claims seriously. Even if they succeed momentarily, they are prone to nondisabled ignorance as a cognitive tendency.

To situate epistemically problematic practices within biomedical ethics, it is useful to consider the broader social context that reinforces nondisabled ignorance and presents it as knowledge. For example, many disability theorists have noted that the media tend to represent disabled people in dichotomous terms: as tragic or heroic figures (Clare 2009; Kafer 2013; Longmore 2013; Johnson 2005; Riley 2005; Wendell 2008). The notion of disabled people as tragic, helpless figures—victims—is prevalent within films, television shows, books, magazine and newspaper articles, and fundraising campaigns. In discussing the technique of renowned screenwriting teacher Syd Field of using visible impairments to convey character flaws, Amundson asserts that he might as well have said, “Physical impairment is popularly associated with character flaws. Like other social prejudices, this stigma can be usefully exploited in constructing screen plays” (2010a, 173). Amundson notes that when this ideology is adopted, a disabled person is typically presented as “bitter and angry at the world because of their impairment,” as deserving to have acquired the impairment because of a character flaw, or as having a character flaw that is “symbolically reflected in their impairment” (173). An alternative to these types of presentation is the poster child, typically a young child with a visible impairment, representing “innocent suffering” (Longmore 2013, 35). The Jerry Lewis telethon run by the Muscular Dystrophy Association, which ran from 1956 through 2015, is probably the most famous fundraising campaign on behalf of disabled people; Charles Riley claims it was “the primary source of media exposure for most nondisabled Americans” (2005, 13). In addition to evoking pity and motivating viewers to make donations, this type of portrayal of disabled

people also urges nondisabled people to “be grateful for what they have” and to recognize that no matter how badly things are going for them, at least they aren’t disabled!⁵⁷ Paul Longmore adds “charity images portrayed them [Americans with disabilities] as dependent objects of beneficence whose most important needs were medical” (38). The medical model’s influence is readily apparent as well as the view that addressing the needs of (deserving) disabled people is a matter of charity rather than justice (Kittay 2002, 271). Underlying these portrayals is the longstanding practice of attempting to sort out the disabled people who deserve charity from those who do not.

Another popular way to portray disabled people is through the overcoming narrative. To clarify this notion, I turn to Simi Linton’s explanation:

One interpretation of the phrase [overcoming a disability] might be that the individual’s disability no longer limits her or him, that sheer strength of willpower has brought the person to the point where the disability is no longer a hindrance. Another implication of the phrase may be that the person has risen above society’s expectation for someone with those characteristics. Because it is physically impossible to *overcome* a disability, it seems that what is *overcome* is the social stigma of having a disability (Linton 1998, 17).

This type of narrative might be thought of as the opposite of the tragic narrative. Rather than evoking pity, the overcoming narrative provides members of the audience—whether they are viewers or readers—the opportunity to rejoice in a disabled person’s triumph over difficult circumstances through adoption of a positive attitude. It tends to decontextualize people with impairments and to focus only on impairment-related aspects of their lives.

Wendell suggests that the primary purpose of overcoming narratives—which are also referred to as “supercrip narratives”—is to bolster the myth that it is possible to control the body (Clare 2009, 2). She states, “some disabled people also become symbols of heroic control against all odds; these are the ‘disabled heroes,’ who are comforting to the able-bodied because they re-

⁵⁷ This idea is succinctly captured in the phrase “I cried because I had no shoes until I met a man who had no feet” (variously attributed).

affirm the possibility of overcoming the body” (Wendell 2008, 835). Of course disabled people are also problematically inundated with this narrative and expected to fulfill the role of disabled heroes. Regarding this, Wendell remarks:

While disabled heroes can be inspiring and heartening to the disabled, they may give the able-bodied the false impression that anyone can “overcome” a disability. Disabled heroes usually have extraordinary social, economic and physical resources that are not available to most people with those disabilities (2008, 835).

Social factors are generally not taken into consideration in such cases—individual effort is the primary focus. Amputee athletes and models, in particular, have received a great deal of attention in the media for being “disabled heroes.”⁵⁸ Wendell points out that they are exceptions insofar as they tend to be “in better health than most disabled people” (2008, 835).

One of the problems with both tragic and overcoming narratives of impairment is that they fail to provide realistic accounts of the everyday experiences of disabled people. Eli Clare asserts, “[t]he dominant story about disability should be about ableism, not the inspirational supercrip crap, the believe-it-or-not disability story” (2009, 3). This framing of the issue conceives of disability as an individual, biomedical condition rather than considering the role of social factors in supporting atypical function or creating obstacles for people with impairments including lack of accessible housing and transportation as well as a much higher poverty rate than the nondisabled population. In addition, disabled people are likely to face problematic

⁵⁸ For instance, Charles Riley remarks:

Every time Aimee Mullins sees her name in the papers she braces herself for some predictable version of the same headline followed by the same old story. Paralympian, actress, and fashion model, Mullins is a bilateral, below-the-knee amputee, who sprints a hundred meters in less than sixteen seconds on a set of prostheses called Cheetahs because they were fashioned after the leg form of the world’s fastest animal. First, there are the headlines: “Overcoming All Hurdles” (she is not a hurdler, although she is a long jumper) or “Running Her Own Race,” “Nothing Stops Her,” or the dreaded and overused “Profile in Courage.” Then come the clichés and stock scenes, from the prosthetist’s office to the winner podium. (...) Mullins’s “inspiring” saga is recycled almost verbatim by well-meaning journalists for audiences who never seem to get enough of its feel-good message even if they never actually find out who Mullins is (2005; ix).

attitudes that are pervasive within society about what it is like to be disabled, how disabled people ought to look and behave, and the related notion that nondisabled laypeople are authorities on impairment (Samuels 2014, 130-140). When bioethicists reduce disability to the medical condition of an individual, they fail to recognize the impact of power relations between disabled and nondisabled people and the ways that disabled people have been and continue to be oppressed through lack of accessibility, forced sterilization, institutionalization, stigmatization, and being judged globally incapable, regardless of actual abilities. When the attitude and efforts of the individual are portrayed as the sole causes of success or failure, then the individual alone is praised or blamed for how well she is able to negotiate the world. Disability is medicalized and de-politicized. Silvers states, “Because people with chronic pathologies have been a powerless minority, the political pressure to acknowledge their standpoints heretofore has not been great” (2005, 63). Nondisabled ignorance is the *status quo* in the context of societies that marginalize disabled people, and it also tends to be the starting point within biomedical ethics.

To this point, the current section has discussed the tendency of bioethicists to sustain ignorance about the lives of disabled people, which I have termed nondisabled ignorance. Bioethicists commonly dismiss the reports of disabled people about their own QOL, if these accounts are referenced at all. I have suggested that ignorance of disabled people’s lives is not a simple lack of knowledge, but rather a phenomenon that must be understood within a broader social context in which disabled people are marginalized. Brock, Singer, Daniels, Buchanan et al., and McMahan start from the assumption that the lives of disabled people *must* be of a lower quality than the lives of nondisabled people, and this prevents them from taking the reports of disabled people seriously.

3.3.3 *Wrongful requests and strategic refusals to understand in biomedical ethics*

In this portion of the chapter, I turn to bioethicists' expectation that disabled people understand the standard view of disability, which fits Pohlhaus' description of wrongful requests due to the effects on disabled people's epistemic agency. When the standard view of disability is accepted as the neutral given, this undermines the claims of disabled people while making it difficult to draw attention to this harm. In addition, when bioethicists refuse to understand the claims of disabled people about their own experiences, they treat nondisabled ignorance as knowledge, rather than questioning their presuppositions.

There are important parallels between Williams' experiences of attempting to point out the racism and harm inherent in the practice of having buzzer systems at stores in New York City and the attempts of disabled people to point out the ableism and harm inherent in epistemic practices of many bioethicists. Like those who focus on abstract individuals in discussion of the buzzer systems, bioethicists such as Singer attempt to distance their support of social practices from the effects on concrete disabled people and potential parents. Just as Williams refused to allow others to claim that the buzzer systems wouldn't affect *her*, Johnson draws out the implications of Singer's arguments in favor of selective abortion and infanticide on the basis of potential or actual impairment. She states:

He insists he doesn't want to kill me. He simply thinks it would have been better, all things considered, to have given my parents the option of killing the baby I once was, and to let other parents kill similar babies as they come along and thereby avoid the suffering that comes with lives like mine and satisfy the reasonable preferences of parents for a different kind of child. It has nothing to do with me. I should not feel threatened (Johnson 2009, 291).

While it is true that Singer makes a distinction between persons, who are capable of having an interest in continuing to live, and fetuses and babies, to say that his position has *nothing* to do with Johnson seems disingenuous. As she points out, he does think that lives like hers entail so

much suffering that it is better to prevent such lives from continuing through selective abortion or infanticide. Singer says this in the face of concrete disabled people, including Johnson, telling him that their lives are worthwhile and cannot be reduced to suffering. He claims to be simply reporting the truth about disabled people's lives, when he is actually promulgating ignorance and making it more likely that practices such as selective abortion will be perceived as the only reasonable choice. Singer does this in the name of objectivity as neutrality, but his position is clearly value-laden. His appeals to abstraction do not erase the effects that his nondisabled ignorance has on concrete individuals.

Singer expects disabled people to understand that nondisabled people think that their lives are less worth living than their own. He thinks that if disabled people were being objective they would realize the truth of this claim. Once again, I turn to Johnson's response to interacting with Singer in person and reading his work. She muses:

How can he put so much value on [nonhuman] animal life and so little value on human life?

That last question is the only one I avoid. I used to say I don't know; it doesn't make sense. But now I've read some of Singer's writing, and I admit it does make sense—within the conceptual world of Peter Singer. But I don't want to go there. Or at least not for long (Johnson 2009, 293).

Singer invites us into his "conceptual world" in which the empathetic imaginations of nondisabled people carry more weight than the testimonies of disabled people and in which it is speciesist to value people with severe impairments more than nonhuman animals. Within the terms of Singer's conceptual world, one is unable to make sense of how his position could be harmful; after all, his goal is to prevent harm by preventing people with severe impairments from existing. However, his reasoning actually relies on a number of assumptions that create harm—epistemic and otherwise. Through her resistance to Singer's narrative, Johnson clarifies the

wrongness of his request to understand. By refusing to understand, by refusing to take on his ableist assumptions and follow his reasoning, it is possible to conceive of other ways of understanding that preserve the epistemic agency of Johnson and other disabled people.

If Singer alone engaged in wrongfully requesting that disabled people understand, it would be possible to chalk this up to idiosyncrasy and the harmful effects would be minimal. However, as the preceding examples of nondisabled ignorance show, this practice pervades discussions of QOL within biomedical ethics. Worse, since bioethicists' assumptions about disability reflect the prevailing assumptions within the broader society, disabled people are confronted with requests—often quite unwelcome demands—to understand that nondisabled people view their lives as burdensome. Again, I turn to Johnson's poignant words to illustrate. She states:

Strangers on the street are moved to comment:

I admire you for being out; most people would give up.
God bless you! I'll pray for you.
You don't let the pain hold you back, do you?
If I had to live like you, I think I'd kill myself (Johnson 2009, 294).

This is where the empathetic imaginations of nondisabled people lead, when unaided by knowledge of actual disabled people's experiences and perspectives. We might think that scholars would be more careful in examining their assumptions, but, in many cases, they are only better at disguising their reasoning proceeding from these assumptions as wholly rational, value-free assessment rather than value-laden responses informed by ignorance.⁵⁹

⁵⁹ Though beyond the scope of the current project, it is important to examine ways that such social values and assumptions impact epistemic practices in medicine as well. Appeals to objectivity as neutrality may serve to undermine the epistemic agency of disabled people in the context of engaging with healthcare professionals, as Wendell observes in the following: “[b]ecause almost everyone accepts the cognitive authority of medicine, the person whose bodily experience is radically different from medical descriptions of her/his condition is invalidated as a knower” (Wendell 2008, 838). Likewise, Anita Ho contends “when a value-laden process that often has negative impact on people with impairments is disguised as

Barnes provides an eloquent testimony of her experiences in philosophy classes of being asked to understand that the lives of disabled people—including her own—are less valuable than the lives of nondisabled people. She states:

I have sat in philosophy seminars where it was asserted that I should be left to die on a desert island if the choice was between saving me and saving an arbitrary non-disabled person. I have been told it would be wrong for me to have my biological children because of my disability. I have been told that, while it isn't bad for me to exist, it would've been better if my mother could've had a non-disabled child instead. I've even been told that it would've been better, had she known, for my mother to have an abortion and try again in hopes of conceiving a non-disabled child. I have been told that it is obvious that my life is less valuable when compared to the lives of arbitrary non-disabled people. And these things weren't said as the conclusions of careful, extended argument. They were casual assertions. *They were the kind of thing you skip over without pause because it's the uncontroversial part of your talk* [emphasis added].

Now, of course, no one has said these things to me specifically. They haven't said "Hey, Elizabeth Barnes, this is what we think about you!" But they've said them about disabled people in general, and I'm a disabled person. Even just thinking about statements like these, as I write this, I feel so much – sadness, rage, and more than a little shame. It's an odd thing, a hard thing, to try to take these emotions and turn them into interesting philosophy and careful arguments. (...) It's a strange thing – an almost unnatural thing – to construct careful, analytically rigorous arguments for the value of your own life, or for the bare intelligibility of the claims made by an entire civil rights movement (Barnes, 2015).

Because ableism sets the terms of the discussion and involves an asymmetrical power relation between disabled and nondisabled people, it is difficult for disabled people to call into question the devaluing of their lives. Just being put in the position of trying to convince others that your life and the lives of people like you are worthwhile constitutes harm, which is compounded when pervasive ableism prevents them from taking you to be credible. Strategic refusals to understand have the potential to facilitate a shift in ableist assumptions, but it is important to point out that disabled people are under no obligation to engage in this epistemic work. The primary responsibility ought to be on nondisabled people to overcome nondisabled ignorance.

scientifically objective, patients' ability to negotiate appropriate responses to their concerns can be limited" (Ho 2011, 111).

In the following section, I consider Silvers' response to the "growing contentiousness between disability and bioethics communities" (2003, 473). She argues it is necessary to eliminate interests and values from conceptualizations of disability. Although Silvers does not use the term "objectivity" in either of her essays discussing a neutral conception of disability, the method she recommends for developing three types of conceptual neutrality is akin to procedures meant to ensure objectivity as neutrality within ethics as well as scientific, historical, and sociological research.

2.4 Conceptual Neutrality and Disability

As discussed at the beginning of this chapter, Silvers advocates developing a "neutral conception of disability" in order to facilitate dialogue between bioethicists and disability advocates. She states that one of her goals is to dispel the "conceptual underbrush that makes us think our idea of disability must be value-laden" (2003, 473). Silvers claims that her method of analyzing prevalent positions on the side of bioethicists and disability advocates in turn and then making recommendations for each side leads to value-free ways of thinking about disability. She recommends three types of conceptual neutrality: neutrality in valuing disability, neutrality in modeling disability, and neutrality in adopting a cooperative social framework (2003, 475). Although my conclusions apply to all of these types of conceptual neutrality, I will limit my discussion to neutrality in valuing disability in order to illustrate that Silvers' approach is value-laden. Rather than constituting a shortcoming, I argue that, with the appropriate level of reflexivity, this is a strength.

2.4.1 Neutrality in valuing disability

Central to this aspect of conceptual neutrality is beginning with “a neutral stance in regard to the intrinsic value of being disabled” (Sivers 2003, 475). Silvers maintains that bioethicists must set aside their assumption that impairments are inherently bad and reducing its incidence is “unquestionably good” (2003, 475). She notes that medical interventions intended to normalize function or appearance can cause harm and reduced level of functionality. Elsewhere, Silvers makes a distinction between mode and level of function, which is helpful for clarifying her point here. A *mode of function* is “the way it [a task] is accomplished,” while *level of function* is a measure of how well it is performed (1998, 101). Thus, a person could perform a function at a typical level using an atypical mode or she could perform a function at a low level using a typical mode. Silvers is concerned with the second scenario, which has at times been judged by medical professionals to be a better outcome than the first scenario.⁶⁰

Furthermore, she suggests that medicine’s preference for normalcy leads physicians to underestimate the risks of medical interventions meant to normalize (2003, 476). It is sometimes assumed that patients should want to eliminate or reduce the effects—whether related to appearance or function—of impairment at all costs. This way of thinking can make the risks of medical intervention seem minimal compared to the “risk” of living with the limitations of impairment. As a result, Silvers recommends empirical research to discover if a given medical intervention actually improves the lives of disabled people rather than assuming it is superior to living with an atypical appearance or mode of functioning.

⁶⁰ Silvers gives the following example:

adults with upper limb phocomelia (congenitally anomalous arms), such as are occasioned by pre-natal exposure to thalidomide, often believe themselves to have been injured as children by having had their natural digits amputated, been fitted with ineffective artificial arms, and forbidden to use the much more functional method of manipulating objects with their feet (2003, 475).

Silvers' recommendations are not value-free or disinterested. The value of normalcy/typical mode of function is put into question in order to consider the priority that disabled people may place on level of function. While she asks bioethicists (and presumably medical professionals) to examine their assumptions about impairment, the motivation is to serve the best interests of disabled people. Empirical research is meant to test some of these ableist assumptions and would constitute a challenge to cultural imperialism insofar as it includes disabled people's accounts. Thus, it seems that Silvers' desideratum is for the inclusion of disabled people's interests in valuing disability rather than a disinterested and value-free account.

Silvers calls on disability advocates to: 1) be open to acknowledging that being disabled is contingently harmful, 2) cease their categorical insistence "that life with a disability is always worth living," and 3) stop assuming that all medical interventions intended to eliminate disabilities "express bias against disabled people" (2003, 476). This third assumption is sometimes referred to as the "expressivist argument" within the biomedical ethics literature and is often discussed in the context of genetic and other prenatal testing and selective abortion (Kass [1973]2013; Buchanan et al. 2000; McMahan 2005; Singer 2006; Asch and Parens 2012).

Regarding the first point, it is important to understand why disability advocates have sometimes avoided acknowledging that impairment is contingently harmful (2003, 476).⁶¹ When disability advocates make this claim, they are attempting to counter the influence of the bad-difference view of impairment, the tendency to assume that if a person has an impairment they are wholly incapable in ways that have nothing to do with the impairment, and the pervasive notion that people with impairments ought to be pitied (Wendell 1996; Kafer 2013; Barnes 2014).

⁶¹ I use the term "impairment" here rather than Silvers' phrase "being disabled" because disability advocates have consistently recognized that being disabled is harmful. Because Silvers doesn't consistently use the terms "impairment" and "disability" as the social model prescribes, I think my substitution is justified. Based on the context, I think use of "impairment" captures what she means here.

They have had success in showing that there is not a necessary link between bodies with impairments and an inferior status within society, but it is feared that discussion of the limitations and pain inherent in some impairments will negatively affect the tenuous progress that has been made in social understandings and policies.

The factors that have lead disability advocates to avoid acknowledging that impairment is contingently harmful are even more salient when we consider the “insistence that life with a disability is always worth living” (Sivers 2003, 476). This is a strong, but I think, understandable response to the view that it is better not to be born or to be dead than disabled. As Kuczewski puts the point, “Behind the right to refuse life-sustaining treatments, the disabled hear a voice saying ‘I would rather be dead than live like you’” (2001, 42). Some disability advocates distrust the broader community, especially bioethicists, to the extent that they do not want to concede anything that may serve to bolster agendas contrary to their interests. Historically, this distrust has been warranted. It seems that the onus is on bioethicists to demonstrate trustworthiness by taking the accounts of disabled people and their advocates seriously.

Third, Sivers considers debates around the so-called expressivist argument to be especially unproductive, stating that neither side has been “fully coherent” (2003, 476). She cites the response of Buchanan et al. that only *disabilities* are devalued within medicine and among bioethicists, not *people* with disabilities.⁶² Sivers points out that the two are often inseparable in practice, stating “Treating disabilities means treating patients. So where medical practice devalues disability, patients with disabilities are made vulnerable by medicine’s fatal attraction to normalcy” (476). On the other side, she charges disability advocates with inconsistency when

⁶² McMahan makes a similar claim in the context of discussing the preference for a nondisabled child, stating “We have to acknowledge that some people’s [nondisabled people’s] lives go better than others’ [disabled people’s]. This is a judgment about the *contents* of people’s lives, not about the people themselves” (2005, 148).

they claim that attempts to prevent impairment express bias and also seek medical interventions in order to prevent impairment. She judges that it is implausible that medical procedures themselves “are the cause of disregard for disability” and suggests that we should consider the influence of broader social attitudes on medicine that recommend procedures such as selective abortion and sterilization of disabled people (2003, 476).

All three of Silvers’ recommendations for disability advocates in regard to valuing disability call for greater inclusion of diverse experiences of impairment and critique of the assumptions made by bioethicists and disability advocates. I would argue that the goals are to serve the interests of disabled people and to develop a more honest and comprehensive concept of disability [impairment]. Her suggestions are more congruent with strong objectivity than neutrality. In spite of her call for conceptual neutrality regarding disability, her recommendations clearly involve considerations of values and interests. I would characterize her approach as involving interrogation of views that are common among bioethicists as well as the opposing views articulated by members of the disability rights community. She considers why each side considers its position to support the interests of disabled people and suggests that both sides need to set aside rigid generalizations (e.g. “life with an impairment is always inferior to life without one” or “life with an impairment is always worth living”). Though she doesn’t frame her discussion in this way, Silvers demonstrates that she is, ultimately, concerned with developing ways of conceptualizing disability that incorporate the concerns and interests of disabled people.

I would suggest that one of the reasons disability advocates’ perspectives are not well-integrated within the literature of biomedical ethics is that bioethicists who think their conceptions of disability are value-free and apolitical consider it epistemically egregious to incorporate views that they consider value-laden and political. Silvers underestimates the

obstacles that prevent many bioethicists from questioning their assumptions about disability and taking the perspectives of disabled people and their advocates seriously—including the view that their conceptions are *already* neutral and that they *know better* than disabled people.

2.5 Conclusion

Disabled people as a group and their allies have a privileged epistemic vantage point on their own lives. Ultimately their accounts ought to serve to fundamentally alter the terrain of discussions within biomedical ethics. The burden of proof regarding claims about the QOL of disabled people ought to be on those whose positions are in line with social prejudices rather than on those who have knowledge of disability based on experience.

Amundson remarks, “When our ‘objective’ judgments happen to match our own social prejudices, that coincidence alone should make us wary of our own objectivity” (2005, 113). Of course, the lack of recognition that one has social prejudices—especially when these prejudices are commonly endorsed—is a substantial obstacle to identification of this coincidence. This is exactly why strong objectivity is needed within biomedical ethics. It is only through the identification and uprooting of dominant prejudices currently maintained under the guise of objectivity that epistemic practices within biomedical ethics can become more trustworthy and work toward alleviating rather than perpetuating oppression of disabled people.

Just epistemic practices involve humility on the part of knowers, and I have suggested that they also require taking the knowledge and experiences of others seriously. In chapter three, I will examine debates within feminist theory on the epistemic value of experience because they are informative for thinking about the status of experience and the body within disability theory.

CHAPTER THREE: THE IMPAIRMENT/DISABILITY DISTINCTION, THE BODY, AND THE STATUS OF EXPERIENCE

Experience is then not a series of data with transparent meaning, and does not provide “incontestable evidence” for a single interpretation. However, it is and must be the basis of explanation. There is no conceivable alternative basis or ultimate justification other than experience of my body in the world (Alcoff 2000, 262).

In chapter two, I argued that epistemic practices within biomedical ethics regarding disability ought to start from the experiences and concerns of disabled people. This assumes that first-person experience has some degree of epistemic legitimacy, a claim some feminist theorists reject and one for which I have not provided an argument. It is necessary to flesh out an argument in favor of the theoretical importance of experience since, if experience in general is epistemically worthless—or worse, only demonstrates how thoroughly one has been duped by ideology—then there is no reason to value the experiences of disabled people. In regard to feminist theory, Linda Martín Alcoff asserts that, “If women are to have epistemic credibility and authority, we need to reconfigure the role of bodily experience in the development of knowledge” (2000, 251). Like feminist theory, disability theory has had a complicated relationship with the body. I argue that it is just as essential for disability theorists to conceptualize bodily experience in such a way that it allows for disabled people to have epistemic credibility and authority.

In section one, I will examine reasons that disability theorists have been hesitant to include the body, and I show that when they do, this often entails conceptualizing the body in terms of impairment. I will focus on two types of approaches disability theorists have taken to

the impairment/disability distinction and theorizing the body. The first type of approach, exemplified in the work of Liz Crow, conceives of impairment as a value-free description of bodies. In section two, I discuss the second type of approach, which builds on Judith Butler's work on sex/gender, contends that discourse creates the illusion that impairment is pre-discursive and exists apart from its performance. According to Shelley Tremain, disability produces impairment, and impairment ought to be understood as performative in nature. Although Crow and Tremain advocate for inclusion of embodied experiences within disability theory, I will show that neither approach is sufficient to allow for this aim. In section three, I will recount debates within feminist theory surrounding experience since they are instructive for disability theory. I will discuss Joan Scott's momentous 1991 essay "Experience as Evidence" because it has been central within these debates. I will then turn to Alcoff's response to Scott, Larry May's remarks on learning from the experiences of others, and disability theorist Tobin Sieber's reply to Scott's position. Alcoff, May, and Siebers clearly consider embodiment and social narratives about bodily particularities to influence the types of experiences one has, which, in turn, serves as an epistemic resource. In light of my agreement with this position, I contend that embodied experiences ought to be central within disability theory.

3.1 The Social Model of Disability and the Body

3.1.1 The Impairment/Disability Distinction and the Body within Disability Theory

As discussed in chapter 1, many accounts of disability, such as those premised on the medical or social model of disability, tend to emphasize one side of the biological/social dichotomy as

constituting disability⁶³ and, thus, as the set of factors we ought to focus on/eliminate. In either case, there does not seem to be room for embodied subjectivity, agency, or disability pride as disabled people are identified by disadvantages of some sort and reduced to products of nature or culture. As Linton puts it, “the relationship between disability and its ‘owner’ has not been adequately studied (1998, 74).”⁶⁴ Both the social and the medical model exclude the subjective experiences and knowledge of disabled people. I will begin by exploring some of the reasons that disability theory has had an ambivalent relationship with the body as well as the role of the impairment/disability distinction.

Disability theorists tend to focus on the contingent disadvantages that people with impairments face as a result of oppression. As discussed in chapter one, the social model of disability, which has been hugely influential within disability theory and activism, makes a distinction between the biomedical condition of an individual and the disadvantages created by social obstacles. Within this model, the former is termed “impairment,” and the latter is called “disability.” The medical and social models both assume that the bodily and social are separate factors, rather than comprising a unified phenomenon.⁶⁵ Within the social model, the impairment/disability distinction is a manifestation of this assumption. I will focus on the social model because I am interested in the ways it has influenced resistance to theorizing the body.

Whether and how bodies ought to be theorized is a controversial issue within disability theory.

⁶³ As I mentioned in the introduction of the dissertation, Amundson notes that it may be the case that the divide between the medical and social models presents a false dichotomy by each attending to only one component of “disability” (2005, 102).

⁶⁴ Although I take Linton’s point to be that disabled people’s experiences have been neglected, it is worth pointing out that this way of referring to the disabled subject might be read as implying that the subject is something other than his or her body, which is “owned” by the subject. Similarly, Simo Vehmas and Pekka Mäkelä speak of “owners” of properties classified as impairments (2009, 53).

⁶⁵ While it is possible to focus on ostensibly “bodily” or “social” aspects of disability, they are always inextricably intertwined. Rather than thinking of “impairment” and “disability” as separate phenomena, I would suggest that we ought to recognize this distinction as one that we make for particular purposes.

This makes sense if we consider the assumptions and conditions that the social model was developed to challenge, namely, the claim that functional limitations and structural abnormalities inevitably directly cause any disadvantages disabled people may have, including but not limited to lack of employment, inability to use public transportation, and poverty. In short, the impairment/disability distinction has tended to frame discussion of bodies within disability studies as, at best, irrelevant, or at worst, taboo.

Colin Barnes attempts to dismiss the need to theorize bodies by stating that it is consistent with the social model to acknowledge “disabled people have illnesses at various points in their lives and that appropriate medical interventions are necessary” (2012, 22). Barnes dichotomizes approaches to disability theory that focus on “constructions of the body” and those that concern “social relations of capitalism” (22). He holds that disability theorists ought to take the latter approach, without considering that there may be connections between them. While I agree that there is much work in and beyond theory to be done in order to address social obstacles, including economic concerns, I disagree that the best way to do this is by focusing on “social relations of capitalism” to the exclusion of embodiment (22). In addition, Barnes seems to equate embodiment with impairment.

Barnes is not alone in thinking that theorizing the body means theorizing impairment. Michael Oliver asserts, “[T]he social model does not deny that impairment is closely related to the physical body. Impairment is, in fact, nothing less than a description of the physical body” (1996, 35). He goes on to state, “it [leaving impairment out] has been a pragmatic attempt to identify and address issues that can be changed through collective action rather than medical or professional treatment” (1996, 38). The social model has had success in disputing that there is a

necessary link between bodies with impairments and disability. Thus, it is feared that theorizing the body, i.e., impairment, will lead to a return to previous understandings and policies.

Tom Shakespeare articulates this concern in the following:

The achievement of the disability movement has been to break the link between our bodies and our social situation, and to focus on the real cause of disability, i.e.. discrimination and prejudice. To mention biology, to admit pain, to confront our impairments has been to risk the oppressors seizing on evidence that disability is “really” about physical limitation after all (Shakespeare 1992, 40).

This quotation captures the fear that seems to inform much of the resistance to theorizing bodies within disability theory. The social model has been effective politically and theoretically in shifting attention away from the notion that disability is solely an individual problem; it contests the assumptions that disability is an asocial phenomenon and that impairments is inevitably a problem. However, the strategy of focusing on social issues also leaves the arguments of disability theorists vulnerable to the suggestion that, if it is the case that disability is unrelated to the biomedical conditions of individuals, then medical professionals and researchers should not address impairment.⁶⁶

In his critique of the social model, Shakespeare states, “[w]hile doctors and professionals allied to medicine seek to remedy impairment, the real priority is to *accept impairment* and to remove disability [emphasis added]” (2013, 216). This seems to be Oliver’s position. He contends that medical treatment for people with impairments often does more harm than good. While he does recognize that doctors should have a limited role in the lives of people with impairments “stabilising their initial condition, treating any illnesses which may arise,” he charges that beyond this they “impose” treatment on disabled people in an attempt to return them

⁶⁶ For instance, Buchanan, Brock, Daniels, and Wikler assert: if taken literally the slogan “change society, not individuals” does not merely insist that we try to make the social world more accessible to those whose impairments cannot be corrected; it would require accommodating those with impairments *rather than* using medical science to prevent or correct impairments (2014, 281).

to normality⁶⁷ or as close of an approximation as possible (1996, 36.) He contends that “many disabled people experience much medical intervention as, at best, inappropriate, and, at worst, oppressive” (36). Oliver is especially critical of medical fields such as physical, speech, and occupational therapy, which he terms “pseudo-professions” (37). While I do think there is much to be done within medical practice to improve treatment for disabled people, I worry that comments such as these may suggest that medicine is not something disabled people should avail themselves of in order to address issues related to impairment. This position may imply that disabled people suffer a sort of false consciousness or disloyalty to the cause of addressing disability if they desire medical treatment related to their impairments, e.g. to increase functionality or reduce pain.

Shakespeare suggests that the social model may “be interpreted as rejecting medical prevention, rehabilitation or cure of impairment” (2013, 218). Comments such as Oliver’s can easily be read in this way. Shakespeare goes on to say:

For individuals with static impairments, which do not degenerate or cause medical complications, it may be possible to regard disability as entirely socially created. For those who have degenerative conditions which may cause premature death, or any condition which involves pain and discomfort, it is harder to ignore the negative aspects of impairment” (218).

Here Shakespeare reminds us that there are a wide variety of biomedical conditions that are classified as impairments. While some may not require medical treatment, it is clearly wrongheaded to assume that all disabled people can bracket their impairments to focus on disability.

One of the tensions for disability theorists is how to acknowledge that people *do* sometimes suffer as a result of their impairments and do desire medical interventions and cures while attempting to wrest the authority to shape narratives about impairment from those with

⁶⁷ See Silvers 1998 for further discussion of this important concern.

greater cognitive authority.⁶⁸ Though it entails its own risks, it is necessary for disability theorists to include embodied experiences in order to challenge the medical model and bad-difference views of impairment in favor of mere-difference or good-difference views. In what follows, I will discuss the approaches of a few of the theorists who advocate increased attention to the body within disability theory.

3.1.2 Impairment as Value-Free Description

In “Including All of Our Lives: Renewing the Social Model of Disability” Crow argues that we should “bring back impairment” (1996, 206-226). While she acknowledges the worry that taking account of impairment will reaffirm the prejudice that the lives of people with impairments are not worth living, she holds that the benefits outweigh the risks. For Crow, it is essential to continue to stress the distinction between disability and impairment in order to avoid collapsing them into each other as the medical model of disability does. She thinks it is important, however, to develop a more comprehensive concept of impairment.

In line with a mere-difference view of impairment, Crow states, “impairment at its most basic level, is a purely objective concept which carries no intrinsic meaning” (1996, 211). She holds that impairment is an objective description that acquires meaning at the individual level through the subjective experience of impairment as well as at the social level “in which

⁶⁸ In response to this issue, Alison Kafer posits a model she calls “the political/social model” that draws on the insights of the social model, but avoids some of the problems. Of this model she states: the political/social model neither opposes nor valorizes medical intervention; rather than simply take such intervention for granted, it recognizes instead that medical representations, diagnoses, and treatments of bodily variation are imbued with ideological biases about what constitutes normalcy and deviance. In so doing, it recognizes the possibility of simultaneously desiring to be cured of chronic pain and to be identified and allied with disabled people (2013, 6).

Kafer’s model attends to the context in which medicine is theorized and practiced and avoids uncritical acceptance or rejection of medical intervention on the basis of impairment.

misrepresentation, social exclusion, and discrimination combine” (213). Crow suggests that impairment must be considered in context in order to recognize social and economic causes (214). Though she acknowledges that what counts as an impairment is contingent, I worry that her account assumes that there is a point at which impairment is asocial or prior to a context of meaning. For example, although the medical model is sometimes characterized as “objective” in the sense of neutrality, it emerged within a social context and incorporates social values and interests. Nonetheless, Crow’s point that impairment need not be devalued is a salient one, with which I agree.

Crow thinks it is necessary for the social model of disability to include experiences of impairment both for better theory and better activism. She suggests that when disability activists and theorists focus on disability to the exclusion of impairment, they fail to address the experiences and needs of many individuals. Crow claims:

As individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence so much of our lives. External disabling barriers may create social and economic disadvantage but our *subjective experience of our bodies* is also an integral part of our everyday reality. What we need is to find a way to integrate impairment into our whole experience and sense of our selves for the sake of our own physical and emotional well-being, and, subsequently, for our individual and collective capacity to work against disability [emphasis added] (1996, 210).

For example, she worries that absent discussions of the needs that impairment can bring with it, many people with impairments will not be able to participate in the disability rights movement.

As Wendell points out, there is great variation within the category “disabled people” in terms of energy level (2008, 835). If the differences between disabled people, including the effects of impairment, are not acknowledged, Crow suggests that we may end up with an “elite” group of disabled people speaking for all disabled people. In sum, her position is that including impairment is necessary in order to address the varied subjective experiences of disabled people.

I agree with Crow that it is essential to include disabled people's experiences in order to develop better approaches to disability theory and activism. However, the concept of impairment is insufficient for this task insofar as it is a medical/scientific description of aspects of bodies, which tends to exclude subjective experiences related to impairment. For this reason, I maintain that disability theory needs to adopt an account of the body that is able to address the lived experiences of disabled people.

In this section, I have recounted reasons that many disability theorists who adopt the social model resist theorizing the body and shown examples in which the body is equated with impairment. I considered Crow's suggestion that impairment needs to be incorporated into disability and activism in order to account for the subjective experiences of disabled people. I argued that theorizing the body in terms of the concept "impairment" as a value-free description cannot accomplish this aim. In the next section, I will evaluate Tremain's attempt to include disabled people's embodied experiences through use of a value-laden, performative concept of impairment.

3.2 Performativity and Disability Theory

There is a parallel between the feminist development of the sex/gender distinction as a response to the biologically determinist assumption that bodily attributes themselves determine social roles, privileges, and disadvantages (often summarized in the catchphrase "biology is destiny"), and disability activists' and theorists' adoption of the impairment/disability distinction. Some have turned to the Judith Butler's work on the sex/gender distinction in order to theorize disability in a way that rejects the notion of impairment as prediscursive reality and attempts to

do away with the impairment/disability distinction.⁶⁹ Tremain considers “sex” and “impairment” to be analogous. Thus, for Tremain, it seems obvious that it is possible to use Butler’s notion of “performativity” to discuss impairment.

3.2.1 Performativity and the Body

Locating the body within Butler’s work can be challenging insofar as there seems to be slippage between bodies and concepts/discursive practices related to bodies. Although there is ambiguity on this matter within all of the essays and books I discuss here, there is a progression in which the body has a clear role within the performativity of gender in her 1988 essay, but the relationship between the body and sex/gender is much more obscure by the time we get to her 1993 book *Bodies That Matter: On the Discursive Limits of “Sex.”*⁷⁰

In “Performative Acts and Gender Constitution: An Essay in Phenomenology and Feminist Theory” (1988) Butler draws on the phenomenological accounts of Maurice Merleau-Ponty and Simone de Beauvoir as well as John Searle’s theory of speech acts. Her stated goal in this essay is to analyze the ways that specific corporeal acts construct gender and to explore “what possibilities exist for the cultural transformation of gender through such acts” (521). Rather than existing prediscursively as something that is expressed, Butler claims that, “gender is instituted through the stylization of the body and, hence, must be understood as the mundane way in which bodily gestures, movements, and enactments of various kinds constitute the illusion of an abiding gendered self” (519). Gender emerges through significant and minute bodily activities alike, which are often assumed to express a fixed essence or gender identity.

⁶⁹ See Samuels 2011 for several examples. An examination of the legitimacy of substituting impairment/disability for sex/gender is beyond the scope of this chapter. Samuels critiques this approach.

⁷⁰ Providing a thorough account of Butler’s treatment of the body within her corpus is beyond the scope of the current project.

In this same essay, Butler attributes the following claim to Merleau-Ponty: “the body is ‘an historical idea’ rather than ‘a natural species’” (520). The French is “*L’homme est une idée historique et non pas une espèce naturelle*,” which Donald Landes translates as “Man is an historical idea, not a natural species” (Merleau-Ponty 2012, 174). This is an interesting misattribution, which hints at the slippage in Butler’s work as to whether “the body” refers to an idea or a material-discursive entity rather than portraying Merleau-Ponty’s view, given that he explicitly rejects the position that the body is an idea. Speaking of one of the aspects of intellectualism he finds problematic, he states:

I take flight from my experience and I pass over to the *idea*. Like the object, the idea claims to be the same for everyone, valid for all times and for all places, and the individuation of the object at an objective point of time and space appears, in the end, as the expression of a universal positing power. I no longer pay attention to my body, to time, or to the world as such as I live them in pre-predicative knowledge, that is, in the inner communication I have with them. I only speak of my body as an idea, of the universe as an idea, and of the idea of space and time (2012, 73-74).

Merleau-Ponty adopts Gabriel Marcel’s conception of the relationship between the self and the body in the formulation “I am my body” (Merleau-Ponty 2012, xxxiii). He also claims that humans are necessarily rather than contingently embodied. “Man” as an historical idea is not interchangeable with “the body” as an historical idea.

To return to Butler, her main point here is that Merleau-Ponty opposes phenomenological accounts of human embodiment that make a distinction between physiological causalities and the ways that meanings are taken up through embodied existence (1988, 520). I am not sure that it is the case that he opposes any distinction at all; rather, it seems that Merleau-Ponty recognizes that physiological causalities and meanings taken up by the embodied subject are always intertwined. Butler contends that any phenomenological theory that wants to describe “the gendered body”

must conceptualize an act as both “that which constitutes meaning and that through which meaning is performed or enacted” (521).

In “Foucault and the Paradox of Bodily Inscriptions” (1989b) Butler further articulates her position on the body by responding to Michel Foucault’s characterization of the body in a number of texts. She argues that Foucault equivocates on the ontological status of the body. In spite of emphasizing the cultural production of bodies and denying that there can be bodies prior to or outside of discourse, Butler claims that he also implicitly endorses a pre-discursive ontology of the body. She states:

Indeed, I shall try to show that, for Foucault, not unlike for Kafka in *The Penal Colony*, the cultural construction of the body is effected through the figuration of “history” as a writing instrument that produces cultural significations—language—through the disfiguration and distortion of the body, where the body is figured as a ready surface or blank page available for inscription, awaiting the “imprint” (*ibid.*, 148) of history itself (603).

This is a view Butler disavows. In the course of her critique, she asks, “How would ‘the’ body as cultural or discursive practice be described?” (607). Although she does not explicitly state this, I would suggest that answering this question became one of the tasks of her work following this essay.

Butler’s notion of *performativity* was initially meant to challenge the sex/gender distinction and to show that human bodies are historical (ideas?). Within the sex/gender distinction, *sex* refers to biological characteristics used to differentiate males and females, whereas *gender* refers to social roles typically imposed on each person, according to sex (Rubin 1975). Sexual dimorphism—the belief that there are two and only two sexes—is commonly adopted, although there are exceptions.⁷¹ Butler argues that the formulation of gender in the sex/gender distinction is problematic insofar as it serves the “heterosexual imperative,” provides

⁷¹ See Fausto-Sterling 2000.

the illusion of a stable gendered self, and uncritically accepts sex as a given (1993, 15). Butler asserts that, “gender proves to be performative—that is constituting the identity it is purported to be” (2006, 34). She claims that gender *produces* sexed bodies and gives rise to the idea that sex exists prior to social practices. Butler elaborates her position as follows, “gender is not to culture as sex is to nature; gender is also the discursive/cultural means by which ‘sexed nature’ or ‘a natural sex’ is produced and established as ‘prediscursive,’ prior to culture, a politically neutral surface *on which* culture acts” (Butler 1990, 10).

Butler opens the introduction of *Bodies that Matter* by asking: “Is there a way to link the question of the materiality of the body to the performativity of gender? And how does ‘sex’ figure within such a relationship?” (1993, 1). According to Butler, the claim that sexual difference is never reducible to material differences that are not, “in some way both marked and formed by discursive practices” is not equivalent to “claiming that discourse causes sexual difference” (1). While it is true that bodily traits that are taken to be indicative of sex are never the *only* factors involved in the practice of determining sex, Butler’s claim is stronger than this; material differences are themselves “marked” or “formed” by discursive practices. This stance seems to rule out the possibility that discourse and material characteristics could be co-constitutive of sex and makes biological and physiological aspects of sex products of the ongoing process of gender performativity.

Although Butler discusses bodies throughout *Bodies that Matter*, she does not flesh out an answer to the question of how their material characteristics are relevant for performativity. Indeed, this task may be fundamentally incompatible with her approach insofar as she contends that discursive practices *produce* rather than function in relation to bodily particularities. Of course, Butler would reject taking what might be referred to as “biological reality” as a given. In

her words: “To claim that discourse is formative is not to claim that it originates, causes, or exhaustively composes that which it concedes; rather, it is to claim that there is no reference to a pure body which is not at the same time a formation of that body” (1999, 10). On this account, “descriptions” of bodies are always performative—they *discursively* produce what is claimed to be *prediscursive*. While it is vital to consider the ways in which discursive practices shape knowledge and lived experiences of bodies, her approach goes further than this; anything we would want to call a body is a product of discursive practices rather than an entity with anything to contribute to the process of being gendered.⁷²

Butler’s discussion of race raises additional questions about the roles of bodies in performativity. While race is a contingent, scientifically illegitimate way of classifying people, it nonetheless remains tied to visible features of people’s bodies and has real social consequences (Alcoff 2006). Butler draws on Nella Larsen’s *Passing* in order to consider ways that sexuality and race are “articulated and assumed” (1993, 168). Here I will discuss an excerpt from Butler’s examination of the relationship between race and visible aspects of bodies within this novel. She states:

Blackness is not primarily a visual mark in Larsen’s story, not only because Irene and Clare are both light-skinned, but because what can be seen, what qualifies as a visible marking, is a matter of being able to read a marked body in relation to unmarked bodies, where unmarked bodies constitute the currency of normative whiteness (1993, 170-171).

⁷² In *Unbearable Weight: Feminism, Western Culture, and the Body* Susan Bordo critiques Butler’s treatment of bodies, stating, “When bodies are made into mere products of social discourse, they remain bodies in name only” (2004, 35). In *The Rejected Body: Feminist Philosophical Reflections on Disability* Wendell maintains that in feminist poststructuralist and postmodernist criticism, “‘the body’ is often discussed as a cultural construction, and the body or body parts are taken to be symbolic. In this latter development, experience of the body is at best left out of the discussion, and at worst precluded by the theory” (1996, 168). While purporting to revalue and attend to bodies, postmodern accounts of embodiment, including Butler’s, have the potential to continue the trend dominant throughout Western philosophy of dismissing the importance of embodiment for knowledge and experience.

Here Butler acknowledges that skin tone is relevant for the ability of Irene and Clare to pass as white. This is the only place in *Bodies that Matter* in which the appearance of a body is recognized as relevant for how one is read racially. Yet, even in this discussion, Butler fails to fully appreciate that having particular visible bodily features is equiprimordial with racial discourse as a condition for being able to perform a particular race or gender, in this case, whiteness.

3.2.2 Performativity, Impairment, and Disability

As disability theorists have begun to question the possibility of maintaining a clear-cut distinction between impairment and disability, many have turned to Butler's work in an attempt to understand how power relations are invested in bodies. Tremain rejects the impairment/disability distinction and draws on Butler and Foucault in order to problematize the notion that impairment is a value-neutral description of bodies. She states, "Most of the materialist analyses in disability studies assume a realist ontology, in whose terms 'real' objects with transhistorical and transcultural identities exist in Nature apart from any contingent signifying practice" (2002, 32). In response to the claim of Bill Hughes and Kevin Paterson that Tremain's approach "entails the 'theoretical elimination of the material body,'" she states, "the materiality of the 'impaired body' is precisely that which ought to be contested" (Hughes and Paterson 1997, 332; Tremain 2002, 34). There are three issues I will focus on within her work: her application of performativity to impairment, how she conceptualizes the connection (or lack thereof) between impairment and the body, and her call for inclusion of disabled people's accounts of lived experiences of corporeality.

Referencing Butler's discussion of sex/gender, Tremain asserts: "If the category of sex is itself a *gendered* category – that is, politically invested and naturalized, but not natural – then

there really is no *ontological* distinction between sex and gender” (Tremain 2002, 41). She maintains that there is similarly no ontological distinction between impairment and disability. Tremain claims, “only people who *have*, or are *presumed to have*, an impairment are counted as disabled. Thus, the strict division between the categories of impairment and disability which the social model is claimed to institute is in fact a chimera” (2002, 42). While I would grant the former claim, the latter does not follow. Impairment and disability are not coextensive; it is possible to have an impairment without being disabled.

Just as Butler claims that it is wrong to think of sex as prediscursive, Tremain maintains that “natural impairment” is wrongly conceived to be prediscursive (2002, 34). She states:

impairment has been disability all along, Disciplinary practices in which the subject is inducted and divided from others produce the illusion of impairment as their ‘prediscursive’ antecedent in order to multiply, divide, and expand their regulatory effects. The testimonials, acts, and enactments of the disabled subject are *performative* in so far as the ‘prediscursive’ impairment which they are purported to manifest has no existence prior to, or apart from, those very constitutive performances (42).

According to Tremain, impairment would not exist without disability. In other words, if disabling social practices had not developed, impairment would not have come into being. Presumably, if these practices cease in the future, impairment will no longer exist. It is through the performative act of identifying as having an impairment—for example, describing the ways in which physical limitations in relation to social practices affect an individual’s daily life—that impairment is continually produced and made to seem real.

Drawing on Foucault, Tremain asserts that in the late eighteenth century “the modern body was created as an effect and object of medical examination, which could be used abused, transformed and subjugated” (2002, 35). On her account, the emergence of the modern body, joined with “dividing practices”—“modes of manipulation through which a science (or pseudo-science) is combined with practices of segregation and social exclusion” (35). Disciplinary

practices that produce impairment are used in order to govern and classify subjects that Tremain claims:

are initially drawn from a rather undifferentiated mass of people. Through these practices, subjects become *objectivized* as (for instance) mad or sane, sick or healthy, criminal or good. Through these practices of division, classification, and ordering, furthermore, subjects become tied to an identity and come to understand themselves scientifically (2001, 619).

The slippage between the body and concepts of the body within Butler's discussions of performativity is also present in Tremain's work, which makes it difficult to distinguish whether she is referring to the *concept* of impairment or *bodies* with impairments.

On Tremain's account, the ideology of normality produces subjects and their experiences. Thus, the social model is counterproductive insofar as it affirms the identities of people with impairments. She suggests:

if the identity of the subject of the social model – people with impairments – is actually produced *in accordance with* requirements of the political configuration which that model was designed to contest, then a political movement which ground its claims to entitlement in that identity will inadvertently *extend* those relations of power (2002, 42).

Affirming the identity one is assigned and articulating one's experiences both serve as evidence that one has been taken in, so to speak, and these actions are thus thought to be incapable of advancing emancipatory political projects. In this case, embodied experiences cannot be considered to have any sort of epistemic legitimacy, given their status as effects of discursive practices imbued with ideology.⁷³

Although the concept of impairment, like all concepts, is socially created, Tremain's account makes it seem wholly arbitrary which bodies are classified as impaired. While Oliver contends that "[d]isablement [disability] *is* nothing to do with the body," we might draw the

⁷³ Though Tremain does not discuss Joan Scott's position on identity and experience, I would suggest that their views are similar insofar as both consider social identity to be a means for naturalization of ideology (Scott 1992, 27).

conclusion that for Tremain, impairment has nothing to do with the body, or, at most, the category of impairment impacts bodies unilaterally (1996, 35). She contends, “impairment and its materiality are naturalized *effects* of disciplinary knowledge/power” (2002, 34). I would concede that many aspects of impairment are contingent, such as the ways any given society conceptualizes impairment, the level of social obstacles to people with impairments, and whether or where a line is drawn between “normal” and “abnormal.” Nonetheless, although the ways that individuals with impairments relate to the societal category of impairment are fluid to an extent, the bodily aspects of impairment matter. They can neither be produced by discourse nor can they be deconstructed away; the body contributes to the materialization of impairment.

Tremain claims that “those of us involved in disability studies and the disabled people’s movement must continue to expand discursive space by articulating our lived experiences, including our experiences of corporeality” (2002, 45). I agree with Tremain that this is how disability theory—including philosophy of disability—and activism should proceed. However, her adoption of Butler’s notion of performativity seems incompatible with the idea that articulating lived experiences of corporeality could be valuable, since bodies are produced by discourse. Furthermore, it is unclear how, if impairment is performative, it is possible to articulate lived experiences of corporeality without reifying impairment as “real.” Within this view, subjects and their experiences are products of ideology, which seems to largely rule out the possibility that they can be sources of knowledge.

If first-person accounts of lived experiences of impairment/disability are performative, then they can only reify, not transform, our understandings of the importance of bodily particularities for identity and subjectivity. In Alcoff’s words, “[t]he bottom line for the postmodern approach to identity is that identities are subjugating and cannot be a cornerstone of

progressive politics” (2006, 79). What is needed is a way to take contributions of bodily particularities into account that neither makes them a product of discourse nor assumes that they necessarily determine one’s quality of life and opportunities.

Like “sex” and “materiality,” more generally, on Butler’s account, “impairment” is enacted through disciplinary norms and practices and made to appear natural or given. However, in wanting to avoid the dualism of the sex/gender distinction, Butler emphasizes social norms too much, making bodies into products of discourse. It is unclear if/how bodies contribute to the process of performing gender. If bodily particularities are products of discourse, it is not possible to account for the ways that they matter for the process of becoming a subject and for experience, more generally. This conclusion is problematic and should, thus, be rejected. In sum, while Butler and Tremain articulate insights that are important for theorizing embodiment, they do not explain how particularities of bodies matter in performativity of gender or disability, rendering them unable to account for embodied experience.

3.3 The Status of Experience in Feminist Theory

As discussed in chapter two, feminist theorists such as Nancy Hartsock and Sandra Harding have found knowledge derived from women’s experiences to provide an important corrective to approaches to political theory and epistemology that claim identity ought to be irrelevant to knowledge while centering men’s experiences. Charles Mills (1988), among others, makes the point that black women critiqued feminist analyses of rape that were developed primarily by white women for missing the “particular historical significance of rape accusations made against black men by white women” (258). White women’s critiques of male theorists’ positions and subsequent critiques women of color developed of white women’s theories led to accounts that

were epistemically better, according to Hartsock, Harding, and Mills.⁷⁴ In other words, experiences that were related to (although not determined by) social identity served as an important epistemic resource for feminist theory. This does not mean that social identities inevitably lead to knowledge regarding social issues—recall the distinction Hartsock makes between a viewpoint and a standpoint—but it does mean that experiences, which are to some extent correlated with social location, make certain people more likely than others to have insights on social reality.

Drawing on women's experiences in this way seems to be the approach to feminist theory Alcoff has in mind in noting:

Although feminist work in the academy began with the project of “making women's experience visible” in light of phallogentric distortions and erasures, since the 1980s this project has been largely displaced out of a concern that experience itself is the site of ideology rather than the source of truth (2000, 251).

While Alcoff herself acknowledges the importance of identifying the ways in which gender ideology impacts women's experiences, this passage indicates the dilemma feminists were purported to face: accept experience as the source of truth or omit experience out of concern for the insidious effects of ideology. Many feminist theorists chose the latter option.

Johanna Oksala asserts that Scott's essay “Experience as Evidence”⁷⁵ “has arguably been one of the most influential contributions to the dismissal of first-person accounts of experience in feminist theory and politics in the recent decades” (2016, 36). Scott considers experience primarily in the context of the discipline of history, but her argument against the epistemic value of experience—especially for emancipatory projects—has had a profound impact within feminist

⁷⁴ See Collins 2000; hooks 1984.

⁷⁵ “The Evidence of Experience” was originally published in *Critical Inquiry* in 1991 and a substantial portion of it was reprinted as “Experience” in the 1992 *Feminists Theorize the Political*. Since the commentators I am drawing on cite the 1992 reprint, I cite the latter version.

theory. In this section, I will explain Scott's position before turning to responses to her claims within feminist and disability theory.

Although Scott cites multiple theorists' definitions of experience, I will limit my consideration to brief remarks on two of them. My purpose is not to assess her claims about these authors; rather, I am seeking to clarify her position. According to Scott, Raymond Williams describes experience in the sense of "subjective witness," as authentic truth that serves as the ground for analytic projects and reasoning (1992, 27). In this case, a subject *has* an experience, which is characterized as truth-revealing and foundational. She notes that Williams also focuses on another usage of "experience," which signifies "influences external to individuals—social conditions, institutions, forms of belief or perception—'real' things outside them that they react to, and it does not include their thought or consideration" (27). In either case, it seems that it is a necessary condition for the individual to be attentive in order to have experience, but in the second instance, attending to external influences is also sufficient.

Scott raises concerns about historian John Toews's assumptions about experience as well. Namely, she claims he takes the position that experience and meaning must be separated in order to enable explanation—experience is "reality which demands meaningful response" (32). Insofar as it is initially separate from meaning, experience is a "shared object" that requires interpretation (32). Scott contends "Toews's 'experience' thus provides an object for historians that can be known apart from their own role as meaning makers and it then guarantees not only the objectivity of their knowledge, but their ability to persuade others of its importance" (32). On Scott's account, this portrayal of experience serves to shore up the authority of historians, while

precluding identification of the ways in which this approach establishes and excludes difference.⁷⁶

Scott raises the concern that when experience is uncritically accepted as the “bedrock of evidence,” then the ways in which ideology shapes experience and subjectivity cannot be critiqued (1992, 25). In her words: “The project of making experience visible precludes analysis of the working of the system and of its historicity; instead it reproduces its terms” (25). When she refers to the “project of making experience visible,” Scott has in mind the ways in which subjects previously excluded from what she calls “normative history” articulate their experiences in order to challenge the accuracy and completeness of orthodox accounts. She contends that this type of approach adopts a problematic account of knowledge and has the effect of presenting social categories as “fixed immutable identities,” rather than critically evaluating how these categories are formed and how they function (25). Scott holds that experience *constitutes* contingent identities; when subjects recount their experiences, this serves to make it seem as though they are simply *expressing* their identities, understood as pre-discursive and essential.⁷⁷

Since the relationship between experience and subjectivity is central for understanding Scott’s position, it is important to elucidate her account of their connection. She holds that:

[i]t is not individuals who have experience, but subjects who are constituted through experience. Experience in this definition then becomes not the origin of our explanation,

⁷⁶ Expanding on this point, Scott asserts:

The unifying aspect of experience excludes whole realms of human activity by simply not counting them as experience at least with any consequences for social organization or politics. When class becomes an overriding identity, other subject positions are subsumed by it, those of gender for example (or, in other instances of this kind of history, race, ethnicity, and sexuality) (30).

Of course this is a legitimate concern, which tends to arise when a particular type of experience is generalized beyond its applicability. However, as discussed in the opening of the current section, it is not inevitable that analyses centered on class will exclude considerations related to gender and other subject positions.

⁷⁷ Her position is in line with that of Butler in this regard.

not the authoritative (because seen or felt) evidence that grounds what is known, but rather that which we seek to explain, that about which knowledge is produced (25-26).

On this conception, experience has no explanatory value—it is, rather, in need of explanation. This passage makes it seem as though there is a unidirectional relationship between experience and subjects; the former constitutes the later while subjects have no active role in constituting experience. Scott repeatedly makes assertions similar to this one. Nonetheless, lest we should draw the conclusion that she denies subjects agency entirely, she states “subjects have agency. They are not unified, autonomous individuals exercising free will, but rather subjects whose agency is created through situations and statuses conferred on them” (34). Although she grants that subjects have agency, it still does not seem as though they have a role in constituting their experiences or social identities.⁷⁸

Scott specifies her view of experience, subjectivity, and language further in the following: “Subjects are constituted discursively, experience is a linguistic event (it doesn’t happen outside established meanings), but neither is it confined to a fixed order of meaning” (34). Although she conceives of experience as a linguistic event, Scott does allow for the order of meaning that constitutes subjects and experience to change. She claims that historians need to engage in analysis of language in order to understand how subjects and experiences are produced (34-36).

On Scott’s account, it is tempting to stop using the word “experience” altogether because of its role in essentializing identities and reifying subjects, but she maintains that this is an unrealistic approach because it is too intertwined in our language and narratives (37). She suggests that we ought to: “analyze its operations and to redefine its meaning. This entails

⁷⁸ Oksala contends that Scott conflates identity and experience (2016, 38). While there is a great deal of overlap between identity and experience within Scott’s account, I am not sure that she treats them as entirely equivalent.

focusing on processes of identity production, insisting on the discursive nature of ‘experience’ and on the politics of its construction. Experience is at once always already an interpretation *and* in need of interpretation” (37). Although Scott would prefer to expel “experience” from our vocabulary altogether, she settles for advocating for a change in how we treat experience, namely, rather than allowing experience to serve as a source of knowledge it is now an indicator of the ways ideology functions in the lives of individuals and communities.

I agree with Scott on some central points, but I do not think that all aspects of her conclusion regarding experience are warranted. Most importantly, I do not think that the choices are limited to uncritical acceptance of experience or entirely rejecting the epistemic value of experience. Scott claims that, “[t]he evidence of experience works as a foundation providing both a starting point and *a conclusive kind of explanation, beyond which few questions need to or can be asked*” [emphasis added] (32-33). Indeed, this is an undesirable outcome; I would concede that it is problematic to conceive of experience as transparent access to truth. My position is also in line with hers in regard to the need to attend to both the role of ideology in experience and the impact that the social identities of theorists have on knowledge production. If social identities can *only* be fixed and oppressive and experience is *solely* a means for ideological reinforcement of social identities as Scott asserts, then there is good reason to focus attention on ideology rather than experience and social identity. However, I deny that either of these claims is correct. Social identities and experience can serve as resources for opposing oppressive ideologies. I agree that we should not think about social identities as fixed, but I disagree that this means we should cease referring to social identity at all for fear of naturalizing social categories. We need to be critical of experience—our own and others’—but this does not mean that experience is epistemically worthless or simply the product of ideology. In this regard, my

position is in line with Alcoff's stance as she articulates it in "Merleau-Ponty and Feminist Theory on Experience" (2000), to which I now turn.

Alcoff contends that feminist theorists have gone too far in rejecting the value of experience. She maintains, "[f]eminist theory has swung from the extreme of taking personal experience as the foundation of knowledge to discrediting experience as the product of phallogocentrism" (Alcoff 2000, 253). Like Oksala, she focuses on the contribution of Scott's work in this shift. Alcoff is especially interested in how Scott's position—along with misunderstandings regarding phenomenology—has been a significant factor in limiting the uptake of Merleau-Ponty's approach to phenomenology within feminist theory. Alcoff agrees with Scott's contention that uncritical acceptance of experience as unmediated access to truth is problematic. She states:

Complex social structures construct subjectivities as sets of habitual practices that create dispositions toward certain affects and interpretations of experience. Subjective experiences, or women's own accounts of our lives and its meaning, cannot be accepted uncritically without relinquishing our ability to challenge the gender ideologies embedded in these structures (253).

As this passage makes clear, Alcoff recognizes that social structures—including gender ideologies—play a role in subjectivity as well as experience. On this point, her position aligns with that of Scott. However, Alcoff takes issue with a number of Scott's claims. I consider the most central of these to be the following: 1) the suggestion that we must either accept experience uncritically or not at all, 2) the claim that we cannot challenge ideology if we grant experience epistemic standing, 3) the position that experience is a linguistic event, and 4) the assumption that all discussion of experiences related to social identity contributes to thinking of identity as fixed and immutable. I will discuss each of these themes, combining Alcoff's responses to the

second and third claim, prior to turning to her position on the fruitfulness of Merleau-Ponty's work for feminist theory.

3.3.1 We must either accept experience uncritically or not at all.

Alcoff conceptualizes the relationship between experience and knowledge differently than theorists whom Scott critiques, such as Williams and Toews. She contends:

acknowledging the cognitive centrality of experience, far from producing pretensions of indubitability as in naive realism, actually has the reverse effect (...) Bringing bodily experience into the center of epistemology has the precise effect of dislodging any hope of certainty or an indubitable foundation (Alcoff 2000, 258).

Because knowers are embodied and socio-historically located, knowledge is situated and partial. Alcoff suggests that as an alternative to Scott's characterization of experience, we should understand "experience as epistemically indispensable but never epistemically self-sufficient" (254). She advocates adopting Merleau-Ponty's approach to phenomenology, which she claims "shifts emphasis away from a foundationalist project and toward acknowledging the fact that knowledge is always unfinished and incomplete, precisely because of the open-ended nature of experience and of meaning" (258). Contra Scott, to start with experience need not entail treating experience as "a conclusive kind of explanation, beyond which few questions need to or can be asked" (Scott 1992, 33). Experience can and should be questioned, and it is open to re-interpretation. The choice of accepting experience uncritically or rejecting it altogether proves to be a false dichotomy (Alcoff 2000, 254).

3.3.2 We cannot challenge ideology if we grant experience epistemic standing. Experience is a linguistic event.

I will address these two claims in conjunction since Alcoff's response to the claim that experience is a linguistic event is closely related to her response to Scott's contention that we cannot challenge ideology if we grant experience epistemic standing. Against Scott's view that appealing to experience can only strengthen the hold of ideology rather than challenging it, she contends, "the experience of 'making experience visible' has sometimes had the effect of disrupting dominant discursive formations" (2000, 255). For Alcoff, thinking of experience as coextensive with discourse can lead to problematic outcomes, such as the idea that it is not possible to have experiences one cannot adequately describe. According to her, experience is not simply a linguistic event—it may be unarticulated or even inarticulate. If experience is necessarily a linguistic event, then she suggests that Scott would be correct in focusing on discourse analysis rather than phenomena (259).⁷⁹ However, although Alcoff concedes, "discourse permeates and affects experience," she maintains that experience cannot be reduced to linguistic practices (256). Thus, if we only engage in discourse analysis, she maintains that we miss experience as it is actually lived. Alcoff turns to bodily experiences that cannot be fully conveyed in words in order to illustrate this point.

Alcoff provides the example of the terms "date rape" and "marital rape," noting that these experiences occurred before it was possible to articulate them with these terms. She expresses the concern that tying experience too closely to discourse would deny that it is possible to have certain types of experience. She notes that this view lends credibility to claims such as the following: "date rape is said to be a fiction invented by feminists that is now having material

⁷⁹ Oksala goes one step further than Alcoff, arguing that even if we assume the correctness of Scott's claim that all experience is linguistic "her dismissal of the epistemic value of first-person experiential accounts is unwarranted" (2016, 40).

effects in needlessly traumatizing young impressionable women” (256). Contra this claim, Alcoff maintains: “Experience sometimes exceeds language; it is at times inarticulate. Feminism has not invented sexism out of whole cloth; it has provided new language by which to describe and understand old experiences and that then alters present and future experience” (256). Rather than considering experience to be a straightforward product of language, she focuses on ways that experience and language interact. On her account, granting experience epistemic standing has the potential to contribute to development of new ways of understanding and challenging ideology by changing discursive practices.

3.3.3 All discussion of experiences related to social identity contributes to thinking of identity as fixed and immutable.

Alcoff characterizes social identity as loosely correlated to the types of experiences one is likely to have. However, this is not equivalent to the claim that identity is fixed or inevitably oppressive.⁸⁰ Indeed, Alcoff suggests that the possibility of transforming identities and the likelihood of sharing certain kinds of experience are reasons that social identity can be politically useful (2006, 85; 2000, 253). In her words: “The focus on identity itself, politically manifested in identity politics, is not justified on the grounds of an intrinsic significance of identity but on the belief that identity is a marker, however imperfect, for a certain body of shared experiences” (2000, 253). Although it is not inevitable that experiences related to social identity will lead members of social groups to engage in political action, Alcoff considers this to be a productive starting point.

⁸⁰ Alcoff queries: “But why assume that the source and effect of identity claims are nefarious? Why assume that the parent/community/society or the discourse/episteme/socius is, in every case and necessarily, psychically pernicious and enabling only at the cost of a more profound subordination?” (2006, 81) Although she does not raise these questions specifically in response to Scott, these are questions that would appropriately be addressed to her.

Alcoff contends that social identities “are hermeneutic locations attached to historical experiences that are also concrete sites of interpretation and understanding” (2006, 195). She not only considers the importance of social identity as a marker “for a certain body of shared experiences” but also the relevance of visible features of bodies for experience and how one is socially identified. In *Visible Identities: Race, Gender, and the Self*, Alcoff emphasizes the connection between visible features of bodies and race and gender; she maintains that the assumption that race and gender can be visually identified is one of the reasons practices related to these categories have continued and seemed natural. She contends that the relationship between raced and gendered identities and the body is “intimate” and involves physiological features that are difficult to alter (2006, 86). In her words:

race and sex are social kinds of entities in the sense that their meaning is constructed through culturally available concepts, values, and experiences. But to say that they are social is not to say that they are some kind of linguistic rather than physical thing or to imply that meanings are conceptual items pasted over physical items. They are most definitely physical, marked on and through the body, lived as a material experience, visible as surface phenomena, and determinant of economic and political status (102).

Descriptions of experience require inclusion of social identity, which is often closely connected with how one’s body is perceived and lived. For example, on Alcoff’s account, to claim “color-blindness” in regard to race or to stop referring to racial categories and identities while race continues to impact our lives is to give up a powerful conceptual tool for understanding and changing racializing practices and experiences.⁸¹

⁸¹ Alcoff mentions disability but does not develop an account of its significance for lived experience. She states, “the markings that signify age, disability, and sex are qualitatively different in significance from those signifying race, ethnicity, and culture” (2006, 165). She notes that the status of disability is contested. Alcoff remarks that visible features that are seen as indicative of race are “almost laughably insignificant” (2006, 199). She implies that this is not the case in regard to age, disability, and sex. One point I would make is that not all impairments are visibly identifiable and whether or not one’s impairment is visible or not will greatly impact one’s experience.

Alcoff's stance on the relationship between social identity, embodied experiences, and knowledge informs her position on feminist theory. She asserts: "Meaning and knowledge are not locked into language, but emerge at the intersection between gesture, bodily experience, and linguistic practice" (Alcoff 2000, 261). Although Merleau-Ponty is less attentive than Alcoff to the role of social identity, he emphasizes the importance of understanding meaning as emerging through gesture, bodily experience, and linguistic practice, and this is one of the reasons she considers his work to be promising for feminist theory.

3.3.4 Merleau-Ponty and Feminist Theory

As mentioned above, the second reason Alcoff cites for the limited influence of Merleau-Ponty's work on feminist theory is a mischaracterization of his phenomenology as "developing metaphysical accounts of experience outside of culture and history" (2000, 252). In addition, she suggests that feminists have been unconvinced that "phenomenology's belief in the epistemic centrality of experience can incorporate or be made compatible with the critique of the ideological content of corporeal experience that has been the cornerstone of feminist social criticism" (251). These concerns assume a notion of experience in line with those Scott criticizes. In addition, although Merleau-Ponty's approach to phenomenology contains oversights regarding assumptions about the relationship between socio-historical context and what counts as typical or "normal" experience—a point that will be developed in chapter four—it is certainly unfair to claim he wholly disregards the relevance of cultural and historical context for experience.

Alcoff raises the concern that phenomenological descriptions related to race may reinforce "racist perception and experience." I would add that the same could be suggested regarding gender, sexuality, and ability (2006, 194). However, she argues that "critical phenomenological description" can facilitate reorientation of habitual ways that we perceive and

embody racialized and gendered ideologies (194). Significantly, such an endeavor has a much broader reach than discourse analysis insofar as it includes bodily experience. Alcoff contends:

Feminist theory needs a better account of the relationship between theory and experience, one in which theory is understood as itself embodied rather than simply formative of, without being formed by, bodily experience. We need also to start from descriptions of specific bodies, with their specific individual histories and inscriptions, rather than an abstract concept of the body or one that exists only in textual representation (2000, 256-257).

She maintains that Merleau-Ponty's approach to phenomenology provides an important corrective to the trend in feminist theory of discrediting the epistemic and political value of experience.

3.3.5 Taking Experience as Evidence

We might wonder, if experience contributes to knowledge, is it necessary to have particular personal experiences in order to gain this knowledge? In "A Progressive Male Standpoint" Larry May suggests:

If experience is intimately connected to understanding, then those who have not had the relevant experience will have to work harder to attain the understanding, in most cases, than those who have had the relevant experience. Any person should be able to gain understanding as long as he or she could at least imagine experiencing the relevant phenomenon. But in most cases, the task of imagination needs to be guided by someone who has had the relevant experience (1998, 338).

Like Alcoff, he contends that experience contributes to knowledge in spite of being fallible. May acknowledges that there are limitations in regard to recounting experiences—such as having a faulty memory or the role of medication (e.g. painkillers) on the experience (340). He also notes that there are limitations to imagining experiences—notably, lack of related experiences and difficulty imagining "temporally extended experiences" such as consistently using a wheelchair (341). This is why it is so important, on May's account, to check with others—both those who have had similar experiences to our own (in order to compare interpretations and identify

patterns) as well as people who have had experiences that are very different from our own. I find it interesting that May uses the example of nondisabled people attempting to imagine living with an impairment, given the pervasive influence of ableism on the imaginations of bioethicists and others of this experience and how seldom disabled people are taken to be credible in regard to their own lived experiences.

In “Disability Experience on Trial” disability theorist Tobin Siebers expresses the concern that dismissing experience as epistemically worthless is counterproductive in regard to making society more inclusive for disabled people. Responding to Scott’s “Experience,” he asks, “Is the banishment of experience, for example, radical or reactionary?” He endorses the latter answer, arguing that, “disability experience has the potential both to augment social critique and to advance emancipatory political goals” (2008, 293). Siebers uses the example of the 2004 Supreme Court case *Tennessee v. Lane* in which the experiences of two plaintiffs who use wheelchairs were taken to provide credible evidence that the Polk County Tennessee Courthouse’s inaccessibility was in violation of Title II of the Americans with Disabilities Act. George Lane recounted his experience of being called to make an appearance in court for a minor traffic violation in Polk County. Upon arrival, he found there was no elevator and proceeded to “crawl up two flights of stairs to the courtroom as the judge and other court employees stood at the top of the stairs and laughed at him” (291). Beverly Jones, the second plaintiff in the case, was unable to accept twenty-three positions at Tennessee courthouses as a court reporter because they were not wheelchair accessible.

Regarding the Supreme Court’s ruling in favor of the plaintiffs, Siebers remarks, “We witnessed an orthodox Court apparently led out of orthodoxy by the power of disability experience” (293). Scott does not consider the role of experiences that go against what ideology

would lead us to expect. Siebers asserts, “[c]onstructions are built with certain social bodies in mind, and when a different body appears, the lack of fit reveals the ideological assumptions controlling the space” (296). If one endorses the view that the disadvantages disabled people face directly caused by their physical limitations, it is possible to affirm this position even in light of the experiences of Lane and Jones only by ignoring obvious social factors. One could say that the reason Lane and Jones could not easily access courthouses in Tennessee is that they have limited mobility (and this is, in a limited sense true), but this is not the best interpretation of their experiences, especially given the legal imperative to reduce inaccessibility.

According to Siebers, attending to experience is necessary in order to understand how oppression occurs in everyday life. Like Alcoff, he conceives of identity as being socially constructed while also being related to the types of experiences one is likely to have (2008, 296). Siebers asserts, “[t]he belief seems to be that oppression will end as soon as minority identities vanish, but without a theory that can verify how social identities are embodied in lived experience, how they become real, it is not clear that we can understand what oppression is and how it works” (297). Like Scott, he contends that it is essential to attend to ways that social identities are formed, but he does not think this approach is mutually exclusive with taking experiences related to those identities seriously. Siebers thinks that drawing on lived experiences of those with marginalized social identities is important not only for understanding oppression, but also for changing the status of members of marginalized groups.

In sum, in this section I have recounted and critiqued Scott’s position on experience. I have shown that we need not think of experience or social identity as hindrances to contesting dominant narratives; indeed, I have provided examples cited by Alcoff and Siebers in which they serve as valuable resources for challenging these narratives. Rather than disavowing the body,

disability theory needs to center bodily experience in order to be effective in continuing to work for improvement of the epistemic and social status of disabled people.

3.4 Conclusion

The debates within feminist theory about whether and how bodily experience should be included have some commonalities with debates within disability theory about how and whether the body ought to be included. In this chapter, I have discussed arguments for and against inclusion of the body within disability theory prior to focusing on two types of approaches to theorizing the disabled body. In spite of some fundamental disagreements—e.g., whether or not the material can be separated from the discursive and whether or not values impact descriptions of bodily characteristics—both approaches address the body in terms of impairment, even when striving to include embodied experiences.

I have argued that although it should not be accepted uncritically, experience ought to be granted epistemic legitimacy. My position contrasts with Scott's insofar as she assumes that experience can only be the product of ideology and thus can only serve to reify identities and sustain oppression. Scott's characterization of experience as a "linguistic event" serves to direct attention away from bodily aspects of experience (1992, 34). Alcoff and Siebers both provide counterexamples in which the embodied experiences of people in marginalized groups served to challenge ideology and to change discursive practices.

However impairment is characterized, it remains tied to scientific/medical discourse that objectifies the body. Although impairment is inadequate for addressing embodied subjectivity, importantly, bodily particularities do have a role in shaping how one is in the world—including how one thinks about oneself as well as how one is perceived and treated by others. Thus, it is necessary to be able to provide an account that can allow for bodily particularities or changes to

impact being in the world. In chapter four, I will demonstrate that Merleau-Ponty's approach is the best starting point insofar as he centers embodied experiences rather than reducing the body to scientific descriptions or a product of ideology.

CHAPTER FOUR: THEORIZING EMBODIED SUBJECTIVITY: MERLEAU-PONTY, DISABILITY, AND SOCIAL IDENTITY

Every day, in the banal, minute interactions with members of society, one's body sets the parameters for what constitutes the reasonable response from others (Lee 2014, 2).

One of the privileges of being normal and ordinary is a certain unconsciousness. When one is that which is taken as the norm in one's social environment, one does not have to think about it. Often, in discussions about prejudice and discrimination I hear statements like these: "I don't think of myself as heterosexual"; "I don't think of myself as white"; "I don't think of myself as a man"; "I'm just a person, I just think of myself as a person." If one is the norm, one does not have to know what one is. If one is marginal, one does not have the privilege of not noticing what one is (Marilyn Frye 1983, 146-147).

Maurice Merleau-Ponty conceives of subjectivity as embodied. He not only maintains that embodiment is necessary for "the things themselves" to appear at all but also attempts to develop an account of the relationship between embodiment and temporality, spatiality, motility, sexuality, and language. In *Phenomenology of Perception* he cites case studies to show that events that affect one's body can radically alter one's structures of experience. Most of the individuals he considers are affected by illnesses of an episodic nature or traumatic injuries. However, these types of life-changing events are not the only ones that shape embodied subjectivity and experience. Bodily particularities,⁸² more generally, and the ways in which they are given meaning play a significant role. For example, although Merleau-Ponty does not consider how race and gender function as structures of experience, philosophers have drawn on his work in order to develop the importance of bodily particularities for one's experiences within

⁸² By "particularities," I mean characteristics (e.g. qualities such as height, weight, skin color, facial features, and hair texture).

a milieu saturated with norms related to race and gender (Alcoff 2000, 2006; Fanon 2008; Lee 2014; Salamon 2010; Yancy 2008; and Young 2006). His phenomenology has been the starting point for numerous theorists concerned with various types of marginalized embodiment, and this work greatly enriches our understanding of the relevance of bodies for lived experiences of race and gender without engaging in biological or cultural determinism. Theoretical approaches that draw on Merleau-Ponty's phenomenological insights are equally useful for understanding how bodies shape experience in relation to dominant narratives about dis/ability, but this area of inquiry has not yet been fully developed within philosophy (Carel 2011; Carel 2013; Diedrich 2001; Salamon 2012; Toombs 1988; 1992; Weiss 2015). Although Merleau-Ponty's concerns differ from those of disability theorists, his approach to phenomenology offers rich resources for theorizing disabled bodies, especially when supplemented with the analytical tools of feminist philosophy and philosophy of race.

Merleau-Ponty is treated as a sort of "patron saint" for philosophers and other theorists concerned with the body (Shusterman 2005, 151). This is certainly true within disability studies. Yet, many of the central assumptions and goals that disability theorists share differ from those of Merleau-Ponty. I would argue that one of the primary aims and effects of *Phenomenology of Perception* was to clarify "normal" (read non-disabled heterosexual white male) being in the world⁸³ by contrasting it with "disordered" ways of being, rather than to consider the richness of other ways of being. I am far from the first to suggest that Merleau-Ponty's approach is androcentric and heteronormative (Butler 1988; 1989a; Alcoff 2000; Grosz 1994; Young 2006) and white normative (Fanon 2008; Weiss 2015). However, little attention has been devoted to the ableism inherent in his approach, by which I mean that he "privilege[s] able-bodied people by centering their needs and experiences" (Wieseler, 2013). Jackie Leach Scully, a molecular

⁸³ I will explain Merleau-Ponty's use of this concept momentarily.

biologist and disability theorist, is the only author I have encountered who raises this concern (2008). With the exception of Scully, disability theorists from disciplines other than philosophy often cite Merleau-Ponty, but they seldom develop any sort of sustained engagement with, much less critiques of, his work (Iwakuma 2002; LaCom 2013; Siebers 2008; Sullivan 2014a). In addition to privileging nondisabled people's experiences, Merleau-Ponty implies that a particular privileged type of racialized and gendered embodied experience is "normal." This assumption is also present in the work of some philosophers who build upon his work, such as Shaun Gallagher. Theorists who adapt Merleau-Ponty's approach in order to think about lived experiences of disability tend not to simultaneously take into consideration the differences that gender and race make. Likewise, theorists focusing on race and/or gender typically concentrate on the experiences of nondisabled people.

In section one, I will begin by briefly explaining some of the key concepts that are necessary for my examination of the role of examples and case studies of people with impairments and illnesses in *Phenomenology of Perception*. As this discussion will show, embodiment is central for all of these concepts. In the course of discussing one case study in particular, I will argue that Merleau-Ponty has two primary aims, which are interconnected. He seeks to clarify "normal" experience and to demonstrate the limitations of empiricism and intellectualism. Section two considers ways that work within disability studies serves to highlight ableist assumptions within Merleau-Ponty's phenomenology. Rosemarie Garland-Thomson's notions of "material anonymity," "fits," and "misfits" provide vocabulary that is helpful for clarifying both the benefits and shortcomings of his approach. I engage with Gail Weiss' discussion of the relationship between the work of Garland-Thomson and Merleau-Ponty, and I respond to Weiss' claims about: 1) Merleau-Ponty's treatment of "normality" and 2) the function

of a case study within *Phenomenology of Perception*. Section three applies Garland-Thomson's notion of material anonymity in order to draw attention to the experience of being enabled through the physical environment and social expectations that Merleau-Ponty and Gallagher, among others, implicitly take as a given for "normal" subjects. I also suggest that her concepts are useful for bridging philosophical work on disabled embodiment with work on bodies marginalized along other axes, namely gender and race.

4.1 Key Concepts and Merleau-Ponty's use of the Case of Schneider in *Phenomenology of Perception*

In order to attend to Merleau-Ponty's use of case studies⁸⁴ in *Phenomenology of Perception*, we must understand his stance on the body as well as some of the concepts that are central within this text. Indeed, these tasks are intertwined insofar as embodiment is implicated in Merleau-Ponty's characterization of being in the world, sedimentation and spontaneity, intentionality, and multiple types of ambiguity. In what follows, I will provide a brief explanation of these concepts.

Merleau-Ponty speaks of *being in the world* in many contexts—from a number of different angles, so to speak. Donald Landes, the translator of the 2012 edition of *Phenomenology of Perception*, notes "[b]y presenting Heidegger's notion [of being-in-the-world] with the French preposition *à* rather than *dans* Merleau-Ponty introduces a rich collection of relational modalities, including 'directed toward,' 'in,' 'with,' 'at,' and 'belonging to,' all of which should be heard in his *être au monde*" (493n22). Importantly, being in the world cannot be reduced to the "sum of reflexes" or "an *act* of consciousness" as empiricism and intellectualism, respectively, would have it (80). Rather, reflexes and acts of consciousness are predicated upon

⁸⁴ I will focus most of my discussion on one case study, but I contend that Merleau-Ponty's use of the other case studies and examples serves the same purposes.

being in the world, which Merleau-Ponty calls “a *pre-objective perspective*” (81). Furthermore, he notes that the notion of being in the world applies to non-human animals as well as humans insofar as the world elicits responses from both (80-81).

Often Merleau-Ponty clarifies the concept of being in the world negatively, by stating what it is not. For example, he asserts:

We are not saying that the *notion* of the world is inseparable from the notion of the subject, nor that the subject *thinks himself* to be inseparable from the idea of the body and the idea of the world, for if it were merely a relation in thought, this very fact would preserve the absolute independence of the subject as a thinker and the subject would not be situated. If the subject is in a situation, or even if the subject is nothing other than a possibility of situations, this is because he only achieves his ipseity by actually being a body and by entering into the world through his body. If I find, while reflecting upon the essence of the body, that it is tied to the essence of the world, this is because my existence as subjectivity is identical with my existence as a body and with the existence of the world, and because, ultimately, the subject that I am, understood concretely, is inseparable from this particular body and this particular world (2012, 430-431).

Throughout *Phenomenology of Perception*, Merleau-Ponty seeks to undermine the subject/object distinction. In the preceding quotation, he shows that he does not think this is simply a conceptual issue; rather he contends that, ontologically, we are initially involved in the world as embodied beings. It is only after we subscribe to the subject/object distinction that it appears that subjects are primarily independent of their worlds and secondarily related to them. Subjectivity is necessarily embodied and situated within a world, and the specific characteristics of both are relevant for how and who one is. These particularities are contingent in the sense that they are not determined, but they are not contingent in the sense that they are necessary for me to be the subject I am. Elsewhere, Merleau-Ponty refers to the body as “the vehicle of being in the world” and “our anchorage in the world” (84, 146).

Sedimentation is essential for this anchorage in the world. Merleau-Ponty claims that there is “a sedimentation of our mental operations, which allows us to count upon the things that

are there and that are given as a whole, without our having to repeat their synthesis at each moment” (2012, 131). Clearly, he is suggesting that our mental operations allow for a stable sense of things. However, it would be a mistake to understand sedimentation in narrowly mental or epistemic terms. Merleau-Ponty maintains,

[T]he responses [to that which solicits action] themselves must no longer require, each time, a unique position-taking and must rather be sketched out once and for all in their generality. Thus, by renouncing a part of his spontaneity, by engaging in the world through stable organs and preestablished circuits, man can acquire the mental and practical space that will free him, in principle, from his milieu and thereby allow him to *see* it (89).

He cautions against understanding sedimentation as involving consciousness *rather than* the body; because consciousness is embodied, sedimentation necessarily involves the body. To illustrate, Merleau-Ponty provides the example of sedimentation in a friendship wherein a current conversation between friends refers back to previous words and gestures exchanged between them without requiring them to make this explicit (131). He also discusses sedimentation in the context of his apartment, which he says is “not a series of strongly connected images” (131). Rather, “[i]t only remains around me as my familiar domain if I still hold ‘in my hands’ or ‘in my legs’ its principle distances and directions, and only if a multitude of intentional threads run out toward it from my body” (131-132). The intentional threads of our bodies are what anchor us in the world. Being situated through sedimentation enables one to respond to novel occurrences as well as to engage in creative activities such as painting and writing poetry.

Use of Merleau-Ponty’s term “intentional threads” requires clarification of what he means by *intentionality*. In the introduction to *Phenomenology of Perception*, he references Husserl’s distinction between

act intentionality—which is the intentionality of our judgments and of our voluntary decisions (and is the only intentionality discussed in the *Critique of Pure Reason*)—and operative intentionality (*fungierende Intentionalität*), the intentionality that establishes the natural and pre-predicative unity of the world and of our life, the intentionality that appears in our desires, our evaluations, and our landscape more clearly than it does in objective knowledge (lxxxii).

Merleau-Ponty does not use Husserl's terminology—opting most of the time to simply use the term intentionality. Occasionally, he is more specific, using the terms “motor intentionality” and “original intentionality” as well as referring to sexuality as “an intentionality” (113, 407, 156). However, it seems clear that his primary interest is in what Husserl calls operative intentionality, and it is for this reason that he focuses on areas of subjective experience such as perception, sexual desire, and love that cannot be reduced to voluntary decisions. He seeks to develop an account of the aspects of intentionality that philosophers have tended to neglect or refer to by other names. Merleau-Ponty asserts, “[b]odily movement can only play a role in the perception of the world if it is itself an original intentionality, a manner of being related to the object that is distinct from knowledge” (407). He emphasizes the embodied nature of intentionality, which is also less apparent in objective knowledge than other domains upon which it is predicated.

For Merleau-Ponty, intentionality may thus be described as ambiguous. Indeed, *ambiguity*, which is at times used interchangeably with *indeterminacy*, is another central concept within *Phenomenology of Perception*. Rather than considering ambiguity as something to be dispelled, he contends that it should be embraced as fundamental to human existence. He asserts:

For man, everything is constructed and everything is natural, in the sense that there is no single word or behavior that does not owe something to mere biological being—and, at the same time, there is no word or behavior that does not break free from animal life, that does not deflect vital behaviors from their direction [*sens*] through a sort of *escape* and a genius for ambiguity that might well serve to define man (195).

For humans, biological being and cultural being are at play in everything we do. Merleau-Ponty discusses a number of types of ambiguity, including ambiguities spanning: the natural and

cultural world, impersonal and personal time, objective and erotic perception, the actual and habitual body, as well as impersonal (or anonymous) and personal existence.

Impersonal (or anonymous) and personal existence are intertwined with bodily and temporal ambiguity. To paraphrase Merleau-Ponty, the ambiguity of time helps us to understand the ambiguity of the body, which is an expression of the ambiguity of being in the world (87). Embodiment is central to being in the world and both are irreducibly ambiguous. Importantly, Merleau-Ponty asserts the agency of the body, rather than treating it as a sort of *tabula rasa* only given direction through culture and the individual inhabiting it.

...so too can we say that my organism—as a pre-personal adhesion to the general form of the world, as an anonymous and general existence—plays the role of an *innate complex* beneath the level of my personal life. My organism is not like some inert thing, it itself sketches out the movement of existence (86).

On this account the body has its own *sens*, which is to say, its own meaning, knowledge, and direction prior to our decisions and to our epistemic relation to the world.

Merleau-Ponty makes a distinction between the *objective body* and *one's own body*.⁸⁵

The first notion refers to the body as it can be measured and described in scientific terms. The second refers to one's body as it is lived. Theorists drawing on Merleau-Ponty have often adopted the terminology of the *lived body* to capture this second sense of the body (Alcoff 2000; 2006; Diedrich 2001; Lee 2014; Young 2005). This bodily ambiguity is important within Merleau-Ponty's discussion of anosognosia and phantom limbs, wherein the actual body and *one's own body* are out of accord with each other. I turn to a footnote within *Phenomenology of Perception* by Landes for further clarification on his translation of the French *le corps propre* as "one's own body." He states, "In general, Merleau-Ponty means 'the body that is necessarily

⁸⁵ Merleau-Ponty uses a number of different terms for these two ways of referring to the body. He also calls the first (the *objective body*) the *actual body* and the second (*one's own body*) the *phenomenal body*, and the *habit body*. For clarity's sake, I will use *objective body* and *one's own body*, except in cases in which Merleau-Ponty and other philosophers use different terms.

lived as mine,' rather than a body that I possess contingently or the body considered from a third person perspective as a simple object in the world" (Landes 2012, 512n6).

Regarding movement and the distinction between the objective and *one's own body*, Merleau-Ponty remarks: "We never move our objective body, we move our phenomenal body, and we do so without mystery, since it is our body as a power of various regions of the world that already rises up toward the objects to grasp and perceive them" (108). Embodied subjectivity always exists in relation to objects and others. He goes on to say:

just as the phenomenal forces at work in my visual field obtain from me, without any calculation, the motor reactions that will establish between those forces the optimum equilibrium, or as the customs of our milieu or the arrangement of our listeners immediately obtains from us the words, attitudes, and tone that fits them—not that we are trying to disguise our thoughts or simply aiming to please, but because we literally are what other think of us and we are our world (109).

Here Merleau-Ponty suggests that just as *one's own body* typically makes adjustments without calculation in order to get the best visual or motor grasp of the surroundings, so too, embodied subjectivity is influenced by one's social milieu.

Since being in the world, sedimentation, spontaneity, intentionality, and multiple types of ambiguity—including ambiguity of the body—are woven together, disruptions in any of these impact the entire system. This is why, for Merleau-Ponty, it should not be surprising that the effects of a bodily injury could include bring about a shift in being in the world. His approach to phenomenology allows for articulation of this type of experience rather than limiting the focus to descriptions of the objective body, such as measurable changes in function. As I will develop in the following, he contends that intellectualism and empiricism mischaracterize such instances as well as the behavior of typical subjects because they miss the centrality of ambiguity within human existence. He maintains that the remedy is to adopt existential analysis, which starts from the perspective of being in the world.

4.1.1 Merleau-Ponty's use of the Case of Johann Schneider

Merleau-Ponty draws on case studies of disabled people in *Phenomenology of Perception* in order to expose the limitations of empiricism and intellectualism as well as to differentiate subjects with impairments from the “normal” subject. In his words, “[t]he study of a pathological case has thus allowed us to catch sight of a new mode of analysis—existential analysis—that goes beyond the classical alternatives between empiricism and intellectualism, or between explanation and reflection” (2012, 138). He maintains that in order to preserve the phenomena—such as perception, movement, and language usage—philosophers and other theorists seek to describe, it is necessary to attend to them as we experience them.⁸⁶ Merleau-Ponty contends that, although empiricism and intellectualism are commonly thought to be opposed to each other, they share some of the same problematic assumptions. The use of case studies is one way he highlights these assumptions and proposes alternatives.

There are many instances in which Merleau-Ponty contrasts the ways in which “normal” or “typical” subjects approach a task in distinction from those with disorders. The primary case study he refers to throughout *Phenomenology of Perception* is that of Johann Schneider, a patient of Adhemar Gelb and Kurt Goldstein. Schneider, a soldier in the German army, was reportedly injured on June 4, 1915 when shrapnel became lodged in the left parietal-occipital region of his brain (Marotta and Behrmann 2004, 634). While one iron splinter was surgically removed a couple of weeks later, X-rays revealed that others remained. Gelb and Goldstein diagnosed Schneider with “psychic blindness” (Merleau-Ponty 2012, 105). His condition is also referred to

⁸⁶ Merleau-Ponty develops this point further in the following:

Behavior can only be grasped by another type of thought—the type of thought that takes its object in its nascent state, such as it appears to him who lives it, with the atmosphere of sense by which it is enveloped, and that seeks to slip itself into this atmosphere in order to discover, behind the dispersed facts and symptoms, the total being of the subject in the case of the normal person or the fundamental disorder in the case of the patient (2012, 122).

as “visual agnosia,” “a disorder of visual recognition, in which a person cannot arrive at the meaning of some or all categories of visual stimuli, despite normal or near-normal visual perception and intact alertness, intelligence, and language” (Morotta and Behrmann 2004, 633).⁸⁷ Merleau-Ponty discusses a number of ways that Schneider’s condition leads him to develop atypical means of accomplishing tasks assigned by his doctors in an experimental setting as well as in everyday life. On his account, the brain damage Schneider sustained pervades his way of being, impacting his ability to situate himself. Merleau-Ponty uses Schneider’s experiences in order to develop insights into typical experiences: concluding, for example, that Schneider lacks ambiguity in a number of domains, and ambiguity is necessary for subjects to be fully situated in regard to spatiality, temporality, language, and sexuality. Although it is not possible to completely separate these, I will focus primarily on spatiality in order to illustrate Merleau-Ponty’s use of this case study.

In his discussion of spatiality, Merleau-Ponty draws on Schneider’s atypical ways of orienting himself in space and engaging in movement in order to showcase the shortcomings of empiricism and intellectualism as theoretical explanations of “normal” subjects because the ways that Schneider’s mannerisms fit with aspects of these theories make clear that this is *not* how typical subjects behave. At other points, Merleau-Ponty demonstrates the inability of these theories to make sense of what is happening, even in Schneider’s case.

Merleau-Ponty is especially concerned to understand why it is that Schneider is readily able to move in some ways but has great difficulty with others. Schneider accomplishes the

⁸⁷ Morotta and Behrmann note that Gelb and Goldstein’s account of Schneider is controversial. For example, they state, “Goldenberg claims Goldstein and Gelb invented fantastic embellishments about Schn [Schneider] and, in turn, Schn [Schneider] learned how to be an ideal case study” (635). My aim here is neither to judge whether or not Gelb and Goldstein’s reports are accurate nor to assess Merleau-Ponty’s recounting of their reports. Rather, I am interested in the function of Schneider as an example in Merleau-Ponty’s phenomenological project.

movements “that are necessary for life with extraordinary speed and confidence, provided that they are habitual movements: he takes his handkerchief from his pocket and blows his nose, or takes a match from a matchbox and lights a lamp” (Merleau-Ponty 2012, 105). However, when his doctors ask Schneider to act out tasks within the context of an experimental setting, he is unable to do so without “preparatory movements” and without treating the tasks as if they actually need to be done—in Merleau-Ponty’s words, to behave as if they are “concrete” rather than “abstract” (105). This is the case even when the motions required for the concrete and the abstract task are almost identical.

Merleau-Ponty reports that there is a discrepancy between Schneider’s ability to point [*Zeigen*] and grasp [*Greifen*]; whereas pointing requires a number of prior steps, he is able to grasp or engage in other movements that involve touch (such as slapping a mosquito that is biting him) (106). This leads Merleau-Ponty to question how it is possible to know where a body part is when one is asked to grasp it but not when one is asked to point to it. He ascertains that it is necessary to conceive of knowledge of a location in multiple senses. According to Merleau-Ponty:

Classical psychology does not have any concepts for expressing the varieties of the consciousness of location because for it the consciousness of location is always a positional consciousness, a representation, a *Vor-stellung*, because as such it gives us the location as a determination of the objective world and because such a representation either is or is not; but, if it is, then it delivers to us its object without any ambiguity and as an identifiable term throughout all of its appearances. We must, on the contrary, forge here the concepts necessary to express that bodily space can be given to a grasping intention without being given to an epistemic one (106).

Location as a determination of the objective world, i.e. objective space, does not capture the multiplicity of ways that it is possible to “know” where part of one’s body is located. Although it is possible to consider one’s body in a scientific manner and one’s relation to objects in terms of

constituting consciousness, these are derivative ways of knowing, whereas the body's capacity to engage in habitual and practical movements is a more fundamental orientation.

Merleau-Ponty considers the explanation that concrete movements “depend upon firmly established conditioned reflexes” (124). This would imply that concrete movement is unaffected by Schneider's brain injury because it bypasses consciousness—it is simply a physiological reaction that occurs automatically, so to speak, as a result of previous associations. He maintains that the physical differences between the “stimuli” and the role of Schneider's nervous system and muscles in concrete and abstract movement cannot explain why one is easily accomplished and the other is not (124). Merleau-Ponty also contends that intellectualist psychology (reflective analysis) is just as inadequate as physiological (empiricist) approaches. For their part, abstract movements would require consciousness in order to be enacted. He suggests that if we take consciousness to be consciousness of something and to require engagement in “pure act[s] of signification,” then it must be concluded that if one is unable to meet this requirement, then one “falls back to the status of a thing” (123). More concisely, he asserts: “Consciousness will thus not admit of degrees. If the patient no longer exists as a consciousness, then he must exist as a thing” (124). However, Merleau-Ponty maintains that, in spite of Schneider's limitations, this is obviously the wrong conclusion. He says that the difference between concrete and abstract movements would then be the divide between physiology and psychology (124). However, he finds this explanation to be untenable, stating:

Every physiological explanation generalizes into a mechanistic physiology, every appearance of consciousness generalizes into an intellectualist psychology, and mechanistic physiology or intellectualist psychology level out behavior and efface the distinction between abstract movement and concrete movement, between *Zeigen* and *Greifen*. The distinction can only be maintained if there are *several ways for the body to be a body, and several ways for consciousness to be consciousness* (125).

As this quotation makes clear, Merleau-Ponty rejects the suggestion that it is possible to appeal to physiology in order to explain concrete movement while simultaneously drawing on psychology in order to explain abstract movement. Each approach would exclude the other, and neither is sufficient alone. Instead, he advocates existential analysis, an approach that starts with being in the world rather than objective thought, which is derivative of being in the world.

Merleau-Ponty claims that in order to understand the difference between these two types of movement, it is necessary to consider “their affective value or their biological sense,” which leads to the insight that *Zeigen* and *Greifen* are “two different ways of relating to the object and two types of being in the world” (124). For this to be possible, the body cannot be construed simply as a mechanism (existence in itself) or as that in which consciousness resides (pure existence for itself) (125). It is only when we reject this dualism and consider concrete and abstract movement through existential analysis, which is to say, from the starting point of being in the world, that it is possible to comprehend why they would elicit such divergent responses from Schneider.

Merleau-Ponty concedes that in some instances the descriptions of human behavior provided by intellectualism or empiricism do approximate how Schneider approaches a task. This demonstrates the inadequacy of these theories as explanations of the ways that typical humans approach tasks. For example, he shows that there are parallels between Schneider and the “Kantian subject” insofar as both need to make significations explicit in order to understand them and incorporate them into experience. When Schneider is asked about analogies (e.g. “fur is to the cat what feathers are to the bird”) and metaphors (e.g. “the foot of the chair”), he must go through intermediary conceptual steps in order to figure out their meanings (129). For

“normal” subjects, the meanings of analogies and metaphors are immediately apparent, but explaining the reasoning behind them may pose difficulties (129).

Merleau-Ponty contrasts the “normal” subject with the Kantian subject as follows:

The Kantian subject posits a world, but, in order to be able to affirm a truth, the actual subject must first have a world or be in the world, that is, he must hold a system of significations around himself whose correspondences, relations, and participations do not need to be made explicit in order to be utilized (131).

Merleau-Ponty suggests that it is possible to detect the error in the Kantian conception of the subject by contrasting Schneider’s way of understanding the meanings of metaphors with the ability of typical subjects to grasp the meanings of metaphors due to being firmly grounded in the world. His point here is that Schneider’s behavior shows us how typical subjects *would* use significations if the Kantian notion of the subject were correct. When Schneider is trying to understand metaphors, he is starting almost entirely “from scratch” so to speak; he doesn’t have an integrated system of significations, and this is why he has to explicitly create connections over and over again. Conversely, for the typical subject, having and being in the world makes these steps unnecessary. It is important to point out that what Schneider is missing is neither an adequate vocabulary nor the ability to understand what others are saying; rather it is what he is unable to do with words and the process he must go through in order to make sense of others’ remarks that differentiate him from typical subjects.⁸⁸ According to Merleau-Ponty: “Another’s words are for him signs that he must decode one by one, whereas for the normal subject these words are the transparent envelope of a sense *in* which he could live” (134-135). Thus, the typical subject is not the Kantian subject, while Schneider’s behavior is akin to the Kantian

⁸⁸ Merleau-Ponty states, “[w]hat the patient had lost, and what the normal person possessed, was not a certain stock of words, but rather a certain manner of using them” (180).

subject insofar as he must posit a world before he can make sense of words, which are initially opaque in their meanings.

Identifying one of the mistakes of intellectualism, Merleau-Ponty states:

For beginning from this transparent consciousness, and from this intentionality that does not admit of degrees, everything that separates us from the true world—error, illness, madness, and, in short, embodiment—is reduced to the status of a mere appearance (126).

Merleau-Ponty contends that this approach is unable to address phenomena because it reduces them to epistemic errors or dishonesty. Whereas, as he points out, “Schneider’s disorder is not initially metaphysical, for it was a piece of shrapnel that injured him in his occipital region” (127). Intellectualism, in focusing on “symbolic function” and “consciousness” as disconnected from embodied being in the world, cannot address how it is that a brain injury could alter consciousness, or, indeed, even the possibility of consciousness being altered at all.

If we are to be able to comprehend the multiplicity of ways for “*the body to be a body*” and “*consciousness to be consciousness*,” it is necessary to understand them as they are lived in the world (125). Changes in one’s body are capable of bringing about changes in one’s world. Thus, atypical behavior must be examined in a way that goes beyond medical descriptions of one’s bodily condition and considers subjects in context. According to Merleau-Ponty:

The structure “world,” with its double moment of sedimentation and spontaneity, is at the center of consciousness, and it is through a certain leveling out of “world” that we will be able to understand Schneider’s intellectual, perceptual, and motor disorders simultaneously and without thereby reducing them to each other (132).

As I mentioned previously, Merleau-Ponty refers to embodied being in the world as “our anchorage in the world,” which maintains our inherence in the world through “intentional threads” (146, 132). Cognition, perception, and movement are all enabled by being in the world; thus, Merleau-Ponty holds that it is necessary to begin from being in the world in order to understand

the underlying unity that underpins the various manifestations of Schneider's brain injury.

Schneider has become unmoored from the world. However, this does not mean that he is entirely disconnected; rather it clarifies why he is able to engage in concrete/habitual movements with ease while abstract/novel ones pose such difficulty. To provide a proper account of Schneider's behavior, it is necessary to allow for multiplicity of ways of being. However, this need not entail the additional claim that each of these ways of being is in some way equivalent to or interchangeable with any other.

Merleau-Ponty judges that Schneider has real, significant limitations, asserting, "Schneider is 'bound' to the actual, and he 'lacks freedom,' he lacks the concrete freedom that consists in the general power of placing oneself in a situation" (137). As this passage makes clear, freedom requires the power to situate oneself. According to Merleau-Ponty, ambiguity enables one to situate oneself in several aspects of life. So, ambiguity is necessary for freedom. Let's return to Merleau-Ponty's conceptualization of situatedness prior to turning to the role of ambiguity. He claims that Schneider is bound to the actual insofar as he is unable to place himself in a situation; this prevents him from envisioning and taking up possibilities. Insofar as he lacks this ability, Schneider "lacks freedom" (Merleau-Ponty 2012, 137). Merleau-Ponty asserts:

the life of consciousness—epistemic life, the life of desire, or perceptual life—is underpinned by an "intentional arc" that projects around us our past, our future, our human milieu, our physical situation, our ideological situation, our moral situation, or rather, that ensures that we are situated within all of these relationships (137).

In this passage, Merleau-Ponty contends that the intentional arc allows for knowledge, desire, and perception to occur within the multiple ways that one is situated. Schneider's atypical intentional arc impacts all aspects of his existence.

Focusing on Merleau-Ponty's discussion of Schneider in regard to spatiality, I have shown that use of this case study serves two main roles in *Phenomenology of Perception*: 1) to clarify the behavior of "normal" subjects by contrasting it with that of Schneider, and 2) to demonstrate the superiority of existential analysis over empiricism and intellectualism. Having established these points, we now turn to consideration of the relationship between, on the one hand, Merleau-Ponty's approach to impairment and illness and, on the other, disability theory.

4.1.2 Merleau-Ponty's Use of Case Studies and Disability Theory

Rather than questioning the distinction between normal and abnormal subjects, Merleau-Ponty's analysis depends upon it. However, although he does not consider the role of cultural norms in making this determination as some disability theorists do, it should be noted that he observes a continuum between experiences of typical individuals and those of people with symptoms of mental illness. Merleau-Ponty suggests that illnesses such as aphonia and hysteria are modes of disengagement from others that are not radically different from the experiences of "normal" subjects, e.g., a husband forgetting the location of book given to him by his wife while he is upset with her (165). His example of aphonia involves a young woman who was unable to speak as a child in the aftermath of an earthquake and then later experienced aphonia after her mother prohibited her from seeing the man she loved (163). In Merleau-Ponty's words:

Whatever can be overcome by this anonymous force must be of the same nature as it, and we must then admit that indifference or aphonia, to the extent that they endure, become solid like things, that they make themselves into a structure, and that the decision that interrupts them comes from beneath the level of the "will" (166).

He denies that the aforementioned examples involve a choice to exhibit these behaviors.

Merleau-Ponty also compares these illnesses and this type of forgetting to sleep insofar as they involve something beyond personal existence. Thus, although he does not question the

legitimacy of the distinction between “normal” and “abnormal” nor consider the social values that are at play in determining this distinction, he works to show that there are parallels between the experiences of individuals categorized as “normal” and “abnormal.”

One of the illustrations Merleau-Ponty uses in order to clarify bodily habits, which he claims have both motor and perceptual aspects, is a blind man who is accustomed to using a cane. He states, “When the cane becomes a familiar instrument, the world of tactile objects expands, it no longer begins at the skin of the hand, but at the tip of the cane” (153). Once a blind man develops the habit of perceiving through use of the cane, Merleau-Ponty suggests that the cane “is an appendage of the body, or an extension of the bodily synthesis” (154). On this account, through development of habits typical subjects incorporate instruments as well as bodily adornments, such as hats with feathers, into their phenomenal body (144).⁸⁹ Thus, Merleau-Ponty does not make a distinction between instances in which disabled people and nondisabled people experience instruments as part of *one’s own body*.

Merleau-Ponty only discusses the functional limitations of Schneider and other individuals he uses as examples. However, given that he considers being in the world to be a system in which one’s own body and the world are fundamentally intertwined, his analysis does go beyond the *objective body* in order to examine some of the implications of impairment and illness for being. He even recognizes that individuals may respond in different ways to the same impairment, stating:

Certain subjects can move closer to being blind without having changed “worlds.” They bump into objects everywhere, but they are unaware of no longer having visual qualities, and the structure of their behavior remains unaltered. Other patients, on the contrary, lose their world as soon as the contents begin to slip away. They renounce their usual life even before it becomes impossible, they become crippled before literally being so, and they break their vital contact with it (81-82).

⁸⁹ Merleau-Ponty also asserts, “Habit expresses the power we have of dilating our being in the world, or of altering our existence through incorporating new instruments” (145).

Here Merleau-Ponty uses the example of becoming blind in order to illustrate his claim that changes in the body alter being in the world. Yet, there is variation among individuals in how exactly one's relation to the world changes; the *objective body* does not dictate *one's own body*. Merleau-Ponty's focus remains primarily on the individual rather than also evaluating the impact of social factors.

Merleau-Ponty's discussion of the phenomena of the phantom limb, in which a person feels sensation or pain in a limb they do not have,⁹⁰ and anosognosia, a condition in which someone does not recognize a part of their body, provides additional examples in which the objective body does not determine *one's own body*. Although he discusses these conditions in tandem, I will focus on the phantom limb. He assesses the limitations of psychological and physiological explanations before developing his own account. Merleau-Ponty remarks, "[i]f the phantom limb depends upon physiological conditions and is thereby the effect of a third person causality, then it is inconceivable how it can *also* result from the personal history of the patient, from his memories, his emotions, or his desires" (2012, 79). It seems that physiological and psychological explanations are mutually exclusive, yet, on his account, neither is sufficient independently.

Regarding physiological and psychological explanations of anosognosia and the phantom limb, Merleau-Ponty remarks:

A physiological explanation would interpret anosognosia and the phantom limb as the mere suppression or the mere persistence of interoceptive stimulations. On this hypothesis, anosognosia is the absence of a fragment of the body's representation that should be given, since the corresponding limb is in fact present; the phantom limb is the presence of a part of the body's representation that should not be given, since the corresponding limb is in fact absent. If these phenomena are now given a psychological

⁹⁰ Merleau-Ponty discusses instances in which a person's limb was amputated. A small percentage of people born without a limb experience a phantom limb, and these instances would need further explanation.

explanation, the phantom limb becomes a memory, a positive judgment, or a perception; anosognosia becomes a forgetting, a negative judgment, or a non-perception. In the first case, the phantom limb is the actual presence of a representation and anosognosia is the actual absence of a representation. In the second case, the phantom limb is the representation of an actual presence and anosognosia is the representation of an actual absence (2012, 82).

Merleau-Ponty continues by arguing that, “In neither case do we escape from the categories of the objective world where there is no middle ground between presence and absence” (82). He suggests that, on the contrary, the phantom limb has an ambivalent presence rather than being a representation (83). Although the person *knows* he no longer has the limb in question, there is another sense in which he does not know. How is this possible?

Merleau-Ponty suggests that having a phantom limb can be attributed to the habit body—one is accustomed to being able to use the limb that has been amputated (84). In expecting to be able to engage in tasks, using a phantom arm, for instance, Merleau-Ponty states, “in the impulse of movement that goes toward it [this complete world in which manipulable objects still figure], the patient finds the certainty of his [bodily] integrity” (84). On his account, the phantom limb seems to remain part of the habit body insofar as the person experiencing it still has intentional threads directed toward the world through the limb that is objectively no longer there. Thus, although changes in one’s actual body have the potential to alter one’s being in the world, exactly *how* is not directly determined and cannot be known ahead of time.

As I will develop further in this chapter, contra Weiss, Merleau-Ponty’s focus on people with impairments and illnesses neither serves to trouble the distinction between “normal” and “abnormal” nor does it suggest that subjects with impairments do not have deficiencies. Rather, Merleau-Ponty’s extensive use of Schneider as a case study serves primarily to clarify normal experience and behavior. More generally, his inclusion of the experiences of subjects with

disorders serves to highlight the deficiencies of intellectualism and empiricism and the strengths of existential analysis.

If my interpretation is correct, one may wonder if Merleau-Ponty's approach to phenomenology is really compatible with the concerns of disability theorists. Although his focus and some of his assumptions differ from those typically endorsed by disability theorists, his emphasis on the philosophical importance of bodies for being in the world lays the groundwork for theorization of the ways that bodily particularities and interpretations influence being in the world. Just as the body is capable of closing us off from the world, so too it is what typically enables us to be in situations and to be involved with others. Discussing the role of the body for Schneider and for "normal" subjects, Merleau-Ponty asserts:

For the patient we have been discussing, movement toward the future, the living present, or the past, and the power to learn, to mature, and to enter into communication with others are all somehow blocked by a bodily symptom; existence has become entangled and the body has become "life's hiding place." (...) Even when the subject is normal and engaged in inter-human situations, insofar as he has a body, he continuously preserves the power to withdraw from it. At the very moment when I live in the world and am directed toward my projects, my occupations, my friends, or my memories, I can close my eyes, lie down, listen to my blood pulsing in my ears, lose myself in some pleasure or pain, and lock myself up in this anonymous life that underpins my personal life. But precisely because it can shut itself off from the world, my body is also what opens me up to the world and puts me into a situation there (167-168).

Given Merleau-Ponty's contention that embodiment is central for being in the world and being with others, it is no mystery that bodily changes can impact being. Thus, his approach to phenomenology has obvious appeal for disability theorists concerned with the body who want to move past the ways that the medical and social models of disability have conceptualized the role of the body. As developed in chapter three, disability theorists who have advocated inclusion of the body have tended to focus on impairment, remaining within the terms of scientific/medical discourse—what Merleau-Ponty would call the objective body. Merleau-Ponty's notion of the

body as ambiguous allows for a much richer account of embodiment that is capable of incorporating subjective experiences of living in accord or discord with social expectations and in physical environments built according to those expectations.

Some disability theorists have explicitly advocated phenomenological approaches and/or emphasized the centrality of material relations between one's body and one's environment for lived experiences of disability. In the next two sections, I will elaborate on the positions of a few of these theorists. In section two, I will focus on concepts developed by Rosemarie Garland-Thomson, along with Gail Weiss' discussion of the relationship between the work of Garland-Thomson and Merleau-Ponty—in order to both draw attention to the assumptions Merleau-Ponty makes about the “normal” subject as well as ways that developing a greater consideration of the social and physical environment could enrich his understanding of embodied subjectivity.

4.2 Garland-Thomson's Concepts and Weiss' View of their Relationship to Merleau-Ponty's Phenomenology

4.2.1 Material anonymity, fitting, and misfitting

I begin by turning to Garland-Thomson's 2011 article, “Misfits: A Feminist Materialist Disability Concept” in order to consider in more depth the range of ways of being in the world. Although she is primarily concerned with disability, some of the concepts she articulates can be used to explore commonalities between the experiences of embodied marginalization and to engage in intersectional analyses.

According to Garland-Thomson, “[a] fit occurs when a harmonious, proper interaction occurs between a particularly shaped and functioning body and an environment that sustains that body” (2011, 594). When there is an adequate fit between a person and his or her environment, one has what Garland-Thomson calls “material anonymity” in which one is “suited to the

circumstances and conditions of the environment, of satisfying its requirements so as not to stand out, make a scene, or disrupt through countering expectations” (596). In other words, one does not experience the material aspects of the environment as hindering one’s projects, and one conforms to the prevailing expectations for how one should be in the world. It is important to note that while material anonymity involves a supportive physical environment, it also entails fitting with social expectations. Although Garland-Thomson describes the material and discursive as “entangled,” at times she seems to leave out consideration of discourse when discussing the material (592). Perhaps this is because she is responding to theorists such as Butler, who, from her perspective, emphasize the discursive at the expense of the material (592, 594).

When there is a *lack* of fit between one’s body and her environment, the built and natural world stand out as obstacles to one’s projects. At the same time, the body that does not fit social expectations or physical constructions stands out. Garland-Thomson calls this occurrence a “misfit,” which she characterizes in the following:

A *misfit*, conversely, describes an incongruent relationship between two things: a square peg in a round hole. The problem with a misfit, then, inheres, not in either of the two things but rather in their juxtaposition, the awkward attempt to fit them together. When the spatial and temporal context shifts, so does the fit, and with it meanings and consequences (592-593).

A misfit lies not within the characteristics of one’s body *or* the environment; it occurs when they do not mesh. However, she uses the term to indicate both this disjunction as well as the individual who experiences it: “to mis-fit renders one a misfit” (593).

In addition, Garland-Thomson seeks to enact a shift from thinking about disability as a discursive event or identity performance to thinking about the ways that physical aspects of disability (bodies and their physical environments) matter. She states, “the concept of misfit

emphasizes the particularity of varying lived embodiments and avoids a theoretical generic disabled body that can dematerialize if social and architectural barriers no longer disabled it” (592). Here Garland-Thomson indicates similar concerns to those discussed in chapter three regarding approaches to disability informed by Butler’s work on gender performativity, such as that of Tremain. Limiting theorization of bodies within disability theory to the biomedical conditions of individuals or discursive products means that either the body is inevitably a problem (bodily particularities are *all that matters*) or the body is discursively constructed as a problem (bodily particularities *do not matter* except insofar as discourse makes them matter). While recognizing that misfits occur in relation to “social oppression encoded in attitudes and practices,” Garland-Thomson’s focus is on the material encounters between humans and their surroundings (594).

As advocates of the social model of disability have tended to do, Garland-Thomson overemphasizes the need for physical access, leaving to the side the experiences of those whose impairments and illnesses—especially but not only those involving cognitive limitations—will greatly limit their options regardless of the physical environment.⁹¹ The notions of fitting and misfitting are more useful for some types of impairments than for others. For instance, in “When Caring Is Just and Justice Is Caring: Justice and Mental Retardation,” Eva Kittay notes that people with severe cognitive impairments have benefitted the least from the disability community’s advocacy. Historically, the focus within this community has primarily been on physical accessibility and has tended to assume disabled people who are cognitively typical, i.e. capable of making their own decisions and participating in the workforce if given a supportive environment. According to Kittay:

⁹¹ This is not to say that the continued focus on physical accessibility is unwarranted; however, there need to be additional priorities.

They have argued that their impairments are only disabling in an environment that is hostile to their differences and that has been constructed to exclude them. Yet, the impairment of mental retardation is not easily addressed by physical changes in the environment (2002, 258).

Although social understandings of severe cognitive impairments are malleable and could help to create better living conditions for individuals with cognitive impairments (including adequate funding for appropriate education and care), physical changes in the environment are minimally effective.

It is also important to note that the notion of a misfit may be appropriated in the service of interventions that are rejected by disability advocates in order to create a fit. For instance, in the case of a girl referred to in the biomedical ethics literature as Ashley X, who was diagnosed with “static encephalopathy,” radical measures were taken in order to alter her body in order to create what was purported to be a better fit physically and in terms of social expectations. At the age of six, Ashley’s cognitive development remained at the level typical of an infant; she was unable to ambulate, sit up, or use language (Kafer 2013, 47). The etiology of her condition is unknown (Kittay 2011, 611). In 2004, when Ashley was seven or eight years of age, her parents opted to have physicians begin growth attenuation therapy (also referred to as “the Ashley treatment”) on her. This involved three types of surgical interventions: a hysterectomy, bilateral mastectomy, and appendectomy, followed by two and a half years of “high doses of estrogen in an attempt to stunt her growth” (Kafer 2013, 49). The primary aim cited by the parents as well as the main physician and pediatric bioethicist involved in her case was to facilitate the provision of care for her in the family’s home. They maintain that if Ashley remains approximately the height and weight of an average nine-year-old girl, then her parents—and possibly others in the future—will be able to move her around easily and include her in more activities than they would otherwise be able. They claim that growth attenuation will prevent the need to institutionalize her.

These types of support may be thought to be responses to a type of misfit between Ashley, if she were allowed to grow, and her physical environment. To create a better fit, either her surroundings need to be accessible and the family must obtain and use equipment to lift and transfer her for activities of daily living or physicians must employ surgical and hormonal intervention in order to facilitate moving Ashley with little or no reliance on such equipment.⁹² One of the reasons some people within the disability rights community have voiced opposition to growth attenuation therapy is that it drastically changes the body of a child who is unable to give consent when changes could be made to her environment to allow her to receive the care that she needs in her parents' home.

Regardless of the merit of these arguments in favor of the “Ashley treatment,” it is important to note that there are other types of rationales provided. They frame the effects of Ashley’s static encephalopathy, namely the low level of cognitive development, as entailing a type of misfit that is seen as in need of correction. In an interview with Christopher Mims in *Scientific American* bioethicist Norman Fost remarks:

[H]aving her size be more appropriate to her developmental level will make her less of a “freak.” ...I have long thought that part of the discomfort we feel in looking at profoundly retarded adults is the aesthetic disconnect between their development and their bodies. There is nothing repulsive about a 2 month old infant, despite its limited cognitive, motor, and social skills. But when the 2 month old baby is put into a 20 year old body, the disconnect is jarring (2007).⁹³

Fost seems to assume that the discomfort some feel in the presence of adults with severe cognitive impairments is appropriate, and that, rather than working to change this, it would be

⁹² Additional arguments are made for the hysterectomy and double mastectomy. The potential for uterine bleeding as a result of the high doses of estrogen is cited as a justification for the hysterectomy. Removal of Ashley’s “breast buds” is said to eliminate the risk that she would experience pain or discomfort from developing large breasts, cancer, or fibrocystic growth—all of which are present in her family (Kafer, 52). I will not evaluate these claims here. For further discussion of the arguments for and against the “Ashley treatment,” see Gunther and Diekema 2006; Kittay 2011; and Kafer 2013.

⁹³ As quoted by Kafer (2013, 55).

best to alter the appearance of such adults so that their developmental level will be readily apparent to observers. In the same article, he goes on to state: “If children like Ashley could magically retain the appearance of an infant, they would not only be easier to care for in the physical sense, but the emotional reaction to them would probably be more favorable” (Mims 2007). Lest the reader should think Fost is the only one who holds this position, I turn to a related remark made by bioethicist George Dvorsky: “The estrogen treatment is not what is grotesque here. Rather, it is the prospect of having a full-grown and fertile woman endowed with the mind of a baby” (2006).⁹⁴ It is unclear what harm being full-grown and fertile could cause Ashley. However, Dvorsky reveals concerns for the dissonance others may experience upon encountering her (perhaps as a result of finding her sexually attractive). Neither of these authors considers that the degree to which Ashley and others like her are deemed misfits could be decreased if social expectations were to shift.

Of course, as Garland-Thomson articulates it, misfitting occurs when a body and environment are not suitable in relation to each other. She wants to distance her conception from ones that would consider bodies themselves to be misfits. Fost and Dvorsky fail to identify their own reactions as well as the possible reactions of the public as a component of the misfit, which means that they do not consider whether that is the problem that needs to be addressed rather than changing Ashley’s body.

Garland-Thomson does not hold that the goal should be to eliminate all misfits or that the effects of misfitting are only negative. She suggests that misfitting may lead to a burgeoning awareness of social injustice and the formation of activist communities (597). According to Garland-Thomson, misfits may facilitate novel ways of negotiating unsupportive environments. She holds, “[a]cquiring or being born with the traits we call disabilities fosters an adaptability

⁹⁴ Also quoted by Kafer (2013, 55).

and resourcefulness that often is underdeveloped in those whose bodies fit smoothly into the prevailing, sustaining environment” (2011, 604). As mentioned in chapter two, Garland-Thomson endorses what she terms “feminist sitpoint theory,” a feminist standpoint informed by the experiences of disabled people. She supports reduction in the frequency of misfits through development of more sustaining environments characterized by “accessibly designed built public spaces, welcoming natural surroundings, communication devices, tools, and implements, as well as other people,” some of which have been made more likely through civil rights legislation (594). However, she contends that the imperative to decrease the number of misfits is harmful when it is taken as a mandate to eliminate “the particularities of embodiment we think of as disability” through technological means such as preimplantation genetic diagnosis, prenatal testing and selective abortion, and medical normalization (602). Thus, on Garland-Thomson’s account, not only are misfits not always something to be prevented, but they also provide potential epistemic resources.

The notion of misfitting does not answer *a priori* whether or how a misfit should be resolved or even than it can be. Yet, it is significant that Garland-Thomson gestures at something that theorists such as Tremain seem to miss—the fact that the materiality of bodies and the social meanings given to bodily particularities in conjunction with the physical environment are relevant for experiences of being enabled or disabled. Not all bodies considered to have impairments misfit. It is equally clear that although social norms are an important aspect of misfits, they are not the only cause of misfits.

Being marginalized on the basis of race and gender may be considered a type of misfit. Garland-Thomson explicitly suggests that her notion of misfitting may be used more broadly than has been discussed to this point in the following:

Although *misfit* is associated with disability and arises from disability theory, its critical application extends beyond disability as a cultural category and social identity toward a universalizing of misfitting as a contingent and fundamental fact of human embodiment (598).

I take her claim to be that misfitting is always a possibility, even if, I would add, misfits are more likely for some people than others. This is consistent with the examples Garland-Thomson provides in the following: “A misfit occurs when world fails flesh in the environment one encounters—whether it is a flight of stairs, a boardroom full of misogynists, an illness or injury, a whites-only country club, subzero temperatures, or a natural disaster” (600). Her primary focus is on vulnerability—the potential for suffering—that she claims manifests when the environment is not sustaining. These types of misfits are difficult to ignore.

Garland-Thomson suggests that fitting as a nondisabled person is similar to being in a dominant position in terms of race and gender insofar as material anonymity is attained. She contends, “[l]ike the dominant subject positions such as male, white, or heterosexual, fitting is a comfortable and unremarkable majority experience of material anonymity, an unmarked subject position that *most of us* occupy at some points in life and that often goes unrecognized [emphasis added]” (2011, 597). Her description of material anonymity or fitting applies to bodily features beyond typical structure, function, and health that have social significance. This implies that one can also experience material anonymity if one’s body and environment are an adequate fit in regard to social expectations related to gender, race, and sexuality. It is difficult to notice one’s own material anonymity. Often those who are privileged in this way, in fact, do not notice until those experiencing misfits draw attention to the phenomenon of material anonymity. For example, a white person may not think about race because the effects of race on her life are not readily apparent to her. One manifestation of inhabiting a privileged social identity is that one may not be required to think about the effects of social categories.

Without elaborating on precisely what she means, Garland-Thomson claims “[m]isfit moves this idea of dissonance [when others’ identifications of us differ from our own] from epistemology into phenomenology” (601). It is clear that she seeks to center lived experiences, but she claims that the concept of misfit deemphasizes “being” in favor of “location” (604). Given the reading of Merleau-Ponty developed in this chapter, it makes little sense to position these as opposed to each other. However, it appears that Garland-Thomson conceives of being as static rather than dynamic, as acontextual/atemporal rather than situated, and this is why she thinks of being as opposed to location. To elaborate on the relationship between Garland-Thomson’s notions of fitting and misfitting and Merleau-Ponty’s approach to phenomenology, I will now turn to Weiss’ discussion of this topic. I will also critique Weiss’ position on Merleau-Ponty’s assumptions about disability and his use of Schneider specifically.

4.2.2 Weiss on Garland-Thomson, Merleau-Ponty, and normality

Although Garland-Thomson does not reference Merleau-Ponty in her 2011 article,⁹⁵ Weiss suggests in “The Normal, the Natural, and the Normative” (2015) that her notions of fitting and misfitting are phenomenological and in line with his discussion of being in the world. She also suggests that Garland-Thomson’s approach to critiquing the medical and social models of disability parallels Merleau-Ponty’s approach to empiricism and intellectualism. Weiss states:

just as Merleau-Ponty argues that both the empiricist and the intellectualist go astray in the same way, despite their opposition to one another, because both are committed to a one-sided, active/passive model that does not accurately describe our experience, so Garland-Thomson argues that whether disability is seen as a function of a deficient body *or* a deficient environment, we are not doing justice to the lived experience of disability (Weiss 2015, 90).

Yet, just as Merleau-Ponty finds aspects of empiricism and intellectualism to be valuable, so too, there are insights within the medical and social models of disability that are worth retaining.

⁹⁵ Garland-Thomson does reference *Phenomenology of Perception* in *Staring: How We Look* (2009).

However, it is a mistake to consider impairment (or scientific descriptions of bodies more generally) to be “the” way to treat bodies in theory and practice. In addition, social context must be considered in order to understand the ways people with impairments are enabled or disabled. The problem arises when either model or even an attempt to combine these models is represented as an adequate description of disability. Just as empiricism and intellectualism omit being in the world while being premised on it, so too the medical and social models of disability, which conceptualize disability as “a function of a deficient body *or* a deficient environment,” respectively, leave out being in the world (*one’s own body*) while resting on it (90). Embodied subjectivity is left out, and the phenomenon of disability escapes theorization.

I agree with Weiss that Merleau-Ponty’s phenomenology of embodiment, with adaptations, is a productive starting point for theorizing experiences related to gender, race, and disability. However, I think that Weiss gives Merleau-Ponty credit for being attuned to the concerns of disability activists and theorists who came after him in a way that he could not have been. She rightly notes that disability studies emerged as a field after his death and thus could not have influenced his thinking. Nonetheless, I think she misconstrues Merleau-Ponty’s rationale for focusing on individuals with illnesses and impairments, leading her to attribute conclusions to Merleau-Ponty that do not have textual support within *Phenomenology of Perception*.

In the course of comparing the assumptions made by Merleau-Ponty and Garland-Thomson, Weiss makes the following claim:

Just as Merleau-Ponty emphasizes Schneider’s adaptability to the bodily and situational limitations that “normal subjects” believe make his experience profoundly deficient, so that *they are lived as normal for him*, Garland-Thomson stresses that what might look like a misfit to others, namely a non-normative body that engages with the world in non-normative ways, with the right support from others and from the environment, may actually be lived as a fit [emphasis added] (Weiss 2015, 92).

Although Weiss' attribution of the claim that it is possible in many cases for those with non-normative bodies to attain a fit with a supportive environment to Garland-Thomson is correct, her suggestion that Merleau-Ponty draws the conclusion that Schneider experiences such a fit does not find textual support within *Phenomenology of Perception*. Merleau-Ponty focuses on Schneider's bodily and relational limitations and the strategies he undertakes in order to complete certain tasks. There are a number of passages that, I would argue, should lead us to conclude that Schneider's bodily and situational limitations are *not*, as Weiss claims, "lived as normal for him" (92). Schneider's brain injury imposes limits on the degree to which he can experience a "fit" in any social and physical environment. He lives with the knowledge that there are things he would like to be able to do that he cannot, such as forming political beliefs and maintaining long-term friendships. I would suggest that, in this case, rather than being limited to the judgments "normal" subjects make about him, Schneider himself experiences a mismatch between his desires and his capabilities. To be clear, I am responding to Weiss' claims here rather than those of Garland-Thomson, since the latter does not discuss Schneider.

Consider the following passage from *Phenomenology of Perception*:

Schneider rarely expands his social milieu, and, when he does establish new friendships, they at times end badly: upon analysis, we see that this is because they never emerge from a spontaneous movement, but rather from an abstract decision. He would like to be able to think about politics or religion, but he never even tries. He knows that these regions are no longer accessible to him, and we have seen that, generally speaking, he never executes an authentic act of thought and he substitutes the manipulation of signs and the technique of using "fulcra" for the intuition of number or the grasping of signs (Merleau-Ponty 2012, 160).

Merleau-Ponty claims that Schneider's efforts to create new friendships are often thwarted by his inability to connect with others in a way that is spontaneous rather than contrived. In addition, Schneider is said to have a desire to consider politics and religion, but he is not able to do so. He

experiences these limitations; they are not interpretations imposed on him by others that distort his own assessment.

As developed earlier in this chapter, at the core of Schneider's limitations is a shift in his situatedness as being in the world. Merleau-Ponty notes that one of the ways this manifests in his behavior is through a lack of spontaneity or playfulness.

"He must now be content with general beliefs and without being able to express them." He never sings nor whistles on his own. We will see below that he never takes the initiative sexually. He never goes for a walk, but always to run an errand, and he does not recognize Professor Goldstein's house when walking by it "because he has not gone out with the intention of going there." (...) ⁹⁶ There is something meticulous and serious in all of his behavior, which comes from the fact that he is incapable of playing. To play is to place oneself momentarily in an imaginary situation, to amuse oneself in changing one's "milieu" (136).

Because Schneider's lack of playfulness is caused by his inability to put himself into an imaginary situation, he would experience a misfit in any "world," regardless of the social and physical environment. While there are ways that those around him can help to lessen the degree of misfitting he experiences (for instance, by having expectations that are in line with his capabilities), a change in his environment cannot create a perfect fit that will allow Schneider to be playful or to achieve other things he would like to be able to do.

Weiss suggests that in *Phenomenology of Perception* Merleau-Ponty discusses "allegedly abnormal experiences, not as negative examples that reinforce the rigid boundaries of normality, but, I would argue, to challenge our conceptions of what is normal, what is natural, and what can and should be normative" (2015, 93). Although it is true that Merleau-Ponty locates a continuity between the behavior of "normal" and "pathological" subjects, as I argued in the previous section of this chapter, rather than calling the distinction between these categories into question, his method in *Phenomenology of Perception* is premised upon it. Here are a few additional

⁹⁶ Merleau-Ponty attributes the portions in quotation marks to W. Benary (1922, 213).

passages that support my position. Merleau-Ponty queries: “How are we to make sense of this series of facts, and how should the function that exists for the normal person, but that is missing for the patient, be understood through them?” (2012, 110) He goes on to say:

Illness, like childhood or like the “primitive” state, is a complete form of existence, and *the procedures that it employs in order to replace the normal functions that have been destroyed are themselves pathological phenomena...* We observe that the patient who is questioned on the position of his limbs or on the location of a tactile stimulus seeks, through preparatory movements, to turn his body into a present object of perception; when questioned about the form of an object touching his body, he seeks to trace it himself by following the contour of the object. Nothing could be more mistaken than to assume that the same operations are at work for the normal person and merely abridged by habit. The patient only seeks these explicit perceptions in order to supply himself with a particular presence of the body and the object that is given for the normal person and that remains for us to reconstitute [emphasis added] (Merleau-Ponty 2012, 110).

He contends that analyses of the behavior of subjects such as Schneider provide insights into “normal” behavior, and this is primarily by way of contrast rather than similarity. Although there may be instances in the text in which Merleau-Ponty provides helpful descriptions of ways that disabled people incorporate implements such as canes into their being in the world, his point is not to call into question conceptions of normality.

I have highlighted Weiss’ claims about the relationship between the approaches of Merleau-Ponty and Garland Thomson as well as my response to her interpretation of Merleau-Ponty’s use of Schneider and his position on normality more generally. I will now develop an assessment of the usefulness of Garland-Thomson’s notions in order to critique phenomenologists such as Merleau-Ponty and Gallagher as well as to bring together work on lived experiences of disability with other types of marginalized embodiment.

4.3 Material Anonymity and Phenomenology: Merleau-Ponty and Some of his Successors

Garland-Thomson’s notions of “material anonymity,” “fit,” and “misfit” are closely related to the notion of being in the world as Merleau-Ponty articulates it insofar as they entail the assumption

that being is situated, embodied, and dynamic. Both theorists begin with lived experience, which enables them to account for embodied subjectivity insofar as they refuse biologically or culturally deterministic assumptions. However, Garland-Thomson attends to the significance of bodily particularities and social context to a greater degree than Merleau-Ponty does. Since he recognizes that ambiguity is fundamental within human existence, I initially thought that what Garland-Thomson takes to be novel insights had already been articulated by Merleau-Ponty. Upon further reflection, however, I realized that her notions of material anonymity, fit, and misfit may serve to highlight important limitations within his approach to phenomenology. While this would be significant in itself, it matters even more due to Merleau-Ponty's extensive influence on theorists concerned with embodiment.

Garland-Thomson's notion of material anonymity can be used to highlight the implicit assumptions that Merleau-Ponty makes about what types of subjects count as "normal" or typical. Although he acknowledges that one's body is essential for enabling or preventing one from being open to the world, his exploration of how bodily particularities and social identity impact the ways in which one is situated is limited. To put the point differently, Merleau-Ponty sometimes does not recognize that he is universalizing the experiences of particular bodies that fit *well enough* to attain material anonymity.⁹⁷ As Alison Kafer states, "there is no mention of 'the' body that is not a further articulation of a very particular body" (2013, 7). I will show that Merleau-Ponty and others drawing on his work, including S. Kay Toombs, Drew Leder, Havi Carel, and Shaun Gallagher assume a sort of material anonymity to be the standard way of being rather than a privileged way of being that only a minority of the population experiences on a consistent basis. Garland-Thomson seems to go back and forth on this point, and I think this is because in some

⁹⁷ For example, as Alcoff states, "on their [Young, Butler, and Grosz's] view Merleau-Ponty's shortcomings result mainly from the fact that his analysis of embodiment did not specify sexual difference, and thus male embodiment was allowed to stand in for the whole" (2000, 265).

parts of her article she uses mis/fitting to refer specifically to dis/ability and in others she broadens the scope to include mis/fitting across additional axes. If an inclusive notion of misfitting is adopted, then I would suggest that material anonymity is the exception rather than the rule. Theorists who provide phenomenological accounts of lived experiences of disability, gender, and race tend to think about these social categories in isolation and to assume that “normal” subjects (i.e., the subjects that are not marginalized along the axis with which the theorist is concerned) attain material anonymity. I call for work that simultaneously considers disability and other axes of marginalized embodiment such as gender and race.

Merleau-Ponty acknowledges some types of variation among subjects categorized as “normal” or “pathological,” but this does not include the ways that bodily features that count as markers of race, gender, and dis/ability matter for being in the world. In *Disability Bioethics: Moral Bodies, Moral Difference*, Scully suggests that this may be a result of his desire to develop a universal account:

Perhaps it is that the commitment to establishing a universal phenomenological ontology renders Merleau-Ponty and other phenomenologists incapable of acknowledging any variation in the primary normative experience that might challenge the claim that being-in-the-world can be described in terms of a common primordial perception (Scully 2008, 94).

If it is assumed that it is possible to talk about being prior to and apart from particular characteristics and embodiment more generally, then development of a universal ontology makes sense. However, since Merleau-Ponty centers embodiment rather than leaving it implicit, doubts arise about the possibility of such a universal account.

Scully maintains that the divide between “normal” and “pathological” encourages homogenization of experiences within the category of “normal.” In her words:

a phenomenology that splits the experience of being-in-the-world into the normal (the one we focus on) and the pathological (variants that are only interesting for what they tell

us about normality) obscures the very obvious fact that even fully functioning people vary enormously in their capacity for certain perceptions or actions that, in principle, all human beings are supposed to be able to do. Whenever the “normal” spontaneous body sense is invoked, we need to keep in mind that this sense operates along something like a continuum with multiple axes (Scully 2008, 94-95).

Her discussion focuses on differences in abilities between members of the category “normal.”

For example, Scully notes that some people “will always have two left feet when it comes to the tango” (95). She claims that phenomenologists who attend to embodiment have tended to focus on the extreme ends of the spectrum when it comes to ability.⁹⁸

Scully notes that feminist philosophers have criticized Merleau-Ponty for focusing almost exclusively on the bodily experiences of men. She observes that this is true not only of Merleau-Ponty but also of later phenomenologists. Worse, they unreflectively equate white male experience with “normal” experience (2008, 94). These experiences are characterized by material anonymity, which, I have argued, is not something most people experience consistently. In addition, Scully asserts “[c]riticism of phenomenology’s neglect of the gendered body applies equally well to its treatment of other types of phenotypic variance” (94). Although she acknowledges that Merleau-Ponty discusses individuals with impairments, she shares my contention that his main goal in doing so is to elucidate “normal” experience. Scully puts the point this way: “Much of his empirical data comes from neuropathology because the effects of disruptions to the standard sensory and motor apparatus were useful in his philosophical modeling of phenomenological norms” (2008, 89). Turning to atypical subjects helps to clarify the experiences of “normal” subjects.

⁹⁸ Perhaps this is a bit of an exaggeration. I appreciate Alex Levine’s remark on this topic: “I don’t know of any phenomenological discussion of the lived experience of Olympic-level athletes.” I believe Scully’s point to be that phenomenologists have not sufficiently taken into consideration the variations in ability between typical subjects.

The trend of assuming that material anonymity is typical is present within the work of philosophers who are focused on developing phenomenological accounts of impairment and illness as well. This matters because, even though these theorists are working to better describe the experiences of people with illnesses and impairments, they are still tacitly assuming a white male able-bodied subject as standard or “normal” and making implicit assumptions about the race and gender of disabled subjects. Here I will briefly discuss three examples.

In “Illness and the Paradigm of the Lived Body,” Toombs asserts that, in illness: “Habitual acts (such as walking, running, lifting, sitting up, eating, talking, and so forth), which were hitherto performed unthinkingly, now become effortful and must be attended to” (1988, 208). Surely, it is often the case that illness makes one more aware of one’s body, especially in situations in which one must find new ways to or is unable to accomplish certain tasks. It is important to detail the ways in which illness and impairment shape being in the world, and this is something Toombs’s work does exceptionally well. However, there is much more to be said about ways that social expectations—including those related to gender and race—create misfits and the corresponding imperative to attend to one’s body, regardless of one’s health and ability status.

Toombs states that in cases of illness, “[t]he lived experience of the body itself becomes the focus of attention. Pain or other bodily dysfunction disrupts one’s ongoing engagement with the world. The body can no longer be taken for granted and ignored” (1992, 35). This quotation suggests that when one’s body is functioning well and one is not experiencing pain, then the body can be “taken for granted and ignored.” Toombs also implies this in the following:

Illness precipitates a fundamental change in the relation between self and body. In the first place the body can no longer be taken-for-granted or ignored. It must be explicitly attended to in various ways. Consequently, rather than being simply lived unreflectively, the body becomes an object for scrutiny. With objectification comes alienation. As an

object, the body is suddenly perceived as a “thing” which is exterior to the self, as something Other-than-me (1988, 214).

Here Toombs attends to the individual’s perception of his or her body. If we combine her insights with those of Garland-Thomson, we might arrive at the conclusion that objectification is the opposite of material anonymity.

Although Toombs focuses on experiences of illness, she notes that there are other factors that may lead one to sense the body as other, stating: “[w]hile the sense of ‘otherness’ of body is by no means peculiar to illness, it is particularly felt in this experience” (1988, 217). While she recognizes that illness is not unique in being correlated with the inability to take *one’s own body* for granted, Toombs does not develop ways that social identity is relevant for the experience of bodily otherness, among ill and healthy individuals alike.

Leder claims in *The Absent Body* that when one is healthy, the body has a tendency to recede, phenomenologically, into the background of one’s awareness. He calls this *disappearance*. He asserts:

Our organic basis can be easily forgotten due to the reticence of visceral processes. Intentionality can be attributed to a disembodied mind, given the self-effacement of the ecstatic body. As these disappearances particularly characterize normal and healthy functioning, forgetting about or “freeing oneself” from the body takes on a positive valuation (1990, 69).

I would suggest that Leder assumes that normal and healthy functioning is sufficient to enable one to forget about the body in favor of focusing on other things. On his account, the body is simply not an issue unless one experiences pain or symptoms of illness. In other words, like Toombs, Leder assumes that material anonymity is the typical form that being in the world takes for healthy, nondisabled subjects.

In “Phenomenology and its Application in Medicine” (2011) Carel contends that when there is a disjuncture between the objective and the lived body, one is forced to attend to one’s

body, as in the cases of anorexia and phantom limb. When the objective and lived body are “in harmony,” on the other hand, she suggests that, “The healthy body is transparent, i.e., taken for granted. Thus, transparency is the hallmark of health and normal function. We do not stop to consider any of its processes because as long as everything is going smoothly, it remains in the background” (Carel 2011, 39). This type of claim is common among philosophers who engage in phenomenological approaches to illness and impairment. While there is a limited sense in which this type of claim seems accurate—we pay more attention to our bodies when they prevent us from engaging in activities or cause us pain (and we have not adjusted to this) than when they facilitate our aims and do not hurt—there are varying *degrees* to which it is possible for any given individual to take their body for granted or have it remain in the background.⁹⁹

Factors such as race, gender, and class play a significant role in influencing the degree to which one is likely to be able to take one’s body for granted or, at the other end of the spectrum, to be compelled to attend to its every move and potential interpretation. Perhaps it is useful to expand what it means for everything to be “going smoothly” beyond an individualistic and medicalized perspective. I contend that many bodily experiences of those who are considered healthy and nondisabled call into question the claim that being able to take the body for granted is a universal experience among members of this group. I will develop this position in the remainder of the chapter, drawing on insights from theorists concerned with disability, race, and gender. I now turn to a critique of Gallagher’s characterization of “normal” subjects in order to

⁹⁹ Young asserts, “The notion of the body as a pure medium of my projects is the illusion of a philosophy that has not quite shed the Western philosophical legacy of humanity as spirit” (2015, 52). Even philosophy that is explicitly focused on embodiment struggles to remain focused on the variety of embodied experiences, i.e., the ways in which bodies are *not* simply mediums for projects. In addition, when bodies are theorized without consideration of context, theorists miss how they are enabled or disabled.

demonstrate the ways that failure to consider gender and race limit the applicability of his account.

In *How the Body Shapes the Mind*, Gallagher's approach to the case study of Ian Waterman is very similar to Merleau-Ponty's use of Schneider. Namely, Gallagher uses Waterman, who "has no sense of touch and no proprioception [which provides one with a sense of bodily position and where one's body parts are] below the neck" in order to help to flesh out how Waterman's strategies for keeping track of his body greatly diverge from typical subjects (2005, 43). Gallagher draws on Waterman's behavior in order to clarify the distinction he makes between body image and body schema, terms whose usage has tended to be inconsistent throughout the literature within philosophy and psychology. *Body image* involves perceptions, beliefs, conceptual understanding, and emotions about one's body. *Body schema*, on the other hand, "involves certain motor capacities, abilities, and habits that both enable and constrain movement and the maintenance of posture" (2005, 24). Although I agree with Gallagher that typical subjects are able to rely on a body schema rather than relying on body image to engage in movements to the extent that Waterman does, I maintain that a more nuanced account of the variations between typical subjects is needed in order to include the impact of norms related to social categories such as gender and race.

Gallagher acknowledges, "[s]ocial and cultural factors clearly affect perceptual, conceptual, and emotional aspects of body image" (30). So, there is room in his account for the ways in which one's social positioning—including relation to gender norms—impact body image. Yet, he doesn't seem to consider the possibility that these factors may impact body schema and thereby, movement and posture. Gallagher assumes that cultural and social factors

affect body image but does not seem to allow that either body image or these factors affect movement in normal cases. He goes on to say of body schema:

In most instances, movement and the maintenance of posture are accomplished by the *close to automatic* performances of a body schema, and for this very reason the **normal adult subject**, in order to move around the world, neither needs nor has a constant body percept. In this sense the body-in-action tends to efface itself in most of its purposive activities [italics in original, bolded text added] (26).

I want to raise two related issues in response to this quotation. First, as noted above, Gallagher allows that social and cultural factors impact body image, but this isn't normally relevant, on his account, for development of motor capacities, abilities, and habits related to movement and posture. Secondly, as I will show, his description of the movements enacted by the "normal adult subject" "in most instances" doesn't address some of the everyday experiences of movement of "normal" (nondisabled) female subjects and may, thus, be more likely to actually describe the typical movements of "normal" (nondisabled) (white) *male* subjects. Gallagher notes that there may be differences between individuals regarding just how much the body effaces itself in action (2005, 27). Of course, this is an important point. What he doesn't consider is that there may be norms in place that influence how likely it is that one's body will be effaced in purposive activities—in other words, whether or not material anonymity is possible.

Though he uses gender-inclusive language, Gallagher makes further claims here regarding the "normal and healthy subject" that I would suggest are not the default in the case of many normal and healthy female subjects' lived experiences. He maintains:

With respect to moving around the world, the normal and healthy subject can in large measure *forget about her body in the normal routine* of the day. *The body takes care of itself*, and in doing so, it enables the subject to attend, with relative ease, to other practical aspects of life. To the extent that the body effaces itself, it grants the subject a freedom to think of other things. The fact that Ian, who lacks proprioception, is forced to think about his bodily movements and his posture much of the time demonstrates the degree to which, in the normal subject, this is not the case [emphasis added]" (2005, 55).

Like Schneider, Waterman “knows” the location of his body in one sense but not the other. It should be noted that Gallagher does concede that body image may affect body schema when one is engaging in some types of novel activities that involve movement. He states in footnote 6 of chapter 6, “in cases of learning dance or athletic movements, focusing attention on specific body parts can alter the established postural schema” (141). Yet, it remains the case that he thinks that it is exceptional for bodily awareness to “interfere with the performance of the body schema” (141). This account may accurately describe many of the experiences that able-bodied men and women have of movement. Yet, I would venture to say that there are more men than women and more white people than people of color in sexist and racist societies who would agree with Gallagher’s assertion that, “With respect to moving around the world, the normal and healthy subject can in large measure forget about her [or his] body in the normal routine of the day” (55). Here again, this description seems more applicable to those whose bodies are privileged through social norms and the built physical environment.

Iris Marion Young’s work is especially helpful for clarifying what is missing in Gallagher’s characterization of “normal and healthy subjects.” In “Pregnant Embodiment: Subjectivity and Alienation” ([1984] 2005) she notes: “The dominant model of health assumes that the normal, healthy body is unchanging. (...) Only a minority of persons, however, namely adult men who are not yet old, experience their health as a state in which there is no regular change in body condition” (2005, 57). The oversights within Gallagher’s discussion are common rather than exceptional. Since he focuses primarily on the relationship between posture and movement, on the one hand, and body schema and body image, on the other, I will turn to another of Young’s essays that deals with gendered negotiation of space.

In “Throwing Like a Girl: A Phenomenology of Feminine Body Comportment, Motility, and Spatiality” Young explores how girls and women “situated in contemporary advanced industrial, urban, and commercial society” develop ways of moving and relating to space that are feminine ([1980] 2005, 30). She draws on Merleau-Ponty’s notion of the lived body in order to consider how women and men come to embody social norms regarding gender. Young defines “feminine” as “a set of structures and conditions that delimit the typical *situation* of being a woman in a particular society, as well as the typical way in which this situation is lived by the women themselves” (31). This definition allows for variation between the situations of women in different societies as well as how particular women within the same society embody norms of femininity (or don’t). Young notes that while boys tend to be socialized to use their bodies in ways that maximize their strength when accomplishing physical tasks, girls are often cautioned to be careful and not to get hurt when engaging in these same tasks, and this is one reason that females tend to approach tasks that require strength with more hesitancy than males. Young also notes that the theme that emerges when comparing the approaches of men and women to tasks requiring strength and coordination, for example, throwing, running, climbing, and swinging, is that men tend to use their entire bodies while women tend to only engage the parts of their bodies that are absolutely necessary (33). As a result, women often use their bodies in ways that are less effective than men’s use of their bodies in these purposive activities.

Young’s account of feminine movement can be used to flesh out Gallagher’s discussion of body image and body schema. In Gallagher’s terms, the body images of women and men are likely to differ greatly insofar as the standards for evaluating their bodies differ, though there is certainly variation within these groups. Even if it is conceded that cultural and social factors directly impact body image on a regular basis but only affect body schema indirectly via

attentiveness to body image when one is learning dance or athletic movements, cultural and social factors would continue to impact subsequent enactments of these movements even without conscious reflection on body image. If Gallagher is willing to allow that we attend to body image when learning dance and athletic movements, it seems he should recognize that other novel movements also require attending to body image. In this case, it is easy to see how social and cultural factors, such as norms of femininity and masculinity, could play an important role in shaping “motor capacities, abilities, and habits that both enable and constrain movement and the maintenance of posture,” i.e., body schema (2005, 24). After all, many novel movements become everyday movements.

In addition to norms of femininity influencing women’s movements indirectly through body schema’s reliance on body image in engaging in unfamiliar movements that may become habitual, I think that body image is more likely to affect women’s movements directly. According to Young, “We [women] feel as though we must have our attention directed upon our bodies to make sure they are doing what we wish them to do, rather than paying attention to what we want to do *through* our bodies” (2005, 34). If this is the case, women’s bodies are unlikely to efface themselves in at least some types of purposive activities. Young claims that women often divide their attention between the task they are accomplishing and their bodies as objects. This is in alignment with the findings of social psychologist Stephen Franzoi that women tend to view their bodies primarily in terms of its status as an object while men tend to focus on the abilities of their bodies. In Franzoi’s words:

Consistent with the perspective of women objectifying their bodies and men having a more process-oriented view, when females engaged in body awareness their focus of attention tended to be on specific body parts, while men’s focus was more global, and tended to be concerned with physical movement and function (1995, 418).

If Young and Franzoi are correct in their suggestion that women are likely to objectify their bodies, i.e., attend to body image, while engaged in everyday physical tasks, then it seems that cultural and social factors may impact body schema and movement in a wider variety of cases than Gallagher acknowledges.

As exemplified in the work of Toombs, Leder, Carel, and Gallagher, theorists of the body often focus on one axis of social identity as it is embodied. It is easy to understand why one would take this approach, given the complexity and range of experiences related to disability or race, for example. Yet, it is not possible to completely separate the effects of the multiple ways one is categorized upon lived experience. When we discuss *one's own body*, we are always already tacitly assuming multiple axes of identity. For instance, discussions of disability that do not talk about race tend to assume whiteness while discussions focused on race tend to assume able-bodiedness. It is time to work toward developing phenomenological approaches that are explicitly intersectional, meaning that they consider the ways that multiple categories impact *one's own body*, and the effects often cannot be neatly delineated into these categories. So far, my discussion has focused on ways that norms related to femininity encourage women to attend to the appearance and movements of their bodies in ways that diverge from what Gallagher characterizes as the normal adult subject. Considering norms related to race adds to the difficulties facing the type of standard account he presents, and adds to the evidence that his description is really most fitting of a nondisabled white man.

As Weiss notes: “Fanon presents a trenchant critique of the race-neutral, generic, and ultimately quite positive account Merleau-Ponty and the Gestalt theorists provide of the body schema” (2015, 86).¹⁰⁰ She goes on to state:

¹⁰⁰ Sara Ahmed makes a closely related remark in “A Phenomenology of Whiteness”:

By providing this confirmatory account of how the body scheme *should* operate in the allegedly “normal” subject, Fanon enables us to see exactly how and why it can become an impossible achievement for those whose bodies are deemed inherently inferior, that is, for those who are ruled out, from the outset, from achieving the status of “normal” subjects. Being viewed and treated as a “normal” subject, then, is revealed by Fanon not to be one’s “birthright” as a human being, but as an inherited privilege that white bodies (if, I would add, they are able-bodied) enjoy and that non-white bodies do not (86).

One of the significant differences between those who are considered “normal” subjects and those who are not is whether or not one’s body is treated as an obstacle to one’s status as human. When a person is in an environment that is sustaining—socially and materially—it is easy to think that the body is irrelevant for their life prospects. However, in the converse instance, the ways in which social norms privilege some types of bodies while marginalizing others—creating fits and misfits—are more readily apparent.

There are cases in which it is inadvisable to ignore one’s body because, in instances of misfitting, doing so may result in misunderstandings or even violence. In “White Gazes: What It Feels Like to Be an Essence” (2014) George Yancy provides an illustration of some of ways that Black men are compelled to attend to their every movement in the presence of white women. He recounts a recurring experience he, a Black university professor, has, of sharing an elevator with a white woman in which her gestures indicate fear that he will harm her or steal her purse. Yancy is placed in a double-bind insofar as there is no good response, only gestures that are, at best, likely to be interpreted in ways that reinforce stereotypes, or, at worst, are seen as manifesting the violent intentions he is assumed to harbor. He states:

She fears that a direct look may incite the anger of a Black predator. She fakes a smile. By her smile she hopes to elicit a spark of decency from me. But I don’t return the smile. I fear it may be interpreted as a gesture of sexual advance. After all, within the social

Husserl and Merleau-Ponty describe the body as “successful”, as being “able” to extend itself (though objects) in order to act on and in the world. Fanon helps us to expose this “success” not as a measure of competence, but as the bodily form of privilege: the ability to move through the world without losing one’s way (2007, 161).

space of the elevator, which has become a hermeneutic transactional space within which all of my intended meanings get falsified, it is as if I am no longer in charge of what I mean/intend. (...) It is through her gaze that I become hypervigilant of my own embodied spatiality. On previous occasions, particularly when alone, I have moved my body within the space of the elevator in a noncalculative fashion, paying no particular attention to my bodily comportment, the movement of my hands, my eyes, the position of my feet. (...) I now begin to calculate, paying almost neurotic attention to the proxemic positioning of my body, making sure that this “Black object,” what now feels like an appendage, a weight, is not too close, not too tall, not too threatening (2014, 56).

Yancy illustrates how race and gender norms, which are structural, influence how one experiences and is compelled to comport one’s body. In this example, he perceives his body through this white woman’s gaze and his interpretation of what her smile means. Yancy’s hypervigilance is a response to the normalization of white men inflicting violence upon black men for even the slightest perceived transgressive manner of comportment.

When philosophers develop accounts of *one’s own body* that purport to be universal or normal, they fail to consider ways that norms related to ability, gender, and race enable the smooth functioning of certain types of bodies while marginalizing and obstructing others. The assumption that being healthy and nondisabled entails being able to ignore one’s body fails to include many people’s lived experiences. By drawing on Garland-Thomson’s notions of fitting, misfitting, and material anonymity, I have suggested that there are some commonalities between experiences of disabled people and people marginalized on the basis of gender and race. It is imperative for future work on embodied subjectivity to center ways that the intersection of these identity categories shapes lived experiences rather than continuing the trends of considering social identity to be irrelevant or theorizing each axis individually.

4.4 Conclusion

In this chapter, I have argued that although Merleau-Ponty’s approach to phenomenology is useful for theorizing embodiment within disability theory, it is important to assess his use of case

studies of people with illnesses and impairments—especially Schneider—within *Phenomenology of Perception* in order to clarify his concerns and assumptions. I have drawn on Garland-Thomson’s notion of material anonymity in order to make explicit the ways that the assumptions of Merleau-Ponty and several of his successors limit the applicability of their approaches. Even theorists of the body who are concerned with disability, gender, or race tend to imply that material anonymity is typical or “normal.” Toombs, Leder, Carel, and Gallagher examine ways that illness and impairment affect being in the world, but they assume, like Merleau-Ponty, that healthy, normal subjects typically only need to pay minimal attention to their bodies. In other words, they assume the experiences of those with illnesses and impairments are exceptional and that material anonymity is the standard experience. Young, Weiss (drawing on Fanon), and Yancy provide examples that illustrate that the experiences of nondisabled white women and black men are likely to diverge from these descriptions and to involve misfitting. Perspectives arising from the starting point of disabled people’s lived experiences add to the trenchant critiques of Merleau-Ponty that feminist philosophers and philosophers of race have developed, and material anonymity helps to clarify his tacit assumptions as well as to tie these critiques together. This shows that the type of embodied experience he takes to be standard or “normal” is actually one that only a privileged few consistently have. Phenomenologists need to account not only for the impact of bodily conditions and particularities but also for the ways in which one’s being in the world is structured by norms related to disability, race, and gender.

Although I have been critical of Merleau-Ponty in this chapter, my position is that his approach to phenomenology—with the appropriate correctives, namely, making considerations related to disability, race, and gender in relation to bodily particularities explicit—is a productive approach to theorizing embodied subjectivity. My focus has been on various ways in which

bodies are marginalized and objectified. In chapter 5, I will engage in the constructive project of highlighting the benefits of applying a Merleau-Pontian approach informed by disability theory to body integrity identity disorder—a condition that entails the strong desire to acquire an impairment in order to embody a certain type of social identity.

CHAPTER FIVE: A PHENOMENOLOGICAL APPROACH TO THE DESIRE TO BE AN AMPUTEE

Healthy people seeking amputations are not nearly as rare as one might think. In May 1998 a seventy-nine-year-old man from New York traveled to Mexico and paid \$10,000 for a black-market leg amputation; he died of gangrene in a motel. In October 1999 a mentally competent man in Milwaukee severed his arm with a homemade guillotine, and then threatened to sever it again if physicians reattached it. The same month a legal investigator for the California state bar, after being refused a hospital amputation, tied off her legs with tourniquets and began packing them in ice, hoping that gangrene would set in, necessitating an amputation (Elliott 2004, 208-209).

to speak of disability *ontologically*, as a way of being, rather than *pathologically*, as a way of being medically out of whack, is to replace a well-charted set of questions with less familiar ones. If disability is a way of being, what sort of being is it? How exactly does it develop? Which (that is, whose) representations of disability have authority? What relationship does disability have to other social or ontological categories, like gender, ethnicity, or class? Is disability in fact a genuine ontological category—is it really an authentic way of being, or is it just a useful organizing category for a motley collection of bodies? And if it *is* an identity, can it ever be anything other than a spoiled one (Goffman 1971) that we are morally obliged to restore to normality if we can, or prevent from happening if we can't? (Scully 2008, 3-4)

In this chapter, I will apply Merleau-Ponty's approach to phenomenology as well as the insights of disability theorists in order to critique some of the assumptions theorists tend to make when discussing what has commonly been called "apotemnophilia" or "body integrity identity disorder (BIID)," less commonly termed "transability." These are a few of the many terms proposed to refer to the desire, which often takes the form of an obsession, to have one's body altered in order to acquire an impairment such as paralysis, blindness, deafness, and loss of one or multiple

extremities (e.g. fingers, toes, legs, arms, and/or penis).¹⁰¹ A phenomenological approach is superior to other ways that this condition has been theorized because it rejects the dichotomies they assume, which manifest, for example, in questions about whether this condition is related to sexuality or identity. In addition, a phenomenological approach informed by disability theory is able to consider living with limb loss and other impairments as ways of being in the world rather than simply lack or pathology.

I will focus on the desire for amputation of limbs, specifically, because this is the instantiation of the desire for impairment that appears to be most common, and most of the literature focuses on it. The first known report of a case of this condition dates back to 1785 (Johnston and Elliott 2002, 431). Those who desire to have one or more healthy limbs removed typically have a very specific point at which they want the limb(s) in question amputated (Blanke, Morgenthaler, Brugger, and Overney 2009, 185) and tend to favor leg amputations and amputations on the left side of the body (Blanke et al. 2009; First 2005). Generally, the focus remains constant, but some have reported a shift in which limb they want to have amputated. Almost all of the participants in studies on this condition are white men with at least a college education (Baril 2016, 146; Blom et al. 2012; First 2005, 921; Noll and Kasten 2014).¹⁰² For example, in Michael First's study, fifty of the fifty-two participants were white, forty-seven were men, and ninety percent had attended college (2005, 921). Some people report seeing what it is like to have an amputation by removing a finger or toe (e.g. with a saw or pruning shear), even though they really want their arm or leg amputated (First 2005, 922). All indications suggest that

¹⁰¹ I will limit my discussion here to cases in which individuals desire to have one or more legs and/or arms amputated. Further, for the sake of simplicity, I will generally speak of the desire to have a limb amputated, with the understanding that some individuals seek to have multiple limbs amputated.

¹⁰² Not all of the studies included race in the demographic information, but, in the studies that did, most participants were white.

this desire is infrequent within the general population, but it is difficult to develop a precise estimate.

Philosophers and other theorists have typically written about the desire of able-bodied people to acquire impairments in order to attempt to understand its origins and whether or not it is ethical or legal for medical professionals to use their expertise to cause impairments upon request.¹⁰³ While there is little consensus on these questions, most authors do share an orientation toward disability, and it is worth clarifying their assumptions. In 2003 Carl Elliott noted that fewer than half a dozen articles had been published on this condition; since then the literature on this topic has increased exponentially (210). I would posit that the desire for impairment is of special interest to bioethicists and other theorists, in part, for the following reasons. First, it challenges the assumption that life with an impairment is inevitably worse than life without an impairment. Second, *prima facie*, it departs from thought experiments in which the reason it is considered wrong to cause impairment is that the person (or potential person) has not provided consent (Barnes 2014, 95). Indeed, these two characteristics are connected. The question of whether or not it is morally permissible to amputate limbs on demand is thought to largely hinge upon whether or not individuals are capable of providing informed consent—the primary concern being that such a decision cannot be truly voluntary because no one who desires to obtain an impairment should be considered competent to make health care decisions (Bridy 2004, 154; Elliott 2003; Sullivan 2014a, 123).¹⁰⁴ Third, this condition raises salient questions about the limits of both patient and physician autonomy as well as the proper scope of medicine (Bridy

¹⁰³ Medical expertise is required in order to cause impairment in ways that are less risky than would otherwise be the case. If it were possible to safely create the desired impairments without surgeons and other medical professionals, these bodily alterations would perhaps have avoided medicalization in favor of being classified as body modifications that differ only in degree from piercings and tattoos (Bridy 2004; Elliott 2003).

¹⁰⁴ This is not a question I will address.

2004, 154-155; Schwartz 1992). Much has been written on the relationship between this condition and gender dysphoria; a detailed analysis of this topic is beyond the scope of the present discussion (Bayne and Levy 2005; Elliott 2003; Kovacs 2009; Noll and Kasten 2014). The literature raises ethical and legal questions as well as attempting to answer the question of how we should understand this condition. Although these are intertwined, my primary focus in this chapter will be on accounts of the latter.

There is a lack of consensus on what this condition should be called and how health care practitioners ought to treat individuals experiencing it. This is a condition that is difficult to research because the level of stigmatization associated with it makes those experiencing it hesitant to participate in studies, which has led researchers to allow individuals to respond to survey questions anonymously through on-line forums or telephone interviews. In the very limited empirical work conducted to date, researchers have recruited participants through encountering them in clinical settings, through snowball sampling (in which people known to have the relevant characteristic find others willing to be part of a study), and via Internet sites centered on the desire to have a limb amputated. Both the format of this research and ways of locating participants raise questions about the reliability and generalizability of the resulting self-reports (Blanke et al. 2009; Blom, Hennekam, and Denys 2012; Brang, McGeotch, and Ramachandran 2008; Everaerd 1983; First 2005, 921; Money, Jobaris, and Furth 1977; Noll and Kasten 2014). Because research participants are scarce, it is vital that the questions they are asked are carefully formulated in order to prompt participants to share as much quality information as possible. Inevitably, the questions posed will, to some degree, shape the responses given. In addition, how and whether this condition is included in future editions of the DSM will be a value-laden decision. As Annemarie Bridy states:

It is important to recognize in this context that the mental disorders and illnesses categorized and defined in the DSM are not natural and immutable constructs; they are instead the products of a fluid and evolving disciplinary discourse that is itself shaped by a constellation of powerful social and cultural factors (2004, 150).

Thus, it is important to articulate the social values and interests informing research on and classification of the desire for amputation of a healthy limb. Although the focus of theorists has been on whether, how, and when it is appropriate to diagnose and treat someone with BIID, their characterizations of this condition are remarkably useful as a gauge of attitudes toward disability.

In focusing on this desire for amputation and the results of interventions (such as self-amputation, black market amputations, or intentional damage to a limb that will medically necessitate its amputation) only in terms of pathology, the broader ontological questions are likely to be obscured. For instance, what are those seeking amputations hoping to attain? How does living with limb loss impact how one is in the world? In section one, I will begin with a survey of the literature, discussing terminological issues in order to provide a sense of historical and contemporary views on the desire for amputation. Section two will examine assumptions about impairment and three types of dichotomies informing theorization, research, and experiences of the desire for amputation. Section three will draw on Merleau-Ponty in order to develop an approach to thinking about the desire for amputation in a way that refuses these dichotomies by starting from being in the world.

5.1 Terminological Issues

Numerous terms have been suggested to refer to the condition of feeling as though one needs to acquire an impairment. Currently, there is a lack of consensus regarding what this condition should be called, which is motivated by disagreement about how to understand the underlying desire. While many agree that the desire for amputation(s) and/or other kinds of impairment is a

type of mental disorder, the decision was made not to include it in the recent (2013) DSM-5 (Diagnostic and Statistical Manual of Mental Disorders) due, in part, to low prevalence. The appendix of the DSM-5 mentions BIID as requiring additional research in order to make a determination about its inclusion in future editions. Paradoxically, the exclusion of BIID from the DSM may impede this research (Elliott 2003). I will provide a brief overview of some of the terms posited, along with the reasoning behind each.

John Money, Russell Jobaris, and Gregg Furth first used the term *apotemnophilia* (“literally ‘amputation love’, from ‘apo’, away; ‘temno’ to cut; ‘philo’ to love”) (De Preester 2013, 172) to refer to the desire to have a healthy limb or multiple limbs amputated in their 1977 article “Apotemnophilia: Two cases of Self-Demand Amputation as a Paraphilia.” A paraphilia is a disorder of sexual arousal in which a person has sexual urges, fantasies, and/or behaviors involving “unusual objects, activities, or situations” which “cause clinically significant distress or impairment in social, occupational or other important areas of functioning” (De Preester 2013, 172). The limited research that has been conducted suggests that there is significant overlap between those who want to have amputations themselves and those who are sexually attracted to amputees, which has been called *acrotomophilia* (Bruno 1997, 253; De Preester 2013, 173; Elliott 2003, 209-210). In less formal parlance, those who want to become amputees are referred to as “wannabes,” those who are attracted to amputees are termed “devotees,” and those who are able-bodied but present themselves as having an impairment are called “pretenders” (Bruno 1997; De Preester 2013, 173; Elliott 2003, 210; Kafer 2012, 332).

Some have posited that the desire to have a healthy limb removed should be considered to be a manifestation of body dysmorphic disorder (BDD), in which those affected are obsessed with altering or at least hiding a part of their body that they perceive to be a defective (Bayne and

Levy 2005, 75-76; Blanke et al. 2009, 192; Bridy 2004; Elliott 2003, 213; Furth and Smith 2000). However, Elliott points out, “[a]mputee wannabes more often see their limbs as normal, but as a kind of surplus” (214). They do not appear to think their limbs are defective or unsightly: rather, they simply want to be amputees. Out of the fifty-two participants in Michael First’s study, only one said that the ugliness of the limb in question was the reason for wanting an amputation (Bayne and Levy 2005, 78; First 2005). As Bridy puts it, the “problem is not that he [the person seeking an amputation] perceives something in his appearance that isn’t there, but that he believes something in his appearance that *is* there shouldn’t be there” (2004, 149). Thus, BDD does not seem to be a fitting classification for this condition.

In “Devotees, Pretenders, and Wannabes: Two Cases of Factitious Disability Disorder” Richard Bruno suggests that there are sufficient commonalities—and indeed, a great deal of overlap—between those who could be labeled devotees, pretenders, and wannabes to warrant classification of these desires and behaviors related to impairment as “factitious disability disorder” (1997). On his account:

That a similar mechanism is operating in pretenders and wannabes is suggested by the finding that the majority of acrotomophiles are also pretenders (61%) and wannabes (51%) whose childhood experiences may have rendered them unable to meet their own needs and caused them to conclude that disability is the only socially acceptable reason—even the only possible reason—for one to be worthy of love and attention (253).

In light of this assessment, Bruno recommends cognitive-behavioral psychotherapy directed at helping patients to attain insight into the role that impairment-related obsessions and compulsions serve as well as working to develop “appropriate behaviors” (1997, 257).

Robert Smith, a surgeon who amputated the healthy legs of two patients upon their request, posits that the desire to obtain amputations is akin to gender dysphoria (formerly called gender identity disorder), which may lead one to seek surgical and other interventions to

transition some of the bodily characteristics that are perceived to be indicators of sex. In some cases of gender dysphoria and all cases of the condition under discussion, individuals want to radically alter their bodies in order to bring them into alignment with the way they conceive of themselves or their desired social identity (Elliott 2003, 212; Barnes 2016, 36). Drastic visible changes to one's body may be felt to be necessary in order to be publicly perceived in a manner consistent with this self-conception. In regard to gender dysphoria, public intolerance for gender ambiguity is likely to play a role in motivating individuals to take steps to surgically and chemically alter their bodies in order to make themselves clearly recognizable as men or women. Lack of tolerance for ambiguity in regard to impairment status and pervasive suspicion among the general public regarding the legitimacy of others' claims to the status "disabled" are likely to be factors that make using durable medical equipment (wheelchairs, walkers, etc.) in order to give the appearance of an impairment a less tenable/satisfying way to live as a disabled person than actually acquiring a verifiable impairment. More concisely, no amount of behaving like an amputee will satisfy the desire to be one. However, it should be noted that not all people who pretend to have an impairment want to acquire one.

In 2002, Furth and Smith suggested the term "amputee identity disorder" because some who are affected by this condition report that they seek surgery due to their identification as amputees. Some research participants claim that they desire an amputation in order to "feel complete" (First 2005, 920). However, the term "amputee identity disorder" may suggest an overly narrow classification, given that people desire to live with a wide range of impairments. There is growing support for categorization of this condition as "body integrity identity disorder" (BIID), a term that combines the focus on identity and completeness (Bayne and Levy 2005; Blom et al. 2012; First 2005, 926). Research participants with this condition report that they

believe that acquiring an impairment—in many cases through amputation of a limb—is necessary for them to feel “whole” (Elliott 2003; Sullivan 2014a, 120-121). As Nikki Sullivan notes, “[r]esearchers have been keen to determine from whence this experience comes, particularly given that the integrity of a fully limbed and fully functional body is commonly taken to be visibly self-evident” (2014a, 121). Indeed, the notion that limb loss could increase one’s sense of body integrity continues to puzzle researchers. Nonetheless, the term BIID presently has the most currency within the literature. However, some authors continue to use the term “apotemnophilia” (First 2005; Patrone 2009). First suggests an approach that uses both terms; he suggests categorizing separately those who desire amputation in order to align their body with their identity (BIID) from those whose desire is sexual (apotemnophilia). Other theorists posit additional alternatives such as “self-demand amputation” (Tomasini 2006), “xenomelia” (“foreign limb” syndrome) (McGeoch, Brang, Song, Lee, Huang, and Ramachandran 2011), and “transabled” (O’Connor 2009).

Sean O’Connor¹⁰⁵ coined the terms “transabled” and “transability” to refer to those who seek to acquire an impairment or illness (2009). This term covers a wide range of impairments and illnesses, such as amputation, blindness, paralysis, and HIV. O’Connor and others who adopt the label “transabled” seek both to reduce the stigma associated with this set of desires and to make an explicit connection with the experiences of transgendered people. He states “[t]ransabled means to me that I am in a transitional position, between a body that is not what I need it to be, and hopefully reaching that body at some point soon” (2009, 89). He explicitly connects this term with “transsexual” as a way of referring to someone with gender identity disorder [gender dysphoria]. Indeed, in line with usage of “trans*” and cis* to refer to a range of

¹⁰⁵ This is a pseudonym for a man who asserts that he needs to become paralyzed from the first lumbar vertebra (L1) downwards (O’Connor 2009, 88).

ways of being sex/gender nonconforming, disability theorist Alexandre Baril uses “transabled” for those who seek to/have altered their ability status voluntarily and “cis(dis)abled” to indicate those who have not altered their ability status (2015, 42). Transability advocates hope to obtain medical legitimatization so that medical professionals will perform the wanted bodily alterations. They also seek social acceptance and support, from the disability community, in particular. As I will discuss later in the chapter, few members of the disability community have voiced such support.

Although there are a number of positions regarding the origins and proper categorization of the condition under discussion, both remain contested. The terminology one uses marks one’s stance; it is readily apparent that there is no neutral position. I will use “BIID” here because it seems to be more inclusive than “apotemnophilia” and compatible with a wider range of views of impairment than the term “transability.” In addition, the label BIID presently has the most support within the literature.

5.2 Psychological Approaches

Anna Sedda and Gabriela Bottini assert: “Understanding whether the desire to amputate a healthy limb is of psychological/psychiatric or neurological origin is a determinant of guiding development of possible treatments, especially considering that most of the approaches that have been tried until now have proven ineffective” (2014, 1256). Until recently, psychiatrists and psychologists were the sole researchers focused on BIID. They have posited that BIID may be a type of paraphilia, response to fears about castration or homosexual desires, obsessive-compulsive disorder, or an identity disorder with some parallels to gender dysphoria (First 2005; Money et al. 1977; Müller 2009, 36-37). Their research typically has taken the form of interviews with one or a few individual patients (Bruno 1997; Everaerd 1983; Money et al. 1977)

or, more recently, surveys involving numerous participants (Blom et al. 2012; First 2005; Noll and Kasten 2014). I will discuss a couple of examples of this type of research before turning to neurological research and speculation on BIID.

Through their involvement with the psychohormonal research unit (PHRU) at Johns Hopkins Hospital, Money et al. (1977) separately came into contact with two male individuals who expressed the need to have an above the knee amputation. These men contacted PHRU because they considered their desires to be similar to the desires of “qualified transsexual candidates” for whom the center provided counseling (1997, 116). In fact, one of the men identified himself as a qualified candidate, adding that, “his problem did not involve his genitals but rather his leg” (116). Thus, from the beginning of research on this condition—in recent history at least—it has been connected with what is currently referred to as gender dysphoria. Although this experience was beyond the purview of PHRU, these two men corresponded extensively with the center through letters, telephone conversations, and, in the case of the second man, in-person interviews.

In the cases Money et al. discuss, both men make explicit connections between the desire to have a leg amputated and their sexuality—in the sense of being aroused by amputees and in the sense that they consider obtaining an amputation to be a way of preserving masculine identity (in the first case) or attempting to be heterosexual (in the second case). The first reports that at times:

I “feel like a woman,” viscerally, in terms of body image, and in these situations I loathe myself—it makes me very apprehensive. Somehow this seems linked with the amputation fantasy. I would rather this [amputation] than lose the penis which would mean that I would be like a woman (...) It is almost as if I will be establishing my male identity by means of the amputation (Money et al. 1977, 118; 119).

Thus, it seems that the patient interprets his condition in psychoanalytic terms, as a response to fear of femininity and castration.¹⁰⁶ In discussing the patient's childhood, Money et al. assert that his mother was very overprotective, and "he closely identified with her," while his father was "hypercritical" of the close mother-son relationship (119). In the case of the second individual, he posits that his desire for amputation of his right leg may be "an avenue out of homosexuality" insofar as he projects that he will enjoy sex with women more as an amputee (123; 122). He also considers the possibility that having an amputation might be a way of responding to rejection by his father (123). Both subjects report that psychotherapy has had little to no effect in regard to decreasing the desire to obtain an amputation. Money et al. conclude that the question of whether self-demand amputations constitute effective treatment will be determined through research involving participants who have managed to obtain the amputations they desire (1977, 125).

Bruno takes a similar approach to that of Money et al. in his examination of two cases in which women perceive impairment as a means for gaining the love and attention that was missing during childhood. The first case study, to which the bulk of the article is devoted, involves a nondisabled white woman referred to as Ms. D who both sought out men with visibly identifiable mobility impairments and publicly presented herself as having an impairment by using a wheelchair. Rather than attempting to acquire an impairment, she simply wanted to be perceived as having paralyzed legs—especially by disabled men. Although she emphasizes the pleasure and excitement she experiences when strangers treat her as if she has an impairment, she states that she would not want to actually have an impairment and expresses pity for a disabled woman she encountered (248). Bruno then turns to analysis of a case in which a white woman referred to as Ms. W claimed to have post-polio syndrome and require the use of

¹⁰⁶ One wonders how much this interpretation owes to his three years of involvement in individual and group psychotherapy prior to contact with PHRU.

crutches, but was able to walk without difficulty or crutches during psychotic episodes (255-256). In both of these cases, the patients are said to have remarked that they thought parents and others would treat them better if they had impairments. In neither of the cases Bruno analyzes did the individual seek to acquire an impairment—Ms. A wanted a relationship with a disabled man and Ms. D believed herself to have an impairment. Nonetheless, he concludes that all of these phenomena should be classified as “factitious disability disorder” and treated in the same way. As mentioned previously, Bruno advocates cognitive-behavioral therapy.

Now that I’ve discussed a couple of influential articles offering psychological accounts of BIID, I turn to theories and research regarding neurological explanations for BIID. While there are exceptions, most authors seem to consider these types of accounts to be mutually exclusive.

5.3 Neurological Accounts

In “Amputees by Choice: Body Integrity Identity Disorder and the Ethics of Amputation” Tim Bayne and Neil Levy enumerate several possible explanations for BIID. They note that there may be “a mismatch between their body and their body as they experience it – what we might call their phenomenal (or subjective body)” (2005, 76). They suggest that this “mismatch” could either take the form of incongruence between the body and the body image or body schema.

Drawing on Shaun Gallagher, Bayne and Levy define body schema as “a representation of one’s body that is used in the automatic regulation of posture and movement” which guides “the parts of one’s body to successful performance of action” (2005, 76). As evidence against this position, they cite a lack of “impairments in control of movement” among people with BIID (76). Bayne and Levy mention that those who obtain the amputations they seek seem “content to use a prosthesis,” which also serves as evidence against the notion that those with BIID have a

distorted body schema (76). They contend that it is more likely that BIID entails a discrepancy between the body and body image.

Bayne and Levy also adopt Gallagher's conceptualization in their definition of body image, characterizing it as:

a consciously accessible representation of the general shape and structure of one's body. The body image is derived from a number of sources, including visual experience, proprioceptive experience, and tactile experience. It structures one's bodily sensations (aches, pains, tickles, and so on), and forms the basis of one's beliefs about oneself (2005, 76).

On this account, experience and body image are co-constitutive. If it turns out that BIID does involve a difference between the objective body and body image, this would not be a unique occurrence: disorders classified as asomatognosias involve this phenomenon. Bayne and Levy explain that asomatognosia can be caused by stroke or as an aspect of depersonalization (77). They note that one might think of BIID and the eating disorders of anorexia and bulimia as being similar insofar as they involve a distortion of body image,¹⁰⁷ but the authors point out "[w]hereas the person with anorexia or bulimia fails to (fully) recognize the discrepancy between her body and her body image, the wannabe is all too aware of this discrepancy" (77). In spite of considering a discrepancy between body image and the actual body to be the most credible of the hypotheses they examine, Bayne and Levy conclude their discussion of this explanation by reporting that they know of no evidence that wannabes manifest behavior in common with those with a form of asomatognosia, e.g. neglecting affected parts of the body (79).

¹⁰⁷ For example, D. Patrone contends, "[b]oth BIID and anorexia nervosa are thought to be disorders concerning a discrepancy between body type and body image, and both express themselves in patient choices that, were they respected, would cause serious physical harm" (Patrone 2009, 544). In the case of anorexia, the affected individual does not perceive a divergence between the body image and body; this is only apparent to observers. Thus, her/his goal is not to bring the body into alignment with the body image, but to succeed making both "thin enough."

In “Apotemnophilia: A Neurological Disorder” Brang, McGeotch, and Ramachandran (2008) suggest that BIID¹⁰⁸ is similar to a type of asomatognosia called “somatoparaphrenia,” which is a neurological syndrome in which a person denies that a part of their body—e.g., an arm, leg, or half of the body—is theirs, possibly claiming that it belongs to another person as well as developing an aversion to that portion of the body (1305). Accordingly, Brang et al. hypothesize that BIID “is caused by dysfunction of the right parietal lobe leading to a distorted body image and a desire for amputation of one or more limbs” (1305). One of the reasons the authors cite for this hypothesis is that, in the research carried out to date, those who wish to have a leg amputated overwhelmingly favor having the left leg amputated—a fact that the authors claim would not be expected if BIID was a psychological disorder but might be explained by dysfunction of the right parietal lobe (1305).

Brang et al. tested the skin conductance response (SCR) of two men with BIID—one who desires a below-knee amputation of his right leg and the other seeks a below-knee amputation on the left and an above-knee amputation on the right. They contrasted their responses to pinpricks above and below the line of desired amputation on each leg (pinpricks were applied to the upper thighs and feet), and found a much stronger response to stimulation below the level of the desired amputation(s). Their test was unable to differentiate responses between the desire to undergo below versus above-knee amputations. Because skin conductance is not thought to be under volitional control, it is considered to indicate “general sympathetic arousal,” and the authors contend that “the failure of a congenitally dysfunctional right superior parietal lobule to form an [sic] unified body image leads to abnormal sympathetic outflow via the insula; manifesting itself as the observed SCR changes” (1306). They contend that BIID is similar to

¹⁰⁸ Brang et al. acknowledge both “apotemnophilia” and “body integrity identity disorder” as terms for this condition. They use the former without explaining their preference for this term. I use BIID for the sake of consistency.

somatoparaphrenia insofar as “the brain seems to rationalize the discrepancy [caused by dysfunction in the right superior parietal lobule] by denying ownership of the limb” (1306). This research is obviously extremely limited insofar as it only involved two participants.

Deborah Vitacco, Leonie Hilti, and Peter Brugger suggest that BIID is the opposite of the experience of a phantom limb and for this reason refer to it as an instance of a “negative phantom limb” (2009, 202). Specifically, they focus on cases in which people with aplasia—meaning they were born without one or more limbs—experience phantom limb(s) (202). They contend that such cases serve as evidence against the conceptualization of phantom limbs as “neural memories of the lost limb” (202). Researchers have hypothesized that “motor representations of a limb are already present at birth and may even be genetically hard-wired (Abramson & Feibel 1981)” or it is the ‘human mirror system’ (Buccino et al., 2001; Rizzolatti et al., 2001)” in which phantom limbs are triggered by observing those who do have those limbs moving them (Vitacco et al. 2009, 205). Vitacco et al. note that neither of these hypotheses is satisfying because they fail to explain why few people with aplasia develop phantom limbs (Gallagher 2005, 87). In addition, they posit that falsification of the human mirror system view would require research participants who are congenitally blind and experience congenital phantom limbs.

I would suggest that Gallagher’s account (2005) of aplasic phantom limbs offers a response to Vitacco et al. He discusses two hypotheses for the experience of a phantom limb among those born without a limb; both involve the notion that the individual’s neural representation (it is left an open question whether this entails the body schema or body image) developed as if the limb was present. For those reporting a phantom limb, this representation persisted, while for the others, it faded before conscious awareness or language to describe the sensation developed and was forgotten (Gallagher 2005, 97-99).

The suggestion that BIID stems from a “negative phantom limb” entails the presupposition that rather than developing a neural representation of a limb that did *not* develop in a typical way, one has failed to develop a neural representation of a limb that *did* develop in a typical way. If it is the case that a person with BIID seeks to have a limb amputated due to a lack of that limb’s inclusion in their neural representation of the body as a result of atypicalities in the somatosensory cortex or a parietal lobe, these atypicalities demand explanation. In the case of the suggestion that BIID is neurologically similar to somatoparaphrenia or other types of anosognosia, the latter is caused by damage to the right parietal lobe, e.g. as the result of a stroke. How might damage to the parietal lobe be sustained in the case of BIID in the absence of stroke or brain damage?

Deborah Vitacco, Leonie Hilti, and Peter Brugger maintain, “BIID is a neurological disorder in the sense that a very early ontogenetic incident may have prevented the establishment of an individual’s proper representation of one or more limbs” (2009, 206). This is as specific as their suggestion gets. Although they find it implausible, Erich Kasten and Frederike Spithaler note that it has been proposed that BIID might be explained as resulting from:

a developmental mistake of the CNS [central nervous system] in a fetal status or in early childhood, e.g. as a consequence of cranio-cerebral injury or of sickness of the mother. In this theory it is supposed that the somatosensory cortex for the limb in question has a dysfunction, i.e. a reduced representation of the concerned leg or arm in the CNS (2009, 27).

If a dysfunction in the somatosensory cortex is responsible for a distorted representation of a limb, which then leads to the desire to have that limb amputated, one would expect that the limb that is the target for amputation would remain constant (27). However, Kasten and Spithaler, among others, have found that the target limb can shift; six of the nine participants in their study reported such a change.

Alternately, if the “human mirror system” contributes to aplasic phantoms, it might be suggested that observation of amputees may play a role in changing the neural representation of a limb. However, even if this is possible, Vitacco et al. report that it is the *pervasive* contact with nondisabled people that is supposed to lead to aplasic phantom limbs. It seems unlikely that this would be the case for people with BIID, unless looking at photographs of amputees was sufficient to activate the mirror system.

Noll and Kasten (2014) contend that if the hypothesis that people experience BIID because of a parietal lobe dysfunction that results in exclusion of a limb in the body image is correct, then those who obtain the desired amputations will not experience phantom limbs. However, in their survey of eighteen “successful wannabes,” seventeen (94.4%) did experience phantom limbs (2014, 229).

Even Vitacco et al. express dissatisfaction with the view that neurological atypicalities provide a comprehensive explanation of BIID. They conclude that BIID “may well have ‘neurological’ and ‘psychiatric’ components” (206). Sedda and Bottini assert, “the few available experiments show discordant results, as do the psychological/psychiatric descriptions and surveys. (...) they lead to the same confounding results” (2014, 1263). They go on to say: “A strict separation between the methods and theories of psychology/psychiatry and neuroscience does not appear to be the solution to understanding such a complex condition” (1264). Their suggestion is for researchers to combine these methods and theories, for example, using neuroimaging along with experiments concerned with “body representations and psychological/sexual components” (1264). Sedda and Bottini do not provide further specification of how this might be done.

5.4 BIID, Being in the World, Fitting, and Misfitting

Merleau-Ponty's remarks on the incompleteness and seeming incompatibility of psychological and physiological accounts of the phenomenon of the phantom limb could just as easily refer to the current state of research on BIID. To reiterate, he asserts, "[i]f the phantom limb depends upon physiological conditions and is thereby the effect of a third person causality, then it is inconceivable how it could *also* result from the personal history of the patient, from his memories, his emotions, or his desires" (2012, 79). In regard to BIID, while there are cases in which evidence of a connection between the desire for an amputation and one's personal history is suggestive, there is also inconclusive evidence that atypical functioning of the brain may play a role. Both types of accounts are tied to categories of the objective world, and are unable to fully address experiences of people with BIID (83).

Merleau-Ponty contends that since existential analysis is carried out at the level of being in the world, it is able to avoid the split between psychological and physiological accounts. He states:

Because it is a pre-objective perspective, being in the world can be distinguished from every third person process, from every modality of the *res extensa*, as well as from every *cogitation*, from every first person form of knowledge – and this is why “being in the world” will be able to establish the junction of the “psychical” and the “physiological” (Merleau-Ponty 2012, 82).

Researchers providing psychological accounts have been able to locate some patterns in subjects' reports of their experiences of BIID. However, participants' narratives are limited at the outset by the format of this research: e.g., the choices they are allowed to select on surveys in regard to why they desire to have a limb amputated. Neurological research largely disregards the experiences of people with BIID as irrelevant epiphenomena—attempts to rationalize what is *really* going on, e.g., dysfunction in the right parietal lobe of the brain (Brang et al. 2008).

Havi Carel notes: “Patients are often quick to mimic the medical discourse, which may lead to a sense of alienation and a lack of first-person voice in patients’ discourse about their illness” (2012, 98). Although, she does not address BIID specifically, her discussion of the relationship between medical discourse and experiences of illness is helpful for considering experiences of this condition. Carel draws on Schkade and Kahneman’s (1998) notion of the *focusing effect*, which is a biasing effect that leads us to focus narrowly on one aspect of a category such as well-being. Carel provides the examples of attending to winning the lottery or having an impairment. She states, “The focusing illusion causes us to overemphasize the significance of that feature, thus overweighting it” (2012, 98). Carel suggests that standardized interview questions may lead research participants to adopt the focusing illusion. This notion is also helpful for understanding reactions to BIID, which have the tendency to narrowly focus on the impairment a person seeks to acquire rather than considering impairment as one component of a person’s life as a whole.

While medicalization may be the pragmatic way forward in terms of being able to obtain medical validation as well as possible social recognition and insurance coverage for treatment for people who desire impairments, it entails its own problems. Sullivan suggests that labeling the desire for impairment as a body integrity identity *disorder*, covers over a multitude of assumptions about what bodily integrity means as well as what is actually experienced. She elaborates:

What is denied in this process is the fact that for (many) wannabes the source of suffering lies not in the bodies they want but do not have, nor even in the fact that they desire amputation, deafness, and so on. Rather, suffering is engendered as the effect of a life lived “out of place,” of not being at-home-in-the-world or in the body that gives one a world, a “here” from which to extend into phenomenal space and by which to shape that space (132-133)

As Sullivan implies, her claim is not true of all people with BIID. Stigmatization of this condition exacerbates the suffering associated with it because it compels many people to keep their desires secret and even to isolate themselves. For instance, some wish to hide usage of durable medical equipment such as a wheelchair in order to simulate living with an impairment.

The obsessive form that the desire to obtain an impairment often takes, combined with lack of social acceptance, can influence those with this condition to withdraw from others. One man with BIID reports:

Through this unfulfilled desire my entire existence has been seriously hindered. It controls and limits my thinking. It has hampered my social intercourse because I cannot be, or can hardly be, interested in others. (...) Even if I only regain my ability to function socially that in itself, in my view, justifies the realization of my desire (Everaerd 1983, 289).

This passage illustrates an experience that is common among people with BIID: limitations in the ability to function as a nondisabled person and the expectation that obtaining an impairment would allow for greater overall functionality, in spite of the accompanying difficulties.

Being perceived and recognized as a disabled person is of central importance within the accounts provided by people with BIID. A blogger who goes by “Gordo” states:

One reason why we’re [people with BIID] so hated is the misconception that we’re doing it “for the attention.”...But sometimes I wonder if it’s a misconception at all...I don’t mean “attention” as in the “look at me, I want sympathy” kind of attention, but rather the “being able to live as a normal active wheelchair user amongst friends” kind of attention (Davis 2014, 443).

“Sophie” asserts:

I think there is a vast difference between doing something purely for the attention and finding an action beneficial as it validates our mental/neurological problems. It’s like anyone with a problem in their lives that can’t be solved with will power, it becomes easier to live with when people treat you as you should be (Davis, 442).

Just like the examples Merleau-Ponty discusses of aphonia and a husband forgetting where a book his wife gave him is while he is angry with her, the desire to acquire an impairment

originates beneath the level of the will. Thus, rather than attempting to will away this desire, many people with BIID seek to obtain an impairment in order to be able to be comfortable with their bodies and to be able to cease directing their attention to an unrelenting unfulfilled desire.

Sullivan contends that “BIID is constituted as an individual(ized) pathology that has little or nothing to do with one’s being-in-the-world” (2014a, 120). We might alternately think of the desire for an amputation as enacting a shift in being in the world—both in the sense of how one is oriented towards others as well as how *one’s own body* is experienced. Obtaining an amputation would then be expected to further—or intensify—this way of being in the world. To adopt Garland-Thomson’s terminology, a normative body engaging with the world in primarily normative ways may appear to be a fit, even as it is experienced as a misfit. To return to a quotation included in chapter four, Gail Weiss asserts: “Garland-Thomson stresses that what might look like a misfit to others, namely a non-normative body that engages with the world in non-normative ways, with the right support from others and from the environment, may actually be lived as a fit” (2015, 92). If amputees encounter an enabling environment, e.g., appropriate and affordable medical care, mobility devices, accessible housing, and social support, they can attain a fit, even if not to the level of material anonymity. In part, it seems that this is what those with BIID seek: not simply to acquire an impairment, but to enact a new way of being in the world and receive social recognition as amputees.

There is ambiguity regarding the relationship between BIID and social identity: should we think of people with BIID as already being disabled and trying to align their self-conceptions with their bodies or as seeking to become disabled through alteration of their bodies (Elliott 2003, 212; Barnes 2016, 36)? Narratives of people with BIID answer this question in different ways, some stating that they identify as amputees while having all of their limbs while others report

that they feel as though they are supposed to be amputees. The distinction between wanting to acquire an impairment and having voluntarily done so is elided in some discussions of this condition (Baril 2015a; Bruno 1997).

Elizabeth Barnes expresses her view on the relationship between BIID and identity in the following:

In the case of transability, a person self-identifies (very strongly) as disabled, and typically has done so since childhood or early adolescence. But that self-conception doesn't match up to what their body is like, and so they will make great efforts to get their body to conform to their self-conception. Perhaps controversially, I want to say that people who are transabled want to *become* disabled, and often successfully do so, but that before they undergo a body-altering procedure, they are not disabled. That is, I don't think self-identification as a disabled person is sufficient to make them disabled.

To press this point, it's worth noting that people who are transabled don't identify as disabled in the abstract. They identify as people with a *particular* disability—as amputees, as paraplegics, etc. And in general, we don't think people can be disabled in the abstract. You're disabled in virtue of having some disability or other. But it would require a fairly extreme amount of conceptual revision to say that, pre-transition, transabled people really are amputees, really are paraplegics, etc. And so I'm inclined to say that, pre-transition, they aren't disabled (Barnes 2016, 36).

If both the objective body and *one's own body* are relevant for social identity, then this interpretation makes sense. Nonetheless, as mentioned above, some people with BIID report already subjectively experiencing themselves as having an impairment. In either case, one aspect of what people with BIID are seeking is to have their actual body be perceived as having an impairment so that others will respond to them in ways that reinforce their own identification.

Although the body is relevant to social identity, it is important to keep in mind that bodies, experiences, and social identities are not always correlated in ways that observers may expect. As Wendell remarks regarding the relationship between impairment and identifying as disabled:

some people are perceived as disabled who do not experience themselves as disabled. Although they have physical conditions that disable other people, because of their

opportunities and the context of their lives, they do not feel significantly limited in their activities...On the other hand, many people whose bodies cause them great physical, psychological and economic struggles are not considered disabled because the public and/or the medical profession do not recognize their disabling conditions (Wendell 2008, 829).

Thus, we ought not think that it is only people with BIID who have a lack of correspondence between their experiences, bodies, and how they are identified by others. Research to date largely fails to critically engage with questions about what it means to identify as a disabled person and how being in the world is affected by having an impairment.

5.5 Is BIID about Sexuality or Identity?

Although the desire to be an amputee was originally classified as a paraphilia, some theorists are attempting to either disassociate this desire from sexuality completely or to separate those for whom it is sexual—they find the idea of being an amputee sexually arousing or otherwise predict that being an amputee would lead to more satisfying sexual experiences—from those for whom it is about identity—the sense that one either is or ought to be an amputee (Everaerd 1983; First 2005; Hilti and Brugger 2010). In “Merleau-Ponty’s Sexual Schema and the Sexual Component of *Body Integrity Identity Disorder*” (2013) Helena De Preester argues that examination of the history of the condition I am referring to as BIID demonstrates that among theorists, there is a “growing reluctance” to address the sexual aspect, despite its pervasiveness (171). She traces the shift from the classification of the desire for amputation as a paraphilia in the article “Apotemnophilia: Two Cases of Self-Demand Amputation as a Paraphilia” by Money et al. (1977), which conceives of the desire for amputation as purely or at least primarily sexual, through Hilti and Brugger’s “Incarnation and Animation: Physical versus Representational Deficits of Body Integrity” (2010), which claims that most people with BIID desire amputation for non-sexual reasons.

In the cases Money et al. discuss, we saw that the desire for amputation of a leg was intertwined with issues related to sexual identity—the attempt to shore up one’s masculinity and whether or not to identify as homosexual as well as the expectation that sex with women would be “more satisfying” as an amputee (1977; 124). One of the interviewees states, “that is not why one would want to have an amputation, because he wants to have a higher or greater orgasm” (1977, 121). Although he cites sexual satisfaction is part of the motivation for seeking an amputation, it is not the sole factor. The analysis of Money et al. does not separate sexuality from identity.

De Preester locates the beginning of an attempt to distance the desire to be an amputee from sexuality in Walter Everaerd’s “A Case of Apotemnophilia: A Handicap as Sexual Preference,” which details a case study of a man seeking to have his leg amputated. Regarding the patient he interviewed, Everaerd concludes: “Now amputation of his own leg has no longer any sexual meaning. He says now that he only could feel complete once his leg has been amputated. Wanting to be amputated plays an important role in his sense of identity” (1983, 292). He makes this remark immediately after discussing the erotic importance of “the image of amputation,” including “self-amputation” for this man’s sexual fantasies! De Preester states of Everaerd’s analysis, “[f]or the first time, apotemnophilia seems released from its prominently fetishist and thus sexual character, and becomes a matter of bodily identity and one’s body image” (2013, 172). However, Everaerd’s attempt to privilege concerns related to identity over sexuality seems to have had minimal impact on research on BIID in the subsequent two decades. Between 1983-2004 a few additional case studies were published, most of which focused on sexual aspects of the condition (e.g., Money and Simcoe 1986; Bensler and Pauw 2003). It wasn’t until 2005, when First published a systematic study involving telephone interviews with fifty-two

subjects that the approach of attempting to separate concerns about identity from sexual aspects gained influence.

De Preester contends that First's study promulgated the idea that the desire to have a limb amputated was most often related to identity rather than sexuality. She shows that his presentation of the data from his study distorts participants' stated motivations in order to bolster this position. First emphasizes that only fifteen percent of participants cited "feeling sexually excited or aroused" as the primary motivation for wanting an amputation (2005, 922). On the basis of this statistic, he suggests that only a small minority would appropriately be diagnosed with apotemnophilia (926). However, as De Preester points out, this framing of the results ignores the fact that fifty-two percent of participants reported that "feeling sexually excited or aroused" was the secondary reason they wanted to become an amputee (2013, 175). First goes on to state that a new diagnostic category is necessary for the majority (73%) of participants who cited "restoring true identity as an amputee" as a primary or secondary reason (926). He advocates usage of the term body integrity identity disorder, of which he states: "this condition might best be conceptualized as an extremely unusual dysfunction in the development of one's fundamental sense of who (physically) one is" (926). De Preester points out First's inconsistency in including those who cited concerns related to identity as their primary or secondary motivation while only counting those reporting sexual excitement as their primary motivation. She claims that his study influenced other researchers and theorists to de-emphasize sexual aspects of BIID in favor of focusing on identity (Bayne and Levy 2005; Blanke et al. 2009; Hilti and Brugger 2010). Hilti and Brugger defend a "pure form" of the desire for amputation that is "relatively *uncontaminated* by aspects related to sexual identity [emphasis added]" (De Preester 2013 178).

De Preester credits First with initiating a new way of thinking about the desire for an amputation. Although Everaerd speaks about apotemnophilia in terms of identity, De Preester says of First's study:

It is the first time that the issue of *bodily identity*, i.e., the feeling of self in relation to one's anatomy is highlighted. Moreover, as we shall see, this happens at the expense of the sexual dimension (2013, 174).

Although De Preester seems to consider bodily identity to be somehow distinct from social identity, it is unclear what it would mean to think about social identity apart from the body. She notes that one's "body image or sense of bodily identity" is not equivalent to "one's objective, anatomical body" (177).

De Preester raises the possibility that people with BIID may deny sexual components of their desire because they consider these to be obstacles to social acceptance. Regarding the term "apotemnophilia," transability advocate O'Connor states, "It implies a sexual fetish ('philia'), which is incorrect, but also seems to be even more undesirable in our society" (2009, 89). Nonetheless, the majority of research participants *do* report that their desire relates to identity as well as sexual arousal.

De Preester asserts that within the literature on BIID, "[t]he role sexuality plays in one's bodily existence and in the feeling of body identity remained largely unaddressed" (180). She maintains that it is impossible to understand BIID without considering the role of sexuality, and she advocates adoption of Merleau-Ponty's approach to phenomenology in order to avoid the false dichotomy of choosing between sexuality or identity.

In "The Body as a Sexed Being" of *Phenomenology of Perception*, Merleau-Ponty examines Schneider's inability to situate himself sexually in order to gain clarity on typical sexuality. Though Merleau-Ponty disputes some of the central tenets of psychoanalysis, he

credits psychoanalysis for reintegrating sexuality into human existence. He contends that sexuality should not be conceived of as a separate realm; rather, it is integral to being (2012, 160). Sexuality orients us toward the world, including our perceptions. Just as we must recognize the necessity and centrality of embodiment for human existence, so too, we need to recognize sexuality's permeation within human life (173). Merleau-Ponty contends:

There is osmosis between sexuality and existence, that is, if existence diffuses throughout sexuality, sexuality reciprocally diffuses throughout existence, such that it is impossible to identify the contribution of sexual motivation and the contribution of other motivations for a given decision or action, and it is impossible to characterize a decision or an action as "sexual" or "nonsexual" (172).

Contra First, on this account, it is impossible to clearly delineate sexual motivations and aspects of existence from nonsexual ones.

Furthermore, Merleau-Ponty maintains, "If the sexual history of a man gives the key to his life, this is because his manner of being toward the world – that is, toward time and toward others – is projected in his sexuality" (2012, 161). This is a helpful way of thinking about the experiences of people with BIID; it is not the case that their attraction to the idea of themselves as amputees is "just" sexual. On the contrary, accompanying this attraction is an entire form of life: one's conception of the self, how one wants to be perceived, and a striving to alter one's being in the world by altering both one's objective body and *one's own body*.

Researchers point out that devotees and people with BIID are fascinated by the everyday activities of disabled people (Noll and Kasten 2014). This orientation toward disabled people (or at least parts of their bodies) often leads to admiration and sexual desire. Regarding one of the two patients they interviewed, Money et al. state:

His amputee fantasies did not invariably entail erotic imagery. Rather, there was a strong nonerotic imagery of overachievement which provided the erotic turn-on, namely, in visualizing an amputee engaged in some activity which required a considerable effort to surmount a physical handicap (...)His fantasies while having sex leading to orgasm with

a nonamputee male often were of amputees functioning in walking and moving activities and not wearing a prosthesis (1977, 121).

Here the imagined “overachievement of an amputee,” typically considered not to have erotic content, takes on a sexual significance. However, these fantasies seem not only to provide a source of sexual stimulation but also an ideal to which those with BIID aspire, i.e., they hope to exhibit the qualities they fantasize about when they become amputees.

People with BIID often simultaneously identify with amputees and find them sexually attractive. One of the problems with the attempt to distinguish between people for whom the desire to be an amputee is sexual and those for whom it is identity-related is that the conception of sexuality is too narrow. As Elliott asserts:

When I asked one prominent wannabe who also happens to be a psychologist if he experiences the wish to lose a limb as a matter of sex or a matter of identity, he disputed the very premise of the question. “You live sexuality,” he told me. “I am a sexual being twenty-four hours a day” (2003, 220).

On Merleau-Ponty’s account, even if sexuality is not always in the foreground, it is a type of intentionality that situates us in the world.

5.6 Views of Impairment and BIID

The views of impairment Elizabeth Barnes characterizes in “Valuing Disability, Causing Disability” (2014) are helpful for thinking about responses to BIID.¹⁰⁹ Although I discussed these views in chapter one, I include her descriptions again below.

Barnes notes that mere-difference views are typically associated with positive claims such as the following:

- (a) Disability [impairment] is analogous to features like sexuality, gender, ethnicity, and race.
- (b) Disability [impairment] is not a defect or departure from “normal functioning.”

¹⁰⁹ Although she makes brief remarks about BIID in *The Minority Body: A Theory of Disability*, she does not apply her framework, instead focusing on questions of identity related to BIID.

- (c) Disability [impairment] is a valuable part of human diversity that should be celebrated and preserved.
- (d) A principal source of the bad effects of disability is society's treatment of disabled people, rather than disability [impairment] itself (2014, 93).

Table 3 Barnes' Three Types of Views of Impairment

1. Bad-difference Views of Impairment	2. Mere-difference Views of Impairment	3. Good-difference Views of Impairment
(i) "Disability [impairment] is something that is an automatic or intrinsic cost to your well-being" (Barnes 2014, 91).	(i') Impairment is <i>not</i> something that is an automatic or intrinsic cost to your well-being.	(i'') Impairment is something that is an automatic or intrinsic benefit to your well-being.
(ii) "Were society fully accepting of disabled people, it would still be the case that for any given disabled person x and arbitrary nondisabled person y , such that x and y are in relevantly similar personal and socioeconomic circumstances, it is likely that y has a higher level of well-being than x " (91).	(ii') Were society fully accepting of disabled people, it would <i>not</i> be the case that for any given disabled person x and arbitrary nondisabled person y , such that x and y are in relevantly similar personal and socioeconomic circumstances, it is unlikely that y has a higher level of well-being than x .	(ii'') Were society fully accepting of disabled people, it would be the case that for any given disabled person x and arbitrarily nondisabled person y , such that x and y are in relevantly similar personal and socioeconomic circumstances, it is likely that x has a higher level of well-being than y .
(iii) "For any arbitrarily disabled person x , if you could hold x 's personal and socioeconomic circumstances fixed but remove their disability [impairment], you would thereby improve their well-being" (92).	(iii') For any arbitrarily disabled person x , if you could hold x 's personal and socioeconomic circumstances fixed but remove their impairment, you would <i>not necessarily</i> thereby improve their well-being.	(iii'') For any arbitrarily disabled person x , if you could hold x 's personal and socioeconomic circumstances fixed but remove their impairment, you would reduce their well-being.

Barnes holds that claims *a-d* are inessential to mere-difference views of impairment. She states:

"[t]he mere-difference view can be understood simply as the denial of claims like (i)-(iii), and of their good-difference converses" (93). Claims *a-d* are also in alignment with good-difference views of impairment.

Discussions about BIID tend to be steeped in ableism and bad-difference views of impairment, by which I mean that it is assumed that it is always preferable to be able-bodied rather than to have an impairment because one's quality of life would be worse in the second case. There is near consensus in the literature on BIID that this is the correct orientation towards impairment. Garland-Thomson nicely sums up the commonly endorsed view of impairment in the following:

Our dominant understanding is that disability [impairment] is something to be avoided and that the world would be a better place if disability [impairment] could be eliminated. This is sensible because...we understand disability [impairment] to confer pain, disease, suffering, functional limitation, abnormality, dependence, social stigma, and economic disadvantage and to limit life opportunities and quality (2012, 340).

Garland-Thomson's focus is on the position that impairment should be prevented or cured whenever possible, and although she does not address BIID specifically, her remarks are relevant for thinking about resistance to the idea of allowing people to intentionally acquire impairments. However, bad-difference views of impairment that inform this reaction are not grounded in the reports of disabled people.

Though impairment might be tolerated when it is unpreventable, most theorists find it unimaginable that anyone would *voluntarily* acquire an impairment with the expectation that it would *improve* quality of life. In "Whose Identity is It Anyway?" Jozsef Kovacs contends that the requests of people with BIID for amputation are considered to be outside of the proper scope of medicine due to fear of impairment and lack of knowledge about their suffering. He asserts:

Our paternalistic prohibition to provide surgery for BIID patients mirrors our own aversion of physical disabilities and our deep ignorance of the psychic suffering that a psychiatric disorder may mean for the person who has it (Kovacs 2009, 45).

He demonstrates greater reflexivity than most theorists about the social concerns that inform thinking about BIID. Even though Kovacs contends that amputations of healthy limbs should be

considered “as a last resort” because he thinks this could improve QOL, he seems to hold a bad-difference view of impairment and to implicitly endorse the medical model of disability. He states, “By requesting the amputation of her healthy limb the BIID patient in fact wants to exchange the symptoms of her mental disorder for a visible and stigmatizing physical disability” (44). This quotation suggests that impairment itself is stigmatizing rather than accounting for the impact of ableism. He goes on to say that, “If BIID is a valid psychiatric disorder, then BIID sufferers do not exchange their health for disability. They exchange the suffering caused by their mental disorder for the suffering caused by a physical disability” (45). Here Kovacs assumes that impairment in general—not the process of acquiring an impairment or adjusting to it—causes suffering. As a result of holding a bad-difference view of impairment, some theorists have attempted to find an alternative explanation, for example, suggesting expected social benefits as motivating the desire for an impairment or dismissing the idea that people want to acquire impairments. In what follows, I will discuss a couple of examples.

Often enough, it is claimed within the literature on BIID that if people are allowed to have healthy limbs amputated, then they will no longer be able to function as productive members of society. Sabine Müller and D. Patrone suggest that lacking a limb dooms one to a life of physical dependence and possibly dependence on government assistance. In some cases, theorists assume that this is, in fact, the intent of those who desire amputations. Müller suggests that people may seek amputation as a means for “financial or social advantages (e.g., insurance rates, retirement, attention)” (2009, 41). She highlights the cost of goods and services required for amputees, pointing out that, “a welfare state has to finance these costs” (41). Müller adds that these financial costs are combined with “lost working income which would stress the society” (41). She cites these factors as constituting an injustice and an argument against allowing people

with BIID to obtain amputations. She does not consider questions of justice in relation to the role of society in assuring accessibility in order to make it more likely that amputees will be able to maintain employment.

Baril asserts, “for researchers and the general public, principal objections to potential transabled surgeries conform to neoliberal concerns for cost and productivity” (2015a, 693). This framing of the issue sets aside the empirical question of whether amputees do negatively affect cost and productivity in comparison to able-bodied people suffering from BIID as well as the question of whether this *ought* to be the primary concern. Of course, if one *causes* oneself to become disabled, one is readily classified as undeserving of charity, assistance, or sympathy.

Vitacco et al. claim that “the assumption that persons with BIID would simply be longing for a state of physical disability” is likely to be false given reports that many “plan to have a prosthesis fitted immediately after amputation, in order to hide being handicapped” (2009, 206). I agree with the position that BIID is unlikely to be explained as “*simply* a longing for a state of physical disability [impairment] [my emphasis],” but the reasoning provided contains assumptions that need unpacking. For example, do the authors hold that having a prosthesis cancels out having an impairment? Why do they assume that use of a prosthetic limb is intended to hide “being handicapped”? Are they assuming that impairments only “count” if they are visible? And further, do they assume that those with BIID could only want to undergo amputations in order to exhibit their residual limbs? Vitacco et al. do not consider, for example, that using prosthetic limbs may facilitate mobility better than wheelchair use in inaccessible environments or that it might be part of the appeal of becoming an amputee.

One man desiring amputation of his leg asserts: “It pleases me, to be visibly, physically different from others: a man with one leg, a man with a wooden leg” (290). He posits that this

idea originated in his childhood, and in regard to observing a boy with a “peg-leg” playing in the street when he was 8 years old he says:

I never felt any pity towards them. (...) They [children who played in the street] got attention and seemed happy to me, even the boy who struck me the most (attracted me the most) had a wooden leg and he was a so-called unhappy boy. Nevertheless I considered him happier than myself and felt it was not so awful to be without a leg. This opinion steadily became stronger and developed into the idea that it must be nice to have a wooden leg (Everaerd 1983, 288).

His characterization of the boy with the wooden leg describes a shift from endorsement of a mere-difference view to a good-difference view of impairment. This type of reaction to encounters with people with visibly identifiable impairments is common among people with BIID.

In First’s survey of fifty-two people who desired amputations, “a majority (56%, $n=29$) reported that it [this desire] began soon after exposure to an amputee (in two cases the exposure was to media images of an amputee) (2005, 924). Among these participants, 21% thought that the amputee they observed had advantages such as “popularity, attention, happiness,” 17% felt sexually aroused, and “one subject admired the amputee because of the adversity he had overcome” (924). Of the twenty-one participants in their study, Noll and Kasten state: “In contrast to normal children, who react with sadness, when they see such a ‘poor’ handicapped amputee, the BIID-subjects were fascinated and developed the idea to be like these people” (2014, 230). While nondisabled people tend to think of people with impairment as pitiable, which is obviously problematic, we might be concerned that people with BIID have an overly positive view of what it is like to live as an amputee.

Research on BIID pays minimal attention to addressing the question of how people with this condition form their views of what it is like to live with an impairment. To the extent that this question is addressed, it seems that participants use their imaginations to form views of what

it is like to be disabled more than they base their judgments on engagement with disabled people. However, it is difficult to draw conclusions about how people with BIID form their views about living with impairment.

While the research conducted to date provides little sense of how or whether participants learn about the lived experiences of amputees, I would certainly not suggest that they seek impairments without careful consideration. One man with BIID asserts:

Certainly it is true that one's desires or fantasies are often more beautiful than reality in that a desire once realized can sometimes lead to nothing more than disillusionment. (...) Naturally it is no joke to go through life with one leg. (...) I have thoroughly considered the possibility of a disappointment, of a let-down, and I feel that I must take the chance and bear the consequences (Everaerd 1983, 290).

After interviewing a number of people with BIID, Elliott summarizes their reasoning in the following:

They realize that life as an amputee will not be easy. They understand the problems they will have with mobility, with work, with their social lives; they realize they will have to make countless adjustments just to get through the day. They are willing to pay their own way. Their bodies belong to them, they tell me. The choice should be theirs. What is worse: to live without a leg or to live with an obsession that controls your life? (Elliott 2003, 234)

Beyond the fact that people with BIID want to acquire impairment in hopes of improving their quality of life (QOL), surveys and interviews provide further indication that people with BIID reject bad-difference views of impairment in favor of mere or good-differences views.

One might think that disability theorists would consider BIID to be evidence that impairment is not always something to be avoided, given that people with this condition actively seek it out. In addition, the limited research conducted to date provides examples in which those who have voluntarily attained impairments report a higher QOL than they had when they were

able-bodied (Noll and Kasten 2014).¹¹⁰ However, Baril claims that, with few exceptions, “disability studies literature, anti-ableist activists, and disabled communities are silent on transability” (2015a, 691). He notes that in these exceptions, disabled people and their allies tend to have negative reactions. Baril suggests:

Anti-ableist activists often consider transabled practices and claims harmful to anti-ableist studies and movements because transabled people are perceived to: be inauthentic, falsely disabled, and deceptive about their “real” identity; steal resources reserved for disabled people; and be disrespectful of disabled people by denying, fetishizing, or appropriating their reality (691).

He goes on to say “[t]ransabled people are considered thieves because transability is seen as a means to exploit the State and obtain resources to which they are not entitled” (2015a, 693).

Some members of the disability community have reacted negatively to those who want to acquire an impairment, in part, due to their endorsement of this position. Like many nondisabled people, those whose impairments are involuntary (in Baril’s words, cisdisabled people) may have difficulty comprehending the intentional creation of impairment. Nonetheless, Baril hopes that disability rights advocates will realize that the difficulties people with BIID face are intertwined with theirs. He advocates for coalition between people with BIID and the disability community in order to transform social understandings of impairment and to improve their access to resources.

Given the overlap between those who seek to become amputees and those who are attracted to amputees, it is worth considering the behavior of devotees and the reactions of

¹¹⁰ While those with BIID are typically referred to as being able-bodied, it is unclear how well they are able to function without or prior to undergoing amputation. This lack of information hinders research on those who have succeeded in obtaining amputations. In regard to his own study, Baril remarks:

for those subjects who reported improvement in functioning following amputation, the absence of assessment in functioning prior to amputation raises the possibility that reported improvement reflected a bias to over-report improvement to justify their having taken such drastic measures (2005, 927).

amputees. Alison Kafer asserts that for devotees, who are often heterosexual men, “taking surreptitious photographs, sharing stories about amputee sightings, secretly following women, and lying about one’s identity are seen not as harassment but as acceptable behavior” (2012, 340). She points out that devotees claim that if society in general, and amputees in particular, were more accepting of their desires, they would not engage in this type of behavior (340). Kafer discusses the ways that amputee women are disempowered by the harassment and deceptive actions of devotees; for example, fear of attending amputee support groups and conferences as well as even worrying that their prosthetists are “closet devotees getting secret thrills” (341). What emerges clearly within the narratives of devotees is how little many of them actually care about the women and men they pursue, reducing them to objects of their desire (Bruno 1997; Kafer 2012; Solvang 2007). In sum, while some amputees welcome the attention of devotees, many members of the disability community find it disturbing. My point here is that these concerns, to an extent, inform the reactions of the disability community to people with BIID. I would surmise that the association of wanting to acquire an impairment with having what is commonly considered a mental illness—even if it is not included in the DSM-5—also contributes to the wariness members of the disability community feel.

As emphasized throughout this dissertation, members of the disability community hold mere-difference and good-difference views of impairment. Does this mean that they/we must endorse the intentional creation of impairments? Regarding good-differences views of impairment, Barnes notes: “A positive take on disability [impairment] doesn’t in any way involve a positive take on all the ways we can cause disability [impairment]” (2014, 108). Using a number of thought experiments to illustrate, she enumerates some of the reasons that those who hold mere- and good-difference views of impairment might find the causation of impairment to

be morally wrong. Among these are: causing a nondisabled person to have an impairment without that person's consent, the risk that they may not adjust well to having an impairment, transition costs related to becoming disabled, and causing impairment carelessly (2014, 95-96). In most cases, one or more of these conditions would be applicable. To return to an example from chapter four, one of the reasons disability advocates object to the "Ashley treatment" is that children under consideration for this set of medical interventions, which limit their growth and result in sterilization, are unable to provide consent (Kafer 2013; Kittay 2011). On Barnes' account, causing impairment is usually morally wrong due to contextual factors, even if impairment does not automatically result in a low QOL.

How does amputating the limbs of people with BIID fare by Barnes' method for evaluation? The question of consent is of utmost importance. Rather than considering people with BIID to be categorically incompetent to make healthcare decisions (or categorically competent, for that matter), individuals must be assessed on a case-by-case basis. There is the risk that people with BIID will not adjust well to living with limb loss, and transition costs are inevitable. Clearly, it would not be permissible for surgeons to amputate limbs without careful consideration and a rigorous assessment procedure for people with BIID.¹¹¹

Barnes focuses on ways that ableism influences people to focus on bad effects of impairment and to have trouble grasping the idea that people want to be or become disabled in the following:

It is very difficult, of course, for most people to imagine anyone wanting to be disabled (or more strongly—wanting to become disabled). But most people associate disability [impairment] merely with lack of ability. In a society with less ableism, it would be the case not only that many of the bad effects of disability [impairment] would be lessened

¹¹¹ Barnes herself contends: "There's nothing wrong with—and much that's good about—a mechanism that allows such disabled people to become nondisabled if they wish (and allows, vice versa, nondisabled people to become disabled if they wish)" (Barnes 2014, 110).

but also that many of the good effects of disability [impairment] would be more widely recognized (Barnes 2014, 110n28).

As I have shown throughout this dissertation, the bad effects of impairment tend to eclipse any good effects within dominant understandings. I agree with Barnes that it is likely that reduction in ableism would contribute to a greater recognition that there are good effects as well. A question that consideration of BIID raises is whether ableism is the *only* reason one might oppose permitting nondisabled people to voluntarily become disabled. While ableism is influential in the literature on BIID, it is reasonable to be concerned that people with BIID may not have an adequate understanding of what it is like to live as an amputee in an ableist society. After all, nondisabled ignorance is pervasive. However, this is a worry that can be mitigated, in part, through learning about the experiences of amputees. Obtaining an amputation is obviously a permanent and life-changing operation—one that some think those who opt to have healthy limbs removed may regret. Certainly, we often misjudge what will make us feel happy or fulfilled, and there is no reason to think this desire is immune from that possibility. Further research is needed—research that provides a clearer sense of the level of understanding people with BIID have of the lived experiences of amputees as well as providing a better sense of what they are seeking.

5.7 Conclusion

Although this chapter comes to no firm conclusions regarding how exactly medical professionals and members of the disability community ought to respond to people with BIID, I have shown that views of impairment impact how researchers and people experiencing this condition understand the desire to have a healthy limb amputated. Neither psychological nor neurological accounts are able to explain BIID, and there are aspects of experience that are excluded from

each, either by the ways research is conducted or by the view that BIID is simply the result of dysfunction in the brain. Phenomenological approaches allow for more robust accounts of the experiences of people with BIID and avoid problematic attempts to clearly demarcate sexual and nonsexual aspects of existence. Although I have suggested that people with BIID are hoping to alter their being in the world through amputation of a limb, I have also pointed out that research to date provides little sense of how much knowledge they have of what it is like to live as an amputee. An adequate understanding of the everyday experiences of amputees is important as a condition for people with BIID being able to make informed decisions.

CONCLUSION

In this dissertation, I have demonstrated that starting from a feminist disability standpoint, which is grounded in the experience and knowledge of disabled people, challenges common assumptions within biomedical ethics and phenomenology and reveals the ableism that informs these areas of philosophy. Bioethicists' assumptions about disability shape their positions on topics such as the right to refuse treatment, euthanasia, physician-assisted suicide, genetic testing, selective abortion, organ transplant policies, and healthcare rationing. Given that disabled people's lives are central, and literally at stake, in many of the ethical and legal debates surrounding these topics, their concerns and knowledge ought to be the starting point for these discussions, but typically they are not because nondisabled people think they know better. Most of the bioethicists and phenomenologists discussed here assume that disability is simply an objective description of the biomedical condition of an individual. Some further assume that illness and impairment—to adopt the terminology of the social model of disability—ought to be prevented on the grounds that they inevitably greatly limit a person's level of opportunities and quality of life. Disability theorists contest this view, arguing that many of the disadvantages and limitations disabled people face are socially created and only contingently related to impairment.

This dissertation has suggested that disability and normality are relational phenomena—simultaneously bodily and social—that contain a great deal of variation. While these categories and the line between them are contingent, they are significant for social practices and embodied subjectivity. Accounts of “the” normal subject exclude many types of experiences and obscure the influence of the physical environment and social expectations related to gender, race, and

ability on who counts as “normal” and the implications of this designation. I have argued that Merleau-Ponty and phenomenologists adopting his approach often implicitly assume that the “normal” subject is able to attain material anonymity, which allows one to pay minimal attention to the body. However, this assumption is not necessary, and I contend that it is possible to incorporate lived experiences that diverge from material anonymity into this type of approach to phenomenology. Merleau-Ponty recognizes that the effects of bodily injuries are relevant to but not wholly determinative of being in the world. Merleau-Ponty’s successors have built on his approach in order to draw attention to the impact of bodily particularities more generally on social identity and experience. Accounts of misfitting—experiences in which social expectations and the physical environment are incongruent with one’s body—serve to increase attention to the privileged status of those who attain material anonymity and allow for identification of the ways that oppression creates unjust misfits rather than construing them as inevitable consequences of inhabiting a particular body. Such accounts also serve to flesh out the richness of various ways of being in the world, which cannot be reduced to lack. This is important for all types of marginalized embodiment, and descriptions of being in the world as a disabled person need to consider other axes related to identity in order to avoid assuming material anonymity is “normal.”

In chapter one, I introduced models of disability as well as key concepts for analyzing the inferior social status of disabled people. The primary goal of this chapter was to examine bioethicists’ assumptions about disability and how those assumptions inform their positions on what types of interventions benefit and make conditions more just for disabled people. I provided numerous examples of articles within bioethics textbooks in which bioethicists uncritically assume the correctness of the medical model of disability, bad-difference views of impairment, and genetic determinism. Although these views of disability are pervasive within the biomedical

ethics literature, the perspectives of those who endorse the social model of disability and mere-difference and good-difference views of impairment as well as those who reject genetic determinism are beginning to be included in bioethics anthologies. I focused on articles dealing with issues related to reproduction such as preconception and prenatal genetic and other testing, preimplantation genetic diagnosis, and selective abortion because bioethicists tend to make their assumptions about disability explicit in discussions of these topics. I have shown that adoption of developmental systems theory would necessitate changes in how bioethicists discuss genetic conditions; they could no longer claim to know a potential child's phenotype, level of opportunities, or quality of life on the basis of genotype alone, given the complex interactions that give rise to development. Opposing assumptions about what disability is and its causes lead the authors under consideration to very different conclusions regarding personal and societal responsibility for preventing harms associated with disability.

The exclusion of disabled people's experiences and knowledge is one of the reasons that bad-difference views of impairment have remained dominant within and beyond biomedical ethics. In chapter two, I argued that this exclusion is not only unjust but also weakens epistemic practices in biomedical ethics, leading to reinforcement of nondisabled ignorance. Appeals to objectivity as neutrality have served to mask the ways that social values and interests impact these practices while framing disabled people's reports of their own lives as too subjective or value-laden to be taken into consideration. Drawing on the insights of Hartsock, Harding, Scheman, and Mills, we learned that knowledge practices are socially located, are likely to involve power asymmetries, and require reflexivity on the part of knowers in order to be inclusive and trustworthy. In order to engage in just epistemic practices, bioethicists have a responsibility to understand the concerns and experiences of disabled people rather than

requesting that disabled people understand dominant narratives that devalue their lives. Contra Silvers, I have argued that conceptual neutrality regarding disability is not a value-free or viable approach to reconciling the tension between bioethicists and the disability rights community. However, Harding's notion of strong objectivity is useful for reframing Silver's method as a way to identify the values and concerns informing these perspectives, which may facilitate dialogue between these groups.

Throughout chapter two, I made the assumption that embodied experience is epistemically valuable. Chapter three examined reasons disability scholars have been hesitant to theorize the body, ways feminist disability theorists have advocated for inclusion of embodied experience, and debates within feminist theory regarding the status of experience. While Crow and Tremain take divergent approaches to incorporating the body into disability theory—the former advocating conceiving of impairment as value-free and the latter considering impairment to be primarily value-driven—both remain tied to impairment in ways that prevent them from being able to capture embodied experiences. I then turned to Scott's position on experience, which has been highly influential within feminist theory, and opposing arguments in order to consider whether or not embodied experiences have sufficient merit to make them worth including within disability theory. After concluding that they do, I argued that a Merleau-Pontian account of embodiment, enriched by the insights of feminists and critical race theorists, is superior to approaches that conceptualize the body as impairment.

In chapter four, I argued that while theorists concerned with marginalized embodiment—including disability theorists—have cited Merleau-Ponty's approach as a starting point for addressing experiences of various illnesses, impairments, and social identities, there has been insufficient attention to the ableism present in *Phenomenology of Perception*. Indeed, Weiss has

claimed that Merleau-Ponty's use of Schneider served the purpose of showing that he attains a fit, even though the brain injury he sustained has resulted in limitations. I have provided textual evidence that this is not the point Merleau-Ponty is making. Rather, I have argued that examination of Schneider's being in the world served to clarify "normal" experience by way of contrast and to bolster his case for existential analysis. Throughout this chapter I used Garland-Thomson's notions of fitting, misfitting, and material anonymity to critique Merleau-Ponty and a few of his successors as well as to provide suggestions for remedying the limitations of their approaches to phenomenology.

While chapters three and four claimed that Merleau-Ponty provides important resources for theorizing experiences of disability, chapter five explored how this type of approach is useful for understanding body integrity identity disorder (BIID). Like the disability theorists discussed in chapter three, theorists focused on BIID tend to think in terms of impairment, which prevents them from adequately addressing lived experience and what people with BIID are seeking. I have argued that being in the world provides a better starting point for research on BIID, which avoids the dichotomies present within the literature and provides the possibility of expanding our understanding of this condition (e.g. what people with BIID think it is like to live as an amputee). Bodily particularities matter, but they are not all that matters for embodied subjectivity.

This dissertation has demonstrated that disability presents numerous interesting philosophical questions. Through examination of issues related to embodied experiences and knowledge of disability, I have shown that assumptions informing biomedical ethics, epistemology, and phenomenology have the potential to contribute to the oppression of disabled people or to incorporate their experiences and concerns. In this dissertation, I have brought together seemingly disparate approaches to philosophy in order to explore their connections as

well as the ways that taking the experiences of disabled people seriously enriches and transforms these areas of philosophy.

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