

DISABLING BIOETHICS: THE CASE FOR A DISABILITY MORAL PSYCHOLOGY AND
EPISTEMOLOGY FOR BIOETHICS

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A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

Philosophy—Doctor of Philosophy

2014

ABSTRACT

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While it may be surprising to some, there is a history of persistent, sometimes heated conflict between the profession of bioethics and the disability movement. Namely, the disability movement has engaged mainstream bioethics in an adversarial way because of radically divergent positions on topics such as: prenatal diagnosis, health care rationing, growth attenuation interventions, physician assisted suicide, and euthanasia. In my dissertation, I argue that this tension between the analyses of the disability movement and mainstream bioethics is not *merely* a conflict between two insular communities of “disability activists” and “bioethicists” but between those who have experienced disability and those who have not. That is, I maintain that it is a mistake to think of this conflict as arising just from a difference in ideology or political commitments, because it represents a much deeper difference—one rooted in moral psychology and epistemology. Analyzing the causes and effects of nuanced differences between the disability movement and field of bioethics’ respective moral psychologies and epistemologies--and then suggesting both theoretical and practical changes that might dissolve the conflict produced by these unacknowledged differences--is the key task of my dissertation.

I lovingly dedicate this dissertation to my spouse, Leah; my parents, Joe and Louise; my siblings (and sibling-in-law), Tina, Kerry, and Daryle; and the many disability activists and scholars who have blazed the trail that I am following in these pages. Without any of these people, this work simply would not exist.

ACKNOWLEDGEMENTS

I owe an immeasurable debt to many people who helped bring this dissertation to completion.

First and foremost, I need to thank my family. This is as much your accomplishment as it is mine. Leah, thank you for all your patience and sacrifice through this process. I know it has not been easy to be in a romantic relationship with both me and my dissertation. Thank you for helping me build a life both through and despite the burden of the creative process. Mom and Dad, thank you for believing in me from day one, even when I know others told you not to. Accepting me into your life with my differences was the initial action that made everything else possible. Your encouragement and support along the way have meant everything.

Thank you to my dissertation committee, but especially Professor Hilde Lindeman. Thank you for introducing me to feminist ethics in the Fall semester of 2007 and helping me see how important it is to what I want to do with my career. Thank you for helping me through this marathon, from advising me about how to refine my ideas into a topic that would be suitable for a dissertation all the way up through your careful copyediting that made the thing more readable.

Thank you to the many philosophers, bioethicists, and disability studies scholars whose work I rely on so heavily in these pages. You have all been my teachers, even though I have not ever met most of you.

Finally, thank you to the disability movement activists who have created a world in which people like me have the chance to write doctoral dissertations.

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CHAPTER 1: WHY BIOETHICS NEEDS A DISABILITY MORAL PSYCHOLOGY AND EPISTEMOLOGY

For decades, the Disability Movement (DM)¹ has often been at odds with the field of mainstream bioethics. It is my belief that more good could come from both projects if they had a collaborative rather than an adversarial relationship. However, creating constructive collaboration between these groups would be no easy task because it also is my belief that the tension between the two is rooted deeply in differences in moral psychology and epistemology. These differences must be confronted if there is to be any hope of constructive dialogue. Analyzing the causes and effects of nuanced differences between the DM and field of bioethics' respective moral psychologies and epistemologies--and then suggesting both theoretical and practical changes that might dissolve the conflict produced by these unacknowledged differences--will be the key task of this dissertation. I will begin by first showing that there *is* a sustained conflict between these two groups, identifying a number of moral and political issues that have pitted them against each other and carefully unpacking one such issue to show the key features of the tension. After I have established the existence of this conflict between the DM and mainstream bioethics, I will examine the notion that the experience of disability can be a source of values and norms because of how it can produce variation in one's moral psychology.

¹ Throughout this project, I will refer to the coordinated, large scale, sustained social and political action of disabled people in the United States as the Disability Movement or DM. This term is deliberately broad and meant to encompass the substantial range of sometimes divergent tactics and ideologies deployed by disabled people throughout the history of their social and political action. It is not assumed that all disabled people engaged in such action use identical approaches, but for the sake of simplicity, I use this umbrella term, while acknowledging the diversity of viewpoints within this grouping. It is meant to include, but is not limited to, approaches grounded in: disability rights, radical disability justice, and independent living philosophy. To clarify further, the term DM is not simple shorthand for people who experience life with an anomalous embodiment or medical impairment of some sort. While the lived reality of disability is an important feature of my argument, when I use the term DM, I am referring to a particular subset of disabled people who are conscious of their own subordinate social position and engage in political action accordingly. In a sense, my use of the term DM may be analogous in some ways to the term "feminist movement" in as far as it captures a range of political viewpoints and approaches, but does not include all people who are biologically female or even all those who identify as women.

Then, I will argue that these differences in moral psychology specifically eventuate in the conflict between the DM and mainstream bioethics, which arises when disabled people attempt to enter in to the moral culture of bioethics that has been constructed according to a *non*-disabled moral psychology, and are then morally alienated within a zone of distrust. I will conclude by offering a brief justification for and outline of how the field of bioethics should be remodeled to account for differences in moral psychology and epistemology, thus establishing itself as a zone of default trust for disabled people and replacing conflict with inclusion and collaboration.

The Moral Conflict at Hand

Infamous among members of the DM, the deeply entrenched, often heated conflict between the DM and Princeton bioethicist Peter Singer is well known and well documented.² His appointment to the faculty of Princeton in 1999 produced vocal protests from the disability community in the United States (Longmore 2003, 225), which have continued more than a decade later when he lectures publicly.³ In fact, Alicia Ouellette calls for bioethics, as a field, to confront what she calls its “Peter Singer problem” by using “philosophical argumentation or public distancing” from Singer in order to facilitate reconciliation with the DM (Ouellette 2011, 337).

² For a compelling firsthand account of a well-known activist’s debate with Singer, see Johnson, Harriet McBryde. 2005. “Unspeakable Conversations” in *Too Late to Die Young*, Picador, New York, NY; For a thoughtful critical analysis of the nature of the conflict between Singer and the DM, see Longmore, Paul. 2003. “Princeton and Peter Singer” in *Why I Burned My Book and Other Essays on Disability*. Philadelphia, PA

³ While there have undoubtedly been many protests of Singer that I am not aware of, the most recent one that has come to my attention happened on November 18, 2010 when Singer gave a lecture in Ottawa, Ontario. The lecture was hosted by Dominion Chalmers United Church and Singer was invited by the philosophy department at Carleton University. The lecture was sponsored by 12 different departments, colleges, and centers at the University. The protest consisted of about 30 Carleton University students, many of whom were disabled or had disabled family members. The protest consisted of passing out informational pamphlets outlining the case against Singer’s views by the Disability Movement. This event was described to me in detail via personal correspondence with Dr Krissy Kelly of Carleton University’s department of Canadian Studies on July 25, 2012.

While Singer remains a divisive figure and perhaps the most persistently visible locus of conflict between the DM and bioethics, this is largely because of his popularity and resulting public visibility. A careful study of the field of professional bioethics and its encounters with disability activism reveals a sustained pattern of conflict that spans the full breadth of bioethical topics and major philosophical positions.⁴

The scholarly literature critiquing prenatal diagnosis and selective abortion from a disability rights perspective is probably the largest and most sophisticated of the instances where disability studies scholars have engaged bioethics.⁵ However, there are many more instances of disability activists and scholars encountering the field of bioethics in an adversarial way.

In 1994, as many bioethicists were arguing in favor of the expansion of public health care coverage to include more poor people, disability activist Alice Mailhot published a scathing article in *Mouth Magazine*, targeting the tendency of bioethicists to ration the health care available to disabled people to contain the costs of expanding the breadth of coverage. After citing several prominent bioethicists advocating for the position that health care costs can only be contained fairly through explicit rationing choices, Mailhot concludes that professional, mainstream bioethics is arguing “money outweighs life” and that bioethicists “teach medical professionals and community elites to decide who lives and who dies” (Mailhot 1994). It is notable that Mailhot’s prosecution of bioethics cites an article by Dr. Willard Gaylin, in which he argues that the cost of health care is driven up by saving the lives of disabled people, specifically pointing out that “The child who would have died from polio will grow up to

⁴ Much of the history of this conflict has been carefully documented and analyzed in Ouellette’s 2011 book *Bioethics and Disability*.

⁵ For a comprehensive entry point to this literature, see *Prenatal Testing and Disability Rights*, ed. Adrienne Asch and Erik Parens. (2000). Washington DC: Georgetown University Press.

be a very expensive old man or woman.... Good medicine keeps sick people alive, thereby increasing the number of sick people in the population” (Mailhot 1994). This is particularly notable because Mailhot herself had polio and lived for more than eighty years.⁶

The conflict between elements of the DM and mainstream bioethics has also found its way into issues surrounding technologically assisted reproduction. One high profile example is that of Sharon Duchesneau and Candy McCullough, who wanted to have a Deaf baby in 2002 and were roundly criticized by many bioethicists when they used the sperm of a family friend with five generations of deafness in his family to conceive their son, Gauvin, who was subsequently born deaf (Teather 2002). An article in *The Gaurdian* quotes Alta Charo, a professor of law and bioethics at the University of Wisconsin as highly critical of this choice, “I think all of us recognize that deaf children can have perfectly wonderful lives. The question is whether the parents have violated the sacred duty of parenthood, which is to maximize to some reasonable degree the advantages available to their children. I'm loath to say it, but I think it's a shame to set limits on a child's potential” (Teather 2002). Candy McCullough, Gauvin's mother, defends her choice in the same article “Some people look at it like, 'Oh my gosh, you shouldn't have a child who has a disability.' But, you know, black people have harder lives. Why shouldn't parents be able to go ahead and pick a black donor if that's what they want? They should have that option. They can feel related to that culture, bonded with that culture” (Teather 2002).

Perhaps physician-assisted suicide (PAS) might be identified as the bioethical issue that has sustained the most long-term division between mainstream bioethics and the DM. To illustrate how the conflict between the profession of bioethics and the Disability Movement plays out in more careful detail than a brief survey of topics could offer, I will highlight in greater

⁶ I know this from being a personal acquaintance of Ms. Mailhot during the last few years of her life, while she used a power wheelchair to remain very active in the DM in the greater Lansing, MI area.

detail the drastically divergent analyses offered by the most dominant voices within the field of mainstream bioethics and the DM when it comes to this issue of PAS. Then, I will argue that the tension between these analyses is not *merely* a conflict between two insular communities of “disability activists” and “bioethicists” but between those who have experienced disability and those who have not. That is, I maintain that it is a mistake to think of this conflict as arising simply from a difference in ideology or political commitments, because it is a much deeper difference—one rooted in moral psychology and epistemology. Further, I will argue that, since the dominant moral framework of bioethics has been constructed around the moral psychology of non-disabled people, disabled people often feel alienated from the project of bioethics, which has been constructed as a zone of distrust for them.

To create a zone of trust within bioethics for disabled people, we need to develop new understandings of bioethics’ core moral concepts and principles that arise from the experience of disability, and re-center the discipline on these revisions. Further, only this sort of full-scale remodeling of bioethics’ core moral principles--taking into account the moral knowledge produced by life with a disability--could possibly hope to realize the field’s potential to truly, fundamentally critique the moral structure of biomedicine’s practices and institutions, which I take to be the field’s function. While dissolving the conflict between the DM and mainstream bioethics is important in its own right, I am also making a normative argument that accounting for the knowledge of the DM will improve bioethics.

The opening paragraph of Beauchamp and Childress’ classic work *Principles of Biomedical Ethics* argues that modern bioethics must avoid the narrow focus of traditional professional ethics for medicine in the West because “developments in the biological and health sciences” have created new ethical problems that the traditional codes of ethics have completely

neglected (Beauchamp and Childress 2009, 1). They eschew reliance on traditional codes of ethics in favor of rigorous philosophical reflection because “it allows us to examine and, where appropriate, depart from dominant assumptions in approaches to the biomedical sciences and health care” (1). While they are surely right that new science has produced new moral problems for bioethics to analyze, I believe that new *social* developments pose similar challenges to bioethics’ task of critiquing the moral structures of biomedicine that traditional philosophical reflection is ill equipped to handle. Changes in the collective knowledge of the social milieu regarding gender, race, sexuality, economic status, disability, and other marginalized identities call on bioethics to examine and, where appropriate, depart from dominant *philosophical* assumptions in critiques of biomedical science and health care that have been narrowly relied upon by the profession. My hope is to contribute to this self-reflection by pointing out ways in which bioethics must depart from these dominant philosophical assumptions about disability that were entrenched well prior to the moral challenges posed by the social changes engendered by the Disability Movement but remain as barriers to the profession’s most fundamental function.

A Particular Point of Conflict – Physician-Assisted Suicide

To more fully illustrate the divergence between mainstream bioethics and the DM, I will briefly review the analyses of physician-assisted suicide (PAS) provided by some of the most prominent figures in each. The literature on this topic is enormous and I do not have space to fully cover it in detail. However, the basic features of the conflict will begin to come into focus through an analysis of the diverging views on the issue of PAS. Describing this divergence is the first step toward analyzing the source of the conflict and recommending specific philosophical and practical remedies for it.

Most mainstream bioethicists see the main moral dilemma of PAS as a classic conflict between the principles of beneficence and autonomy, while disabled scholars and activists understand the moral significance of this issue primarily in terms of justice. I will argue that mainstream bioethics mostly view those seeking PAS as vulnerable patients needing to be empowered to express their autonomous choices in defiance of the illegitimate authority of paternalistic physicians, while the DM largely see them as marginalized citizens needing to be empowered against oppressive social structures that have created a context of deep injustice. Of course, neither of these groups approach the topic with absolute unity, but the most powerful voices in each group have certainly been set in opposition to each other over the PAS issue for a very long time.

Much of mainstream bioethics' analysis of PAS can be traced back to the very origins of the field itself. Alicia Oulette writes that "Despite its many faces, bioethics has as its core a central concern with respect for persons through respect for individual autonomy and good medical care" (Oulette 2011, 30). The story of how the field came into existence is a description of the radical shift away from medical paternalism, the standard practice of "hiding information from and making choices for patients" (30), and toward "today's patient-centered model largely in response to abuses of people involved" (30). This history is reflected in how the concept of autonomy is now deployed in the field. For example, Beauchamp and Childress's classic *Principles of Biomedical Ethics* places a great deal of importance on the principle of respect for autonomy, arguing that "to respect autonomous agents is to acknowledge their right to hold views, to make choices, and to take actions based on their personal values and beliefs" (Beauchamp and Childress 2009, 103). From the very inception of their chapter on autonomy, they apply this principle in a medical context as, fundamentally, a buttress against a possibly

paternalistic physician who has overstepped his authority in a misguided attempt to benefit the patient (102). This is the dominant view of how and why the moral notion of autonomy ought to be applied to issues in bioethics generally and PAS in particular.

Beauchamp and Childress are clear about autonomy being the guiding principle of their support for physician-assisted suicide as they argue:

“if a person freely authorizes death and makes an autonomous judgment that the cessation of pain and suffering through death constitutes a personal benefit rather than a setback to his or her interests, then active aid-in-dying at the person’s request involves neither harming or wronging . . . Assisting an autonomous person at his or her request to bring about death is, from this perspective, a way of showing respect for a person’s autonomous choices. Similarly, denying the person access to other individuals who are willing and qualified to comply with the request shows a fundamental disrespect for the person’s autonomy.” (Beauchamp and Childress 2009, 181)

Beauchamp and Childress do not unequivocally endorse the legitimacy of every case of physician assisted suicide and concede that it must be done in way that prevents “abuse, lack of social control, absence of accountability, and unverifiable circumstances of a patient’s death” (182). However, it is notable that Beauchamp and Childress do not use the presence of terminal illness as a criterion for distinguishing between justified and unjustified cases of PAS, but look to the presence of “unacceptable suffering by a patient” (183).

Philosopher Dan Brock, a longtime supporter of both PAS and voluntary active euthanasia, also grounds his support for PAS in a commitment to respect the autonomy of individual patients. Brock devotes a great deal of his article “A Critique of Three Objections to Physician-Assisted Suicide” to dismantling the moral distinction some would make between

refusing life-sustaining treatment, which is currently almost universally accepted in American philosophy, law, and policy, and the more controversial practice of PAS. For Brock, these practices are morally similar because both are justified by a patient's right to autonomy. Brock first argues that "the underlying moral values that ground the consensus regarding patients' rights to refuse life support is that this right respects patients' self-determination or autonomy and reasonably supports patients' well-being. Here I understand self-determination to consist in making important decisions about one's life for oneself and according to one's own values and conception of a good life" (Brock 1999, 523). He goes on to argue that PAS is similar to refusing life-support in all of the morally relevant ways such that "the same underlying moral values of patient self-determination and wellbeing that ground the consensus about patients' right to refuse life-sustaining treatment also support patients' access to PAS" (524).

Judith Jarvis Thomson makes an argument that mirrors Brock's, also drawing upon the moral similarities between voluntarily withholding or withdrawing life sustaining treatment and voluntarily requesting PAS. She argues that the anti-PAS position is mostly untenable because the most powerful arguments against PAS would apply equally well to the widely accepted practice of withholding or withdrawing life support. By trying to dismantle the most common anti-PAS arguments, Thomson mostly provides a negative argument for why we should accept PAS as a moral practice, recognizing that she has not provided a set of positive reasons why PAS should be accepted. However, she points to a variation of an appeal to individual autonomy--or in her words, liberty --as to why these negative arguments against opponents of PAS should be sufficient: "We are to be concerned throughout, in all four kinds of cases, with people who are terminally ill and who wish to be helped; I take it that placing restrictions on what can be done for them is a serious infringement of liberty and, for my own part, therefore, I think that the

restrictor has the burden of proof” (Thomson 1999, 499).⁷ Thus, a sort of appeal to a respect for autonomy is the basis for why Thomson assumes PAS should be accepted if no valid arguments against it are available.

Rather than focusing on the ethics of PAS as an individualized practice, Gerald Dworkin assumes that plausible moral arguments exist that justify caregivers’ helping their patients die when it is requested under the right circumstances and focuses on developing a case for why the practice should be accepted by public policy (Dworkin 1998, 133-134). Part of Dworkin’s argument is also very similar to Brock’s and Thomson’s, in that he argues that any plausible case against PAS would work equally well against the accepted practice of allowing patients to refuse or withdraw from life sustaining treatment. He argues since we do not accept these arguments as reasons to deny patients a right to refuse or withdraw from life sustaining treatment, we cannot accept them as valid reasons to have a policy against PAS, when both practices entail “a willing doctor and a patient basing a claim on us (to respect autonomy and for relief of suffering)” (138). Turning to the notion that suicide and attempted suicide without assistance is not criminalized in American policy, Dworkin argues that this logic should be extended to PAS because this shows how “we think that autonomy extends to the decision about continued life as well as decisions within a life” (139). He states that this argument for the autonomy to choose suicide would be strengthened in cases involving “persons in the last stages of their terminal illness, or in medical conditions which threaten their autonomy and dignity” (139). While there are other arguments supporting a person’s right to access PAS, an appeal to individual autonomy is a common thread that runs through much of this literature from mainstream bioethics.

⁷ It might be that Thomson is appealing to *liberty* rather than *autonomy* here because she is framing the issue of PAS as a matter of public policy. Perhaps this is why Thomson deploys the political principle of liberty rather than the ethical principle of autonomy. I take both to mean a right to self-determination without the interference of other individuals/groups (autonomy) or the state (liberty).

As with mainstream bioethics' support of PAS, the DM is not homogenous when it comes to their opposition to the practice. However, the majority of members of the politically active community of disabled people who have expressed their opinion on the matter are vocally against it. Carol Gill offers a list of the largest Disability Movement organizations that have adopted official positions against PAS and these include: the National Council on Disability, American Disabled for Attendant Programs Today (better known as ADAPT), the National Council on Independent Living, World Associations of Persons with Disabilities, Justice for All, the Association for Persons with Severe Handicaps (better known as TASH), the National Spinal Cord Injury Association, and the World Institute on Disability (Gill 2000, 526). Not Dead Yet is group formed specifically to organize the DM's opposition to PAS and identifies itself as "a national, grassroots disability rights group that opposes legalization of assisted suicide and euthanasia as deadly forms of discrimination against old, ill, and disabled people . . . [that] helps organize and articulate opposition to these practices based on secular social justice arguments" (notdeadyet.org).

The most important secular social justice argument against PAS, offered by the DM, is aimed at problematizing the sort of simple appeal to autonomy used by mainstream bioethics to support PAS. Namely, many in the DM argue that appeals to the autonomy of the individual to choose PAS do not recognize the social context of injustice and oppression within which the supposed choice is made and these conditions compromise the authenticity of the individual's choice. To better illustrate this argument, I will deploy the often cited cases of two people with non-terminal physical disabilities who sought and won medical assistance with committing suicide, Elizabeth Bouvia and Larry McAfee. These cases are examined by Gregory Pence in his chapter on PAS in *Classic Cases in Medical Ethics*.

In 1983, Elizabeth Bouvia admitted herself to the psychiatric ward of a California hospital because she was suicidal. Bouvia had cerebral palsy that resulted in impairment in all four of her limbs, so she used a power wheelchair to be mobile. After spending part of her childhood in an institution, at the age of 18 she was able, with the assistance of personal attendants, to live by herself in an apartment, earn her bachelor's degree, and begin graduate school. Immediately prior to admitting herself to the hospital, Elizabeth had dropped out of her graduate program under duress because she had been told by faculty members that she would never be hired in her field with her disability, suffered a miscarriage, and been left by her husband. It must also be noted that Ms. Bouvia had degenerative arthritis and was in quite a bit of physical, as well as emotional, pain. In the years that followed, she was at the center of a long, involved legal battle over her right to a hospital-assisted suicide by starvation (Pence 2000, 63-69).

Unlike Bouvia, Larry McAfee did not have a disability from birth. Nevertheless, strong parallels exist between these two cases. McAfee was a 29-year-old mechanical engineering student at Georgia State University in 1985, when he sustained a high-level spinal cord injury from a motorcycle accident. As a C-2 quadriplegic, Mr. McAfee used a power wheelchair for mobility and a ventilator to help with his breathing. This meant that he needed quite a bit of assistance to perform tasks of daily living. With this sort of need, the structures of private, federal, and state providers made it financially and logistically impossible for McAfee to live outside of a hospital or nursing home for a period of four years, including a stretch of several months in an intensive care unit many years after his accident. In the summer of 1989, Larry McAfee filed a lawsuit demanding assistance in turning off his ventilator while being provided

palliative care so the process would be less painful. McAfee won his lawsuit and, like Bouvia, gained a legal right to have medical assistance in committing suicide (Pence 2000, 69-72).

To his credit, by the third edition of his book, Pence includes consideration of the DM's objection to PAS in these sorts of cases. Most of Pence's analysis focuses on an interpretation of the work of historian Paul Longmore, who challenges the mainstream appeal to autonomy in a way that is paradigmatic for the DM. Pence quotes extensive passages where Longmore points out how Bouvia's efforts at living an independent, productive life were repeatedly thwarted by prejudicial treatment by the administration of her graduate school program. He also quotes a section of Longmore's writing that describes the court cases as a failure of the legal system to adequately account for the socially constructed disadvantages she experienced and a tendency toward an undue emphasis on her physical condition as the primary determinant of her quality of life and motivation for her desire to die. Pence reports that the "disability advocate" Longmore (a term which arguably undercuts Longmore's epistemic authority as a fully credentialed scholar publishing in peer-reviewed journals) depicts Bouvia "as a victim of a prejudiced system and of misguided, do-gooder lawyers" (Ibid. 67). Pence goes on to summarize Longmore's position: "A prejudiced system destroys the independence of disabled people, leaving them in a position where their so-called autonomous decisions to die are actually bogus" (Ibid. 77).

Longmore's argument against assisted suicide in the context of structural discrimination that limits the choices of an oppressed class of people should not be entirely alien to those versed in feminist moral and political philosophy. It is quite reminiscent of Marilyn Frye's concept of the double bind. In the first chapter of *The Politics of Reality* Frye describes the notion of a double bind this way: "One of the most characteristic and ubiquitous features of the world as experienced by oppressed people is the double bind – situations in which options are reduced to a

very few and all of them expose one to penalty, censure or deprivation” (Frye 1983, 2).

Longmore applies exactly this sort of argument to the case of assisted suicide for disabled people, whose choices are restricted to living in an institutional setting like a nursing home; facing policy disincentives that put their lives at risk for living independently, working, and marrying; or ending lives that have been made so unbearable by hostile social policy. Pence gestures toward this double bind of “limited, grim choices” for disabled people and seems to endorse the idea that “society should explore and offer more and better choices” conceding that improved options for independent living may be at least a partial answer to problem of assisted suicide and “both Elizabeth Bouvia and Larry McAfee would have accepted such arrangements all along” (Pence 2000, 79).

In describing how Longmore and others from the DM argue that it is less important for the legal system to give disabled people the authority to autonomously evaluate their quality of life and choose to end it than it is for the social service system to provide them with greater access to the resources needed to live independently and improve their quality of life, Pence does an adequate job of setting their position on assisted suicide in a social justice framework. He effectively contrasts this line of thought with the common view from mainstream bioethics, namely, that the Bouvia and McAfee cases could be quintessential examples of how respect for autonomy must be defended in the face of overreaching physician beneficence and nonmaleficence.

It is worth unpacking Longmore’s argument more fully, putting it in the context of his larger theoretical project so that the contrast between mainstream bioethics’ simple reliance on autonomy to justify support for PAS and the DM’s challenge to this argument can be brought into sharper relief. Broadly, Longmore argues that the double bind of institutionalization versus

assisted suicide highlights how the dominant notion of autonomy and the common standards applying it to these sorts of cases of PAS are themselves flawed and in need of serious reconsideration.

Longmore does argue that the principle of autonomy is mistakenly applied to assisted suicide cases because of the double bind experienced by disabled Americans, but his point is much broader than this: “Health care ‘choices’ are never made in a vacuum. Given the absence of real options, death by assisted suicide becomes not an act of personal autonomy, but an act of desperation. It is a fictional freedom, it is a phony autonomy. The rhetoric of ‘choice’ is deployed to hide the realities of coercion” (Longmore 2003, 195).

Longmore’s critique of how the flawed, dominant understanding of the concept of autonomy warps the mainstream assisted suicide discussion finds its roots in his analysis of how the larger, flawed, dominant understanding of disability – the medical model – warps the mainstream response to disability in general. Longmore links the dominant understanding of autonomy and the dominant understanding of disability when he writes that the medical model “not only medicalizes disability, it thereby individualizes and privatizes what is in fundamental ways a social and political problem” (Longmore 2003, 4). Longmore is arguing that by relegating the problems of disability to the private sphere, we limit the range of possible solutions to matters of private choice governed by personal autonomy rather than public institutions governed by social justice. If the medical model individualizes and privatizes the harms of disability, it seems accurate to argue that this privatization is also at work when “phony autonomy” is deployed to obscure the double bind faced by a disabled person forced to choose between institutionalization and death, because the choice is misrepresented as between two privately experienced harms.

We can weave together Longmore's arguments by observing how this misrepresentation of the double bind fails to take into account the fundamentally social harms of disability, thus treating assisted suicide as a purely private choice subject to patient autonomy rather than a public problem subject to social justice. To Longmore, framing assisted suicide in terms of autonomy holds up a "phony autonomy" because this is not a moral problem that should be understood in terms of a respect for autonomy. Longmore, then, is arguing that, by putting it at the center of the assisted suicide discussion, we completely misuse 'autonomy.' Mainstream bioethics makes this mistake consistently by appealing to a privileged view of autonomy, which assumes that everyone has a wide range of options, as the moral principle of greatest relevance to whether physician assisted suicide is justified.

We can further illuminate Longmore's critique of mainstream bioethics' treatment of physician assisted suicide by placing it in the context of Longmore's larger project of critiquing broad moral and political values – including autonomy – that have been developed and institutionalized by non-disabled people. Longmore explicitly argues that the articulation of disabled values and critique of nondisabled values is and should be part of the work of disabled activists and scholars:

Beyond proclamations of pride, deaf and disabled people have been uncovering or formulating sets of alternative values derived from within the deaf and disabled experiences. ... They involve not so much the statement of personal philosophies of life, as the assertion of group perspectives and values. ...

For example, some people with disabilities have been affirming the validity of values drawn from their own experience. Those values are markedly different from, and even opposed to, non-disabled majority values. They declare that they prize not self-

sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community.

This values formation takes disability as the starting point. It uses the disability experience as the source of values and norms.

The affirmation of disabled values also leads to a broad-ranging critique of non-disabled values. American culture is in the throes of an alarming and dangerous moral and social crisis, a crisis of values. The disability movement can advance a much-needed perspective on this situation. It can offer a critique of the hyperindividualistic majority norms institutionalized in the medical model and at the heart of the contemporary American crisis. That analysis needs to be made not just because majority values are impossible for people with disabilities to match up to, but more important, because they have proved destructive for everyone, disabled and nondisabled alike. They prevent real human connection and corrode authentic human community. (Longmore 2003, 222)

So we see the radical character of Longmore's project of calling for a fundamental reframing of basic values like autonomy from a disabled person's point of view.

Even if, like Pence, other mainstream bioethicists are able to almost perfectly recount the details of arguments growing out of the DM, the field will continue to come into conflict with the DM if it continues to assume that there is no difference between disabled and non-disabled people in how basic moral concepts are understood and applied within moral reasoning. If bioethics continues to take for granted that the dominant, non-disabled moral psychology and epistemology is all there is, moral conflict between bioethics and the DM will persist.

The Disability Experience as a Source of Values and Norms

Paul Longmore's call for the acceptance of "the disability experience as the source of values and norms" which are "markedly different from, and even opposed to, non-disabled majority values" (Longmore 2003, 222) signals his awareness that the tension between the DM and the field of bioethics is not *merely* a conflict between two insular communities of "disability activists" and "bioethicists" but between those who have experienced disability and those who have not. That is, this tension is not only produced by a difference in ideology or methodological approach, even though these differences often exist, but by a difference in how a person's experience of the world shapes his or her moral psychology and epistemology.

Longmore argues that the disability experience becomes a source of alternative values or norms through a collective process that involves a group of people rather than isolated individuals. These values, Longmore writes, "have been collective rather than personal efforts. They involve not so much the statement of personal philosophies of life as the assertion of group perspectives and values. This is a process of Deaf culture elaboration and disabled culture building" (Longmore 2003, 222). Later, I will explore exactly what the role of community is in the construction of a disability moral psychology and epistemology. For now, I will argue my key claim that, while Longmore may be right that a system of disability ethics can only arise from a communal social movement, differences in moral psychology due to differences in a lived experience of disability are prior to any development and articulation of a system of disability ethics. That is, a systematic ideology of disability ethics and politics is clearly developing within the DM, but this alternative ideology is primarily driven by the differences in the lived experiences of disabled people, who come to develop differences in their moral psychology.

This is why any resolution to the conflict between the DM and the field of bioethics cannot rely solely on a critique of competing moral and political ideologies. Instead, this underlying divide in moral psychology must be addressed.

Ideological divides are persistent and permeate moral and political discourse both in academic philosophy and in popular discussion. Academic journals and scholarly conferences abound with ideological conflict, just as newspapers, cable news networks, talk radio, and Facebook pages do. Kantians compete with utilitarians and Democrats debate Republicans. However, it would be a mistake to reduce the conflict between the DM and mainstream bioethics to this sort of ideological competition, as some bioethics and disability scholars would like to do.⁸ Pence's chapter on the Bouvia and McAfee cases indicate that, perhaps, even he has a rudimentary awareness that the divergent views of the DM and field of bioethics have to do with lived experience rather than mere ideology. Namely, in the "Update" section that concludes his chapter on requests to die, Pence notes that Longmore revealed in a 1997 column that he had a disability himself that resulted in partial paralysis and the need to use a ventilator similar to McAfee's (Pence 2000, 83-84). With the inclusion of this personal information about Longmore, Pence is at least suggesting that a person's lived experience of disability can change how they analyze and perceive a moral problem involving other disabled people. There seems to be some appreciation on Pence's part that the ideological conflicts between Longmore and mainstream, non-disabled bioethicists grow out of very different life experiences.

One explicit recognition of the causal link between lived experience and bioethical ideology is Ron Amundson and Gaile Taira's article "Our Lives and Ideologies: The Effect of Life Experience on the Perceived Morality of the Policy of Physician Assisted Suicide" in *The*

⁸ In the second chapter of this project, which will serve as my literature review, I will investigate this mistake in much greater detail.

Journal of Disability Policy Studies. Amundson and Taira admit that their article is not a theory-heavy, explanatory essay, but a brief descriptive piece. As they put it, “This is not a philosophy paper, but a sort of combined intellectual autobiography” (Amundson & Taira 2005, 53). They do not aim to explain why the experience of disability has an impact on a person’s moral reasoning and perception regarding assisted suicide. Their much more modest goal is purely observational. They aim to point out *that* this happens and to briefly describe how it happened in their experience.

Amundson and Taira write, “Our opinions about assisted suicide have changed because our lives have changed. We both now live with disabilities” (Amundson & Taira 2005, 53). It is notable that this observation of a difference in moral reasoning and perception is coming from two people who acquired a disability, rather than being born with one. This fact is significant because they are not identifying the difference between disabled and non-disabled moral reasoning and perception as someone who has only ever experienced life from the position of a disabled person. That is, Amundson and Taira are able to see these differences in moral psychology and epistemology as a shift in their own perspective. This view from the inside seems valuable to any argument that such a difference exists and can be attributed to the experience of disability.

For his part, Amundson describes his shift in opinion on physician-assisted suicide as the result of a broader shift where his new experience of disability made him more attuned toward the presence of ableism in American society. Amundson writes, “Ableism is a doctrine that falsely treats impairments as inherently and naturally horrible and blames the impairments themselves for the problems experienced by the people who have them” (Amundson & Taira 2005, 54). Amundson argues that this sort of ableist ideology is at the heart of a myriad of harms

experienced by disabled people,⁹ but lists physician-assisted suicide among those harms. “When I replaced in my own mind the ideology of ableism with the ideology of the disability rights movement,” he continues, “it caused my conversion from an advocate to an opponent of physician-assisted suicide” (Amundson & Taira 2005, 54). Amundson explains that he changed his mind when he began to see how the arguments favoring physician-assisted suicide relied heavily on moral reasoning and perception that he now understood as deeply ableist. In particular, his new experience with disability made him aware of a tendency of advocates for assisted suicide to ground their arguments in a fear of disability that rested on the assumption that the harms of disability are caused solely by biological difference rather than a social oppression (54).

In the same article, Gayle Taira is able to pinpoint her change of mind to a single, dramatic event. While recovering in the hospital from a car crash resulting in her traumatic brain injury, two health care professionals discussed her condition in front of her in an elevator and one casually proclaimed to the other “You know, I’d kill myself if that ever happened to me. I don’t want to end up like that” (Amundson & Taira 2005, 55). To Taira, this represents the often powerful coercion implicit in what she has come to see as a decision to die that is not truly autonomous. Taira’s non-disabled self that had supported the notion of physician assisted suicide had done so on the assumption that “the individual making the choice would be free from coercion and would be making a choice based on his or her own interests, free from the forced perspective of others” (55). Her experience as a disabled person cued Taira in to the idea that

⁹ It should be noted that this definition of ableism, which takes it to be nearly synonymous with what is often referred to as the medical model of disability, is not how I would define the term. To be sure, the medicalization of the disadvantages of disability is often a basic assumption of ableist structures or practices, but it is neither necessary nor sufficient for defining which structures or practices are ableist. For example, it is my position that the prejudicial mistreatment of disabled people existed long before Western medicine participated in this mistreatment and in areas of the non-Western world where the medical model of disability is not a determinant of the treatment of disabled people. Likewise, there are some instances in which the harms of disability can be mitigated through medical intervention. Many thanks to Professor Hilde Lindemann for suggesting this clarification.

such a choice cannot be thought of as autonomous when disparate power relationships put the chooser at the mercy of individuals and of a society that pressures them toward a particular decision by how it structures their experience. Taira summarizes her line of thought about how familial or professional caregivers, who are by definition in a position of power, can apply pressure toward the choice of suicide by rhetorically asking herself, “Well now, which do I choose? Life with what my family and society views as unbearable pain, uselessness, boredom, and indignity? Or do I choose to kill myself, heroically sparing my family and society the time and effort to care for me?” (55).

This summary of Longmore’s, Amundson’s, and Taira’s views on physician assisted suicide is not intended as a principled, rigorous philosophical argument against the practice. Rather, I hope to show that there are important differences in how disabled and non-disabled people reason about and perceive the key moral problems of the field of bioethics. The differences that divide the DM from mainstream bioethics are not purely ideological ones that are best left for the court of public opinion, but psychological and epistemological differences that must be carefully analyzed if contentious conflict is to be replaced by productive discourse. It’s not that disabled people have a radically different, global moral psychology from non-disabled people, but rather that they exhibit different sorts of moral concern within different spheres, one sphere being the central issues of the field of bioethics.

Disability Moral Psychology, Alienation, and Bioethics as a Zone of Distrust

Thus far, I have argued that the tensions that exist between the DM and the field of bioethics can best be explained by a difference between disabled and non-disabled people’s moral psychology, focusing on how this divergence plays out in the context of the analysis of a

particular bioethical issue. However, I have yet to offer much detail about the key features of this alternative disability moral psychology. A fully fleshed out argument for the existence of differences in moral psychology and epistemology between disabled and non-disabled people and a careful account of exactly what the differences are and how they are generated will be offered later as an entirely separate chapter of its own. However, for now, in an effort to show that such a project is warranted, I will put forward a very brief description of one key feature of these differences and an argument for how they actually produce the sort of conflict between the DM and the field of bioethics that we have observed in the last two sections.

Paul Longmore's assertion that "deaf and disabled people have been uncovering or formulating sets of alternative values derived from within the deaf and disabled experiences" that are "markedly different from, and even opposed to, non-disabled majority values" (Longmore 2003, 222) might indicate that Longmore sees the gap between disabled and non-disabled people's moral psychology and epistemology as being enormously broad as well as well as profoundly deep. Perhaps Longmore even believes that radically different life experiences produce a gap in values that is all-encompassing. In other words, Longmore may be arguing for a difference in moral psychology that is truly global, affecting every aspect of moral reasoning and perception in every context one encounters.

For my part, I do not think it is necessary for the differences between the groups to be global for there to be enduring conflict between the DM and the field of bioethics. A much more modest difference could still produce the sort of tensions I have been trying to highlight.

A core thesis of Owen Flanagan's groundbreaking book in moral psychology, *Varieties of Moral Personality*, is that current claims of a global difference in moral reasoning between groups of people are incoherent and unsupported by empirical evidence. In particular, Flanagan

takes aim at supposed gender differences in moral psychology, which he takes to be the claim that “there is not one psychological space within which all moral personality takes shape and within which it locates its regulative ideals. There are (at least) two such spaces, one for males, one for females” (Flanagan 1991, 198). These two distinct psychological spaces give rise to what Flanagan calls different “global voices,” which is a term he seems to use as shorthand for the seventeen logically distinct gendered differences in moral reasoning that “one sees sometimes in the literature but which are seldom carefully distinguished” (198). Flanagan identifies Carol Gilligan as the main proponent of the view that “there are two and only two global moral orientations” (206) that map on to gender, because of gendered differences in psychological development. However, Flanagan argues that the two-voice hypothesis cannot be understood in a way that “(1) maintains an independent coherence for each voice and (2) is inclusive enough to cover all of morality” (209). On his view, Gilligan’s description of how the two global voices develop in childhood is also much too simplistic when the full breadth of evidence is considered from the field of child developmental psychology (210-212). In sum, Flanagan argues that a portrayal of two different, gendered global voices is flawed because it attempts to squeeze the enormous complexity and variation of moral psychology into a “gross-grained picture of the bases of moral personality and an equally gross-grained picture of what these basic experiences eventuate in” (212). While I will not lay his argument out in painstaking detail here, one might summarize Flanagan’s position against gendered, global voices as, “Moral personality is, in the end, too variegated and multipurpose to be analyzable in terms of a simple two-orientation scheme – even blended together” (Ibid 233).

Taking Flanagan’s criticisms as a warning, I have no reason to believe that there are two distinct, mutually exclusive global moral voices for disabled and non-disabled people. It is

almost surely not the case that every disabled person reasons about and perceives every moral problem she encounters in a way that is radically different from the perception and reasoning of non-disabled people. In addition to the experience of disability,¹⁰ many other variables are likely to contribute to a person's moral psychology in ways that make their moral development much more complex than any two-voiced hypothesis could account for. However, I do not believe a global theory is needed to explain the tensions between the DM and the field of bioethics.

Flanagan does, ultimately, find some important, if more nuanced gender differences in moral psychology that can serve as a starting point for thinking through what a disability moral psychology might look like. In particular, he argues that there are gender differences in the patterns exhibited by the *content* of moral reasoning, and such differences produce corresponding patterns of difference in the way problems are grappled with. "There are some sex differences in the types of problems men and women choose to talk about and claim to confront. Furthermore, the type or content of a problem is a far better predictor of orientation used (on that type of problem) than is gender" (232). The argument here is that there is no global gender-based difference in moral voice; however, different problems demand different moral-psychological processes and different gendered experiences encounter different moral problems with varied frequency and so use different moral-psychological processes with varied frequency.

It then becomes likely that such patterns of lived moral experience lead to differences in the types of moral competencies that are developed just from more frequent practice deploying

¹⁰ Also, to add even more nuance to my argument and further distance it from a "two-voice hypothesis," I would add the reminder that even the experience of disability itself is not singular. Overlapping oppressions like class, race, gender, and sexual identity all have powerful effects on how one experiences the biological and social elements of her disability. Further, there are almost certainly some differences between the many types of disabilities themselves that would provide further variation to disabled people's moral psychology. For example, there will be variation between people with cognitive disabilities and physical disabilities. This is not to say that my argument only applies to some disabled people and not others, but, rather, I am trying to recognize that a nuanced moral psychology is needed to account for variation within the disability experience itself, which will produce corresponding differences even within disability moral psychology itself.

these moral skill sets. As Flanagan puts it: “Given that different kinds of problems make different sorts of considerations and salencies differently relevant, one would expect there to be some significant effects of the amount of practice one has in dealing with certain kinds of problems” (234). I suggest that Flanagan has mounted an argument for different spheres of moral experience that correspond with different spheres of moral expertise. In the same vein, I argue that there is enough difference in the lived experience of disabled and non-disabled people that they also encounter different moral problems and acquire different moral expertise.

However, while Flanagan’s argument may allow for different spheres of moral experience and expertise, it fails to adequately account for the power dynamics that determine which spheres of moral experience are open to which individuals. Of course, in effect, power dynamics that determine entry into spheres of moral experience also determine who can develop which sorts of moral expertise. Normatively, this means that certain classes of individuals operate more or less effectively in different moral spheres. I would argue that this is exactly what produces the conflict between the DM and the field of bioethics. While it is not the case that disabled and non-disabled people grapple with all moral problems in radically different ways, it seems quite possible that the field of bioethics is a sphere of moral experience that has been structured in ways that preclude the effective participation of many disabled people. This explains the alienation expressed by Longmore, Amundson, and Taira, when they attempt to enter the bioethical discourse.

To more fully flesh out this relationship between social position and moral alienation, I will turn to the work of Jamie Nelson, who argues that people who do not participate in the construction of a moral culture are often alienated by it because they are not motivated by the reasons that seem to the socially powerful to be “obviously” motivating. In her “Social Situation

of Sincerity: Austen's Emma and Lovibond's Ethical Formation," Nelson argues that the typical motivational internalist position—that moral beliefs are automatically motivating if they are truly held—is too simple because this linkage between moral belief and motivation is created through a socialization process that not everyone experiences in the same way. The reason is that agents occupy a range of positions within the social world that determines which norms are taken as motivating, as culture “enfolds us into a way of life that strives to make us as sensitive as possible to the patterns assumed by moral values and reliable responders to just what those patterns demand” (Nelson 2004, 86).

Nelson's argument is that we should not understand internalism or externalism as expressing some sort of deep metaphysical truth about how human moral psychology operates. Not everyone is equally motivated by their moral beliefs, nor are moral reasons always external to us and never themselves motivating. Rather, Nelson argues, how strongly an agent is motivated by the moral reasons on offer by a given evaluative culture can be understood as a matter of degree that is determined by the social position of the agent within that culture. Non-dominant social positions that have not had a hand in constructing the evaluative culture will often find themselves alienated within it because that culture never intended for the people occupying those positions to be full moral agents motivated by these reasons (Nelson 2004, 95). Ultimately, this means that, for Nelson, “Internalism and externalism can be seen as points on a scale that registers the relationship between an agent and the moral understandings considered authoritative in her moral-social world” (88).

Nelson isn't arguing that there are social positions that close off the possibility of moral agency entirely. Rather, she argues that, while it is logically possible to have an agent who is so comfortable in his evaluative culture that he always motivated by his belief in its moral reasons,

in the real world we occupy differing postures toward the moral reasons of our dominant culture and are only sometimes motivated to act in accordance with them (Nelson 2004, 95).

My project is to explain how and why disabled people are often alienated by the supposedly obviously motivating moral reasons offered by non-disabled physicians and ethicists who hold the dominant social position that has constructed the evaluative culture of bio-medicine as it is articulated in the field of bioethics. It is surely not the case that every disabled person is alienated in the same way when presented with a similar moral problem. There may not even be two distinct voices or moral orientations presented within the limited moral sphere of bioethics. Disabled people who engage the field of bioethics are not all in the same social position, even if they all experience disability oppression of one sort or another, and the issues and approaches found in the field of bioethics are far from homogenous. However, even a more limited two-voice hypothesis that is confined to the moral sphere of bioethics is not necessary, according to the view of the internalism/externalism divide I am borrowing from Nelson. Thinking of moral psychologies as a range of social positions¹¹ creating a spectrum of moral motivation rather than a dichotomy of two distinct moral orientations accounts for the full complexity of the disability moral psychology I am proposing for the field of bioethics. So, we can use this line of thinking to explain the pattern of alienation that has presented itself in the conflict between the DM and

¹¹ While my focus is primarily on disability as a marginalized social position that affects moral motivations and not disability as a biological phenomenon here, it should be noted that there is probably quite a bit of variation provided to this scale of moral motivation by what sort of disability a given agent has, as well as other social facts about them. It is quite likely that the social positions of people who are Deaf, have dwarfism, have quadriplegia, or have Down syndrome are all very different in morally relevant ways that contribute to variations in their moral psychology. However, this variation can be accommodated by Nelson's argument, which already assumes variation in motivation among agents according to social position. I don't think the source of the variation in social position in any way makes her argument less relevant to a given agent that has been marginalized within an evaluative culture. Admittedly, there may be some limits on how well my argument for variation in moral psychology according to disability applies to people with some sorts of intellectual disabilities. However, I will not bracket any single population as not covered by my theory because even those with the most atypical modes of functioning cognitively can express a wide range of morally relevant thoughts and emotions if an observer is careful and familiar with their communication style.

field of bioethics when engaging in bioethical deliberations premised on disparate power relationships, without relying on an overly simplistic conception of moral psychology.

To be sure, there are disabled people who feel alienated from the field of bioethics because of how power relationships affect their motivational structure. Recall that both Amundson and Taira report that the reasons they once found morally compelling lacked persuasiveness when they began to occupy a social position that was, in some ways, further from the dominant one that structures bioethical discourse. They implicitly acknowledge the moral alienation they experience as disabled people engaging the field of bioethics and explicitly forecast that their arguments may not be motivating to a non-disabled audience occupying a different social position when they write:

This special issue of the *Journal of Disability Policy Studies* is premised on the notion that disability-rights opponents of assisted suicide can find common ground with conscientious advocates of the policy. We (the authors) are not entirely convinced that this is true. The nondisabled mainstream of modern society is steeped in the notion that disability is something that happens only to others. Average people spend no more time thinking about their own future disability than they do thinking about suddenly changing into the other sex or into a different race. And so we suspect that our reports will simply be read for anthropological interest: “What life is like to the native.” Nevertheless, statistics indicate that the majority of the nondisabled readers of this article will experience serious disability at some time in their lives. If you’re lucky you will live a long time with that disability, rather than die from it. So you are us. Think of us as citizens of a county you may be moving to, rather than aliens from a world far, far away. (Amundson & Taira 2005, 53)

Notice that Amundson and Taira are not claiming that there are entirely distinct global moral voices for disabled and non-disabled people. Their claim is more modest in that they believe their social position as disabled people has changed their motivational structure when it comes to the bioethical issue of physician assisted suicide, putting them at odds with the dominant, non-disabled moral framework of bioethics in this instance. Being at odds with the dominant moral framework around the issue of assisted suicide seems to have made them *distrustful* of the dominant moral framework of bioethics that has been constructed by non-disabled people. This distrust is not limited to Amundson and Taira, but has become a hallmark of the history of tension between the disability movement and the profession of bioethics.

To describe the distrust that exists in the exchange between the DM and the profession of bioethics and work toward mitigating that distrust, we must first get clear about what we do when we ‘trust.’ I will begin my analysis of the distrust many disabled people have toward the field of bioethics by briefly considering some of the competing philosophical accounts of what constitutes trust.

Karen Jones offers a well-known definition of the concept of trust. In “Trust as an Affective Attitude,” Jones deploys a two-part definition of trust that can be understood as a truster’s: 1) attitude of optimism about another’s goodwill and competence and 2) expectation that the one trusted will be directly and favorably moved by the thought that they are being counted on by the truster. I will briefly unpack each of these two parts of Jones’s definition of trust and then evaluate how well her account of trust would explain the distrust that exists between the DM and mainstream bioethics.

First, Jones clarifies what it is the truster is optimistic about by arguing that trust is aimed at the good will *and* the competence of another because “some people have very good wills but

very little competence” (Jones 1996, 6). This is why we would trust a professional, licensed pilot to safely fly a jetliner we have purchased tickets for rather than our cousin Eddie, even if we have never met the pilot but have a very close, loving friendship with Eddie—assuming, of course, that Eddie is not a trained and experienced pilot. Centrally, the first component of Jones’s definition, the attitude of optimism, is an emotion. However, she uses a very specific conception of what an emotion is, arguing it is “constituted by patterns of salience and tendencies of interpretation [that] suggests a particular line of inquiry and makes some beliefs seem compelling and others not, on account of the way the emotion gets us to focus on a partial field of evidence” (11). Ultimately, for Jones, emotion is a cognitive phenomenon that filters our view of the world, mediating our experience. Jones argues the attitude of optimism in another’s goodwill and competence is one such emotion and this “way of seeing the other is constituted by a distinctive trusting cognitive set, which makes one’s willingness to rely on the other seem reasonable” (11).

Jones then argues that the first, affective component of her definition of trust must be supplemented by a second, cognitive component: an expectation about the motivations of the one we are trusting. Namely, any truster must hold “the expectation that the one trusted will be directly and favorably moved by the thought that someone is counting on her” (Jones 1996, 8). The argument is that for trust to exist, the one doing the trusting must believe that the person they trust is trustworthy. Jones maintains that belief is always grounded in the expectation that their relationship of reliance will do some of the work necessary to motivate the trusted person to act accordingly (8). Jones points to two ways in which relationships that almost look like trust fail to measure up because they lack this element of expectation. There can be unwelcome trust where we are not frustrated that someone is optimistic about our goodwill and competence but

rather by her *expectation* that we will be motivated by her expressed optimism. If that expectation was not a part of the trusting process, it would not be there to weigh so heavily when trust is not welcome. Secondly, there are plenty of instances in which “a reliably benevolent person's actions and motives might yet fall short of the actions and motives that we would demand of someone we trust” (9) because they might do what they believe will benefit us, regardless of what we ourselves would want them to do (or not do).

Jones’s two part definition is plenty serviceable in describing an individual disability activist or scholar that regards the profession of bioethics with distrust. Some disability activists have serious reservations about the good will of bioethicists—like Alice Mailhot who opens her *Mouth Magazine* article “Bioethics: Introduction to Theories from Hell” with “If I were listing the most dangerous people in the U.S. today, bioethicists, aka medical ethicists, would top my list - 'way above skinheads, whose beliefs they appear to share” (Mailhot 1994). While Amundson and Taira surely are not skeptical of the good will exhibited by proponents of assisted suicide when they proclaim that they are cynical toward the notion that “disability-rights opponents of assisted suicide can find common ground with conscientious advocates of the policy” (Amundson & Taira 2005, 53), they very well may be skeptical about the competency of bioethicists and advocates in acting upon their good will.

For my purposes, a serious limit of Jones’s theory is that it is so focused on the trust relationships between *individuals*. To fully describe why the DM largely holds a deep distrust toward professional bioethics, we need an account of how a *group* of people comes to distrust another group. For this, we can turn to the resources in Margaret Urban Walker’s *Moral Repair: Restructuring Moral Relations after Wrongdoing*. Walker accounts for how disparate power relationships between groups can, in effect, create distrust between those groups. We might even

consider how Walker's theory allows for Nelson's account of alienation from the dominant moral framework to explain one way in which distrust might be produced. Walker writes of "zones of default trust" as spaces in which "one believes one knows what to expect and from whom to expect it, and one knows what is normal and what is out of place" (Walker 2006, 85). Conversely, Walker argues that there will be some spaces that are hostile to default trust and, most importantly for our purposes, one's social position determines which spaces one can or can't occupy with default trust:

In settings where particular groups of people are slighted, dominated, oppressed, stigmatized, or exposed to violence on the basis of their sex, race, caste, religion, sexual practice, economic disadvantage, political beliefs, and the like, large zones of social life will not permit those people the ease of default trust that others routinely enjoy, and specific areas of social interaction may require them to be wary or extremely cautious.

(87)

Clearly, Walker's account of what distrust is seems to match up quite nicely with Nelson's account of what moral alienation is.

In fact, we might even think of distrust *as* a sort of moral alienation. For Nelson, we are alienated from the moral reasons of the dominant moral framework when our social position closes off our possibilities for acting on those reasons in a given context. Walker argues that we experience an environment of default distrust when we find ourselves in a context where we cannot rely on others to be motivated by the same sorts of moral reasons that motivate us, because we occupy a non-dominant position within that normative structure. After repeated experiences in which persons with a disability discover that "obviously motivating" moral reasons do not motivate them because of their marginalized social location in the normative

framework of biomedicine, and that the reasons they hold may appear completely absurd within that moral framework, they adopt an orientation of default distrust when they find themselves there.

I propose that this distrust resulting from moral alienation is exactly what lies at the heart of the conflict between the DM and the field of mainstream bioethics. Despite the good will of many individual, non-disabled bioethicists, many disabled people find that their moral reasoning about bioethics is dismissed by the dominant moral framework and this pattern has created a zone of distrust.

Establishing a Zone of Default Trust for Disabled People by Remodeling Bioethics

I hope I have successfully argued that there is a persistent, deeply entrenched conflict between the Disability Movement and the field of bioethics, which can be more effectively explained as a difference in moral psychology than a mere difference in ideology. While this psychological difference is not a global one that results in two distinct moral orientations or voices that approach all moral problems in radically different ways, there are some patterns of difference in the lived experiences of disabled and non-disabled people that result in variation in the frequency with which different types moral problems are encountered and this results in a corresponding variation in moral competencies. In part, this variation can be traced back to power dynamics that structure an evaluative culture in a way that marginalizes certain classes of people such that they are not motivated by the moral reasons that are taken to be “obviously motivating” by those who occupy the dominant social position that has constructed that evaluative culture. In my view, such an argument is entirely compatible with an account of moral psychology that is more nuanced than the two-voice hypothesis. Namely, I would argue

that there can be pockets of an evaluative culture that marginalize different groups in different ways. This means the claim that bioethics is morally alienating to disabled people is not equivalent to the claim that disabled people have a radically different global voice with which they approach all moral problems. My more modest assertion can be aided by Walker's description of zones of distrust, in which an evaluative culture can marginalize certain sorts of people in different moral spaces and put them on guard, without a pervasive and total moral alienation that would threaten their very agency.

I would argue that the Disability Movement is its own zone of trust in which disabled people can develop alternative moral competencies and develop their agency, yet when they engage the field of bioethics with these alternative moral competencies, they are marginalized and alienated by a moral structure that they have had no hand in creating. Thus, if we wish to defuse the conflict between the DM and the field of bioethics, the question becomes: how can the field of bioethics be remodeled to establish it as a zone of trust for disabled people rather than alienating them? I believe that this remodeling job must happen at both a conceptual and an institutional level.

As a starting point for the conceptual remodeling of the field of bioethics, I help myself to what I think is an important distinction made by Jackie Leach Scully, between the often scrutinized ethics of disability and under-theorized disability ethics. She differentiates them this way:

The ethics of disability is the systematic reflection on morally correct ways to behave toward disabled people – in everyday interactions, in healthcare or employment policy, or in law. By disability ethics, on the other hand, I refer to the particular moral understandings that are generated through the experience of impairment. (Scully 2008, 9)

One might draw this distinction as the difference between thinking *about* disability and thinking *from* disability. To be sure, a similar distinction could be drawn between a moral psychology of disability and a disability moral psychology.¹² My project aims to be a further development of both disability ethics and disability moral psychology, in that I hope to argue from the experiences of disability to contribute to understandings of moral psychology as a foundation for re-forming some key concepts in bioethics from a disabled point of view. Of course, as my positions regarding moral psychology develop, they will unavoidably be *about* disability, as well, just as Scully's arguments surely have bearing on how we ought to behave toward disabled people, despite her explicit eschewing of the ethics of disability.

I am trying to work out a more detailed conceptual basis for the development of the ethical theory called for by Scully and Longmore, both of whom have motivated this project and given me some of the tools needed for the remodeling job. In the second chapter, I will place my argument for the development of a disability moral psychology and epistemology in the context of the bioethics literature already addressing the conflict between the disability movement and field of bioethics. Developing a detailed, rigorous disability moral psychology and epistemology that has the potential to both alleviate the conflict at hand and improve bioethics will be the topic of the third chapter of this project. Namely, I will make the case that disability moral psychology provides variant moral competencies for disabled people and disability moral epistemology has produced an alternative moral knowledge within the DM. With these arguments for variation in the moral perception, reasoning, feeling, and knowledge as a foundation, I wish to map out a blueprint of the remodeled version of some of the most influential moral principles and concepts within the discipline of bioethics. So, in the fourth chapter, I will critique mainstream bioethics' dominant understanding and application of

¹² Many thanks to Hilde Lindemann for originating this analogy and suggesting I think it through.

autonomy, justice, beneficence, and nonmaleficence. By re-centering bioethics on new ways of understanding and applying these concepts, the field would make great strides toward becoming a zone of default trust for disabled people and account for the moral knowledge of the DM, which has the potential to improve bioethics because of its epistemic privilege.

Finally, if bioethics is serious about wanting to establish itself as a zone of default trust for disabled people and improve itself with their collective knowledge, it must use the conceptual revisions arising from a disability moral psychology and epistemology to make concrete reforms that foster – or at least allow for – reasoning and action that are consistent with these refashioned moral concepts. I hope to gesture toward a few such reforms in my fifth and final chapter. To become a zone of default trust for disabled people, bioethics must deploy the moral knowledge gained from a careful study of disability moral psychology and epistemology to reform its own institutions so as to open up the mainstream moral psychology and epistemology of future generations of bioethicists to include the moral knowledge of disabled people. Flanagan suggests that such social reform is quite possible for a society that wishes to deliberately improve the deeply held, but socially determined moral psychological traits of its members:

Even deep-seated, socially specific traits, however, would remain adjustable in a way certain natural traits are not. If we were to find some of our distinctive practices and our associated attitudes about their normalcy and acceptability somehow rationally indefensible, we could seek to change the practices and attitudes of future generations, even if it were very difficult to purify completely our own entrenched attitudes and dispositions. I take it that something like that is still happening in our culture with respect to racism and sexism. (Flanagan 199, 43)

To be sure, the causal story I have begun to outline about the origins of the differences between a disability and a mainstream moral psychology and epistemology in bioethics is a social one. These differences are clearly not reducible to inherent, biological differences between the psychology of disabled and non-disabled people. Rather, the structures of evaluative cultures that include some types of people and alienate others as a zone of distrust are determined by culturally contingent and, thus, revisable social power relationships. Ultimately, my aim is to fundamentally reform *non*-disabled moral psychology and epistemology within the field of bioethics.

By myself, I cannot offer a comprehensive blueprint of how the moral concepts and institutions of bioethics must be reformed to foster a future zone of default trust for disabled people engaging in bioethical discourse. A complete blueprint of exactly how ethical discourse and social power relations need to change within these institutions will have to be developed through wide-scale engagement with the disability movement. However, I will offer some suggestions about how bioethics might start such a conversation.

Why Bother Remodeling Bioethics?

Recently, several scholars have attempted to understand and address the persistent conflict between the disability movement and the field of bioethics. Two of the most notable recent attempts have been Scully's *Disability Bioethics: Moral Bodies, Moral Difference* and Oullette's *Bioethics and Disability: Toward a Disability-Conscious Bioethics*. These two books, as well as several articles by both disabled and non-disabled authors, have contributed tremendously to my understanding of the conflict and helped me develop my own positions on it. However, while many make important contributions toward resolving the conflict between the

DM and bioethics, all of them fall short in some way. Namely, none adequately develop a framework that both addresses the most fundamental source of the conflict (different moral psychologies and epistemologies) and also provides specific revisions for mainstream bioethical thought and practice that are justified by the development of these moral psychologies and epistemologies. In the next chapter, I will conduct a review of this literature that argues current attempts to address the conflict between the DM and bioethics fail to do so adequately because they: (1) characterize the conflict as merely ideological and fail to analyze the fundamental differences in moral psychology and epistemology that create and maintain the ideological differences; (2) suggest practical policy changes without sufficient systematic philosophical justification that would persuade mainstream bioethicists that such changes are morally required; or (3) only describe differences in moral psychology and epistemology as the source of conflict without offering specific practical or theoretical revisions to repair the core philosophical underpinnings of bioethics that currently neglect the insights of disability ethics and alienate disabled people. In other words, no one has yet taken up the task of outlining a full scale remodeling project for the field of bioethics.

However, one who is equally concerned with the conflict between the disability movement and field of bioethics might nevertheless object that my project is neither realistic nor necessary. This naysayer may argue that, even if there are variations between the moral psychology of disabled and non-disabled people or moral knowledge originating in the DM that needs to be accounted for, it would be a tremendous, unwarranted effort to carefully analyze these differences, revise the understanding and application of key bioethical concepts to account for these differences, and reform the institutions of biomedicine in ways that sustain these revisions over the long term. Instead, the naysayer could suggest that it would be more practical

to just engage in a “project of translation” in which non-disabled bioethicists would have disabled people provide moral data to be used in cases involving disability.¹³

In response to such an objection, I would begin by pointing out that if the naysayer admits that the conflict between the DM and bioethics is grounded in subtle but important differences between disabled and non-disabled people’s moral psychology and epistemology, then there is a serious problem here. The translation solution still implies that there will be non-disabled gate-keepers deciding when and how disability moral psychology and epistemology will be recognized as relevant to the field. Not only is the solution patronizing to the perspective of disabled people, but it is epistemically paradoxical. How will non-disabled bioethicists who are not positioned in a way that grants them access to the moral reasoning of disabled people know when they are confronted with cases “involving disability” that make the unknown moral knowledge of disabled people useful to bioethics? Relying on people who do not share in a marginalized perspective to accurately determine when to rely on that perspective hardly seems to have any chance of resolving the conflict between these groups.

In addition to its epistemic difficulties, I do not think this suggestion of merely translating moral data takes into account my arguments about alienation and trust. Above, I argue that we can use Nelson’s arguments to show how power relationships between members of the disability movement and non-disabled bioethicists have alienated disabled people from the discipline by making the moral reasons that are “obviously motivating” within the evaluative culture of bioethics ring hollow for them. Additionally, I tried to show how Walker’s definition of a zone of default distrust that is established by social power relations accurately applies to the field of bioethics for disabled people, who do not have “the ease of default trust that others routinely enjoy” (Walker 2006, 87). The marginalization of disabled people’s moral knowledge has

¹³ Again, many thanks to Hilde Lindemann for supplying me with this objection.

constructed the field of bioethics as one of the “specific areas of social interaction [that] may require them to be wary or extremely cautious” (87). In sum, both of these arguments identify a sharply disparate power relationship between disabled and non-disabled people within the field of bioethics as the fundamental source of moral conflict between disabled members of the DM and the field. Any solution to this problem that preserves this power imbalance within the field of bioethics is clearly untenable. Trying to defuse the conflict with a mere “project of translation” that maintains the power disparity between the non-disabled bioethicists who continue to think, write, and decide about cases and disabled people being used by bioethics as source of moral data would be entirely in vain. At its core, this project intends to be a roadmap for how bioethics can and should change this power relationship within the field between disabled and non-disabled people.

CHAPTER 2: IMPROVING UPON PAST ATTEMPTS AT RESOLVING THE CONFLICT

This project is not the first attempt to understand and resolve the conflict between the Disability Movement (DM) and mainstream bioethics. Multiple book length texts, as well as numerous journal articles and book chapters, have been devoted to these goals. Most of these previous attempts to grapple with this conflict have contributed in fundamental ways to both my understanding of the problem and my proposed solutions. However, I will argue that none of these attempts have both adequately explained the conflict and offered adequate theoretical and practical resolutions for it.

In this chapter, I will review the key attempts from bioethics and disability studies at explaining and reconciling the tense, often adversarial relationship between the DM and mainstream bioethics. I will highlight each of their strengths as they contribute to my project, but ultimately show how all exhibit at least one of three possible flaws that make them inadequate for dealing with this problem. Roughly, the literature fails to sufficiently deal with the conflict between the DM and bioethics because it either: (1) characterizes the conflict as merely ideological and fails to analyze the fundamental differences in moral psychology and epistemology that create and maintain the ideological differences; (2) suggests practical policy changes without sufficient systematic philosophical justification that would persuade mainstream bioethicists or the DM that such changes are morally required; or (3) only describes differences in moral psychology and epistemology that are the source of conflict without offering specific practical or theoretical revisions to repair the core philosophical underpinnings of bioethics that currently neglect the insights of disability ethics and alienate disabled people.

A project aimed at reducing or dismantling the environment of distrust within bioethics for disabled people that has caused this persistent history of conflict must avoid these flaws by accomplishing three major goals. To adequately address this conflict, it must: (1) accurately and persuasively describe the specific differences between the moral psychology and epistemology of disabled people and non-disabled people as they navigate the moral structures of bio-medicine as expressed by bioethics; (2) propose adjustments that can be made to principal moral concepts and principles that are frequently deployed in bioethics, so that they take into account the moral perception, reasoning, and knowledge produced by disabled people (which can sometimes overlap with similar moral knowledge that is produced from the experiences of other marginalized groups); and (3) suggest practical changes that can be made in policy and practice that encourage (or at least allow for) the adoption of these adjustments to widely shared moral concepts and principles by changing the social/cultural context within which both disabled and non-disabled moral psychologies (as they relate to the field of bioethics) develop. This is what I hope my more encompassing approach contributes to the discussion.

What follows is a taxonomy of sorts, identifying how key work from bioethics and disability studies makes contributions to my project, while still falling in to one or more of these three categories of flaws listed above. I will conclude each section with a brief argument for how I hope to build upon each category of this taxonomy, but avoid these flaws by incorporating the three goals also listed above into my overarching strategy.

Ideological Difference as the Source of Conflict

Perhaps the most common flaw in scholarship that is otherwise often quite sophisticated in describing the conflict between bioethics and the DM is that it stops the description at the

level of ideological analysis.¹⁴ Much very good work has been done in bioethics and disability studies that describes the conflict in terms of competing ideologies regarding the ontology of disability itself. That is, several theorists frame the fundamental tension between bioethics and the DM as a politicized struggle over whether disability is primarily a socially constructed disadvantage or primarily an inherently negative, individual biological flaw or defect. These scholars maintain that the ideological divide causing this conflict is rooted in competing commitments to the *social model* or the *medical model* of disability. Fundamentally, for these scholars it is a political disagreement over what disability *is*.

Christopher Newell falls neatly into this category when he argues in his article “Disability, Bioethics, and Rejected Knowledge” that power relationships within the field of bioethics marginalize, ignore, or reject the knowledge of disabled people. The specific knowledge being generated by disabled people that Newell argues is being rejected is “the social account of disability – an account that claims that disability is more than individual pathology” (Newell 2006, 270). With its close relationship to the practice of medicine, Newell argues that the discipline of bioethics is firmly committed to “largely uncritical use of the biomedical model” (269). Newell goes on to show how the biomedical model of disability is assumed by mainstream bioethics in its treatment of the topics of, as he puts it, genetics, euthanasia, and biotechnology. Newell argues that mainstream bioethics frames “the cultural and political understanding of the way in which disability is constituted in our society” as rejected knowledge (273).

¹⁴ In this section of my project, I am using the term “ideology” as it is used in the tradition of liberal political philosophy, rather than how it is meant in a radical or Marxist tradition. Namely, for this section, the term ideology should be taken to mean “a system of political ideas . . . ideas whose purpose is not epistemic, but political. Thus an ideology exists to confirm a certain political viewpoint, serve the interests of certain people, or to perform a functional role in relation to social, economic, political and legal institutions” (Synowich 2010). To be clear, I am making my argument from the assumption that the medical and social models of disability are not just explanations of biological or social phenomena, but systems of political ideas that serve the interests of the field of bioethics and the DM, respectively.

He believes that, despite some bioethicists' acknowledging these theoretical contributions of the DM in limited ways, "these are still seen as critiques and not as knowledge central to the discussion" (Newell 2006, 273) and are ultimately held up as an alternative view that "is always presented in such a way as to foster and reinforce dominant western, non-disabled norms" (281). As an alternative, Newell suggests that the field of bioethics has quite a bit to gain from re-thinking the DM's socially mediated definition of disability in a way that does not reject it out of hand, set it at the margins of discourse, or restrict it to "mere" philosophical reflection without having any effect on clinical and policy decisions. To do this, Newell argues that the power and politics of bioethics must be altered because by "exploring the ways in which disability is constituted within bioethics, we will perhaps find a way for the actual stories of people living with impairment – rather than the rhetoric of power brokers – to become central to the debate about cure and care" (281).

Ron Amundson has taken a similar approach to explaining the conflict between the DM and mainstream bioethics in terms of a divergence in the commitment to the social model of disability as the theoretical foundation of the DM. In his 2007 article with Sheri Tresky, "On a Bioethical Challenge to Disability Rights," he argues that the tensions between the DM and bioethics can be seen clearly in the very influential book *From Chance to Choice: Genetics and Justice*. Amundson and Tresky describe how bioethical arguments arising from the disability movement have historically been ignored by most prominent professional bioethicists, but the four authors of *From Chance to Choice* chose to engage these arguments at various points in their book with the idea that "it is perfectly possible to simultaneously endorse the civil rights of people with impairments and the prenatal policy [of prenatal diagnosis and selective abortion of impaired fetuses]" (Amundson and Tresky 2007, 542). However, Amundson and Tresky argue

that the authors of *From Chance to Choice* fail in this regard because their defense of the “prenatal policy” from its critics in the DM spirals into “a series of moral criticisms of the disability rights movement” that are much more fundamental than a mere defense of prenatal screening. Amundson and Tresky claim that Buchanan et al. judge the DM itself so harshly that it is “said not to have the same moral legitimacy as other civil rights movements” (541).

Amundson and Tresky argue that this rejection of the legitimacy of the DM is embedded in *From Chance to Choice*’s rejection of the theoretical grounds upon which the DM has been built.

Amundson and Tresky first draw a link between the paradigm of the social construction of the disadvantages caused by disability, on the one hand, with the DM’s identification with other historical and contemporary social movements, on the other. “The DR movement’s self-conscious alignment with other civil rights movements is crucial for understanding its arguments. Without it – with only the perspective of the medical model – the arguments are incoherent” (Amundson and Tresky 2007, 545). Then they point out how other social movements are grounded in strikingly similar paradigms, without being undercut by the field of bioethics: “The political ideology used to justify racism, sexism, and oppression of people with impairments is the assertion that disadvantages of these groups are not socially mediated, but are biological and innate and therefore unavoidable. . . . Disadvantages are often still assumed to be innate and the DR movement is seen to be asking for the impossible” (547). Amundson and Tresky then go on to argue how, even though Buchanan et al. seem to endorse the social model of disability at one point in their book when they explicitly examine it in chapter 7, the medical model of disability is assumed to be obviously correct throughout the rest of text.¹⁵ In fact,

¹⁵ For a more complete documentation of the specific instances in which the authors of *From Chance to Choice* uncritically accept the medical model of disability that ignores the socially mediated nature of disability disadvantage, see the companion article: Amundson, Ron and Shari Tresky. 2008. “Bioethics and Disability Rights: Conflicting Values and Perspectives.” *Bioethical Inquiry*. 5: 111-23

Amundson and Tresky argue the inevitable disadvantage of disability is even relied upon for the moral force of *From Chance to Choice*'s core thesis that using genetic technology to avoid or cure disability is morally required by a commitment to equality of opportunity because health (which they define as the absence of disease and disability) is a necessary condition for such equality of opportunity (548).

Finally, Amundson and Tresky go into quite a bit of detail to show how, when the authors of *From Chance to Choice* do choose to take a careful look at the social construction of disability disadvantage, they end up arguing that the social corrections required by a commitment to the social model would be impossible and immoral because these corrections would be unjust to non-disabled people. More specifically, Amundson and Tresky point out that that, after describing how the disadvantage of being disabled is constructed through social barriers, Buchanan et al. argue that non-disabled people have a legitimate moral interest in maintaining those barriers, which they call the "maximizing interest" (Amundson and Tresky 2007, 553-55). Amundson and Tresky again point out how these prominent bioethicists do not offer any sort of parity between the DM and other social movements, as they argue that there is no possible morally legitimate interest in maintaining other sorts of discrimination like sexism, racism, and homophobia, even if such discriminations would offer benefits to the groups doing the discriminating (553). Thus, Amundson and Tresky identify the fundamental source of conflict between the DM and bioethics as a conflict in commitments to divergent ideological explanations of disability disadvantage.

In an earlier book chapter, Amundson is even more explicit about the *ideological* character of the conflict between the DM and bioethics, which he again identifies as a struggle between the competing models of disability: "The Medical and Social Models of disability are

ideological, as explanations of social disadvantage often are” (Amundson 2005, 103). Amundson is clear that his intent in this essay is not to argue for the correctness of the social model, but to show how mainstream bioethics makes an ideological choice when it presupposes the social model’s falseness; this ideological choice serves the interest of non-disabled society – of which bioethics is a part – at the expense of disabled people. He argues that, like other explanations of disadvantage based on difference, our choice of causal story for that disadvantage is deeply ideological, such that “a causal account that depicts a social phenomenon as natural and inevitable (or changeable only at great cost) works to the advantage of the people who benefit from the phenomenon, and to harm of the people who are hurt by the phenomenon” (103). Recall how, in his essay with Tresky, Amundson argues how the prominent bioethicists who authored *From Chance to Choice* seem to fear that a full commitment to a social explanation of disability will have too high a cost for non-disabled people, who have an interest in maintaining the status quo of exclusion.

Anita Silvers has also identified the conflict between the DM and the field of bioethics as largely driven by the competing ideologies of the medical and social model of disability, offering in her article “On the Possibility and Desirability of Constructing a Neutral Conception of Disability” some conceptual tools that she hopes will dissolve this ideological dichotomy. After a brief but comprehensive and astute rehearsal of the history of the practice of grouping people with an immense variety of impairments into the single social category of “disabled,” Silvers identifies the central conflict between bioethics and the DM as one of several “disputes over the boundaries of disability and debates about characterizing the individuals these boundaries surround” (Silvers 2003, 472).

At issue for Silvers is whether the term *disability* is an “essentially contested concept” between the DM and bioethics, which would mean that the conflict over its definition would be “propelled by intractable emotional or political differences, whose resolution requires altering people’s feelings or shifting the balance of political power” (472-73). The reason is that essentially contested concepts “have underspecified definitions that permit people with different beliefs to flesh them out in different ways” (473). She hopes to show that disability is not such a concept, so that reasoned debate regarding disability policy is not precluded by the impossibility of common ground regarding what disability even *is*. Silvers hopes that, by deploying a neutral conception of disability that is not so thin that “interlocutors load the term variously with their assumptions about value with no mutual method of resolving differences,” the DM and bioethics can enter productive discourse and “talk with, rather than against, each other” (474).

To achieve this neutral concept of disability, the DM and bioethics must both relinquish “dogmatically held normative convictions about disability” (475). The dogmatic convictions that Silvers refers to are those that guide groups “in valuing disability, in modeling disability, and in adopting a cooperative framework” (475). All three of these convictions seem to be at least related to and perhaps determined by one’s commitment to either the social or medical model of disability, the competing ideologies often designated as the source of the conflict between the DM and bioethics.

Indeed, Silvers actually identifies the tension between social and medical models of disability as one of the three areas of dogmatic conviction within the DM and bioethics that need to be abandoned for fruitful discussion to ensue. Conceptualizing a neutral model of disability, she hopes, will help move discussion forward because it “disentangle[s] the limits associated with disability that are medical problems from the limitations that are social problems” (477).

Silvers has teased apart causation from value and makes a separate argument that “the conversation must take a neutral stance in regard to the intrinsic value of being disabled” (475). However, recall that a major assumption of the medical model is that the disadvantage of disability is caused by biological malfunction, which this model takes as constitutive of the concept of disability itself. Conversely, the social model assumes that the disadvantage of disability is socially constructed and there is nothing about an impairment that is inherently negative in isolation from these social conditions.

Taking up the controversy already laid out above by Amundson and Tresky, Silvers also addresses the need for a neutral cooperative social framework. She argues that such a framework should not be built so that it realizes the fears of the authors of *From Chance to Choice*, by privileging disabled people and including them completely at the expense of the non-disabled majority’s right to a scheme that maximally rewards their talents by allowing them to maximize their level of function through free competition (481). Nor should this neutral framework for social cooperation bestow on a privileged majority a maximally rewarding scheme at the expense of disabled people. Instead, it should “identify justice with the most maximally rewarding inclusive scheme, not with divisive schemes that entitle some privileged individuals to maximal benefit” (481-82). Of course, as has already been discussed, the authors of *From Chance to Choice* want to privilege the interests of non-disabled people because they assume that disability is an inherently negative trait that invariably implies some lack of competence that would diminish a cooperative scheme’s efficiency if such people were included in it. This assumed lack of competence is embedded in medical-model thinking that says that the disadvantages of disability are inherent to the individual’s physiology and not in social arrangements that have put them at a disadvantage. For the medical model, disability disadvantage and disability

incompetence are one in the same. Thus, I argue all three of the “dogmatically held normative convictions about disability” that Silvers identifies as the sources of conflict between the DM and bioethics can be reduced to competing commitments to the medical or social model of disability.

Adrienne Asch is another prominent DM scholar who has addressed the conflict between the DM and mainstream bioethics, again locating much of the source of conflict in competing models of disability. Asch states that there are “serious problems in the bioethics literature for anyone with a minority group or social model of disability” (Asch 2001, 297), which I take to mean that the major source of conflict resides in a clash of ideologies. Her chapter in the *Handbook of Disability Studies* aims to “review the major intersections of disability studies with bioethics, describing the principal issues that have sparked controversy between disability rights activists and scholars and those in traditional bioethics” (297). She begins this analysis by documenting how the DM and mainstream bioethics typically part company in their definitions of terms like health, normality, impairment, and disability; she then argues that these theoretical differences lead to corresponding practical differences in judging disabled people’s quality of life (300-301). This theme is drawn out through the rest of Asch’s chapter and is the focal point of her descriptions of clashes between the DM and mainstream bioethics over cases regarding newborns with impairments, prenatal testing and selective abortion, surrogate decision making in the withdrawal of life saving treatment, individual decision making regarding physician-assisted suicide, and health care rationing.

Asch’s discussion of these topics is nuanced and she does account for a diversity of positions and arguments within both the DM and bioethics when describing the conflict. However, ultimately, she is arguing that the conflict between these two groups is largely driven

by a difference in ideological models of disability that leads to variant quality of life judgments. To her credit, Asch acknowledges that disabled people generally judge their own quality of life to be considerably higher than most health professionals would predict (301); presumably this is true even of the majority of disabled people, who are neither activists nor scholars and may never have heard of the social or minority group models of disability. However, Asch's analysis of the conflict also emphasizes the importance of ideology as it pertains to quality-of-life judgments: "Like many in the medical professions, bioethicists are typically highly educated individuals who prize intellect, rationality, and the goal of human health. Few bioethicists identify as people who have impairments *or as members of the disability rights movement*. The values and perspectives of bioethicists profoundly influence their assessments of the quality of life of persons with disabilities and in turn influence central debates about how or whether to use such assessments to settle questions of clinical decision making or resource allocation" (301, emphasis added).

The solution Asch proposes for working toward resolution likewise lends itself to categorization as identifying the conflict between the DM and bioethics as ideological: she calls on the field of disability studies to be more flexible in its ideological commitments, pointing out that mainstream bioethics offers questions that "pose an important challenge to both the social model and the minority group model of disability and compel people to reconsider the social, moral, and policy implications of forms of human variation" (297). As this chapter appears in a disability studies textbook, it would be a mistake to read Asch as putting the primary burden on that audience for resolving this conflict. However, it is notable that her suggestion amounts to an abandonment of an attitude of ideological dogmatism toward the social model of disability. Asch calls for disability studies to continue showing how the social and minority group models

reformulate disability as more than just personal tragedy, while simultaneously taking up “the philosophical, moral, and policy implications of the difference between physiologic and non-physiologic explanations of the inability to perform certain tasks” (319). For Asch, this is only a partial concession, as she argues that reconciliation between the DM and bioethics will only be possible once the fields can occupy a theoretical space where it can be acknowledged that “no social changes will permit a blind person to take in a sunset using sight, although society can eliminate its fixation that without such experiences, life is pitiful” (319). So, ultimately, Asch is inviting both the DM and bioethics to move away from ideological, dogmatic commitments to these competing models of disability and embrace a more complex, nuanced view of disability that allows for cooperation.

All of these analyses and descriptions of the conflict between the DM and mainstream bioethics as ideologically driven are tremendously valuable to anyone who seeks to understand and resolve it. To be sure, these writers are correct in noting that the conflict between the DM and mainstream bioethics often plays out as a struggle over the nature or definition of this phenomenon called disability. The literature these writers cite clearly bears out that ideological struggle, as does a careful examination of key court cases involving bioethical decisions and disabled people. Many times, perhaps even most times, the DM comes into conflict with mainstream bioethics over divergent analyses that rest on very different definitional assumptions.

However, I would still contend that, while the conflict between the DM and mainstream bioethics is often *expressed* through the ideological divide that is documented above, it does not *originate* with that divide and cannot be resolved if we limit ourselves to this level of analysis. A more fundamental analysis of the moral psychology and epistemology of bioethics is still needed

to understand the root causes of the conflict and address them in philosophically persuasive and pragmatically effective ways.

Newell, Amundson, and Tresky all recognize, to some degree, that the social power differential between the DM and mainstream bioethics needs to be brought into greater balance for a resolution to the conflict to be reached. They argue that the ideological tension between the DM and bioethics persists so stubbornly because of the power imbalance that exists between the two fields. As summarized above, the social model of disability remains on the margins of the field of bioethics and the medical model remains as a mostly unexamined assumption of mainstream bioethical thinking because, put simply, non-disabled bioethicists are in a position of social privilege that benefits from ignoring this theoretical contribution of the DM. Newell frames this as the field of bioethics “rejecting” disabled knowledge as “merely” political and not recognizing how its own view of disability is also politically mediated (Newell 2006, 270-73). Similarly, Amundson frames mainstream bioethics’ reluctance to adopt the ideology of the social model as a matter of trying to protect the benefit non-disabled people gain from using their social power to maintain the status quo: “A causal account that depicts a social phenomenon as natural or inevitable (or changeable only at great cost) works to the advantage of people who benefit from that phenomenon” (Amundson 2005, 103).

In this way, Newell, Amundson, and Tresky gesture toward the notion that the social power of non-disabled bioethicists maintains the ideological clash between the DM and mainstream bioethics. However, they never fully cash this idea out, which leaves their analysis open to damaging criticisms. Even if they are able to show that the ideology of those with more social power outshouts that of those with less, until they clearly lay out how and why social position has a negative impact on how a person reasons about and perceives disability, there is

no good reason to think that this is a bad thing. The mere fact that social power pushes some ideologies to the side does not necessarily make those so pushed worthy of serious consideration, much less earn them a place at the center of practice and policy. For example, it does not follow from the mere fact that Christian fundamentalism is marginalized by those with social power in Saudi Arabia that Christian fundamentalism is somehow superior to Islam in explaining the universe and human experience and ought to be embraced. Thus, merely pointing out that social power plays a role in the ideological conflict between the DM and bioethics does not do the job. Instead, a rigorous argument to the effect that social power distorts the ability of its possessors to perceive and reason about the key moral concepts of disability is needed to motivate changes in that structure of social power that produces those flaws.

Silvers and Asch seem to give even less of a role to social power in explaining the conflict between the DM and mainstream bioethics. When addressing the conflict, Silvers worries, “Are disputes over the boundaries of disability, and debates characterizing the individuals these boundaries surround, beyond the reach of reason? Are they propelled by intractable emotion or political differences, whose resolution requires altering people’s feelings or shifting the balance of political power?” (Silvers 2003, 472-73). She hopes that the dispute is not at all a matter of emotion or power and attempts to develop “a neutral notion of disability, one free of passionate presumptions and politicized interests” (473) so that the DM and mainstream bioethics can enter into a productive discourse that can be settled with reason. Admittedly, the view that these matters should be decided based on who has the most valid arguments rather than who holds the biggest political stick has tremendous appeal from the DM’s perspective, as it is at the margins of politics. However, this position does not recognize how social power largely determines the framework by which the supposed validity of an argument is

judged. As I argued in the previous chapter and will continue to explain, the debate is already rigged against the DM in how the evaluative culture of mainstream bioethics has been set up according to the moral psychology and epistemology of non-disabled people. Thus, until we analyze and dismantle the ways in which social power puts disabled people at a disadvantage when they do bioethics by how it appraises their *reasons*, we cannot hope for a fair and balanced dialogue that will be settled with reason.

As mentioned above, Asch suggests that disability studies, which falls under the DM umbrella as I have defined it, can work toward the resolution of the conflict with mainstream bioethics by relinquishing its dogmatic devotion to the social model of disability. On its face, this is a very good idea for a variety of reasons, especially given the enormous breadth of political views and methods that the big tent of the DM tries to encompass. One major advantage of Asch's approach is that it implicitly accounts for the fact that the DM is not a homogenous group with a unitary point of view, which is a basic premise of my project. This diversity within diversity is not always recognized by theorists trying to dissolve the conflict at hand by focusing on distinctive ideological differences, as if the DM and mainstream bioethics were ideological monoliths. So, by suggesting the DM take a less dogmatic approach to its ideology regarding the disadvantages of disability, Asch is both suggesting a way in which disability theory can contribute to the resolution of the conflict with bioethics and a way that it can be flexible enough to capture more of the diversity present within the disability movement itself.

Of course, as I have also already noted, Asch is writing for an audience of disability scholars and not necessarily bioethicists and so it would be unfair to say that her proposal puts the responsibility for resolving the conflict solely or even primarily on the DM. However, one probably can say that her proposal does not fully recognize the role social power has in creating

and maintaining the conflict at hand by constructing the evaluative culture of bioethics in ways that will be alienating to those with a disability moral psychology and epistemology. In suggesting that the DM can resolve the conflict by simply distancing itself from its ideological origins, Asch fails to fully recognize how mainstream bioethics has created the tension between itself and the DM by largely ignoring, dismissing, misinterpreting, or otherwise marginalizing even the most nuanced disability scholarship because it did not fit with the norms of the dominant evaluative culture.

Of course, Asch is correct that addressing bioethical problems with more nuance and less dogmatism will make for better bioethical analysis from the DM, which incidentally more fully captures its own diversity. However, if her point is that the conflict with mainstream bioethics can be resolved by simply adding more nuance to the DM's analysis, she is not accounting for how the evaluative culture of mainstream bioethics will need to be fundamentally remodeled if even these more nuanced arguments are to be understood as coherent. Even if disabled people build more complexity and flexibility into their moral reasons, those reasons will still be dismissed so long as they are judged by the moral reasoning and perception of an evaluative culture that has been constructed according to non-disabled moral psychology and epistemology. If anything, disability scholars who approach bioethical issues with careful nuance and yet are *still* widely misinterpreted or summarily dismissed will be even *more* alienated and distrustful toward the field of mainstream bioethics. Instead, the conflict must be resolved primarily by restructuring the evaluative culture in such a way that it appreciates the nuance of good disability scholarship and allows for the moral reasoning, perception, and knowledge that grows out of the experiences of being disabled and participating in the DM.

Surely, the conflict between the DM and mainstream bioethics cannot be adequately addressed without these sorts of ideologically based analyses. In fact, my fourth chapter will be devoted to a detailed look at how key moral concepts and principles in bioethics must be reworked to account for the typically marginalized moral knowledge of disabled people. The most important source of this moral knowledge is the ideology of the DM, as it is expressed by disabled scholars and activists in their literature. So, these scholars are correct when they identify divergent ideology as the focal point of the struggle between the DM and bioethics.

However, these divergent ideologies did not spring up spontaneously and arbitrarily. If they did, there would be very little philosophical reason to try to address this conflict at all. Rather, it is essential to unpack the roots of these competing ideologies by considering the ways the moral psychologies and epistemologies of the members of the DM and field of bioethics diverge, with an eye toward how social power relationships have constructed such divergence. This is the foundational analysis that must first be done to ground and motivate the conceptual and practical changes that could dissolve the conflict between the DM and bioethics. An analysis of the impact of power on reasoning about and perception of disability must be central to this project and will be addressed in my third chapter.

Philosophically Unsupported Practical Solutions to the Conflict

In contrast to those who see the conflict purely as an ideological struggle, some deemphasize or even gloss over the ideological elements of the tension. They offer suggestions for practical reforms within the field of bioethics that they hope will make it more agreeable to the DM without supplying argumentation that either adequately connects their suggestions with the points of tension or sufficiently motivates either group toward resolution. As I will argue

later, some of these practical solutions are ones that would be helpful resolving the conflict, but these authors have made serious mistakes in how they have tried to justify their proposed changes in practice.

Identifying the origins of the conflict at hand in the psychological and epistemic differences that exist between the DM and mainstream bioethics is only worthwhile insofar as it provides grounds for conceptual and practical reform that will reduce or eliminate the conflict. However, theoretically unmotivated suggestions for practical reforms are equally useless. Practical suggestions will not be taken up by the field of bioethics as a solution to the conflict if they do not provide rigorous philosophical argumentation that connects the suggestions to the problems at hand. Moreover, without a clear case for how such reforms will address the specific grievances of the disability activists, they too are unlikely to find these suggestions satisfying. After all, bioethics is a field in which philosophical justification takes a central position as a nearly universal methodological standard. In the field of disability studies, rigorous argumentation is as important as in bioethics and even disability activists who don't identify as scholars and are not as concerned with systematic theory building won't be much interested in reforms that have little bearing on what they find most problematic about bioethics' treatment of disability. Suggestions for practical reform cannot be freestanding, or else they appear ungrounded and irrelevant to both bioethics and the DM. This is the major flaw in the second category in my taxonomy of attempts to address the conflict between the DM and mainstream bioethics.

For example, much of Mark Kuczewski's work on the tensions between the DM and bioethics falls under the "theoretically unmoored" category in my taxonomy. He argues that the conflict between the DM and bioethics originates in the lack of attention bioethicists have paid to

issues that are of importance to disabled people. On his view, disability activists come into conflict with bioethicists because “what attention has been given to disability has largely focused on requests to terminate potentially life-sustaining treatment or requests for assistance in dying” and “this tendency to reduce all questions to those of life and death has sometimes . . . been interpreted as advocating death over life with a disability” (Kuczewski 2001, 36). It is curious that Kuczewski correctly identifies a major point of conflict between the DM and bioethics – withdrawal of life-sustaining care and PAS – but reduces that conflict to a mere misinterpretation on the part of the DM. Far from addressing this problem in any of his suggestions for reform, Kuczewski explains that bioethicists “have had to align themselves with money and power” so that the young profession can survive and flourish and have, in consequence, paid *too much* attention to life and death issues (36). He reasons that, with so much attention being given to the niches in medicine that are well funded and powerful, subspecialties like physical and rehabilitative medicine that address the lives of disabled people have gone neglected (36).

Kuczewski proceeds to offer a series of 5 recommendations for how the field of bioethics can enter into dialogue with the DM. These include: (1) broadening the focus of bioethics to include areas other than acute care through pro-bono work in long term care, home care, and respite care so that “the disabled will benefit from the spotlight, complete with its media and policy-maker access, that bioethicists enjoy” (38); (2) developing a “casuistry of the right to healthcare and the right to community integration” (38); (3) promoting “the public’s understanding of disability in the life cycle” in a way that is similar to how recent work in bioethics has engendered “a consciousness of what death is actually like and provided thick descriptions of the context of decision making and the process of death” (40); (4) helping to “aid in the understanding and reform of research and treatment related to disability,” which he largely

defines as the development of research and treatment that is developed and supplied in “the home or community environment” (40 – 41); and (5) engaging disability studies scholarship (42).

To be fair, Kuczewski admits at the outset that he has not set out a full-fledged philosophical argument for why bioethicists should adopt his suggestions. As he puts it, “In one sense, these are conclusions that are in search of good arguments. They are rather obvious and hard to dispute. But, they are also convictions that require courage to implement” (37). The problem with this way of going about encouraging dialogue between bioethics and the DM is that, while he may believe that his suggestions for reform are “rather obvious and hard to dispute,” none of the suggestions confront the history of conflict between these two groups in a substantive way. Some of these suggestions may very well be improvements to the field, but Kuczewski has not shown why any of the suggestions would improve the field in the specific ways needed to address the tensions between bioethics and the DM. Any prescriptive suggestion for resolving the conflict between bioethics and the DM must rest on a careful descriptive analysis of the specific historical facts of that conflict or else it will, at best, defuse the long held tensions as a lucky by-product.

At worst, Kuczewski’s lack of attention to the historical details of the conflict between bioethics and the DM runs the risk of reproducing that conflict. In fact, I believe the historical tensions between bioethics and the DM are likely to surface if bioethicists attempt to implement any of his suggestions: (1) broadening the scope of bioethics to include ethical analyses of long term care, home care, and respite care could be just as fraught as bioethics’ analysis of acute care if non-disabled bioethicists remain oblivious to the mistakes in their assumptions regarding the quality of life of disabled people; (2) the aforementioned tension between the most prominent

justifications for a right to healthcare and the most prominent justifications for a right to community integration may be unavoidable¹⁶; (3) many disabled people are likely to be quite skeptical of any thick descriptions of life with a disability offered by non-disabled bioethicists, when such descriptions are already freely available in the form of detailed memoirs by actual disabled people¹⁷; (4) just as broadening the scope of bioethics would reproduce tensions if some of the fundamental assumptions of mainstream bioethics remain intact, any reform to research and treatment “related to disability” that does not address these fundamental assumptions will simply reproduce the old conflict; and (5) merely reading disability studies scholarship will only extend the conflict between bioethics and the DM if the more fundamental tensions between mainstream bioethics and the DM remain unexamined.

Thus, Kuczewski provides little justification for either side of the conflict to support the adoption of the reforms he outlines with any degree of confidence that they will defuse the long standing tensions. While some of his practical ideas would be welcomed by many members of the DM, Kuczewski does not provide much of an argument for why they would remedy the very specific tensions between the DM and mainstream bioethics. So, these reforms may be nice things for the field of bioethics to do, but there is no reason to think that they will directly lead to a decrease in hostility between bioethics and the DM. It is curious that, while he calls for bioethics to engage the disability studies literature, he does not address any of the many criticisms that literature has leveled toward bioethics, with the exception of a vague statement that “the disability literature documents an animosity toward the medical establishment. This

¹⁶ See Amundson, Ron and Shari Tresky. 2008. “Bioethics and Disability Rights: Conflicting Values and Perspectives.” *Bioethical Inquiry*. 5: 111-123 and 2007. “On a Bioethical Challenge to Disability Rights.” *Journal of Medicine and Philosophy*. 32: 541-561

¹⁷ For a thoughtful, nuanced review of some of the most important of these memoirs and how they are morally significant to the field of bioethics, see chapter 6 “Narratives of Disability: Models and Mentors” in Scully, Jackie Leach. 2008. *Disability Bioethics: Moral Bodies, Moral Difference*. New York, NY: Rowman & Littlefield Publishers.

tension is between the agenda of researchers and providers and the disabled. However, bioethicists are positioned to see that this tension is not the product of a conspiracy of medical professionals but simply a by-product of the way medicine and research are organized” (41). Kuczewski will hardly make progress in resolving the tensions between the DM and mainstream bioethics by implying that disability scholars and activists chalk up their grievances to “a conspiracy of medical professionals” and then offering suggestions that not only ignore these grievances but also lack any theoretical support that connects the reforms to the problem areas. His freestanding practical suggestions, then, are not enough to resolve the historical conflict between bioethics and the DM.

It would be unfair to dismiss the solutions offered by Alicia Oulette’s book *Bioethics and Disability: Toward a Disability Conscious Bioethics* as entirely unacquainted with and disconnected from the major points of conflict between mainstream bioethics and the DM. After all, of its eight chapters, numbers three through seven are devoted to detailed case studies of the “points of tension” she has identified between disability and bioethics experts. She calls for a process of reconciliation and hopes that by presenting the perspectives of these competing groups regarding these cases, she can “start the process on paper” and “provide enough information to allow the reader to ‘listen’ and explore what one group might learn from the other” (Oulette 2011, 71). Oulette supplements her case studies with analyses from both mainstream bioethics and the DM, hoping that because they “reveal a great deal about the fears, alliances, and values at play in these debates, as well as several important points of consensus,” these analyses will provide the “raw materials for a disability conscious bioethics” (71).

Prior to her presentation of the ethical cases across the human life cycle and corresponding differences in how mainstream bioethics and the DM interpret them, Oulette

devotes two book chapters to describing a sort of intellectual history of the groups that highlights where they have converged and digressed in their overarching ideologies, so that the divergent analyses of the cases she reviews can be placed in context (Oullette 2011, 1-71). After her cases studies, Oullette argues that if mainstream bioethics and the DM are to stop talking past each other and allow “bioethicists to make the knowledge gleaned by disability experts about the experience of disability central to their work” (316), they should engage in the process of reconciliation, which she says “generally involves bringing parties together to explore and acknowledge the sources of fear and anger behind a conflict, acknowledge and apologize for past wrongs, and build bridges of trust between former adversaries” (317). Oullette prescribes three steps: “listening closely to develop a clear understanding of opposing points of view; acknowledging fears, alliances, and values; and working to identify points of agreement on which a preliminary framework for collaboration can be developed” (318).

However, even when deploying a case-based approach that has been placed within a historical account of the intellectual development of each group, Oullette fails to adequately link her proposed solutions to the points of friction and show how her solutions will dissolve this conflict. In this sense, her solutions remain philosophically freestanding.

Oullette’s two main justifications for why bioethicists ought to be motivated to move toward reconciliation with the DM are that: (1) disabled people can “provide deep knowledge of the meaning of disability in society . . . important data that is directly relevant to bioethical inquiry” and (2) reconciliation will allow bioethicists to “operate from positions of trust in discussions of equity and justice issues surrounding resource allocation and health reform . . . [and] diffuse the distrust of the medical system at the heart of so many bioethical cases” (Oullette 2011, 69).

Oullette argues that the goal of good medical decision making is undermined by “indifference to or ignorance about the contributions of disability scholars to the body of knowledge relevant to good patient care” (Oullette 2011, 315). She states that avoiding this indifference or ignorance “will require bioethicists to make the knowledge gleaned by disability experts about the experience of disability central to their work – a project that will invite the development of mutually beneficial relationships between bioethicists and disability experts” (316).

Recall, in the first chapter, how I considered an objection to my project: a full-scale remodeling of bioethics might be unrealistic and unnecessary. All that is needed is a “project of translation” in which non-disabled bioethicists would have disabled people provide moral data to be used in cases involving disability. The way Oullette frames the first justification for reconciliation sounds suspiciously similar to my hypothetical objector. By arguing that the conflict between bioethics and the DM can be reconciled if bioethics uses “the knowledge gleaned by disability experts about the experience of disability” (Oullette 2011, 316), Oullette seems to be arguing for something well short of the full-scale remodeling necessary if the field is to be grounded in an alternative disability moral psychology and epistemology.

As I read Oullette’s justification for reconciliation, it is vulnerable to the same critique leveled against the objector in chapter 1. If all she is talking about is a project of translation in which the field of bioethics uses “knowledge gleaned by disability experts about the experience of disability” (Oullette 2011, 316), then she is still implying that there will be non-disabled gatekeepers deciding when and how the moral knowledge of disabled people will be recognized as relevant to the field. I remain convinced that this position is epistemically paradoxical. How will non-disabled bioethicists who are not positioned in a way that grants them access to the moral

knowledge of disabled people know when they are confronted with cases involving the experience of disability that make the moral knowledge of Oullette's "disability experts" useful to bioethics? Depending on people who do not share in a marginalized perspective to accurately determine when to rely on that perspective hardly seems to have any chance of resolving the conflict between these groups. Far from motivating reconciliation, such an approach will reproduce the conflict between bioethics and the DM.

Oullette also justifies her appeal for reconciliation by claiming that it builds greater trust. After stating that "working with disability experts can be a challenge" (Oullette 2011, 69), Oullette quotes a blog post that is skeptical of what the blogger sees as a pattern of attempted appeasement toward the DM that does little to change the power imbalance that preserves the public policy status quo. "The reality is the 'discourse' around bioethics is more than just an exchange of philosophies, ideas, and experiences. At the core, this is a political struggle over public policy – a struggle between those who have power and seek to hold onto it and those directly affected by the policies who want to take power" (70). Oullette acknowledges that the distrust felt by the DM toward the field of bioethics is "deeply rooted and well founded": isolation and marginalization has resulted in activists having "to shout to be heard" (70).

Curiously, after stating that disabled scholars and activists can be a challenge to work with because of their distrust of bioethics from their history of marginalization, Oullette immediately abandons any discussion of how distrust is caused by an imbalance of power and focuses instead on how distrust has a negative impact on clinical interactions in general. In fact, Oullette tries to justify her desire for reconciliation between bioethics and the DM with an argument that highlights how trust is important to the clinical relationship between a physician and patient:

In my view, it is in the interest of bioethics to earn the trust of disability experts – including the new activists – and cultivate trust between the disability community and the medical community more generally. Lack of trust erodes the doctor-patient relationship, the ability to develop sound policies regarding the provision of health care, and can harm individual patients and their family who make fear based decisions. Trust is an essential component of the doctor-patient relationship, especially in this era of evidence based medicine. . . . Defensive decision making by a patient or family will likely generate more requests that ‘everything be done,’ even when professional judgment of the treating team is that treatment should not be continued. To the extent bioethics is concerned with overtreatment and its negative consequences (the bad death, suffering, waste of resources), bioethics has a role to play – and work to do – to create an environment of trust and collaboration with the disability community. (Oullette 2011, 70-71)

So, Oullette’s trust-based argument that purports to justify her suggestions for reconciliation with the disability community ends up having very little to do with establishing an environment of trust between the mainstream bioethics and the DM. Instead, it frames the DM as composed not by activists and scholars, but by potentially non-compliant patients or persons who have influence over such patients. Oullette’s trust-based argument does not encourage mainstream bioethicists to reconcile with the DM in order to examine how their interpretations of core moral values and principles have been effected by inequalities of power, but to facilitate better patient compliance.

Of course, Oullette is correct that dissolving the conflict between mainstream bioethics and the DM ought to be justified by a desire to incorporate the moral perceptions and knowledge of disabled people and build an environment of trust within the discipline that allows for such a

collaboration. However, the specific arguments that attempt to link these justifications with her practical suggestions regarding reconciliation seem to be counterproductive to the process of reconciliation. Neither justification takes up the role that power plays in producing and maintaining the conflict between bioethics and the DM. As I argued in the previous chapter, the skewed power relationship between mainstream bioethics and the DM must be addressed if the normative culture of bioethics is to become receptive to the moral perceptions and knowledge of the DM in an environment of trust. Insofar as Oullette's two main justifications for the practical process of reconciliation fail to actually justify her suggestions and instead reproduce the conflict, her suggestions remain philosophically freestanding and unjustified. But without adequate justification, mainstream bioethics and the DM are unlikely to take up her suggestions.

For my project to be at all worthwhile, the abstract arguments that showing the differences between disabled and non-disabled moral psychology and epistemology as they pertain to bioethics must ground specific suggestions for modifications in both the theory and practice of bioethics. Without changes in theory and practice, mainstream bioethics would continue on as a morally alienating environment of default distrust for most disabled people. However, changes like those that will be necessary to establish bioethics as a zone of default trust for disabled people will be difficult and require those with power to relinquish some of it. This means that there is a need to offer very specific, very compelling reasons for why these changes are necessary and how they will diminish or demolish the conflict. In my view, these reasons must be grounded in a careful analysis of how the differences between disabled and non-disabled moral psychology and epistemology have established mainstream bioethics as a morally alienating environment of default distrust for disabled people in such a way that the conflict is produced and maintained.

Theoretical Explanations sans Practical Solutions

Writing that offers detailed descriptions of how differences in moral psychology and epistemology create and maintain the conflict between mainstream bioethics and the DM, but does not offer much in the way of specific theoretical or practical solutions to remediate the conflict, constitutes the third and final category of my taxonomy. The best example of this sort of work is Jackie Leach Scully's book *Disability Bioethics: Moral Bodies, Moral Difference*.

To be sure, Scully's book breaks new ground and makes an enormous contribution to understanding the source conflict of between mainstream bioethics and the DM. Many of her insights will be critical for the arguments I make later in this project. However, Scully's text only gestures toward some of the specific theoretical and practical changes that could be made by bioethics to gain new insight into disability and impairment. She does not fully cash out the implications of her arguments for bioethics taking up disability moral psychology and epistemology and show exactly what this would mean for how bioethics is done with the sort of breadth and depth that would be called for by her book. In some sense, this section of my taxonomy will be an argument for expansion upon and extension of Scully's case for a disability moral psychology and epistemology to show what it would mean in practice, something I will attempt to do in chapters four and five. For now, I will briefly summarize Scully's main arguments for a bioethics that engages disability and impairment in a fuller sense, cover the suggestions for reform that follow from these arguments that she does make, and argue that a full-fledged disability moral psychology and epistemology would call for even further changes in theory and practice to bioethics than what Scully suggests.

Scully does not consistently use the language of moral psychology and epistemology as I have in this project, but the core of our arguments both revolve around the notion that “to claim that bioethical analysis would benefit from greater input from experiences of impairment and disability implies that there is something about those experiences that might make a difference to moral evaluation. It suggests that the experience of phenotypic variation can modify moral understandings, in obvious and more subtle ways” (Scully 2008, 154). Scully’s book outlines several mechanisms¹⁸ that may produce this sort of difference in moral understanding and evaluation in disabled people, which include: “prediscursive, presocial somatic experience, the embodied interaction of the self and the social world, and the development of personal identity and political identification” (154-55). Scully argues that these mechanisms produce differences that ought to hold normative force and change how bioethics is done because such “additional epistemic resources” could “provide a more complete, accurate, and insightful description of morally troubling situations” and, more radically, provide “a different picture, from a different place, for the exercise of normative analysis” (156). In addition to “refining bioethics’ normative function,” Scully makes the case that paying careful attention to the moral perspectives of disabled people might also, “(1) enlarge our understanding of foundational moral concepts, (2) affirm the role of bodies in moral life, (3) contribute to theorizing the ontological and moral meaning of disability, and (4) assert respect for moral subjectivity” (160).

In my view, Scully’s important book has not yet done enough to explicate exactly what mainstream bioethics must do to make space for her alternative perspective, both conceptually and practically. Indeed, if it is to account for the moral knowledge of disabled people, mainstream bioethics needs guidance with more breadth and depth than what is currently on offer in Scully’s book. This is not to say that one cannot glean at least some practical guidance

¹⁸ Some of which I will draw from later in this project.

from Scully. In fact, all four of the ways in which she believes moral knowledge of disabled people can contribute to bioethics can also be read as changes that could be made by mainstream bioethics to become more receptive to that moral knowledge.

Of these, I believe the first holds the most potential for bringing the moral knowledge of disabled people into mainstream bioethics. To show disability bioethics' potential to contribute moral knowledge to mainstream bioethics, Scully carefully examines how the lived experience of disability might contribute to the unraveling and reconstruction of the traditional conception of autonomy, which she rightly takes to be a key moral notion for bioethics. I will examine her argument, along with others, more closely in my fourth chapter. For now, I will merely point out that the moral perspective of disabled people is likely to reformulate the application of many other important bioethical concepts as well, such as justice, beneficence, non-maleficence, and care, some of which I will address later. Further, these conceptual changes ought not to be understood only as contributions of disabled people *to* bioethics, but rather necessary conditions for the full participation of disabled people *in* bioethics. Establishing and maintaining these conceptual changes should be a major focal point in creating a zone of default trust for disabled people so they are not morally alienated from the discipline, as I began to argue in chapter one. Such conceptual shifts will allow disabled people to more fully and rigorously develop their moral understandings within the scholarly community and to move more freely through the moral space of the discipline.

Scully carefully attends directly and indirectly to the effects of social power on the formulation of moral knowledge throughout her book. She offers detailed theoretical accounts of how this happens. However, she does not offer much in the way of specific suggestions for how social power can be reassessed and rearranged within the field of bioethics so that the moral

perspectives of disabled people aren't continually marginalized. Pointing out how social power structures produce alternative moral reasoning and perception is an important step in the development of disability bioethics that cannot be overstated. Beyond this though, it remains necessary to understand and change the conditions produced by social power structures that lead to the marginalization of these alternative ways of morally reasoning and perceiving. Only concrete practical changes will allow disability bioethics to truly flourish and improve the field as a whole.

In my fifth chapter, I will make some suggestions for these sorts of practical reforms that will allow disability bioethics to progress. Specifically, I will argue for more empirical research regarding the specific areas of distrust felt by disabled people engaging biomedicine so that disability bioethics can target specific, problematic areas of moral conflict that go beyond the hot-button bioethics cases that get the attention of disability activists and bioethicists (physician assisted suicide and euthanasia, selective abortion, the Ashley X treatment, and the like). Additionally, more disabled people must become full-fledged members of field. To do this, the dichotomy between "bioethicists" and "disability activists" must be dissolved with the improvements in accessibility offered by reasonable accommodations and universal design, as well as affirmative action programs designed to recruit and formally train disabled people in bioethics. As for content, bioethics should devote much more attention to the analysis of the moral and political issues prioritized by the disability movement, such as forced institutionalization and the resulting social isolation. Finally, another concrete change I will suggest is for the basic history, culture, and theory of the disability movement to be included in the ethics curriculum taught to students in the medical professions and medical humanities.

I believe that these conceptual and concrete changes to the profession are not at all at odds with the theoretical explanations that have been developed by Scully but, in fact, follow from them. My criticism of her work at this point in my taxonomy is only that she did not formulate these or other changes that the discipline must make to allow for the full development of the moral knowledge of disabled people that she insists would be an important contribution to the field. One cannot assume that the potential contributions of disabled people will get uptake in the field as it is currently structured or that these contributions will be developed to their fullest potential by a group that is largely morally alienated by that structure. Finally, since, as Scully argues, bioethics has yet to account for the moral perspective of life with a disability, it is also unsafe to assume that bioethics will see the need for these sorts of theoretical and practical reforms by itself.

An Attempt at a More Comprehensive Approach

I hope it is clear from the above taxonomy that I am not trying to diminish or denounce the previous scholarship that has attempted to address the conflict between mainstream bioethics and the DM. Rather, I am hoping to take my cue from this work and find ways to supplement and extend it. That is, I hope my approach is more comprehensive in that it will both adequately explain the origins of the conflict in differences in moral psychology and epistemology and begin the process of outlining the kinds of conceptual and practical reforms that will be necessary to dissolve the conflict. In part, the explanation of the causes of the conflict will serve as justification for the suggested remedies. The next chapter will further develop the theoretical foundations of the differences between the moral psychology and epistemology of disabled people and non-disabled people as they navigate the moral structures of bio-medicine as

expressed by bioethics. This explanation of the cause of the conflict between mainstream bioethics and the DM will, with any luck, persuade those in the field that they are justified in seriously considering the corrections I propose in the fourth chapter for some of the principal moral concepts and principles that are frequently deployed in bioethics. Finally, I hope to build on all of this with suggestions for concrete, practical changes that can be made in policy and practice within the field of bioethics so that it allows for the adoption of these conceptual adjustments by changing the social/cultural context within which both disabled and non-disabled moral psychologies (as they relate to the field of bio-medicine) develop.

CHAPTER 3: TOWARD A DISABILITY MORAL PSYCHOLOGY AND EPISTEMOLOGY

Thus far, in my first two chapters, I have offered preliminary arguments for why the field of bioethics needs to take account of disability moral psychology and epistemology if the decades long conflict between the discipline and the disability movement is to be replaced by cooperation and dialogue. This chapter aims to give a more detailed account of how the differences in moral perception, reasoning, and feeling between disabled and non-disabled people are likely generated in individuals, and why they result in alternative moral social knowledge that has some degree of epistemic privilege.

I will begin by reminding my readers that I have adopted Flanagan's nuanced view of moral personality that leaves plenty of room for the existence of differences between how disabled and non-disabled people reason about morality, without relying on an overly-simple "two-voice hypothesis" that misrepresents these groups as unitary monoliths. I will point out how Flanagan's argument calls for variation in self concept that can produce an infinite array of corresponding variations in moral perception, feeling, action, and so on. Flanagan argues these variations can roughly map on to gender (and presumably other social differences like disability) because differences in how lived experience is structured according to social identity can produce differences in the sorts of problems people encounter and think of as prototypically moral. Thus, people with different social identities develop different degrees of skill at being able to perceive various sorts of problems as moral ones and deploy the salient moral considerations appropriately.

Next, I will make the case that differences in the experience of disabled people specifically produce these sorts of variations without creating global moral gestalt shifts.

Specifically, I will explore evidence provided by Jackie Leach Scully's *Disability Bioethics* to show how the experience of disability is influential as a variant in the development of self concept and moral point of view because it mediates many of a disabled person's experiences and produces different social practices and forms of embodied cognition. Specifically, I will argue that experiencing life with a disability has the potential to change how disabled people think about the world and their position in it by drawing from Scully's thought about how a disabled person's identity and moral point of view is shaped by the interactions of her body with the social world. Flanagan and Scully both contribute to my argument for how disabled people develop variations in moral perception and reasoning based on variation in their lived experience.

Of course, moral reasoning and perception aren't the only pertinent elements of moral knowledge. The next step in this chapter's argument will explore how differences in moral feelings can also be generated by this variation in the identity formation and types of moral situations encountered by disabled and non-disabled people. I argue that, regardless of the specific role of emotion in moral cognition—which is a hotly contested topic--differences in moral emotion almost surely would have *some* sort of impact on moral experience. If the mechanisms described by Flanagan and Scully have a bearing on moral emotion, in addition to perception and reasoning, then there is likely to be relevant variation in the moral emotion of disabled people as well.

Finally, I will argue that these variations in moral perception, reasoning, and feeling generated by differences in lived experience collectively result in differences in social moral knowledge. This alternative moral knowledge of the disability movement might even be framed as a disabled standpoint epistemology. Here, I will draw on Mary Mahowald's argument

outlining the possible development of a disabled standpoint epistemology in *Disability, Difference, and Discrimination*, where she argues that the knowledges of disabled people regarding the moral saliences of life with a disability ought to be privileged by non-disabled people who hold a dominant social position. I will then bring further nuance and clarity to Mahowald's normative argument for why the moral knowledges of disabled people ought to be regarded as important by developing an argument for how it is participation in the DM raises the consciousness of disabled people to their own subordination, giving them a measure of epistemic privilege as described in the feminist Marxist tradition. Here, my argument will be that the epistemic privilege that grants authority to the moral knowledge of the DM is derived not only from its members developing variant moral psychologies from their lived experience of disability, but from their consciousness being raised via political activity around the disability identity. This normative argument for epistemic authority of the DM will then be supplemented by Kathryn Pyne Addelson's descriptive argument for how these variant moral knowledges are constructed in the first place through the collective political action of *social worlds*.

I will conclude this chapter by responding to two distinct but related objections: my disability moral psychology and epistemology is either a step toward nihilism or a reproduction of the sort of falsely unitary moral theory I have been trying to unhinge. I hope to respond to these criticisms with a clarification of my overall goal for this project that will also chart a path forward.

A General Account of Variations in Moral Personality

In the first chapter, I briefly touched upon Owen Flanagan's classic work in moral psychology, *Varieties of Moral Personality: Ethics and Psychological Realism*, as I argued that

an alternative disability moral psychology and epistemology need not rely on a naïve or rudimentary view of moral psychology. Here, I will revisit these arguments in order to set the stage for a more complete analysis of the subtle differences in how many disabled people reason about and perceive moral problems in the bioethical arena.

Flanagan's main goal in writing his book is to examine how moral theories can be constructed in such a way that they account for what he refers to as the Principle of Minimal Psychological Realism (PMPR). He defines the PMPR as: "Make sure when constructing a moral theory or projecting a moral ideal that the character, decision processing, and behavior prescribed are possible, or are perceived as possible, for creatures like us" (Flanagan 1991, 32). He seems to be arguing that accounting for the PMPR is necessary, but not sufficient for the construction of an acceptable moral theory because "vastly many more kinds of moral personality are realizable than are good" (32).

Indeed, this is the case for Flanagan because of his Thesis of the Multiple Realizability of Moral Psychologies (TMR), which claims "vastly many more kinds of moral personality are realizable than have been realized up to now" (Flanagan 1991, 32). He even goes as far to call the range of possible moral personalities "infinitely large" (32). For Flanagan, this claim is grounded in the idea that moral personalities "are largely dependent on particular social, economic, and institutional arrangements" which have not yet been "remotely exhausted" (32). Flanagan's position that the counterfactual possibilities for moral personalities are infinitely large because the counterfactual possibilities for social, economic, and institutional arrangements are infinitely large reveals just how much bearing he believes a being's socialization has on the development of their moral capacities. Arguing that having been socialized in a specific way determines a person's moral personality is not the same as saying a human being's moral

personality is completely malleable once it has actually been developed. As Flanagan puts it, “the moral psychology of a Kalahari Bushman would be very hard, perhaps impossible, for me to realize. But this is only because I have been socialized into a radically different life form, not because of some intrinsic psychological limitation” (38). So, for Flanagan, moral personalities can be rigid once they are developed, but their development can be taken in a myriad of directions through variation in the socialization process.

Further, the Thesis of the Multiple Realizability of Moral Psychologies (TMR) is possible because of a lack of a specific, content thick “deep structure” to moral personality that outlines “certain universal features which include just a small set of determinate forms, as well as a certain developmental direction—a certain natural teleology” (Flanagan 1991, 161). Flanagan considers the well-known theories of Jean Piaget and Lawrence Kohlberg, who both make empirical claims to have discovered such universal features of a deep structure to moral personality. He concludes that any deep structure or universal features of moral personality are minimal and do not go much beyond “universal human capacities to desire and believe” (161). The claims made by Piaget and Kohlberg “that moral personality can take only the shapes described by the theory, looks, when set against the multifarious array of actual human lives, to be simply false” (162).

Of course, Flanagan goes into much greater detail in his criticism of Piaget and Kohlberg’s empirical claims. I don’t have the space here to lay out Flanagan’s full range of evidence and arguments that call the validity of these empirical claims into question. However, Flanagan’s strongest argument against the dominant descriptions of a deep structure to moral personality also seems to unhinge any *possibility* of describing such a deep structure. Flanagan argues that any investigation into the features of a deep structure of moral personality would be

biased by the subjectivity of the researcher herself. Any such supposedly exhaustive description of the range of possibilities for moral psychology would be premised on a certain conception of the nature and scope of morality that is held by the researcher. Thus, Flanagan's deepest criticism of Piaget and Kohlberg would likely unravel any such attempt: "It is inconceivable that a psychologist interested in studying moral psychology could start with a completely neutral and uncontentious conception of the moral domain, or without privileging some kinds of moral issues or competencies over others, even if only in the first instance for methodological reasons or for motives having to do with his or her particular, possibly idiosyncratic interests" (Flanagan 1991, 168). Flanagan is arguing that any content-thick description of the deep structure of human moral psychology would be built on very particular and perhaps parochial assumptions about morality that are held by the researcher who has developed the theory he is trying to verify empirically. The subjectively held moral beliefs and experiences of the researcher would inevitably have an influence on which features of her research subjects' moral psychology she chooses to include in her description of the deep structure.

Without being able to identify any deep structure to human moral personality, it seems that Flanagan's TMR calls for variation across moral personality that is not just determined by variations in broad forms of life across societies and cultures, but also by variations of individuals' experiences of a particular society or culture. If the TMR is infinitely massive because persons are morally socialized within the context of social, economic, and institutional arrangements which can vary infinitely, it would seem that the possibilities for moral personality would be even further enlarged by variations in how individuals are socialized within this context. Perhaps it would be logically possible for a society or culture to be so homogeneous that there was little or no variation among the moral personalities of individuals socialized within

those particular social, economic, and institutional arrangements. However, it doesn't seem that any such uniform society has ever actually existed or ever will outside the pages of an Aldus Huxley novel. So, it can be understood that, in a heterogeneous society such as ours, we can expect to find tremendous variation across individuals in moral personality.

So, if a lack of any substantive deep structure within human moral psychology leads to infinite possibilities for moral personality, the next question becomes: how much does social identity matter to this variation in moral psychology or, better yet, are there any patterns of variation among individual's moral psychology that correspond to variation in social identity? For my project to be viable, there does not need to be some sort of deep structure within moral psychology. In fact, such a deep structure, if it were universal among human beings, would pose a serious challenge to my explanation for the long standing conflict between the DM and mainstream bioethics. However, if moral psychology is going to contribute to an explanation of the conflict, it can't be that this variation in moral personality only exists among either entire cultures or among random patterns of individuals within a culture. Indeed, there must be some sort of difference among social *groups* located within the same social structure if my project is to be fruitful.

In chapter one, recall my sketch of Flanagan's argument against different gendered moral global voices as being too simplistic an account of moral psychology. In effect, Flanagan's argument against the two-voice hypothesis draws on reasoning that is quite similar to his case against any sort of deep structure for moral psychology in general. His argument against a deep structure seems to extend into his argument against the two voice hypothesis in that he thinks both are attempts to oversimplify the myriad of ways in which human beings reason about moral problems.

However, also recall from chapter one how Flanagan suggests that there are alternatives to a two-voice hypothesis to explain how social identity can and does sometimes have an effect on moral psychology. Flanagan contends the content of a moral problem determines more about how a person approaches it than any sort of facts about that person's social identity. However, Flanagan also observes that "there are some sex differences in the types of problems men and women choose to talk about and claim to confront" (Flanagan 1991, 232) because of how differently their lived experience can be structured by gender roles. Further, this gendered difference is not limited to language, but also includes practical skill. Flanagan hypothesizes that men and women encounter different sorts of moral problems in their daily lives because of how gender encourages some morally relevant experiences but inhibits others. This difference in the frequency in which certain sorts of problems are encountered leads to different proficiencies with various kinds of moral problems that roughly map on to gender (234). So, for Flanagan, it is not that there are moral concepts that women use that are altogether alien to men or vice versa. Rather, while it may be that "almost everyone both knows and can represent almost every sort of consideration that has some claim to [moral] relevancy," it is the case that "different problems make different sorts of considerations and salencies differently relevant" so as gendered moral habits develop, there can be differences in how adept men or women are at perceiving a problem as moral and then reconciling it once it is perceived as such (234).

If a human being's habits create different proficiencies in her moral perception and reasoning and these habits are sometimes determined by the experiences open to her by her social identity, it doesn't seem that there would be any reason to limit this line of thought to gender identity. In as far as any social identity structures a human being's lived experience, it should likewise structure their moral experience and the proficiencies they develop through the

habits developed when encountering a given sort of moral problem. Disability, in as far as it mediates a person's lived experience as a social identity and form of embodiment, should have this same sort of impact.

In my next section, I will consider evidence for how disability specifically might have such an impact without producing the entirely separate *second global voice* that Flanagan has argued against. Specifically, Scully's *Disability Bioethics* makes the argument for just such a nuanced view that allows for limited differences in moral reasoning and perception based on the ways in which disability effects the interactions of the body with the physical and social world.

Sources of Variation in Disability Moral Psychology

In Jackie Leach Scully's *Disability Bioethics: Moral Bodies, Moral Difference*, she suggests ways in which the lived experience of disability can create variation in how disabled people perceive and analyze moral problems. While Scully does not focus on repetition in problem solving for developing particular moral skills, the causes for variation she describes aren't necessarily at odds with Flanagan's thesis and certainly do not inevitably lead to the two-voice hypothesis Flanagan rejects. Indeed, Scully's arguments leave plenty of room for nuance and do not rely on a crude view of moral personality that attempts to force all moral psychology into rigid, distinct global moral voices. In addition to accurately representing human psychology, another benefit of Scully's view that eschews a global voice is that it allows for moral variation and nuance within the DM itself, rather than portraying it as a homogenous group of people with a singular set of moral and political views.

Central to Scully's work is the distinction she makes between the often scrutinized ethics of disability and under-theorized disability ethics. She distinguishes between the two this way:

“The ethics of disability is the systematic reflection on morally correct ways to behave toward disabled people – in everyday interactions, in healthcare or employment policy, or in law. By disability ethics, on the other hand, I refer to the particular moral understandings that are generated through the experience of impairment” (Scully 2008, 9). Scully believes that, when it does address disability, mainstream bioethics has almost exclusively concerned itself with the ethics of disability and has given little if any consideration to disability ethics. Her book is aimed at clarifying and extending the latter. Of course, implicit to her project is the basic notion that the experience of disability matters to how a person perceives and reasons about certain moral problems. While Scully does not rely on the language of moral psychology to make her arguments, her book can and should be read as an explanation of some of the ways in which disabled people develop variant moral psychologies through their lived experience.

Of course, I do not have space here to relate Scully’s entire argument unfolding the origins of disability ethics in the lived experience of disabled people.¹⁹ However, I will attempt to adequately summarize one of her key lines of thought that will be especially useful to moving my own arguments forward. Specifically, Scully shows how variation in biological function can lead to variation in moral perception and reasoning. Admittedly, her arguments do, at times, go beyond Flanagan’s thesis that social identity determines the development of certain moral skill sets by determining the frequency with which one encounters problems that demand those skills. However, some of her reasoning parallels Flanagan’s approach and none of it sets up disabled moral psychology as entirely and fundamentally detached from the moral lives of non-disabled people with a second, alternative global moral voice. In particular, she argues that the lived experience of disability affects how a person might perceive or reason about some of the moral

¹⁹ I would strongly encourage any reader who has an interest in the topic of my project to read Scully’s *Disability Bioethics* in its entirety.

features of their life by influencing how their body interacts with the world as their most fundamental moral background assumptions develop.

To make this argument, Scully begins with Pierre Bourdieu's concept of *habitus*, which she defines as "patterns of being and doing in the world that people acquire through becoming habituated to a particular social field . . . [which] generates its own system of tacit rules governing practices and behaviors" (Scully 2008, 65). So, in other words, habitus is a deeply entrenched way of life that human beings learn from observing the norms demonstrated in their given social environment, which can shift according to context. Scully points out that habitus refers to *both* "habits of physical behavior" *and* "habits of thought and affect," deliberately eschewing a sharp distinction between the two and emphasizing that "the schemes of habitus owe their enormous potency and persistence to the fact that they operate outside the reach of conscious control" (65). Scully argues that this concept of habitus is useful because it describes how a human being's reality is "cognitively structured, through bodily processes that originate in the social world" and supply her with the most fundamental set of moral assumptions that are taken to be so self-evident that "things out of alignment with it are obviously absurd or illogical or barbaric" (65). Scully points out that habitus structures the basic assumptions of a human being's morality and is, thus, not easily made the subject of philosophical reflection because it is "prereflexive and embodied" to the point that it is "not readily accessible to conscious scrutiny" (66).

Scully explicitly spells out habitus's relevance to moral perception and reasoning by explaining that "ingrained habits of feeling and thought will include moral ideas and emotions about things like the good life, responsibilities to others and how they should be fulfilled, what sorts of acts exhibit genuine moral agency, and so on" (Scully 2008, 66). She goes on to

interpret Bourdieu as claiming that the processes of habitus may be preflexive and outside conscious control, while human actions are “a conscious decision that emerged within the dispositional constraints of habitus” (67). It follows that these decisions are based on reasons that can be laid out as justification for an action, but things then circle back around to habitus because “reasons given are found compelling to the agent because of this indwelling sense of rightness and will be found convincing to others to the extent that the reasons line up with their own ‘durable dispositions’” (67). Strikingly, Scully points out how a mismatch could arise between the sorts of reasons people take to be compelling when they are embodied in very different ways because “anomalous embodiment generates at least some moral dispositions that fit awkwardly to the schemes of evaluation driven by the dominant habitus” (67).

Thus, Scully’s use of Bourdieu’s concept of habitus connects nicely with and rounds out my discussion of moral alienation and group based distrust in chapter 1. Recall Nelson’s argument that not everyone is equally motivated by every reason to act because agents occupy a range of positions within the social world that determines which norms are taken as motivating, as culture “enfolds us into a way of life that strives to make us as sensitive as possible to the patterns assumed by moral values and reliable responders to just what those patterns demand” (Nelson 2004, 86). The “way of life” that Nelson refers to here seems very close to the concept of habitus that Scully is deploying. Likewise, habitus is somewhat similar to what Walker refers to as “zones of default trust”: spaces in which “one believes one knows what to expect and from whom to expect it, and one knows what is normal and what is out of place” (Walker 2006, 85).

What Scully seems to add to this conversation with the concept of habitus is an overt focus on how embodiment plays a role in developing a specific habitus and how it can preclude an individual from participation in the dominant habitus. She explains, “Bourdieu is trying to

articulate a way in which a physical body interacts with a social world to generate meaning. The individuality of this production derives, in part, from the specifics of the body: what the constraints of biology and physics allow the body to do, and the possibilities that are open to *that* kind of body in *that* social organization” (Scully 2008, 67). For Scully, bodies are of key importance in how moral alienation or distrust come into being because they are essential to the development of habitus and so disability, understood as a differently functioning body, can be framed as “an ill fitting set of dispositions that are generated by being chronically unable to keep the tacit rules of normal comportment, timing, speech, and so on. . . . Hence to a greater or lesser extent there will be a persistent mismatch between the demands of the prevailing habitus and what a person’s body is in practice able to do” (68).

In this way, Scully may even successfully bridge the gap between Flanagan’s thesis about difference in moral personality and the origins of disability ethics. Recall Flanagan’s position that, while everyone may be familiar with the sorts of reasoning that would be used to deal with a given sort of moral problem, social identity can determine how practiced one is, and therefore how effectual one is, in actually dealing with the problem. Flanagan drives this point with a sports analogy, “Many persons both know and can represent the rules of soccer and golf. But if one plays soccer and not golf, then the fact that one can talk competently about both is surprisingly inconsequential with respect to one’s practical ability to stay out of the rough” (Flanagan 1991, 234). Likewise, for Scully, a disabled person may know the rules to the game of the dominant habitus but, because of the way their body functions within that social world, have some difficulty staying out of the rough, so to speak. Scully explains, “This does not mean that disabled people are unable to play the majority game at all: they patently can, and in fact this is fundamentally what is going on when disabled people engage with others in ways that enable

those others to say, *But I never think of you as disabled*. What they often cannot do is play it with the same degree of unthinking ease. The condition of not sharing the effortless habitus of normal embodiment is central to what disability is all about” (Scully 2008, 68). In a sense, Scully adds the dimension of embodiment to Flanagan’s thesis that practice in a given moral activity can and does develop one’s skill at it. Having a certain sort of body that interacts with an evaluative culture can matter to which moral skill sets one *can* develop. To draw out Flanagan’s sports analogy, a person with quadriplegia would certainly have more success with developing the skills needed for quad rugby than for the standard game of basketball.

An example of how embodiment, disability, and habitus are relevant to *moral* practice would probably be instructive at this point. We might take as an example fatherhood. To be sure, in many or perhaps even all societies, there is a dominant habitus for fatherhood that is a prereflexive, mostly unconscious set of moral perceptions, reasons, and feelings regarding what it is to be a *good* father. As with many or perhaps even all societies, in middle-class, 21st century United States, some of the activities of the dominant habitus of *good* fatherhood are ones that would be difficult, if not impossible, for a man with a significant physical disability. For instance, while other social identities like sexual preference, gender identity, class, race, or ethnicity may also have an impact on how easily one matches up with a dominant habitus for fatherhood, a man who is perhaps blind or has a high level spinal cord injury may not be able to teach his son²⁰ how to play the game of baseball in the same manner as the dominant habitus of fatherhood would call for. This inability, in isolation, may not be terribly morally significant, but in combination with the many other ways his mode of function would affect the manner in which he raises his son, it would not be a stretch that those who participate in the dominant

²⁰ I am deliberately describing a situation involving a son and not a daughter in my example to highlight the ways in which sexism intersects with ableism to define the dominant habitus of “good” fatherhood.

habitus might very quickly question whether he is or can be a *good* father to his son. In fact, this dominant habitus may even determine that it would be immoral for him to take the role of father at all. This, of course, is despite the fact that the disabled father may be developing a variant habitus for fatherhood that fits his mode of function. Scully might argue that, perhaps, there is a minority disabled habitus that would define “good” fatherhood according to “its own system of tacit rules governing practices and behaviors” (Scully 2008, 65).

Notice that, in my example of the development of a variant disability moral psychology via Scully’s use of habitus, I am not arguing that the disabled father has an entirely separate global moral voice. Perhaps his atypical embodiment as a quadriplegic or blind man may also be relevant to other moral spheres as well, but it does not follow that for every moral problem the disabled person encounters, he will be alienated because of a radically different, unified “disabled” moral psychology. There are likely many ways in which his habitus will smoothly integrate with the dominant habitus and he will feel no moral alienation at all. Where and how his moral psychology does not fit with the dominant mode of moral life will likely be influenced by the sort of disability he has. For example, a Deaf man may quite easily teach his son how to play baseball in a mostly typical fashion, but may have other ways in which his fatherhood seems alien to the dominant moral framework. Moreover, there will be other relevant facts about the embodiment and social position (i.e. gender, sexual identity, economic class, race, ethnicity, and so on) of any given disabled person that will be as or more relevant to how closely her moral psychology resembles the dominant habitus and where exactly they depart. Further, with the emphasis on habituation, Scully’s thesis that an alternative habitus can produce variation in what amounts to a disabled person’s moral personality is not at odds with and even seems to overlap somewhat with Flanagan’s suggestion that the frequency with which a person encounters a

certain kind of moral problem is influenced by her social identity and, in turn, determines her proficiency with identifying and resolving that sort of problem.

Sentimentalism, Rationalism, and Variation in Moral Emotion

Up to now, I have mostly examined the difference that disability may make to moral psychology through subtle differences in moral reasoning and perception. However, it would be mistaken to just assume that human moral psychology consists of only the perception of moral problems and the subsequent reasoning that is deployed to solve them. That is, it would be mistaken to operate on this unexamined assumption if, built in to that assumption is the second assumption that all moral reasoning is completely divorced from any sort of moral emotion or feeling. The precise role that emotion does or should play in moral decision-making is contestable, but, in everyday life we can be fairly sure that it plays *some* sort of role in moral experience. Surely, if it is likely that there are differences between disabled and non-disabled people in moral emotion, these differences are also worthy of close consideration for how they might contribute to the conflict my project is trying to unravel.

Whether emotion is inevitably embedded in moral processes (i.e. sentimentalism) or a distorting force on moral reasoning that ought to be suppressed (i.e. rationalism) has been a contested topic in metaethics for centuries. Of course, most notably in the history of the Western philosophical tradition, David Hume and Emmanuel Kant are perhaps the standard bearers for the competing positions.

As the most famous figure in the Western philosophical canon to support the sentimentalist position, Hume argues that moral practice depends on reason in as far as “that faculty can instruct us in the tendency of qualities and actions, and point out their beneficial

consequences to society and to their possessors” (Hume 1751, 32). So, according to Hume, careful reasoning can assist a person in moral decision making by sorting out the facts of a moral choice and predicting cause and effect relationships between these facts that will determine the outcome of their choice. However, also according to Hume, this is the extent of the role of reasoning in moral choice because after these facts of the choice are understood, “a *sentiment* should here display itself, in order to give a Preference to the useful above the pernicious tendencies” (32). If a feeling or sentiment were not involved, a chooser would not have a preference for any of the possible outcomes she predicts her actions might have. Hume identifies the specific sentiment that motivates a chooser to pick the outcome that is most likely to have good consequences as “a feeling for the happiness of mankind, and a resentment of their misery” (32). Hume goes on to make several detailed arguments supporting his position that reason can only clarify facts and relationships, but not provide a preference for a particular outcome as good that is then acted upon.

One such argument is an analogy that Hume makes between ethics and aesthetics, or, as he terms them, moral beauty and natural beauty. He offers an example to explicate his analogy: “Euclid has fully explained all the qualities of the circle; but has not, in any proposition, said a word of its beauty. The reason is evident. The beauty is not a quality of the circle. It lies not in any part of the line, whose parts are all equally distant from a common center. It is only the effect, which that figure operates upon the mind, whose peculiar fabric or structure renders it susceptible of such sentiments. In vain, would you look for it in the circle, or seek it either by your Senses or by mathematical reasonings, in all the properties of that figure” (Hume 1751, 34-35). However, relating all of Hume’s arguments supporting the priority of moral feeling over

reasoning would bring me too far afield from the goals of my project. Fortunately, these goals do not depend on this claim, as I will argue below.

In contrast, Immanuel Kant took up the rationalist position that sentiments often run contrary to morality and ought to be resisted, or at least ignored, in favor of reason, which he argues is the only reliable foundation for morality. He explicitly describes this tension between the morally distorting effects of sentiment and morally foundational reason, “The human being feels in himself a powerful counterweight against all commands of duty, which reason represents to him as so worthy of esteem, in his needs and inclinations, whose satisfaction he summarizes under the name of ‘happiness.’ Now reason commands its precepts unremittingly, without promising anything to inclinations, thus snubbing and disrespecting, as it were, those impetuous claims, which at the same time seem so reasonable (and will not be done away with by any command)” (Kant 1785, 39). Kant goes as far as to say that the rules of duty that are revealed by reason are so vulnerable to sentiment that happiness can “corrupt them and deprive them of their entire dignity” (39).

Famously, Kant develops several different articulations of the categorical imperative. For our purpose of unpacking his position regarding moral feelings, the most notable of these is probably: “I ought never to conduct myself except so that I could also will that my maxim become a universal law” (Kant 1785, 37). Here, Kant is arguing that, when faced with a moral choice, the right action is the one that, if everyone did it in a similar circumstance, it would not create a logical contradiction. The example he uses to illustrate this version of the categorical imperative is promise making. He argues that, if everyone made false promises to gain some sort of advantage, then a logical contradiction would arise because promises would no longer be of any value and so no advantage could be gained from making them falsely. Since this action

leads to a contradiction when universalized, it should not be taken (37-38). This move to universalize moral experience into an absolute moral law is the hallmark of Kant's ethics. In contrast to Hume, who, as we see above, even deploys analogies to relativistic aesthetic judgments, Kant wants moral judgments to be universal and true for every person and not reliant on individual moral experience. This is his basis for the strong stance he takes against moral feelings as anything other than a distorting force on moral reasoning. For Kant, duty as the basis of morality is derived from universal reason, whereas feelings are always individualistic and subjective.

Of course, whether or not moral feelings are essential to moral decision making or some sort of peripheral--perhaps distorting--phenomenon is an empirical question more than anything else. Some of the most powerful empirical tools contemporary psychology and neuroscience have to offer have, in fact, been brought to bear on the matter. Bryce Huebner's forthcoming article, "Do Emotions Play a Constitutive Role in Moral Cognition?" synthesizes much of the recent cognitive science research that has attempted to address this question empirically. Huebner summarizes the evidence as follows: "Behavioral experiments have revealed that the presence of an emotion-eliciting stimulus can affect the severity of a person's moral judgments, while imaging experiments have revealed that moral judgments evoke increased activity in brain regions classically associated with emotion, and studies using patient populations have confirmed that damage to these areas has a significant impact on the ability to make moral judgments" (Huebner 2014, 1). Of course, after such empirical data is gathered, its relevance to the question at hand must be interpreted. Huebner rejects the notion that we can say with certainty that these experimental results settle the metaethical question of whether "emotions may play a robustly *causal* or perhaps even a *constitutive* role in moral cognition" (1), as many

try to do. In contrast, he recognizes that “others have noted that the existing data are also consistent with the possibility that emotions operate *outside of* moral cognition, ‘gating’ off morally significant information, or ‘amplifying’ the output of distinctively moral computations” (1). For his part, Huebner does not think even modern science can resolve this long standing question with empirical investigation because “the theoretical foundations of moral psychology are themselves to blame for this intractable dispute” (1). More specifically, Huebner argues, by way of his detailed review of the available empirical data, that the dichotomy between reason and emotion does not map on to actual moral cognition that, in actuality, “relies on *predictive* and *evaluative* mechanisms rather than affective and cognitive mechanisms” (1). These predictive and evaluative mechanisms that Huebner identifies “are neither wholly affective nor straightforwardly cognitive” (article abstract). So, Huebner is arguing that studying the existing mechanisms in closer detail will not settle the controversy if the basic terms of the controversy are themselves in error.

To be sure, I have neither the space nor the inclination to settle this controversy over the precise role of moral emotion. Hume may be right that, at bottom, a moral decision or judgment is always motivated by some sort of emotion after reason has sorted out all of the facts and relationships. Likewise, in as far as he argues that sentiments do not play a causal role in moral decisions, Kant may also be correct. Finally, Huebner may be correct that this question itself is assuredly not going to produce any sort of definitive answer, no matter how sophisticated our experimental methods become.

Luckily, my project does not hang on this metaethical question. Indeed, whether moral feelings play a *constitutive* or a *peripheral* role in moral decision making does not matter all that much to my main claim that the moral experience of disabled people produces differences in

moral psychology that give rise to conflict between the disability movement and mainstream bioethics. All that matters to my argument is that, if emotions play *some sort* of role in moral decision making, it is likely that, along with moral perception and moral reasoning, the experience of disability gives rise to differences in these moral emotions that contribute to the conflict between the DM and mainstream bioethics. Sentimentalists and rationalists seem to agree that emotions play some sort of role in our moral lives and *this* consensus is far more important to my project than identifying the precise nature or extent of the role they play. I maintain that the respective positions of Hume, Kant, and Huebner about this metaethical question would all accommodate my explanation of the conflict between the DM and bioethics. The reason is that they would all allow for the mechanisms that produce differences in moral reasoning and perception to also operate on moral emotions, further contributing to the conflict.

Hume attempts to construct his sentimentalist position that moral emotions motivate moral decision making and corresponding moral action in a way that it is subjective, but not relativistic. That is, for Hume, these moral sentiments arise from within the subject herself, but each such subject is similar enough to the others that there is not a great deal of variation within these subjectivities and so the moral judgments that are made will be similar enough to form a recognizable moral standard. Hume argues that this moral standard “arising from the internal frame and constitution of animals, is ultimately derived from that supreme will, who bestowed on each being a particular nature, and arranged the several classes and orders of existence” (Hume 1751, 36). So, Hume is arguing that human moral personality produces certain sorts of motivating moral sentiments that are found in all such personalities. For moral feelings to be consistent across all human beings, they would have to arise from some sort of substantive deep structure of moral personality, whether derived from a divine creator, evolutionary chance, or

some other mechanism. Of course, with Flanagan, we already rejected the notion that there is a substantive deep structure to moral personality because of the role socialization plays in the formation of infinitely variable human moral personalities. If these arguments against a deep structure hold, we are left with a sentimentalist picture of moral judgment that is motivated by moral feelings that derive from an individual's experience of socialization in a particular social position, within a particular, historically situated culture. Surely, these motivating moral feelings would be subject to the same mechanisms of differentiation that we already established as likely to influence moral perception and reasoning.

Recall my claim that Flanagan's arguments regarding gendered experience also apply to disability: disabled people's moral lives are structured in such a fashion that they encounter certain sorts of moral problems with greater frequency and, subsequently, develop greater proficiency in recognizing and solving those problems. To be sure, sans the possibility of a substantive deep structure to moral personality, the frequency with which moral problems are encountered should also have some sort of impact on a person's development of or sensitivity toward morally relevant feelings regarding that problem. Perhaps this would mean that a person who is well practiced in dealing with a particular sort of problem has a more robust or more sophisticated set of feelings regarding the correct response to that scenario. Or, maybe that person is more attuned to easily recognize their feelings on the matter and are more capable of sorting through any ambiguity or nuance these feelings contain.

Likewise, the mechanisms Scully identifies that produce variation in moral psychology between disabled and nondisabled people also would have an effect on moral affect, in as far as it might be constitutive to moral decisions. Recall her interpretation of Bourdieu's process of habitus as explicitly pertaining to moral feelings: "Ingrained habits of feeling and thought will

include moral ideas and emotions about things like the good life, responsibilities to others and how they should be fulfilled, what sorts of acts exhibit genuine moral agency, and so on” (Scully 2008, 66). Variations in *habitus* surely would produce variations in the moral feelings one has as one regards life with disability.

Even so, I am trying to remain agnostic regarding the competing claims of sentimentalists like Hume and rationalists like Kant who contend that moral decisions are matters of *reason* and not feeling. Kant’s moral psychology sets up a tension between a person’s commitment to their duty, which is revealed through their reason, and their feelings that are constantly assailing that duty. As a quintessential example of the sort of moral sentiment that challenges and potentially derails reason, Kant identifies a person’s “needs and inclinations, whose satisfaction he summarizes under the name of ‘happiness’” (39). If Kant is right in arguing that correct moral decisions are grounded in reason and only distorted by emotions, it would seem that such distorting emotions would be as universal as the reason with which they are contrasted. Perhaps, as Kant advises, a person ought to *try* to be as emotionally disinterested as possible when making a tricky moral decision, but everyone would be subject to the *inducement* of their emotions. There would be no social position or identity that would be immune to such influences, which would, in a sense, be part of any sort of universal moral experience. Sentiment would always be present, even if only as a temptation away from well-reasoned duty.

For Kant, it is reason and not sentiment that is static and unchanging. So, my position that both Flanagan and Scully’s arguments regarding variation in moral psychology apply to feelings would be uncontroversial. From a rationalist viewpoint, applying this thinking to feelings would amount to a case for how and why people develop different sorts of distortions in their moral decision making that roughly correspond to their social identity. This position would not

necessarily diminish the explanatory power of the mechanisms described by Flanagan and Scully, so long as it is recognized that sentiment is always potentially present in everyone's moral experience.

In fact, pointing out how sentiment has a distorting effect on moral reasoning regarding disability has been a key strategy of the disability movement. For example, many members of the DM have argued that an irrational fear of and disdain for life with disability is the basis for wrongheaded arguments favoring the moral acceptability of physician-assisted suicide.

Amundson and Taira take this tack in pointing out how feelings of fear and disdain distort the lived realities of disability in the minds of nondisabled advocates for PAS: "When assisted suicide advocates really wanted to scare their audience, they didn't use unremitting pain to do it. They used disability. The need for help to go to the toilet was the big stick. Wouldn't you rather die than have someone else wipe your butt? It never seemed to cross these advocates' minds that thousands of people in the United States get help to wipe their butts every day. Many of them are my friends." (Amundson and Taira 2005, 54). Like Kant, Amundson is arguing here that, when regarding PAS, the morally relevant facts and logical relationships are obscured and distorted by a certain set of emotions. Arguments such as Amundson's imply that these morally distorting feelings correspond with a particular social identity: nondisabled people who live lives that are far removed from the lived realities of disability.

It is not farfetched to argue that such variation even in distorting emotions could be produced via the mechanisms proposed by Flanagan and Scully. If most non-disabled people do not come into sustained, intimate contact with actual disabled people so that they come to understand the complexities of life with a disability, it would not be surprising to find that they then orient themselves toward fear of such a life. To explain this in Flanagan's terms: without

developing the sorts of moral sensitivities and proficiencies that would be needed for grappling with the sorts of moral problems encountered through life with a disability, many non-disabled people may be fearful of that potential experience, especially when there are so many culturally perpetuated stigmas that produce and maintain this distorting fear. Similarly, Scully is not a moral relativist who proposes equal moral merit for every possible *habitus* that has been or could be developed by a human culture. Clearly, at least some of the affects cultivated by some forms of habitus will distort moral experience in problematic ways and, perhaps, the commonly held fear of and disdain toward disability that Amundson is referring to is one such distorting affect produced by the dominant habitus.

For variations in moral feelings to hold relevance for the conflict between the DM and mainstream bioethics, then, these feelings need not be the basis for all moral experience so long as they have some sort of impact on that experience. Ultimately, if Huebner is correct and there is no way to settle this dispute over the precise role of moral sentiment empirically, I can still move on with my project of trying to identify the ways in which variations in moral psychology produce the conflict I have taken up.

From Variant Moral Psychology to Privileged Moral Knowledge

While I have used the term epistemology often and offered some brief discussions of the moral knowledge that can be gleaned from the DM, to this point, I have focused almost exclusively on developing arguments regarding disability moral psychology. Indeed, by describing variation in disabled moral psychology, I intend to offer an explanation for why individual disabled people often experience moral alienation or distrust when engaging with mainstream bioethics. However, if my project is to advance past these sorts of explanations of

the conflict and toward some sort of reform, it must examine the possibility of moral knowledge claims that arise from variations in moral psychology. Especially since disabled people are a numerical minority in a disadvantaged social position, any reforms to the field of bioethics will have to be, at least in part, implemented by non-disabled people as well. For this responsibility to be shared, we need moral knowledge that is derived from disability but can be grasped by those who have not directly experienced disability. That is, bioethics needs to be able to draw from a normative disability moral *epistemology* in addition to the description of disability moral psychology.

Scully explicitly argues throughout her book that her project is as much epistemology as it is ethics because “serious bioethical engagement with disability issues should raise fundamental questions about the *kind of knowledge* that is needed to make moral decisions concerning people with different embodiments from our own, and the nature of the decisions that it is possible to make with the knowledge that can be obtained” (Sully 2008, 40). Of course, Scully’s aim is not merely to describe a normatively neutral account of how experiences of disability produce differences in individual or social moral knowledge. Rather, her project is both descriptive in that it gives a sketch of these epistemic differences and prescriptive in that it argues that bioethics will be *improved* by taking into account the distinctive moral knowledge produced by the lived experience of disability. This normative element of her project means that Scully can be read as proposing that the experiences of disability provide disabled people with a sort of epistemic privilege regarding the moral features of life with a disability. A case for a sort of privileged epistemology is also an important element of my project. Without making the claim that the variations in moral psychology that I have described result in some sort of moral *knowledge* that has not yet been considered, I wouldn’t have much to contribute to the field of

bioethics. So far, my argument has yet to establish a link between the description of the processes of human moral psychology that can produce variant perception, reasoning, and feeling and the production of variant moral knowledge that should be considered by the field of bioethics because of its privileged status.

While Scully's arguments for a disability epistemology do make a sort of appeal for the epistemic authority of disabled people regarding some assumptions within mainstream bioethics that are often glossed over and remain unexamined, she is not proposing that the disability movement's epistemic authority can be derived from any sort of standpoint epistemology. However, standpoint epistemology is often deployed as a normative justification for the epistemic privilege of non-dominant people, so some version of it may be useful in as far as it could offer motivation for the profession of bioethics to take account of the moral knowledge produced by DM. After all, like Scully, I am not merely trying to describe differences in the moral knowledge of disabled and non-disabled people who do bioethics. I want to motivate the profession to make specific renovations that are grounded in the moral knowledges of politicized disabled people. This will require normative arguments for why these knowledges are privileged.

Mary Mahowald's section of *Disability, Difference, and Discrimination* makes exactly this claim with an appeal to standpoint epistemology as the starting point for her analysis of disability and justice. She summarizes a fairly straightforward account of feminist standpoint epistemology, implying that her analysis of disability will rely on the nondominant perspectives of disabled people that are often ignored or marginalized in political or bioethical discussions. She argues that feminist standpoint epistemology can provide ethical theory and political

philosophy with epistemic resources it needs to perceive what it has previously missed about disability:

A feminist standpoint articulates a particular perspective that is not “dominant.” In general, the dominant perspective of white, middle-class, able, heterosexual males who predominate in positions of power defines the rules and practices that are applied to everyone in their society. In contrast, a feminist standpoint is the perspective of those who have little or no part in determining those rules and practices because they mainly occupy a non-dominant position in society. It thus provides a corrective lens for the inevitably limited perspective (i.e. myopia) of the dominant group. . . . A feminist standpoint imputes privileged status to non-dominant perspectives not because those perspectives are more valid or more accurate (although they sometimes are) than the dominant perspective but because nondominant perspectives are typically missing from the perspective that dominates society at large. Living in that society, nondominant groups and individuals cannot help but be aware of the dominant group’s perspective, while the dominant group may be totally unaware of the nondominant groups’ and individuals’ perspectives unless it grants a privileged status to them. In other words, dominant people need nondominant people more than the latter need the former to reduce the limitations of their perspective. (Mahowald 1998, 210-211).

Mahowald continues by recognizing her own epistemic limitations that have been produced by the ways in which she experiences life from a dominant position. The remainder of her essay can, in effect, be read as her attempt to use the non-dominant moral knowledge of disabled people to correct the “myopia” of egalitarian feminism that has mostly been constructed according to the perspective of non-disabled feminists and the non-dominant moral knowledge of

feminism to correct the “myopia” of the disability rights movement that has mostly been constructed according to the perspective of non-feminist disabled people.

It is exactly this possibility of corrective analysis that makes a disability moral epistemology so important. By arguing for a disability standpoint(s) that cannot be occupied by non-disabled people, but which can be – albeit with some serious effort – appreciated and learned, Mahowald is supplying the analytic tools needed for reforming the field of bioethics. A non-disabled person could never inhabit the lived experience of the variations of disabled moral psychologies, but they can be exposed to the knowledge that is derived from this epistemic position and, to some degree, learn to think *from* that position.

Nancy Harstock’s classic paper “The Feminist Standpoint: Developing the Ground for a Specifically Feminist Historical Materialism” gives a more detailed argument for a feminist standpoint epistemology that is firmly grounded in and, to an extent, mirrors Marxist epistemology, which posits, “a correct vision of class society is available from only one of the two major class positions in capitalist society” (Hartsock 1983, 284). Hartsock and Marx both argue that the knowledge available from this position “grows in a complex and contradictory way from material life” (285) with material life referring to the concrete practices of lived experience. While material life “not only structures, but sets limits on the understanding of social relations” (285), Marx seems to have developed his critique via his “adoption of the standpoint of the proletariat” (288) because he was not himself actually a member of the laboring class. It seems that this “adoption” of an alternative, non-dominant point of view is a sort of cognitive shift in which a person is exposed to, accepts, and attempts to analyze the social structure from that perspective. Similarly, Mahowald is attempting a similar “adoption” of the

standpoints of disabled people. Arguing for this sort of adoption of the standpoint(s) of disabled people and the moral knowledge produced by them is a major goal of my project.

The political goals of the disability movement are wide ranging and sometimes perhaps even radical, but Mahowald's epistemic claims are quite a bit more modest than those of Marx or Harstock. Harstock unpacks Marx's theory of knowledge and argues that it contains 5 distinct claims, some of which identify the scope and depth of his epistemology, such as: "(2) If material life is structured in fundamentally opposing ways for two different groups, one can expect that the vision of each will represent an inversion of the other, and in systems of domination the vision available to the rulers will be both partial and perverse. . . . [and] (5) As an engaged vision, the understanding of the oppressed, the adoption of a standpoint exposes the real relations of human beings as inhuman, points beyond the present, and carries a historically liberatory role" (Hartsock 1983, 285). The notion that "one can expect that the vision of each will represent an inversion of the other" implies Marx's theory of knowledge offers radically different moral voices that cover all or most of moral experience such that it sounds suspiciously like the global "two-voice hypothesis" that I am deliberately trying to eschew in favor of greater nuance. This suspicion that his epistemology is all encompassing is verified by the claim that his epistemology "exposes the real relations of human beings as inhuman."

For her part, Hartsock argues that the feminist standpoint epistemology she is developing is even broader in scope and more fundamentally dissimilar than that of Marx's proletariat:

The feminist standpoint which emerges through an examination of women's activities is related to the proletarian standpoint, but deeper going. . . . the proletarian (if male) is immersed in this world only during the time his labor power is being used by the capitalist. If, to paraphrase Marx, we follow the worker home from the factory, we can

once again perceive a change in the *dramatis personae*. He who before followed behind as the worker, timid and holding back, with nothing to expect but a hiding, now strides in front while a third person, not specifically present in Marx's account of the transaction between capitalist and worker (both of whom are male) follows timidly behind, carrying groceries, baby and diapers. (Hartsock 1983, 290-291)

Hartsock here seems to be arguing that the social domination of the male member of the working class by the capitalist is less pervasive and complete than that of the woman by the patriarchy, thus the scope and depth of her epistemic differences are also more profound. So, Hartsock is almost surely claiming that women occupy a different epistemic position that produces something very much like a different global moral voice.

Mahowald's claim for privileging the epistemic position of disabled people is much more modest than this. Clearly, Mahowald is not arguing that the experience of disability positions someone such that they are epistemically privileged in all ways and have no areas of moral or political life that are obscure to their moral perception and reasoning: "Many individuals are dominant in some respects, but non-dominant in others" (Mahowald 1998, 211). So, Mahowald is not arguing that disability or any other non-dominant social status produces a truly "global" epistemic shift with a unified, complete, and radically different moral knowledge as a result. However, she *does* seem to be claiming that a non-dominant social status gives a person or a group some sort of privileged epistemic access that grants special epistemic authority regarding some morally relevant topics (i.e. features of a social structure that dominate, oppress, or otherwise marginalize disabled people based on that disability).

There is no obvious reason why a non-dominant standpoint epistemology would inevitably and necessarily entail a global scope any more than an alternative moral psychology

would. It seems likely that the effects a social identity has on moral knowledge could be as varied as the effects it has on moral reasoning and feeling. Thus, this seems like a strength of Mahowald's version of standpoint theory over the more traditionally Marxist theories of knowledge of Harstock and other feminists standpoint theorists.

Another difference that may exist between Mahowald's analysis and more traditional framings of standpoint epistemology is that she is not entirely clear whether mere membership in the social group of disabled people is by itself sufficient for privileging an individual's moral knowledge about disability. Recall Mahowald's description of standpoint theory, where she posits, "a feminist standpoint is the perspective of those who have little or no part in determining those rules and practices because they mainly occupy a non-dominant position in society" (Mahowald 1998, 211). This claim is somewhat vague in that it does specify whether occupying a non-dominant social position is necessary and sufficient for accessing the privileged epistemic standpoint of that social position. It is unlikely that Mahowald is taking the position that actually identifying with a particular marginalized identity is necessary for accessing the moral knowledge of that standpoint. If this was the case, she would be presenting her reader with a paradoxical argument in that she is writing about the standpoint of disabled people while explicitly acknowledging that she does not herself identify as disabled. She would have to regard such a task as a lost cause if she believed that it was necessary to have a particular social identity in order to grasp the knowledge that is generated by that social position. It would be plausible, however, to read Mahowald as claiming that merely occupying a marginal social position is *sufficient* for grasping the privileged moral knowledge offered by that epistemic standpoint.

Such a framing would be a departure from traditional Marxist standpoint epistemology and likely present a problem for Mahowald's argument. While Harstock describes Marx as

proposing “a correct vision of class society is available from only one of the two major class positions in capitalist society” (Hartsock 1983, 284), she is not claiming for Marx or for herself that every member of that marginalized class has the correct vision by mere virtue of class membership. We know Hartsock is not arguing that mere identification with the working class or with women is sufficient for producing a privileged epistemic standpoint because she regards this standpoint as an *achievement* rather than an inevitability. Namely, she argues that, for both women and the proletariat, “the vision of the oppressed group must be struggled for and represents an achievement which requires both science to see beneath the surface of social relations in which all are forced to participate, and the education which can only grow from struggle to change those relations” (285). Following Marx, Harstock is arguing here that the dominant class constructs ideology that protects and maintains their dominant status with the pervasive proliferation of false knowledge that, if not challenged, keeps the dominated group ignorant of the details of their own subordinate social position. Thus, in order to access the more accurate knowledge of the social structure available to them, members of non-dominant social groups must somehow first abandon the false knowledge that has been constructed and propagated by the dominant class.

The ideologies that protect and maintain domination are often referred to as forms of *false consciousness*, while the process of struggling against this ignorance of one’s own oppression is termed *consciousness raising*. While she does not explicitly place her work within the Marxist tradition, Sheila Ruth goes as far as to say that consciousness raising is “the most fundamental factor in the contemporary women’s movement,” when responding to charges that feminism has concerned itself with the trivial details of life rather than the large scale policy problems it has grappled with in the past (Ruth1973, 290). She argues for the importance of

raising consciousness and defines the process in more detail: “overt changes must follow upon, and are secondary to, another more radical change, the change of consciousness, an alteration of psychic, emotional, and phenomenal stance of the woman vis-à-vis her environment and experience” (291). She further clarifies that this is not just a change in a woman’s stance toward her environment and experience, but an increase in awareness toward the fine-grained oppressive details of her life (291-292).

For Ruth, this shift in awareness is also tied to political struggle. First, she gestures toward the notion that such an increase in awareness happens within particularly fertile political and cultural background conditions. Namely, she argues that consciousness raising happens because of the internal moral tensions present within women who experience a disconnect between the steps they have achieved toward liberation and how these achievements move them further from the role that has been socially prescribed for their gender: “she wants to be woman; she wants acceptance as woman; by heaven, she *is* woman. But what does that mean? According to all tradition she cannot be woman unless she assumes her assigned sex role and internalizes the assigned consciousness, yet the traditionally defined characteristics, interests, and perceptions are repugnant to her” (Ruth 1973, 295). Thus, some options for liberation must be open to her before the internal conflict arises that is the first step toward a raised consciousness. These options are, of course, a result of previous political action on the part of her dominated group.

Not only are these background conditions for consciousness raising politically produced, but the actual process of raising consciousness is political itself, according to Ruth. Ruth argues this internal conflict has been traditionally dealt with through suppression or individual rebellion in isolation from others, but an alternative is:

to confront head on the conflicts, contradictions, and confusion. This is the function of consciousness raising. The consciousness raising session is also called a rap-session, because that is what one does there—one talks. One talks, however, not aimlessly, not merely as a "purge," but with direction, with critical, rigorous persistence to investigate the nature of the female situation and potentiality. With the emotional, spiritual, and intellectual support of her group each woman attempts to surface, to bring to exquisite awareness, the conflicting female Weltanschauungen in order to explore, comprehend, evaluate, and, where necessary, change them. (Ruth 1973, 296-297)

Thus, Ruth describes in very personal terms the political process of raising one's consciousness to the features of one's socially subjugated position and deliberately abandoning the false notions that are promulgated by the dominant class to maintain their power.

This personal and political process of consciousness raising is of key importance to the development of any epistemically privileged but politically marginalized standpoint, at least so long as that standpoint must be developed under conditions of false consciousness that epistemically obscure and maintain the relationship of dominance. There is certainly reason to think that false consciousness abounds regarding the social experience of disabled people.

Elsewhere,²¹ I have highlighted one prominent feature of this false consciousness that obscures and, thus, maintains the marginal social position of disabled people: the common liberal response of pity. Correspondingly, there are several well-known memoirs²² of disability scholars and activists that prominently feature descriptions of the process through which their consciousness

²¹ Stramondo, Joseph. "How the Ideology of Pity is a Social Harm to People with Disabilities." In *Social Philosophy Today*, vol. 26: *The Public and the Private in the 21st Century*, ed. John R. Rowan. Charlottesville, Va.: Philosophy Documentation Center. (2010)

²² Some of these include: Linton, Simi. 2005. *My Body Politic*. Ann Arbor, MI: University of Michigan Press; Hockenberry, John. 1995. *Moving Violations: War Zones, Wheelchairs, and Declarations of Independence*. New York, NY: Hyperion; Murphy, Robert. 1987. *The Body Silent: The Different World of the Disabled*. New York, NY: Henry Holt.; Johnson, Harriet McBryde. 2006. *Too Late to Die Young: Nearly True Tales from a Life*. New York, NY: Picador.

was raised toward their own oppression. There is much, deeply personal scholarly and political work left to do before the false consciousness that protects the systematized oppression of disabled people has been fully exposed, but these preliminary steps indicate that the privileged standpoint of disabled people regarding the moral and political features of social life with a disability needs to be produced by those who have been attuned to these matters through the consciousness raising process.

It may be the case that the raw, everyday experiences of disability produce variations in moral psychology that are prior to any consciousness raising experience. However, if the moral knowledge produced by these variant modes of perceiving, reasoning, and feeling are to be taken as privileged, it cannot be observed through the lens of the dominant false consciousness that often prevails on most people's understandings of disability—disabled and non-disabled alike.

Another limit to Maholwald's chapter is that she never really lays out the process by which the moral knowledges of disabled people are differentiated from those of the dominant, non-disabled group. She gives reasons why the non-dominant group's knowledges ought to be taken as epistemically privileged in some cases, but she doesn't give an argument as to how the moral knowledges of those who are dominant or non-dominant come to be different in the first place. We have already addressed mechanisms by which the moral perception, reasoning, and emotions of individuals can be differentiated by membership in a social group, but how is it that distinct sorts of moral knowledge can be generated by these psychological variations within the social group of disabled people?

Such an explanation is on offer from Kathryn Pyne Addelson, who has argued that epistemic differences originate in the politics of the production of knowledge by competing groups. Addelson argues that while "the traditional epistemology of the Anglo-American canon

was a theory for *knowledge makers*,” this fact was obscured by the theory’s key assumption that all knowers were “interchangeable individuals” (Addelson 1993, 265). Any details about the knowers themselves were dropped from this view and epistemology was taken to be the study of knowledge itself. Put another way, Addelson argues that epistemology should not be a normative theory *for* supposedly abstracted and interchangeable knowledge makers to use as a means of validating the legitimacy of knowledge so much as it is a descriptive project *about* knowledge makers and how knowledge is constructed through political struggle (266). While she describes it as descriptive more than prescriptive, for Addelson, this is a largely self-critical project that she hopes “shows how elite feminist knowledge makers in the academy and elsewhere make knowledge and how we might do so responsibly,” because her suggestions for change “should help us knowledge makers know ourselves” (266). For her descriptive moral epistemology to be successful, Addelson argues that “we must know precisely and practically how our work operates to undermine dominant elites – or, alas, how it operates to support them” (268).

To properly describe how the production of knowledge undermines or supports dominant power structures, Addelson argues that feminists must “jettison the old assumption that knowing is a matter of the beliefs or conceptual schemes of individuals” (Addelson 1993, 267) in favor of a description of how groups or, as she puts it, *social worlds* “operate as knower/doers in the dynamic process of making knowledge and upholding or undermining a dominant order” (272). Addelson seems to be arguing that social worlds are the most appropriate epistemic unit to describe knower/doers, but that the traditional view of the individual as knower has obscured the ways in which the process of knowledge production is political. Addelson argues that the traditional view has buttressed “the separation between knowledge and the social organization of

cognitive authority,” thus erasing the fact that “making knowledge is a political act” (267). For Addelson, to fully understand how the production of knowledge operates within the power struggle of groups who are organized in opposition to each other, the basic epistemic unit must be the group (i.e. social world) as knower/doer.

Addelson goes on to argue that a political conflict arises between social worlds that work to define the object of the conflict in terms that will be advantageous to their group. She defines this as the process of *making a problem public* within an *arena*. This struggle is itself the production of moral knowledge that maintains or undermines power relationships of dominance:

The social worlds relevant to public problems consist of group knowers/doers whose collective action involves creating and struggling over public problems. They are doers because they (the social worlds) take part in the process of making moral problems public, and they are knowers not only because they know facts (moral or otherwise) about a given problem but also because they organize knowledge and in fact create definitions of the social problem under which to organize and interpret the scientific, philosophical, religious, and other knowledge. They make knowledge and construct morality as they act and know (281).

Thus, groups, rather than individuals, produce moral knowledge through political struggle and are thus identified as the knowers/doers. The variations in moral psychology we have examined produce politically motivated and constructed group knowledge.

Addelson’s descriptive moral epistemology seems quite useful for understanding how moral knowledge is produced and organized throughout the political conflict between mainstream bioethics and the DM. For example, Addelson’s descriptive epistemology serves as a useful complement to Amundson’s claim, explored in the last chapter, that the conflict between

the DM and bioethics is an ideologically driven struggle to define the problem of disability in a way that advantages one group and disadvantages the other: “The Medical and Social Models of disability are ideological, as explanations of social disadvantage often are” (Amundson 2005, 103). Addelson’s descriptive epistemology of social worlds struggling to make a problem public in a way that maintains or subverts power structures applies quite well to Amundson’s analysis of how mainstream bioethics makes an ideological choice when it presupposes the social model’s falseness and this ideological choice serves the interest of non-disabled society – of which bioethics is a part – at the expense of disabled people. Amundson’s argument is deeply epistemological because he is arguing about the political features that account for what sorts of knowledges are supported by what sorts of groups. He argues that explanations of disadvantage based on difference – or our choice of causal story for that disadvantage – is deeply ideological, since “a causal account that depicts a social phenomenon as natural and inevitable (or changeable only at great cost) works to the advantage of the people who benefit from the phenomenon, and to harm of the people who are hurt by the phenomenon” (103). This *is* the sort of description Addelson has in mind for showing how groups “operate as knower/doers in the dynamic process of making knowledge and upholding or undermining a dominant order” (Addelson 1993, 272).

Hence, a descriptive epistemology like Addelson’s is useful to my project because it further illuminates the epistemological features of the political conflict between the DM and mainstream bioethics. It highlights how these groups are struggling over how to frame the moral knowledge in question in ways that either preserve or challenge the status quo of power.

Ultimately, however, a purely descriptive effort such as this does not do the work necessary to adequately justify the disruption of the social status quo that my project is calling for. The friendly criticisms and counterexamples I leveled toward Amundson’s treatment of the conflict

between the DM and bioethics in chapter two are also relevant here when thinking about Addelson's epistemology. That is, even if an accurate description can be produced of how some moral knowledge props up the status quo while other moral knowledge chips away at it, until we clearly lay out how and why the subversive knowledge is *better*, there is no good reason to think that propping up the status quo is a bad thing. Indeed, the mere fact that competing moral knowledges maintain or challenge power structures does not necessarily make those that subvert power more worthy of serious consideration, much less earn them a place at the center of practice and policy. Recall my example from chapter two where I argue that it does not follow from the mere fact that Christian fundamentalism is marginalized by those with social power in Saudi Arabia that Christian fundamentalism is somehow superior to Islam in explaining the universe and human experience and ought to be embraced. Thus, merely describing the process by which knower/doers produce moral knowledge through their struggle to make a problem public in a given arena and thus challenge or support the existing power structure of that arena does not do the job. Instead, we need at least a minimally *normative* account of epistemology that can explain how social power distorts the ability of its possessors to perceive and understand the key moral concepts of disability to motivate changes in that structure of social power that produces those flaws. In sum, Addelson's descriptive project is useful, but my arguments require a *normative epistemology* that does, in fact, give some guidance as to "how knowledge makers ought to reason to reach knowledge of the true or the good or the right" (Addelson 1993, 265). This will require an epistemology that considers the impact of social power, but is not reducible to a description of that power. It must argue for how the contexts of social power hold *normative* force for evaluating the adequacy of moral knowledge produced in the sort of struggle described by Addelson.

To accomplish this, we can turn back to Mahowald's standpoint theory to supplement Addelson's descriptive moral epistemology in such a way that adds a normative element. That is, these epistemologies may be read as complementary in some sense. Mahowald's standpoint theory is normative in so far as it gives a justification for why a non-dominant group's epistemic position ought to be regarded as more privileged or authoritative than a dominant group's standpoint: "A feminist standpoint imputes privileged status to non-dominant perspectives not because those perspectives are more valid or more accurate (although they sometimes are) than the dominant perspective but because nondominant perspectives are typically missing from the perspective that dominates society at large" (Mahowald 1998, 210-211). Addelson's descriptive epistemology gives an explanation for how there comes to be a difference in these standpoints in the first place as groups construct competing moral knowledges in the struggle to define problems as public within a given arena.

Yet, Addelson's argument might not be able to do all of the philosophical heavy lifting I need for an adequate explanation of a disability moral epistemology, in that it defines the group or "social world" rather than the individual as the basic epistemic subject. This claim has some undeniable strengths, not the least of which is its capacity to avoid the problems of the radically individualistic theories of traditional epistemology that gloss over the epistemic effects of the social context of group power relationships by assuming "the democratic claim that anyone might have knowledge if only they used the certified method" and "as far as knowledge went, we were all interchangeable individuals" (Addelson 1993, 265). For Addelson's epistemology to work, she must use group political struggles as her level of analysis. After all, it seems unlikely that an isolated individual could construct moral knowledge in a public political struggle. This

knowing/doing must be done by a group “of people who, over a period of time, perform some sort of collective action together” (280).

Can such a group-based epistemology adequately explain a moral conflict that I have consistently argued originates in a moral psychology that is *prior to* any particular political ideology? Would an epistemology of *social worlds* as knower/does inevitably lead to the sort of untenable position that there are radically distinct, *global moral voices* for individual members of these social worlds? Ultimately, I do not think this is a worry because I believe that Addelson can be read with enough nuance to avoid these sorts of problems.

The reason is that, despite forcefully arguing for groups as the basic epistemic unit, Addelson explicitly recognizes the need for an epistemology that does not completely erase the individual. “The difficulty is how to find an alternative to individuals without making individuals disappear entirely” (Addelson 1993, 272). She strikes this balance with a careful definition of her unit of *social world* that avoids any tendency toward reifying or falsely unifying moral differences into distinct global moral voices by (1) allowing for individuals to belong to multiple social worlds and (2) allowing for complex knowing/doing *within* social worlds themselves.

Addelson’s definition of a social world starts off simply enough, as “communities of knowers/does” that are composed of “people who, over a period of time, perform some sort of collective action together” (Addelson 1993, 280). However, it is clear from the examples she offers that individuals always belong to multiple social worlds: “Social worlds may be enormous and complex, with many subworlds: for example, a large corporation or the philosophy profession. Or they may be small, with a relatively simple goal: for example, an ad hoc effort to stage a benefit family burned out of its home or the world of pick-up basketball at a local park” (280). Thus, of course, it is quite plausible that an individual, over her lifetime, would be

involved with a myriad of social worlds. These units of political action or “knowing and doing” produce knowledge but do not define the sole epistemic position of the individual subject. Thus, while these social worlds do construct moral knowledge, there is no risk of interpreting them as creating distinct global moral voices for their individual members.

Likewise, another built-in safeguard against the possibility of interpreting Addelson’s argument as a case for a global moral voice is the fact that she recognizes that political struggle *within* social worlds is an important part of the construction of knowledge. She observes, “In cases of disagreement, either within a social world or among social worlds, an ‘arena’ is created” (Addelson 1993, 281). As an example of the struggle of knowing/doing that happens *within* a social world, Addelson describes the contemporary women’s movement. She highlights how this is indeed a social world in that it shares at least some political goals across difference, such as “credit discrimination, issues of economic equity, pregnancy discrimination, and all the various Title IX issues of sex discrimination” (283). And yet, she also recognizes that a great deal of diversity exists within the social world of the women’s movement. “The subworlds might not share all of the ends and . . . might disagree on the means” (282). As an example of this, Addelson highlights how defining the public problem of abortion “divides, rather than unites, women even in the social world of the women’s movement” (283). Clearly, for Addelson, as social worlds operate as knower/doers to construct moral knowledge in a particular arena, this moral knowledge is not generated from a distinct global moral voice that attaches to a particular identity. Moreover, this feature of Addelson’s argument also supports my basic premise that the DM is composed of a variety of evolving moral and political positions. Thus, when I refer to the “moral knowledge of the DM” or the “DM’s moral epistemology,” I need not be read as claiming that the DM has a discreet, rigid, static set of unitary views.

I would argue that Addelson's moral epistemology and Mahowald's standpoint theory hang together in such a way that explains how alternative moral knowledge is generated by the disability movement and justifies why this alternative moral knowledge should be privileged by the profession of bioethics if "nearsightedness" is to be avoided. Moreover, this explanation allows for enough nuance that the individual disabled person is not erased through the establishment of a newly reformulated "two voice hypothesis" and the DM need not be understood as homogenous.

It might be tempting to see the trajectory of my argument as showing that the individual disabled person's moral reasoning, perception, and emotion develop in a variant fashion through the mechanisms described by Flanagan and Scully and then, through the collective action described by Addelson, a group of such individuals work together as knower/doers to produce alternative knowledge that ought to be privileged for the reasons that Mahowald, Marx, Hartsock, and Ruth provide. However, this flawed interpretation of what I have set forth describes individuals as always prior to and constitutive of the social groups to which they belong. This is the sort of hyper-individualistic epistemology that I am trying to avoid by deploying Addelson's thought. Rather, we must be reminded that both Flanagan and Scully highlight the role of social identity in the development of someone's moral reasoning, perception, and emotion. These social identities are determined by membership in social groups. So, it is not that individuals constitute the identities of the social groups to which they belong, but the groups to which an individual belongs shapes her identity. Therefore, the relationship between disability moral psychology and epistemology is not a straightforward causal path from individual cognitive and emotive processes to group knowledge production. Alternatively, we can distinguish between disability moral psychology and epistemology as the difference between

the development of variant patterns of perception, reasoning and emotion versus variant interpretations and understandings. Of course, both are deeply political.

Some Objections Considered

This chapter has attempted to provide a plausible account of how variations in the moral psychologies of disabled people and variations in the social epistemology of the disability movement ultimately result in moral and political conflict with mainstream bioethics. However, there are two distinct but related objections to my approach that need to be addressed. In responding to these objections, I hope to chart a clear path forward for my project.

First, someone might plausibly ask how, without a stable, unitary moral psychology of disabled people, there can be any sort of general overarching theory to be built in bioethics by disabled people. By failing to endorse any sort of content-thick, substantive deep structure to moral psychology that would support a singular or binary moral voice, I have also abandoned any grounds for using facts about moral psychology to construct a plausible alternative to the mainstream bioethical theorizing I am critiquing.²³ This objection asks the metaethical question: if the moral psychology of disabled people is so messy and nuanced that it precludes an alternative moral voice, how can we build an alternative moral theory? Perhaps I could be accused of demanding that bioethics remodel itself to be more welcoming for disabled people while simultaneously arguing that it is impossible to provide any sort of blueprint for the reconstruction. Perhaps all I have to offer is a new façade for moral nihilism.

Conversely, it might also be objected that I have gone too far in the other direction and, in some ways, have not been able to avoid reproducing exactly the same sort of falsely unitary

²³ Many thanks to Professor Bryce Huebner for raising this concern in his commentary on an early version of this project I presented at the 2013 Meeting of the Central Division of the American Philosophical Association.

moral theory that I am trying to critique.²⁴ That is, while I say that I am eschewing a two voice hypothesis for moral psychology and making all sorts of proclamations about my commitment to nuance, I am still arguing that disabled people as individuals develop specific sorts of moral *proficiencies* and *habits* that correlate with their identity and even go as far as to call for the profession of bioethics to use the moral knowledge that this social group has put forth to modify its theories and practices. This may begin to look suspiciously like theory building that erases difference and presents an illusory image of a unified and fixed “disabled moral knowledge.”

I hope both of these concerns can be alleviated by clarifying further the main goal of my project, which is *not* to construct an alternative moral theory for bioethics. My suggestion that the field of bioethics ought to be mindful of the moral perception, reasoning, emotion, and, ultimately, knowledge of disabled people and the disability movement is not a call to develop a more perfect and more universal moral theory for the field. Any attempt to construct a universalizable theory for bioethics, even one that has supposedly been adjusted to account for *the* disabled point of view, would lead to the alienation and exclusion of *someone* who has been marginalized in some way because of differences in their embodiment and social position. So, if my call for a remodeling of bioethics to account for the multifaceted and messy moral psychologies of the disability movement is not a call for an adjustment to a still universalizable theory, what is it and how can it provide any moral guidance to the field of bio-medicine?

To answer this question, I would turn briefly to Margaret Urban Walker’s early article “Moral Understandings: Alternative ‘Epistemology’ for a Feminist Ethics.” I think Walker places the term ‘epistemology’ in scare quotes throughout her article because, like me, she does not aim to develop a moral epistemology in the traditional sense or, as she puts it, “moral

²⁴ Many thanks to the faculty members in the audience of a talk I presented at Drexel University’s College of Nursing and Health Professions in the autumn of 2013 for raising this concern with my project.

knowledge as comprising universal moral formulae and the theoretical justification of these” (Walker 1989, 15). By rejecting the goal of developing a unified moral theory for feminism, Walker hopes her view of moral epistemology “does not imagine our moral understandings congealed into a compact theoretical instrument of impersonal decision for each person, but as deployed in a shared process of discovery, expression, interpretation, and adjustment between persons” (16). Walker goes on in her article to excavate certain modes of moral reasoning that are common in the feminist literature across its many different strands and proposes that an alternative epistemology would include these as a way of opening up ethics to those who have been excluded from it historically.

However, I don’t think that, by suggesting these modes of moral reasoning, Walker has somehow developed a new unified moral knowledge that she would close off from further revision. She explicitly argues that her proposal is an anti-theory of sorts when she states: “Although I’ve cast the discussion here in terms of moral “epistemology,” my point has been that there is a way of looking at the understanding critical to and distinctive of full moral capacity on which this understanding is not really an episteme, not a nomologically ordered theory. From the alternative view, moral understanding comprises a collection of perceptive, imaginative, appreciative, and expressive skills and capacities which put and keep us in unimpeded contact with the realities of ourselves and specific others” (Walker 1989, 21). Yet, even without a unified moral theory, Walker is clearly offering specific moral guidance that goes beyond just criticizing the philosophical status quo. Her suggestions for moral theory are specific, action guiding methodologies for embracing the otherwise marginal moral knowledge to be found in the lived experience of women. Thus, her anti-theory is both critical and constructive, blurring the boundaries of this distinction, “Here the tasks of restoration, reconstruction, and new

construction are not sharply divided; all involve suspension and re-examination of unquestioned assumptions and standard forms” (16).

I hope that my development of a disability moral psychology and epistemology can serve as a way of expanding and developing Walker’s project of exploring new modes of moral reasoning and perception that have so far gone unexamined and not informed the field of bioethics. I do not aim to contribute a new, static moral theory that can be applied to bioethics, but to offer some loosely connected observations regarding themes found in the moral knowledge that has been constructed by the disability movement through the lived experience of disabled people that have developed moral reasoning, perception, and emotion that is informed by their embodiment and social position. This is neither a purely destructive project that fails to offer any constructive moral guidance to bioethics nor is it an attempt to replace the dominant, mainstream theories with an alternative, all-encompassing theory. Rather, it is an attempt to expand the way bioethics is done beyond the mere application of supposedly universal theory. In my next chapter, I will address specific moral concepts and principles that predominate the field of bioethics in an attempt to open them up to new modes of bioethical inquiry that are informed by the moral psychologies of disabled people and the moral epistemology of the DM.

CHAPTER 4: REVISING, OPENING, AND EXPANDING DOMINANT BIOETHICAL FRAMEWORKS

Again taking my cue, in part, from Margaret Urban Walker's development of an alternative "epistemology" for moral philosophy, this next section of my project will describe a "lattice of similar themes" (Walker 89, 16) within the literature of the DM that can be used to begin a critique and an expansion of the dominant bioethical framework. By opening up some of the most widely deployed bioethical concepts so that they better account for disability moral psychology and epistemology, I hope to reduce the alienation of disabled people, who often experience the mainstream field of bioethics as an environment of distrust. My revisions of these popular concepts are not meant to be the cure for all that ails bioethics, but a contribution to a sustained conversation about how the moral framework of mainstream bioethics must change if it is to be inviting to disabled people. Both activists and scholars with disabilities have been criticizing mainstream bioethics for decades, so I will not say that I hope to *begin* this conversation. However, I hope to provide an opportunity to fundamentally shift the terms of this prolonged conversation, so that it can be more fruitful.

Moreover, as I argued in the previous chapter, the social standpoint of disabled people who are cognizant of their marginal social position, as those who participate in the DM are, provides them with some degree of epistemic privilege. Therefore, reconsidering the bioethical concepts under review in terms of the moral knowledge of the DM will not just serve the *political* purpose of reducing the conflict between the DM and mainstream bioethics, but will also serve the *normative* function of improving bioethical thought.

My analysis of these dominant bioethical concepts will be grounded in an excavation of patterns of disabled moral perception, reasoning, and feeling found in a wide variety of the DM's

literature. Of course, this is not to say that if mainstream bioethicists adopted the moral knowledge I am attempting to synthesize in this chapter, the conflict with the DM would evaporate. However, if mainstream bioethics were to take up some of these suggestions en masse, disabled people could engage the field in such a way that more such contributions of disabled knowledge would be forthcoming. Thus, we would see a more sustainable shift from conflict to dialogue.

In the following sections, I offer suggestions for how mainstream bioethics can shift its understandings and applications of the very commonly invoked concepts of autonomy, justice, beneficence, and nonmaleficence to accommodate a moral psychology and epistemology of disability. This is not meant to be an exhaustive list of all the moral concepts used by bioethicists within every tradition. Likewise, even if my suggestions regarding these concepts were taken up by those who teach, research, and practice bioethics, it would still not constitute the sort of radical psychological and epistemological shift bioethics' moral framework needs, but it would be a first step in the right direction.

Accessing Autonomy through the Intervention of Others

As a major focal point of her attempt to find common ground between the DM and mainstream bioethics, Alicia Ouellette rightly argues that both the DM and the profession of bioethics are deeply committed to respecting the autonomy of individual persons. She observes that “disability advocates also share with bioethicists an interest in allowing individuals with disabilities to make autonomous choices and direct their own lives” (Ouellette 2011, 330), providing several examples of how the DM respects individual autonomy from the cases she deployed earlier in her book, to convince readers that the DM really values self-determination for

individuals. Of course, she likely feels the need to assure readers of this because she has characterized so much of the conflict between these two groups as a struggle over the *limits* of personal autonomy, with the DM consistently taking the more paternalistic position (e.g. in its opposition to physician-assisted suicide as discussed in chapter 1). In fact, even when describing this common commitment to autonomy, Ouellette characterizes the conflict in such a fashion: “The fact of the common commitment to self-determination or respect for autonomy by disability and bioethics experts is, in my view, more important than the disagreements about the limitations on autonomy, because the agreement that people with disabilities should have the same right to control their lives as anyone else provides a broad platform from which to search for mutually agreeable limiting principles” (330).

In my view, this framing of the conflict between the DM and mainstream bioethics regarding respect for personal autonomy is deeply flawed and its flaw originates in Ouellette’s failure to recognize the psychological and epistemic differences between these two groups. She—along with virtually all other mainstream bioethicists—characterizes the struggle as a disagreement over the *degree* or *quantity* of autonomy disabled people should have over their lives, when it is clearly about the *kind* or *quality* of the autonomy they should have. Some of the cases she describes are, in fact, quite useful in showing how it is not that the DM somehow believes that disabled people should have *less* autonomy than bioethics would grant them, but that the DM understands and applies the very concept of autonomy to these cases differently from how mainstream bioethics would. In this section, I will explicate in greater detail what the psychological and epistemic differences are regarding the concept of autonomy and how they develop. In sum, the primary difference is that the DM would consider access via the intervention of others to be a necessary condition for individual autonomy in addition to the

criteria of sufficient knowledge and non-coercion that are upheld by the dominant moral framework of mainstream bioethics.

While the principlism most famously described by Tom Beauchamp and James Childress (henceforth referred to as B&C) is not the *only* or necessarily even the most widely used methodology for doing bioethics, their treatment of the concept of autonomy is quite representative of the field. It is important to note that B&C view all of the ethical principles that they are advancing for bioethics, including autonomy, as part of what they term “common morality.” For B&C, common morality is universal in that it is “the set of norms shared by all persons committed to morality. . . . The common morality is applicable to all persons in all places, and we rightly judge all human conduct by its standards” (Beauchamp and Childress 2009, 3). So, for B&C, there may be moral norms that are particular to certain social or cultural groups, but the common morality that they are appealing to in establishing their principles “is found in all cultures . . . [and] is not relative to cultures or individuals, because it transcends both” (4). B&C go on to claim that autonomy and the other principles they describe are a way of organizing and refining this common morality so that it can be applied to bioethics. “The set of moral principles defended in this book functions as an analytic framework intended to express general norms of the common morality that are a suitable starting point for biomedical ethics” (12). B&C argue that the principles they have identified may not be justified in the same way by the dominant competing moral theories existing in the Western philosophical tradition, but such competing theories “accept similar general principles or values, including respect for autonomy, nonmaleficence, and the like” because they all come from the common morality and, hence, often converge on similar solutions to moral problems (362).

However, despite claiming that autonomy is derived from common morality and often converged upon by the full range of theories, B&C recognize “little agreement exists about its nature, scope, or strength” (Beauchamp and Childress 2009, 99). Even with that caveat, B&C claim matter-of-factly, “personal autonomy encompasses, at minimum, self-rule that is free from both controlling interference by others and from certain limitations such as inadequate understanding that prevents meaningful choice” (99). Again focusing on a consensus that has been built among the dominant figures in Western philosophy, B&C move their project forward by observing, “Virtually all theories of autonomy view two conditions as essential for autonomy: *liberty* (independence from controlling influences) and *agency* (capacity for intentional action). However, disagreement exists over the meaning of these two conditions and over whether any additional conditions are required” (100). B&C add the additional requirement of a minimum of understanding a few paragraphs later, but that seems to be the extent to which they seriously consider any other criteria for a choice to qualify as autonomous. They recognize that “some feminist critics fault theories that place an overriding value on autonomy or fail to see communal relationships involved in acting autonomously” but dismiss any view of autonomy that emphasizes relationships as “illuminating and defensible as long as it does not neglect or obscure the main features of autonomy that we analyze in this chapter” (103). So, for B&C, the universally applicable principle of respect for autonomy that they have derived from common morality is a matter of individual agents having a right to “hold views, to make choices, and to take actions based on their own personal values and beliefs” (103) by simply acting “(1) intentionally, (2) with understanding, and (3) without controlling influences that determine their action” (101).

So it seems that the main threats to this widely accepted view of autonomy highlighted by B&C are ignorance and explicit coercion. Thus, to judge whether a person has the opportunity to act autonomously, the bioethicist must simply check to see if they have “a substantial degree of understanding and freedom from constraint” (Beauchamp and Childress 2009, 101). Of course, on this view of autonomy, “constraint” or “controlling influences” are characterized as interference from others with greater power, such as governments or physicians. As B&C illustrate, within bioethics, the physician’s paternalistically influencing the patient’s choice is the paradigmatic case of such a constraint. “We encounter many problems of autonomy in medical contexts because of the patient’s dependent condition and the medical professional’s authoritative position. . . . In these circumstances, the patient’s autonomy is sometimes compromised because the physician has assumed an unwanted degree of authority, as in certain paternalistic actions” (102).

So, B&C put forth a set of criteria for ensuring that individuals have the right to “hold views, to make choices, and to take actions based on their own personal values and beliefs” (Beauchamp and Childress 2009, 103) that they argue are grounded in a universally held common morality and converged upon by “virtually all theories of autonomy” (103), except, of course, for any theories that “neglect or obscure the main features of autonomy that we analyze in this chapter” (103). While the DM has not developed its own comprehensive *theory* of autonomy, it holds a view of self-determination that would find B&C’s criteria—which they are correct in claiming is shared by most mainstream bioethicists—profoundly inadequate. The reason is that B&C’s claim that an action is autonomous if it is intentional, knowledgeable, and independent of outside influence both neglects and obscures a necessary condition for the self-determination of disabled people: access.

To be sure, the DM's struggle for access could be and often is framed according to the moral concept of justice and not autonomy. However, while justice is well suited to describing the political struggle for access by the DM as a group, I believe there is a strong case for conceptualizing access as a necessary criterion for disabled people's ability to "hold views, to make choices, and to take actions based on their own personal values and beliefs" (Beauchamp and Childress 2009, 103). Autonomy in making life choices requires access as a matter of course for everyone; however, disabled people's frequent *lack* of access likely makes them more attuned to this necessary condition for choosing.

Recall my argument from previous chapters that draws upon Owen Flanagan's claim that "different problems make different sorts of considerations and salencies differently relevant" (Flanagan 1991, 234). Since people with different social identities encounter different sorts of problems with greater and lesser frequency because of how their lives are structured, they develop different aptitudes for applying the differently relevant moral considerations and salencies to the problems they encounter. I argue that this difference in how the moral concept of autonomy is understood and applied is an example of exactly this sort of phenomenon.

At this point, a hypothetical would be quite useful in illustrating both how the concept of autonomy could be understood and deployed differently by a disabled person and how that variation in moral psychology might develop. I will deploy what might be thought of as a paradigmatic example of the expression of personal autonomy in American society: career choice.

Let's say that there were three Ph.D. candidates who were wrapping up their dissertations and applying for entry-level, tenure-track philosophy faculty positions. All three were nearly identical in most of the relevant respects. All three studied at universities with similar

reputations, had advisors and recommenders of similar professional stature, and had similar areas of specialization and competence that were in the same level of demand on the job market. They had very similar teaching backgrounds, publication records, and experience presenting at conferences. Also, these candidates had similar social identities regarding race, ethnicity, class, sexual orientation, religion, and gender. For the sake of the hypothetical, let us say that the only relevant difference between the three is that Candidate A is non-disabled, Candidate B has a high level spinal cord injury and uses a power wheelchair, and Candidate C is Deaf and uses American Sign Language (ASL). Let us also assume that no philosophy department to which our candidates might apply has any sort of explicit policy or practice that would intentionally discriminate against any of the social identities held by the three candidates, such that their choice to compete for a position would be unduly constrained or controlled through direct coercion.

As a preliminary step to entering the academic job market, all three candidates must develop and fine-tune their written application materials with the help of their advisor or other faculty in their department. Candidate B must have physical access to the building and room where the departmental workshop to assist graduate students with the development of their materials is being held. Candidate C must have an ASL interpreter present at the workshop. After the workshop, Candidate B must have access to uncommon and expensive computer hardware and software that allows her to craft her first drafts of the materials and email them to her faculty advisors without using her fingers for typing or clicking a mouse.

Once the written application materials are prepared, all three must provide these to faculty along with an email request for letters of reference. Candidate B must again have access

to uncommon and expensive computer hardware and software that allows her to use her computer without using her fingers for typing or clicking a mouse.

Next, all three must diligently scour the internet for job openings that fit their qualifications and develop a list of jobs to apply for. Candidate B must again have access to uncommon and expensive computer hardware and software that allows her to use her computer without using her fingers for typing or clicking a mouse.

The candidates must then apply to faculty openings that suit their credentials via the internet or via postal mail. For the internet applications, Candidate B must again have access to uncommon and expensive computer hardware and software that allows her to use her computer without using her fingers for typing or clicking a mouse. For the mailed applications, Candidate B must attain wheelchair-accessible transportation to the post office or Fed-Ex store and arrange for a personal attendant to accompany her to assist with navigating what is likely to be an inaccessible physical space with inaccessible doors and an inaccessible business counter.

Hopefully, all of the candidates will secure first round interviews on the telephone, via Skype, or in person at the Eastern Division Meeting of the American Philosophical Association (APA). For the telephone interviews, Candidate C must have access to a video phone with an ASL interpreter. For the Skype interviews, Candidate B must have her personal attendant work a couple of extra hours that day to assist with changing into her business suit for the interview and then back into her street clothes; and Candidate C must have access to an ASL interpreter. For the APA interviews, Candidate B must have accessible ground transportation to and from the airport both at home and in the destination city, a personal attendant to travel with her and assist with her activities of daily living at the conference, an accessible conference hotel room, and an

accessible interview space; and Candidate C must have an ASL interpreter for, at minimum, the interviews and any receptions where she is likely to encounter potential employers.

The next step is to travel to respective campuses for final round interviews, including a job talk. To do this, Candidate B must have accessible ground transportation to and from the airport both at home and in the destination city, accessible ground transportation to and around campus, a personal attendant to travel with her and assist with her activities of daily living, an accessible hotel room, an accessible lecture room and AV equipment for the job talk, accessible restaurants for any meals that are taken as part of the interview process, and an accessible interview space; and Candidate C must have an ASL interpreter for the interviews, the job talk, meals, and any other interactions with her interviewers, formal or informal.

If an offer of employment is—I hope—extended to these candidates, access of these sorts will, of course, continue to be necessary for all three candidates to “hold views, to make choices, and to take actions based on their own personal values and beliefs” (Beauchamp and Childress 2009, 103) as professional academics. Access is necessary for all three to make autonomous choices and determine the direction of their lives, and barriers to access exist for all three (gender, race, class, sexual orientation, and other social oppressions and identities also create access barriers). However, I would argue that this matter of access is highlighted in the foreground of the lived experiences of Candidates B and C in a way that it is not the case for Candidate A. As I hope my hypothetical illustrates, through repetition, a disabled person develops the habit of anticipating and, when possible, arranging to circumvent barriers to the access needed to make major life choices. This attunement toward access as a necessary condition to autonomous choice has been habituated through a socially structured experience of living with disability in a social and physical environment that is often largely inaccessible.

While I hope my hypothetical is a useful illustration, the DM's scholarly literature supports this trajectory of thought as well. For example, the importance of disability for specifically highlighting certain elements of autonomy that might otherwise be obscure is also underscored by Jackie Leach Scully's discussion of disability experiences' potential contributions to feminist concepts of relational autonomy:²⁵ "Embodiment and interdependence are realities for everyone, all the time. In a relational view of autonomy, self-determination can never be entirely down to the self because it is constituted in relationship (negotiation, compromise) with others. Under conditions of impairment, however, these universal features are experienced in unfamiliar ways, and they suddenly become more visible" (Scully 2008, 162). While Scully is not specifically using the language of access to describe the features of autonomy highlighted by disability in this passage, her argument that disability makes certain features of autonomy less obscure clearly supports my point. To be sure, there are ways many different social structures of domination and oppression create barriers to accessing certain sorts of choices. Perhaps disability's contribution to bringing these access barriers to the foreground is that it often excludes in ways that are less subtle than modern sexism, racism, or classism. Recalling my hypothetical, the potential of socially constructed disability barriers to close off access to basic communication or physical presence in a built space might make access more of an obvious precondition to autonomy than something like the gendered glass ceiling to career advancement.

²⁵ The alternative view of autonomy I describe in this section and attribute to disabled people in general and the American DM in particular is mirrored by the feminist literature on relational autonomy. In fact, my conception of autonomy that I am developing here could and should be thought of as a subset of relational autonomy developed by feminist philosophers and sometimes applied to bioethical problems. This view of autonomy does not typically use the language of access that I deploy here to highlight the specific contributions of the DM, but it does offer a sophisticated analysis of how personal autonomy is always the result of interpersonal relationships that develop and support the capacity for free choice. For more, see *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. 2000. Eds. Catriona Mackenzie and Natalie Stoljar. New York, NY: Oxford University Press.

Additionally, as I hope my hypothetical illustrates, while barriers to access that deter and sometimes preclude disabled autonomous choice are often quite concrete, sometimes in the literal sense, they are a result of a complex set of oppressive group relationships. This means, as Scully states, that “the ethical requirement to respect autonomy asks for something more substantial than not interfering with a patient’s decisions about treatment options” (Scully 2008, 168). The liberal framework of autonomy that mainstream bioethics has adopted, as evidenced by B&C’s arguments regarding freedom from controlling influence and constraint, focuses on autonomy as a property of the individual that obtains so long as no one with greater power interferes with her otherwise free choice. However, it is not mere *non-interference* that would create access to choice for disabled people living in an inaccessible society. Autonomous choice is often limited for disabled people by a full range of “economic, environmental, social, cultural, and psychological forces of the kind that do not generally feature in mainstream moral philosophy’s discourse on autonomy” (168). Thus, autonomous choice can only be fully respected from a disabled person’s point of view through the *intervention* of others, not their non-interference. These barriers to accessing autonomous choice can be removed through a combination of large-scale political action and the help of individuals, but only through active involvement and intervention in both cases. It is to be hoped that my hypothetical illustrating how the intervention of others that is essential to accessing autonomous choice for disabled people can take a variety of forms in practice. This intervention to provide access can be through ASL interpretation services, the provision of assistive technology, the construction of wheelchair-accessible space, or a myriad of other adjustments, large and small, to the economic, environmental, social, cultural, and psychological forces that Scully argues create access barriers.

A key claim of this project is that the experiences of disability create variation in the moral psychology and epistemology of disabled people as they engage mainstream bioethics. However, I have not yet given an actual example from the literature of the DM of when this has actually happened regarding understandings of autonomy. For such an example, I will turn to Paul Longmore's autobiographical account of fighting for the access necessary to express his autonomous choices, coupled with his ethical analysis of the concept of autonomy as it is deployed in bioethical decision making regarding physician-assisted suicide.

In his essay "Why I Burned My Book," Longmore relates his firsthand experience of struggling for the basic access that allowed him to pursue his educational and career goals. An implicit critique of the traditional liberal understanding of autonomy is embedded in this account of his personal struggle, which is introduced with the claim: "We are instructed that if we too adopt an indomitable spirit and a cheerful attitude, we can transcend our disability and fulfill our dreams. It is a lie. The truth is that the major obstacles we must overcome are pervasive social prejudice, systematic segregation, and institutionalized discrimination. Government social services policies, in particular, have forced millions of us to the margins of society. Those policies have made the American Dream inaccessible to many disabled citizens" (Longmore 2003, 231). As Longmore relates his experience, it becomes clear that he is using the term "American Dream" as shorthand for something very close to autonomous choice in career prospects, as the essay is about his struggle to access what he needed to realize his "rather simple personal dream . . . to write about American history and teach it to college students" (232). Further, Longmore describes how his decades-long struggle for autonomous choice centered around his need for access to essential services and technologies. These included a personal attendant to "do the housekeeping and assist me with tasks like showering, shaving, dressing,

and eating” and the rental of a ventilator that he used much of the time because of his spinal curvature (236).

To access these services and technologies, which would have cost him about \$20,000 a year while he was completing his Ph.D. and \$45,000 by the turn of the millennium, Longmore drew upon publicly funded programs that only those who receive SSI or SSDI are eligible for. As he observes, without these programs, Longmore would not have attained his goal of becoming an American political history professor, but “would have had to spend my adult life in some sort of nursing home” (Longmore 2003, 236). However, the difficulty for Longmore and many other disabled people is that the provision of these supports and technologies is contingent on their refraining from making certain autonomous choices. Namely, what is known as “work disincentives” are built into the programs that support disabled people’s ability to live in their own homes rather than nursing homes or other institutional settings. Longmore describes this contradictory policy that purportedly gave him access “to life and to work” while, at the same time, meaning that “in order to maintain eligibility for this governmental aid, I had to refrain from work” (236). This is because the federal government defines eligibility for this sort of assistance as an inability to engage in paid work. Thus, in order to get the sort of access a disabled person needs to make autonomous choices about the sort of life they want to live, they must sometimes severely restrict the range of those choices to an excessively narrow vision that does not include any of the ways of life aspired to by most of their non-disabled counterparts (236).

Ultimately, Longmore’s chapter is both an autobiographical narrative of his struggle against this contradictory policy—culminating in a public burning of his first scholarly book in protest of federal rules that would not allow him to collect royalties from it and still retain his

homecare and ventilator—and a careful historical and political explanation of how and why this policy developed in this way. For my project, the important take-away from this piece is the thought that this struggle for access to the support and technology that would allow Longmore to make basic autonomous choices was “the fundamental problem of my adult life” (Longmore 2003, 236). Further, it is important to note that the barriers to Longmore’s personal autonomy could not be easily framed as the sort of “controlling interference from others” (Beauchamp and Childress 2009, 99) that the dominant understanding of the concept warns against. The greatest threat to Longmore’s autonomy is not that others with more power were *interfering* with his choices but that those with power systematically and consistently *refused* to be involved in supporting these choices. As I hope my hypothetical illustrated, disabled people are constantly confronted with access barriers to their autonomy. My hypothetical case offered a brief snapshot of how someone might be habituated to understanding access as a necessary condition for autonomous choice, whereas Longmore’s chapter captures decades of such a socialization process.

Still, I don’t think this process describes the development of any sort of alternative moral “global voice” that would approach *all* moral problems with a radically distinct understanding of the concept of autonomy. To be sure, while Longmore and others are more attuned to the necessity of accessibility through the intervention of others, this does not mean that disabled people somehow reject the notion that there can be direct coercive forces that interfere with autonomous choice through the interference of others that restrict free choice. Generally, the DM is quite aware of historical abuses to autonomy through the interference of the government and others with power. As an historian, Longmore is especially aware of these coercive practices which he lists as part of a description of disability oppression:

People with mental retardation, epilepsy, or cerebral palsy were often permanently institutionalized as dangers to society. Others with physical disabilities were at times segregated by such ordinances as Chicago's "ugly law." Reacting to a growing Deaf subculture, an "oralist" movement began in the 1880s to oppose sign language and to insist that deaf people learn speech and speech reading. Led by Alexander Graham Bell, the oralists took over deaf education and sought to disperse the deaf community. Eugenacists lobbied for sterilization of people with various disabilities. By 1931, more than half the states had adopted sterilization laws. Proponents of euthanasia advocated putting to death people with certain kinds of disabilities, an idea implemented in Nazi Germany under the T-4 Euthanasia program. (Longmore 2003, 206)

Many of these are clear examples of external coercion that interfered with the autonomy of disabled people, all of which would assumedly also be condemned by B&C's principle of respect for autonomy because of their explicitly coercive nature. So, it is not that the moral concept of autonomy is *always* applied differently by those who have this alternative understanding of it.

However, there are also some circumstances in which access through the intervention of others becomes a necessary condition for autonomous choice without being recognized by non-disabled mainstream bioethicists who have constructed and remain committed to the dominant moral framework that does not typically consider the relevance of access to autonomy. For an example of how an alternative understanding and application of autonomy bears out in a disabled person's bioethical thinking, let us return to Longmore's work on physician-assisted suicide (PAS) that we first explored in Chapter 1. Here, we find the clearest instance of Longmore's deploying his habituated conception of autonomy that is attuned to access via the intervention of others to analyze a problem in bioethics.

Longmore finds deep fault with the typical liberal conception of autonomy that has predominated the field of bioethics and appears to lend support for PAS for patients who have the appropriate cognitive capacities, enough knowledge of their available options, and are not being actively coerced by the interference of others. His critique, at its heart, is not a claim that personal autonomy is an irrelevant principle or that it should be curtailed when it comes to PAS. Rather, he is arguing that the very conception of autonomy being used is flawed because it does not include access via the intervention of others as a necessary condition in addition to rationality, information, and non-interference. Without including this other criterion, which Longmore has come to prioritize through his own personal experience of having his autonomy restricted because of a lack of access, he argues that any choice favoring PAS will not be fully autonomous: “Health care ‘choices’ are never made in a vacuum. Given the absence of real options, death by assisted suicide becomes not an act of personal autonomy, but an act of desperation. It is a fictional freedom, it is a phony autonomy. The rhetoric of ‘choice’ is deployed to hide the realities of coercion” (Longmore 2003, 195). Here, the “coercion” Longmore is referring to is not the sort of interference that B&C’s arguments safeguard against, but a social structure that makes options that are better than death entirely inaccessible to some disabled people.

Longmore’s analysis of an actual PAS case will help us unpack exactly what he means by coercion in this instance and highlight the important role played by access through intervention in respecting the autonomy of people with disabilities. In “The Strange Death of David Rivlin,” Longmore’s main thesis is that “David Rivlin’s 1989 court-sanctioned, physician-assisted suicide exemplifies the social conditions that drive some disabled persons to their deaths and the ignorance and bias of some nondisabled people that lead them to support such suicides”

(Longmore 1991, 615). When Longmore specifies the conditions Rivlin found himself in, it becomes clear that he is referring to a lack of access to viable choices driven by a lack of intervention by others, specifically the state. Longmore cites Rivlin as maintaining that it was not his disability *per se* that motivated him to request assistance in dying, but a lack of access to the means a disabled person would need to choose common lifestyle options like work, marriage, family, and social interaction. Longmore points out that there is a broad variation between American states in the amount and type of funding available to disabled people who want to live in the community rather than in a nursing home such as Rivlin lived in for several years before he requested help to die. Longmore argues that Rivlin's home state, Michigan, was at the very low end of this spectrum at the time and did not provide access to the resources needed for the self-determination of someone with quadriplegia who uses a ventilator (615).

Clearly, Longmore's personal experience of disability has habituated him to think about autonomy differently from how a non-disabled observer of this case might. Rather than relying on the mainstream view of respecting personal autonomy by merely not interfering with individual choice, Longmore's personal experience and bioethical argumentation lay out a view of autonomy that adds the necessary condition of access to choice through the intervention of others. In his words, it is essential that society provide disabled people with both "the right *and the means* to control those lives" (Longmore 1991, 615, emphasis added).

Of course, Longmore is just one case of a scholar-activist who has experienced disability and developed an alternative way of conceptualizing and applying autonomy to bioethical problems. However, this correlation between opposition to assisted suicide and support for access to the means of self-determination for disabled people also bears out in the explicit policy positions of many organizations that represent the disability movement. From chapter 1, recall

Carol Gill's list of the largest Disability Movement organizations that have adopted official positions against PAS: the National Council on Disability, American Disabled for Attendant Programs Today (better known as ADAPT), the National Council on Independent Living, World Associations of Persons with Disabilities, Justice for All, the Association for Persons with Severe Handicaps (better known as TASH), the National Spinal Cord Injury Association, and the World Institute on Disability (Gill 2000, 526). All but one of these organizations²⁶ have also explicitly called for the end of what is referred to as the *institutional bias* in long term care policy that makes accessing long term care in the community much more difficult than attaining admission to a nursing home or other institution that precludes self-determination in most other areas of a disabled person's life. I would argue that this widespread opposition to PAS, coupled with equally widespread support of public policy that would give disabled people access to the means by which they could make major life choices, is evidence of the DM's overarching commitment to access through the intervention of others as a necessary condition for personal autonomy, in addition to the criteria regarding information and noninterference endorsed by the dominant moral framework of mainstream bioethics.

Ultimately, I am arguing that the lived experiences of disability in an often inaccessible world attunes a person to the importance of accessing certain sorts of choices through the intervention of others and this, over time, habituates that person toward a view of autonomy that

²⁶ Long Term Services and Supports: National Council on Disability http://www.ncd.gov/policy/long_term_services; ADAPT: Community Choice Act <http://www.adapt.org/ccca>; NCIL: Legislative & Advocacy Priorities Guide <http://www.ncil.org/wp-content/uploads/2014/02/PolicyPrioritiesFebruary2014.pdf>; "Statement of the National Disability Leadership Alliance on the 23rd Anniversary of the Signing of the Americans with Disabilities Act" (formerly the Justice for All Action Network) http://www.disabilityleadership.org/index.php?option=com_content&view=article&id=41; 2010 TASH National Agenda <http://tash.org/about/initiatives/>; National Spinal Cord Injury Association: Support Greater Access to Community-Based Services for Wheelchair Users <http://www.spinalcord.org/support-greater-access-to-community-based-services-for-wheelchair-users/>; World Institute on Disability: Mission, Vision, and Values http://wid.org/about-wid/copy_of_mission-vision-and-values all accessed on 3-2-14

does not merely exist so long as others do not interfere. Thus, when disabled people with this alternative way of understanding and applying autonomy come into contact with bioethical problems, they often resolve them in ways that are quite different from what is seen in the mainstream. However, it would be a mistake to characterize the DM's alternative view of autonomy as a more narrow view that would limit the range of acceptable personal choices. Rather, it is a view of autonomy that places these personal choices into the context of an inaccessible social environment and calls for the intervention of others to help gain access to a *broader* range of choice. This is not only true for disabled people, but for anyone, especially members of marginalized groups that face social barriers to choices others enjoy.

It might be objected that the view of autonomy that I am advancing has this principle confused with the widely deployed ethical concept of *justice* because access via the intervention of others could be justified with appeals to arguments for equality of opportunity or a fair distribution of resources. To be sure, the sorts of access I describe in this section with my hypothetical case of the job candidates and my descriptions of Longmore's personal life and ethical analysis of PAS are very much matters of justice. Careful arguments deploying both formal justice and distributive justice to defend a person's right to these sorts of access have been constructed in the philosophy of disability literature.²⁷

However, it does not follow that access to choice via the intervention of others is an incoherent or indefensible necessary condition for autonomous choice. If it were the case that the criteria for autonomy needed to be completely conceptually divorced from theories of justice, then at least one of the necessary conditions for autonomous choice advanced by B&C and

²⁷ For, perhaps, the most sophisticated comparative account of how various systems of justice might justify the political agenda of the most prominent members of the DM, see: Silvers, Anita; David Wasserman, and Mary B Mahowald. 1998. *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy*. Lanham, MD: Rowman & Littlefield Publishers, Inc.

widely embraced by mainstream bioethics would also be precluded. Namely, the criterion of non-interference or non-coercion is also often justified by and is conceptually tied to justice. Slavery is, perhaps, the paradigmatic example of coercion that interferes with autonomy. American history is rife with the stories of slaves who have had their ability to make even the simplest of choices taken away from them by the interference of others via violence or threat of violence.²⁸ Like justifications for access for disabled people, the most powerful arguments against slavery would draw upon theories of justice, including equality of opportunity and the fair distribution of resources. Neither of these contemporary or historical appeals to justice, in calling for widespread social change to grant access to choice for disabled people or the abolition of the coercive institution of slavery, in any way undercut the validity of either access to choice via the intervention of others or non-interference from the coercion of others as necessary criteria for respecting—or perhaps more accurately promoting—autonomy.

In some sense, with its alternative view, the DM is arguing that it is impossible to unhitch a respect for autonomy from concerns regarding justice, but this is not without precedent. Therefore, I will not balk from using similar examples in my next section that takes up the DM's concept and application of justice.

Healthcare Justice via Multifunctionalism and the Replacement of Normal Function

As I have tried to reinforce throughout this project, disabled people do not have a fundamentally different set of moral concepts resulting from a distinct disabled moral voice. Thus, it is not surprising that the scholars and activists of the DM appeal to many of the theories of justice that have been developed by the prominent moral and political philosophers of the Anglo-American tradition. For instance, many of the political goals of the DM have been

²⁸ For a first person account of the coerciveness of American slavery that has enjoyed a recent popular resurgence, see: Northup, Solomon. 1853 and 2013. *Twelve Years a Slave*. Vancouver, Canada: Inklight Publishing.

justified with appeals to equality of opportunity,²⁹ the fair distribution of resources,³⁰ and the development of capabilities.³¹ Yet, as we will see, applications of these same sorts of theories of justice to problems in healthcare ethics by mainstream bioethics has largely resulted in a deepening of the rift between the DM and mainstream bioethics.³² The reason is that, here as with the principle of autonomy, the lived experience of disability habituates people toward applying the moral concept of justice to different sorts of problems in different ways from most non-disabled people. In this section, I will argue that most of the conflict between the DM and mainstream bioethics over healthcare justice originates in mainstream bioethics' strong commitment to applying the concept of justice only in the service of *normal function*. By making the widespread achievement of normal function the primary goal of mainstream theories of health care justice, professional bioethics has mostly ignored and sometimes even actively opposed many of the political goals of the DM. After outlining this point of conflict, I will propose that, rather than assuming normal function is a necessary condition for equal opportunity that must be restored and maintained by healthcare, a theory of healthcare justice would be greatly improved by the premise that equality of opportunity can be promoted by *either* restoring, maintaining, *or replacing* normal function.

²⁹ Silvers, Anita. 1998. "Formal Justice" In *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy*, Anita Silvers, David Wasserman, and Mary B Mahowald. Lanham, MD: Rowman & Littlefield Publishers, Inc.; and Wong, Sophia. 2009. "Duties of Justice to Citizens with Cognitive Disabilities." *Metaphilosophy*. 40(3-4): 382-401.

³⁰ Wasserman, David. 1998. "Distributive Justice." In *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy*, Anita Silvers, David Wasserman, and Mary B. Mahowald. Lanham, MD: Rowman & Littlefield Publishers, Inc.

³¹ Nussbaum, Martha. 2006. *Frontiers of Justice: Disability, Nationality, Species Membership*. Cambridge, MA: Harvard University Press

³² For an example of this conflict, see the political response of the disability movement to arguments for healthcare rationing, such as: Mailhot, Alice. 1994. "Bioethics: Introduction to Theories from Hell." *Mouth Magazine*. Accessed on the internet on September 15, 2012 at: <http://www.cilt.ca/Documents%20of%20the%20CILT%20Website/Bioethics.txt>

The enormously influential Norman Daniels has articulated his theory of healthcare justice for decades, arguing that individuals' need for normal functioning ought to justify a more equitable balance of social resources devoted to treating and preventing disease. To make this argument that more equal access to health care deserves our attention as a matter of justice, Daniels needs to first define health care as distinct from other sorts of social goods and then give an argument for why equitable access to it, in particular, promotes greater justice. Daniels argues that a theory of health care justice must accord a special status to healthcare by answering this question about health care: "Is it morally important in ways that justify (and explain) the fact that many societies distribute health care more equally than many other social goods?" (Daniels 2002, 6). In reply, he argues that healthcare must be conceptually distinct from other social goods and of greater moral importance than many of them. To establish this distinction and justification, Daniels turns to the notion of normal functioning, "Specifically, the central function of health care is to maintain normal functioning. Disease and disability, by impairing normal functioning, restrict the range of opportunities open to individuals. Health care thus makes a distinct but limited contribution to equality of opportunity" (6). Daniels goes on to more fully flesh out what he means by equality of opportunity, as it relates to normal functioning, "Specifically, by keeping people close to normal functioning, health care preserves for people the ability to participate in the political, social, and economic life of their society. It sustains them as fully participating citizens—normal collaborators and competitors—in all spheres of social life" (7). Daniels's argument that health care restores and maintains normal function brackets what health care *is* by defining what it *does*. Simultaneously, Daniels places 'normal function' in a position of primary importance for justifying why society ought to provide fairer access to health care: it is a necessary condition for equal opportunity. So Daniels argues that,

since normal function is necessary for equality of opportunity, “any theory of justice that supports a principle assuring equal opportunity (or giving priority to improving the opportunities of those that have least opportunity) could thus be extended to health care” (8).

Here we see that it is not only the disability movement that argues autonomy is closely dependent on justice. Daniels too proposes that equal access to an adequate range of life choices is the primary justification for a more fair distribution of healthcare resources. “By maintaining normal functioning, healthcare protects an individual’s fair share of the normal range of opportunities (or plans of life) that reasonable people would choose in a given society” (Daniels 2002, 7). In his own way, Daniels is arguing that health care protects autonomous action and so ought to be distributed more fairly.

The division arises, however, because of Daniels’s basic premise that normal functioning is a necessary condition for people’s “ability to participate in the political, social, and economic life of their society” (7). At its very essence, the disability movement is a rejection of this assumption because it argues that individuals who, by definition, do *not* have normal functioning can and should still have access to this normal opportunity range via social accommodation and intervention. The DM is largely constituted by political action aimed at divorcing the normal opportunity range from any prerequisite normal function.³³

This rejection of normal function as a necessary condition for social participation in favor of accommodating *alternative* function is deeply embedded in the DM’s ideology because it is deeply embedded in the experiences of disability. Recall from Chapter 3 Scully’s use of Bourdieu’s concept of habitus to describe how a human being’s experience is “cognitively

³³ One of the most sophisticated accounts of the disability movement’s appeal to equality of opportunity frames the argument in terms of the social accommodation of atypical function being morally required by formal justice: Silvers, Anita. 1998. “Formal Justice” In *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy*, Anita Silvers, David Wasserman, and Mary B. Mahowald. Lanham, MD: Rowman & Littlefield Publishers, Inc.

structured, through bodily processes that originate in the social world” (Scully 2008, 65). More specifically, Scully explains, “Bourdieu is trying to articulate a way in which a physical body interacts with a social world to generate meaning. The individuality of this production derives, in part, from the specifics of the body: what the constraints of biology and physics allow the body to do, and the possibilities that are open to *that* kind of body in *that* social organization” (67).

Disabled people have generated meaning through their embodied experience of alternative function and social accommodation. The fact of the matter is that people with permanent, incurable disabilities living in a largely inaccessible world still *do* participate in that world and are very aware that their participation is often more fully realized through modifications in the social arrangement than it is through burdensome or futile attempts to mimic normal function. If there is any shared experience of disability, it is the common experience of finding ways to adapt one’s mode of function and one’s environment atypically to allow for the sorts of participation in the social milieu that Daniels urges we protect with healthcare. It is no wonder that this repeated, pervasive experience would alienate the DM from the notion that normal function is necessary for social participation such that it ought to motivate considerations of justice in healthcare.

Daniels or others with this common view of health care justice may reply to members of the DM that the reliance of mainstream views of healthcare justice on normal function does not diminish the DM’s justice claims in any way because the sorts of atypical functional, environmental, and social remedies they seek in order to participate equally in the social milieu are simply not matters of health care. They might tell the DM that the normal function provided by health care is one of many conditions required for equality of opportunity and that the conditions they require as disabled people would be provided by other, non-health care related means. Surely, this response is partially correct. It is true that many of the social remedies that

would provide equality of opportunity for disabled people are not most accurately defined as health care. Many of the more frequently encountered accommodations that already exist in some instances, like wheelchair accessible public transportation or sign language interpretation of public events, are not instances of the provision of health care.

However, this response from mainstream bioethics is far from complete because, in fact, some of what many disabled people need to participate equally in the social milieu *is* commonly characterized as health care. Some clear examples of health care that allow for disabled people to participate in the social milieu would be access to mobility aids like wheelchairs or community based long term care to assist with the tasks of daily living without institutionalization. When theories of health care justice inextricably bind normal function to equality of opportunity as an argument for supporting fairer access to health care, these sorts of mechanisms for supporting atypical function and social participation are easily overlooked. So long as there are some sorts of health care that are needed by disabled people for full social participation *with and through* their atypical function, mainstream theories of health care justice that rely on normal function for their justification will remain inadequate. This response from mainstream bioethics that the means of equality of opportunity sought by disabled people are not matters of health care justice also ignores the deeper critique that any theory that claims normal function is a necessary condition for equality of opportunity is inevitably opposed to the equality of opportunity sought by the DM, regardless of whether we characterize the means toward this equality as health care or not.

Before fully laying out my case that a theory of health care justice that relies on normal function ignores or opposes considerations of the equality of opportunity for disabled people, I want to acknowledge a related critique of mainstream theories of health care justice's treatment

of the rationing problem. This critique, also originating from within the DM, points out the potential—sometimes seen in practice—for the methods of cost containment that nearly always accompany theories of health care justice to unfairly “ration out” disabled people. The critique is: if a theory of justice aimed at maintaining or producing normal function and hence equality of opportunity and quality of life must somehow set limits on an indefinite amount of health care want and need, it will attempt to maximize its efficiency partially by withholding health care from those who are permanently disabled and will always function atypically.³⁴ Of course, this critique is of great priority to the DM and deserves serious consideration. However, I am not going to focus on it here. This is because I am not entirely convinced of the inevitability of the rationing out of disabled people by theories of health care justice that rely on normal function, especially if, as Daniels’s does, the theory prioritizes the health care needs of the least well off, which could, at least in principle, be interpreted as meaning those who are perceived as the most “severely”³⁵ disabled. What’s more, even a theory of health care justice that took into account the socially constructed barriers to the social participation of people with disability, and did not simply conflate normal function with equality of opportunity, would still need some sort of method for prioritizing the use of limited health care resources. This prioritization would, in effect, be a rationing process and I would not want to take the relevance of *any* sort of disability completely off the table for this prioritization process.³⁶

³⁴ For a more sophisticated and nuanced explanation of this critique, see: Bickenbach, Jerome. 2002. “Disability, Justice, and Health Systems Performance Assessment” in *Medicine and Social Justice: Essays on the Distribution of Healthcare*. New York, NY: Oxford University Press.

³⁵ Here I am deliberately using scare quotes around “severe” to indicate that I am only repeating a term that is widely used to describe some sorts of disability because I am not aware of any better alternatives for identifying the group who may be seen as at the greatest risk for being rationed out. However, I do not fully endorse its usage in everyday speech because of its vagueness and potential to contribute to a social hierarchy within the DM.

³⁶ In the very extreme case, for example, if there were an individual with a clearly diagnosable disability that was certain to shorten their life expectancy (e.g. Duchenne Muscular Dystrophy) who would also benefit medically from a kidney transplant, it may be plausible that others who did not have this additional risk of decreased life expectancy

Instead, my argument will focus on how a theory of health care justice based on normal function will ignore the role health care should play in promoting the equality of opportunity of disabled people who function atypically and, if it remains self-consistent at least, will actively oppose the philosophical underpinnings and the political goals of the DM. Ultimately, a theory of health care justice that understands normal function as a necessary condition for equality of opportunity has the potential to actually *reduce* equality of opportunity for disabled people.

Anita Silvers gives an interesting argument showing how a theory of health care justice that assumes normal function is required for equality of opportunity can actually thwart this goal by narrowing the range of choices a patient can make within the confines of this theory. Her book chapter “Bedside Justice and Disability: Personalizing Judgment, Preserving Impartiality” makes the argument that each patient should be seen as an individual with her own conception of the good life that can help determine the treatment plan that will maximize her equality of opportunity, regardless of whether it moves them closer to normal function or not.

She points out that assuming normal function is necessary for equality of opportunity is an example of unfairly privileging a certain, narrow mode of functioning and closing off other choices that others may wish to make that better fit the life goals they wish to pursue. “Whose preferences about modes and levels of functioning justly take precedence in determining what medical services a patient should get – the patient’s? the medical professional’s? the dominant social group’s?” (Silvers 2002, 236). In answer to this rhetorical question, Silvers argues that our society tolerates pluralism in conceptions of the good as central to the question of justice and so we ought to extend this pluralism to develop a concept of “multifunctionalism” in which we support “the equivalent value of various modes of performing such important human functions as

might be of greater priority for receiving this very limited resource. It does not follow, however, that *anyone* with *any* sort of disability ought to be given lesser priority in the rationing of organs for the sake of efficiency.

mobilizing, socializing, acquiring information, and communicating” (236). By justifying health care justice only in terms of preserving or restoring normal function, mainstream bioethics has not supplied a theory that can account for this sort of multifunctionalism and allow for the fullest range of choices in treatment options.

Like many scholars associated with the DM, Silvers is making the move to divorce the notion of normal function from the concept of equal opportunity range in favor of the idea that many modes of function are compatible with an equal opportunity range, especially if those alternative modes of function are equally supported by considerations of justice. Silvers suggests that we can still pursue the equal opportunity range as an overarching goal of medicine, while respecting the pluralism that exists within the sorts of choices people may make about the specific goal of their treatment plan as it relates to their mode of functioning. That is, different people need different modes of functioning to open up different opportunities in different social contexts. Silvers even argues that, for disabled people, many times a mode of functioning that is closer to so called normal function is actually *less* conducive to full access to equal range of opportunity. This is why she endorses the notion of multifunctionalism.

For Silvers, this is especially true in rehabilitative medicine – as opposed to acute or preventive – as it is the branch that pertains most directly to restoring or increasing functioning for disabled people who may find alternative, atypical function to be more conducive to maximizing their range of desirable opportunities. She sees this area of medicine as the largest threat to multifunctionalism as the goal of healthcare justice is sought (Silvers 2002, 243). Her examples are, accordingly, drawn from this domain. She offers the instance of a college student who is coerced into receiving counseling as a tradeoff for the continuation of service because he prefers to mobilize with a wheelchair rather than go through the arduous process of learning to

use a prosthetic leg. She points out that this student chose his mode of functioning based on his particular circumstance as a student on a large and often wheelchair accessible campus, because he valued “moving efficiently more than moving in a species-typical mode” (243). For this student and many other disabled people, normal function does not equate with equality of opportunity but would, in fact, pose a significant barrier to this goal. Expending the time and effort to become adept at using prosthetic legs would surely detract from his studies and other life opportunities, while offering very little additional opportunity that could not be accessed via wheelchair.

A theory of health care justice that assumes the restoration or maintenance of normal function is essential for equality of opportunity, if it were to remain consistent, could not allow—or at least could not justify—the sort of multifunctionalism Silvers is defending in her essay. The mainstream theory does not seem to fully confront this flaw. Daniels glosses over some important instances where health care provides access to equality of opportunity without restoring or maintaining normal function. One example of this is his treatment of the problem of long term care: “It follows from the equality of opportunity account of just health and health care that long-term care is just as important as acute care. Both have the same function: protecting an individual’s share of the (age-relative) normal opportunity range. Nevertheless, in many health-care systems in both developed and developing countries, long term care is undervalued. As a result, the needs of many people with disabilities, regardless of age, have not been met fairly” (Daniels 2008, 176-177). Here, Daniels correctly identifies the provision of long-term care as essential to the equality of opportunity of disabled people, as I have argued above. However, he makes the mistake of assuming that, since it is important to equality of opportunity, it must be justified by his theory of health care justice. In fact, the provision of long-term care is not

justified by his theory because it does not, by its very definition, maintain or restore normal function.

Acute care, preventive medicine, and rehabilitative medicine are very often aimed at maintaining or restoring normal function. However, long-term care is provided to people who, through aging, injury, or genetics function atypically in some way and need assistance with some tasks of daily living in order to survive. The care is *long-term* because it does not restore normal function, but rather supplements atypical function for an extended period of time. So, although he is not recognizing this unfortunate and unintended consequence of his theory, Daniels's argument itself undervalues long-term care and is not equipped to provide reasons that would fully justify its provision.

Not only does Daniels's reliance on normal function make his theory ill equipped to justify the provision of long-term care generally, but this feature makes the theory altogether inadequate for distinguishing between the moral implications of the different modes of long-term care, as well. Daniels does gesture toward the notion that there are different models according to which long term care may be provided: "In some universal access systems, like the Canadian and some European systems, long term care services, including many social support and home services, are already incorporated in the benefits package" (Daniels 2008, 177). However, Daniels's does not morally distinguish between home or community based long-term care and more typical institutional settings.

As I have argued, community based long-term care is *prima facie* morally preferable because of considerations of equality of opportunity. Most institutional settings, such as nursing homes, are so isolating that many of the civil rights protections and accessibility requirements of the Americans with Disabilities Act are pointless for their residents, who rarely have prolonged

access to the world outside of the institution. Thus, community based long-term care for those who need it is seen by members of the DM as a fundamental prerequisite to any access whatsoever to the normal opportunity range. Yet, even if Daniels were to recognize this and support community based care rather than institutional care, it would have to be on grounds other than those established by his theory of health care justice. The reason is that there is nothing, in principle, about community based long-term care that restores or maintains normal function any better than providing these services in an institutional setting would. Thus, it can be seen how this dominant theory of health care justice again fails to fully justify the provision of the sorts of health care that are most sought after by the disability movement, whose members, by definition, are unlikely to be restored to normal function but still seek equality of opportunity through various sorts of health care.

Further, this commitment to the notion that normal function must be protected by health care because it is necessary for equality of opportunity holds an implicit criticism of some of the most fundamental goals of the disability movement, which aims at promoting the autonomy and equality of disabled people. Recall from my second chapter Ron Amundson's complaint that bioethics as a whole is biased against the goals of the disability movement, due to its failure to grasp and adopt the social model of disability—the theoretical foundation of the Americans with Disabilities Act, which affords the strongest civil rights protection available to disabled people in the U.S. (Amundson 2005, 102). Amundson is not arguing for the *truth* of the social model as the only viable way to conceptualize anything about the causation of disability; he remains open to the idea that the medical and social models of disability may “present a false dichotomy, each attending to only one aspect of disability” (102). However, he contends that the medical and social models of disability are not merely explanatory, but deeply *ideological* in that “contrasting

causal accounts of the same phenomenon (here disability) serve and harm the interests of different groups of people. A causal account that depicts a social phenomenon as natural and inevitable (or changeable only at great cost) works to the advantage of the people who benefit from the phenomenon, and to harm of the people who are hurt by the phenomenon. When the same phenomenon is depicted as artificial and changeable, the reformist interests of those harmed by the phenomenon are served” (103).

In this same essay, Amundson turns to Norman Daniels’s theory of health care justice as an example of a prominent mainstream theory in bioethics building on the problematic assumption that the harms of disability are natural and inevitable. The theory thus unfairly advantages those who benefit from these harms. “The very purpose of the ADA is to remove barriers to opportunity that disadvantage ‘abnormals,’” writes Amundson. “To assume that ‘normal opportunity range’ is available only to a narrow range of body types is to assume that the Social Model is false and the ADA fruitless. . . . The assumed ‘naturalness’ of the linkage of normality to opportunity harms the interests of disabled people, just as the linkage of race and sex to opportunity has been harmful to other disadvantaged groups. . . . The notion that opportunity is *by definition* out of the reach of disabled people is rightly rejected by them, just as the same claims were rejected by women or minorities” (Amundson 2005, 107-108).

Clearly, Amundson’s argument is much more fundamental than those I advance above. By binding normal function to equality of opportunity, he charges, Daniels is creating a theory that is unavoidably at odds with the bedrock theoretical assumptions of the disability movement. In effect, Amundson is arguing that Daniels’s theory is inescapably anti-disability rights because it assumes that normal function is required for equality of opportunity, while the DM works to divorce these concepts from each other in both thought and action.

At best, Daniels's theory of health care justice fails to justify the provision of certain sorts of health care that promote equality of opportunity without normalizing function; at worst, his assumption that normal function is required for equal opportunity is implicitly an anti-disability rights political position. The question then becomes: how can health care resources be allocated in a just way that does not assume that normal function is necessary for equality of opportunity, but instead takes the moral experiences, reasoning, and knowledge of the members of the DM into account?

To answer this question, we should turn back to the reasons Daniels gave for wanting to tie normal function to equality of opportunity in the first place. Daniels premised his argument on the notion that normal function was required for equality of opportunity because he needed a way to define health care as distinct from other sorts of social goods and then give an argument for why equitable access to this particular social good promotes greater justice. Thus, he defines health care as a phenomenon that restores or maintains normal function and then argues that normal function is needed for a normal range of opportunity, which is required by the principle of justice.

To be sure, the DM does not and should not take issue with the idea that equalizing access to health care is justified, at least in part,³⁷ by concerns of equality of opportunity. The examples referred to above such as adaptive mobility equipment like wheelchairs or community based long term care are all sought by disabled people largely because of their potential to provide greater access to social participation. Equal social participation is perhaps the

³⁷ There are likely other justifications for more equal access to health care that would be defensible in a way that accounts for the moral reasoning and knowledge of disabled people as well. For example, health care that relieves extreme suffering, even if it does not provide increased equality of opportunity, may justify more equal access to health care for disabled people and non-disabled people alike. However, these considerations are beyond the scope of this project.

overarching goal of the DM's decades-long struggle and access to various forms of health care have been an essential component of that goal.

However, even if the DM grants that Daniels is right that the provision of health care is important to promote justice because it promotes equality of opportunity, we are still left with the problem of determining how health care does this in a way that is distinct from other social goods that serve this function, like education, for instance. So, if it is not that health care promotes equality of opportunity by maintaining or restoring normal function, there must be another way to define it for there to be any possible argument for *health care* justice.

The solution to this dilemma is to recognize that health care does not *only* promote equality of opportunity by maintaining or restoring normal function. Often, health care promotes equality of opportunity by *replacing* normal function with other modes of function that also can grant access to the social milieu.

Silvers's concept of multifunctionalism can give us guidance here. Multifunctionalism is not an argument against the notion that normal function can be important to equality of opportunity, but against the idea that *only* normal function can and should be sought by medicine in order to achieve an adequate opportunity range. Embracing multifunctionalism would mean that mainstream health care justice would need to be premised on "the equivalent value of various modes of performing such important human functions as mobilizing, socializing, acquiring information, and communicating" (Silvers 2002, 236).

Surely, these various modes of function would include normal function as well as the alternatives. Further, Silvers would not be alone taking the broad stance that it is sometimes appropriate or even necessary for the goal of health care to be the maintenance or restoration of normal function. For instance, not even the most committed advocate for the social model of

disability would argue that, all else being equal, a person diagnosed with lymphoma should not seek treatment for it that could bring her into remission and prolong her life. Such treatment could plausibly be understood as a restoration of normal function that a multifunctionalist approach to health care would fully endorse in most conceivable circumstances.

A commitment to multifunctionalism would depart from the mainstream view of healthcare justice by justifying the use of health care to produce other various modes of function to replace normal function in order to access a larger portion of the range of opportunity.³⁸ Mobilizing with a wheelchair is very different from walking. It requires a different set of skills and the movement itself is not very similar. In fact, wheelchair use is so different from walking that it would be absurd to characterize the provision of a wheelchair as maintaining or restoring normal function. Rather, a version of health care justice that draws on multifunctionalism could very well justify providing such a mobility aid as a *replacement* for normal function that grants access to a similar range of opportunity in a certain sort of – wheelchair accessible – environment. Likewise, the provision of home and community based long term care services to aid in tasks of daily living do not in any way maintain or restore normal function to the individuals receiving these services. As with the wheelchair example, home-based long term care would be more accurately described as replacing normal function in order to access a more fair range of opportunity.

Thus, we see that a commitment to multifunctionalism would go a long way toward accounting for the moral experiences, reasoning, and knowledge of disabled people who use health care resources in ways that do not restore their normal function, but still produce greater equality of opportunity by replacing normal function. These important priorities for disabled

³⁸ It is likely that this view of multi-functionalism may also have bearing on arguments regarding the use of health care to enhance function, as well as replace it. This would be an interesting line of thought to explore but would take me too far afield from this project.

people, some of whom are active members of the DM, could be more adequately justified with an account of health care justice that is premised on multifunctionalism. I would further argue that a view of healthcare justice that is still motivated by equality of opportunity but that has abandoned a strict commitment to normal function in favor of multifunctionalism would not be vulnerable to Amundson's critique that it is inevitably opposed to the theories and goals of the DM.

Above, I summarize Amundson's forceful argument that Daniels's assumption regarding normal function is at odds with the DM's ideological and practical goal of severing any socially constructed requirement for normal function from the range of equal opportunity (Amundson 2005, 107-108). However damaging Amundson's critique is to Daniels's particular theory because of the importance it places on normal function, there is no reason why Amundson or other DM scholars would oppose any theory of health care justice as a matter of principle. For example, it would appear that an account of health care justice deploying multifunctionalism would not be inevitably opposed to unhinging normal function from equal opportunity, but quite the opposite. Multifunctionalism assumes that valuable life opportunities can be accessed via a variety of atypical functional modes in addition to normal function. Therefore, health care justice revised as such would not be grounded in an anti-DM ideology, but would actively promote a view that is consistent with and advances the goals of the DM in a way that Daniels's theory cannot.

Of course, premising a rendering of health care justice on multifunctionalism rather than normal function does not, by itself, fulfill all of the important purposes of such an account, though it does greatly improve its chances of being compatible with the moral psychologies and epistemologies of disabled people. After all, normal function's role in Daniels's mainstream

account only clarifies how health care promotes justice in a way that is separate from other social goods. Even if multifunctionalism can serve a similar purpose in such a theory, questions will remain about how to most fairly distribute this important, limited resource. It's possible that, even with premising such a theory on multifunctionalism, it could come into conflict with the DM as it unfolds further and answers some of these rationing questions. However, a fully developed theory of health care justice that is compatible with the DM's moral reasoning and knowledge is beyond the scope of this portion of my project, which merely aims to be a starting point and example of how mainstream bioethics can begin to take disability moral psychology and epistemology into account with regard to health care justice.

Nonmaleficence, Beneficence, Quality of Life Judgments, and Adaptive Preferences

While quality of life (QOL) judgments are often implicitly and sometimes explicitly pertinent to a great deal of bioethical reasoning, they are most clearly central to the application of the principles of nonmaleficence and beneficence. Of course, there is room for serious error when judging the quality of someone else's life, as the application of these principles require. While there is at least one prominent example of a non-disabled bioethicist attempting to establish his QOL judgments about life with a disability as more objective and authoritative than the self-evaluation of disabled people (Brock 2005, 69-75), it is also the case that the DM has a history of advancing arguments that hinge on QOL assessments made by representatives of the DM that conflict with the first-hand testimony of the disabled individuals whose lives are being assessed.³⁹ While the term is not always used in these sorts of arguments, both contend that the self-assessment of disabled people is sometimes distorted by *adaptive preferences*, complicating

³⁹ Below, I offer an argument for how many arguments against physician-assisted suicide that originate in the scholarly and activist literature of the DM take this form.

the QOL judgments that are so central to applying nonmaleficence or beneficence. Thus, we are left with a question of whether we can coherently delineate between the QOL judgments made by non-disabled mainstream bioethicists and those made by the DM, when both sometimes claim that the first-hand QOL judgments of disabled subjects themselves have been distorted by their adaptive preferences. In this section, I will argue that members of the DM have a degree of epistemic privilege when they make judgments about the QOL of other disabled people that non-disabled bioethicists do not enjoy when they claim to have a more objective view of life with a disability than those that experience this life first hand. While these are good reasons to be more skeptical toward the claims of epistemic authority made by mainstream bioethics than we are toward similar claims made by the DM, we cannot just assume that members of the DM always enjoy this epistemic privilege and defer to their QOL judgments uncritically when they diverge from the testimony of the disabled people they are evaluating. Instead, there must be some sort of measure to safeguard disabled subjects from any false claims about adaptive preferences existing where they do not, regardless if this appeal to epistemic authority is made by the DM or mainstream bioethicists. I will further argue that Serene Khader's deliberative perfectionist approach to adaptive preferences intervention includes such safeguards for accurately identifying cases where disabled people have developed preferences that would diminish their flourishing because of oppressive background conditions. Thus, when making the sort of QOL judgments needed to apply nonmaleficence and beneficence, mainstream bioethics has good epistemic reasons to default to the moral knowledge of the DM, but when any QOL judgments diverge from the self-assessment of the subjects of that life, they must be carefully assessed by standards like Khader's deliberative approach to adaptive preferences before they are acted upon.

There are sometimes good reasons to keep the moral principles of nonmaleficence and beneficence conceptually distinct⁴⁰ from each other when engaging in bioethical reasoning. However, in this section of my project, I will address them together because the application of both concepts to bioethical analysis requires the analyst to make quality of life judgments and I am here concerned with the difficulties in making these judgments. Beauchamp and Childress (B&C) rightly point out the centrality of quality of life judgments to both nonmaleficence and beneficence. They argue that the use of both principles entail judgments about what harms a person and what is good for them when they describe the distinction between each this way: “Beneficence requires taking action by *helping*—preventing harm, removing harm, and promoting good—whereas nonmaleficence requires only *intentionally refraining* from actions that cause harm” (Beauchamp and Childress 2009, 151). In turn, B&C define the term harm as “X’s action had an adverse effect on Y’s interests” (152) and argue that promoting good “includes all forms of action intended to benefit other persons” (197).

In their discussion of nonmaleficence, B&C argue that their definition of harm is “nonnormative” in that “*wronging* involves violating someone’s rights, but *harming* need not signify such a violation. People are harmed without being wronged in attacks by disease, natural disasters, bad luck, and acts by others to which the harmed person consented” (Beauchamp and Childress 2009,152). Even while claiming this view of harm is nonnormative, B&C contend that a particular sort of value judgment is the key to their view of nonmaleficence, explicitly stating that “central to this framework is an interpretation of the commitments of the principle of

⁴⁰ For one prominent account of why these principles ought to be distinguished from each other, see: Beauchamp, Tom L. and Childress, James F. 2009. *Principles of Biomedical Ethics, Sixth Edition*. New York, NY: Oxford University Press. pp. 149-152

nonmaleficence that strongly supports, rather than suppresses, quality of life judgments” (151). In making their case for the centrality of quality of life judgments in determining whether the principle of nonmaleficence would warrant non-treatment, B&C consider and reject several other distinctions as “outmoded and untenable,” such as the distinctions between: withholding and withdrawing treatment; extraordinary and ordinary treatment; sustenance technologies and medical treatments; intended and merely foreseen effects; and killing and letting die (155-172). To replace these distinctions, B&C turn to quality of life judgments for determining when the principle of nonmaleficence would require non-treatment to avoid harming a patient. “We have relied on the premise that when quality of life is sufficiently low and an intervention produces more harm than benefit for the patient, caregivers may justifiably withhold or withdraw treatment” (169).

Unpacking the necessity of quality of life judgments in applying the moral concept of nonmaleficence, B&C rightly indicate that “it is impossible to determine what will benefit a patient without presupposing some quality-of-life standard and some conception of the life the patient will live after a medical intervention. Accurate medical diagnosis and prognosis are indispensable, but a judgment about whether to use life-prolonging measures rests unavoidably on the anticipated quality of life of the patient, not merely on a standard of what is medically indicated” (Beauchamp and Childress 2009, 170). Here they are arguing that harm and benefit are always a type of valuation and cannot be determined based solely on purely descriptive, scientific medical criteria that are devoid of value judgment. While this is most explicitly put forth in B&C’s chapter on nonmaleficence, they are clearly arguing that quality of life judgments are not only central to determining what course of treatment or non-treatment will cause *harm*, but also for judging how much of a *benefit* can be expected from a medical intervention. This

means that quality of life determinations are also quite clearly required for deploying both sorts of beneficence that B&C are proposing when they summarize how each type requires a prediction of the benefit gained from a given intervention. “*Positive beneficence* requires agents to provide benefits to others. *Utility* requires that agents balance benefits, risks, and costs to produce the best overall results” (197).

B&C are correct in arguing that value-laden QOL judgments are required to determine what sort of medical decision would result in a harm or a benefit to a patient. I would go as far as to say that few, if any, medical decisions can be made without some sort of QOL judgment being made by someone. These sorts of judgments are central to the controversial topics that have been the focal points of the conflict between the DM and professional bioethics. In fact, it is likely that the conflict is at least partially caused by the gap that has historically existed between the QOL judgments made by members of the DM and those made by non-disabled professional bioethicists when evaluating bioethical problems like prenatal diagnosis and selection, health care rationing, growth attenuation interventions, physician assisted suicide, and euthanasia. Morally analyzing any of these topics requires some determination of the likely QOL a person would have with a disability, based on predictions about the harms and benefits of life after a particular medical intervention. The controversy arises when there is a difference in this determination between the DM and mainstream bioethics.

The way in which this gap on QOL judgments between the DM and mainstream bioethics produces conflict between these groups is, perhaps, the most evident in the bioethics literature addressing the use of genetic technology and other forms of prenatal diagnosis to avoid the birth of disabled people. Dan Brock, for example, argues that disability objectively reduces a person’s QOL and, thus, society is justified when, “at the level of research funding, health insurance

coverage, professional practice, and the desires of prospective parents, there is public support for efforts to prevent the birth of children with serious disabling diseases or conditions” (Brock 2005, 68). Brock holds that there are objective criteria for making QOL judgments that go beyond the self-evaluation of disabled people, such that these efforts to prevent the birth of disabled children are justified on the grounds of preventing harm despite evidence that many disabled people do not actually experience their disability as a harm.

Brock first sets out to argue that, in principle, QOL judgments ought not to rely only on a “subjective level of satisfaction or happiness with one’s life” but also according to “the activities, accomplishments, and personal relations that actually make up that life, that make up what could be called the objective content of the life” (Brock 2005, 69). So, accordingly, Brock argues that, in principle, a person can be quite subjectively satisfied with a life that can be judged low in quality according to this objective content. He offers the *happy slave* thought experiment to show that this can be the case: “To take an extreme case, even if there in fact were happy or contented slaves during the period when slavery existed in this country, their condition of slavery was bad for them and diminished the quality of their lives; being a slave to another is a condition unworthy of an individual capable of being an autonomous human being” (69). Brock warns that, when deciding what sort of objective content ought to be used as criteria for determining someone’s QOL that is separate from their own self-assessment, we need to be careful our standard is not biased toward “the dominant preferences and way of life of the society at the expense of both disabled persons and others who pursue unusual plans of life” (69).

Nevertheless, Brock assumes such biases can be circumvented, though he never offers any sort of mechanism that would control for them, and goes on to argue that genetic technologies should be used to prevent the birth of some disabled children because “serious

disability can have a negative impact on people's lives by significantly restricting their opportunities even if, through adjustment to their disability, their subjective satisfaction with their lives is undiminished" (Brock 2005, 70). Here, he is framing disability as a loss of opportunity and not merely a varied preference for an unusual life plan, setting it up as a more objective measure of lowered QOL. He deploys the example of deafness as an objective loss of opportunity that some with the disability would mistakenly describe as just a preference for a non-dominant way of life. "In cases such as deafness, where the deaf [*sic*] community claims that its alternative sign language and the culture it supports are just as rich and functional as the spoken language and culture of hearing persons, there are still valuable human activities, such as the appreciation of music, that are closed off to deaf persons" (75).

Brock further defines the mechanisms by which he believes people may adjust to their disability and find subjective satisfaction despite a diminished objective content to their life:

Adaptation is the process by which a person improves her functional performance through new learning and skill development. *Coping* is the process by which persons adjust and lower their expectations for functioning to reflect their lowered performance, thereby increasing their satisfaction with their level of performance. *Accommodation* is the process by which individuals adjust their life plans and activities to deemphasize or eliminate activities made more difficult or impossible by their disability and substitute activities not similarly limited. (Brock 2005, 73)

What Brock is referring to as the mechanisms *coping* and *accommodation* bear a resemblance to what has been referred to elsewhere in the philosophical literature as the development of *adaptive preferences*.

The notion of adaptive preferences was first proposed by Jon Elster in the context of his broader examination of autonomous choice. He argues, “The most prominent example of non-autonomous preferences discussed in the present work is that of ‘sour grapes’, i.e. adaptation of preferences to what is seen as possible” (Elster 1983, 22). However, even though Elster frames the phenomenon of adaptive preferences in terms of the moral principle of autonomy, the concept has held relevance for the evaluation of harm and benefit since its very inception, when it was developed to challenge preference utilitarianism as an adequate measure of the collective balance of harm and benefit. “Why should individual want satisfaction be the criterion of justice and social choice when individual wants themselves may be shaped by a process that preempts the choice? And in particular, why should the choice between feasible options only take account of individual preferences if people tend to adjust their aspirations to their possibilities?” (109). Donald Bruckner has defended Elster’s account of adaptive preferences, explaining with greater clarity the particular significance of the fable about the fox and the sour grapes—“the fabled fox who, upon realizing that he cannot reach the grapes hanging just out of reach, decides that he does not want those grapes anyhow because they are sour” (Bruckner 2009, 307). Similar to Brock’s account of the happy slave and the disabled person who has found subjective contentment with diminished objective content in their life, the fox’s subjective preferences are based on a fiction he has convinced himself of in order to cope with the objective circumstances in which he finds himself. Thus, the subjective preference for a diminished QOL is understood as suspect when measured against an objective standard of harm and benefit.

In her analysis of how adaptive preferences pose a deep practical and theoretical challenge in the ethics and politics of international development, Serene Khader completely jettisoned the notion that adaptive preferences should be understood as distortions of autonomy.

Instead, she argues that they are ought to be used to assess harm and benefit more objectively than would be possible by examining a person's explicit expressions of their preferences alone. She rejects the notion that adaptive preferences are primarily deficits in individual autonomy because this view "discourages us from treating people with adaptive preferences as the types of people who can make authoritative decisions about their own lives. . . . Characterizing people with adaptive preferences as incapable of choice leads us toward seeing people with adaptive preferences as appropriate objects of coercion" (Khader 2011, 14). Instead, Khader argues that people develop adaptive preferences when "social conditions have encouraged them to sometimes choose and care about things that are not consistent with their flourishing" (32). This emphasis on *flourishing* distinguishes her view of adaptive preferences from those that are primarily focused on autonomy. As we will see later, this makes Khader's view even better suited to my goal of understanding how adaptive preferences can identify harms to an individual that she has not recognized herself while, at the same time, avoiding the position that she is inescapably deluded and incapable of autonomous choice.

Not surprisingly, Brock's attempt to dismiss disabled people who claim that their disability does not substantially diminish their QOL as somehow deluded by "adjusting to their disability" has not been well received by the members of the DM that have engaged it. Namely, Ron Amundson has responded to Brock's claim by pointing out how *epistemologically* dubious it is that Brock would have reliable, objective knowledge about life with a disability despite the constraints placed on *his* epistemic position (and preferences) as a non-disabled person.

Amundson maintains that Brock's happy slave argument "shows that logic alone does not prohibit a third person judgment of QOL that differs from the judgment of the subject. But something more than logic is needed to warrant specific judgments. . . . It requires epistemology.

... The epistemics of the Happy Slave case cannot be extrapolated to every other case in which we want to pass judgment on someone else's life" (Amundson 2009, 111).

Amundson argues that epistemic authority is on the side of the self-assessment of disabled people who hold that they experience a good QOL because they hold this view despite frequent challenges from dominant stigmas that assume they must be suffering. The need to constantly defend their life satisfaction means that this judgment is quite a bit more reflective than most non-disabled people's self-assessments of their lives. Further, most people with disabilities acquire them after some non-disabled experience of the world and still judge their QOL to not be significantly diminished by the presence of disability. By contrast, Brock and the non-disabled proponents of the happy slave argument have never experienced disability and "know about impairment only through its social stigma" (112). Even if we agree that the happy slave or sour grapes arguments show that it is logically possible for a person to be mistaken about their subjective judgment of their own QOL, we are left with the question of how third party judges have escaped their own subjectivity to access a more objective set of criteria by which to judge the content of a person's life. Amundson rhetorically asks, "*When* non-disabled people claim to know better than disabled people what their lives are like, why should they be believed?" (112) and then provides these reasons why their dominant non-disabled viewpoint being presented as objective ought to be regarded with suspicion.

By presenting an *epistemological* argument against Brock's happy slave analogy, Amundson is deliberately leaving room for the possibility of a legitimate "third person judgment of QOL that differs from the judgment of the subject" that is more epistemically justified than Brock's attempt (Amundson 2009, 111). Perhaps he leaves room for this sort of judgment because he realizes how central it is to the DM's critique of Physician Assisted Suicide (PAS).

Presumably, Amundson's argument against PAS (explored in Chapter 1), and many others like it that I have outlined throughout this project, partly hinges on a claim to epistemic privilege that also strongly resembles a description of adaptive preferences. Elster summarizes this consequence of social oppression as actual preferences that are shaped by available options: "Adaptive preferences bring it about that my preferred alternative in the feasible set also is my preferred option within a larger set of conceivable alternatives" (Elster 1983, 114). Paul Longmore's critique of PAS in general and the David Rivlin case in particular, which I refer to above, takes up exactly this sort of argumentative structure. That is, despite not using the term adaptive preferences, Longmore is clearly arguing that high-profile cases in which disabled people have sought PAS often involve the expression of an adaptive preference for PAS, developed under oppressive conditions that have severely constrained their other choices.

Longmore argues, "Health care 'choices' are never made in a vacuum. Given the absence of real options, death by assisted suicide becomes not an act of personal autonomy, but an act of desperation" (Longmore 2003, 195). With regard to David Rivlin specifically, Longmore has emphasized has the preference for death developed because of a severe deprivation of other, better options. He argues, "David Rivlin's 1989 court-sanctioned, physician-assisted suicide exemplifies the social conditions that drive some disabled persons to their deaths and the ignorance and bias of some nondisabled people that lead them to support such suicides" (Longmore 1991, 615). When Longmore specifies the social conditions under which Rivlin developed his preference for death, it becomes clear that he is referring to the deprivation of other common lifestyle options like education, work, marriage, family, and social interaction. When evaluating Rivlin's case, Longmore points out that some states do provide adequate funding for disabled people who want to live in the community, rather than in a nursing

home as Rivlin did for several years before he requested help to die. In Michigan, where Rivlin lived, these programs did not exist and so, as a person with quadriplegia who used a ventilator, Rivlin did not have the option of living a life outside of a nursing home (615). Ultimately, Longmore is arguing that, in as far as Rivlin developed a *preference* for death over time, he did so because his other options for life were so severely constrained.

Of course, it is not the case that every disabled person requesting PAS is expressing an adaptive preference based on a deluded QOL judgment or even that David Rivlin had actually developed a preference for death. Some cases of disabled people experiencing a severe deprivation of plausible life choices because of social conditions may be better characterized as examples of *tragic choices* than they are *adaptive preferences*. This distinction is meaningful in as far as people can make choices that are not accurately described as preferences. Khader's description of how adaptive preferences develop is instructive for making this distinction. She argues that adaptive preferences are formed for a person when "social conditions have encouraged them to sometimes choose and care about things that are not consistent with their flourishing" (Khader 2011, 32). So, for adaptive preferences to be present, it is not just that someone makes a choice that is inconsistent with her basic flourishing, but she must also "care about" this choice. I argue that this distinction highlights the evaluative component to a preference that distinguishes it from a choice. This evaluative component is that when one prefers something, they regard it in a positive way and value it as good for them. However, to merely choose something, one need not value it in this way. That is, one can make a tragic choice that is the least harmful among the bad options without believing that the choice being made is a benefit. So, one can make a tragic choice that one does not prefer because their preferred choice is outside of their attainable set. Adaptive preferences, in contrast, are choices

that are actually preferred to those outside of the attainable set, but as we will see later, we can predict would change if the attainable set were actually expended.

There is also a further distinction to be made between varieties of tragic choices. When a person is presented with a severely constrained set of choices, this is very often the result of social oppression and marginalization of various sorts. Namely, if social power was structured differently, the individual facing the tragic choice very well may have her preferred choice among her set of options and not have to choose the least of the evils. This category of tragic choices would cover any PAS requested by a disabled person who has some awareness of his own oppression and realizes that socially constructed barriers are closing off his preferred life choices but is resigned to accepting these barriers as insurmountable. By way of an imperfect analogy, we can imagine a prisoner in a Nazi concentration camp choosing to die even though they were perfectly aware that their preferred life options were not inevitably restricted, but had been constrained by the exercise of social power that could be rearranged differently.⁴¹ However, there may also be other cases in which a person's preferred life choices really are inevitably constrained by natural facts about the world and their body such that they are presented with a choice that is inevitably tragic. For instance, we can imagine the case of a person with a tremendous amount of untreatable physical pain and a terminal prognosis that is certain. If this person chose to hasten his death because his pain could not be relieved, it would be an example of a tragic choice that was not constructed in any way by social power.

Yet, as pain management techniques have improved, these sorts of cases have become less much less common to the point that palliative care in the United States and other developed nations can relieve pain so effectively that PAS may never be necessary to relieve pain. Siegel,

⁴¹ Ron Amundson attempts to illustrate this analogy with his short story "The Story of Compassionate Hans: An Historical Fiction." Accessed on May 18, 2014 at <http://www.uhh.hawaii.edu/~ronald/hans.htm>

Sisti, and Caplan argue against a new policy in Belgium that extends the 2002 *Belgium Act on Euthanasia* to children based on exactly this assumption. Namely, they argue that euthanasia is not warranted for children because children do not have the “intellectual capacity to develop a sophisticated preference against palliative interventions of last resort” (Siegel, Sisti, and Caplan 2014, E1). In contrast to cases involving children, “For adults, the decision to end their life can be based upon the fear of a loss of control, not wanting to burden others, or the desire not to spend their final days of life fully sedated. These desires might be supported by the experience they have had witnessing a loved one express a loss of dignity or because they understand what terminal sedation is and wish to refuse it” (E1). In this way, Siegel, Sisti, and Caplan make a moral distinction regarding PAS (and voluntary euthanasia) between children and adults on the grounds that adults can prefer death for reasons other than pain and these reasons unrelated to pain are the only viable ones. This entire argument is premised on the notion that “competently provided aggressive palliative care is generally adequate to relieve pain” (E2) and this assumption is supported in their article with a citation to the most recent edition of Eric Cassell’s book *The Nature of Suffering and the Goals of Medicine*. So, if Siegel, Sisti, and Caplan are correct in their empirical assertion that the preference for PAS is derived entirely from “a loss of control, not wanting to burden others, or the desire not to spend their final days of life fully sedated,” then this third sort of tragic choice that is determined by natural facts about the world and their body and not constructed in any way by social power would be exceedingly rare, though logically possible.

When dealing with requests for PAS, delineating between adaptive preferences, socially constructed tragic choices, and inevitably tragic choices need not be insurmountably murky. A patient who prefers PAS and believes it is better for them than other alternatives that are outside

of their attainable set because of how social power is arranged is expressing an adaptive preference. A patient who is requesting PAS but would prefer a different option that is outside their attainable set because of how social power is arranged, such as community-based long term care that would not burden their family members, is expressing a socially constructed tragic choice. Finally, a patient who is requesting PAS but would prefer a different option that is outside their attainable set because of natural facts about the world and their body, such as untreatable pain, is expressing an inevitably tragic choice.

I would argue that the trickier question is how the DM could possibly delineate between appeals to adaptive preferences that are epistemically dubious like Brock's and those that they may want to classify as more legitimate, like Longmore's. Amundson gestures toward a solution that rests on epistemic grounds similar to those I developed in chapter 3, when I argued that there are good epistemic reasons for sometimes privileging the moral knowledge of the DM's standpoint when it comes to bioethical analysis in general.

It should not be surprising that Amundson's *epistemological* argument against Brock's happy slave analogy leaves room for the possibility of a legitimate "third person judgment of QOL that differs from the judgment of the subject" (Amundson 2009, 111). Recall Amundson's description of how his opinion regarding PAS shifted when he became disabled and subsequently adopted the ideology of the DM. He describes this shift as entailing *both* the direct experience of disability *and* the adoption of a raised consciousness toward disability oppression that the ideology of the DM offers. He argues that his shift on PAS was perhaps triggered by his disability experience, but it was buttressed by an ideological attunement toward the politics of ableism in American society. "When I replaced in my own mind the ideology of ableism with the ideology of the disability rights movement it caused my conversion from an advocate to an

opponent of physician-assisted suicide” (54). Amundson explains that he changed his mind when he began to see how the arguments favoring physician-assisted suicide relied heavily on moral reasoning and perception that he now understood as deeply ableist. In particular, his new experience with disability made him aware of a tendency of advocates for assisted suicide to ground their arguments in a fear of disability that rested on the assumption that the harms of disability are caused solely by biological difference rather than a social oppression (54).

What is notable, however, is that Amundson’s claim to epistemic authority regarding PAS is not based in some supposedly universal experience of disability itself, but on his raised his consciousness regarding the oppression of disabled people. This is exactly the feature of his argument that would allow him to challenge Brock’s claim to epistemic objectivity in his valuation of life with a disability that diverges from those who are directly experiencing it, while simultaneously claiming this same sort of epistemic privilege regarding PAS. The account of a normative disability moral epistemology I argued for in chapter 3 supply us with the theoretical tools to clarify this distinction.

In chapter 3, I argued that Mahowald’s explanation of feminist standpoint epistemology was a useful starting point for establishing the epistemic privilege of the DM because, as she argues, “A feminist standpoint imputes privileged status to non-dominant perspectives not because those perspectives are more valid or more accurate (although they sometimes are) than the dominant perspective but because nondominant perspectives are typically missing from the perspective that dominates society at large. Living in that society, nondominant groups and individuals cannot help but be aware of the dominant group’s perspective, while the dominant group may be totally unaware of the nondominant groups’ and individuals’ perspectives unless it grants a privileged status to them” (Mahowald 1998, 211). Yet, I also argued that the experience

of disability by itself was not sufficient justification for granting epistemic privilege to a particular point of view. To develop an analogy with gender, I called upon the arguments of Nancy Hartsock, who describes how a feminist standpoint might be developed but is not a result of merely identifying as female: “The vision of the oppressed group must be struggled for and represents an achievement which requires both science to see beneath the surface of social relations in which all are forced to participate, and the education which can only grow from struggle to change those relations” (Hartsock 1983, 285). I then go on to argue that it is this epistemic “achievement” of an oppressed person’s becoming aware of the typically obscured features of her oppression that grants her epistemic privilege. This gives us the resources to distinguish between people who experience disability and members of the DM that have a raised consciousness toward the features of the disability experience that constitute oppression. The ability to make this distinction is central to my argument for why the DM has more epistemic authority for correctly identifying the adaptive preferences of disabled people—that are presumably not aware of their own oppression as these preferences develop—than non-disabled bioethicists who do not have any special epistemic access to knowledge regarding the valuation of life with a disability.

Correctly identifying legitimate instances of a person holding adaptive preferences is not simple in either theory or practice. Brock has described the psychological processes of coping and accommodation that he believes might produce adaptive preferences in disabled people who, judging from the “objective content” of their life, are in some sense deluding themselves when they claim to be satisfied with the quality of that life. However, deciding what should count as the “objective content” being used by Brock to make QOL judgments would be a valuation that is subject to bias. Brock responds that the objective content of life is composed by a range of

opportunities that are restricted by disability (Brock 2005, 70), but this is not sufficient for establishing the epistemic objectivity of his QOL judgments. This response only pushes the problem up one level of analysis. A determination must still be made regarding which opportunities are valuable enough to make it on to this list of opportunities that are necessary for an objectively good life. Surely, not every conceivable opportunity would make it on to the list of the objective content of life, or else Brock would be forced to say that people are deluding themselves like happy slaves when they believe they have good lives despite not being able to slam dunk a basketball or wiggle their ears. He gives no objective criteria by which he chooses which of these opportunities make the cut on to the list of those that matter for an objectively good life, nor does he give us any reason for believing that he has some sort of privileged epistemic status that would enable him to make these sorts of value judgments. Ultimately, Brock does not have any way of justifying his claim that he can determine when disabled people express *adaptive* preferences rather than merely *unfamiliar* preferences. He is staking a claim to objective knowledge without a clear argument for any sort of epistemic justification for that claim.

Of course, a theoretical argument based on standpoint epistemology for why the DM may be epistemically justified in claiming that it has the sort of knowledge that would equip its members to sometimes identify and intervene in cases where adaptive preferences are at play does not do the practical work of accurately picking these cases out for intervention that is justified. To help refine my argument for how the DM ought to go about identifying and intervening in these sorts of cases of adaptive preference formation, I turn back to Serene Khader's arguments regarding the feminist ethics of international development.

Khader's *deliberative perfectionist* approach to adaptive preference intervention is particularly well suited to the problem I am raising because of its fundamental premise that adaptive preferences are not *global*. She explicitly rejects a view that "adaptive preferences affect and undermine the *entire* selves of deprived people" (Khader 2011, 14). She does not deny that adaptive preferences can diminish a person's self worth or sense of self-entitlement to even the most basic of human needs or rights, but her approach is nuanced because she argues "we should think of adaptive preferences as *selectively* rather than *globally* affecting people's senses of self-entitlement" (15). She goes on to argue that the same individual may view herself as unworthy compared to one group, but not compared to another. Further, she observes that person's view of their self worth is too complex and fluid for adaptive preferences to be global because many people experience their sense of self-entitlement as the object of an internal struggle that is influenced by a wide variety of factors, including the very different sorts of relationships they may have within their lives (15). Khader's nuanced approach to the effects of adaptive preferences on the self-entitlement of those that hold them complements my project's overall attempt to approach disabled moral psychology and epistemology with similar nuance rather than the sweeping arguments of a more global approach. Indeed, it does not follow that if a person has maladapted preference for PAS, it in some way delegitimizes their preferences for chocolate ice cream or horror films. They are still the sort of being that can make choices, which ought to be respected as such.

This rejection of a global approach to adaptive preferences immediately undercuts Brock's argument regarding the faulty QOL judgments made by disabled people about their own lives. This is because Brock's view is clearly quite global. Brock is not arguing that some disabled people have selectively developed some particular life preference that is contrary to

their flourishing. Rather, he argues that any disabled person who expresses satisfaction with her life in general must be incapable of making an accurate determination of their overall QOL because they have accepted what he takes to be a diminished objective content to their life (Brock 2005, 69-75). For Brock, disabled people who do not view their QOL as any worse than that of non-disabled people are no longer capable of making this sort of judgment accurately because there has been a global reduction in their ability to appreciate the opportunities they have lost as detrimental to their overall well-being.

One example of the nuance Khader's selective, rather than global, approach brings to the issue of adaptive preferences is her skepticism toward a privileged person's ability to accurately identify adaptive preferences based on their own intuitions rather than a reliable methodology. She argues that people with privilege who try to identify adaptive preferences can easily experience confusion that causes them to "misunderstand the causes of people's adaptive preferences or see adaptive preferences where none exist" (Khader 2011, 10). She identifies three sorts of confusion that present this risk when attempting to "engage in a complex, high stakes practice of making judgments about those who are different from them" (10). The third of these risks, "confusing difference with deprivation," is perhaps, the most relevant to the QOL judgments made by mainstream bioethicists like Brock. She defines it as "treating unfamiliar preferences that are fully compatible with flourishing as though they were adapted preferences" (12). According to Khader, this can happen when "a practitioner assumes that the way of flourishing to which she is accustomed is the only way" (12). This confusion between difference and deprivation is exactly the sort of epistemic problem Amundson points out regarding Brock's Happy Slave argument. As both Khader and Amundson point out, privileged people are just as likely to develop subjective preferences through socialization as marginalized people, and these

can wreak havoc when attempting to identify adaptive preferences, if they do not have some sort of check for this bias.

Ultimately, Khader believes these biases are surmountable and argues for a method of identifying adaptive preferences that I contend provides safeguards for this sort of confusion. The first such safeguard is embedded in Khader's definition of what adaptive preferences actually are: "Preferences inconsistent with basic flourishing that a person developed under conditions nonconducive to basic flourishing and that we expect her to change under conditions conducive to basic flourishing" (Khader 2011, 10). This definition seems to immediately lend itself to the sorts of adaptive preferences regarding PAS identified by the DM. Paul Longmore's arguments, for example, point out that the preference of some disabled people for PAS are very much dependent on social conditions that deprive them of other options and which, if changed, would also change their preference for assistance with carrying out their suicide. As argued above, this is distinct from cases of socially constructed tragic choice in that the person with adaptive preferences actually believes that death is better for them than life with a disability, even under better social arrangements. The argument that Khader and I are both making is that we can expect that sort of preference to change when the person is actually presented with those improved social arrangements.

Note that for Brock, the only condition that could change the accuracy of a disabled person's QOL self-assessment is that they become a non-disabled person. This sort of change would be to beg the question of adaptive preferences altogether, akin to arguing that the preferences of women living in developing countries must be adaptive because they would change if they became men or if they became women in industrialized countries. This is not a

change in condition, but a fundamental change in identity that does not help in making the distinction between adaptive preferences and merely unfamiliar ones.

Khader provides further, more specific safeguards against confusing difference with deprivation by insisting on a necessary corollary to her definition of adaptive preferences: a definition of flourishing “that is acceptable to a diverse group of people” because it is “basic” (Khader 2011, 20). She argues that we can identify the features of flourishing that are basic through a *deliberative* conception of human flourishing that “should be the result of a cross-cultural deliberative process” (20). Khader does not think any one person or even one society can construct an appropriate deliberative conception of human flourishing, but it can be argued that any such conception will be “substantively minimal, justificatorily minimal, and vague” (21). She gives further content to these descriptions by offering examples of each:

By substantively minimal, I mean confined to the basic levels of human flourishing; I believe it is safe to say that we have stronger agreement about what basic human needs are than what excellence is. By justificatorily minimal, I mean not based on a culturally specific set of justifications and compatible with a variety of different justifications; for instance, we can support basic mobility on the grounds that it is God’s will for us to be able to interact with one another or on the grounds that people have rights to mobility that should not be abridged. And by vague, I mean described at a very high level of generality; we should expect a deliberative conception of human flourishing to include items like “adequate nutrition” and “mobility” rather than “access to meat” or “the capacity to go to shopping malls.” (21)

All three of these features are aimed at safeguarding against confusing difference with deprivation when trying to determine whether adaptive or merely unfamiliar preferences are

present. Namely, by referring to a conception of flourishing that is substantively minimal, justificatorily minimal, and vague when evaluating when someone's preferences are adaptive, we decrease the chances that we will mistakenly label a preference as adaptive merely because it is unfamiliar to our culturally or personally subjective conception of what is good for us.

I would argue that Dan Brock's argument that disabled people who are satisfied with their QOL are only adapting to a diminished objective content for their life is much farther from these three features of a deliberative conception of human flourishing than the DM's identification of some disabled people's preference for PAS as adaptive. Brock does not give many specific examples of the objective content of life that he believes disabled people are missing out on, but he does give some clues as to what he assumes must be required for human flourishing. We can be reasonably sure from these gestures toward a conception of human flourishing that its content is not substantively minimal in the way Khader argues it should be. Recall, for instance, Brock's argument that culturally Deaf people are mistaken in their belief that Deaf culture provides them with a satisfying life because the appreciation of music is closed off to them (Brock 2005, 75). Surely, the appreciation of music is not a basic human need that must be met for flourishing. It is conceivable that a person could flourish without an appreciation for music just as much as they could flourish without an appreciation of competitive sport or film. Likewise, I would argue that the objective content that Brock has in mind also fails to meet the standard of being justificatorily minimal. His position that disabled people, by definition, have a diminished quality of life can only be justified by appeals to the medical model of disability, which defines disability as inevitably harmful. Finally, Brock's objective content for a life that is of a good quality is not very vague: he insists specifically on the appreciation of music rather than speaking in more general, abstract terms of aesthetic appreciation.

The DM's position on adaptive preferences seems to be committed to a conception of human flourishing that is much more closely aligned with the features of the deliberative approach described by Khader. The reason is that the DM's position only requires a conception of human flourishing that contains life itself as a specified characteristic of that flourishing, but leaves the details of that life ambiguous and open to further specification by the individual—a conception that is minimally substantive, justificatorily minimal, and most certainly vague.

However, it may be objected that the DM's conception of human flourishing meets Khader's specifications so completely that it does not include enough content to judge whether a disabled person's preference for PAS is, in fact, adaptive. "Mere life," the objector might point out, is not enough substance for a conception of flourishing because if that life includes harmful features, then it ought not be described as flourishing. Additionally, while many ideologies would require life for flourishing, many fewer would describe life by itself as sufficient for flourishing. Finally, it may be argued that the requirement of life for flourishing is so underdetermined that it is too vague to be of any use when deciding which *forms* of life are good for a person.

In reply, I would argue that these critiques may be effective against a vitalist position toward PAS, but Longmore and other proponents of the DM's position are not vitalists. A careful reading of Longmore and others reveal that the DM view rejects the notion that life itself is *sufficient* for human flourishing, and this rejection is at the center of their claim that preferences for PAS are often adaptive. Longmore's argument was *not* that Rivlin's preference to end his life must be adaptive because Rivlin's life was good for him despite his testimony to the contrary. Rather, Longmore argued that the reason Rivlin preferred death to further life was that he found himself in deeply undesirable social conditions and the solution for this dilemma would have

been to change those social conditions so that his life would *become* good for him (Longmore 1991, 615).

My point, and I think the point of the DM, is that a preference for PAS that is expressed by many disabled people in the context of pervasive and acute social oppression ought to be regarded with apprehension because of the likelihood that it is an adaptive preference that meets Khader's definition of "preferences inconsistent with basic flourishing that a person developed under conditions nonconducive to basic flourishing and that we expect her to change under conditions conducive to basic flourishing" (Khader 2011, 10).

All of this is to highlight that QOL judgments are central to the application of the moral principles of beneficence and nonmaleficence, but these judgments are not always straightforward because there can be a divergence between a person's self-assessment of their QOL and the assessment of a third party. Ultimately, the upshot of my argument is that, all else being equal, there are reasons why bioethics should privilege the QOL judgments made by members of the DM when considering how to apply the principles of beneficence and nonmaleficence. This is especially true when those judgments come into conflict with those made by non-disabled bioethicists from a dominant social position.

With that said, representatives of the DM should not just be issued a blank check regarding QOL judgments, but they should be held to the same standard as non-disabled bioethicists when they make claims about QOL that differ from the subjective self-assessments made by disabled people themselves. Claims by both groups ought to be evaluated according to a deliberative perfectionist approach to human flourishing that features a conception of flourishing that is substantively minimal, justificatorily minimal, and vague. Finally, it ought to be noted that this ought not be seen as a definitive solution to the problem of QOL judgments,

but the beginning of an inclusive deliberative process employing a conception of flourishing that can be applied to bioethical problems of beneficence and nonmaleficence, drawing on the moral knowledge of a disability standpoint.

CHAPTER 5: “REMODELING” THE MATERIAL AND SOCIAL STRUCTURE OF BIOETHICS

Throughout this project, I have argued that differences in moral psychology and epistemology ultimately originate in differences in lived experience, which is structured by the interplay between the material and social conditions of a person’s life and their embodiment. Further, these material and social conditions are not arbitrarily assigned to individuals, but are largely determined by one’s position in the complex social web of overlapping oppression and domination. Specifically, in my third chapter, I attempted to pick out a particular strand of this web and examine the mechanisms by which a person’s lived experience of disability can have an effect on their moral reasoning, feeling, and knowledge. Since such differences in moral psychology and epistemology have produced and maintained a deep moral divide between the DM and mainstream bioethics and since we have good reasons to believe that the dominant moral psychologies and epistemologies of mainstream bioethics could be much improved by the moral knowledge produced by the non-dominant position of the DM, I have argued that mainstream bioethics ought to be reformed so that it adopts the moral reasoning, feeling, and knowledge of the DM. A “remodeling” of sorts could both improve the quality of bioethical thinking and diminish conflict by reducing the alienation experienced by people trying to engage mainstream bioethics with the moral reasoning and feelings that are characteristic of disability.

In chapter 4, I made some suggestions for how mainstream bioethics’ dominant *theoretical* structures could begin to be revised to account for the non-dominant moral psychology and epistemology of the DM. In this chapter, I will offer some preliminary thoughts about how the material and social conditions of mainstream bioethics could also be reformed to establish the field as a zone of default trust for disabled people. Before I begin the business of

arguing for specific reforms in the material and social conditions of bioethics, I will more firmly establish the philosophical grounds that justify these sorts of practical reforms in more careful detail.

Justifying the Material and Social Remodeling of Bioethics

In chapter 3, I laid out an argument for how variation emerges among disabled and non-disabled moral psychologies. More specifically, I draw upon the ideas of Owen Flanagan to show how particular sorts of embodiment and social identity can create these variations when placed in particular material and social contexts. What follows is an argument for why his position also supports the idea that moral psychologies can and sometimes should be changed via the restructuring of material and social environments.

Flanagan consistently rejects the idea that there are distinct *global* voices that correlate directly with various forms of embodiment or social identity, but leaves room for the idea that people with different social identities do encounter different sorts of moral problems with greater or lesser frequency such that they develop different proficiencies at identifying and resolving these variable moral problems (Flanagan 1991, 232-234). For Flanagan, it is clear that this variation in moral personality is determined by how people with different identities engage with the material and social structure of a world that presents them with different sorts of opportunities for the development of their moral capacities. After all, the role of the material and social environment in moral development cannot easily be overstated for Flanagan: his core Thesis of the Multiple Realizability of Moral Psychologies (TMR) states, “The set of realizable moral psychologies is infinitely large” *because* “such personalities are largely dependent on particular social, economic and institutional arrangements. And there is no reason to think—and

every reason to think the contrary—that possible social, economic, and institutional arrangements which we are capable of creating and living under have been remotely exhausted” (32).

Not only does Flanagan believe that human personality is largely determined by these contexts, but he also argues that we sometimes have good reasons to deliberately attempt to restructure the contexts in which moral personalities develop because “vastly many more kinds of moral personality are possible than are good” (32). Flanagan further argues that the grip these material and social conditions have on our moral development is so strong that changing these conditions may sometimes be the *only* means at our disposal for moral improvement because “the existence of a socially constructed trait can also set deep, possibly unyielding constraints on our ability to realize a particular psychology once we are mature members of some community and well socialized in its values and attitudes” (43). Thus, moral improvement, for Flanagan, is a matter of both psychological *and* social change. Taking the social struggle against racism and sexism as examples, he points out that it is brought about by deliberately manipulating the contexts of moral development such that “we could seek to change the practices and the attitudes of subsequent generations, even if it were very difficult to purify completely our own attitudes and dispositions” (43).

So, here Flanagan supplies a description of how moral psychology can and sometimes should be shifted via the restructuring of material and social conditions. My argument for a disabled standpoint epistemology in chapter 3 supplies reasons for why bioethics *ought* to do this along the lines of the moral knowledge that can contribute to the field by the DM. If I am correct that the DM has something important to add to mainstream bioethics, it follows that, for this moral knowledge to be accepted as a legitimate and useful theoretical tool, we must do more

than suggest ways in which bioethical theory can be expanded and revised to account for this knowledge. That is, Flanagan has given me reason to think that the serious, long-term *uptake* of the sorts of theoretical suggestions I made in chapter 4 is largely contingent upon the adjustment of more concrete practices and institutions that are the context of the development of *non-disabled* moral psychology within the mainstream bioethics. In addition to improving professional bioethics, improving the uptake of the moral knowledge of the DM will also diminish the degree to which disabled people are morally alienated by the field and experience it as a zone of default distrust.

Clarifying the View of the Conflict with Empirical Research

The first step to any material and social change in the field of bioethics would be to clarify further the scope and depth of the variations in moral psychology between disabled and non-disabled people as they arise in biomedicine. I hope that my analysis throughout this project has presented compelling textual and argumentative evidence that a conflict exists between the DM and mainstream bioethics, which originates in variation in moral psychology. However, very little exists in the way of empirical research that gives shape and clarity to the variations in moral psychology that produce this conflict. This need for empirical study is especially pronounced if I am correct in arguing that these differences between disabled and non-disabled moral psychologies are not *global*. Further empirical study would be enormously useful for identifying exactly which contexts these differences occupy, how prevalent they may be, and what their main features are.

There is some existing empirical research describing variations in moral psychology between disabled and non-disabled people in the context of bioethics and bio-medicine. For

example, much of the empirical evidence outlining the difference between disabled people's judgments about the quality of life (QOL) they directly experience and the judgments made by non-disabled, third party health professionals about their beliefs regarding QOL with a disability is reviewed in Ron Amundson's article "Quality of Life, Disability, and Hedonic Psychology." Amundson goes on to argue that the empirical research from the field of hedonic psychology provides good reasons to give the experiential knowledge of disabled people a sort of default epistemic authority when considering this variation in psychology and valuation.

Another example of relevant empirical research is Carol Thomas's article "Medicine, Gender, and Disability: Disabled Women's Health Care Encounters," which draws on qualitative empirical studies that highlight the features and causes of conflict arising in clinical settings between disabled women and health care providers. This article is particularly useful to my argument that the conflict between the DM and mainstream bioethics is fundamentally a matter of divergence in moral psychology because it does not just recite the ideological conflict between the DM and mainstream bioethics, but highlights conflict in clinical practice between providers and patients: "With very few exceptions, it was clear from their accounts that these were not political activists in the disabled people's movement . . . and the majority would not have considered themselves feminists" (Thomas 2001, 251).

While these empirical data do not always deploy the terms distrust or moral alienation, there is some reason to believe that the conflicts described, if they are representative of a larger pattern, may contribute to the creation of moral alienation and a zone of default distrust for disabled people in biomedicine more broadly and not just in professional bioethics. If it is the case, for instance, that there is a widespread and persistent tendency for healthcare providers to undervalue the QOL of their disabled patients, it is likely that insofar as the reasons offered by

disabled people for their health care choices are based on QOL judgments, they will be met with skepticism or even dismissed by providers. If this response were widespread, it would certainly contribute to the moral alienation of these patients. Intuitively, it would not be surprising if these different QOL judgments led to healthcare providers' not giving full consideration to the reasoned medical choices of disabled patients, but more empirical examination would be needed to determine how pervasive this might be in clinical practice.

Accordingly, research needs to be conducted that produces data on the prevalence of moral alienation and distrust of the DM within bioethics *and* in clinical contexts. While my argument has focused on the moral conflict between the DM and mainstream bioethics because of my commitment to the idea that epistemic privilege is only available to those who have had their consciousness raised toward their own oppression, there is a wide spectrum of degrees to which this consciousness can be raised and it would be a mistake to confine the discussion of moral conflict to only the struggle that plays out in the literature produced by disability activists or scholars. To be sure, as Thomas's research suggests, there are very likely instances of conflict that arise in clinical contexts between disabled people who are partially aware of their own subordinate social position as disabled people, but not active in the DM.

It may even be the case that the power structure of the DM itself sometimes morally alienates these individuals because of overlapping oppressed identities, so that they have not contributed to the moral knowledge of the DM as it pertains to its struggles with mainstream bioethical thought. While the DM is far from monolithic in its political commitments and already contains an array of viewpoints as it exists, it would be a mistake to believe that it is immune to reproducing social hierarchy within itself. Thus, even if the DM does not represent a single set of

views, the knowledge it does contain is narrowed in so far as it reproduces social structures of domination and subordination.

In fact, this may be why there are likely many under-theorized moral conflicts within clinical contexts that do not appear in the conflict between the DM and mainstream bioethics. Empirical study of this possibility ought to be pursued aggressively. These data are necessary for both the theoretical *and* the material/social restructuring of both mainstream bioethics *and* clinical medicine.

Participation of Disabled People in Bioethics Scholarship, Teaching, and Practice

Perhaps the most obvious way in which mainstream bioethics can and should be restructured to become a zone of default trust for disabled people would be to make efforts to include actual disabled people in doing bioethics. In this section, I will argue that this can be done by providing disability access for disabled bioethicists within the institutions where bioethics happens and implementing affirmative action programs to actively recruit disabled scholars to bioethics faculties or graduate degree programs.

Being forced to navigate inaccessibility across wide swaths of life may be the only common experience among all disabled people. This is, of course, also true for disabled scholars who work in the field of bioethics. Bill Peace, an anthropologist working in bioethics who uses a wheelchair, is one such scholar who has documented much of his experience with engaging the field in his blog *Bad Cripple*. These records of his experience often highlight the barriers that exist to his full participation in the profession as a disabled person, such as his recent experience trying to book a hotel room for the annual meeting of the American Society for Bioethics and the Humanities:

For the last year I have advocated for the inclusion of disability related topics and disabled scholars at the American Society for Bioethics and Humanities annual meeting. Last year I was the Ombudsman for disability at the annual meeting. In looking back at my work and the great deal of time I spent advocating for the most basic forms of access at the ASBH meetings I accomplished virtually nothing. I have spent approximately ten days trying to do something very simple. Reserve a room at the discounted rate given to ASBH members in San Diego. This should take no more than ten minutes on line. However if a scholar with a disability wants to share a room and have a roll in shower (a standard request) the work involved is significant. It took me many phone calls and emails to the ASBH and hotel offices to reserve room. The reason for this is obvious: I am a problem. My attendance is a problem. An ADA room is a problem. No one wants to think of disability as being more than an individual problem. This plays out reserving a room, attending a conference and publishing and presenting papers. Everywhere I go I am a problem. (Peace, 6/22/14)

Peace's blog includes the fine-grained details of many such examples of how he, as a chair user, has been forced to expend an enormous amount of emotional and physical energy to achieve the most basic level of physical access to bioethics conferences. Further, he often explicitly draws the conceptual link between his physical isolation from these conferences and the deep moral alienation he experiences at the substantive content of the scholarship presented that does not take into account the moral psychology and epistemology of the Disability Movement.

Providing access that is free of emotional burden to disabled scholars through reasonable accommodations and the universal design of conference or university programming would be the first step to allowing for the full participation of disabled people in the field. Of course, theories of justice and actual civil rights law already require this sort of access, but it has yet to be achieved. I hope the arguments presented in this project provide further moral and epistemic justification for doing this.

Of course, especially given the entrenched dispute between the DM and mainstream bioethics, to achieve adequate representation of disabled people in the profession, it is likely that measures will be necessary well beyond removing barriers to accessibility. Providing access via

universal design or reasonable accommodation is a necessary condition for the participation of disabled people in bioethics scholarship, teaching, and practice, but it is surely not sufficient.

Additionally, more attention should be given to the particular rhetoric used by professional mainstream bioethicists who are inviting disabled people to dialogue about the entrenched conflict between mainstream bioethics and the DM. For example, many scholarly conferences and journals that have attempted to address the moral conflicts between mainstream bioethics and the DM frame the issue in terms of a conflict between two distinct, seemingly mutually exclusive groups of people: “bioethicists” and “disability activists.” This false dichotomy of identities not only homogenizes the DM, but also erases disabled people who are already doing bioethics and discourages more disabled people from becoming trained in bioethics. This is a disincentive for potential scholars who identify as activists to attempt to seek entry to the field of bioethics as full and equal participants because it implies that politically engaged disabled people are, and perhaps should be, a distinct group from serious scholars researching and teaching bioethics. For my part, I have tried to avoid this mistake of presenting a false dichotomy between mutually exclusive groups of “scholars” and “activists” by referring to the conflict I am attempting to analyze as a rift between mainstream bioethics and the Disability Movement, defining the DM as inclusive of both activism and scholarship, and emphasizing that not all members of the DM speak with one voice. Even if this is not a significant difference in language, I hope I have avoided contributing to this problem, given that this is a complex, multi-chapter analysis that draws on the scholarship of several disabled bioethicists and not a call for papers for a conference or journal.

Like any scholarly endeavor, bioethics is a field with a specific jargon and a specific canon of literature that one must have a grasp on to effectively participate. Many times, this

familiarity comes via formal training in the form of graduate study. Thus, maybe the most important step that could be taken to help promote the inclusion of disabled people in the field of bioethics would be to actively establish affirmative action programs that specifically recruit them to graduate programs and, later, faculty appointments. As with the removal of barriers to accessibility that I mention above, a case could be made on the basis of justice that disabled people ought to gain entry into higher education in general via affirmative action. However, I hope the previous chapters of this project have presented additional reasons as to why the moral perception, reasoning, and knowledge of the DM are necessary for bioethics to improve as a field of inquiry. In turn, this ought to provide some reasons for academic programs in bioethics in particular to recruit and retain disabled students and scholars.

Inclusion of the DM's Political and Moral Goals in Bioethics' Research Agenda

Some of the literature I reviewed in chapter 2 contended that mainstream bioethics' major failing regarding disability was that it did not pay adequate attention to the sorts of moral problems that are most relevant to disabled people. I argued that these authors⁴² were mistaken in as far as they maintained that the conflict between mainstream bioethics and the DM is reducible to mere priority setting and could be addressed with a shift in research focus toward rehabilitative medicine rather than an exclusive commitment to clinical ethics in acute care settings.

That said, while the conflict between mainstream bioethics and the DM is not reducible to a difference in research priorities, I do think part of the solution to the conflict could be a shift

42 For a specific example of this sort of argument, see: Kuczewski, Mark G. 2001. "Disability: An Agenda for Bioethics." *The American Journal of Bioethics*. 1(3): 36-44

in focus of the research agenda of mainstream bioethics. If this shift in research priorities is intended to reduce the moral alienation experienced by members of the DM engaging bioethics, however, it would not just be a shift toward rehabilitative medicine with the assumption that this medical sub-specialty must be of increased importance to people experiencing chronic disabilities. Rather, the shift would need to follow the actual moral and political concerns of the DM.

The reason for this is twofold. First, most simply, any evidence we currently have that a conflict even exists between mainstream bioethics and disabled people locates that conflict in instances of disagreement between bioethicists and members of the DM, not any or every person who has a biological impairment of some sort. So, if our aim is to reduce or eliminate the conflict being assessed, then defining disability identity as a purely medical phenomenon and tailoring a research agenda to fit the possible concerns of those with permanent or chronic impairments misses the point entirely. This is not to say that moral problems in rehabilitative medicine ought to go unattended, just that this is no way to address the conflict between bioethics and the DM.

Second, as I argued in chapter four, mainstream bioethics stands to benefit from the privileged moral knowledge of disabled people specifically who have raised consciousness. The argument was for a standpoint epistemology that derived the epistemic privilege of the DM from its members' raised consciousness toward their own social subordination and oppression, not their biomedical impairments. Thus, again, if we intend to remodel the material and social structures of bioethics to account for the contributions of the DM, any changes to the research agenda would need to be derived from the priorities of politicized disabled people, not just people who happen to experience any sort of bio-medical impairment.

Of course, the boundaries are quite blurred between who ought to be considered members of the DM or who has a raised disability consciousness. Surely, there is no bright line and it is not a simple dichotomy between “member of the DM” and “merely biologically impaired.” There is likely no viable litmus test for determining who ought to be included in these categories. However, for our purposes, mainstream bioethics would do well to at least start reformulating its research agenda to prioritize some topics that are clearly of concern to a wide swath of individuals and organizations that represent politically engaged disabled people. Surely, as these threads of bioethical discussion are spun, nuance and complexity can be added to address any worries about capturing the full range of concerns within every corner of the DM, in all its diversity. However, at least as a starting point, the field of bioethics ought to make a real effort to understand and engage with some of the clearest priorities of the DM.

For example, since its inception, long term care reform has been a major political priority for the DM. Namely, the DM has devoted an enormous amount of energy toward promoting public policy that provides disabled people with the sorts of resources they would need to live self-directed lives in the community rather than being forced to exist in an institutional setting as a tradeoff for their long-term care. This is a philosophically rich topic that has been largely ignored by mainstream bioethics. Bioethicists who address issues of justice could and should explicitly confront the issue of institutionalization as part of the discussion regarding the fair allocation of health care resources. Further, bioethicists who are more inclined toward clinical ethics would do well to analyze the moral implications various modes of providing long term care have for both disabled people receiving care and their caregivers, perhaps even developing new models of long term care that are more morally defensible. Feminist bioethics has begun some of this work on long term care but it surely not a settled issue, especially when one

considers the enormous moral complexity added by the overlapping and intersecting oppressions of race, economic class, and gender.

To be sure, these discussions about long term care will not always lead to consensus. Few complex moral issues ever lead to consensus within bioethics generally and wide spread agreement may become even more elusive when the perspectives of the DM are added to the mix. However, explicitly addressing the moral elements of long term care will demonstrate bioethics' willingness to allow the DM some part in setting the agenda for the discussion rather than always appearing in a reactionary role to the controversial positions that are common in the field.

Opening up the research agenda for the field will also likely indicate a willingness to seriously engage the moral knowledge of the DM as it has been developed over the past decades. Like the other suggestions made in this chapter, by itself, this reform would not be enough to change the environment of bioethics such that it fosters default trust. However, serious engagement with the moral and political goals of the DM would be a good step toward fostering a richer understanding of the values of the DM and, thus, the sorts of reasons that members of the DM find motivating when deliberating about bioethical concerns. This deeper change is at the heart of my remodeling project.

Inclusion of Disabled Knowledge in Bioethics Curriculum

Finally, to refashion the field of bioethics as an environment of default trust for the DM that seriously considers the reasons growing out of its moral psychology and knowledge produced by its moral epistemology, the bioethics curriculum would need to be refashioned to include the basic history, culture, and theory of the DM.

At minimum, this would include detailed accounts of the origins of laws like Section 504 of the Rehab Act and the Americans with Disabilities Act, both of which were born from decades of social and political struggle of the DM.⁴³ It also should include nuanced, politically aware narratives of life with disability that challenge the stereotypical tropes of popular cultural and give aspiring bioethicists and health care professionals a richer understanding of disability from which to deliberate. Some of these even engage in bioethical reasoning, like Harriet McBride Johnson's autobiography *Too Late to Die Young*, in which she devotes a chapter to her conversations with Peter Singer about infant euthanasia, or Paul Longmore's *Why I Burned My Book*, in which he analyzes physician assisted suicide in the context of his lived experience as a disabled person existing in an ableist society. Lastly, medical ethics curriculum should include some of the classic works of disability theory, some of which have been around for more than 30 years but are still ignored by the training of bioethicists and medical professionals. For example, medical sociologist Irving Zola's most influential book *Missing Pieces: A Chronicle of Living With a Disability* was first printed in 1982, the same year he and four other scholars founded the Society for Disability Studies.

Placing this material into the bioethics curriculum would shift the starting point from which bioethics engages the DM. Developing a widespread, richer understanding of the phenomenal experience of disability from a social and political viewpoint rather than a purely medicalized one would go a long way toward remodeling bioethics as a zone of default trust for the DM. It is only in this sort of context that the moral perception, reasoning, and feeling of the DM regarding bioethics could possibly become motivating and the specific contributions of the DM's moral knowledge could possibly become coherent.

⁴³ For one such account, see Joseph Shapiro's political history of the DM, *No Pity*.

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