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Epistemic Oppression and Ableism in Bioethics

Christine Wieseler

Department of Philosophy, California State Polytechnic University, 3801 W. Temple Blvd, Pomona, CA 91768

Corresponding author. cmwieseler@cpp.edu

(Received 5 February 2019; revised 7 June 2020; accepted 19 June 2020)

Abstract

Disabled people face obstacles to participation in epistemic communities that would be beneficial for making sense of our experiences and are susceptible to epistemic oppression. Knowledge and skills grounded in disabled people's experiences are treated as unintelligible within an ableist hermeneutic, specifically, the dominant conception of disability as lack. My discussion will focus on a few types of epistemic oppression—willful hermeneutical ignorance, epistemic exploitation, and epistemic imperialism—as they manifest in some bioethicists' claims about and interactions with disabled people. One of the problems with the epistemic phenomena with which I am concerned is that they direct our skepticism regarding claims and justifications in the wrong direction. When we ought to be asking dominantly situated epistemic agents to justify their knowledge claims, our attention is instead directed toward skepticism regarding the accounts of marginally situated agents who are actually in a better position to know. I conclude by discussing disabled knowers' responses to epistemic oppression, including articulating the epistemic harm they have undergone as well as ways of creating resistant ways of knowing.

When you are forced to realize that other people have more social authority than you do to describe your experience of your body, your confidence in yourself and your relationship to reality is radically undermined. What can you know if you cannot know that you are experiencing suffering or joy; what can you communicate to people who do not believe you know even this?

—Susan Wendell, "Toward a Feminist Theory of Disability," 121

The dominantly situated treat them [the marginalized] as fodder for skeptical responses and harvest them for content that can be developed into straw man arguments and rejected out of hand. This practice gives the appearance of a balanced, reasoned debate from which the privileged position of active ignorance emerges as the rational victor. The dominantly situated feign engagement with the marginalized but refuse to listen to them.

—Nora Berenstain, "Epistemic Exploitation," 587

In "Toward a Feminist Theory of Disability," Susan Wendell asserts, "I learned at first by listening to other people with chronic illnesses and disabilities; suddenly[,] able-

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bodied people seemed to me profoundly ignorant of everything I most needed to know” (Wendell 1989, 104). The epistemic significance of disability communities is apparent in this remark, yet disabled people are likely to be socially isolated—in general, and specifically, from one another (Garland-Thomson 1997, 14; Amundson 2005, 119). Disabled people face obstacles to participating in epistemic communities that would be beneficial for making sense of our experiences and are susceptible to epistemic oppression. Knowledge and skills grounded in disabled people’s experiences are treated as unintelligible within an ableist hermeneutic, specifically, the dominant conception of disability as lack.

Ableism is a type of oppression that values bodyminds¹ on the basis of assumptions about ability, privileging those considered “normal” or able-bodied over those deemed “abnormal.”² Ableism informs how society is designed, creating obstacles to not only the flourishing but also the very survival of some people while producing opportunities for others; in other words, ableism informs social practices that disable and enable individuals. I will focus on disabled people, but it should be noted that 1) ableism is deeply intertwined with white supremacy and patriarchy, and 2) disabled people’s identities are multifaceted in terms of race, gender, and other social identities; there are no generic disabled people.³ These factors make it difficult in some cases to distinguish ableism from racism and sexism.⁴ In addition, racism and sexism have often functioned by attributing various sorts of lack to members of the groups constructed as subordinate.⁵

Disability theorists have often noted that it is problematic to characterize disabled people’s bodyminds and experiences in terms of lack; what has received less attention until recently is that disabled people are categorically assumed to lack the ability to make epistemic contributions, even—or perhaps, especially—when it comes to reports regarding our own lived experiences (Wendell 1989; Ho 2011; Barnes 2016; Clare 2017; Garland-Thomson 2017; Scully 2018; Peña-Guzmán and Reynolds 2019; Cupples 2020; Reynolds 2020). David Peña-Guzmán and Joel Michael Reynolds suggest that we should think of ableism as an epistemic schema composed of “implicit and explicit values, norms, biases, impulses, desires, fantasies, and assumptions that condition what counts as knowledge, who counts as a knower, and how knowledge claims are interpreted, assessed, and adjudicated within a given epistemic community” (Peña-Guzmán and Reynolds 2019, 208). Philosophers of disability have argued that disabled people face, due to ableism, testimonial and hermeneutical injustice—two forms of epistemic injustice—within the discourse of bioethics as well as within the practice of medicine. I will argue that a third form of epistemic injustice—willful hermeneutical ignorance—as well as the concepts of epistemic exploitation and epistemic imperialism are useful for articulating additional ways that the epistemic agency of disabled people is limited. Although epistemic oppression of disabled people is a problem more generally, I will discuss examples primarily within bioethics since the pervasiveness of ableism as a hermeneutic serves to prevent recognition of disabled people’s knowledge claims and status as knowers in the work of many bioethicists.

Philosophers of disability critique philosophical bioethics at multiple levels: from a global critique (for example, Shelley Tremain’s position that bioethics is inherently against the interests of disabled people [Tremain 2017a]) to representing perspectives that arise from careful reflection on disabled people’s experiences in debates on specific moral issues, such as prenatal genetic testing and selective abortion (Silvers 2005; Asch and Parens 2012; Saxton 2013). Debates surrounding moral issues in bioethics are premised on epistemic and ontological claims about what the world is like, including

claims about the lives of disabled people. In this article, I focus on critiquing bioethicists at this epistemic level.

My discussion will focus on a few types of epistemic oppression—willful hermeneutical ignorance, epistemic exploitation, and epistemic imperialism—as they manifest in some bioethicists’⁶ claims about and interactions with disabled people. One of the problems with the epistemic phenomena with which I am concerned is that they direct our skepticism regarding claims and justifications in the wrong direction. When we ought to be asking dominantly situated epistemic agents to justify their knowledge claims, our attention is instead directed toward skepticism regarding the accounts of marginally situated agents who are actually *in a better position to know*. After explaining the types of epistemic oppression with which I am concerned, I provide examples in which nondisabled bioethicists compromise the epistemic agency of disabled people. I focus on evaluations of quality of life (QOL) because they are so central within the bioethics literature: many moral arguments are premised on the assumption that disabled people inevitably have significantly lower QOL than nondisabled people in spite of evidence to the contrary. In the final section, I discuss disabled knowers’ responses to epistemic oppression, including articulating the epistemic harm they have undergone as well as ways of creating resistant ways of knowing.

Epistemic Oppression and Related Concepts

Epistemic Injustice, Willful Hermeneutical Ignorance, and Epistemic Oppression

Epistemic practices are multifaceted, and individuals, structures, and their interaction can benefit or harm knowers in numerous ways (Kidd, Medina, and Pohlhaus 2017). Feminist philosophers have argued that oppression has components that are specifically epistemic, which cannot be reduced to social and political aspects of oppression (Fricker 1999; Ho 2011; Medina 2013; Dotson 2014; Berenstain 2016; Aragon 2017).

Miranda Fricker claims that there are two types of epistemic injustice—testimonial and hermeneutic. In testimonial injustice, listeners attribute lower credibility to a speaker than they otherwise would due to stereotypes related to the speaker’s identity; hermeneutical injustice occurs when “a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences” (Fricker 2007, 1).⁷ Fricker assumes that when hermeneutical injustice occurs, neither marginalized nor dominant knowers are able to articulate a certain type of experience and that this asymmetrically disadvantages marginally situated knowers.

Gaile Pohlhaus, Jr. posits a third type of epistemic injustice—willful hermeneutical ignorance—in order to account for cases in which members of marginalized groups do have suitable hermeneutical resources to make sense of their experiences but are unable to influence the broader epistemic community’s understanding. In her words:

willful hermeneutical ignorance does not describe a thwarted epistemic agent who is not believed or cannot make sense of her world. Instead, *willful hermeneutical ignorance* describes instances where marginally situated knowers actively resist epistemic domination through interaction with other resistant knowers, while dominantly situated knowers nonetheless continue to misunderstand and misinterpret the world. (Pohlhaus 2012, 716)

Thus the problem is not a complete lack of hermeneutical resources to describe a set of experiences; rather the epistemic injustice lies in the refusal of dominantly situated

knowers to allow a warranted revision to shared hermeneutical resources. Dominantly situated knowers continue to conceptualize the world in ways that lead them to erroneous conclusions in spite of having the opportunity to adopt hermeneutical resources that serve as correctives.

Following Kristie Dotson, I use the term *epistemic oppression* expansively, with the assumption that there may be types of epistemic exclusion that have not yet been conceptualized and that diverge from Fricker's necessary and sufficient conditions for epistemic injustice (Dotson 2012). Dotson recommends classifying epistemic injustice as a subset of epistemic oppression. On her account, "[e]pistemic oppression refers to persistent epistemic exclusion that hinders one's contribution to knowledge production. Epistemic exclusion, here, will be understood as an unwarranted infringement on the epistemic agency of knowers" (Dotson 2014, 115). She defines epistemic agency as "the ability to utilize persuasively shared epistemic resources within a given epistemic community in order to participate in knowledge production and, if required, the revision of those same resources" (Dotson 2012, 24). When a person's epistemic agency is compromised, it is likely that their agency is unfairly limited in other ways as well.⁸ Epistemic exclusion can occur in ways that may not be readily identifiable; like willful hermeneutical ignorance, the terms *epistemic exploitation* and *epistemic imperialism* refer to epistemic practices that may *prima facie* appear to be epistemically virtuous because they involve dominantly situated knowers engaging with marginally situated knowers.

Epistemic Exploitation

Drawing on the work of Toni Morrison and Audre Lorde, Nora Berenstain characterizes epistemic exploitation as happening "when privileged persons compel marginalized persons to produce an education or explanation about the nature of the oppression they face" (Berenstain 2016, 570). I will use the term more broadly than pertaining only to providing descriptions and explanations of oppression. Epistemic labor is exploitative, on Berenstain's account, insofar as 1) marginalized people are manipulated into spending time and energy on this labor rather than on pursuits that might be more rewarding or otherwise beneficial for them, 2) they are placed in a double bind when asked to engage in this work, and 3) this work makes little to no impact due to the "default skeptical responses from the privileged" (572). The double bind consists in having to choose between allowing ignorance or false claims about marginalized people to go unchallenged or providing epistemic labor with the knowledge that it is improbable that dominantly situated knowers will change their understanding. Even though members of privileged groups pressure marginalized people to educate them, they are unlikely to treat their knowledge claims and ways of knowing as legitimate.

Building on Berenstain's account, Corwin Aragon states that epistemic exploitation entails a pattern whereby members of oppressed groups are expected to "exercise their epistemic labor to produce knowledge and confirm the epistemic authority of some other group of people" (Aragon 2017, 18). The epistemically privileged retain the use of their epistemic agency to determine whether and how to apply the insights of the epistemically exploited—most often, they ignore or distort them—while undermining the epistemic agency of the contributors and refusing to recognize their epistemic labor. At the same time, those engaged in epistemic exploitation are able to point to the fact that they received input from members of oppressed groups to shore up their own credibility, that is, as evidence that they were engaging in just epistemic practices.

Epistemic imperialism

Epistemic imperialism is similar to epistemic exploitation insofar as both serve to legitimate the epistemic agency of dominantly situated knowers. This term is closely related to the term *cultural imperialism*, which Iris Marion Young adopts from María Lugones and Elizabeth Spelman (Lugones and Spelman 1983; Young 1990). Aragon asserts that epistemic imperialism

occurs when members of an oppressed group are forced to take on the dominant thought and conform their epistemic agency to dominant modes of epistemic interaction. . . . These dominant systems of belief and ways of knowing are imposed on all in a manner that both obscures the fact that they represent the experiences, understandings, and values of the dominant group as well as constrains the epistemic agency of the oppressed (Aragon 2017, 22–23).

Epistemic imperialism simultaneously involves forcing dominant “systems of belief and ways of knowing” on members of oppressed groups and attempting to conceal that this is occurring through presenting these epistemic claims and practices as value-free (for example, “just the way it is” or “the only reasonable way to understand x”) rather than being based on dominant experiences, understandings, and values.

Wrongful requests to understand are a subset of epistemic imperialism. Pohlhaus defines wrongful requests to understand as occurring when dominantly situated knowers ask marginally situated knowers to take on ways of understanding that are grounded in the experiences and values of dominantly situated knowers and to disavow their own. She adds, “the sense of our claims depends on a set of background attitudes, comportments, and habits of thought” (Pohlhaus 2011, 235). Thus, attending to another person’s claims and reasoning requires not only that we accept their explicit assumptions for the sake of argument but also that we “inhabit the world that gives these claims their sense” (235). To be clear, Pohlhaus is not finding fault with members of marginalized groups who do understand from dominant perspectives; she points out that it may be necessary to do so in order to ensure one’s safety. Her focus is on those who request “that type of understanding from others” (237).

Pohlhaus points out that the epistemic practices of institutions and individuals in dominant social locations need not be *intended* to harm in order to cause harm (236). Indeed, these practices may be intended to be inclusive. Young states:

Where social group differences exist, and some groups are privileged while others are oppressed, this propensity to universalize the particular reinforces that oppression. The standpoint of the privileged, their experience and standards, is constructed as normal and neutral. Not only are the experience and values of the oppressed thereby ignored and silenced, but they become disadvantaged by their situated identities. . . . Commitment to the ideal of impartiality thus makes it difficult to expose the partiality of the supposedly general standpoint, and to claim a voice for the oppressed. (Young 1990, 116)

In such contexts “the call for neutrality and for ‘understanding all sides’ in our communication with one another is anything but neutral and can make certain ‘sides’ of the situation invisible without appearing to do so” (Pohlhaus 2011, 232).⁹ Claims to be

neutral do not solve the problem at hand; worse, they obscure the power relations at play and create obstacles to addressing the problem.

In “Objectivity as Neutrality, Nondisabled Ignorance, and Strong Objectivity in Biomedical Ethics,” I focus on how the framework of epistemologies of ignorance is useful for making sense of how ableism presents an obstacle to some bioethicists in their attempts to know about disabled people’s lives (Wieseler 2016). I examine how appeals to objectivity as neutrality and ignorance about disability are mutually sustaining. By “objectivity as neutrality,” I mean the ideal of excluding values from epistemic practices (Harding 1991). I am assuming that this type of objectivity is impossible, and that bioethicists sometimes appeal to it in order to present certain value-laden assumptions and claims as value-free. I will not argue for this position here.¹⁰ One might object: *of course* ethics involves value-laden claims; no one maintains that moral judgments are value-free.¹¹ My response is that bioethicists purport to make objective epistemic claims that are actually informed by ableist hermeneutical resources. Although there is much to be said about the broader impacts of problematic epistemic practices in bioethics, here I am specifically concerned with ways that willful hermeneutical ignorance, epistemic exploitation, and epistemic imperialism harm disabled people as knowers.¹²

Epistemic Oppression and Ableism in Bioethics

In this section, I turn to the expectation that some bioethicists have that readers or interlocutors—including disabled people—take the standard view of disability as a given.¹³ This expectation qualifies as epistemic imperialism—specifically, a wrongful request to understand—due to its effects on disabled people’s epistemic agency. It can also lead to epistemic exploitation and willful hermeneutical ignorance.

In Ron Amundson’s words, the *standard view* of disability is “that disabilities have very strong [negative] impacts on the quality of life of the individuals who have them” (Amundson 2005, 103).¹⁴ The standard view is closely related to what Reynolds refers to as “the ableist conflation,” which equates “disability with pain and suffering” (Reynolds 2017, 150). In spite of encountering empirical studies in which disabled people, on average, rated their own quality of life (QOL) as only slightly lower than nondisabled people ranked their own QOL (Bach and Tilton 1994; Nosek, Fuhrer, and Potter 1995; Albrecht and Devlieger 1999; Ubel, Loewenstein, and Jepson 2003; Goering 2008; Campbell and Stramondo 2017), many bioethicists continue to espouse the standard view of disability (Singer 1993; Buchanan et al. 2000; Daniels 2002; Brock 2005; McMahan 2005; Glover 2006; Davis 2009). Amundson critiques bioethicists who take this approach, maintaining that their judgments about disability are shaped by social stigma and ignorance rather than objectivity (Amundson 2005, 110–13). When the standard view is treated as a value-free starting assumption, it centers what dominantly situated knowers believe and undermines the claims of disabled people about our own lives while making it difficult to draw attention to this epistemic harm.¹⁵

As Amundson, Elizabeth Barnes, and Laura Cupples point out (Amundson 2005; Barnes 2016; Cupples 2020), disabled people are discredited as knowers when their testimony conflicts with the standard view (Nussbaum 2001; Brock 2005). They address the following objections to treating the testimony of disabled people as credible: 1) the notion that disabled people adjust their expectations in line with their limited options (adaptive preference), 2) the charge that disabled people’s assessments of their own QOL is only *subjective* whereas nondisabled people’s assessments are

objective, and 3) that disabled people are mistaken in their assessment because they are unable to compare their own experience with the experience of being nondisabled. I find the arguments of Amundson, Barnes, and Cupples convincing and will not recount them here.

Amundson asks, when the topic is the QOL of disabled people, “Why should the opinions of nondisabled people be epistemologically privileged over those of disabled people?” (Amundson 2005, 112). Similarly, Anita Silvers contends, “[it] is . . . epistemologically aberrant to grant precedence about anomalous health states made by species-typical people over those made by individuals actually experiencing those health states. Ordinarily we defer to first-person reports of subjective states” (Silvers 2005, 60). As Havi Carel and Ian James Kidd point out, there may be instances in which a health-care provider has an epistemic advantage over a patient with a chronic illness regarding technical details of their medical condition due to education and clinical experience (Carel and Kidd 2017). However, nondisabled bioethicists have no such justification for privileging their knowledge claims about the QOL of disabled people. In fact, they are likely to have an epistemic disadvantage, unless they have had relevant experiences, such as raising a disabled child (Kittay 2009).

Licia Carlson notes, “in many ethical discussions about intellectual disability, a dissonance is found between the presumed authority of the disengaged moral philosopher and the authority of those who have embodied, concrete relations with persons with intellectual disabilities” (Carlson 2010, 122). Although it is sometimes assumed that the claims of a nondisabled philosopher who lacks any kind of relation to a person with an intellectual impairment are more objective and thus more credible than the claims of nondisabled philosophers who do have such relations, Carlson asserts that the latter ought to be given a higher level of epistemic authority.

Recognizing the epistemic limitations of nondisabled bioethicists, bioethicist Mark Kuczewski recommends engaging with and learning about the lives of disabled people. He suggests that such engagement would lead bioethicists to more carefully examine the values related to disability and visions of the good life that influence their claims (Kuczewski 2001, 42). When the prospect of including critical disability standpoints is considered, bioethicists such as Peter Singer as well as physicians are quick to point out the dangers of introducing politics into bioethics.¹⁶ Under the guise of being neutral while dismissing the claims of disabled people regarding their experiences, Singer and other bioethicists engage in epistemic oppression, namely epistemic imperialism, epistemic exploitation, and willful hermeneutical ignorance.¹⁷

Rather than enumerating the numerous instances in which bioethicists have assumed the correctness of the standard view of disability and dismissed the testimony of disabled people, I would like to closely examine a set of dialogues between nondisabled bioethicist Singer and disabled attorney and disability rights activist Harriet McBryde Johnson in order to draw attention to the ways in which Singer—a dominantly situated knower—participates in epistemic oppression in his interactions with Johnson—a marginally situated knower. Notably, this would not be possible without the broader context of oppressive practices—epistemic and otherwise.

In “Terrible Purity: Peter Singer, Harriet McBryde Johnson, and the Moral Significance of the Particular,” Mark Hopwood examines exchanges between Singer and Johnson, arguing that the significant difference between their positions on disability is that they take different approaches to moral reasoning (Hopwood 2016). Specifically, Hopwood asserts that Singer is concerned with establishing general, abstract claims whereas Johnson is concerned with making particular claims based

on her experiences as a disabled woman. In Johnson's words, "[m]y goal isn't to shed the perspective that comes from my particular experience, but to give voice to it" (Johnson 2005, 228). Hopwood focuses on a thought experiment Singer posed in an email to Johnson in order to illustrate the difference between their approaches.

Singer asks Johnson to entertain the following thought experiment: if there is a disabled child at the beach watching nondisabled children playing, "Isn't it reasonable to think that this child's disability makes her worse off?" (Hopwood 2016, 640). The clear implication is that it is *unreasonable* to think otherwise. In recounting this email exchange, Johnson states:

I respond: "As a little girl playing on the beach, I was already aware that some people felt sorry for me, that I wasn't frolicking with the same level of frenzy as other children. This annoyed me, and still does." I take the time to write a detailed description of how I, in fact, had fun playing on the beach, without the need of standing, walking, or running. (Johnson 2005, 208, as quoted in Hopwood 2016, 640)

Notice that Johnson describes the fun she had playing on the beach and also draws attention to her awareness of how other people perceived her, through an ableist lens. This awareness, not her body, detracted from her experience on the beach. While Singer is positing thought experiments, Johnson is describing her actual lived experiences.

Hopwood suggests that Johnson correctly anticipates that her testimony is unlikely to "make much difference to the conversation" for the reason that they are taking "fundamentally different ways of approaching the business of moral reasoning itself" (Hopwood 2016, 640). Elsewhere, Singer maintains that ethics demands that we adopt "the standpoint of the impartial spectator or ideal observer" (Singer 1993, 12). Hopwood's position is correct, as far as it goes, but he is missing the role of epistemic oppression.

Hopwood seems to take Singer at his word that his knowledge claim about the lower quality of disabled people's lives when compared to that of nondisabled people, in general, has good epistemic grounds. On this basis, he suggests that Johnson's report of her own quality of life rightly should not count against Singer's position, maintaining, "[a]ll he needs to establish is that, all things being equal, disability tends to make people worse off" (Hopwood 2016, 641). I will set aside for the moment that Singer does no such thing here or elsewhere. Although Hopwood asserts that Johnson's testimony contains important philosophical insights and that Singer ought to listen carefully, he does not demonstrate awareness of the elements of epistemic oppression within this exchange.

I agree with Carlson's claim that "excusing oneself from possessing knowledge about the particulars of the condition while simultaneously making generalized statements that presume such knowledge is problematic" (Carlson 2010, 116). Singer makes his assertions in the face of concrete disabled people, including Johnson, telling him that their lives are worthwhile and cannot be reduced to suffering. He claims to be simply reporting the truth about disabled people's lives, when he is actually promulgating dominant assumptions about the value and lived experiences of disabled people. Singer does this in the name of objectivity as neutrality, but his position is clearly value-laden. His appeals to abstraction do not erase the harm—epistemic and otherwise—that his assumptions and arguments have on concrete individuals.

Singer presents himself as an epistemic peer—as on equal epistemic footing as that of Johnson with regard to disability (Berenstain 2016, 579) when actually Johnson is in a better position to make sense of disability as a result of her own experiences. She is in the epistemic double bind that Berenstain characterizes as a component of epistemic exploitation: she can refuse to continue to engage with Singer on the question of whether disability makes a person worse off or provide testimony about her experiences, knowing that it is unlikely to change how Singer thinks about or perceives disabled people.

There is slippage within the literature in philosophical bioethics between attributions of low quality of life and the value of that life. As Cupples reports, “one problem with mistakenly assuming a poor quality of life for disabled people and people with chronic illnesses is that it is easy to make the further assumption that those lives are somehow less valuable” (Cupples 2020, 46).¹⁸ In some cases this is left implicit, but in other instances it is stated. Singer claims quite explicitly that disabled people’s lives are less valuable than the lives of nondisabled people:

It may still be objected that to replace either a fetus or a newborn infant is wrong because it suggests to disabled people living today that their lives are *less worth living* than the lives of people who are not disabled. *Yet it is surely flying in the face of reality to deny that, on average, this is so.* That is the *only way* to make sense of actions that we all take for granted. (Singer 1993, 188–89; my emphasis)

Singer is making an empirical claim, indicated by the use of “reality” and “this is so.” Rather than using empirical evidence about the lives of disabled people to ground his claims, he claims that it is necessary to assume that disabled people’s lives are less worth living in order to make sense of selective abortion, an action “that we all take for granted” (189). That the ableist *assumption* that the lives of disabled people are less worth living is dominant does not make it true. He also explicitly disagrees with the claim that the presupposition “that life is better without a disability” is a form of prejudice (53).

How does Singer justify his claims about the lives of disabled people? One might think that knowledge claims about disabled people would need to be grounded empirically. At times he even *seems* to acknowledge the reports of disabled people. For instance, in a tribute he authored on Johnson after her death in 2008, which was published in the *New York Times*, he asserts, “I know that surveys have found that people living with disabilities show a level of satisfaction with their lives that is not very different from that of people who are not disabled.” Singer’s very next words call these studies into question: “Have people with long-term disabilities adjusted their expectations downward, so that they are satisfied with less? Or do even severe disabilities really make no difference to our happiness, once we get used to them?” (Singer 2008). He characterizes Johnson as being “happy nevertheless”; in other words, as happy *in spite of* her disability.¹⁹ Elsewhere, Singer suggests that when disabled people report that their QOL is at a similar level to that reported by nondisabled people, we should not take this “at face value” (Singer 2009, 207).

Rather than treating marginally situated disabled knowers as credible, Singer urges presumably dominantly situated, nondisabled knowers to imaginatively put themselves in the place of disabled people. Singer advocates “empathetically imagining ourselves in their situation” (Singer 1993, 53).²⁰ Unfortunately, however well-intentioned this suggestion may be, it is likely that dominantly situated knowers will draw on ableist hermeneutical resources in imagining what it is like to be disabled.²¹

If Singer were the only one to endorse ableist assumptions as common sense while dismissing the testimony of disabled people, it would be possible to chalk this up to idiosyncrasy, and the harmful effects would be minimal. However, it is exactly because ableism is so pervasive that he can assume that his audience also takes it to be the obvious lens through which to understand disabled people's lived experiences. These epistemic practices are common within discussions of QOL within biomedical ethics. Worse, since bioethicists' assumptions about disability reflect and reinforce the prevailing assumptions within the broader society, disabled people are confronted with requests—often quite unwelcome demands—to understand that nondisabled people view our lives as burdensome or even worse than death. Again, I turn to Johnson's poignant words to illustrate.

Strangers on the street are moved to comment:
 "I admire you for being out; most people would give up.
 God bless you! I'll pray for you.
 You don't let the pain hold you back, do you?
 If I had to live like you, I think I'd kill myself." (Johnson 2005, 2)

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

Epistemic Harm and Resistance

Nondisabled philosophers being closed off to being affected and altered by the hermeneutical resources and knowledge claims of disabled people is both ethically and epistemologically problematic. However, disabled epistemic agents' refusal to take on the assumptions of perspectives grounded in the experiences of nondisabled knowers can be a defense against epistemic harm (Pohlhaus 2011). Marginally situated knowers develop their own ways of understanding and valuing their experiences (Dotson 2012; Pohlhaus 2012; Medina 2013).

Sharing instances of epistemic harm that one has endured and having them recognized as such by similarly situated knowers may be an important means for rebuilding one's epistemic agency. In "Epistemic Injustice and Phenomenology," Lisa Guenther suggests:

For the survivor [of epistemic injustice], testimony about the epistemic injustice she has experienced is a practice of resistance and performatively contests the patterns of silencing and discrediting that it describes and analyzes, and for the perpetrator, such testimonies are precisely what s/he needs to hear and understand in order to address the harm of past injustice, to develop a critical awareness of present, ongoing injustice, and to develop more just practices for the future. (Guenther 2017, 202)

In addition, learning about marginally situated knowers' experiences of epistemic harm may inform the future actions of dominantly situated knowers, though the former are under no obligation to provide these narratives.

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

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

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

Because ableism sets the terms of the discussion and involves an asymmetrical power relation between disabled and nondisabled people, it is difficult for disabled people to call into question the devaluing of our lives. Just being put in the position of trying to convince others that your life and the lives of people like you are worthwhile constitutes harm, which is compounded when pervasive ableism enables your interlocutor(s) to dismiss or downplay your credibility. Once again, I turn to Johnson's response to interacting with Singer in person and reading his work. She muses:

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

That last question is the only one I avoid. I used to say I don't know; it doesn't make sense. But now I've read some of Singer's writing, and I admit it does make sense—within the conceptual world of Peter Singer. But I don't want to go there. Or at least not for long. (Johnson 2005, 203)

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

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

Disability theorists have developed various concepts to refer to knowledge that is grounded in lived experiences of being disabled. Wendell maintains that disabled people are in a better position than nondisabled people to develop a critical consciousness regarding disability: "From the standpoint of a disabled person, one can see how society could minimize the disadvantages of most disabilities, and, in some instances, turn them into advantages" (Wendell 1989, 109). Wendell conceives of a critical standpoint as something that is achieved through dialogue. She states: "[b]ecause I do not want simply to describe my own experience but to understand it in a much larger context, I must venture beyond what I know first-hand. I rely on others to correct my mistakes and fill in those parts of the picture I cannot see" (106). Significantly, Wendell is suggesting that experience is fallible and should not be uncritically accepted. She also notes the limitations on any one person's experience and knowledge.

More recently, disability theorist Merri Lisa Johnson coined the term *cripistemology* to name thought stemming from "the critical, social, and personal position of disability" (Johnson and McRuer 2014, 134).²² Like Wendell, Johnson and McRuer emphasize the importance of collaborative epistemic practices. They draw on the work of Janet Price and Margrit Shildrick, who reject "the suggestion that disability is not an issue for nondisabled people, and that there is some privileged standpoint from which disabled people alone can speak" (Price and Shildrick 2002, 64). According to Johnson and McRuer, "the production of knowledge about disability comes not only from being disabled but from *being with and near* disability, thinking through disabled sensations and situations, whether yours or your friend's" (Johnson and McRuer 2014, 141). Cripistemology emphasizes the social aspect as well as the effort required to develop a critical disability position.

Disability theorist Jackie Leach Scully coined the term *global epistemic incapacity* for instances in which the "fact of impairment *by itself* is taken to render someone incapable of being a source of reliable knowledge, irrespective of whether the impairment itself might reasonably be expected to do so" (Scully 2018, 116).²³ She characterizes a "Does she take sugar?" occasion as "the moment when a nondisabled person directs a question not at a disabled person herself but at a companion, clearly believing that, say, a mobility impairment renders her incapable of knowing or communicating how sweet she likes her tea" (116). Requesting information from nondisabled companions of disabled people when the latter are capable of responding is obviously problematic.

Of course, some types of impairments do affect cognition and/or abilities related to communication, and others do need to speak for them. This situation raises a set of complex issues that I cannot fully explore here, but I will turn to Eva Kittay for insight on this topic. In *Learning from My Daughter: The Value and Care of Disabled Minds*, Kittay cautions against the assumption that nondisabled parents automatically know what is in the best interest of their disabled child. She contends:

the epistemic access of the parent is far more limited than many parents wish to acknowledge. Able parents of disabled children, especially at the beginning of their child's life, are subject to the same ableist assumptions that disabled people have attempted to dislodge. Therefore, the additional judgment of others whose lives are closer to the child's likely adulthood may be the better judge of what that child needs to flourish. (Kittay 2019, 228)

Kittay makes this remark in the context of discussing parental decision-making regarding medical interventions on behalf of disabled children who are unable to convey their preferences. Here we once again encounter the importance of disability communities for developing knowledge that does not rely on ableist assumptions.

In “Disability Bioethics,” Rosemarie Garland-Thomson advocates striving to develop disability competence among disabled and nondisabled people alike rather than promoting cultural humility (Garland-Thomson 2017, 327). She is concerned that humility serves as an unnecessary corrective, given that disabled people tend not to exhibit epistemic arrogance. I agree that disabled people as a group are hardly in need of such a corrective. However, many nondisabled bioethicists demonstrate an unwarranted epistemic overconfidence in their claims about what it is like to be disabled. In order to be receptive to the testimony of disabled people, they need to engage in epistemic humility in order to recognize: first, what they do not know, and second, that disabled people have epistemic contributions—in Garland-Thomson’s words, “disability competence”—deserving of uptake.

Leah Lakshmi Piepzna-Samarasinha, a sick and disabled femme of color reflects on her recognition of what Garland-Thomson terms disability competence:

I’m not sure when I started hearing and using the terms “crip skills” or “crip science.” . . . But it meant something. It meant something to name and talk about all the crip skills I was seeing and learning that I and other disabled folks had. It meant something because, well, the deficiency model by which most people view disability only sees disabled people as a lack, a defect, damaged good [sic], in need of cure. The idea that we have cultures, skills, science, and technology runs counter to all of that. In a big way.

Naming that also means having to field some able-bodied blank stares. Able-bodied people are shameless about really not getting it that disabled people could know things that the abled don’t. That we have our own cultures and histories and skills. That there might be something that they could learn from us. (Piepzna-Samarasinha 2018, 69)

Importantly, crip skills and knowledge are not automatically bestowed on disabled people at birth or upon becoming disabled; they are acquired and recognized through participation in disability communities engaged in resistant sense-making. Epistemic oppression that disabled people face is not hermeneutical injustice; rather, willful hermeneutical ignorance better captures the situation insofar as disabled communities develop ways of making sense of and conveying our experiences and ways of knowing that tend not to be recognized as hermeneutical resources within broader epistemic communities.

Asymmetry in Social Position, Epistemic Agency, and the Value of Disabled People’s Lives

Multiple types of asymmetry between the social positioning of disabled and nondisabled people are relevant for questions related to the quality of life of disabled people. The ontological stakes—so to speak—for nondisabled people are nil, unless there are disabled people in whose well-being they are invested. These questions are armchair philosophical exercises. Furthermore, there seems to be no penalty for consistent demonstration of a stubborn ignorance—if anything, philosophers who proclaim that disabled people’s lives are less worth living than those of nondisabled people are

rewarded professionally. It is a diversion of precious energy for disabled philosophers to have to respond to claims based purely on ableist assumptions—especially when our claims seem to receive little uptake. Nonetheless, it is difficult to allow ableist claims to stand unchallenged. This is the double bind of epistemic exploitation. Disabled people's lives are literally at stake, given that our purported low quality of life has been used as justification to ration healthcare (Amundson 2005; Cupples 2020). Importantly, I am not making the argument that disabled people's knowledge claims should be uncritically accepted. Rather, I am claiming that when disabled people make certain types of claims that conflict with dominant narratives, we are likely to have our epistemic agency compromised by not being taken seriously as knowers and thereby being prevented from revising the hermeneutical resources of the broader epistemic community. The more ableist beliefs are treated as common sense, the worse disabled people are likely to be treated. While disabled people are occupied with insisting that we have a sufficient QOL, we are distracted from asking the questions Amundson raises: why should QOL levels be used to determine access to healthcare for disabled people (Amundson 2005, 116)? Why is QOL being conflated with the value of or ability to live a meaningful life? Why do philosophers make these claims only in regard to disabled people? Moreover, nondisabled philosophers simply are not put in the position of having to advocate for the value of their lives—this is taken as a given.

Acknowledgments. Thank you to Amy Kind and participants at the Gaslighting and Epistemic Injustice conference at Claremont McKenna College for comments on an early draft of this article; to Camisha Russell, Sarah LaChance Adams, Julie Perkins, and Alison Bailey for their work on this cluster; and to the anonymous referees for this article. Susan Blake provided detailed and helpful feedback. I am especially grateful for Gaile Pohlhaus, Jr.'s thoughtful, generous, and encouraging comments on multiple drafts of this article.

Notes

1 Disability theorist Sami Schalk states, “[b]odymind is a materialist feminist disability studies concept from Margaret Price that refers to the enmeshment of the mind and body, which are typically understood as interacting and connected, yet distinct entities due to the Cartesian dualism of Western philosophy ([Price 2015], “The Bodymind Problem and the Possibilities of Pain,” 270). The term *bodymind* insists on the inextricability of mind and body and highlights how processes within our being impact one another in such a way that the notion of a physical versus mental process is difficult, if not impossible to clearly discern in most cases (269)” (Schalk 2018, 5). In addition, I use this term as a reminder that it is not always readily apparent—visibly or otherwise—who is disabled.

2 Here is social-justice activist Talila Lewis's definition of ableism: “a system that places value on people's bodies and minds based on socially constructed ideas of normalcy, intelligence, excellence and productivity. These constructed ideas are deeply rooted in anti-Blackness, eugenics, colonialism and capitalism. This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person's appearance and/or their ability to satisfactorily [re]produce, excel, and 'behave.' You do not have to be disabled to experience ableism” (Lewis 2020). What I appreciate about this definition is the expansiveness and recognition of how ableism is connected with anti-Blackness, eugenics, colonialism, and capitalism. Lewis's mention of eugenics suggests recognition of racism against people of color more generally as well as classism. I would add that judgments regarding the value and worth of individuals are based not only on appearance and abilities but also on assumptions about their abilities and whether it is deemed appropriate or desirable for them to reproduce.

3 Shelley Tremain suggests, “vulnerability, pity, sympathy, and asexuality are ‘compliments’ that white supremacy pays to white (disabled) people only” (Tremain 2017b, 181).

4 There are significant limitations in claiming that racism and ableism are analogous, such as the implication that they are separate and cannot converge. Indeed, many historical and contemporary examples

believe the notion that they can be entirely disentangled. For example, disability activist Eli Clare describes how ableism and racism converge in the notion of defectiveness, which has been appealed to in attempts to justify social practices as wide-ranging as slavery, immigration policy, ex-gay conversion therapy, selective abortion, and racism in psychiatry (Clare 2017, 23). Racism, ableism, and the intersection of these types of oppression produce epistemic oppression.

5 For example, people of color and white women have been portrayed as lacking reason and being overly emotional (Jaggar 1989, 163).

6 I am referring to what might be termed *philosophical bioethics* insofar as all of my examples are concerned with philosophers.

7 In “Evolving Concepts of Epistemic Injustice,” she acknowledges that the term *epistemic injustice* has been used more broadly than she intended—for example, David Coady urges considering unjust distribution of epistemic goods to constitute epistemic injustice (Fricker 2017, 53). Thus, Fricker suggests that the term *discriminatory epistemic injustice* might better capture the two types of harms to knowers that she describes (53).

8 Disability theorist Jackie Leach Scully asserts, “[h]aving their claims and accounts epistemically downgraded is guaranteed to unsettle a person’s trust in the epistemic and moral value of their own narratives and judgments and, if internalized, their confidence in their overall agential capacity” (Scully 2018, 111).

9 James Hamblin provides another type of example in which calling for “understanding all sides” functions as a barrier to productive discussion of an issue: “The serious structural problems that most conceptions of rape culture describe—under-prosecution of rapists, limited education and understanding with regard to what constitutes consent, lacking resources for victims, male entitlement, female objectification, social power dynamics, misinformation among both men and women about what constitutes rape, traditions of looking the other way, etc.—are productive to address. When the media makes an effort to ‘present both sides’ and one of the sides involves denying the importance of these factors in sexual assault, it undermines productive discourse” (Hamblin 2014).

10 Elsewhere I state: “feminist philosophers have called into question the ideal of objectivity as neutrality and the method of reflective equilibrium because theorists have tended to unreflectively generalize their own perspectives, including their interests, values, and prejudices” (Wieseler 2016, 93).

11 I thank the anonymous reviewer who posed this objection.

12 In Wieseler 2016, I examined ways that bioethicists’ claims of objectivity serve to conceal bias and sustain ignorance regarding disabled people’s lives.

13 Although bioethicists may not be directly interacting with disabled people on a regular basis, they affect public policies, laws, medical research, and how healthcare providers think about and treat disabled people. In addition, although disabled people may not be philosophers’ primary target audience, we do read their work.

14 Elizabeth Barnes refers to this as the “bad-difference view of impairment” (Barnes 2016).

15 Interestingly, some of the bioethicists I have mentioned who endorse the standard view of disability acknowledge that disabled people, on average, report a similar QOL to the average QOL that nondisabled people report or that their QOL is much higher than nondisabled people imagine it would be. However, they then revert to equating disability with reduced opportunities (Daniels 1981 or reduced QOL (McMahan 2005). Relatedly, Amundson notes that in *From Chance to Choice: Genetics and Justice* (Buchanan et al. 2000), “[t]he authors give their liberal endorsement to the general goals of the disability rights movement, while rejecting almost every specific argument of its advocates. . . . the authors show only a verbal understanding of the Social Model. Even after reporting, reasonably accurately, on the perspective itself, the authors immediately refer to the biomedical conditions of impairment and disability as the *direct causes* of disadvantage (Amundson 2005, 121). Here are two examples in which the authors return to assuming or implying the correctness of the standard view: “We know that disabilities as such diminish opportunities and welfare, even when they are not so severe that the lives of those who have them are not worth living” (Buchanan et al. 2000, 278).

16 In his “Response to Mark Kuczewski,” Singer asserts: “Bioethics, as a field or discipline, should not dedicate itself to advocacy for anyone. Its only commitment, as a field, is to pursue knowledge and understanding with integrity and respect for the views of other scholars in the field. . . . Individual bioethicists who come across something that they regard as wrong may choose to dedicate themselves to advocacy for the cause of those who they see as wronged, but if they become mere partisans, dismissing without adequate consideration the views of others who are not advocates for the same group, they risk becoming

propagandists rather than scholars. The difference lies in the readiness to consider and perhaps even be moved by good arguments that count against a position one has previously held" (Singer 2001, 55).

17 For example, in response to the Washington Protection and Advocacy System's recommendation that disability advocates be included in ethics committees at Seattle Children's Hospital, physician Douglas Diekema states, "ethics committees are not for people with political agendas" (Kafer 2013, 60). Alison Kafer suggests that Diekema "positions people living with disability—family members, disability advocates, and disabled people . . . as political actors in ways that doctors and bioethicists are not" (60). However, these bioethicists and physicians fail to notice that bioethics already serves particular agendas and is thoroughly political.

18 If the bioethicists discussed here were actually concerned about the QOL of disabled people, they would do better to attend to the factors that actually reduce it—such as social isolation, unemployment, lack of transportation, inadequate access to healthcare, and poverty—rather than assuming disabled people *inherently* have a low QOL (Amundson 2005).

19 This essay was republished in Singer 2016.

20 See Mackenzie and Scully 2007; Wieseler 2012; Wieseler 2016 for further development of the many problems with this suggestion.

21 In Barnes's words, "[i]f 'common sense' is affected by ableist bias, then we should expect that our intuitions aren't a particularly good guide to thinking about disability" (Barnes 2014, 104). Ableist bias clearly does affect what is taken to be common sense.

22 I would like to thank an anonymous referee for directing me to this article.

23 Scully observes: "Aside from some discussion of epistemic power processes operating in the broad context of health care (Carel and Kidd 2014), detailed considerations of what epistemic injustice might mean for disabled people are scarce: Elizabeth Barnes's recent work stands out here (Barnes 2016; see also Tremain 2017b)" (Scully 2018, 107).

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Christine Wieseler is Assistant Professor in the Department of Philosophy at California State Polytechnic University, Pomona. She earned her PhD in philosophy at the University of South Florida in 2016. Her areas of specialization are biomedical ethics, feminist philosophy, and philosophy of disability. She is co-editing *The Disability Bioethics Reader* (under contract with Routledge) with Joel Michael Reynolds. Information on her research and teaching is available at christinewieseler.com. cmwieseler@cpp.edu