



# How Disability Activism Advances Disability Bioethics

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## Abstract

In this paper, I argue that, even when disability rights activists are most clearly acting as activists, they can advance the scholarly activity of disability bioethics. In particular, I will argue that even engaging in non-violent direct action, including civil disobedience, is an important way in which disability rights activists directly support the efforts of disability bioethics scholars. I will begin by drawing upon Hilde Lindemann’s work on relational narrative identity to describe how certain damaging master narratives about disability hinder the uptake of arguments from disability bioethics. Then, I will argue that disability activism, especially non-violent direct action and civil disobedience, provides an effective counterstory to some of the worst of these master narratives, thereby laying the groundwork for the scholarly arguments of disability bioethicists to be given more serious consideration. Ultimately, I conclude that the field of bioethics is improved when it abandons the gross grained, generalizations about who disabled people are and how they act put forth by oppressive master narratives in favor of the more nuanced self-descriptions offered by the counterstories being offered by disabled people themselves. So it is that, by challenging these oppressive master narratives that constrain and distort the social meaning of disability, disability activism can improve mainstream bioethics.

**Keywords** Narrative Ethics · Disability · Bioethics · Narrative Identity

## 1 Introduction

The journal *Bioethics* recently published a special issue entirely devoted to the question of whether bioethicists ought to be activists. A wide variety of answers are offered. For instance, Wendy Rogers argues that bioethicists can and, in some cases, should be activists because “Some degree of advocacy is an uncontroversial part of the role of academic bioethicists, such as advocating for patients’ rights. However, when this professional advocacy becomes overt activism, potential tensions arise between the responsibilities and expectations of the two roles. . . . these tensions can be resolved” (Rogers 2019, 881). Similarly, Jackie Leach Scully argues that there is no clearly defined bright line between

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bioethics and activism, “If orientating yourself in a normative direction is the first small step along the advocacy/activist continuum, then asking if bioethicists *should* be activists is pointless: actually, they already are” (Scully 2019, 879). Instead, she argues, there is a continuum of activist activity that moves a bioethicist closer or further from the typically assumed role of the impartial academic seeking objective knowledge.

Tom Shakespeare is much more skeptical of the role of the activist bioethicist, arguing that these activities require incompatible styles of thinking, borrowing from Jonathan Haidt, who:

“looks at the rational and the intuitive, and distinguishes between two ways in which people think. . . . He describes the judge, who explores all the evidence, and weighs it up carefully, before coming to her opinion. The second is . . . the barrister, who knows the position he wants to adopt in advance, and then selects the evidence to support his intuitions. Most lay people, Haidt argues, are more like barristers than judges. We have biases, we don’t want to shift our position when new evidence comes to light, we are stubborn in our prejudices. As an academic, I think my duty is to be a judge. If new evidence or argument comes to light, which is irreconcilable with my current position, but nonetheless robust, then I have to change my position” (Shakespeare 2019, 916).

Thus, Shakespeare argues that bioethicists run an enormous risk of failing to meet their obligation to the standards of the academy by trying to be “barristers” or activists.

Whether bioethicists should also be activists is a question that is both philosophically interesting and of practical importance. However, I wish to reverse this question and ask whether activists should engage with bioethics. In particular, I aim to explore whether disability activists should take action that exerts influence on bioethical discourse.

Mainstream bioethics has historically had a contentious and sometimes adversarial relationship with disability activism. Indeed, some powerful voices within the field have regarded disability activism as fundamentally opposed to its goals. Perhaps most famously, Peter Singer has, for years, claimed to be the target of “attacks” from disability activists, arguing that such activism is antithetical to the work of applied ethics, “Taken together, they amount to a concerted attack, not just on a particular ethical position, but on the very possibility of pursuing applied ethics as a free and critical inquiry” (Singer 1992, 85). To protect the “free and critical inquiry” of professional bioethics from the “attacks” of disability activists and others, Singer has even helped found *The Journal of Controversial Ideas* “that would, first, be prepared to publish controversial ideas and not retract articles because there were petitions or letters signed against them, and second, to allow articles to be published under a pseudonym—which, as far as we’re aware, no peer-reviewed academic journal does. If the argument is good, and if the referee says, “Yes, this is well-argued,” we won’t rule it out on the grounds that this is too controversial. It’s an attempt to provide a sort of place that can’t be cancelled, in the sense that discussion can’t be shut down by intimidation” (Peter Singer as quoted by Gross 2021).<sup>1</sup>

Unlike Singer who seems to regard disability activism as an existential threat to academic bioethics, Shakespeare would allegedly answer my question of whether disability activists should engage with bioethics in the affirmative, “I welcome the contribution of activists to bioethics, and think that there should be more space for different voices. In

<sup>1</sup> For a more comprehensive description and analysis of the long-standing conflict between disability activism and mainstream bioethics, see: Ouellette 2011.

particular, we need to hear the diverse voices of disabled people” (Shakespeare 2019, 920). However, this strikes me as contradicting his earlier characterization of the incompatible styles of thinking of the academic and the activist. If bioethics requires one to be a rational “judge” and not an intuitive barrister, then how can a disability rights activist engage bioethics productively, so long as they remain a barrister, for which “simplicity is useful, complexity is not. Dichotomies are useful, multiple stakeholders are not. Clarity is vital, nuance is not” (917)? At best, these purportedly incompatible styles of thinking would lead to a bioethics that is grossly dismissive of the arguments of activists. At worst, this implies that a disability activist should only engage with bioethics if they cease being a disability activist.

In contrast, I will argue that, even when disability activists are most clearly acting as activists, they can advance the scholarly activity of bioethics. In particular, I maintain even engaging in non-violent direct action, including civil disobedience, is an important way in which disability activists directly support the efforts of disability bioethics scholars. I will begin by drawing upon Hilde Lindemann’s work in narrative ethics to describe how certain damaging master narratives about disability hinder the uptake of arguments from disability bioethics. Then, I will argue that disability activism, especially non-violent direct action and civil disobedience, can provide an effective counter-story to some of the worst of these master narratives, thereby laying the groundwork for scholarly disability bioethicists to be given more serious consideration.

Before I begin filling out my argument, I should clarify and defend some of my conceptual choices. First, there is the term *disability bioethics*. Jackie Leach Scully first developed this concept by making the distinction that, “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 is defending a sort of standpoint epistemology that finds value in the moral knowledges disabled people have in virtue of their socially mediated experiences of disability. Elsewhere, I have made a similar argument, which takes note of how social power structures within the field of bioethics lead it to marginalize these ways of perceiving and reasoning about central moral problems (Stramondo 2016). In a sense, this paper is an attempt to suggest that disability activism, including direct action and civil disobedience, is one legitimate way of challenging those power structures and their epistemically questionable effects.

Conceptually, non-violent direct action and civil disobedience are likely far more familiar to a reader, but picking this sort of activism as my focus still deserves some explanation. After all, there are more efficient ways to do narrative ethics that more directly challenge the sorts of master narratives that obstruct the uptake of disability bioethics. Blocking an intersection with a wheelchair or clogging a U.S. Senator’s office seems like an odd way to engage in bioethics discourse. Still, I maintain that this lack of easy fit between direct action and bioethics discourse strengthens the central claim of my paper. If my thesis is that disability activism advances disability bioethics, despite the allegation that activism and scholarship entail incompatible methodologies, then I would want to test my position against the hardest case possible. If my central example was the publishing of op-ed articles about bioethics, it would hardly show that there is a place for activism writ large in the field. To borrow Shakespeare’s terminology, I want to show that activism enriches bioethics discourse when activists are thinking the least like a judge and the most like a barrister.

## 2 Disability Bioethics and the Barrier of the Master Narrative of the Pitiful Disabled Person (MNPDP)

It still might seem strange to argue that disability activists performing civil disobedience *increase* the uptake of scholarly arguments made by disability bioethics. After all, there is some reason to think that tactics like direct action fuel the resistance mainstream bioethics has toward their views. For example, one might fear that such activities could close off otherwise fruitful collaborations between disabled people and bioethics scholars. Raising emotional tension with direct action may be understood as thwarting discourse and deliberation, not enhancing it.

The reason I am, nevertheless, maintaining that disability activism does more good than harm to disability bioethics is that none of us are actually “judges” in the sense that Shakespeare means. It is a fiction that anyone can impartially weigh evidence and arguments so that a rational verdict can be made. Bioethics is not the objective, apolitical enterprise that Singer believes is under threat by disability activism and that Shakespeare believes should be kept distinct from it.<sup>2</sup> One need not be a full-blown moral relativist to recognize that human beings can only make sense of the moral problems they encounter with the specific discursive tools they develop in their very particular cultural and experiential context. This context is a thick soup of influences that all contribute to what philosophers like to call “our intuitions.”

There is an enormous literature challenging the notion that there is an objective, purely rational standpoint one can occupy when evaluating moral claims. I do not have the space to even begin summarizing the empirical evidence and theoretical argumentation that challenges this view of moral perception and reasoning. However, I can underscore Jackie Leach Scully’s argument that the presence or absence of impairment impacts how one understands and resolves moral questions. Scully argues that the experiences of disability affect how one understands the moral features of life by influencing how their body interacts with the world as their most fundamental moral background assumptions develop.

Accordingly, 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, habitus is a deeply entrenched way of life that human beings learn from observing the norms demonstrated in their given social environment. Importantly, Scully points out that the concept of habitus refers to *both* “habits of physical behavior” *and* “habits of thought and affect,” deliberately eschewing a sharp distinction between the two and emphasizing how one’s embodiment and one’s cognition are inextricably bound together. Further, she highlights how “the schemes of habitus owe their enormous potency and persistence to the fact that they operate outside the reach of conscious control” (65). Thus, one’s habitus is developed in the context of their particular embodiment and is not easily made the subject to their deliberative processes, but sets the stage for those processes by forming how a human being’s reality is “cognitively structured, through bodily processes that originate in the social world” and supply them with the most fundamental set of moral assumptions that are taken to be so self-evident that “things out of alignment with it

<sup>2</sup> For a distinctive and fully developed argument that bioethics is actually an entirely political enterprise that harms disabled people, please see: Tremain 2017.

are obviously absurd or illogical or barbaric” (65). For Scully, habitus structures the basic assumptions of a human being’s morality and is “prereflexive and embodied” to the point that it is “not readily accessible to conscious scrutiny” (66).

Scully even more explicitly spells out habitus’s relevance to moral life 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). Since the processes of habitus are prereflexive and outside conscious control, while human actions are “a conscious decision that emerged within the dispositional constraints of habitus” (67), it follows that moral decisions are based on reasons, but “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).

If Scully is right that one’s embodiment – especially the presence or absence of disability – has influence on one’s moral perceptions and reasoning, then Shakespeare’s dichotomy between judges and barristers quickly breaks down. None of us can remove ourselves from our own subjective point of view as it has been shaped by our habitus. We are all intuitive barristers rather than rational judges.

At the same time, I would like to contend that ethical discourse *is* possible, even across the chasms created by divergent embodiments and the different social positions they occupy. One way forward might be via a narrative ethics that examines how a range of people deliberate about moral problems with their *shared culture discourse* as the point of departure. Hilde Lindemann offers one such methodology with her discussion of Master Narratives, or “the stories found lying about in our culture that serve as summaries of socially shared understandings ... consisting of stock plots and readily recognizable character types” (Nelson 2001, 6). These Master Narratives are necessary for understanding the world and one’s place in it. First, they decrease cognitive load by helping us make inferences about who people are and what we can expect from them. We see a cishet white man pull up to a daycare in a shiny black SUV in the late afternoon, wearing a tie and jacket and we know he is there to collect his son or daughter, not to work as part of the evening cleaning crew. Additionally, these Master Narratives provide the raw materials for one to tell their own story of who they are as an individual, weaving them together and adding bits of color from their unique experience to construct the tapestry of a narrative self. When I say I am a father or a collegiate sports fan or a philosopher or a disabled person, I am constructing myself from the shared social meanings of these Master Narratives.

Master narratives have a variety of impacts on human cognition, but the one I am most concerned with here is the influence they exert over which beliefs one finds compelling. Namely, when someone is presented with an argument that rests on premises that contradict certain widely accepted Master Narratives, that argument is likely to be dismissed as absurd. This happens regularly to people who occupy subordinate social positions, simply because Master Narratives are constructed from the dominant social position. For example, there is a Master Narrative that says the use of force by police is not only justified, but something to be lauded. This Master Narrative says that the police are the “good guys” and can be found in everything from children playing cops and robbers to an enormous variety of television shows and films that glorify police violence. So, it is no surprise that the arguments about racially biased police violence being advanced by the Black Lives

Matter movement are frequently dismissed by many white people because they do not fit this dominant story relating who police officers are and what they do.

One deeply entrenched Master Narrative that undercuts many arguments from disability bioethics pertains to what I elsewhere refer to as *an ideology of pity* toward disabled people. I have argued that this ideology of pity maintains ableist social structures by obscuring the fact that many of the disadvantages of disability are produced by oppressive power relationships. More specifically, I argue that an ideology of pity helps naturalize the socially constructed harms of disability by regarding them as sad, but inevitable. Responding to the suffering of disability with pity does not require one to recognize the disparate power relationship that exists between the one doing the pitying and the one pitied. Thus, the ideology of pity maintains that power relationship and conceals how it is itself the cause of much of the suffering being pitied (Stramondo 2010).

Of course, the ideology of pity is not the only relevant social attitude or belief that is damaging to the prospects of disabled people,<sup>3</sup> but it is of key importance to an analysis of the lack of uptake within mainstream bioethics of the arguments of disability bioethics. In as far as mainstream bioethics tends to assume that disability inevitably leads to severe suffering and the arguments of disability bioethics challenge that assumption,<sup>4</sup> the ideology of pity stands as a bulwark against this challenge. Consequently, an analysis of the ideology of pity specifically is warranted because of how it protects some of mainstream bioethics' basic assumptions from critique.

I suggest we can examine how an ideology of pity has become so pervasive in contemporary American society and, thus, in mainstream bioethics by looking at it through the theoretical lens of Lindemann's narrative ethics. Much of the heavy lifting has been done by what I would call the Master Narrative of the Pitiful Disabled Person (MNPDP): disability is fundamentally an experience of suffering and so disabled people deserve our pity. Examples of the MNPDP can be found in everything from ancient Greek myth to Disney animated films. After all, the ugly, crippled Greek god Hephaestus may be clever, but everyone feels badly for him as his wife Aphrodite brazenly cheats on him. Similarly, is there a more tragic character than the Hunchback of Notre Dame, whether he is portrayed by Victor Hugo or Disney's animation studio? A subset of the MNPDP that is useful to this discussion is the Master Narrative of the Pitiful Disabled Person Better Off Dead (MNPDPBOD): disability is fundamentally an experience of suffering that is so severe that some disabled people are so pitiful they would be better off dead. For instance, readers of Steinbeck's *Of Mice and Men* look on sympathetically as George euthanizes his intellectually disabled pal Lennie. Spinal cord injury is the fate worse than death often portrayed by contemporary film. *Million Dollar Baby*, *Gattaca*, and *Me Before You* all feature protagonists who are made so miserable by their physical paralysis that they seek out death, just to name a few.<sup>5</sup>

All of these instantiations of the MNPDP seem to be of the morally dubious kind. In Lindemann's language, they have "been generated by an abusive power system to impose on a particular group an identity the system requires" (Nelson 2001, 155). The system of structural ableism that generates these characterizations of disabled people as tragically

<sup>3</sup> For an early, but still instructive taxonomy of *models of media representation* of disabled people, see: Haller 1995.

<sup>4</sup> For an analysis of how much of the argumentation of mainstream bioethics assumes that disability inevitably and severely diminishes human well-being, see: Amundson 2005.

<sup>5</sup> For a parallel discussion of this master narrative in a different context, see: Stramondo (Forthcoming)

and inevitably suffering objects of pity requires this ideology of pity for its own maintenance. If the suffering of disability wasn't primarily natural and inevitable, but a product of an oppressive social system, then that oppressive social system and those that benefit from it would be at considerable risk.

Another, related, way in which the MNPDP and MNPDPBOD are morally and epistemically vexing – which is more straightforwardly connected to my goals in this paper – is that they generate much of the resistance in mainstream bioethics toward the arguments of disability bioethics. While pity is almost never a value that is explicitly invoked in bioethical argumentation, master narratives are virtually never explicit premises in any sort of reasoning. That's just not how they work. Rather, they operate as part of the background conditions that determine what kinds of reasons are taken to be reasonable. As Wittgenstein famously said, "The limits of my language mean the limits of my world" (Wittgenstein 1961, 5.6). So, if master narratives are some of the basic building blocks of meaning, claims that run counter to them are rendered almost meaningless. This is what Lindemann refers to as *epistemic rigging*: "As they construct the identities required by abusive power systems, these narratives hide the forces that subjugate or marginalize certain groups of people so that nothing objectionable appears to be going on. The resulting story is so smooth and slippery that the opposition can't grab hold of it" (Nelson 2001, 162).

In short, when pitying disabled people is widely taken to be a virtue because of the proliferation of the MNPDP, objections raised to the ableist premises underwriting much of mainstream bioethics comes across as nonsensical. For example, if one just assumes as common sense that disability equates with suffering and so we ought to pity disabled folks, it is absurd to argue that we should use genetic technology in a way that conserves disability as a resource, as Rosemarie Garland Thomson proposes (Garland-Thomson 2012). Why would we want to make more Quasimodos?

### 3 Counterstories by Way of Direct Action

In answer to these "master narratives' morally degrading representations [that] must be resisted" Lindemann suggests that counterstories can "root out the master narratives in the tissue of stories that constitute an oppressive identity and replace them with stories that depict the person as morally worthy" (Nelson 2001, 150). Lindemann illustrates several ways a master narrative may be vulnerable to a counterstory. Here, I will argue that disability activism can and sometimes does produce a counterstory to the MNPDP and MNPDPBOD by exploiting "the gap between the conduct that it [a master narrative] prescribes for a particular class of people and how such people actually behave" (167). As one example, Lindemann explains "the patriarchal master narratives that constitute gender identity contain such maxims as 'a lady never contradicts'... In point of fact, however, ladies do sometimes contradict ... so there is a lack of fit between prescription and practice ... [that] creates an opening into which a counterstory can be inserted" (167).

In this way, direct action from the disability movement might point out the inconsistency between the prescriptions of the MNPDP and MNPDPBOD and descriptions of the lives and actions of actual disabled people in a way that is impossible to ignore. Direct action has the potential to force the issue in a way that other modes of offering a counterstory may not. It may even be able to overcome what Lindemann refers to as the *epistemic rigging* of master narratives, which is a matter of power. Those who tell the stories that constitute our shared cultural understandings determine if these stories obscure the

“forces that subjugate or marginalize certain groups of people so that nothing objectionable appears to be going on” (Nelson 2001, 162). For a counterstory arising from a non-dominant position to gain purchase and clearly exhibit the gap between prescription and description, that power dynamic must be shifted. Nonviolent direct action can be quite effective in this regard.

In his famous argument for direct action in “Letter from Birmingham Jail,” Martin Luther King describes how civil disobedience generally works: “we who engage in nonviolent direct action are not the creators of tension. We merely bring to the surface the hidden tension that is already alive. We bring it out in the open, where it can be seen and dealt with” (King 1963). He is arguing that, by accepting punishment for deliberately violating an unjust law, an activist brings to the foreground the injustice of that law. However, this was not the *only* function of King’s activism. Direct action also did “bring to the surface hidden tension that is already alive” in the lack of fit between a master narrative’s prescription of his group’s identity and a realistic portrayal of how they actually are.

By using non-violent direct action, King and his companions were not only giving the lie to the brutal, unjust policies of Jim Crow, but also the distorted, unjust identity that has been placed on Black people that allegedly justified these structures of white supremacy. As they took abuse at lunch counters and in the streets, these activists were thoughtful, calm, determined, and everything contrary to the racist portrayals of centuries of master narratives that were generated from and maintained white supremacist and colonial ideology. These actions forced the world to notice, at least for a moment, just how wrong the ideologies that maintain these systems of power actually are about who Black people are and what they are like. Non-violence offered a counterstory. In sum, the non-violent direct action of the Black civil rights movement shifted power and resisted white supremacy in, at least, two ways: 1. It brought to the surface the injustice of the policies of Jim Crow; and 2. It exploited the gap between some of the Master Narratives that distort Black identity and the actual facts about who Black people are, putting forth a counterstory.

The direct action of the disability movement is not typically able to underscore the injustice of laws or policies as directly and clearly as the Black civil rights movement of the 1960s. After all, the segregation of ableism is not entirely like the segregation of Jim Crow. Unlike, sitting at a “whites only” lunch counter, it would be impossible to violate the federal Medicaid funding structures that force many disabled people to receive services in segregated settings like nursing homes rather than in their own homes in the community. Instead, disability activists might block traffic on Independence Avenue in front of the Health and Human Services headquarters. This raises tension in the way King describes, but it isn’t necessarily tension that forces a wide-ranging recognition of unjust *laws*. For the most part, folks stuck in traffic are probably quite unclear about exactly why all these disabled people are so very upset and what policy changes they are demanding.

However, this sort of non-violent direct action *can* succeed in a way that parallels the Black civil rights movement’s second way of resisting white supremacy with non-violence. Namely, it can disrupt identity distorting Master Narratives about disabled people. Specifically, blocking Independence Avenue challenges the typical view of who disabled people are and how they act by advancing a counterstory to the MNPDP. Like King’s nonviolence, the direct action of the disability movement challenges the epistemic rigging of the MNPDP by forcing at least some of the general public, perhaps those stuck in traffic, to recognize the gap between the identity distorting prescriptions of that master narrative and the lived realities of disability.

Here is a fact: it is very difficult to pity someone who is deliberately using their 300lb power wheelchair to block your commute. You might be angered by them or you might



even admire them, but you almost surely will not pity them. This is how the civil disobedience of the disability movement forces recognition of their counterstory about disability and pity. The commuter stuck in traffic may not understand the policy failures the activists are upset about, but he surely understands they *are* upset. It seems that *they* are at least convinced their suffering is not inevitable. They are agitating for action in a way that would not be conceivable if such action was driven by an ideology of pity. The emotion they are trying to evoke is perhaps anxiety or anger, not pity. They are not wheelchair bound, the commuter is.

Perhaps this success at telling this counterstory hinges on how non-violent direct action makes disabled people *visible*. The MNPDP may dominate the moral imagination of the typical non-disabled person because they lack exposure to the real, lived experiences of disability. Non-violent direct action then forces a confrontation between one's prejudicial stereotypes as they have been structured by the MNPDP and the realities of disabled embodiment, thus exploiting "the gap between the conduct that it [a master narrative] prescribes for a particular class of people and how such people actually behave" by making disability visible (167).<sup>6</sup>

However, a reliance on visibility may expose a limit to direct action as a mode of counterstory telling. It raises the question of whether direct action can be an effective antidote to the MNPDP for disabled people that are sometimes characterized as *invisible*. Perhaps someone with epilepsy, dyslexia, or autism can not force the casual passerby to confront their prejudices about disability with non-violent direct action because they are not able to make their lives *as disabled people* visible in the way those with mobility disabilities can. While there may be some truth to this worry, there may be ways for those with a variety of disabilities to challenge the stereotypes advanced by master narratives by making themselves visible with direct action. For instance, the Autism Self Advocacy Network (ASAN) has a history of being particularly active with direct action methods.<sup>7</sup> One variation of the MNPDP, especially as it has arguably been advanced by the organization Autism Speaks, tells us that autism diminishes a person's well-being by limiting their capacity to form rich, complex relationships with others via robust interpersonal communication. Of course, among other things, a direct-action protest is a form of robust interpersonal communication. So, when protesting the master narratives advanced by Autism Speaks the autistic people of ASAN are making themselves visible and advancing a counterstory that, once again, exposes "the gap between the conduct that it [a master narrative] prescribes for a particular class of people and how such people actually behave" (Nelson 2001, 67).

#### 4 Risks and Possible Successes

Epistemic rigging is only one way a master narrative can be durable against the challenges of a counterstory. Lindemann discusses several others, as well; and most especially *assimilation of opposition*. This is when "master narratives assimilate resistance by enveloping

<sup>6</sup> I would like to thank a reviewer for suggesting the importance visibility holds for my analysis.

<sup>7</sup> As an example, please see footage from the Vancouver Chapter of ASAN's protest at Autism Speaks' Walk Now Event on September 27, 2015 in Burnaby, BC. According to the content creator, they "protested the event to spread education, awareness, and to expose families and non-autistic friends of autistic people to the Neurodiversity movement, disability rights, and autism acceptance." <https://www.youtube.com/watch?v=6OXozFEnLEw> (accessed on 12/14/21)

it with plausible stories” (Nelson 2001, 161). Resistance might mean “disconfirming instances, complaints, and other forms of opposition” that is swallowed up by a master narrative via alternative explanations that compliment and support the master narrative rather than challenge it. In the case of the MNPDP, one of the most prominent examples of assimilation of opposition is that of *inspiration porn*.

This term was first coined by comedian Stella Young who used it to describe stories and images of disabled people doing normal things in everyday life that are taken to be inspirational merely because of the presence of disability. Young explained “I use the term porn deliberately, because they objectify one group of people for the benefit of another group of people. So, in this case, we’re objectifying disabled people for the benefit of non-disabled people. The purpose of these images is to inspire you, to motivate you, so that we can look at them and think, ‘Well, however bad my life is, it could be worse. I could be that person’” (Young 2014). I would argue that this is an example of assimilation of opposition because these same stories and images *could* resist the MNPDP. A photo of an amputee running on their prosthetic legs or a woman using her mouth to grip a paint brush could serve as evidence that disability does not equate to inevitable suffering.

However, these images and stories become inspiration porn because they are swallowed up by the MNPDP. As Jan Grue explains, they are a “representation of disability as a desirable but undesired characteristic” (Grue 2016). That is, disability becomes a feature of a person that is admirable in them, but to be avoided in “us.” By framing everyday actions as wildly inspirational when done by disabled people, one reveals just how low one’s expectations are for life with a disability. This is why Young jokes “I’ve lost count of the number of times that I’ve been approached by strangers wanting to tell me that they think I’m brave or inspirational, and this was long before my work had any kind of public profile. They were just kind of congratulating me for managing to get up in the morning and remember my own name. And it is objectifying. These images, those images objectify disabled people for the benefit of non-disabled people. They are there so that you can look at them and think that things aren’t so bad for you, to put your worries into perspective” (Young 2014). The alleged admiration expressed by inspiration porn is just another way of dressing up the MNPDP. Disabled people doing everyday things are regarded as inspirational because it is assumed that they are doing these things amidst a life of suffering.

One worry is that the counterstory of non-violent direct action could also be assimilated. Specifically, it could be swallowed up and explained away by the Master Narrative of the Angry Cripple (MNAC). The MNAC is closely aligned with the MNPDP, each buttressing each other in the larger network of the cultural understanding of disability. If a disabled person is angry, it must be that he is angry about being disabled. Perhaps he is angry at God for giving him a disability or maybe his parents for giving birth to him and causing his suffering.

However, none of this is much of a risk for non-violent direct action. The reason is that these stories that assimilate some of the opposition to the MNPDP virtually always regard disability as an *individual* tragedy. If the achievement of buying a loaf of wonder bread is regarded as inspirational, it is an individual achievement. Likewise, the anger of the angry cripple who rages against the flourishing he sees in others must also be individualized. We do not see protest actions against God. Being a part of a social action is about sharing collective righteous anger toward a perceived injustice, not having a surly attitude because of your lack of luck when playing life’s lottery. Thus, the collective nature of non-violent direct action should safeguard its challenge to the MNPDP because it drives home the idea that the primary “problem” of disability is social-political and not individual, as both the assimilating stories inspiration porn and MNAC would maintain.

## 5 The Scope of Direct Action's Ability to Create a Counterstory

Up until now, I have used the term “disability” in a way that may imply it is a singular, universal experience. Of course, it is not. The variety of ways a person might experience this phenomenon referred to as disability are myriad. Of course, there is a multitude of embodiments that fall under the concept of disability in everyday speech. Each offers what can be a vastly different set of potential experiences, even if they all are described as disabilities. Further, other overlapping and intersecting identities have an impact on how disability matters to the unfolding of one's life. There is no authentic core experience of disability “in and of itself” that can be discovered if we strip away all of these messy, complicating factors. An Asian, queer, gender non-conforming, college educated, upper-middle class, chair user with cerebral palsy will have very different experiences of disability than a Black, straight, cis, low income, non-verbal, autistic man.

However, master narratives are not this nuanced and gloss over these sorts of differences when characterizing who disabled people are and what they are like. In many contexts, especially when bioethical judgements are being made based on assumptions regarding quality of life, both of the disabled people described above would be subject to the MNPD. For example, if either were gravely ill, either might be visited by a physician in the dead of night in their hospital room and offered the chance to die peacefully like the protagonists of *Million Dollar Baby*, *Gattaca*, and *Me Before You*. William Peace relates having exactly this experience in 2010 because, “Many people—the physician I met that fateful night included—assume disability is a fate worse than death. . . . In a visceral and potentially lethal way, that night made me realize I was not a human being but rather a tragic figure. Out of the kindness of the physician's heart, I was being given a chance to end my life” (Peace 2012, 15).

However, just because most or even all disabled people might be subject to the MNPD in many contexts, it doesn't follow that non-violent direct action will be equally effective for all disabled people in crafting counterstories. For example, the risk to personal safety entailed by participating in non-violent direct action will be unevenly distributed across different experiences of disability. The Black, straight, cis, low income, non-verbal, autistic man described above may be at more risk of serious bodily injury from encounters with police during a direct action than the Asian, queer, gender non-conforming, college educated, middle class, power-chair user with cerebral palsy. Both would be at considerably more risk than a white, cis male, straight, grad school educated, wealthy, manual-chair user with a spinal cord injury. This uneven distribution of risk is the result of how civil disobedience is one context in which all disabled people are *not* subject to the MNPD, especially in as far as their other intersecting and overlapping identities subject them to other master narratives that make them more or less vulnerable to police brutality. In such a context, there are some disabled people that police officers may not regard as pitiful but as threatening. For them, non-violent direct action may be more of a risk to personal safety than it is a mode of challenging oppressive master narratives.

There is a related, but additional concern that foregrounds how non-violent direct action's ability to create a counterstory might be constrained: inequity exists among disabled people in their ability to access it as a mode of resistance. Many structural barriers can hinder disabled people's participation in non-violent direct action protest. They may include: a lack of income needed to travel to and secure lodging near the protest; long hours of energy expenditure that may not be possible for someone with chronic illness; a lack of accessible transportation to get to the protest; a lack of ASL interpreters or other barriers

to effective communication at the protest; a lack of childcare during a direct action; a lack of medical support at the protest to ensure participants' health and well-being; or even residency in a long term care facility like a nursing home, which would surely preclude participation in civil disobedience. To be sure, organizations like ADAPT<sup>8</sup> make a serious effort to mitigate many or most of these barriers. However, such underfunded, grassroots organizations are severely limited in their capacity to ensure everyone is always included.

Inevitably, there are many disabled people who cannot or will not participate in direct action and this exclusion will track how impacted a disabled person is by systems of overlapping oppression like racism, classism, ableism, sexism, transphobia, and so on. Consequently, it will be the most privileged disabled people that will be able to engage in these actions the easiest. This is a significant limit to non-violent direct action's capacity to challenge widespread oppressive master narratives like the MNPDP.

Finally, we should consider how non-violent direct action may sometimes be *counter-productive* as a challenge to the MNPDP, especially since intersecting identities and systems of oppression complicate the construction of counterstories. As noted above, the MNPDP is not the only or even necessarily the most dominant master narrative that damages the prospects of disabled people. Another master narrative that seems to have particular relevance to bioethical discourse might be the Master Narrative of the Socially Costly Disabled Person (MNSCDP): the existence of disabled people is costly to a society that must support them without getting sufficient return on the investment.<sup>9</sup> This damaging narrative that disabled people require more than their fair share of social resources could be amplified by related master narratives that attach to class, race, and gender identity. A poor, Black disabled woman participating in a non-violent direct action may, for deeply unjust reasons, be doing more harm than good by reinforcing the MNSCDP more than she is challenging the MNPDP.<sup>10</sup> So, again, participation in and benefit from non-violent direct action is not fairly distributed across the disability community.

Nevertheless, these limitations of non-violent direct action's capacity to challenge oppressive master narratives do not give us reason to abandon it as a method entirely. Unfortunately, multiply marginalized disabled people will be at a disadvantage when engaging in a whole range of modes of resistance. This problem is not unique to non-violent direct action. Compounding oppressions would also impact a person's ability to produce counterstories to the MNPDP by becoming a star on HBO,<sup>11</sup> publishing a column in the *New York Times*,<sup>12</sup> or getting a sponsorship deal with Nike.<sup>13</sup>

Such limitations of a method's capacity to challenge oppressive master narratives should not motivate the disability movement to abandon it, but to *also* fully embrace and support other modes of counterstory telling that center the identities of multiply marginalized disabled people. One such example might be *Sins Invalid*, which describes itself as, "a disability justice based performance project that incubates and celebrates artists with disabilities,

<sup>8</sup> See: <https://adapt.org/>

<sup>9</sup> Perhaps this master narrative is the root of Allen Buchanan's famous "go fish" argument appearing first in his 1996 paper "Choosing Who Will Be Disabled: Genetic Intervention and the Morality of Inclusion" in *Social Philosophy & Policy* and later in 2000 *From Chance to Choice: Genetics and Justice*.

<sup>10</sup> Thank you to a reviewer that raised this very helpful concern.

<sup>11</sup> See the character with achondroplasia played by Peter Dinklage, Tyrion Lannister, on the critically and commercially successful series *Game of Thrones*.

<sup>12</sup> See: Catapano and Thomson 2019.

<sup>13</sup> In 2018, Justin Gallegos became the first athlete with cerebral palsy to be offered a Nike sponsorship deal: Borchers 2018.

centralizing artists of color and LGBTQ / gender-variant artists as communities who have been historically marginalized” (*Sins Invalid*).

A range of activities can destabilize oppressive master narratives and they are not mutually exclusive. Multiple tactics can and should be deployed when trying to get a counter-story to take hold as a liberatory alternative to an oppressive master narrative. Therefore, a range of activities can and should challenge the MNPDP and advance disability bioethics.

## 6 Counterstories and the Uptake of Disability Bioethics

Ultimately, I am proposing that the counterstory told by disability direct action has wide ranging impact. The causal outcomes of such actions are not limited to whichever policy activists are trying to challenge or promote that day. Rather, direct action might also shift our shared cultural understanding of disability away from the inevitably tragic and toward something else that recognizes how disabled people do flourish and how barriers to their flourishing are, much of the time at least, social and political. In this way, direct action drives a wedge between the prescribed way disabled people are supposed to behave according to the MNPDP and a fully fleshed, rich description of how they actually exist in the world (Nelson 2001, 67).

To be sure, disability is not a universal monolith. There is no one way to be disabled. Some disabled people may suffer directly and inevitably because of their disabilities rather than from social and political barriers to flourishing. However, as Campbell and I – along with Barnes and others – have tried to remind mainstream bioethics, it does not follow that we can make sweeping generalizations about disability always or even typically reducing human well-being (Campbell and Stramondo 2017). It is this kind of sweeping generalization that the MNPDP undergirds and it is one that the counterstories told by direct action may help unravel.

This is why my answer to the question posed at the start of this paper is a confident yes. Activists – especially disability activists – *should* engage in action that has an influence on bioethical discourse and mainstream bioethics should, in turn, enlarge its understanding of what sorts of engagements are beneficial to it as a field. Of course, non-violent direct action shouldn’t be the *only* engagement disabled people ought to have with the field. There needs to be more disabled scholars participating in the “free and critical inquiry” of the academy. Yet, while systematic, carefully developed analytic arguments are necessary for the development of a bioethics that regards disabled people as a crucial source of moral knowledge, I worry that they are not sufficient.

One reason argumentation by itself is insufficient is that oppressive master narratives – like the MNPDP – have an epistemic function as they construct identities. Claims and arguments that run contrary to an oppressive master narrative that describes and prescribes how a marginalized group *just is* will be too easily dismissed as wishful thinking rather than actual, morally significant knowledge.<sup>14</sup> In particular, when oppressive master narratives have a hold on the social meaning of a marginalized group’s identity, arguments that challenge that widely endorsed social meaning will not get sufficient uptake.

In sum, for the arguments of disability bioethics to gain uptake, oppressive master narratives like the MNPDP must be challenged with counterstories. One way to offer a counterstory to the MNPDP is with disability activism and, perhaps especially, non-violent

<sup>14</sup> As an example, see discussions of disability, well-being, and adaptive preferences in: Barnes 2016; Goering 2008; and Stramondo 2021.

direct action. In this way, disability activism has the capacity to directly advance disability bioethics scholarship. After all, bioethicists are part of the broader cultural milieu. While that makes them vulnerable to the same epistemic risks as lay people that misunderstand disability because of damaging master narratives, it also opens the possibility of repairing that damage with counterstories advanced via direct action.

By challenging the MNPD and other oppressive master narratives that constrain and distort the social meaning of disability, disability activism can improve mainstream bioethics. It is, for instance, a marked improvement to abandon gross grained generalizations about who disabled people are and how they act in favor of the more nuanced self-descriptions offered by the counterstories being put forth by disabled people themselves.

So it is that arguments like Rosemarie Garland-Thomson's case for conserving disability can begin to become intelligible to mainstream bioethics (Garland-Thomson 2012). If we abandon the narrative that disability is a medicalized, naturalized personal tragedy, then we begin to have the narrative tools to understand why we ought not pursue the elimination of disability from the world wholesale. By challenging the MNPD with direct action and a range of other means, disability activism might help bioethics toward a more expansive view of what it means to be disabled and, thus, toward a far more sophisticated response to it.

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## Declarations

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