

# Why **Bioethics** Needs a **Disability** Moral **Psychology**

BY JOSEPH A. STRAMONDO

The serious, long-term uptake in mainstream bioethics of the moral perceptions and reasoning deployed by disabled people depends on adjusting concrete practices and institutions within which a nondisabled moral psychology develops.

The deeply entrenched, sometimes heated conflict between the disability movement and the profession of bioethics is well known and well documented.<sup>1</sup> Critiques of prenatal diagnosis and selective abortion are probably the most salient and most sophisticated of disability studies scholars' engagements with bioethics,<sup>2</sup> but there are many other topics over which disability activists and scholars have encountered the field of bioethics in an adversarial way, including health care rationing, growth-attenuation interventions, assisted reproduction technology, human enhancement, physician-assisted suicide, and euthanasia.

The tension between the analyses of the disabilities studies scholars and mainstream bioethics is not *merely* a conflict between two insular political groups, however; it is, rather, also an encounter between those who have experienced disability and

those who have not. This paper explores that idea. I maintain that it is a mistake to think of this conflict as arising just from a difference in ideology or political commitments because it represents a much deeper difference—one rooted in variations in how human beings perceive and reason about moral problems. These are what I will refer to as variations of moral psychology.<sup>3</sup> The lived experiences of disability produce variations in moral psychology that are at the heart of the moral conflict between the disability movement and mainstream bioethics.

While I do not have the space or the appropriate all-encompassing experience to provide an exhaustive list of the differences in moral psychology that may play a role in creating and maintaining this conflict, I will offer a brief description of how the disability movement and mainstream bioethics come into conflict when perceiving and analyzing the moral problem of physician-assisted suicide via the lens of the principle of respect for autonomy. To reconcile its contemporary and historical conflict with the disability movement, the field of bioethics

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must engage with and fully consider these sorts of differences in moral perception and reasoning, not just the explicit moral and political arguments of the disability movement.

It should be noted straightaway that, throughout this project, I will deploy the umbrella terms “disability movement” along with “professional bioethics,” “mainstream bioethics,” and “field of bioethics.” However, I will do so with an explicit awareness that these groups are not unified monoliths.

When I use the term “disability movement,” I mean the coordinated, large-scale, sustained social and political action of disabled people in the United States. This term is deliberately broad and meant to encompass the substantial range of sometimes divergent tactics and ideologies deployed by disabled people, but it is not assumed that all disabled people engage in such action, have the same political beliefs, or use identical advocacy approaches. In addition, while the lived reality of disability is an important feature of my argument, the “disability movement” is not simple shorthand for people who experience life with an anomalous embodiment or medical impairment but instead refers to a particular subset of disabled people who are conscious of their own subordinate social position and engage in political action accordingly. As used here, “disability movement” may be analogous to “feminist movement” insofar as that term captures a range of political viewpoints and approaches but does not include all people who are biologically female or even all those who identify as women.

Likewise, it is important to recognize that the field of bioethics is a plurality of methodologies, activities, and ideologies, some of which have come into conflict with the disability movement more than others. When I generalize about “bioethics,” I am identifying the most common ideas and practices of those who professionally analyze, teach, and write about bioethical problems at American universities and hospitals. This is

not to say that those outside of the academy engaging these issues are *not* doing bioethics or that *everyone* inside academic bioethics is adversarial to the disability movement but only to recognize that there is a sustained pattern of conflict between these two

not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community. This values formation takes disability as the

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groups. I hope that my argument, as it develops, allows for more nuance than this dichotomy at first may indicate.

### Disability Experiences as Sources of Ideology, Values, and Norms?

Others have already called for the possibility of an alternative ethics arising out of the lived experience of disability. For example, political historian Paul Longmore, partly in response to his engagement with bioethics, has begun a critique of moral and political values that have been developed and institutionalized by nondisabled people. Longmore explicitly argues that an articulation of disabled values and critique of non-disabled values should be a key part of the work of disabled activists and scholars:

Beyond proclamations of pride, deaf and disabled people have been uncovering or formulating sets of alternative values derived from within the deaf and disabled experiences. . . . They involve not so much the statement of personal philosophies of life, as the assertion of group perspectives and values. . . . For example, some people with disabilities have been affirming the validity of values drawn from their own experience. Those values are markedly different from, and even opposed to, non-disabled majority values. They declare that they prize

starting point. It uses the disability experience as the source of values and norms. The affirmation of disabled values also leads to a broad-ranging critique of non-disabled values.<sup>4</sup>

Here Longmore proposes a fundamental reframing of basic social values—many of which are central to the field of bioethics—from a disabled person’s point of view. Longmore asserts that the disability experience becomes a source of alternative values or norms through a collective process that involves a group of people rather than isolated individuals. He sees a system of disability ethics being developed by a communal social movement of disabled people, but I maintain that this first begins with differences in moral psychology caused by the lived experiences of disability, which are prior to any expression of an alternative ideology.<sup>5</sup>

Indeed, most of the theorists who have examined this conflict between the disability movement and mainstream bioethics have framed it in terms of a difference in political ideology.<sup>6</sup> For example, much very good work has been done in bioethics and disability studies that describes the conflict in terms of competing ideologies regarding the ontology of disability itself.<sup>7</sup> That is, several thinkers frame the fundamental tension between bioethics and the disability movement as a politicized struggle over whether disability is primarily a socially constructed disadvantage

or primarily an inherently negative, individual biological flaw or defect. These scholars maintain that the ideological divide causing this conflict is rooted in competing commitments to the *social model* or the *medical model* of disability. Fundamentally, for these scholars it is a political disagreement over what disability *is*.

In contrast, I argue that although the conflict between the disability movement and mainstream bioethics may often be *expressed* through the ideological divide that these scholars have identified, it does not *originate* with that divide and cannot be resolved at that level of analysis. If the divide were only ideological, then perhaps the disability movement and mainstream bioethics could set aside their tense history and enter into a productive discourse that settles the conflict with reason. Admittedly, the view that these matters could be decided based on who has the soundest arguments has tremendous appeal. However, this position does not recognize how social power largely determines the framework by which the supposed validity of an argument is judged. Like many segments of social life, the profession of bioethics has been constructed by those with all manner of social power and privilege, and thus, its evaluative framework has been constructed according to the moral perception and reasoning of these elite. If I am correct that disabled people differ from mainstream bioethicists with respect to moral psychology, then that difference partially explains how the debate is already rigged against the disability movement when it enters into this discourse. Thus, until we analyze and dismantle the ways in which social power puts disabled people at a disadvantage when they do bioethics by how it appraises their *reasons*, we cannot hope for a fair and balanced dialogue that will be settled with *reason*. Ultimately, this is why I argue that any resolution to the conflict between the disability movement and the field of bioethics cannot rely solely on an analysis of competing moral and

political ideologies. Instead, the field must take up the more ambitious task of identifying and bridging this underlying divide in moral psychology by addressing these questions of social power within the profession. First, the question must be asked, do disabled people sometimes perceive and reason about moral problems in ways that are foreign to mainstream bioethics?

Fully analyzing the causes and effects of nuanced differences between the respective moral psychologies of the disability movement and bioethics—and then suggesting all of the theoretical and practical changes that might dissolve the conflict produced by these unacknowledged differences—is well beyond the scope of this paper. However, I do hope to provide enough of a sketch of how this process might work to motivate bioethics to take up this task. By remodeling mainstream bioethics conceptually, socially, and materially, we will open up the possibility of the full participation of disabled people, thus reducing the conflict and improving the quality of bioethical thought with heretofore marginalized moral knowledge.

### Variant Moral Psychologies

The problem of physician-assisted suicide exemplifies the variation in moral perception and reasoning that is at the heart of the conflict between the disability movement and mainstream bioethics. How the moral issues in PAS are perceived and analyzed, especially as the principle of respect for autonomy is applied, is strikingly different.

Most mainstream bioethicists perceive the main moral dilemma of PAS as a classic conflict between the principles of beneficence and autonomy, mostly viewing those seeking PAS as vulnerable patients needing to be empowered to express their autonomous choices in defiance of the illegitimate authority of paternalistic physicians. Of course, bioethics does not approach the topic with absolute unity, but much of mainstream bioethics'

analysis of PAS can be traced directly back to the origins of the field itself and the particular, dominant view of autonomy it has typically endorsed.

Alicia Oulette writes that “[d]espite its many faces, bioethics has as its core a central concern with respect for persons through respect for individual autonomy and good medical care.”<sup>8</sup> The story of how the field came into existence is a description of the radical shift away from medical paternalism, the standard practice of “hiding information from and making choices for patients,” and toward “today’s patient-centered model largely in response to abuses of people involved” (p. 30). This history is reflected in how the concept of autonomy is now deployed in the field. For example, Beauchamp and Childress’s classic *Principles of Biomedical Ethics* places a great deal of importance on the principle of respect for autonomy, arguing that “to respect autonomous agents is to acknowledge their right to hold views, to make choices, and to take actions based on their personal values and beliefs.”<sup>9</sup> From the very inception of their chapter on autonomy, they apply this principle in a medical context as, fundamentally, a buttress against a possibly paternalistic physician who has overstepped his authority in a misguided attempt to benefit the patient.

For Beauchamp and Childress, the main threats to this widely accepted view of autonomy are ignorance and explicit coercion. Thus, to judge whether a person has the opportunity to act autonomously, the bioethicist must simply check to see if he or she has “a substantial degree of understanding and freedom from constraint” (p. 101). Of course, in this view of autonomy, “constraint” or “controlling influences” are characterized as interference from others with greater power, such as governments or physicians. As Beauchamp and Childress illustrate, within bioethics, the physician’s paternalistic influencing of the patient’s choice is the paradigmatic case of such a constraint. “We encounter many

problems of autonomy in medical contexts,” they write, “because of the patient’s dependent condition and the medical professional’s authoritative position. . . . In these circumstances, the patient’s autonomy is sometimes compromised because the physician has assumed an unwanted degree of authority, as in certain paternalistic actions” (p. 102). This is the dominant view of how and why autonomy ought to be applied to issues in bioethics generally and PAS in particular.<sup>10</sup>

Beauchamp and Childress are clear that this view of autonomy is the guiding principle for thinking about physician-assisted suicide:

[I]f a person freely authorizes death and makes an autonomous judgment that the cessation of pain and suffering through death constitutes a personal benefit rather than a setback to his or her interests, then active aid-in-dying at the person’s request involves neither harming or wronging . . . . Assisting an autonomous person at his or her request to bring about death is, from this perspective, a way of showing respect for a person’s autonomous choices. Similarly, denying the person access to other individuals who are willing and qualified to comply with the request shows a fundamental disrespect for the person’s autonomy.<sup>11</sup>

Of course, Beauchamp and Childress do not unequivocally endorse the legitimacy of every case of PAS, and they concede that PAS must be done in a way that prevents “abuse, lack of social control, absence of accountability, and unverifiable circumstances of a patient’s death” (p. 182). Yet they have a narrow, if extremely common, view of what constitutes coercion and, thus, a narrow view of the kinds of factors that may limit patient choice.

As with mainstream bioethics and support of PAS, the disability movement is not homogenous when it

comes to opposition to the practice. However, the majority of members of the politically active community of disabled people who have expressed their opinion on the matter are vocally against it. Carol Gill offers a list of the largest disability movement organizations that have officially adopted positions against PAS; these include the National Council on Disability, American Disabled for Attendant Programs Today (better known as ADAPT), the National Council on Independent Living, World Associations of Persons with Disabilities, Justice for All, the Association for Persons with Severe Handicaps (better known as TASH), the National Spinal Cord Injury Association, and the World Institute on Disability.<sup>12</sup> Not Dead Yet is a group formed spe-

cially to organize the DM’s opposition to PAS and identifies itself as “a national, grassroots disability rights group that opposes legalization of assisted suicide and euthanasia as deadly forms of discrimination against old, ill, and disabled people . . . [and that] helps organize and articulate opposition to these practices based on secular social justice arguments.”<sup>13</sup>

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The most important secular social justice argument offered by the disability movement against PAS is aimed at problematizing the sort of simple appeal to autonomy used by mainstream bioethics to support PAS. Many argue that appeals to the autonomy of the individual to choose PAS do not recognize the social context of oppression within which the supposed choice is made and that the conditions of this context compromise the authenticity of the individual’s choice by obscuring the coercive

impact of systemic, institutionalized discrimination.

We can turn back to Longmore’s scholarship for a clear development of this sort of argument. Longmore finds deep fault with the typical liberal conception of autonomy that has dominated the field of bioethics and appears to lend support for PAS for patients who have the appropriate cognitive capacities, understand their available options well enough, and are not being actively coerced by the interference of others. At its heart, his critique is not a claim that personal autonomy is an irrelevant principle or that it should be curtailed when it comes to PAS. Rather, he argues that bioethicists who hold Beauchamp and Childress’s view are misapplying the concept of autonomy in these

sorts of cases because they do not account for the coercion perpetrated by oppressive social structures that narrow a person’s range of viable options. Thus, Longmore argues that the act of choosing PAS will often not be fully autonomous even if it is made with full information and without direct interference from others: “Health care ‘choices’ are never made in a vacuum. Given the absence of real options, death by assisted suicide becomes not an act of personal autonomy, but an act of desperation. It is a fictional freedom, it is a phony autonomy. The rhetoric of ‘choice’ is deployed to hide the realities of coercion.”<sup>14</sup>

Here, “coercion” refers, not to the sort of interference that Beauchamp and Childress’s arguments safeguard against, but to a social structure in which options that are better than death are entirely inaccessible to many disabled people. Longmore

### **Resolving the conflict between the disability movement and mainstream bioethics cannot rely solely on analyzing competing moral and political ideologies. The field must identify and bridge the underlying divide in moral psychologies.**



contends, for example, that “David Rivlin’s 1989 court-sanctioned, physician-assisted suicide exemplifies the social conditions that drive some disabled persons to their deaths and the ignorance and bias of some nondisabled people that lead them to support such suicides.”<sup>15</sup> Longmore cites Rivlin as maintaining that it was not his disability per se that motivated him to request assistance in dying but a lack of access to the kinds of state funding that a disabled person would need to participate in higher education, work, marriage, family, and social interaction. He points out that there is a broad variation between American states in the amount and type of funding available to disabled people who want to live in the community rather than the sort of nursing home that Rivlin had lived in for several years before requesting aid in dying. Longmore argues that Rivlin’s home state, Michigan, was at the very low end of this spectrum at the time and did not provide access to the resources needed for the self-determination of someone with quadriplegia who uses a ventilator. Without this support, instead of pursuing his life plan according to his values and preferences, Rivlin lived his life confined to a nursing home and “chose” to turn off his ventilator only after several attempts to live in the community were thwarted by a lack of public funding.

This example illustrates how the principle of autonomy is deployed by Beauchamp and Childress in a way that neglects and obscures some of the most important moral features of a situation in which a disabled person might attempt to “hold views, to make choices, and to take actions based on their own personal values and beliefs.”<sup>16</sup> The moral feature that the traditional application of autonomy misses in cases involving disability is the necessary condition of accessibility. Autonomy in making life choices requires access to multiple options as a matter of course for everyone; however, disabled people’s common lack of access to viable choice likely makes

them more attuned to this necessary condition for choosing.

A thought experiment about a paradigmatic manifestation of personal autonomy in American society, namely, career choice, enables us to see how a moral problem requiring the application of the concept of autonomy might be perceived and reasoned about differently by a disabled person and how that variation in moral psychology might develop. Let’s say that there are two Ph.D. candidates applying for entry-level, tenure-track philosophy jobs who are nearly identical in most of the relevant respects. They studied at universities with similar reputations, had advisors and recommenders of similar professional stature, and have similar areas of specialization and competence that were in the same level of demand on the job market. They have very similar teaching backgrounds, publication records, and experience presenting at conferences. These candidates also have similar social identities in terms of race, ethnicity, class, sexual orientation, religion, and gender. Let us say that the only relevant difference between them is that candidate A is nondisabled and candidate B has a high-level spinal cord injury and uses a power wheelchair. Let us also assume that no philosophy department to which our candidates might apply has any sort of explicit policy or practice of intentionally discriminating against either of the candidates, such that their autonomy would be unduly constrained through direct coercion.

As a preliminary step to entering the academic job market, they must develop and fine-tune their written application materials. Both should attend the departmental workshop guiding the development of these materials, but candidate B must first ensure her physical access to the building and room location. After the workshop, both must draft these documents and email them to their faculty advisers and recommenders, but candidate B must first make sure that her unique, expensive, and sometimes unreliable adaptive computer

hardware and software is in working order so she can do this without typing or clicking a mouse.

Next, both must diligently scour the Internet for job openings that fit their qualifications and develop a list of jobs to apply for. Of course, candidate B must again make sure she can access her assistive technology to accomplish this task.

The candidates must then apply to faculty openings via the Internet or traditional mail. For the Internet applications, candidate B must plan to access her specialized computer equipment, and for the mailed applications, she must attain wheelchair-accessible transportation to the post office and arrange for her attendant to assist with navigating what are likely to be inaccessible doors and an inaccessible business counter.

Hopefully, both candidates will secure first-round interviews on the telephone, via Skype, or in person at the Eastern Division Meeting of the American Philosophical Association. For Skype interviews, candidate B must ask her personal attendant to work a couple of extra hours in the middle of that day to help her change into and back out of her business suit for the interview. For APA interviews, candidate B must plan ahead for accessible ground transportation to and from the airport both at home and in the destination city, a personal attendant to travel with her to assist with activities of daily living, an accessible conference hotel room, and an accessible interview space.

The next step is for both to travel to respective campuses for final-round interviews, including a job talk. Candidate B must make arrangements that are similar to those she needed for Eastern APA but perhaps more arduous if the job is in a rural area.

Access is necessary for both candidates to “hold views, to make choices, and to take actions based on their own personal values and beliefs” (103), and barriers to access exist for both.<sup>17</sup> However, I would argue that this matter of access is highlighted in the foreground of the lived experiences of

candidate B in a way that it is not for candidate A. As I hope my example illustrates, a disabled person develops the habit of anticipating and, when possible, arranging to circumvent barriers to the access needed to make major life choices. This attunement toward access as a necessary condition to autonomous choice has been habituated through a socially structured experience of living with disability in a social and physical environment that is often largely inaccessible.

The scholarly literature in the disability movement supports this line of thought as well. For example,<sup>18</sup> Jackie Leach Scully's discussion of the potential contributions disability experiences make to feminist concepts of relational autonomy underscores how disability highlights important specific features of moral problems that might otherwise be obscure.<sup>19</sup> "Embodiment and interdependence are realities for everyone, all the time," writes Scully. "In a relational view of autonomy, self-determination can never be entirely down to the self because it is constituted in relationship (negotiation, compromise) with others. Under conditions of impairment, however, these universal features are experienced in unfamiliar ways, and they suddenly become more visible."<sup>20</sup>

### The Origins of Alternative Disability Moral Psychologies

Thus far, I have argued that the tensions between the disability movement and the field of bioethics are best explained by a difference in moral psychology between disabled and nondisabled people. I have also offered an illustration of how these differences in moral perception and reasoning are exhibited in bioethical discourse via divergent applications of the principle of autonomy to the question of PAS. However, except with the brief thought experiment regarding the development of an alternative mode of applying a particular moral principle, I have yet to give any account of how differences in moral

psychology might be generated by the experiences of disability.

One might be tempted to read this paper as claiming that the gap between disabled and nondisabled people's moral psychologies is so enormously broad and deep that each is truly global, affecting every aspect of moral reasoning and perception in every context one encounters. Perhaps the radically different life experiences of disabled people produce a difference in values that is all-encompassing.

This claim would be much too strong because it implied that there is a singular, unified moral psychology derived from *the* experience of disability. In fact, there is infinite variation in disability experiences arising from, for instance, intersecting identities like race, gender, social class, and sexual orientation. Further, if disability moral psychology were

**We should reform the curriculum of bioethics to include nuanced, politically aware narratives of life with disability—narratives that give aspiring bioethicists and health care professionals a richer understanding of disability from which to deliberate.**

thought of as a global, unified monolith, bridging the gap between the disability movement and mainstream bioethics might seem impossible. After all, productive deliberation might not even be possible across radically different, global moral psychologies. Fortunately, it is not necessary for the differences in moral perception and reasoning between the disability movement and mainstream bioethics to be global for them to effectively explain the enduring conflict at hand. A much more modest and plausible difference in moral perception and reasoning could produce those tensions. While I do not have the space to fully flesh out the causal story of how such differences may arise, the key features of such an explanation can be sketched.

A core thesis of Owen Flanagan's groundbreaking book in moral psychology, *Varieties of Moral Personality*, is that claims of a global difference in moral reasoning between groups of people are incoherent and unsupported by the evidence. Flanagan takes aim at the assertion that there are global gender differences in moral psychology, which he takes to be the claim that "there is not one psychological space within which all moral personality takes shape and within which it locates its regulative ideals. There are (at least) two such spaces, one for males, one for females."<sup>21</sup> These two distinct psychological spaces give rise to what Flanagan calls different "global voices" in moral reasoning. Flanagan challenges the view that "there are two and only two global moral orientations" (p. 206) that map on to gender because of gendered differences in psychologi-

cal development. He argues that the two-voice hypothesis cannot be understood in a way that "(1) maintains an independent coherence for each voice and (2) is inclusive enough to cover all of morality" (p. 209). He argues that the most common accounts of how the two global voices develop in childhood are much too simplistic when the full breadth of evidence is considered from the field of child developmental psychology. In sum, Flanagan posits that theorizing two different, gendered global voices attempts to squeeze the enormous complexity and variation of moral psychology into a "gross-grained picture of the bases of moral personality and an equally gross-grained picture of what these basic experiences eventuate in . . . . Moral personality is, in the end, too variegated

and multipurpose to be analyzable in terms of a simple two-orientation scheme” (pp. 212, 233).

As with gender, it is surely not the case that there are two distinct, mutually exclusive global moral voices for disabled and nondisabled people. It would be absurd to claim that every disabled person reasons about and perceives every moral problem in the same way, which is radically different from the reasoning and perceiving of any and all nondisabled people.

Flanagan ultimately finds some important, if more nuanced, gender differences in moral psychology that can serve as a starting point for thinking through what disability moral psychology might look like. He argues that there are gender differences in the patterns exhibited by the *content* of moral reasoning and that such differences produce corresponding patterns of difference in the way problems are grappled with: “There are some sex differences in the types of problems men and women choose to talk about and claim to confront. Furthermore, the type or content of a problem is a far better predictor of orientation used (on that type of problem) than is gender” (p. 232). So, while there is no global, gender-based difference in moral voice, different problems demand different moral-psychological processes, and different genders encounter these problems with varied frequency, using different moral-psychological processes at different rates.

This difference in lived experience leads to the development of different types of moral competency from frequency of use. As Flanagan puts it, “Given that different kinds of problems make different sorts of considerations and salencies differently relevant, one would expect there to be some significant effects of the amount of practice one has in dealing with certain kinds of problems” (p. 234). The idea here is that social identities structure our lives such that different groups of people encounter different sorts of moral problems and thus develop different sorts of moral

competencies. Everyone may be familiar with the sorts of reasoning that would be used to address a given sort of moral problem, but social identity can determine how practiced one is, and therefore how effectual one is, in actually dealing with the problem. Flanagan drives this point with a sports analogy: “Many persons both know and can represent the rules of soccer and golf. But if one plays soccer and not golf, then the fact that one can talk competently about both is surprisingly inconsequential with respect to one’s practical ability to stay out of the rough” (p. 234).

My thought experiment with the two Ph.D. candidates can be read as an example of how the social identity of disability can structure personal experience so that an individual more easily perceives and reasons about the morally salient features of a situation in which one is trying to protect a disabled person’s autonomy in a context of ableist structural oppression. In effect, because of lived experiences of disability, many disabled people are more able to “stay out of the rough” when grappling with many of these sorts of bioethical questions.

When disabled activists and scholars deploy these alternative moral competencies in their engagement with mainstream bioethics, deep moral conflict often arises. This is because the moral perceptions and reasons that give content to these alternative moral competencies are often summarily dismissed by evaluative standards that have been structured by and for a nondisabled moral psychology. Scully describes the evaluative standards of mainstream bioethics in terms of 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 . . . [that] generates its own system of tacit rules governing practices and behaviors.”<sup>22</sup> *Habitus* supplies a moral agent with her most fundamental set of moral assumptions that are taken to be so self-evident that “things out of alignment with it are

obviously absurd or illogical or barbaric” (p. 65). The conflict between mainstream bioethics and the disability movement arises because disabled moral psychologies are often out of alignment with the *habitus* of mainstream bioethics, which has been constructed based on the lived experiences of nondisabled people.

### Charting a Path Forward

One might see my claim that the conflict between the disability movement and mainstream bioethics is more about psychology than it is about ideology as hopelessly pessimistic. If members of the disability movement and mainstream bioethicists differently perceive and think about some moral problems, then how can they ever engage in constructive discourse?

Again, Flanagan provides some guidance. As noted, he argues that variation in moral psychology is determined by how people with different identities engage with the material and social structures of a world that presents them with different opportunities for the development of their various moral capacities. The roles of the material and social environments in moral development cannot easily be overstated for Flanagan. He encapsulates the point in what he calls the “thesis of the multiple realizability of moral psychologies”: “The set of realizable moral psychologies is infinitely large” because “personalities are largely dependent on particular social, economic and institutional arrangements. And there is no reason to think—and every reason to think the contrary—that the possible social, economic, and institutional arrangements that we are capable of creating and living under have been remotely exhausted.”<sup>23</sup>

Flanagan goes on to argue that we sometimes have good reasons to deliberately attempt to restructure the contexts in which moral personalities develop because “vastly many more kinds of moral personality are possible than are good” (p. 32). In fact,

the grip of these material and social conditions on our moral development is so strong that changing them may sometimes be the only means at our disposal for moral improvement; “the existence of a socially constructed trait can . . . set deep, possibly unyielding constraints on our ability to realize a particular psychology once we are mature members of some community and well socialized in its values and attitudes” (p. 43). In the social struggle against racism and sexism, for example, it is by manipulating the contexts of moral development that “we could seek to change the practices and the attitudes of subsequent generations, even if it were very difficult to purify completely our own attitudes and dispositions” (p. 43). The serious, long-term uptake in mainstream bioethics of the moral perceptions and reasoning deployed by disabled people depends on adjusting concrete practices and institutions within which a *nondisabled* moral psychology develops.

Here are some examples that could be starting points for making these structural changes. The first step would be to further clarify the scope and depth of the variations in moral psychology between disabled and nondisabled people as they arise in biomedicine. While there are compelling reasons to believe the moral perception and thinking varies between the disability movement and mainstream bioethics, there is very little empirical research to give the picture shape and clarity. Empirical research is especially important if, as I have argued, the differences between disabled and nondisabled moral psychologies are not global. Empirical study could help identify which contexts these differences occupy, how prevalent they may be, and what their main features are.

Perhaps the most obvious way in which mainstream bioethics can and should be restructured to account for the moral perceptions and reasoning of disabled people would be to make efforts to include disabled people in the practice of bioethics. Progress

could be made here by meeting accessibility standards for disabled bioethicists within institutions where bioethics happens. Being forced to navigate inaccessibility across wide swaths of life may be the only common experience among all disabled people. Indeed, many disabled scholars who work in bioethics still struggle to attain reasonable accommodations so that they can fully access the physical and social spaces where bioethics happens.

Of course, given the entrenched dispute between the disability movement and mainstream bioethics, achieving adequate representation of disabled people in bioethics will require much more than removing barriers to accessibility. Like any scholarly endeavor, bioethics has a specific jargon and literary canon that must be mastered if one is to participate effectively in the field. Many times, this familiarity is acquired via formal training. Thus, maybe the most important step that could be taken to help promote the inclusion of disabled people in the field of bioethics would be to actively establish affirmative action programs that recruit them to graduate programs and, later, faculty appointments. As with the removal of barriers to accessibility, a case could be made on the basis of justice that disabled people ought to gain entry into higher education in general via affirmative action. However, I hope I have presented additional reasons that the moral perception and reasoning of disabled people is necessary for bioethics to improve as a field of inquiry. In turn, this ought to provide some additional reasons for academic programs in bioethics to recruit and retain disabled students and scholars.

Finally, to give bioethics a better understanding of disability moral psychology, we must reform its curriculum so that it includes the history, culture, and theory of the disability movement. At minimum, this would include detailed accounts of the features and origins of laws like section 504 of the Rehabilitation Act

and the Americans with Disabilities Act, both of which were born from the disability movement's decades of social and political struggle.<sup>24</sup> It also should include nuanced, politically aware narratives of life with disability—narratives that challenge the stereotypical tropes of popular culture and give aspiring bioethicists and health care professionals a richer understanding of disability from which to deliberate. An example of such a narrative, widely considered a classic in disability studies, is medical sociologist Irving Zola's influential book, *Missing Pieces: A Chronicle of Living with a Disability*,<sup>25</sup> which was first printed in 1982, the same year he and four other scholars founded the Society for Disability Studies. Some of these memoirs even engage in bioethical reasoning, like Harriet McBride Johnson's autobiography *Too Late to Die Young*,<sup>26</sup> in which she devotes a chapter to her conversations with Peter Singer about infant euthanasia. Finally, medical ethics curricula should include some of the classic works of disability theory, some of which have been around for decades but are still mostly ignored by the training of bioethicists and medical professionals.<sup>27</sup> Including this material in the bioethics curriculum would shift the starting point from which bioethics engages the disability movement. Developing a widespread, rich understanding of the phenomenal experience of disability from a social and political viewpoint, rather than a purely medicalized one, would go a long way toward establishing the conditions in which nondisabled bioethicists and health care providers could develop the moral perception and reasoning that would let them enter into constructive dialogue with the disability movement.

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## Notes

1. Much of the history of this conflict has been carefully documented in A. Ouellette, *Bioethics and Disability: Toward a Disability Conscious Bioethics* (New York: Cambridge University Press, 2011).

2. For a comprehensive entry point to this literature, see A. Asch and E. Parens, eds., *Prenatal Testing and Disability Rights* (Washington, D.C.: Georgetown University Press, 2000).

3. While Jackie Leach Scully prefers the language of epistemology to that of moral psychology, she outlines several important mechanisms that may produce the sort of differences in moral understanding and evaluation in disabled people that I am also trying to address. This paper aims to support, refine, and expand her arguments by suggesting some additional mechanisms by which disabled people may develop alternative moral perceptions and reasoning and to offer some practical suggestions for how mainstream bioethics can respond to this critique. See J. L. Scully, *Disability Bioethics: Moral Bodies, Moral Difference* (New York: Rowman & Littlefield, 2008).

4. P. K. Longmore, *Why I Burned My Book and Other Essays on Disability* (Philadelphia: Temple University Press, 2003), 222.

5. A related but separate approach that reaches a similar conclusion can be found in the literature describing how the phenomenology of disability can shape human value. For a clear, striking example of this, see T. B. Burke, "Armchairs and Stares: On the Privation of Deafness," in *Deaf Gain: Raising the Stakes for Human Diversity*, ed. H.-D. L. Bauman and J. J. Murray (Minneapolis: University of Minnesota Press, 2014), 3-22.

6. Here, I am using the term "ideology" as it is used in the tradition of liberal political philosophy, rather than how it is meant in a radical or Marxist tradition. Namely, "ideology" should be taken to mean "a system of political ideas . . . ideas whose purpose is not epistemic, but political. Thus an ideology exists to confirm a certain political viewpoint, serve the interests of certain people, or to perform a functional role in relation to social, economic, political and

legal institutions" (C. Sypnowich, "Law and Ideology," in *Stanford Encyclopedia of Philosophy*, ed. E. N. Zalta, fall 2010 ed., article first published October 22, 2001, substantially revised July 28, 2010, <http://plato.stanford.edu/archives/fall2010/entries/law-ideology/>). To be clear, I am making my argument from the assumption that the medical and social models of disability are not just explanations of biological or social phenomena but systems of political ideas that serve the interests of the field of bioethics and the disability movement, respectively.

7. For examples of this sort of argument framing, see R. Amundson, "Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics," in *Quality of Life and Human Difference: Genetic Testing, Health Care, and Disability*, ed. D. Wasserman, J. Bickenbach, and R. Wachbroit (New York: Cambridge University Press, 2005); A. Asch, "Disability, Bioethics, and Human Rights," in *Handbook of Disability Studies*, ed. G. L. Albrecht, K. D. Steelman, and M. Bury (Thousand Oaks, CA: Sage, 2001); C. Newell, "Disability, Bioethics, and Rejected Knowledge," *Journal of Medicine and Philosophy* 31 (2006): 269-83; A. Silvers, "On the Possibility and Desirability of Constructing a Neutral Construction of Disability," *Theoretical Medicine* 24 (2003): 471-87.

8. Ouellette, *Bioethics and Disability*, 30.

9. T. L. Beauchamp and J. F. Childress, *Principles of Biomedical Ethics*, 6th ed. (New York: Oxford University Press, 2009), 103.

10. For a representative sample of similar arguments supporting PAS with respect for autonomy in contrast to medical paternalism, see D. W. Brock, "A Critique of Three Objections to Physician Assisted Suicide," *Ethics* 109, no. 3 (1999): 519-47; G. Dworkin, "Physician-Assisted Suicide and Public Policy," *Philosophical Studies* 89 (1998): 133-41; and J. J. Thomson, "Physician-Assisted Suicide: Two Moral Arguments," *Ethics* 109, no. 3 (1999): 497-518.

11. Beauchamp and Childress, *Principles of Biomedical Ethics*, 181.

12. C. Gill, "Health Professionals, Disability, and Assisted-Suicide: An Examination of Relevant Empirical Evidence and Reply to Batavia," *Psychology, Public Policy, and Law* 6, no. 2 (2000): 526-45, at 526.

13. Not Dead Yet, "Who We Are," accessed August 10, 2015, <http://www.notdeadyet.org/about>.

14. Longmore, *Why I Burned My Book and Other Essays on Disability*, 195.

15. P. K. Longmore, "The Strange Death of David Rivlin," *Rehabilitation*

*Medicine—Adding Life to Years*, special issue, *Western Journal of Medicine* 154 (1991): 615-16, at 615.

16. Beauchamp and Childress, *Principles of Biomedical Ethics*, 103.

17. Of course, people can also be subjected to marginalization and barriers to access based on gender, race, socioeconomic class, sexual orientation, and other social identities.

18. For another example of scholarship that uses disability as an entry point to a conceptual revision of the principle of autonomy, see A. Ho, "The Individualist Model of Autonomy and the Challenge of Disability," *Journal of Bioethical Inquiry* 5, no. 2 (2008): 193-207.

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

20. Scully, *Disability Bioethics*, 162.

21. O. Flanagan, *Varieties of Moral Personality: Ethics and Psychological Realism* (Cambridge, MA: Harvard University Press, 1991), 198.

22. Scully, *Disability Bioethics*, 65.

23. Flanagan, *Varieties of Moral Personality*, 32.

24. For one prominent, detailed account of the political history of the disability movement, see J. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Three Rivers Press, 1993).

25. I. K. Zola, *Missing Pieces: A Chronical of Living with a Disability* (Philadelphia: Temple University Press, 1982).

26. H. M. Johnson, *Too Late to Die Young: Nearly True Tales from a Life* (New York: Henry Holt and Company, 2005).

27. For example, see M. Oliver, *The Politics of Disablement: A Sociological Approach* (London: Palgrave Macmillan, 1990).