

American Medical Association Journal of Ethics

April 2016, Volume 18, Number 4: 399-405

IN THE LITERATURE

A Defense of “The Case for Conserving Disability”

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Garland-Thomson R. The case for conserving disability. *J Bioeth Inquiry*. 2012;9(3):339-355.

Garland-Thomson’s Case for Conserving Disability

Rosemarie Garland-Thomson makes a moving case for conserving the existence of disability [1], which she describes as “preserving intact, keeping alive, and even encouraging to flourish” disability in society and humanity [2]. She begins her paper by making the point that disability affects everyone who lives long enough, making her readers feel the conversation is relevant to them. She then poses the question of how it can be possible for disability—something that all humans will have eventually, if we are lucky to live long enough—to “disqualify us from full membership in the human community” [3]. To answer this question, she next turns to David Mitchell and Sharon Snyder, who explain that we associate disability with, in Garland-Thomson’s words, “pain, disease, suffering, functional limitation, abnormality, dependence, social stigma, and economic disadvantage” [4]. With this understanding of disability and what Garland-Thomson refers to as “[eugenic logic](#),” we are left to conclude that “the world would be a better place if disability could be eliminated” [4].

In her paper, Garland-Thomson defines eugenic logic as “a utopian effort to improve the social order, a practical health program, or a social justice initiative that is simply common sense to most people” [4]. Eugenic logic is a controversial phrase, which Garland-Thomson acknowledges in a footnote. John Banja [deems](#) the fear of eugenic logic to be “unreasonable” based on his assessment that disability rights advocates misunderstand the medical model and are perhaps using “motivated reasoning”—choosing a conclusion before gathering all the facts [5]. Michelle Bayefsky [6] asserts that the term eugenic is “vastly overused” [7]. By using a term that critics deem to be unreasonably fear inspiring or unnecessary, Garland-Thomson makes a point: if eugenic logic as she defines it is “common sense to most people” [4], our commonsense understanding of disability is part of the problem, indicating the need for Garland-Thomson’s case for conserving disability.

The bioethical question being considered is why we should conserve disability—as opposed to trying to eliminate it. Garland-Thomson explains that her choice to use the term “conserve” is intentional, as it does the semantic work of suggesting that

disabilities can be understood as resources or benefits to be kept [2]. Furthermore, although she is answering a bioethical question, she does not reference the bioethical debates about genetic enhancement and philosophical questions about personhood. This implies that her argument is geared not toward a particular debate but to our cultural or commonsense understanding of disability in general. Although Robert Sparrow and others refer to Garland-Thomson's argument for disability conservation as a critique of preimplantation genetic diagnosis and prenatal testing [6, 8], I maintain that the most moving aspect of her piece is its push for a broader reshaping of cultural perceptions of disability.

It is important first to understand how Garland-Thomson defines disability. Garland-Thomson provides both a political and cultural definition of the term. She refers to the Americans with Disabilities Act of 1990 and the United Nations Convention of Rights of People with Disabilities of 2009 to make the point that, though these frame disability in social and political terms, they remain dependent on the medical understanding of disability as "impairment, restriction, dysfunctionality, abnormality" [2]. For a cultural definition of disability, Garland-Thomson turns to constructivism and phenomenology, which share the idea of "disability as a way of being in an environment" produced by the "discrepancy between body and world, between that which is expected and that which is" [9]. Combining this idea with her earlier point that everyone who survives long enough will age into disability, she concludes that "disability is thus inherent in our being: What we call disability is perhaps the essential characteristic of being human" [9].

Garland-Thomson's case for conserving disability depends on the idea that disability is a preservation-worthy resource in three unique but interconnected ways: narratively, epistemically, and ethically. For understanding of disability as a narrative resource, she turns to the work of Leslie Fiedler and Arthur Frank. Fiedler argues that disability is a narrative resource for people without disabilities; Frank posits that disability is a narrative resource for people with disabilities themselves. Fiedler advocates "disability-as-freakdom"; freaks, in Garland-Thomson's words, "inspire...wonder through their extravagant differences from ordinary folks and their simultaneous eerie, distant sameness to their unexceptional brethren" [10]. Frank focuses instead on how illness contributes to understanding the self and one's identity.

Epistemically, Garland-Thomson argues, disability offers new ways of experiencing the world around us. Garland-Thomson cites Hellen Keller's experiences as an example of how some senses are heightened in the absence of others. She introduces the idea of embodied cognition from psychology to explain "that people draw on their bodily experiences not only to think and know but also to construct our social reality" [11].

Finally, she frames disability as an ethical resource that contributes to our sense of community; in philosopher Eva Kittay's words, conserving disability "will build solidarity with others, cultivate human sympathies, and create an open human community" [12].

Raising Three Concerns

Although Garland-Thomson makes a compelling argument for disability as a sociocultural resource, there are a few concerns that I would like to discuss. The first concerns willingness to embrace conservation of disability on an individual and institutional level, and the second concerns whether disability is the sole source of the benefits that Garland-Thomson presents in her argument; and the third concerns the choice of the word "inherent" to describe disability.

Willingness to conserve disability. Although it seems that disability enables the human community to benefit from interdependence, the practical worry is that perhaps not all people want—or maybe are even capable of—enduring the downsides of disability in order to participate in that interdependence. In his article, "Imposing Genetic Diversity," Sparrow asserts that "different experiences produced by being disabled are ones that one might reasonably desire to seek out or avoid" [13], as becomes clearer when considering whether one would want one's child to have a disability.

On an institutional level, the concern is similar—whether institutions want to conserve disability. Some have argued that, currently, institutions such as workplaces operate according to the "eugenic logic" Garland-Thomson describes. The idea is that, if institutions are currently constructing a workplace environment that is not accommodating to disabilities, we might infer that they are either unable or unwilling to conserve disability in the workplace for the future. In a recent *New York Times* article, Tara Siegel Bernard points out that the critics of wellness programs worry that these programs are a form of discrimination against "less healthy workers" [14]. Indeed, Carrie Griffin Basas [argues](#) that companies are using wellness programs as a way to discriminate against those with disabilities and that our society's philosophy of neoliberalism, which prioritizes independence or autonomy in the workplace, manifests in these programs [15]. Griffin Basas explains that "state intervention is kept to a bare minimum unless it supports these goals" and that "ethical problems become economic ones" [16]; wellness programs promote discrimination by inadvertently punishing those with disabilities who cannot participate. Griffin Basas makes a compelling argument that wellness programs institutionalize disability bias not only in the workplace, but also in today's society.

Consider the American Medical Association's wellness program, for example. For those who cannot participate in the suggested exercise activities (which exclude exercises that individuals with disabilities can participate in), there is an option to attend "lunch and lecture" sessions. A closer look at these lunch lectures, posted as videos on the

organization's internal website, reveals that 27 percent (7 of 26) focus on exercise (American Medical Association internal communications)—undermining the lecture program's potential to include those with disabilities who cannot exercise in the suggested ways. A problem here is that the definition of *exercise* that wellness programs tend to promote presumes able-bodiedness and is, therefore, exclusionary. As I discuss in the following section, Garland-Thomson addresses these concerns about wellness programs in her work.

The uniqueness of disability as a source of benefit. The second question I have is whether we need disability to attain these benefits. Garland-Thomson cites Arthur Frank when making her case for disability as a narrative resource, but Frank writes about those with illness more generally, not disability, the permanent state Garland-Thomson defines as a "discrepancy between body and world" [9]. This characterization does not seem to clarify whether the phenomenological benefits attributed to permanent disability could not also be garnered from temporary illness. The worry, then, is that illnesses, which can be temporary, can also be a narrative resource for understanding oneself or others—making it unclear whether disability is unique in providing such a resource.

It is also not clear that disability is unique as an ethical resource. Garland-Thomson states that disability as an ethical resource "will build solidarity with others, cultivate human sympathies, and create an open human community" [12]. It seems reasonable to believe that there are other phenomena and circumstances that promote solidarity, sympathy, and community. She does make a case that disability contributes to the development of these things, but it is not clear whether that would be enough for some to be persuaded of her overarching case to conserve disability.

The claim that disability is inherently human. The last concern is an issue of semantics. Garland-Thomson asserts that disability is "inherent in the human condition" [17]. The Oxford Dictionary defines inherent as "existing in something as a permanent, essential, or characteristic attribute" [18]. In a later article, Garland-Thomson uses the term "inevitable" to describe disability [19]. If the claim of permanence or inevitability were based solely on her idea that all who live long enough experience disability, then it would be questionable, since many such people have lived a life prior to developing disability and some people die without ever having personally had disabilities. Consider Bob, who has lived a life without disability, and has passed away from a cardiac event prior to developing a disability in old age. To say that Bob is not human, because he has at no point experienced disability, would not make sense. But Garland-Thomson's use of the term "inherent" is intended, however, to describe humanity, as I conclude in the next section.

Defense: Answering these Concerns

Individual willingness to conserve disability. With regard to the problem of whether “experiences produced by being disabled are ones that one might reasonably desire to seek out or avoid” that Sparrow poses [13], Garland-Thomson’s story of the mother who has a child with Tay-Sachs, a fatal disease, can provide some insight into approaching that problem. The mother admits that had she known her son would have Tay-Sachs, she would have had an abortion. What is moving about this specific story is that a mother who stands by the claim that she would have aborted her child if she had known about his disability also describes the love she has for her son as “blissful” [20]. Garland-Thomson uses this story to make a few different compelling points about suffering. One is that “suffering expands our imagination about what we can endure” [20]. A second is that the dependency that people with disability have on their loved ones provides the “opportunity to profoundly love another human being” [21]. A third point is about the effect that disability has on our control of the future—the problem being that the existence of disability “present[s] the difficult challenge for modern subjects not only to live in the moment but also to engage in a relationship not based on the promise of the future” [22].

It’s worthwhile to take a moment to emphasize the implications of Garland-Thomson’s third observation about suffering. Consider how often and how carefully you have made a plan for the future, whether it is simply for what you will do with your time tomorrow or years from now. Imagine not being able to do that—not being able to have an idea of what your tomorrow or future might look like (or what Garland-Thomson calls not having “predictable narratives”). If the thought makes you uneasy—feel vulnerable even—then Garland-Thomson has accurately described your relationship with the future and how disability challenges it. She eloquently concludes that “disability’s contribution, its work, is to sever the present from the future” [23]. This is not to say that disabilities make it impossible to plan for tomorrows. Rather, Garland-Thomson explains, the existence of disability is not only “an antidote to modernity’s overreaching” focus on curing and fixing, but also the source of “a narrative of a genuinely open future...not controlled by the objectives, expectations, and understandings of the present” [23].

In her commentary on Sparrow’s article critiquing Garland-Thomson, Bayefsky concludes of Garland-Thomson’s definition of disability, “we are left not far from where we began—with vaguely positive intuitions regarding the value of human genetic diversity” [24]. Bayefsky’s conclusion seems unwarranted. Garland-Thomson’s conclusion is not vague but specific: she has identified three ways in which disability, some of it attributable to human genetic variation, contributes to our world—as a narrative, epistemically, and ethically. Additionally, she has given us a new perspective on disability, describing it in phenomenological terms. Ultimately, Garland-Thomson is redefining disability. The act of redefinition changes our understanding or perceptions of what is being redefined. Rather than leaving us “not far from where we began,” Garland-

Thomson's argument increases our understanding of disability and gives us an opportunity to shift our perspectives on what it means to have a disability. Garland-Thomson digs deeply into human fears about the future and provides novel insight into why people might have an aversion to conserving disability.

Institutional willingness to conserve disability. Garland-Thomson's work addresses issues in today's working world, confronting disability issues on an institutional level. In a later paper, Garland-Thomson specifically discusses the idea of "world-building" [25]. She makes the point that, while it is not the kind of world we are currently building, it is possible to build a world of inclusion. She specifically mentions the workplace as a space that can be made more inclusive [9]. One might imagine that an inclusive workplace means making wellness programs accessible to those with disabilities and de-emphasizing the value of autonomy in the workplace for the sake of building an inclusive world. Although her vision does not solve practical problems, it does raise awareness about the world that we are building.

The uniqueness of disability as a source of benefit. What remains unclear is whether disability is necessary in attaining the three benefits that Garland-Thomson argues to be reasons for conserving disability. The worry is that, for example, temporary illness might provide similar narrative resources; other diverse experiences might provide similar epistemological resources; and community-based cultural practices could provide similar ethical resources. In other words, it is not clear why disability ought to be conserved in order to attain resources that might be available elsewhere. If the argument is that X ought to be conserved because it provides Y resources, then it must be the case that Y is only attainable from X.

The claim that disability is inherently human. The use of the term "inherent" ultimately does not pose a threat to Garland-Thomson's overall argument of how disabilities are benefits because her claim is not that disability is inevitable or permanent for all individual people, but that it is inevitable for some and inherent in the human community overall.

Conclusion

Garland-Thomson's paper inspires readers to reconsider their commonsense or cultural understanding of disability and goes much further, answering the question of how disabilities are benefits. In doing so, Garland-Thomson ultimately gives her readers a novel insight into what it means to experience disability in today's world.

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ISSN 2376-6980**