

The Case for Conserving Disability

Rosemarie Garland-Thomson

Received: 9 May 2012 / Accepted: 23 May 2012 / Published online: 18 July 2012
© Springer Science+Business Media B.V. 2012

Abstract It is commonly believed that disability disqualifies people from full participation in or recognition by society. This view is rooted in eugenic logic, which tells us that our world would be a better place if disability could be eliminated. In opposition to this position, I argue that that disability is inherent in the human condition and consider the bioethical question of why we might want to conserve rather than eliminate disability from our shared world. To do so, I draw together an eclectic, rather than systematic, configuration of counter-eugenic arguments for conserving disability. The idea of preserving intact, keeping alive, and even encouraging to flourish denoted by *conserve* suggests that disabilities would be better understood as benefits rather than deficits. I present, then, a reading of disability as a potentially generative resource rather than unequivocally restrictive liability. In other words, what I consider here is the cultural and material contributions disability offers to the world.

Keywords Queer health · Disability · Bioethics · Community

“Disability is the master trope of human disqualification.”

—David Mitchell and Sharon Snyder

“What we call disability is perhaps the essential characteristic of being human.”

—Rosemarie Garland-Thomson

David Mitchell and Sharon Snyder’s (2003, 3) claim suggests that disability restricts, excludes, renders one exceptional: disqualifies. At the same time, my own assertion (Garland-Thomson 2011) suggests that disability gathers us into the everyday community of embodied humankind. It reflects the truth that we will all become disabled if we live long enough and that every life, every family has disability in it at some time. If disability is inherent in the human, how can it at the same time disqualify us from full membership in the human community? These quotes express a contradiction between disability’s persistence in the human condition and our apparent collective urge to refuse disability.

The disqualification of disability and disabled people Mitchell and Snyder note is expressed ideologically and historically in what I call eugenic logic (Mitchell and Snyder 2003; Snyder and Mitchell 2006). Eugenic logic tells us that our world would be

R. Garland-Thomson (✉)
Department of Women’s Studies, Emory University,
Candler Library, Suite 128,
Atlanta, GA 30322, USA
e-mail: rgarlan@emory.edu

R. Garland-Thomson
AY 2011–2012 Contact,
Radcliffe Institute for Advanced Study Fellow,
83 Brattle St., #602,
Cambridge, MA 02138, USA

a better place if disability could be eliminated. Enacted worldwide in policies and practices that range from segregation to extermination, the aim of eugenics is to eliminate disability and, by extension, disabled people from the world. Eugenic logic is 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 and is supported by the logic of modernity itself, a point developed in this paper more fully later on.¹ Why—eugenic logic asks—should the world we make and occupy together include disability at all?

Our dominant understanding is that disability is something to be avoided and that the world would be a better place if disability could be eliminated. This is sensible because, as Mitchell and Snyder suggest, we understand disability to confer pain, disease, suffering, functional limitation, abnormality, dependence, social stigma, and economic disadvantage and to limit life opportunities and quality. In a more general sense, disability also represents aspects of the human condition that are unpredictable, unstable, and unexpected: in short, contingency itself. (A survey of utopian and dystopian fiction will confirm this; utopias are without disability and dystopias are filled with it. See José Saramago's *Blindness* [1999] and Charlotte Perkins Gilman's *Herland* (1915, 1979) as examples.)

Because disability is understood to disqualify us from access to the benefits and status of the properly human, it is a place that we do not go willingly or welcome into a life, perhaps especially in our contemporary time and place. The birth of a disabled child or

the onset of disability is seen as a catastrophe or a failing. This is reasonable because being disabled reduces our social capital by shifting us into an unappealing and unexpected position that the medical sociologist Talcott Parsons (1951) called “the sick role,” a place on the far edge of the circle of human commonality where one is exempt from normal social roles and obliged to fight hard to reenter society by getting well soon (Parsons 1951). More poetically, disability makes people into what the Brazilian writer Malu Fontes (1998) calls “strangers in their own land.” Freud (1916) declares that disabled people are the neurotic “exceptions”; sociologist Erving Goffman (1986) observes that disability “spoils” one's identity.

Psychoanalytic understandings of disability underscore the negative social position that disability identity yields. Poststructuralist theorist and psychoanalyst Julia Kristeva, an official advocate for the disabled in France (and president of the *Conseil National Handicap*), puts forward a dire cultural and psychoanalytic interpretation of disability that clarifies why anyone might eschew rather than embrace being identified as disabled. Kristeva concludes that the disabled enter into a social position of “incomparable exclusion” that is “different from the others” in its psychic threat to the nondisabled subject. According to Kristeva:

The disabled person opens a *narcissistic identity wound* in the person who is not disabled; he inflicts a threat of *physical or psychical death*, fear of collapse, and, beyond that, the anxiety of seeing the very *borders of the human species* explode. And so *the disabled person is inevitably exposed to a discrimination that cannot be shared* (Kristeva and Herman 2010, 251, *emphasis original*).

In Kristeva's account, to enter into the cultural category of disabled is not simply to be understood as “sick” or “spoiled,” then, but to endure “sufferings,” “exclusions,” and “isolation” distinct from and more acute than any other marginalized identity group. Being understood as disabled is to be subjected by one's fellow humans who can claim nondisabled status to the disqualification she sums up as “rejection, indifference, or arrogance, [and] the will to eradicate by euthanasia” (Kristeva and Herman 2010, 261 and 258). Moreover, to enter into disability is to be forcibly disqualified from the privileged social position of the nondisabled and forced to assume the threatening

¹ The very term eugenics is a controversial and complicated word that I use here intentionally. The history of eugenics as a way of thinking and a set of historically specific practices and policies has been well laid out by authors such as Daniel Kevles (1985), Henry Friedlander (1995), Edwin Black (2003), Harry Bruinius (2007), and others. Bioethicists have made important distinctions among eugenic practices and policies that work toward explicating the complexity of eugenic logic. Thus, we have positive, negative, liberal, and authoritarian, each of which is manifest in overlapping but also differing solutions with different levels of ethical acceptability. For my purposes, I present the concept of eugenic logic, carried out in widely differing practices and policies, which aims fundamentally to eliminate the human traits and ways of being in the world that we probably understand as disability. What I wish to bring forward here is not what kinds of eugenic logic are acceptable or unacceptable but rather counter-eugenic logic, a way of thinking that does not rely on the assumption that disability should be eliminated.

and vengeful figure of wounding, death, collapse, and explosion described by Kristeva's overwrought psychoanalytic vocabulary. A myriad of sociological and psychological studies that reveal negative attitudes toward disabled people support this account. (For example, see Gerhart et al. [1994] and Jack Levin's "The Invisible Hate Crime" [2011].)

Counter-Eugenic Logic

This strongly negative collection of cultural understandings about disability and life with a disability comprises what Mitchell and Snyder call the "disqualification" that disability confers and underpins the commonplace eugenic assumption that disability should be eliminated. What I consider here is the bioethical question of why we might want to conserve rather than eliminate disability from the human condition. To do so, I draw together an eclectic, rather than systematic, configuration of what I call counter-eugenic arguments for conserving disability. I use the verb *conserve* here intentionally to do the precise semantic work of explicating counter-eugenic logic. To *conserve* means to "maintain (a person or thing) in continuous existence; to keep alive, existing, or flourishing; to preserve ... intact" (*Oxford English Dictionary* 2000). *Conserve* and *conservation* allude as well to the environmentalist project of biodiversity conservation and the material practice of architectural and historic preservation or conservation. These conservation initiatives are based on the concept of valuing a historically sedimented environment as it has materialized over time and in response to both random and intentional influences that shape that environment. The principle of honoring the "is" rather than the "ought," the contingent rather than the intentional nature of an environment, is what I wish to capture with the word *conservation*. The idea of preserving intact, keeping alive, and even encouraging to flourish denoted by *conserve* suggests that the characteristics, the ways of being in the world, that we think of as disabilities would under such a definition be understood as benefits rather than deficits. Furthermore, I would distinguish the concept of conservation subtly from the concept of protection. Something in need of protection is understood as more vulnerable than something to be conserved. I intend the term *conserve* to suggest the prevalence, persistence, and enduring

sturdiness of disability rather than its fragility or vulnerability. In other words, to make the case for conserving disability, I need to make a case for disability as a resource to be conserved rather than a liability to be protected. While the distinction here may be a nuanced one, it is crucial to the counter-eugenic logic I bring forward.

Taken together, the expressions of counter-eugenic logic I gather here explicate the case for disability conservation. At the same time, these expressions of the case for conservation I offer honor the complexity of how disability acts as "the master trope of human disqualification" (Mitchell and Snyder 2000, 3). I present, then, a reading of disability as a potentially generative resource rather than unequivocally restrictive liability. In other words, what I consider is the cultural and material contributions disability offers to the world.

What is Disability?

To bring forward counter-eugenic logic that makes a case for conserving disability, I need first to lay out a clarifying explanation of the current cultural understanding of disability by drawing from both critical disability theory and recent political history. Since the 1960s in the United States and increasingly worldwide, civil and human rights legislation, policies, and treaties that aim to integrate people with disabilities as full citizens, such as the Americans with Disabilities Act of 1990 and 2009 and the United Nations Convention on the Rights of People with Disabilities, have shaped definitions of disability. Whereas these collective policy initiatives frame disability in social and political terms, they at the same time necessarily rely on medical understandings of disability as impairment, restriction, disfunctionality, abnormality, and exclusion. The very word *disability* at once denotes a lack of capability as it simultaneously signifies a group identity brought forward through the civil and human rights discourse. Thus, what counts as disability legally ranges across a broad spectrum of physical, motor, mental, sensory, behavioral, medical, and appearance conditions that restrict function and full participation and are understood as stigmatized and exclusionary ways of being. Because of both the limitations and discrimination people with disabilities face, the principle of equality under the law requires that people

with disabilities become a protected class (Bagenstos 2009). In this sense, disability functions in terms of antidiscrimination legislation similarly to both femaleness and disadvantaged racial identity.

In contrast, a cultural analysis of disability such as the one I offer here retains the politicized term *disability* but draws on (what philosophers call) phenomenological and (what sociologists call) constructivist understandings of identity, materiality, and being. To put this more clearly, what we think of as disability begins in bodily variation and the inherent dynamism of the flesh. Because the human body is made from flesh, its movement through time and space in the process we call life constantly transforms it. We think of human development as emanating from within and evolving according to an unbroken genetic script of phenotypicality, which is of course accurate, in part.² The human variations we think of as disability are interruptions or departures from a standard script of human form, function, behavior, or perception that in contemporary thought we call normal. Indeed, fully normal is the status few of us can hold onto for very long over a lifetime. What we consider disability is the transformation of flesh as it encounters world. In this sense, disability is the body's response over time to its environment. Disability occurs when the shape and function of bodies come into conflict with the shape and stuff of the world. The discrepancy between body and world, between that which is expected and that which is, produces disability as a way of being in an environment. Put more poetically, disabilities are the etchings left on flesh as it encounters world.

So whereas disability is certainly an index of capability in context, it is also a witness to our inherent susceptibility or receptiveness to being shaped by the particular journey through the world that we call our life. Although our modern collective cultural consciousness denies vulnerability, contingency, and mortality, disability insists that our bodies are dynamic, constantly reformed by the call and response between flesh and world. In this way, we evolve into disability. Our bodies need care; we need assistance to live; we are fragile, limited, and pliable in the face of life itself. Disability is

thus inherent in our being: What we call disability is perhaps the essential characteristic of being human.

Because the human variations that we think of as disabilities are so fundamental to every life over time, our culture has many understandings about disability that have evolved in response to cultural developments and patterns. The understanding of disability I call eugenic logic tells us that we can avoid disability and even eliminate it from the human condition. This understanding of disability as somehow detachable from human life rather than essential to it fosters the idea that disability does not have much to do with us unless we have the misfortune of having it descend upon us. Rather than being unusual or avoidable, disability is, in fact, everywhere both in the world and in our shared cultural imagination.

The Case for Conserving Disability

Before presenting the specific case for conserving disability, I will briefly outline as background context for my explication the place of disability in three broad historical traditions in Western thought and institutional practice. Disability has a historical place and a value in religious, medical-scientific, and political traditions, which are primary cultural discourses through which we understand our lives, ourselves, and other people. The Western religious argument for preserving disability tends to be some variation on disabled people acting as an analog to the suffering Christ and thus an exceptional conduit to salvation for disabled and nondisabled alike. Alongside this necessity for disability's presence in Christian logic and doctrine is the concomitant requirement for disability to be cured as evidence of divine power. A related sanctity-of-human-life rationale in Christianity is the argument from design that says God does not make mistakes and thus loves all of his children. (See, for example, Eiesland [1994]; Orsi [2005]; and Schipper [2006; 2011].) The medical-scientific argument for conserving disability rests as well on a reading of disability as both exceptional and instrumental. Scientific medicine understands disability as the atypical illuminating by contrast the typical and an occasion for the challenging project to normalize. (See, for example, Canguilhem [1989] and Davis, *Enforcing Normalcy* [1995].) The more recent political argument for preserving disability comes from the Enlightenment, egalitarian political idea of equality under the law, which yields the concept that accommodating

² Recent work in feminist science studies and elsewhere has addressed the complexity between what has been redundantly understood as the nature/nurture opposition, or the relationship between genetics and environment. See, for example, Anne Fausto-Sterling, *Sexing the Body* (2000); Karen Barad, *Meeting the Universe Halfway* (2007); and Jackie Leach Scully, *Disability Bioethics* (2008).

disability is the responsibility of the political order to ensure basic rights of citizens. This equal justice principle gives us the civil and human rights movements along with legislation and codes that mandate equal rights for people with disabilities and guard against exclusion through discrimination and barriers.³ These broad religious, medical-scientific, and political justifications for conserving disability are complicated and have been elaborated in critical disability studies, civil and human rights histories, medical history, and religious studies. Traces of these larger understandings of disability and the histories they have wrought underwrite the logic for conserving disability I offer in this paper.

For my purposes here, I differentiate my case for disability conservation from two interrelated contemporary conversations about eugenics and disability. One is the extensive bioethics debate carried out in the discourse of ethical philosophy, which centers on articulating possible ethical positions that will shape policy and practice recommendations about genetic enhancement.⁴ The other related debate takes place in the academic discipline of philosophy and focuses on the question of what constitutes the borders of the human and thus what kinds of persons should be accorded full human rights. This conversation takes up questions concerning theories of justice, thresholds of moral personhood, and speciesism that have been debated productively and fiercely by philosophers such as Eva Kittay, Adrienne Asch, Martha Nussbaum, Hilde Lindemann, Anita Silvers, Michael Berubé, Licia Carlson, Peter Singer, Jeff McMahan, and others. Together, these scholars put forward a combination of eugenic and counter-eugenic arguments about what

constitutes humanness, life quality, and social value that address the aggressive argument for killing cognitively disabled newborns proposed specifically by Singer and McMahan. While this debate focuses on people with cognitive and developmental disabilities, it is nonetheless generalizable in some ways to a wider understanding of disability itself and to people with a broad range of disabilities. Arguments for why disabled people should be in the world sometimes rely more on the logic of protection than the logic of conservation that I am offering here. Some of the arguments for conserving disability put forward by these philosophers rest on the assumption that cognitively disabled people need protection against the accusation that they are socially unproductive, primarily because they may not meet standards for rationality traditionally set by philosophical and political discourse. Kittay, for example, wants to insist that personhood should not rest on contribution. To a certain extent, this conversation echoes the religious, medical-scientific, and political justifications for conserving disability that rely as well on the often tacit assumption of disability as a way of being in the world that needs to be protected or compensated for in some regard. (Nussbaum's theory of capabilities and Kittay's challenge to traditional measures of personhood avoid, for important strategic reasons, asking disability to contribute to world building, in part to eschew an instrumental view of disability and arguing against disability euthanasia.)

Disability as a Resource

The case for conserving disability I offer rests on what I call because-of-rather-than-in-spite-of counter-eugenic positions. In other words, I explore what disability-as-disability and what disabled people-as-they-are contribute to our shared world. By contribute, I do not mean economic productivity, nor contribution through individual agency or acts, but rather I consider the generative work of disability and people with disabilities through their presence in the world. This because-of-rather-than-in-spite-of framework refuses the dominant understanding of disability as a deficit to be tolerated and protected and seeks to bring forward the benefit disability brings to the human community. Put another way, I ask what we lose besides the individuals themselves if we eliminate disability and disabled people from the world.

The tension I suggested at the outset between disability as a universal and persistent human experience

³ See, for example, Joseph Shapiro, *No Pity* (1993); Richard Scotch, *From Good Will to Civil Rights* (1984), and the United Nations Convention on the Rights of People with Disabilities, available online at <http://www.un.org/disabilities/convention/conventionfull.shtml>.

⁴ See, for example, Allen Buchanan, *From Chance to Choice: Genetics and Justice* (2000); Nicholas Agar, *Liberal Eugenics* (2004); Nikolas Rose, *The Politics of Life Itself* (2007); Jürgen Habermas, *The Future of Human Nature* (2003); John Robertson, *Children of Choice: Freedom and New Reproductive Technologies* (1994); Philip Kitcher, *The Lives to Come: The Genetic Revolution in Human Possibilities* (1996); Carl Elliott, *Better Than Well* (2003); and Erik Parens (1998, 2005, 2006). In addition, Mara Hvistendahl's *Unnatural Selection: Choosing Boys Over Girls, and the Consequences of a World Full of Men* (2011) takes up the recent complex and disturbing issue of what might be called a combination of liberal eugenics and negative eugenics involving the population imbalance in some areas of the world created by sex selection abortion.

and disability's cultural work as a disqualifier clarifies and intensifies disability's generative potential. As critical disability studies has amply pointed out, once we begin to attend to it, disability is everywhere in the cultural products arising from our collective consciousness. (This idea is most explicitly brought forward by Douglas Baynton in his important 2001 work on disability and immigration, but it is implicit in almost all critical disability studies theory.) As both a generative concept and a fundamental human experience, then, disability generates circuits of meaning-making in the world. I organize this meaning-making potential of disability into a taxonomy of three inter-related registers—narrative, epistemic, and ethical. Under these rubrics, I find sustained and complicated counter-eugenic arguments for disability conservation.

Disability as Narrative Resource

From the unsettling contradiction of disability's universality and disqualifying potential come our most enduring and canonical cultural narratives. Disability is apparently close to the quick, a perpetual narrative resource. Perhaps, this suggests, something resolutely human and inherently interesting inheres in disability itself and the lives we make with disabilities. The potential of disability to generate singularly vivid narrative is at the heart of Leslie Fiedler's 1978 book, *Freaks: Myths and Images of the Secret Self*. Fiedler—the 1960s bad boy of literary criticism, known most widely for establishing *Huckleberry Finn* as the antiracist apotheosis of American literature—offers an impassioned, explicitly counter-eugenic polemic for conserving disability that steers clear of religious, medical-scientific, political, or ethical justifications for why disabled people should be in the world.

Fiedler argues that the unexpected and most unusual human forms or conditions that are the greatest affront to medical normalcy and phenotypicity are the most worthy of conservation. Equating Nazi eugenics with contemporary reproductive technology that selects for elimination the so-called most severe disabilities, Fiedler wants particular kinds of disabled people in the world—the ones who have historically qualified as freaks—because of what might be called their extravagant manifestation. He is scornful of political equality, identity politics, medical normalization, or any kind of sentimental sympathy. Using a defiant, 1970s anti-establishment rhetoric, Fiedler dismisses political equality for defanging his

freaks. Integrating freaks as ordinary citizens into the social order would attenuate their narrative-generating potential to inspire the “quasi-religious awe” available to the ordinary through “a live confrontation with nightmare distortions of the human body” (Fiedler 1978, 16). What Fiedler wants to conserve is prodigious disability, the didactic function of hyperbolic otherness, performed in the live encounter most effectively staged in historic freak shows. The contribution of the ornately disabled that Fiedler ardently defends is to keep “fear and loathing” alive in the mundane, nondisabled soul. For Fiedler, people with extravagantly manifest disabilities should inhabit the world to provide theatrical, edifying encounters between ordinary folk dulled by the ordinary, needing an abrupt consciousness-raising exercise to be awakened to their own internal monster. To keep his ultimately instrumental drama vivid, Fiedler wants to draw a bright line between those of us who inspire awe rather than pity, dividing us into one category of “unfortunates” composed of “the blind, deaf, dumb, lame, crippled ... hunchbacks ... Hair lips ... amputees, paraplegics, and other victims” to be differentiated from the “true Freaks,” who “challenge the conventional boundaries” (Fiedler 1978, 23 and 24). Of course, Fiedler's distinctions between the awesome and the pathetic disabled figures falter when actual people move off the freak show stage and into the quotidian world or a medical context. Nonetheless, Fiedler's insistence on preserving extravagant disability in the world as it is provides a beginning for laying out counter-eugenic logic.

The edifying narrative of disability-as-freakdom that Fiedler advocates has generated some of our most significant cultural figures: Shakespeare's Caliban, Shelley's Frankenstein, Poe's Hop Frog, Treve's Elephant Man, vast arrays of Dwarfs and Giants, and all manner of Dickensian characters. Fiedler's prodigious freaks come from the premodern understanding of disability as wondrous augury and from the religious tradition of salvific witnessing of disability. The fundamental plot here is that the spectacularly disabled among us contribute the cultural work of teaching the nondisabled how to be more human. True freaks—as opposed to everyday cripples—inspire wonder through their extravagant difference from ordinary folks and their simultaneous eerie, distant sameness to their unexceptional brethren. So Fiedler wants to conserve disability, keeping it strange and distinct to serve as a narrative resource for the world of the familiar and comfortable.

In contrast to the contribution of Fiedler's edgy, outsider freaks, Arthur W. Frank puts forward a strong argument for disability as a narrative resource in the form of self-story that leads to inclusion in his 1995 book, *The Wounded Storyteller: Body, Illness, and Ethics*.⁵ Whereas Fiedler appreciates disability as a narrative resource for the nondisabled, Frank values the narrative potential of disability for disabled people, for people thrust into the sick role. The contribution of disability narrative in Frank's account is to counteract the social disqualification and accompanying alienation from self Mitchell and Snyder identify. Narrative is a productive rather than compensatory resource in Frank's fervent defense of disability's contribution to self-understanding and identity formation.⁶ Using the more belletristic language of *wound* and *illness*, rather than the politicized and rights-invoking language of *disability*, Frank asserts that being the author of one's own disability story "transforms fate into experience" through narrative's restorative potential (Frank 1995, xi). Frank considers the narrative of his own wounding and the proposed utility of a wound-telling story to be a "survival kit" that anyone exiled from the community of the well can access to reach toward reintegration (Frank 1995, xiii).

Disability in Frank's account is an opportunity to develop "voice," by which he means the capacity for creating a coherent, causal account from the arbitrary temporal incidents that compose acquiring, adjusting to, and experiencing the transformation of self that is becoming disabled. For Frank, voice expresses body in storytelling, redeeming through order-making and reintegration into the human community. The work of narrative is selecting and linking random incidents to make a

structured story with a beginning, middle, and end that puts retrospective order to the baffling chaos of experience that washes over us each moment. Fortified and calmed with story, we are equipped to navigate what happens next by folding it into our story of what has already happened and into the stories of those who have gone before and will follow us. In Frank's account, telling one's disability story as an illness narrative is an antidote to disqualification, to the social banishment and apartness of the sick role and the stranger-making function of disability stigma. To narrate disability integrates one into the human community by generating "the common bond of suffering that joins bodies in their shared vulnerability" (Frank 1995, xi). Frank thus transforms the tragic narrative of disability as isolation into the comic narrative of disability as belonging. "Sooner or later," Frank assures us, "everyone is a wounded storyteller" (Frank 1995, xiii). Thus, Frank's notion of wounded storytelling illustrates how disability can be an occasion for both exclusion and inclusion. The resolution of such a contradiction can come through the process of narrative-making. Crucial to both Fiedler's and Frank's accounts of disability as a narrative resource is suffering as ennobling. Experiencing suffering bonds Frank's wounded storytellers; witnessing suffering bonds Fiedler's freak show audiences. The cultural work of the suffering requirement in disability narrative is a point that I will return to later.

Disability as Epistemic Resource

For both Leslie Fiedler and Arthur Frank, the generative work of narrative is to produce knowledge through rendering life experience into coherent and usable form. Disability narrative can thus contribute to knowledge-making as an epistemic resource. What psychologists call "embodied cognition" suggests that people draw on their bodily experiences not only to think and know but also to construct our social reality.⁷ In other words, our bodily form, function, comportment, perceptual apprehension, and way of mind shape how we understand our world. The current critical generation's critique of objectivity,

⁵ Human rights activist and author Terry Tracy makes a distinction between illness and disability narratives in an unpublished paper delivered at Columbia University in March 2012.

⁶ Linda Martin Alcoff's 2005 account of identity formation, *Visible Identities*, corresponds with Frank's understanding of disability as a generative resource for self-story. Alcoff's concern is the "perceptual habit" of visual exchange that produces identity formation, especially in the context of gender and racial legibility. Whereas Frank's stories of wounding are textual and linguistic, Alcoff's version of narrative identity begins in visual perception and material propinquity leading to self-story that finds its reference in the received identity categories generated by systems of race and gender—and I would add the ability system. Identity, for Alcoff, does not reside in visible features but emerges from shared, dominant interpretations of "visual markers on the body," markers of belonging that operate similarly to the "wounds" Arthur Frank's narratives explicate (Alcoff 2005, 6).

⁷ An extensive research literature exists in the field of psychology on embodied cognition; for an accessible summary of this concept, see "When Truisms Are True" by Suntae Kim, Evan Polman, and Jeffrey Sanchez-Burks, published in *The New York Times* (February 25, 2012). The philosophical tradition of phenomenology posits a humanistic equivalent of the social scientific concept of embodied cognition.

master narratives, and a universal standpoint has not only discredited the so-called “view from nowhere,” it has also advanced a material turn that furthers a phenomenological approach bringing together epistemology and ontology in productive accounts of assemblages and material-discursive understandings. (See Thomas Nagel, *The View from Nowhere* [1986], as well as Alaimo and Hekman, *Material Feminism* [2008], and Hennessy and Ingraham, *Materialist Feminism* [1997], as examples.) This critical exploration has yielded terms that range from oppositional consciousness to standpoint epistemology, outsider/insider perspective and privileged epistemic state to subjugated knowledge.⁸

Bioethicist Jackie Leach Scully offers an account of how disability can act as an epistemic resource in her 2008 book, *Disability Bioethics: Moral Bodies, Moral Difference*. Scully argues persuasively that a distinctive and morally privileged knowledge can arise from the experience of living in a disabled body. Disabled bodies, as Scully explains it, produce “experiential gestalts,” or ways of knowing shaped by embodiment that are distinctive from the ways of knowing that a nondisabled body develops as it interacts with a world built to accommodate it (Scully 2008, 91). This “thinking through the variant body,” as Scully describes it, can be a resource (2008, 83–85).

One example of disability as an epistemic resource can be drawn from the deaf-blind activist and writer, Helen Keller, who, in her 1908 collection of essays, *The World I Live In*, gives an account of how what Scully calls “embodied cognition” generates what we also might term alternative or minority ways of knowing (2009, 90). Keller’s necessary independence from relying on the dominant senses of hearing and sight provides her a generative opportunity to develop vivid tactile, taste, and olfactory knowledges that often remain dormant in sighted and hearing people. Keller narrates what one might call disability synesthesia when she smells horizons, recognizes people by the touch of a hand, and analogously knows scarlet from crimson through

perceiving the olfactory distinction between the smells of oranges and grapefruits. Her well developed, subjugated knowledge leads her to the observation that the typically sensed are limited by being “smell-blind-and-deaf” (Keller 2009, 31). Touch, she concludes from her distinctive way of knowing, “is a great deal the eye’s superior,” as phenomenology has suggested (Keller 2009, 34).⁹

⁹ The subjugated knowledge that comes from disability might be understood as an asset rather than a liability, not just in terms of diversity or human rights categories, but as what might be called an advantageous minority skill set. For example, South African double amputee runner Oscar Pistorius, who races on fiber carbon legs, challenged the Olympic Committee to allow him to compete in the Olympics rather than the Paralympics. The Olympic Committee initially refused Pistorius on the basis that his prosthetic legs gave him an advantage over runners with fleshly legs, although this decision was overturned. The idea that metal rather than fleshly legs might be an advantage in sports, and perhaps by extension life, questions our dominant cultural assumptions about both fitness and quality of life.

Disability can develop advantageous expertise as one navigates barriers and unsupportive material and attitudinal environments. For example, managing disability can sharpen strategic planning and time management skills, as a recent *New York Times* article pointed out (Klaus 2012). The opportunity to learn to live effectively in an environment built for someone else’s body can be generative rather than a catastrophe for human beings. For example, the architect Chris Downey developed an effective form of tactile drawing after becoming blind by substituting a standard pencil with a kind of Play-Doh spaghetti that added another sense to his design creativity. Navigational skills that blind and low-vision people use can benefit the sighted majority when visual navigation fails. Such minority body consciousness can foster a resourcefulness that also extends to the nondisabled and not yet disabled as they relate to and live with people with disabilities. The blind writer, Georgina Kleege, for instance points out the irony of the airline policy that instructs disabled passengers to remain in their seats in the case of a disaster and wait for help. “It’s the blind passenger who can in an instant,” notes Kleege, “pull a folding cane from her pocket who will lead everyone else out of a darkened and smoke-filled fuselage” (Kleege, personal communication). Acquiring or being born with the traits we call disabilities fosters an adaptability and resourcefulness that often is underdeveloped in those whose bodies conform smoothly into the prevailing, sustaining environment. People born without arms, for example, all learn to use their toes to accomplish tasks that those of us with arms are not able to do and often cannot imagine. Deaf people develop modes of communication that are silent, reach across long distances, and are particularly effective in babies whose capacity to speak is undeveloped. Disability can provoke intellectual development as well. The philosopher Jürgen Habermas (2008) has said that the experience of having a cleft palate from birth and the accompanying multiple surgeries and social exclusions he experienced positively shaped his intellectual trajectory by making it clear to him the importance of participation in the public sphere.

⁸ In accordance with Scully (2008) and following Patricia Hill Collins (2000) and others, I have suggested elsewhere that the material experience of navigating a world built for the majority while living with a minority form of embodiment such as disability can produce a politicized consciousness, or an epistemic epiphany regarding the relativity of exclusions that the status quo explains as natural or essentializes as inherent inferiority. For a further explication of this argument, see my recent essay in *Hypatia* (Garland-Thomson 2011).

A more recent explication of the resourceful experiential gestalts disability generates comes from music theorist Joseph N. Straus in his 2011 book, *Extraordinary Measures: Disability in Music*. Straus proposes that experiencing music through the variant body can be an epistemic resource that expands our understanding of music itself in fresh ways. The generative experience that Straus identifies as “disablist hearing” can be what the dominant order calls a hearing impairment or hearing loss. In total, Straus describes four kinds of disablist hearing: blind hearing, deaf hearing, autistic hearing, and mobility inflected hearing. In each case, he suggests ways that particular kinds of embodiment might affect musical hearing in distinctive, valuable, and interesting ways. He proposes that disablist hearing, that is the sort of hearing that might be associated with deafness, blindness, autism, or mobility impairment, expands our understanding of musical experience and production through its distinctive capacity to “encompass marvelous, fantastic, or arcane musical relationships.” Like “prodigious listeners” (the most highly skilled and trained listeners who can hear the most recondite sorts of musical relationships), disablist listeners, Straus contends, “may hear things in music that normal listeners do not” (2011, 152).

Straus continues the case for conserving disability by proposing the experiential gestalt generated by living on the autistic spectrum as a source for a counter-eugenic logic that has been recently formulated under the concept “neurodiversity” (Straus 2011, 160). (As a supporting example, see the case of Ian Hacking’s autism in the 2010 *Cognitive Disability and Its Challenge to Moral Philosophy*). To do so, Straus offers a variation on disablist hearing that he terms “autistic hearing” and further proposes that “autistic performance and composition” is characterized by originality of interpretation arising from the distinctive embodied cognition associated with autism, which may have contributed to the musical distinction of artists such as Glenn Gould and Thomas Wiggins, also known as “Blind Tom.” Thus, Straus puts forward the counter-eugenic argument that actual deaf people might contribute productively through disablist hearing and that people with autism might contribute original musical performances and compositions.

The case for conserving disability I find in Straus’ account of disablist musical reception and production is vital to my explication of counter-eugenic logic

because it formulates so effectively a descriptive vocabulary of generativity rather than deficit. The dominant language of disability is overwhelmingly the language of deficiency. Straus extends the revisionist work of neurodiversity by rewriting autism-as-deficit with his descriptive phrases of autism’s distinctive traits. Characteristics we have learned to understand as pathological symptoms become, in Straus’ account, musical gifts, such as “a preference for ‘local coherence,’ a proclivity for ‘private association,’ and a talent for ‘imitation’” (Straus 2011, 161). The existence of the kind of hearing and music-making Straus describes supports disability conservation in the tradition Helen Keller modeled a century earlier by revaluing people identified as deaf, autistic, or blind and those ways of being in the world.¹⁰

Disability as Ethical Resource

The cascade of rationales I offer for disability conservation begins in disability’s propensity to generate narrative, which in turn generates knowledge and an explicitly ethical counter-eugenic logic. Similarly to Joseph Straus’ framing of disability as a gift, Michael J. Sandel’s 2007 book, *The Case Against Perfection: Ethics in the Age of Genetic Engineering*, shifts the conversation from disability as an aesthetic resource to disability as an ethical resource. Sandel argues that disability, specifically children born with disabilities, offers us the ethical opportunity, fundamental to the human condition, to accept and make a life from what he calls “giftedness.” (Sandel is particularly addressing his jeremiad to parents with ambitious expectations for the current, culturally sanctioned forms of achievement and success. He writes: “The ethic of giftedness, under siege in sports, persists in the practice of parenting. But here, too, bioengineering and genetic enhancement threaten to dislodge it. To appreciate children as gifts is to accept them as they come, not as objects of our design or products of our will or instruments of our ambition” [2007, 45].) Sandel argues for preserving disability and disabled people, in particular the opportunity to parent disabled children, rather than eliminate them through selective

¹⁰ A related argument has been put forward stridently by Deaf activists contending that cochlear implants for Deaf people are eugenic.

abortion and genetic manipulation. Sandel's counter-eugenic position rests on his critique of the hubris he finds inherent in the modern individual. The mandate of modernity to control the shape of the future by intentional human action in the present is, Sandel passionately argues, a form of ethical overreaching that results in the loss of openness to forces and events outside the self. This cultural impulse toward control so characteristic of modern man reduces our humanness, according to Sandel.¹¹ He suggests, as well, that a restrictive rigidity and narrowness coming from the urgency to control outcomes is not only hubris but also narcissism. Although Sandel never calls it this, he is arguing for conserving an opportunity for psychological and character development inherent in embracing the unexpected, a psychological position sometimes quite negatively considered as fatalism. What he is calling for is flexibility and openness to forces outside of our will as a form of creative and flexible dialectical engagement with the world.

In this sense, Sandel's argument to conserve disability and disabled people illuminates and accords with a conservatism, in the strict sense, present in my own proposition about preserving disability and disabled people in that it proposes preserving rather than improving through changing the embodied status quo. Sandel particularly objects to medical treatment that enhances normalcy and normalizes disability. To lift people out of not only disability but also typicality toward some kind of super normalcy signals a "moral quandary" Sandel sees as "a kind of hyperagency—a Promethean aspiration to remake nature, including human nature, to serve our purposes and satisfy our desires" (2007, 26). This "drive to mastery," Sandel argues eloquently, "misses and may even destroy ... an appreciation of the gifted character of human powers and achievements." Sandel understands this Promethean aspiration as a fundamental principle of eugenic logic. He puts eugenics and genetic engineering in the same category and objects

morally to eugenics as the "triumph of willfulness over giftedness, of dominion over reverence, of molding over beholding" (Sandel 2007, 85). In this way, Sandel's argument is closely related to that of philosopher Eva Kittay, who argues that our modern ethic of autonomy and the denigration of dependence and interdependence diminishes the humanness of us all. Like Leslie Fiedler, Sandel wants to contemplate disability experientially in the moment as it is in all its distinctiveness. Like Jackie Leach Scully, Sandel wants to wrest knowledge from disability that will make us ethically sound. Like Arthur Frank, he suggests that conserving rather than eliminating disability to, as he puts it, "abide the unexpected, to live with dissonance, to rein in the impulse to control" will build solidarity with others, cultivate human sympathies, and create an open human community in which we live in "the given world" that the present bequeaths rather than "a gated community writ large" of our scrupulously managed future. The ethical community Sandel envisions would be filled with unexpected offerings of fate, which are the variant bodies Scully proposes can generate moral knowledge (Sandel 2007, 86).

In Sandel's view, the cultural work of disability is to defeat our hubris. This argument draws perhaps inadvertently on Aristotelian tragedy. Sophocles' exemplary tragic hero, Oedipus, as a founding figure of Western culture provides one of many cautionary tales about the limitations of knowledge and the power to control. Oedipus' tragic flaw is hubris, the Promethean aspiration to know the terrible truth of his own fate. Oedipus' life journey is bookended by disability. To avoid the predicted dreadful fate, Oedipus' royal parents expose their newborn to die on a mountaintop with his ankles bound together, for which he is named Oedipus, meaning swollen foot. The mark of the damaged foot provides the irrefutable evidence of his identity and his terrible fate. Laden with this inescapable self-knowledge, Oedipus seizes the truth of who he is and enacts this fate by blinding himself and staggering down the road alone. For Sophocles, as for Sandel, disability stands for an antidote to hubris.

Both Leslie Fiedler and Michael Sandel ultimately offer a rationale for conserving disability that is familiar: Disabled people can teach nondisabled people things and make them better people. Nevertheless, this variation of the religious argument that disabled people are a conduit to salvation for the nondisabled is fuller and more complicated in the hands of Fiedler and Sandel. Fiedler's freaks are instrumental others at the same time

¹¹ Although Sandel does not discuss gender distinctions in his understanding of hubris, a vibrant conversation in feminist ethics and theology suggests that the kind of hubris Sandel discusses has historically been the province of men and masculinity, where women historically have been excluded from the benefits and liabilities of hubris. See, for example, Christ and Plaskow (1979), particularly Valerie Saiving's (1979) essay on gender and sin in that volume, and a whole range of feminist scholarship on the ethic of care, including: Gilligan (1982), Kittay and Meyers (1987), Beauchamp and Childress (1994), Held (2006), and Nussbaum (2006), among others.

that they are fellow travelers accorded the same opportunity to flourish in their distinctiveness as the normals in their ordinariness. The “openness to the unbidden” that Sandel values is a quality he wishes his implicitly nondisabled audience—the “we” he addresses—to develop in relation to disabled people, whether they be the unexpected children “we” get or perhaps his readers themselves as potentially or actually disabled people. To strengthen Fiedler’s and Sandel’s counter-eugenic arguments, one might extend this openness to the unbidden as a gift to develop unexpected resourcefulness or opportunities for flourishing that disability could present to the entire human community. Accepting the people with disabilities who enter our lives as unexpected and often unwelcome gifts would be an ancillary benefit. The primary benefit would be valuing the inevitable growing into disability inherent in the human condition.

Counter-Eugenic Logic and the Problem of Suffering

The case for conserving disability as an ethical resource must consider the problem of suffering, because eliminating disability to eliminate suffering is a fundamental rationale of eugenic logic. Historically and rhetorically, suffering has come to be separate and differentiated from pain through processes of modernization and secularization. The introduction of anesthesia in 1846 begins to separate pain from suffering by locating pain firmly in the body (Pernick 1985; Morris 1993). Pain becomes discrete and medicalized as antisepsis, sanitation, and vaccination emerge and modern allopathic medicine comes to dominate the late nineteenth century. Suffering, in the form of fear, anxiety, melancholy, and even humiliation, subsequently comes to be thought of as separate from pain, which can be therapeutically treated. Pain becomes a medical anomaly at precisely the same time that modern benevolence shifts suffering from being a central part of the human condition to an exception worthy of reform efforts to eliminate it. Without pain anchoring suffering, it becomes a more diffuse and expansive target of sympathy (Halttunen 1995; Clark 1995). The concept of alleviating rather than enduring pain gets transferred onto the concept of alleviating rather than accepting suffering. The concept and reality of curing pain through medical treatment suggests that the diffuse and medically unverifiable

experience of suffering might also be curable. So sympathy moves from a response to an unchangeable human experience. Sympathy, then, comes to motivate benevolence and reform movements directed at curing what is imagined as suffering. This distinctly modern understanding of suffering as a broad target of cure underwrites the logic of eugenics as a social cure that develops in the first decades of the 20th century in the modern world (Garland-Thomson 2004).

To consider this problem of suffering, I turn now to Emily Rapp, whose wrenching account of her experience and understanding of parenting a child with a fatal disease necessarily provides a more complicated case for conserving disability than that put forward by Fiedler, Sandel, and Straus. Rapp’s 18-month-old son, Ronan, was born with Tay-Sachs, a rare genetic condition that causes a slow developmental regression into paralysis and sensory loss that is irrevocably fatal by the age of about three. The condition represents a perverse reversal of our imagined developmental trajectory, foreshortening an entire life-course to a chillingly compact arc. With Tay-Sachs, the disintegration we expect to languidly stretch over seven decades instead rushes by in mere months. Tay-Sachs is, of course, the exemplary worst-case instance widely put forward in arguments for reproductive counseling, eugenic testing, and selective abortion. Tay-Sachs is the consummate case of disability as deficit, yielding a person with steadily attenuating capacities that finally cannot support life. It is the anchor of any reasonable eugenic argument. As such, Rapp’s son Ronan offers the most difficult and controversial case for disability conservation. This life and this person present Rapp with an opportunity to consider what kind of eugenic and counter-eugenic logic might be found in her family’s situation. The humble argument for disability conservation I find in Rapp’s account at once honors the pain, loss, and suffering that is fundamental to much disability even while it acknowledges disability’s potential as what I term an epistemic resource (Rapp 2011).

Two aspects of Rapp’s situation I am wrestling from her story clarify the deep complexity and ambiguity of arguing for why we might want disability in the world and, thereby, make the case for conserving disability. First, Rapp did not choose for her family to have this disability as any kind of openness to the unbidden. In fact, Rapp apparently wanted knowledge in advance of what kind of child to expect. Ronan’s condition, in fact, eluded two screenings that did not indicate its presence. Ronan is a welcome child with an unwelcome disability.

This terrible paradox—this unexpected gift of Ronan—flies in the face of the pragmatic rationalism offered by liberal eugenics that parents should select the children they want, relying as it does on the efficacy of genetic testing, counseling, and selective termination (see Agar, *Liberal Eugenics* [2004]). Indeed, Rapp says that had she known Ronan would have Tay-Sachs, she would have selectively aborted her pregnancy in order to prevent the suffering both her son and his family have experienced (Rapp 2012). Rapp's conviction that she would not have brought Ronan into the world because of his disability comes not from acculturated disability prejudice on Rapp's part. In fact, she understands disabled lives, disability politics, and disability rights very well. She herself identifies as disabled, has lived with a significant mobility disability all her life, and has experienced disability's gifts along with its difficulties (Rapp 2007). Rather, her retrospective conviction that she would not have preserved this disabled child had she known what their shared life would be comes from a careful assessment of the costs and benefits to her and her family of Ronan's suffering and ultimate fate.

The prevention of suffering that Rapp invokes in her moving account of this particular aspect of reproductive rights is one of the major eugenic arguments for eliminating disability and disabled people, at all life stages. The Nazis, Peter Singer, supporters of physician-assisted suicide, and the reproductive rights movement have, in some way, all presented suffering as a justification for eliminating disability and disabled people. Only the religious right, Sandel's case against perfection, and Bob Flanagan's provocative explication of masochism suggest that enduring might offer a benefit that balances the terrible costs of suffering (Dick 2003). Indeed, disability rights advocacy groups such as Not Dead Yet warn that a common prejudicial belief that people with disabilities suffer more than the nondisabled underwrites cultural support for various forms of euthanasia. The disabled 20th-century American author Flannery O'Connor cautions against the peril—rightly, I think—that empathy, what she calls “tenderness,” for the suffering of others can lead to the gas chamber (O'Connor 1969). (See particularly “A Memoir of Mary Ann.” O'Connor says: “In the absence of ... faith, now we govern by tenderness. ... It ends in forced labor camps and in the fumes of the gas chamber” [1969, 227].) The Nazis, of course, created with their mass eugenic euthanasia program a hyperbolic parody of this logic under the

banner of mercy killing. Bioethicist Rebecca Garden further clarifies the limitations of empathy on the part of medical professionals toward people with disabilities and illness. The problem with empathy, Garden cautions, is that it may lead to a “preoccupation with self that obscures the other” (2007, 555). Because empathy depends upon the experiences and imagination of the empathizer in regarding another person, prejudices, limited understandings, and narrow experience can lead one person to project oversimplified or inaccurate assessments of life quality or suffering onto another person. In other words, our own failure to imagine how another person lives or our own reluctance to live as another person lives determines the actions we take in relation to what we imagine as the suffering of others. When we imagine ourselves as charged with the mission of relieving the suffering of others, it is all too easy for projection to overtake empathy and for our own failure to imagine living with disability to lead to alleviating suffering by eliminating the person with a disability. This is exactly the logic of so-called mercy killing; it is an inability to tolerate or even witness in others what we fear we cannot endure in our own lives.

Emily Rapp's careful balancing of suffering's costs with the benefits of the “blissful” love Ronan begets and receives is at the heart of what I am calling the counter-eugenic logic in her explication of Ronan's disability. That she tolerates, even embraces, such a contradiction by acknowledging the simultaneous suffering and joy of Ronan's existence in all its intensity draws into sharp relief the contribution disability makes to the human experience.

While it would be perverse to reduce the intricate, contradictory understandings Rapp offers about her son's dreadful situation, one point that Rapp's story makes clear is that suffering expands our imagination about what we can endure. Similarly, another parent of a disabled child expands Emily Rapp's eloquent account of the ways unexpected joys are inextricably entangled with considerable distress in living with disabilities. Chris Gabbard's 10-year-old son, August, lives with a set of significant disability traits, including cerebral palsy, quadriplegia, legal blindness, cognitive disability, nonverbalness, incontinence, and immobility (Gabbard 2010). In the view of many people, this collection of conditions renders August's life unworthy of living and yields great suffering for his family. Gabbard observes that many “well-meaning people

would like to put an end to August's suffering, but they do not stop to consider whether he actually is suffering." August brings joy to his family. His younger sister plays with and loves him; his father enjoys his company, and August enjoys his father's company. In fact, August seems to his family "merely ... a little eccentric," the bearer of "a few odd quirks" (Gabbard 2010, ¶2).

Like Rapp, Gabbard acknowledges the losses and difficulties of August's life. Caring for August is demanding and sometimes very hard for his parents, as is providing care for any human being. Having August in his family, Gabbard explains has "limited" his career accomplishments, but at the same time it has "broadened" his understanding and experience of the world and led his academic career in unexpected and productive directions. Gabbard makes clear the balance of loss and gain that August's disability entails: "It would be better for everyone," Gabbard acknowledges, "if August could run around and shout intelligible language" (2010, ¶28). That August cannot do this does not mean that his presence fails to enrich his family or that his disabilities disqualify him from rich, loving interpersonal relationships with his family members. Ultimately August's gift to Gabbard, like Ronan's gift to Rapp, is what any human relationship provides to any of us: the "opportunity to profoundly love another human being" (Gabbard 2010, ¶30). Implicit in Gabbard's explanation of August's gift is that loving August as he is has stretched the imaginations of his family members and brought unexpected joys. Gabbard's story of August and Rapp's story of Ronan clarify the entanglement of suffering and joy that is inherent in human enfleshment. The opportunity to tolerate not these children's disabilities but the contradiction of simultaneously lamenting and embracing disability contributes, I suggest, to the case for conserving disability.

More than this, however, Rapp's account of what her child's disability imposes upon her, and perhaps Gabbard's as well, clarifies a less-recognized aspect of disability's distinctive work in the world that is worth conserving. Disability in general, and in particular Ronan's dramatic disability manifestation, offers an experience-based counter-narrative to the modern subject's understanding of the present moment as an opportunity to shape the future. Living with her son's disability compels Emily Rapp to live "without a future," to cultivate a primary self-

defining interpersonal relationship in the lived present that presumes no future. One aspect of modern acculturation is to fear a future that is unpredictable and uncontrollable. The modern subject has a deep investment in a tractable future. A world and life trajectory that is unpredictable or uncontrollable is anathema to our liberal modern ethic of self-determination, design, and freedom. One reason we do not expect people with disabilities to appear in our world is because we do not have predictable narratives of their future; we do not imagine them as having tractable futures or life trajectories. In this sense, Rapp's compulsory acceptance of living without a future forces her to abandon any reach for what Sandel calls the Promethean aspiration, which he thinks diminishes our capacity for aliveness. Similar to Fiedler's "confrontation in the flesh" and even Straus' "disablist hearing," Rapp's forcible abandonment of the future stretches toward understandings and experiences that expand what she, and perhaps Ronan, might have had in an ordinary, nondisabled life together. Like the wonder that prodigies prompt in Leslie Fiedler, the terrible contribution of Ronan's disability is rooted in the present and in presence. Disability speaks only of the present; the prodigious cannot be prepared for, and it anticipates nothing in our control. Like Arthur Frank's wound-telling stories, Rapp's story of the "even blissful," "magical world" of the mundane and its "terrible freedom" from expectations could not be restorative, in Frank's sense, but may indeed be transformative. Emily Rapp's story exceeds the familiar lessons from the disabled for the nondisabled. I suggest instead that the forcible abandonment of the future that Rapp explains constitutes something more complex and capacious: It is a modern counter-eugenic ethics.

Eugenics is about controlling the future. It is the ideology and practice of controlling who reproduces, how they reproduce, and what they reproduce in the interest of controlling the composition of a particular citizenry. The very idea of shaping a community or a national citizenry through the technological and legislative practices that control reproduction is distinctly modern (conversations on futurity with Kristin Peterson, personal communication). This understanding of the relationship between present actions and future outcomes is expressed in many aspects of modern cultures and is one of the hallmarks of modernity,

codified in modern nation–states, culture, subjectivity, and even design.¹² Zygmunt Bauman finds modern genocide, for example, rooted in rationality, efficiency, science, bureaucracy, and its manifestation in the nation–state—in short what Max Weber called rationalization, which is perhaps the hallmark of modernity. The interrelated concepts of evolution, progress, and improvement comprise a temporal aspiration for both individuals and societies that is crucial to modernity. The conviction that control in the present over the outcomes of the future—what James R. Beniger calls the “control revolution” and what Thomas Haskell shows to be the relationship between benevolence and capitalism—is crucial to the project of modernity. (See Thomas Haskell [1985a; b] on benevolence and capitalism and James R. Beniger’s [1986] *The Control Revolution: Technological and Economic Origins of the Information Society*.) Although Sandel offers more of a quasi-religious than historical framing, this impulse to control the future is the overreaching that he decries in his case against perfection.

Disability is, then, a conceptual category that represents something going beyond actual people with disabilities.¹³ Disability represents a problem with temporality as it is formulated in modernity. Disability and illness frustrate modernity’s investment in controlling the future. Douglas Baynton (2001) argues, for example, that efficiency and increased pace in task performance in all aspects of daily living, which became the dominant value and way of life during 19th-century modernization, shaped the cultural understanding of disability as representing inefficiency and intractability. Baynton’s historical account suggests that, as the modern understanding of time as a commodity—of the present moment as an opportunity for investment in the future—developed, disability came to be seen not just as a misfortune, punishment, blessing, or omen from an either benevolent or angry God, but also as intransigence embodied. Disability and people with disabilities are eugenic targets because we embody the unpredictable and intractable nature of temporality. The persistence of disability in the

human condition frustrates modernity’s fantasy that we determine the arc of our own histories.

Thus disability becomes for modernity’s Promethean aspiration at once its greatest opportunity and its greatest repudiation. Michael Sandel, Emily Rapp, and Chris Gabbard confront our collective investment in futurity, which differs from traditional worldviews. Even the freaks that Leslie Fiedler wishes to conserve are secular versions of the portents in a world where the hand of God determines the future. Fiedler’s freaks are narrative and epistemic resources for present understandings only. Curing cancer, sundering the conjoined into singletons, and flushing out the elusive gene for Tay-Sachs are challenges in the interest of controlling the future by shaping how human beings are in the world and who we have among us. I object less to the idea of controlling outcomes in the future in general than I do to the problem of what outcomes we attempt to influence. In other words, it is not so much making the future we want that is the problem; it is rather how we go about deciding what that future might be.

So disability’s contribution, its work, is to sever the present from the future. More precisely, disability can be a narrative resource that does not trade the present in on the future. More than simply an antidote to modernity’s overreaching, disability contributes a narrative of a genuinely open future, one not controlled by the objectives, expectations, and understandings of the present. Perhaps counterintuitively, rather than dictating a diminished future, disability opens a truly unpredictable, even unimaginable, one and, in doing so, confounds Promethean prognosis—that narrative of the future upon which we premise so much of our present.

The disability rights activist, lawyer, and writer Harriet McBryde Johnson captures this point in her memoir, where she wryly quips that living with a disability provided her with what I would call the epistemic resource of recognizing that for her it was always “too late to die young” (Johnson 2005, 7). Despite a medical prognosis of early death, Johnson lived well into middle-age, long enough to become a well-known and influential figure in disability activism, law, and literature. This is no familiar narrative of valiant overcoming of disability through medical heroics or the imposition of personal will and drive. For Johnson, her life journey was an open road because no imagined future dictated its shape. The prediction of life “without a future” was for Johnson something of a liberation, the gift of freedom from script and

¹² Christina Cogdell (2004) argues that streamlined modern design is inherently eugenic; its stripping of ornamentation and understanding of ornamentation as a drag on efficiency and an impediment to effective function (form follows function) represents a eugenic commitment to evolutionary progress.

¹³ Zygmunt Bauman (1989) calls Jews a prismatic group; see also Baynton (2001) on the concept of disability.

expectations that ended up bringing her again and again to moments of opportunity she and others had never imagined.

Johnson explains this apparent contradiction of death sentence and open future beginning with her recognition as a small child watching commercials on TV for charity campaigns and telethons that living as she does with muscular dystrophy means that she will die young. She keeps this knowledge a secret so as not to distress her parents. Nonetheless, she realizes that her imagined life trajectory is different from her peers, and she knows they know this about her as well. She comes to think of herself as a dying child: a secret, a distinction, and a motivating challenge for her. That she expects death at any moment frees her from the burden of using the present as an investment in a future. There is some family consultation about whether she should go to kindergarten. Her own response is both dread and an oddly cavalier conclusion that she might as well die in kindergarten as anywhere else. She undertakes and understands her entrance into school not as the first step in an educational process that leads to a life of successful achievement but simply as kindergarten itself, where she imagines herself dying. Although this “death sentence” hangs over her like a cloud in childhood, it strangely affirms the life she has, a kind of *momento mori* that creates a “why not?” response that seems actually to relieve rather than intensify anxieties. Her secret knowledge of her own mortality begins to act as a link to a deep chain of ancestors and the enormous community of the dead who have gone before us. That her living peers do not seem to recognize their own mortality creates a sense of privileged knowledge in Johnson. As she lives on, she develops a skill set to manage other people’s discomfort with her dire medical diagnosis and an accompanying pride of accomplishment in not crumbling under this death sentence. “Concealing my exact diagnosis ... remains the easiest way to deal with popular fears,” she pragmatically concludes (Johnson 2005, 14). Thus, she provisionally moves through her life, continuing to “enjoy the many delights that fall on” her (Johnson 2005, 11). She advances into the future with a liberating truncated trajectory. In her 20s she decides she might as well die in law school and may even get a couple of years to practice. To her surprise she becomes “unexpectedly middle-aged” (Johnson 2005, 15). With the self-consciousness neither Ronan nor August will express, Harriet McBryde Johnson, who died in middle age, makes the case for disability conservation like this: “I

decide to embrace the death sentence. No need to fear it; no need to hasten it. Mortality is something all people share, a unifying force. ... When I die, I might as well die alive” (Johnson 2005, 16). Johnson’s concept of dying alive affirms what I have called here the because-of-rather-than-in-spite-of aspect of the case for conserving disability.

Ronan’s imminent and vivid aliveness and his equally vivid mortality—indeed, people with disabilities and disability in general—present 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. Disability demands that we all might imagine a subject without a future life trajectory perpetually managed in the present moment. In doing so, disability rescripts modernity’s, and the modern subject’s, temporal practices and understandings. The important complexity of Rapp’s story of her son and family is to be able to hold the contradiction (the Keatsian negative capability) of the work disability does in the world; for Rapp, it is suffering entangled with joy. Her navigation of this contradiction is her story of Frank’s woundedness, both hers and Ronan’s. This, I offer, is the “giftedness” of disability.

References

- Agar, N. 2004. *Liberal eugenics: In defence of human enhancement*. Malden: Blackwell Publishing.
- Alaimo, S., and S. Hekman, eds. 2008. *Material feminisms*. Bloomington: Indiana University.
- Alcoff, L. 2005. *Visible identities: Race, gender, and the self*. New York: Oxford University.
- Bagenstos, S.R. 2009. *Law and the contradictions of the Disability Rights Movement*. New Haven: Yale University.
- Barad, K.M. 2007. *Meeting the universe halfway: Quantum physics and the entanglement of matter and meaning*. Durham: Duke University.
- Bauman, Z. 1989. *Modernity and the Holocaust*. Ithaca: Cornell University.
- Baynton, D. 2001. Disability and the justification of inequality in American history. In *The new disability history*, ed. P. Longmore and L. Umansky, 33–57. New York: New York University.
- Beauchamp, T., and J. Childress. 1994. *Principles of biomedical ethics*, 4th edition. New York: Oxford University.
- Beniger, J.R. 1986. *The control revolution: Technological and economic origins of the information society*. Cambridge: Harvard University.
- Black, E. 2003. *War against the weak: Eugenics and America’s campaign to create a master race*. New York: Four Walls Eight Windows.

- Bruinius, H. 2007. *Better for all the world: The secret history of forced sterilization and America's quest for racial purity*. New York: Knopf.
- Buchanan, A., D. Brock, N. Daniels, and D. Wikler. 2000. *From chance to choice: Genetics and justice*. New York: Cambridge University.
- Canguilhem, G. 1989. *The normal and the pathological*. New York: Zone Books.
- Christ, C.P., and J. Plaskow, eds. 1979. *Womanspirit rising: A feminist reader in religion*. San Francisco: Harper & Row.
- Clark, E.B. 1995. "The sacred rights of the weak": Pain, sympathy, and the culture of individual pain in antebellum America. *The Journal of American History* 82(2): 463–493.
- Cogdell, C. 2004. *Eugenic design: Streamlining America in the 1930s*. Philadelphia: University of Pennsylvania.
- Collins, P.H. 2000. *Black feminist thought: Knowledge, consciousness, and the politics of empowerment*, 2nd edition. Routledge: New York.
- Davis, L. 1995. *Enforcing normalcy: Disability, deafness, and the body*. London, New York: Verso.
- Dick, K., director. 2003. *Sick: The life and death of Bob Flanagan, supermasochist*. Santa Monica, CA: Lions Gate Home Entertainment.
- Eiesland, N. 1994. *The disabled god: Toward a liberatory theology of disability*. Nashville: Abingdon.
- Elliott, C. 2003. *Better than well: American medicine meets the American dream*. New York: W.W. Norton.
- Fausto-Sterling, A. 2000. *Sexing the body: Gender politics and the construction of sexuality*. New York: Basic Books.
- Fiedler, L. 1978. *Freaks: Myths and images of the secret self*. New York: Simon & Schuster.
- Fontes, M. 1998. Disabled people are strangers in their own land. The World Association for Christian Communication's Media Development, no. 2. <http://waccglobal.org/en/19982-communication-and-disability/884-Disabled-people-are-strangers-in-their-own-land-.html>. Accessed May 9, 2012.
- Frank, A. 1995. *The wounded storyteller: Body, illness, and ethics*. Chicago: University of Chicago.
- Freud, S. 1916. Some character-types met with in psycho-analytic work. In *The standard edition of the complete psychological works of Sigmund Freud, Volume XIV (1914–1916): On the history of the psycho-analytic movement, papers on metapsychology and other works*, ed. J. Strachey, 309–333. New York: W.W. Norton & Company.
- Friedlander, H. 1995. *The origins of Nazi genocide: From euthanasia to the final solution*. Chapel Hill: University of North Carolina.
- Gabbard, C. 2010. A life beyond reason. *The Chronicle of Higher Education: The Chronicle Review*, November 7. <http://chronicle.com/article/article-content/125242/>. Accessed May 9, 2012.
- Garden, R. 2007. The problem of empathy: Medicine and the humanities. *New Literary History* 38(3): 551–567.
- Garland-Thomson, R. 2004. The cultural logic of euthanasia: "Sad Fancyings" in Herman Melville's "Bartleby." *American Literature* 76(4): 777–804.
- Garland-Thomson, R. 2011. Misfits: A feminist materialist disability concept. *Hypatia* 26(3): 591–609.
- Gerhart, K.A., J. Koziol-McLain, S.R. Lowenstein, and G.G. Whiteneck. 1994. Quality of life following spinal cord injury: Knowledge and attitudes of emergency care providers. *Annals of Emergency Medicine* 23(4): 807–812.
- Gilligan, C. 1982. *In a different voice: Psychological theory and women's development*. Cambridge: Harvard University.
- Gilman, C.P. 1979. *Herland*. New York: Patheon Books.
- Goffman, E. 1986. *Stigma: Notes on the management of spoiled identity*. New York: Simon & Schuster.
- Habermas, J. 2003. *The future of human nature*. Cambridge: Polity.
- Habermas, J. 2008. *Between naturalism and religion: Philosophical essays*. Malden: Polity.
- Hacking, I. 2010. How we have been learning to talk about autism: A role for stories. In *Cognitive disability and its challenge to moral philosophy*, ed. E. Kittay and L. Carlson, 261–279. Malden: Blackwell Publishing.
- Halttunen, K. 1995. Humanitarianism and the pornography of pain in Anglo-American culture. *The American Historical Review* 100(2): 303–334.
- Haskell, T.L. 1985a. Capitalism and the origins of the humanitarian sensibility, part 1. *The American Historical Review* 90(2): 339–361.
- Haskell, T.L. 1985b. Capitalism and the origins of the humanitarian sensibility, part 2. *The American Historical Review* 90(3): 547–566.
- Held, V. 2006. *The ethics of care: Personal, political, and global*. Oxford and New York: Oxford University.
- Hennessy, R., and C. Ingraham, eds. 1997. *Materialist feminism: A reader in class, difference, and women's lives*. New York: Routledge.
- Hvistendahl, M. 2011. *Unnatural Selection: Choosing boys over girls, and the consequences of a world full of men*. New York: PublicAffairs.
- Johnson, H.M. 2005. *Too late to die young: Nearly true tales from a life*. New York: Henry Holt and Co.
- Keller, H. 2009. *The world I live in and optimism: A collection of essays*. Mineola: Dover Publications.
- Kevles, D. 1985. *In the name of eugenics: Genetics and the uses of human heredity*. Cambridge: Harvard University.
- Kim, S., E. Polman, and J. Sanchez-Burks. 2012. When truisms are true. *The New York Times*, February 25. <http://www.nytimes.com/2012/02/26/opinion/sunday/when-truisms-are-true.html>. Accessed May 9, 2012.
- Kitcher, P. 1996. *The lives to come: The genetic revolution and human possibilities*. New York: Touchstone.
- Kittay, E., and D. Meyers. 1987. *Women and moral theory*. Totowa: Rowman & Littlefield.
- Klaus, P. 2012. A chance to see disabilities as assets. *The New York Times*, February 4. <http://www.nytimes.com/2012/02/05/jobs/disabilities-can-be-workplace-assets.html>. Accessed June 3, 2012.
- Kristeva, J., and J. Herman. 2010. Liberty, equality, fraternity, and ... vulnerability. *Women's Studies Quarterly* 38(1/2): 251–268.
- Levin, J. 2011. The invisible hate crime. *Miller-McCune*, March 1. <https://www.miller-mccune.com/legal-affairs/the-invisible-hate-crime-27984/>. Accessed May 9, 2012.
- Mitchell, D., and S. Snyder. 2003. The eugenic atlantic: Race, disability, and the making of an international eugenic science, 1800–1945. *Disability & Society* 18(7): 843–864.
- Mitchell, D., and S. Snyder. 2000. *Narrative prosthesis: Disability and the dependencies of discourse*. Ann Arbor: University of Michigan.

- Morris, D.B. 1993. *The culture of pain*. Berkeley: University of California.
- Nagel, T. 1986. *The view from nowhere*. New York: Oxford University.
- Nussbaum, M. 2006. *Frontiers of justice: Disability, nationality, species membership*. Cambridge: Harvard University.
- O'Connor, F. 1969. *Mystery and manners: Occasional prose*. Ed. S. Fitzgerald and R. Fitzgerald. New York: Farrar, Straus & Giroux.
- Orsi, R. 2005. *Between heaven and earth: The religious worlds people make and the scholars who study them*. Princeton: Princeton University.
- Oxford English Dictionary. 2000. Oxford University Press. <http://dictionary.oed.com/entrance.dtl>.
- Parens, E. 1998. *Enhancing human traits: Ethical and social implications*. Washington: Georgetown University.
- Parens, E. 2005. Authenticity and ambivalence: Toward understanding the enhancement debate. *The Hastings Center Report* 35(3): 34–41.
- Parens, E. 2006. *Surgically shaping children: Technology, ethics, and the pursuit of normality*. Baltimore: Johns Hopkins University.
- Parsons, T. 1951. *The social system*. Glencoe: Free Press.
- Pernick, M.S. 1985. *A calculus of suffering: Pain, professionalism, and anesthesia in nineteenth century America*. New York: Columbia University.
- Rapp, E. 2007. *Poster child: A memoir*. New York: Holtzbrinck Publishers.
- Rapp, E.. 2011. Notes from a dragon mom. *The New York Times*, October 15. <http://www.nytimes.com/2011/10/16/opinion/sunday/notes-from-a-dragon-mom.html>. Accessed May 9, 2012.
- Rapp, E. 2012. Rick Santorum, meet my son. *Slate Magazine Online*, February 27. http://www.slate.com/articles/double_x/doublex/2012/02/rick_santorum_and_prenatal_testing_i_would_have_saved_my_son_from_his_suffering_.html. Accessed February 27, 2012.
- Robertson, J. 1994. *Children of choice: Freedom and the new reproductive technologies*. Princeton: Princeton University.
- Rose, N. 2007. *Politics of life itself: Biomedicine, power, and subjectivity in the twenty-first century*. Princeton: Princeton University.
- Sandel, M. 2007. *The case against perfection: Ethics in the age of genetic engineering*. Cambridge: Belknap Press of Harvard University.
- Saramago, J. 1999. *Blindness*. Trans. G. Pontiero. San Diego: Harcourt Brace & Co. Originally published as *Ensaio sobre a cegueira* (Lisbon: Editorial Caminho, 1995).
- Saiving, V. 1979. The human situation: A feminist view. In *Womanspirit rising: A feminist reader in religion*, eds. C.P. Christ and J. Plaskow, 25–42. San Francisco: Harper & Row.
- Schipper, J. 2006. *Disability studies and the Hebrew Bible: Figuring Mephibosheth in the David story*. New York: T&T Clark.
- Schipper, J. 2011. *Disability and Isaiah's suffering servant*. New York: Oxford University.
- Scotch, R. 1984. *From good will to civil rights: Transforming federal disability policy*. Philadelphia: Temple University.
- Scully, J.L. 2008. *Disability bioethics: Moral bodies, moral difference*. Lanham: Rowman & Littlefield.
- Shapiro, J. 1993. *No pity: People with disabilities forging a new civil rights movement*. New York: Three Rivers Press.
- Snyder, S., and D. Mitchell. 2006. *Cultural locations of disability*. Chicago: University of Chicago.
- Straus, J. 2011. *Extraordinary measures: Disability in music*. New York: Oxford University.