Building a World with Disability in It

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In this essay, I consider the question of why we might want disabled people in the world.[1] I begin with the 1568 Peter Bruegel painting, *The Cripples*. This painting suggests a fundamental contradiction about disability as a human condition. *The Cripples* shows a humble group of four men, with what we today call mobility impairments, using a variety of prosthetic devices that range from crutches to a proto-wheelchair. The men are out and about in the public world amongst fellow subjects and public buildings, perhaps scouting out the area for the best begging situation. The faces of two of the gnome-like figures express a confused attentiveness, with mouths agape and searching, if perplexed, eyes. The other two seem concentrated on the task at hand – getting about in inaccessible terrain. Although this is most probably a scene of begging, all four are deeply engaged in the challenges of navigating their world with a disability. This representation expresses uncertainty rather than assurance, humility rather than entitlement, persistence rather than privilege, and ordinariness rather than distinction. In short, the parable I wish to draw from these paintings is that disability presents at once a problem and an opportunity for solutions. There inheres, in other words, in all things disability a contradiction.

This contradiction is summed up in the following two assertions from disability studies scholars: Disability is "the master trope of human disqualification" (Snyder and Mitchell 125), and "What we call disability is perhaps the essential characteristic of being human" (Garland-Thomson, "Integrating" 21). Sharon Snyder and David Mitchell's claim suggests that disability restricts, excludes, renders one exceptional: disqualifies. But, at the same time, my own assertion suggests that disability gathers us into the everyday community of embodied humankind. If disability is inherent in the human condition, how can it simultaneously disqualify us from full membership in the human community? How can disability be both an occasion for inclusion and exclusion?

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1 | Portions of this essay appeared in "The Case for Conserving Disability," *Journal of Bioethical Inquiry* 9.3 (2012): 339-55.

World Building

This contradiction inherent in disability can be found in what I call world building, the shared project of making and using our world together. The premise of world building is that the shape of the material world we design, build, and use together both expresses and determines who inhabits it and how we use it to exercise the duties and privileges of citizenship within that world.[2] Modern culture in the U.S. and other developed and developing societies is now undertaking two contradictory world building initiatives that are expressed in social, legislative, material, cultural and attitudinal practices.

One initiative, which I call inclusive world building, seeks to integrate people with disabilities into the public world by creating an accessible, barrier-free material environment. Inclusive world building frames disability as valued social diversity and supports the civil and human rights-based understanding of disability encoded in legislation like the Americans with Disabilities Act of 1990 and 2009 and broader initiatives, such as the United Nations Convention on the Rights of Persons with Disabilities of 2006, which aims to integrate people with disabilities as full citizens.

In contrast to this inclusion initiative, is the initiative I call eugenic world building, which strives to eliminate disability and, along with it, people with disabilities from human communities through varying social and material practices that range from seemingly benign to egregiously unethical. Restrictive environments that segregate people with disabilities from one another and from the nondisabled are one form of eugenic world building. Scientific and medical technologies are another form – for example, genetic manipulation, selective abortion, and medical normalization justified by the idea that social improvement and freedom of choice require eliminating devalued human traits in the interest of reducing human suffering, increasing life quality, and building a more desirable citizenry. Eugenic world building, in short, is the ideology and set of practices that control who enters and participates in the shared public spaces of a democratic order.

2 | This essay follows on an earlier discussion I presented in "Welcoming the Unbidden: The Case for Conserving Human Biodiversity" (2006).

Inclusion and Exclusion

This material contradiction between inclusive and eugenic world building suggests that the world we are making at this time and in this place simultaneously wants and does not want disabled people in it. In other words, in these two contemporary world building initiatives, disability is an occasion for both inclusion and exclusion. The question this contradiction raises, of course, is how we reconcile a world that rewards diversity of all types and still emphasizes particular standards of acceptable bodies.

One recent, specific example of this world building contradiction appears in a July, 2011 *New York Times Magazine* article, reporting that the neuroscientist and physician Alberto Costa, whose daughter has Down syndrome, is researching drugs that he hopes will yield treatment (see Hurley). His aspiration is to increase the quality of life and develop the potential for inclusion of people with Down syndrome in a world that values intellectual capability. Costa explains that he is in a losing race for funding with scientists developing new prenatal genetic tests, which are less invasive and can be administered earlier to identify fetuses with Down syndrome for possible elimination. This funding disparity, he suggests, reflects our cultural preference for building a world without people who bear the human variations we think of as disabilities. Costa's story suggests that the kind of research he is undertaking supports an inclusive world building initiative, whereas the preferentially funded prenatal testing research supports a eugenic logic that would eliminate people like his daughter from our shared world.

Eugenic Logic

How then do we understand this eugenic logic, modernity's sustained commitment to eliminating disability from the human condition, this literalizing of disability as disqualification that Sharon Snyder and David Mitchell identify as the master trope of our shared world? Why, eugenic logic asks, should the world we build together include disability at all? Our dominant understanding is that disability confers pain, disease, functional limitation, disadvantage, and social stigma; limits opportunities; and reduces quality of life. Eugenic logic tells us that our world would be 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.

Counter-Eugenic Logic

Against the eugenic commonplace that assumes we should eliminate disability, I consider the bioethical question of whether disability and disabled people are something we might want to conserve rather than merely tolerate. To do so, I take up an eclectic, rather than systematic, variety of counter-eugenic positions and perspectives, ranging from instrumental to pragmatic, ardent to skeptical. Taken together, these perspectives honor the complexity of how disability acts as "the master trope of human disqualification" and also constitute a conversation asserting that disability might better be conserved (Mitchell and Snyder 3). These speculations about what disability might be good for reframe it as a resource rather than restriction, offering a reading of disability as generative rather than limiting. In other words, this conversation asks what cultural and material work disability does in the world.

What I endeavor to explicate here are '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 this, I do not mean productivity in capitalist economies, nor contribution through individual agency or acts, but I want, instead, to think about the generative work of disability and people with disabilities through their presence. Put another way, I ask what we lose besides the individuals themselves if we eliminate disability and disabled people from the world.

Attending to what disability contributes requires focusing on its generative potential rather than its restrictive potential. The tension between disability as a universal and persistent human experience and disability's cultural work as a disqualifier intensifies its generative potential, I suggest. As 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. As both a generative concept and a fundamental human experience, then, disability creates circuits of meaning making in the world. The meaning-making potential of disability can be organized into a taxonomy of three interrelated registers – the 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 some of our most enduring and canonical cultural narratives. Disability is apparently close to the quick, a perpetual narrative resource. Perhaps something resolutely human and inherently interesting inheres in disability itself and the lives we make with disabilities. Sophocles's tragic

figure, Oedipus, for example, is one of the founding protagonists of Western culture. Oedipus's tragic flaw is of course hubris, the Promethean aspiration to know the terrible truth of his own fate. Oedipus's life journey is also bookended by disability: his parents, the King and Queen, 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 his damaged foot provides the irrefutable evidence of his identity and terrible fate. Laden with this inescapable self-knowledge, Oedipus seizes the truth of who he is, knowingly taking his fate into his own hands by gouging out his eyes and heading down the road alone. As such, disability defeats hubris. With this dramatic act, Sophocles expresses an alignment of the hero's body and identity by making Oedipus, like Tiresias before him, into one of the canonical figures of classical Greek tragedy, the blind seer.

In another example, Arthur W. Frank's *The Wounded Storyteller: Body, Illness, and Ethics* (1995) puts forward a strong argument for disability as a narrative resource in the form of self story. Frank values the narrative potential of disability for disabled people, and the contribution of disability narrative in Frank's account is to counteract disability's social disqualification. As Snyder and Mitchell suggest, few of us willingly welcome disability into life today. The birth of a disabled child or the onset of disability is seen as a catastrophe or a failing. This is so because being disabled shifts one into an unappealing and unexpected social position.

Narrative is a productive rather than compensatory resource in Frank's ardent defense of disability's contribution to self-understanding and identity formation. 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 xi).[3] Frank considers the narrative of his own wounding and the proposed utility of a wound-telling story to be a "survival kit" (xiii).

Disability in Frank's account is an opportunity to develop "voice" (109), by which he means the capacity for making 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

3 | Independent scholar Terry Tracy makes a distinction between illness and disability narratives in an unpublished paper entitled, "Disability Narrative vs. Illness Narrative: Different Wounds, Different Stories," delivered at Columbia University in March 2012.

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. Telling one's disability story is an antidote to disability disqualification, to the social banishment and apartness of the sick role and the stranger-making function of disability stigma. Making disability narrative integrates one into the human community by generating "the common bond of suffering that joins bodies in their shared vulnerability" (xi). Frank 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" (xiii). Thus, Frank's notion of wounded storytelling illustrates how disability can be an occasion for both exclusion and inclusion and that resolution of contradiction can come through the process of narrative making.

Disability as Epistemic Resource

For Frank, the generative work of narrative is to produce knowledge through rendering life experience into a 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.[4] In other words, our bodily form, function, comportment, perceptual apprehension, and way of mind shape how we understand the world. The current critical generation's critique of objectivity, master narratives, and a universal standpoint has not only discredited 'the so-called view from nowhere' but 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. This critical exploration has yielded terms that range from oppositional consciousness, standpoint epistemology, outsider/insider perspective, privileged epistemic state, to subjugated know-ledge.

The bioethicist Jackie Leach Scully has argued persuasively that a distinctive and morally privileged knowledge can arise from the experience of living in a disabled body. In accordance with Scully and following Patricia Hill Collins, I maintain that the material experience of navigating a world built for the majority while living with a minority form of embodiment like disability can produce a politicized consciousness or epistemic epiphany regarding the relativity of exclusions that the status quo explains as natural or essentializes as inherent inferiority. Disabled bodies, as Scully explains it, produce "experiential gestalts" (91), or ways-of-knowing shaped by embodiment that are distinctive from the ways of knowing that the nondisabled body develops as it interacts

4 | See, for example, Gibbs (2005) and Shapiro (2010).

with the world built to accommodate it. This "thinking through the variant body," as Scully calls it, can be a resource (83).

For example, the deaf blind activist and writer, Helen Keller, gives an account of how embodied cognition generates subjugated knowledge in her 1908 collection of essays, *The World I Live In*. Keller's enforced unreliance on the dominant senses of hearing and sight provide 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 31). Touch, she concludes from her distinctive way of knowing, "is a great deal the eye's superior," as phenomenology has suggested (34).

Disability as Ethical Resource

This cascade of rationales for disability conservation I offer begins in disability's propensity to generate narrative, which in turn generates knowledge, and finally generates an explicitly ethical counter-eugenic logic. The final and most nuanced counter-eugenic argument I will offer comes from Emily Rapp's wrenching account of her experience and understanding of parenting a child with a fatal disease, which she published in *The New York Times* and *Slate Magazine Online*. In these two pieces, Rapp offers a humble argument for disability conservation that honors the pain, loss, and suffering that is fundamental to much disability.[5]

At nine months old, Rapp's son Ronan was diagnosed with Tay-Sachs, a rare genetic condition which 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" put widely forward in arguments for reproductive counseling, eugenic testing, and selective abortion. 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. Moreover, that Rapp had two screenings for the

5 | Rapp has since written in greater detail and at length about her experience of parenting a terminally ill child and about her son's short life in her memoir *The Still Point of the Turning World* (2013).

condition which did not indicate its presence complicates what is often taken to be a clear-cut case for genetic testing and selective termination. Rapp herself has said 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 parents have experienced.

The prevention of suffering 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 all used it in some way.[6] A wary Flannery O'Connor has even warned of the peril – rightly, I think – that sympathy for the suffering of others can lead to the gas chamber.[7] But Emily Rapp and her son's situation offer a consideration other than the well-worn conversation about suffering. While it would be wrong to reduce the complicated and contradictory understandings Emily Rapp offers about her son's condition, one point that her story makes clear is that suffering expands our imagination about what we can endure.

More than this, however, Rapp's account of what Ronan's disability imposes upon her clarifies a less-recognized aspect of disability's distinctive work in the world that is worth conserving. Disability in general, and Ronan's dramatic disability manifestation in particular, 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 Rapp to live "without a future," to cultivate a primary self-defining interpersonal relationship in the lived present that presumes no future (Rapp, *Still Point* 11). 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. The 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.

6 | In Practical Ethics (2009), Peter Singer argues for selectively killing, in particular, infants and disabled people as a reasoned, utilitarian principle. He presents this case in order to argue against and refute the sanctity of human life principle as an absolute position uninflected by utilitarianism or liberalism. In order to put forward his position of secular speciesism, Singer argues for killing disabled people as conscienceless newborns or sufferers, which is related to his critique of vitalism as a bio-conservative position rooted in Judeo-Christian culture. His argument for killing disabled people, therefore, is less an argument for this position than it is one against the logical flaws in conservative, vaguely nonsecular positions holding to a moral boundary between human and nonhuman life forms.

7 | In "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" (O'Connor 227).

Like 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 (Rapp, "Notes" n. pag.).

One might say that Rapp's story could be just one more version of lessons from the disabled for the nondisabled. I want to 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. 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, modern culture, and modern subjectivity – even modern design. 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," 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 insistence on 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 perhaps the fundamental aspect of modernity and modern subjectivity. This impulse to control the future is the overreaching that Michael Sandel has so effectively decried in his case against perfection.

Disability is, then, a conceptual category that represents something which goes beyond actual people with disabilities. It represents a problem with temporality as it is formulated in modernity. Disability and illness frustrate modernity's investment in controlling the future. Douglas Baynton argues that the 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 rather as intransigence embodied. Disability and people with disabilities are eugenic targets because we embody the unpredictable and intractable nature of temporality. We frustrate modernity's fantasy that humans determine the arc of their own histories.

Rapp's narrative confronts our collective investment in futurity, which I have suggested is distinctly modern and differs from traditional worldviews. Thus, disability becomes for modernity's Promethean aspiration to control the future at once its greatest opportunity and its greatest repudiation. 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 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 a future we want that is the problem but, rather, the problem lies in 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, it is to be a narrative resource that does not mortgage the present on the future. Not 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. Disability, then, rescripts modernity's and the modern subject's temporal practices and understandings. Ronan's imminent and 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 premise of the future. Disability demands that we all might imagine a subject without a future life trajectory that is perpetually managed in the present moment. 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 the world; for Rapp, it is suffering entangled with joy. Rapp's navigation of this contradiction is her story of Frank's woundedness, both hers and Ronan's. This, I offer, is what Michael Sandel calls the "giftedness" of disability (Sandel 27 and 91).

References

Bauman, Zygmunt. *Modernity and the Holocaust*. Ithaca, NY: Cornell University Press, 1989. Print.

Baynton, Douglas. "Disability and the Justification of Inequality in American History." *The New Disability History*. Eds. Paul Longmore and Lauri Umansky. New York: New York University Press, 2001. 33-57. Print.

Beniger, James R. *The Control Revolution: Technological and Economic Origins of the Information Society*. Cambridge: Harvard University Press, 1986. Print.

Frank, Arthur. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press, 1995. Print.

Garland-Thomson, Rosemarie. "The Case for Conserving Disability." *Bioethics, Sexuality, and Gender Identity*. Special issue of *Journal of Bioethical Inquiry* 9.3 (2012): 339-55. Print.

—. "Welcoming the Unbidden: The Case for Conserving Human Biodiversity." *This is What Democracy Looks Like: A New Critical Realism for a Post-Seattle World*. Eds. Amy Schrager Lane and Cecelia Tichi. New Brunswick: Rutgers, The State University, 2006. 77-87. Print.

—. "Integrating Disability, Transforming Feminist Theory." *National Women's Studies Association Journal* 14.2 (2002): 1-32. Print.

Gibbs, Raymond W. *Embodiment and Cognitive Science*. New York: Cambridge University Press, 2005. Print.

Haskell, Thomas L. "Capitalism and the Origins of the Humanitarian Sensibility, Part 1." *The American Historical Review* 90.2 (1985): 339-36. Print.

—. "Capitalism and the Origins of the Humanitarian Sensibility, Part 2." *The American Historical Review* 90.3 (1985): 547-566. Print.

Hurley, Dan. 2011. "A Drug for Down Syndrome." *The New York Times Magazine* 29 July 2011. Web. 29 July 2013. <http://www.nytimes.com/2011/07/31/magazine/a-fathers-search-for-a-drug-for-down-syndrome.html?pagewanted=all>.

Keller, Helen. *The World I Live in and Optimism: A Collection of Essays*. 1905. Mineola: Dover Publications, 2009. Print.

Mitchell, David T. and Sharon L. Snyder. *Narrative Prosthesis: Disability and the Dependencies of Discourse*. Ann Arbor: The University of Michigan Press, 2000. Print.

O'Connor, Flannery and Sally Fitzgerald. "Introduction to *A Memoir of Mary Ann* and Sally Fitzgerald." *Mystery and Manners: Occasional Prose*. Eds. Robert and Sally Fitzgerald. New York: Farrar, Straus & Giroux, 1969. Print.

Rapp, Emily. *The Still Point of the Turning World*. New York: The Penguin Press, 2013.

—. "Notes from a Dragon Mom." *The New York Times* 15 October 2011. Web. 9 May 2012. <http://www.nytimes.com/2011/10/16/opinion/sunday/notes-from-a-dragon-mom.html>.

—. "Rick Santorum, Meet My Son." *Slate Magazine Online* 27 February 2012. Web. 29 July 2013. <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>.

Sandel, Michael. *The Case Against Perfection: Ethics in the Age of Genetic Engineering*. Cambridge, MA: Belknap Press of Harvard University Press, 2007. Print.

Scully, Jackie Leach. *Disability Bioethics: Moral Bodies, Moral Difference*. Lanham: Rowman & Littlefield, 2008. Print.

Shapiro, Lawrence. *Embodied Cognition*. New York: Routledge, 2010. Print.
Snyder, Sharon L. and David T. Mitchell. *Cultural Locations of Disability*. Chicago: The University of Chicago Press, 2006. Print.
Singer, Peter. *Practical Ethics*. 3rd ed. Cambridge: Cambridge University Press, 2009. Print.
Tracy, Terry. "Disability Narrative vs. Illness Narrative: Different Wounds, Different Stories." Columbia University. March 2012. Lecture.
Weber, Max. *The Protestant Ethic and the Spirit of Capitalism*. 1905. New York: Routledge, 2001. Print.