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The Cultural and Religious Production of Disability Shame and the Saving Power of Heretical Bodies

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Abstract: This paper explores the cultural and religious production of disability shame, and the ways able-bodied people unknowingly perpetuate that shame—to our own detriment. My analysis suggests that nondisabled people benefit from challenging disability shame by embracing the prophetic perspectives of those who refuse to repent for their somatic heresies.

Keywords: Disability; Shame; Religion

When I asked my friend Hannah—a passionate, brilliant young woman who has cerebral palsy and uses a wheelchair—to tell me about her experiences of shame, she said it is hard to know where to start.[1] This is just one of many stories she shared:

> When she was fifteen, Hannah participated in a self-advocacy class with other kids with disabilities. As a 'problem solving' exercise, the kids were tasked with imagining what they would do if they were going on a field trip and the teacher forgot to schedule an accessible bus. The answer was easy for Hannah: she'd call her mom, who worked part-time outside the home and who she knew would be able to give her a ride. Hannah's peers thought this was a sensible plan; but her able-bodied case manager responded disappointedly: "Is that really fair to your mom?" he asked. "Shouldn't you do things that allow her to live her *own* life—to do her *own* thing?" Hannah recalls that in her own mind, what this man was really saying (without saying it) was: *You should develop more autonomy to compensate for being less-than-whole; you should try to be less of a problem for others*. When Hannah got home later that day, she immediately asked her mom if she was a burden. Her mother insisted that she was not—and that driving her places was not an inconvenience. "This is what you sign up for when you become a parent," her mother explained reassuringly. Nonetheless, this incident and the feelings of shame it catalyzed marked the beginning of Hannah's suicidal ideation (H. Papenfuss, personal communication, May 17, 2018).

Several years ago, I probably would have seen the case manager's shaming response as an indication of his insensitivity or incompetence. From my privileged able-bodied perspective, I might have written it off as an unfortunate incident of ableism that, thankfully, Hannah managed to survive. I may have also felt sorry for Hannah and tried to make her feel better by praising her for being "so strong" despite her case manager's ignorance. It took my own temporary but debilitating episode of severe osteoarthritis, along with some excursions into the field of disability studies, for me to understand that disability is neither a private misfortune nor an inherently miserable condition, to paraphrase Rosemarie Garland Thomson

(1997), and that ableist oppression is not a series of isolated incidents, but a deeply entrenched sociopolitical system. This system depends on the disability shame it produces—the same shame that made Hannah wonder whether death might be preferable to living with a disability.

This paper explores that shame—both the shaming of people with physical disabilities and the shame they are encouraged to internalize. My analysis suggests that shame is not a natural response to bodies that are physically impaired, but a culturally/religiously conditioned reaction to corporeal diversity that able-bodied people unknowingly perpetuate—to our own detriment.[2] My discussion begins by highlighting a crucial way nondisabled Americans participate in the systemic production of disability shame, namely, through their yearning and quest for a "better" body—a body defined through a decidedly nondisabled ideal. Though seemingly secular, both the contemporary pursuit of physical improvement and the shame that shadows this quest bear traces of traditional religious narratives that disparage disability. These narratives have been recycled through Cartesian notions of selfhood to produce the illusion that you *should* and *can* control your body—and that failure to do so is shameful. This illusion enables nondisabled people to project our fears of losing control of our bodies/our lives onto the flesh of individuals who are physically impaired. Ultimately, I suggest that nondisabled people benefit from challenging disability shame and embracing the prophetic perspectives of those who refuse to repent for their somatic heresies.[3]

Where There Is Shame, There Is a System:
The Cultural Production of Disability Shame in the U.S. Today

Of the various meanings of "shame" Merriam Webster (2018) offers, the one defining shame as the feeling of "dishonor" or "disgrace" best captures the sense of impropriety, inadequacy, and humiliation that disability shame frequently entails. This definition resembles Brené Brown's understanding of shame as "*the intensely painful feeling or experience of believing we are flawed and therefore unworthy of love and belonging*" (2012, p. 69). According to Brown, who specializes in shame research, this feeling is often manifest in the sense of never being "good enough" (pp. 24–26).

America's Culture of Physical Improvement

Shame is often thought of—and experienced as—a private emotion. But to paraphrase anthropologist Mary Douglas, where there is shame, there is a system (Douglas, 1992). As Brown (2012) points out, shame flourishes in cultures that are steeped in comparison and competition— cultures like the U.S., where the relentless pursuit of a better body has become a quasi-religious requirement for virtuous citizens. This obligation is part of a broader culture of physical improvement—a system of beliefs, images, rituals, and moral codes that promise "salvation" (i.e., happiness, health, fulfillment) through a better body. Oriented by commercially-produced fantasies of physical perfection—represented in idealized images of young, mostly white, affluent-looking, cis-gender, slender, nondisabled bodies—this culture teaches us to value some corporeal configurations more than others, even as it encourages *every* body to look, feel, and function like the normative ideal (Lelwica, 2017). In contemporary America, the salvation myth of physical improvement plays a central though largely hidden role in the systemic production of disability shame, and in nondisabled people's complicity with this production.

This myth is predicated on the assumption that you can control your body—a foundational belief in the culture of physical improvement that reflects the tenacious influence of Cartesian dualism on Western culture. Descartes's view of a person/soul as a "ghost in a machine"—i.e., a rational, autonomous, sovereign will that inhabits and rules over an unintelligent, involuntary, biodegradable body (Descartes, 1956)—implies that people ought to be able to master their flesh, and that inability to do so constitutes a kind of moral failure. The Cartesian dream of rational self-mastery supports commercial culture's view of bodies not just as objects we can work on and work out, monitor and manipulate, defy, compel, renovate, and fix, but as advertisements for who we are as a person. Paradoxically, the improvable body is believed to be both subject to the will of the sovereign self and a visible manifestation of that self.

In the U.S. today, the presumed correspondence between the sovereign/autonomous self and the well-trained/obedient body is constructed through commercial culture's iconography. Photoshopped images of physical perfection glorify/glamorize bodies whose "owners" (e.g., models, movie stars, athletes, and other celebrities) appear to be in charge of their destiny. Deployed to sell everything from new cars, to hamburgers, to underwear, the idealized body/self is both a linchpin of consumer capitalism and a commodity in itself (Betcher, 2007). In case it is not obvious, the corporeal fantasy that orients the culture of physical improvement gains its authority through its visible association with intersecting forms of social privilege. Thus the "good body" we are conditioned to want is a ticket to the "good life" that is central to the American Dream—a dream characterized by upward mobility and freedom from suffering.

If we zoom in a little closer, however, we will see that the somatic ideal is constructed not only in relation to what's socially *desired*, but also in connection with what's commonly *feared*: the lack of control, inefficiency, dependency, pain, and limits associated with bodies that are physically impaired. Disabling perceptions of such bodies as not-normal, not-healthy, not-beautiful, and not-in-control render them "shameful." Indirectly, these apostate bodies tacitly support the fantasy of somatic perfection that everybody is encouraged to want and become—by providing its quintessential "other": the ultimate "not-me" figure (Betcher, 2007, p. 51).

Nondisabled Americans may not see how the culture of physical improvement trains us to participate in the production of disability shame. We may not recognize the extent to which ableist assumptions about "normalcy" and the imperative to be "in control" shape our ideas about the kind of body we want to have—and the kind of body we *don't* want to have. By defining "improvement" as conformity to an autonomous-looking, nondisabled ideal, dominant cultural body norms encourage everybody to collude with a system of invisible prejudices and privileges—whether or not we know or intend it. In this system, nondisabled people enjoy the psychic ease that comes from being considered "normal," along with social access to buildings, jobs, leadership positions, and educational and recreational opportunities that nondisabled status bestows. This same system deprives people with bodily losses or limitations the sense of belonging that perceived normalcy bestows, while encouraging them to feel ashamed of their bodies' refusal to comply with able-bodied norms, and excluding them from equal participation in society.

The Normalizing/Shaming Gaze and the Somatic Hierarchy/Heresy It Constructs

In a society that places such a high premium on getting "ahead," looking "good," being "normal," and feeling "in control," the irregularities, vulnerabilities, and/or limits of physically impaired bodies relegate them to the lower ranks of a social/symbolic hierarchy of bodies. This ranking system is constructed through what Michel Foucault called a "normalizing gaze"—a way of seeing and valuing that measures, classifies, compares, and judges physical differences based on a singular standard (Foucault, 1973). This homogenizing optic/ethic gained prominence during the modern period as medical science pathologized bodies that deviated from the Anglo-Saxon, bourgeois ideal, and as capitalist economies delegated inefficient or "unproductive" bodies (e.g., people who were sick, poor, insane, or disabled) to society's margins (Foucault, 1980, 1988, 1995). According to the moral-scientific-aesthetic taxonomy this gaze constructs, "normal" bodies are good, healthy, and beautiful, while others are degenerate, sick, and ugly (Young, 1990). Despite its supposed "objectivity," the normalizing gaze is a *shaming gaze*. While it generates awe and admiration of figures at the top of America's somatic hierarchy, it directs dread, gawking, and pity at those at the bottom. Circulated through commercial, medical, and self-help discourses today, this way of seeing/valuing corporeal diversity teaches us to distinguish between "right" and "wrong" bodies, to internalize this distinction, and to judge and improve ourselves/our physicality accordingly.

However well intended, *improvement* here is code for *controlling* and *conforming* bodies to the normative/nondisabled ideal—an ideal whose authority is constructed through intersecting forms of privilege, e.g., as disproportionately white, affluent-looking, cis-hetero, thin, young, and so on. This translation of "improvement" reveals how the shaming gaze is also a colonial gaze insofar as it circulates an imperial-like imperative to conquer, convert, and ultimately save (i.e., fix or cure) unorthodox flesh from its anatomical heresy. The colonial dimensions of the culture of physical improvement are evident in *rituals* designed to "help" us create a better body (e.g., dieting, working out, anti-aging therapies, cosmetic surgery, prosthetic enhancements) and in commercial and medical discourses' combative *rhetoric*, which encourages us to triumph over bodily flaws and afflictions (e.g., to fight fat, defy aging, conquer chronic pain, battle cancer)—or to at least camouflage our corporeal mutinies. According to the normalizing optic/ethic that oversees the better body crusade, every*body* could stand a little improvement, but people with disabilities are particularly good candidates for the salvation that better-body rhetoric and rituals promote. They are encouraged to overcome their physical losses or limits, or, at the very least, to heroically convert them into inspiring stories—preferably the "supercrip" kind that will impress nondisabled people (Clare, 2009; Kafer, 2013). Failure—or *refusal*—to vanquish disability invites the kind of shaming disappointment directed at Hannah when she solved the problem her case manager presented without buying into the myth of self-sufficiency—i.e., the illusion that individuals should and can be entirely self-reliant, and the corresponding belief that needing help or support from others is a sign of weakness.

Since few bodies live up to the somatic expectations that guide the popular pursuit of physical improvement, the shame that shadows this quest has the potential to infect virtually everybody. Women are especially susceptible to body shame because their worth (or lack thereof) is so often tied to their physicality—a linkage that reflects longstanding views of female flesh as dangerously unruly (remember the story of Eve) or as intrinsically deformed (recall Aristotle's "misbegotten male"). However, the culture of physical improvement is especially and acutely disabling/shaming for people whose bodies blatantly refuse to obey its mandates for how flesh is supposed to look, function, and feel. And, as Garland Thomson observes (1997), "Corporeal departures from dominant expectations never go uninterpreted or unpunished, and conformities are almost always rewarded" (pp. 7-8). For people with disabilities, punishments for somatic blasphemy come in the form of ostracism, stereotypes, "invisiblization", dehumanization, isolation, and internalized perceptions of never being "good enough." Situated in stark contrast to the flawless form at the hierarchy's apex, representing all that Americans are conditioned to loathe and fear, unorthodox disabled bodies are deemed in dire need of salvation. Though, according to this cultural system, most bodies fall short of perfection, the corporeal "sins" of disabled bodies are seen to desperately need forgiveness.

A Shameful Legacy: Some Biblical Views on Physical Impairment

Because of its deep roots in commercial, medical, and self-help culture, the contemporary quest for physical improvement seems to have little to do with religion. But this is largely because dominant (i.e., white, bourgeois, patriarchal, Protestant) theological traditions have tended to promote an overly narrow, privatized, and disembodied understanding of religion, namely, as comprised primarily of personal beliefs, concerned above all with otherworldly things, and categorically distinct from "nonreligious" cultural phenomena (Schaefer, 2015). This stereotypical understanding ignores the human/embodied origins of religion, its meaning-making functions, and its ambiguous sociopolitical consequences (i.e., its liberating and oppressive potential) (Lelwica, 2017). A more complex, fluid, and contextual concept of religion that is commonly used among religion scholars today (Asad, 1993; Asani, 2011; Miller, 2012; Schaefer 2015) enables us to see how traditional religious teachings and practices are tacitly embedded in seemingly non-religious attitudes, habits, values, and institutions, including those that shape our notions of "right" and "wrong" bodies, and our corresponding perceptions of disability.

Since Christianity has had the most prominence and thus the most power to influence these perceptions in America, my analysis of religion's entanglement with the cultural production of disability shame focuses on this tradition. Three prominent Christian narratives support the disparaging view of disability embedded in the culture of physical improvement: 1) A *moralizing narrative* interprets bodily impairment as a visible manifestation of sin, a kind of blemish on God's perfect creation. In this storyline, the visible body is an index of the state of the invisible soul; 2) An *eschatological narrative* equates salvation/healing with curing or eliminating anatomical abnormalities. In this storyline, "defects" in form or functioning are overcome through God's saving power; and 3) A *spiritualizing narrative* views disability as an opportunity for cultivating virtue. In this storyline, disabled individuals become inspiring role models, while their caretakers are charitable heroes.

I believe that many people, including many Christians, are unaware of the extent to which these ancient narratives have influenced our assumptions about how bodies are supposed to look, function, and feel. Whether or not you are religious, learning to recognize these storylines is a crucial step in challenging their lingering influence.

The Moralizing Narrative: Disability as a Sign of Sin

In her groundbreaking work, *The Disabled God* (1994), Nancy Eiesland identified Christianity's long-standing association between bodily impairment and moral impurity. The sin/disability nexus is exemplified in New Testament texts like John 5:14, in which Jesus heals a man who was unable to walk, then tells him: "Do not sin anymore, so that nothing worse happens to you." Throughout Christian history, this text (and similar miraculous healing stories) fostered a symbolic connection between physicality and morality—and specifically between disability and shame: bodily impairment was a visible punishment for spiritual depravity and unbelief.

The symbolic association between disability and sin supported other demeaning beliefs about somatic impairment that became part of Western culture's DNA. Within the biblical tradition, blind, deaf, or lame bodies are seen to besmirch the image of God, who is envisioned as fully intact and unencumbered. As New Testament scholar John Hull (2013) points out, "God walks in the Garden of Eden; God does not limp (Gen. 3.8)" (pp. 42-43). Given the biblical God's anthropomorphized status as able-bodied, it is not surprising that people with physical impairments have been prohibited from serving as spiritual leaders—both historically and as recently as the 1980s (Eiesland, 1994, Lowe, 2012). Throughout Christian history, visibly flawless bodies were seen to manifest inner states of holiness, while somatic imperfections were seen to express internal states of disgrace (Eiesland, 1994). Thus, a disabling theology constructed impaired bodies as shameful and needing redemption.

The Eschatological Narrative: Healing/Overcoming Disability

If disabled bodies manifest sin, then salvation depends on disability being "cured." Stories of Jesus' miraculous healings were understood to anticipate the final redemption/perfection of the flesh at the end of time (Hull, 2013). A vision of resurrected bodies as flawless is central to classic Christian eschatology (the part of theology that deals with the final judgment and the afterlife). In this storyline, virtuous believers will enjoy the rewards of eternal life in flesh that is fit for paradise. Freed from the corruption of sin, decay, and death that hamper life on earth, resurrected bodies represent an angelic/imperishable state. Like the photo-shopped fantasies of somatic perfection that proliferate in today's culture of physical improvement, these heavenly forms are relieved of (and redeemed from) the burdens, needs, changes, limits, and vulnerabilities of embodied existence.

Historian Candida Moss (2011) describes how early Christians envisioned bodies in the resurrection as having been "cleansed" or "cured" of their deformities and afflictions. In her analysis, the eradication of bodily "defects" in paradise was part of the narrative of salvation history, whose trajectory moves away from physical diversity/adversity, which signified humanity's fallen/shameful state, toward a celestial future in which the lame walk, the blind see, the crooked are made straight, and all other physical maladies are erased. In this heavenly scenario, "salvation" is synonymous with "healing," which is interchangeable with "curing," and God plays the role of cosmic/cosmetic surgeon, "augmenting, extracting, and appending in order to produce aesthetically pleasing, harmonious bodies" (p. 993). By equating bodily redemption with physical perfection, early church leaders systematically eliminated somatic impairments, anomalies, and infirmities from God's kingdom, implicitly reinforcing biblical links between disability, impurity, and punishment (p. 996, 1008-1009). Ultimately, traditional Christian eschatology defines healing as the removal of disability and equates salvation with conformity to an able-bodied ideal (Hull, 2013). This equation leads theologian Sharon Betcher to observe that "Theologies of healing…can be unwitting agents of imperial ideals" (2007, p. 119).

Spiritualizing Narratives: Disability as Opportunity

Narratives depicting disability as a sign of moral fault in need of redemption coexist with the biblical theme of virtuous suffering (Eiesland, 1994). In this storyline, the difficulties surrounding bodily impairment are a kind of divine test through which one is purified: disability is not just a burden but an opportunity to develop spiritually—i.e., to cultivate exceptional faith by enduring somatic losses or limits with saintly grace and courage. Seeing disability as a "cross to bear" suggests that people with disabilities need not (and thus ought not) fall into despair and can even experience impairment as a blessing. Trusting that God can use an undesirable situation for redemptive purposes, this logic suggests, disabled persons can and should obediently accept and adjust to their conditions (Reynolds, 2008).

Within this narrative, the spiritual opportunity that disability presents is also expressed through nondisabled people's charitable acts and attitudes. An ethic of charity orients many contemporary hospitals, nursing homes, rehabilitation centers that serve individuals with "special needs." Although many have benefited from these institutions, a charitable ethic positions "the disabled" as "objects of pity" on which benevolent caretakers can exercise their virtue (Reynolds, 2008). Somewhat ironically, the charity ethic offers a "suffocating surplus of compassion" to people with disabilities (Hull, 2013, p. 85), even as it distances "the disabled" from those in superior/helping positions, who ostensibly have no need for healing. In the end, this ethic solidifies the separation between "normal" and "not-me" bodies by treating disability as a private tragedy—one that can be managed thanks to the goodwill of the nondisabled—without challenging the social/symbolic systems that view physical deviations from the normative ideal as dreadful.

Traditional Christian narratives are neither the cause of, nor the sole contributors to, disparaging views of disabled bodies. Nonetheless, these narratives lend conceptual support to the cultural production of disability shame by depicting impairment, in Thomas Reynolds' words: "as something to be healed or gotten rid of—a fault, a lesson in lack of faith, a helpless object of pity for the non-disabled faithful to display their charity, a vehicle of redemptive suffering, a cross to bear, or fuel for the inspiration of others" (2008, p. 28). Becoming familiar with Christianity's shaming narratives enables us to recognize—and resist—their damaging effects beyond the realm of traditional religion.

Recognizing and Resisting Religious/Cultural Conditioning to Perpetuate Disability Shame

These days, shaming perceptions of bodily impairments are not typically couched in explicitly religious terms. Of course, there are exceptions to this general rule. Joan Tollifson, an American Buddhist teacher who was born without a right hand, recalls that when she was a toddler, someone stopped her mother on the street to inform her that God was punishing them (1997). More often, however, theologically-sanctioned disability shame echoes in hushed questions, pointed fingers, gawking stares or averted glances, in "feeling sorry" for "those poor, unfortunate people," turning them into heroes, and/or segregating or striving to "rehabilitate" (as in, *normalize*) their bodies. In *Too Late to Die Young* (2005) the late Harriet McBryde Johnson shares some (perhaps) well-intended but nonetheless shaming reactions to her unconventional body, which she describes as frail and withered as the result of a wasting disease, and which required a wheelchair for mobility:

> "I admire you for being out; most people would give up."
>
> "God bless you! I'll pray for you." [note: McBryde Johnson was an atheist]
>
> "You don't let the pain hold you back, do you?"
>
> "If I had to live like you, I think I'd kill myself" (p. 2).

Religiously-supported disability shame also reverberates in the kind of well-intended "be happy" advice that Hannah told me she profusely dislikes. When the topic of her disability comes up in conversation, people regularly encourage Hannah to, "look on the bright side of things," or to, "have a positive attitude"—as if her disability were simply a personal challenge that she could rise above with enough willpower and the proper (i.e., sunny) disposition.

Whether implicit or explicit, contemporary expressions of disability shame recycle Christianity's moralizing, eschatological, and spiritualizing narratives, integrating them with a

Cartesian view of the self as a sovereign, autonomous individual. While Christianity's narratives authorize the undesirability/shame of disability, the Cartesian legacy promises that this undesirability/shame can be overcome *in this life*—if not physically, then by "positive thinking." This mind-over-matter mentality fuels America's pull-yourself-up-by-your-bootstraps ideology of individualism; it also supports this country's creeds of progress, efficiency, and speed—creeds that coalesce in the cultural imperative to create a body that is streamlined, productive, and mobile. The ubiquitous belief that we *should* and *can* control our bodies normalizes disability shame, making it seem (and feel) natural, if not God-given.

And yet, none of us came out of the womb believing that bodies without certain parts or functions are inferior. We learn to see impaired bodies this way. Tollifson observes that when babies approach her arm, "the one that ends just below the elbow…they aren't frightened or repulsed by it. They don't feel sorry for me. They don't think I'm heroic or amazing. They see the actual shape of what's in front of them without concepts or labels" (1997, p. 22). The same religious/cultural conditioning that teaches us to view disabled bodies as shameful and needing redemption/curing encourages us to perceive nondisabled bodies as normal and therefore better. For nondisabled people, the belief that a better body equals a normal body equals an able-body is difficult to question partly because dominant religious/cultural norms and narratives constantly reinforce these equations and partly because we regularly benefit from them.

Despite such benefits, however, many nondisabled people struggle with body shame. I know this because I have spent the past few decades studying American women's troubled relationships with their bodies—particularly their obsession with losing weight and their devotion to thinness (Lelwica, 1999, 2009, 2017). My studies reveal that in the U.S. today, the majority of women (and a growing number of men) are unhappy with their bodies. These are mostly nondisabled individuals of varying sizes who feel ashamed of their flesh, which they believe has betrayed them by refusing to get or stay slim. To counteract fears and/or experiences of fat shame, many devote inordinate amounts of time, energy, and money to make their bodies "better," even when such efforts exacerbate the very shame they are trying to diminish.

I understand the painful feelings of inadequacy that drive this devotion to a better body not just intellectually, but personally. I experienced such feelings both as an adolescent struggling with an eating disorder, and decades later when debilitating arthritis caused me to walk with a noticeable limp (until I had hip replacement surgery). In fact, it was the similarities I recognized between these two experiences that catalyzed my interest in disability studies. In both instances, I was utterly frustrated with my body for not doing what I thought it *should* do. In both situations, I felt not just mad but embarrassed by my inability to control how my body looked, felt, and functioned. In both cases, I saw this inability as a *moral* weakness—a sense that there was something wrong with me—having absorbed cultural/religious narratives that conflate bodily control with virtue. Obviously, the situations were very different. My desire to control the arthritic pain and functioning of my middle-aged body was far removed from my adolescent yearning to be skinny. Yet the feelings of wanting to conquer, fix, or transcend my body were similar, and so were the feelings of shame surrounding this desire.

My point in highlighting the connections between different kinds of body shame is not to minimize the distinctly acute pain of disability shame. Instead, I want to suggest that the same normalizing optic/ethic that produces disability shame also fosters feelings of physical inadequacy among nondisabled people. The pervasive dissatisfaction that many able-bodied people feel toward their flesh suggests that *every*body has a stake in recognizing and resisting complicity with the shaming gaze projected by a culturally/religiously-sanctioned nondisabled ideal—an ideal that *no*body can achieve. This resistance is not something able-bodied people should do as a favor to people with disabilities. Rather, it is something we can do to explore our relationship with our own physicality, to examine what "health," "healing," or "improvement" might mean for our own one-of-a-kind body.

Resisting the able-bodied "dream of normalcy" requires nondisabled people to wrestle with a question Sharon Betcher poses: "What do we hide from or reject about ourselves in that classification of physiological variations known as disablement?" (2007, p. 19). Investigating the insecurities nondisabled people feel and the judgments we direct toward our own tentatively able-bodies may help us stop projecting them onto the nonconforming anatomies of others, start cultivating a more friendly relationship to our own uniquely vulnerable flesh, and engage in the multifaceted work of creating a world in which diversely configured bodies are respected, nurtured, and loved.

What the World Needs: An Atypical Perspective

As disability scholars and activists point out, disabled bodies are the target of fear and shame because they remind the nondisabled majority of the very things we find disgraceful or intolerable in our lives—e.g., loss of control, suffering, and death. Theologian Mary Lowe suggests that the dread of disability, "can be framed in theological terms as the failure of the temporarily able-bodied to accept their limits as mortal, fragile, embodied and vulnerable creatures of God" (2012, pp. 187-188). Whether or not we envision ourselves as "creatures of God," anyone who suffers under the pressure to create a better body can benefit from the counter-cultural perspective religions at their best have provided. Religion scholar and rabbi Julia Watts Belser captures this perspective when she marvels at the holy mystery that permeates her disabled flesh: "Muscle, heart, body, and bone testify to the One who made me, to the Source of wind and rain and soil who cobbled my elements into form and breathed soul into my veins. Who had the brilliant audacity to call it good and know it whole" (2014, p. 28).

This affirmation of disability as an expression of humanity's irreducible diversity—a diversity that is *good*—represents what Simi Linton calls, "the vantage point of the atypical" (2007, p. 81). Able-bodied people need this unorthodox vision to free us and everybody from the imprisoning beliefs that some bodies are better than others and that happiness depends on converting/conforming our flesh to an impossible ideal. In making this suggestion, I don't mean to romanticize disability. Nor do I wish to turn disabled people into "inspiring heroes," gloss over the diversity of their somatic conditions and life situations, or downplay the multiple exclusions they experience in an ableist society. Rather, I want to suggest that tentatively nondisabled people like myself have a lot to learn by not averting our gaze from, or gawking at, or feeling pity for, or assuming the misery or valor of people with disabilities. In what remains of this article, I unpack and endorse McBryde Johnson's suggestion that, "We [people with disabilities] have something the world needs" (2005, p. 208).

Deconstructing Idealized Views of "Body" and "Self"

The world needs people who challenge a religious/cultural optic and ethic that trains us to judge and rank each other based on physical appearances. After years of living with a disability, Alison Kafer (2013) still marvels at the assumptions nondisabled people make about her based on the sight of her body: "my wheelchair, burn scars, and gnarled hands apparently tell them all they need to know" about how miserable, frustrating, and isolated her life supposedly is and will be (pp. 1-2). They do not see a woman whose unconventional thinking and solidarity with other heretical bodies enables her to enjoy life, love passionately, and contribute to a more just society. Similarly, McBryde Johnson says most people she encounters "think they know everything there is to know just by looking at me." (2005, p. 2). Mostly, she says, they see a life of suffering. Were they to read her book, however, they would discover a woman who is quick-witted, sharp-thinking, feisty, assertive, adventurous, audacious, playful, and extremely funny.

The perspectives of people like Kafer and McBryde Johnson interrupt our habitual assumptions about the relationship between our "bodies" and our "selves." On the one hand, their experiences challenge the belief that "who I am" is transparently communicated through "my body;" on the other hand, they resist the notion that "self" and "body" are separate entities. For example, throughout McBryde Johnson's life, nondisabled people encouraged her to view her frail and twisted body as "unimportant" and to focus on her mind instead. But rather than dissociate from her unusually configured flesh, she embraced it as a fundamental aspect of herself: "the body I live in doesn't only affect me. It is me" (2005, p. 255).

The paradox of embodiment McBryde Johnson experiences—her sense of her "self" and "body" as neither identical nor separate—reminds me of Kafer's suggestion that we approach disability as "a site of questions" rather than a self-evident condition (2013, p. 11). As a site of questions, disability invites everyone to ask: what do we really know about a person based on anatomical functioning or appearance? How should we understand the relationship between our blood, bones, organs, cells, and tissues and the thinking/feeling/conscious part of us typically referred to as "self," "soul," or "spirit?" Which cultural and religious norms and narratives shape our thinking about (and experience of) this relationship? Able-bodied people need to spend more time with the questions disability raises in order to remember just how much we *don't* know about the relationship between human physicality, consciousness, and the larger mysteries surrounding our existence.

We also need to critically interrogate our attractions to the fantasy of physical perfection and to the icons and rituals that support this fantasy. Such images and the better body instructions surrounding them flatten the relationship between flesh and spirit into a linear trajectory, with a supposedly sovereign self ritually driving our docile flesh toward the "dream of normalcy"—and the control, happiness, and privilege this dream represents. Against the grain of this trajectory, disabled bodies expose, "the illusion of autonomy, self-government, and self-determination that underpins the fantasy of absolute able-bodiedness" (Garland Thomson, 1997, p. 46). These bodies' insubordination reveals the rather obvious flaw in the eschatological narrative: some physical heresies refuse to be eliminated/cured/saved.

Refusing to Be Conformed/Converted

What's more, many disability activists and scholars are not preoccupied with overcoming their noncompliant bodies. Some, like Kafer, identify as "crip" to express opposition to "compulsory able-bodiedness," to resist the shame assigned to transgressive flesh, and to eschew the obsession with being "cured" (2013, p. 27). These scholars and activists are not so much rejecting a cure as they are opting not to spend their lives yearning, waiting, and striving for one. This choice opens the door for a different kind of healing—one that involves the agency of acceptance. These days, for example, Hannah responds to the question of whether she hopes to be able to walk in heaven—a question members of her church have been asking her for years—with a rather noncommittal, *maaaaybe*. "It *might* be *kind of* interesting to be able to walk," she says. "I *might* decide to get up and take a few laps around heaven, just to see what it's like. But then I think I'd be happy to sit back down in my chair" (H. Papenfuss, personal communication, May 17, 2018). Hannah smiles with amusement as she tells me this—both because she does not believe heaven is a place where dead/resurrected people walk around, and because she knows her nonchalant answer is likely to baffle (and maybe even disappoint) her able-bodied inquisitors.

By refusing to buy into the notion that happiness/salvation hinges on her disability being removed, Hannah reverses the shaming gaze of ableism, directing it back at a society that classifies and judges people based on physical abilities and appearance. In *Exile and Pride* (2009), Eli Clare expresses a similar reversal: "it is ableism that needs the cure, not our bodies." Instead of a medical cure:

> …we want civil rights, equal access, gainful employment, the opportunity to live independently, good and respectful health care, desegregated education. We want to be part of the world, not isolated and shunned. We want a redefinition of values that places disability not on the margins as a dreaded and hated human condition but in the center as a challenge to the dominant culture (pp. 122-123).

Although Clare does not identify as "religious," his perspective resembles the prophetic critique of systemic injustice within the biblical tradition. This critique relocates the "sin" of disability from individual bodies to social/symbolic systems that punish nonconformity with shame, discrimination, and exclusion. This critique shifts the paradigm from charity towards disabled people, to solidarity among those seeking to transform disabling stereotypes and structures (Lowe, 2012).

The world needs people who recognize that human dignity, pleasure, power, health, and beauty stem not from conforming to a normative ideal, but from the kind of agency that can "make a way out of no way." Womanist theologian Monica Coleman (2008) uses this Black folk expression to affirm the creative and ingenious ways African American women have collectively navigated the harsh realities of a racist-sexist-classist society. The spirited agency of the Black women she describes resembles the audacious self-determination of disability activists like McBryde Johnson: "We take constraints that no one would choose and build rich and satisfying lives within them" (2005, p. 208). In a society where some people imagine they would rather die than be disabled, McBryde Johnson's decision to live "openly and without shame" (p. 256) in/as her unconventional body, her insistence on enjoying the many pleasures of her life, and her commitment to collaborating with others to expose the ignorance of ableist stereotypes suggest a different kind of salvation—not as a future state of perfection when "the lame shall walk and the blind shall see," but as diversely incarnated wholeness, health, and liberation in the here/now. Salvation, as Eiesland suggests, is the healing and freedom that comes from "the revolutionary act of accepting our bodies" (1994, p. 96). Salvation, as Womanists affirm, involves the capacity to love oneself—"*Regardless*" (Walker, 1983, p. xii).

Isn't this the kind of salvation most of us want: an unconditionally accepting, shame-free relationship with our bodies and with each other? Isn't this radical acceptance of our "brilliant imperfection" (Clare, 2017) a fundamental aspect of health, happiness, and healing?

Resisting Eschatological Perfection and Embracing the "Corruption" of Interdependence

Whether we are physically impaired or provisionally nondisabled, Tollifson believes that the various body issues with which we struggle would cease to be problems if we perceived them as babies do: free of preconceptions. From Tollifson's Buddhist perspective, to experience the body shamelessly is to enjoy, "the perfection of imperfection," opting to embrace, "life as it actually is from moment to moment. Asymmetrical. Messy. Unresolved. Out of control. Imperfect. Terrible. And miraculous." (1997, p. 23). Betcher shares Tollifson's resistance to eschatological purity by replacing idealized notions of "the body" with a view of flesh as "the locus of flux." For her, flesh represents, "that which we know to be true of lives—pain, difficulty, disease, transience, aging, error, and corporeal limit," as well as the, "epiphanies and critical insights" that come with those experiences (Betcher, 2010, pp. 106-108). Betcher urges Christians to develop those insights by "renovat[ing] Christian theology's own commitment to the flesh"—not its conventional obsession with mortifying and controlling the body in the pursuit of virtue, but its affirmation of the interplay of matter and spirit and the ways an incarnation unfolds in diversely configured bodies (2010, pp. 111–112). For Betcher, resisting eschatological perfection and the shame it encourages means "'keeping trust' with the Spirit of life" (2007, p. 200).

By trusting the diverse, changing, and imperfectly perfect Spirit of life in the flesh, heretical bodies abandon faith in the illusion of control. Hannah describes this illusion as "a kind of weird lie" to which able-bodied people seem especially drawn (H. Papenfuss, personal communication, May 17, 2018). This strange fallacy is connected to the myth of self-sufficiency. If you are fully able to control your body, you are unlikely to need the help of others. Indeed, you may never have to call your mother for a ride.

McBryde Johnson challenges the myth of self-sufficiency that the illusion of control supports. "Throughout my life," she says, "I have needed help from other people to bathe, dress, and get out of bed in the morning" (2005, p. 179). While the prospect of having to depend so heavily on caretakers would horrify many nondisabled people, McBryde Johnson ponders, "how strange it would be to do these morning things in solitude as nondisabled people do…it is so natural to feel the touch of washcloth-covered hands on the flesh that is glad to be flesh, to rejoice that other hands are here to do what I'd do for myself if I could" (2005, p. 251). As Betcher points out, for people living with disabilities, "human interdependence names the infrastructure of our freedom" (2010, p. 115). Thus rather than view her life as, "dreadful and unnatural," as she knows many nondisabled people do, McBryde Johnson welcomes, "the corruption that comes from interconnectedness," honoring, "the muck and mess and undeniable reality of disabled lives well lived" (2005, p. 228).

The world needs people who unsettle our ableist assumptions not only about how our bodies should be, but also about how our lives are supposed to go. Most Americans are culturally/religiously conditioned to believe that both our bodies and our lives should and could be more perfect. The belief that we should not have to suffer—that every problem has a solution, that we can rise above pain and vulnerability—may well be one of American culture's most insidious, shame-producing deceptions. Those of us with white, middle-to-upper-class, able-bodied privilege may be especially susceptible to this happy-ever-after chimera, and our privilege may make us prone to projecting the suffering and disappointment we think we are not supposed to have onto the nonconforming flesh of others. By contrast, people with disabilities do not have the luxury of denying life's difficulties. In Betcher's words, "the socially abject bodies of the disabled" are, "bodies that admit suffering" (Betcher, 2007, p. 194). Amid a culture dedicated to the denial of finitude, uncertainty, and death, their conspicuous losses and limits bear witness to pain that cannot be overcome, pain that doesn't, "happen for a reason." By "reconciling [them]selves with the contours of corporeality" (Betcher, 2007, p. 204), the heretical bodies/perspectives of people with disabilities show nondisabled people how we might begin to alleviate suffering—in ourselves and in the world—by refusing to look away from it.

With the help of the atypical perspective of those who refuse to repent for their somatic heresies, tentatively able-bodied people like myself can begin to own and examine the dread and shame we project onto disability, critically investigate the cultural, religious, and existential sources of our fear and disapproval, and transform insecurities into energy to create a world that respects, embraces, nurtures, and appreciates everybody.

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References

Asad, T. (1993). *Genealogies of religion: Discipline and reasons of power in Christianity and Islam*. Baltimore, MD: Johns Hopkins University Press.

Asani, A. (2011). "Enhancing religious literacy in a liberal arts education through the study of Islam and Muslim societies." In J. Shephard, S. Kosslyn, and E. Hammonds (Eds.). *The Harvard sampler: Liberal education for the twenty-first century* (pp. 1–31). Cambridge, MA: Harvard University Press.

Betcher, S. (2007). *Politics and the spirit of disablement.* Minneapolis, MN: Augsburg Fortress.

Betcher, S. (2010). "Becoming flesh of my flesh: Feminist and disability theologies on the edge of posthumanist discourse." *Journal of Feminist Studies in Religion, 26*(2), 107–118.

Brown, B. (2012). *Daring greatly: How the courage to be vulnerable transforms the way we live, love, parent, and lead.* New York: Gotham.

Clare, E. (2009). *Exile and pride: Disability, queerness, and liberation*. Cambridge, MA: South End Press. (Original work published 1999)

Clare, E. (2017). *Brilliant imperfection: Grappling with cure*. Durham, NC: Duke University Press.

Coleman, M. (2008). *Making a way out of no way: A womanist theology.* Minneapolis, MN: Fortress.

Descartes, R. (1956). *Discourse on method* (L. Lafleur, Trans.). Upper Saddle River, NJ: Prentice Hall. (Original work published 1637)

Douglas, M. (1992). *Purity and danger: An analysis of concepts of pollution and taboo.* New York: Routledge. (Original work published 1966)

Eiesland, N. (1994). *The disabled god: Toward a liberatory theology of disability*. Nashville: Abingdon.

Foucault, M. (1973). *The order of things: An archeology of the human sciences*. New York, NY: Vintage. (Original work published 1966)

Foucault, M. (1980). *Power/Knowledge: Selected interviews and other writings, 1972-1977*. (Colin Gordon, Ed.). New York, NY: Vintage.

Foucault, M. (1988). *Madness and civilization: A history of insanity in the age of reason*. New York: Vintage. (Original work published 1961)

Foucault, M. (1995). *Discipline and punish: The birth of the prison*. New York: Vintage. (Original work published 1975)

Garland Thompson, R. (1997). *Extraordinary bodies: Figuring disability in American culture and literature*. New York, NY: Columbia University Press.

Hull, J. (2013). *The tactile heart: Blindness and faith*. London, UK: SMC Press.

Kafer, A. (2013). *Feminist, queer, crip*. Bloomington, IN: Indiana University Press.

Lelwica, M. M. (1999). *Starving for salvation: The spiritual dimensions of eating problems among American girls and women*. New York: Oxford University Press.

Lelwica, M. M. (2009). *The religion of thinness: Satisfying the spiritual hungers behind women's obsession with food and weight*. Carlsbad, CA: Gürze Books.

Lelwica, M. M. (2017). *Shameful bodies: Religion and the culture of physical improvement*. London, UK: Bloomsbury Academic.

Linton, S. (2007). *My body politic: A memoir*. Ann Arbor, MI: University of Michigan Press.

Lowe, M. (2012) "'Rabbi, who sinned?' Disability theologies and sin." *Dialog*, *5(*2), 185–194.

McBryde Johnson, H. (2005). *Too late to die young*: *Nearly true tales from a life*. New York, NY: Picador.

Miller, M. (2012). *Religion and hip hop*. New York: Routledge.

Moss, C. R. (2011). "Heavenly healing: Eschatological cleansing and the resurrection of the dead in the early church." *Journal of the American Academy of Religion*, *79*(4), 991–1017.

Reynolds, T. (2008). *Vulnerable communion: A theology of disability and hospitality*. Grand Rapids, MI: Brazos.

Parenfuss, H. (2018, May 17). Personal interview with [M. M. Lelwica].

Schaefer, D. (2015). *Religious affects: Animality, evolution, and power.* Durham, NC: Duke University Press.

"Shame". (updated 2018 May 19). *Merriam Webster Dictionary*. Retrieved from http://www.merriam-webster.com/dictionary/shame

Tollifson, J. (1997). "Enjoying the perfection of imperfection." In L. Friedman and S. Moon, (Eds.). *Being bodies: Buddhist women on the paradox of embodiment* (pp. 18—24). Boston: Shambala Press.

Walker, A. (1983). *In search of our mother's garden: Womanist prose.* New York, NY: Harcourt Brace Jovanovich.

Watts Belser, J. (2014). "God on wheels: Disability and jewish feminist theology." *Tikkun, 29*(4), 27–29.

Young, I. M. (1990). *Justice and the politics of difference.* Princeton, NJ: Princeton University Press.

Endnotes

1. I'm deeply indebted to Hannah Papenfuss for sharing her stories of shame with me. I've known Hannah for several years now. She is currently a junior at Concordia College in Moorhead, Minnesota. She is also a poet and a disability activist.
2. My experience with osteoarthritis (a degenerative joint disease that continues to produce chronic pain in my body) catalyzed my awareness of and interest in disability as an issue that affects everybody; however, for the most part, I inhabit the world as an able-bodied person, with all the privileges associated with that status. Thus throughout this article, I identify with the (tentatively) nondisabled, who, I argue, have a responsibility to better understand and challenge the various ways we may unwittingly perpetuate disability shame.
3. This article draws on and expands material previously published by the author in *Shameful Bodies: Religion and the Culture of Physical Improvement* (London: Bloomsbury Academic, 2017).