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ROSEMARIE TONG

Jackie Leach Scully's book *Disability Bioethics: Moral Bodies, Moral Difference* is a brilliant account of disability. Scully's study wades into ontological, epistemological, and literary streams of thought as well as ethical and bioethical pools of reflection. Her contribution moves the field of disability studies forward. As Scully sees it, bioethics has not asked nearly a sufficient number of important questions about disability. Instead, it has largely confined itself to asking how disability might be eliminated through gene therapy, embryo selection, abortion, and the like; or how to treat/cure disability through surgeries, medical devices, and/or pharmaceutical interventions. Because of the narrow way in which it has approached disability, says Scully, bioethics has failed to ask important ontologi-

cal and epistemological questions about disability: What is it like to be disabled in the world? How is a person's thinking shaped by disability?

Early in her consideration of disability, Scully draws a crucial distinction between the ethics of disability (how should one treat disabled people?) and disability ethics ("the particular moral understandings that are generated through the experience of impairment") (9). According to her, disabled people's experience of impairment is by definition heterogeneous. Impairments include everything from Down's syndrome to paraplegia to cystic fibrosis. Also encompassed in the category of impairment are the chronic ailments associated with aging and the limitations that broken bones impose. As a society, we have become familiar with the distinction between an impairment (a biological anomaly), on the one hand, and social reactions to an impairment per se (disadvantaging someone or discriminating against someone on account of his or her impairment), on the other hand. Nonetheless, we have made relatively little progress in improving the lives of people with disabilities. We talk the talk, but don't walk the walk.

Although Scully thinks that both biological and social views of disability have their place in disability studies, she faults each of them for failing to provide an adequate account of how it *feels* to have an impaired body and, just as important, how the concept of disability is constructed culturally and linguistically. There is more to disabilities than their exteriority; they have a rich interiority. Repeatedly, Scully urges us to ask the following: How do disabled people experience the world? Do the motor and sensory experiences of disabled people construct not only their bodies but also their understandings differently?

One of Scully's more controversial claims is that bioethics is more compatible with a biological understanding of disability than a "strong" social understanding of disability, according to which disability could be eliminated by "redistributing economic resources, and changing educational and employment policies" (36). Her point is that although social justice questions are ethical, they are not primarily bioethical. Bioethics is likely to find more fertile territory for expansion in the psyches of disabled people than in the intricacies of cost-benefit analysis and the vagaries of political negotiation. Although I am not sure that Scully has drawn the boundary between bioethics and ethics correctly, I do think she is right to push bioethics to mine the empirical experience(s) of being disabled, for in this experience(s) are significant normative questions about the desirability as opposed to the undesirability of human bodily variation.

Invoking the work of philosopher Margaret Urban Walker, Scully affirms the so-called empirical turn in bioethics. We need to understand how people *actu-*

ally think about their disabilities before we presume to make judgments about their decisions or actions. Particularly important in this regard is Scully's reminder that different moral understandings, created by different sensory and motor perceptions of the world, are not a sign of "psychological defenses" or "epistemic inadequacy" (56). Rather, they are the sign of a way of being-in-the-world that is capable of seeing rightness where people without disabilities see wrongness.

Two of the more dense chapters in Scully's book are Chapter Four, "Different by Choice," and Chapter Five, "Thinking through the Variant Body." In the former, Scully taps into the work of French anthropologist Pierre Bourdieu. She thinks his concept of *habitus* is likely to help us understand not only ways of being disabled but also ways of being nondisabled. As Scully understands Bourdieu's concept of *habitus*, it is "the patterns of being and doing in the world that people acquire through becoming habituated to a particular social field" (64). Here I think of my childhood family, a Czech working-class foursome (mom, dad, grandma, and me), struggling to make ends meet in Chicago in the 1950s and 1960s. We had a certain way of talking, walking, eating, laughing, and working. These ways of being had an "unthinking ease" about them: they were who we were. Only later, when I left my childhood home, did I become critical and self-aware of my familial ways of being. Thrust into the larger society, I started to view these ways of being as bad, lacking, wanting. I took on what my mother called "airs" as I started to talk, walk, eat, laugh, and work differently from mom and dad (grandma was deceased by then). Gradually, I became an alien in my family; I no longer shared their *habitus*. Thus, it does not surprise me that Scully uses *habitus* to present deaf culture in a particularly sympathetic way (79). For deaf parents to want deaf children makes sense to me simply because I understand, in retrospect, the panic my dad but especially my mom felt when I started consciously and deliberately to erase my childhood *habitus*. I was, they thought, rejecting the goodness of this *habitus*.

As useful as the concept of *habitus* is, it has its limits as a methodological tool. Because *habitus* is confined to external practices, one needs a phenomenologist like Maurice Merleau-Ponty to understand disability's inside, its consciousness. As Merleau-Ponty sees it, the human body is the basis of the mind. In other words, prior to developing conscious rational thought and representation, our minds are constituted through the multiple physical (sensory and motor) interactions we have in the world. I think here of my two sons when they were infants and toddlers. Through the myriad actions of learning to eat, walk, go to the bathroom, and dress themselves, they gradually became selves with

identities. My boys had “standard” bodies. But what if they had had “anomalous” bodies (95, 109)? My guess is that if they had had “anomalous” bodies, they would have had identities different from the ones they now have. Scully holds back from making this claim “strongly,” but, intuitively, the claim that body makes mind seems right to me. Not only do I want to make this claim strongly about people who are born with impairments, but also about people who develop an impairment later in life and, for that matter, people who never have an official impairment. I truly believe that significant impairments can and usually do change one’s identity. I am not the same person I was before a car ran over me a year ago and broke my leg. That much I know.

Scully is also too tentative in her claim that different bodily experiences lead to different ways of understanding moral terms such as “reflective equilibrium” or “balancing rights” (101). Conjoined adult twins probably have a way of balancing their personal rights far differently than others might. The bodily experience of being conjoined literally makes a world of difference that matters morally (102).

One of the most illuminating sections of Scully’s book relies on Hilde Lindemann Nelson’s work on narrative ethics. According to Nelson, we construct our personal narratives from so-called master narratives that help us situate ourselves in the world. Master narratives tell stories about who we are—a woman, an African American, an immigrant, a mother. These mega-stories are not unproblematic, however. They are often limiting and untrustworthy because they fail to speak specifically and honestly enough to particular embodied experiences. To the extent that master narratives disempower or lie about us, they damage us. When this happens, we need to resist them with so-called counterstories that enable us to reconstruct ourselves creatively. Scully gives the example of the “disabled mother” master narrative, according to which disabled mothers are utterly dependent on the state for support, and ultimately use their children as their caregivers. But this master narrative is a damaging one for disabled mothers, many of whom have counterstories to tell about how resourceful they are, and how they are able to provide for their children by relying on a community of people they can summon as needed.

Perhaps my favorite part of Scully’s book is Chapter Six, “Narratives of Disability: Models and Mentors.” Here she stresses that the number of illness memoirs far outweigh those of disability narratives, perhaps because it is easier for “normal” readers to identify with the teller of an illness story. She also points out that most of the available disability memoirs are about “the experience of posttraumatic paraplegia or quadriplegia” (121). Largely absent are stories about

“steady state” (121) or “unexciting slow decline” (121), memoirs of people who have lived their disability from birth somewhat matter-of-factly.

Scully deftly compares and contrasts Simi Linton’s *My Body Politic* (2007) with John Hockenberry’s *Moving Violations* (1995). Whereas Linton used her body as an in-your-face, political statement in her work as a disability activist, Hockenberry initially tried, as best he could, to hide his impairment from the larger society, most especially from his employers. To a greater or lesser extent, he thought his professional success as a reporter depended on his being viewed as independent. Yet despite their different ways of handling their respective impairments, both Linton and Hockenberry used their disability experiences to empower and reconstruct themselves: to give themselves enhanced meaning.

Particularly insightful is Scully’s interpretation of yet another memoir of impairment: Harriet McBryde Johnson’s *Too Late to Die Young* (2005). In her narrative, Johnson tells her readers about living with her impairment in ways that construct it as standard for normality. Refusing to state the name of her impairment, Johnson proclaims its peculiar pleasures, normalizing them for others to discover and perhaps share.

Finally, Scully discusses two memoirs written by men with hearing impairments. In *What’s That Pig Outdoors* (1990), Henry Kizor explains how he has been able to “pass” as a “regular guy” who can hear in the world of journalism. Although Scully asks the question she must—“Can an identity in which passing plays a major role be morally exemplary” (127)—she does not answer it, leaving her readers to decide. Probably most helpful for the exercise of raising identity questions is Scully’s reading of Michael Chorost’s *My Journey Back to the Hearing World* (2006). Hearing impaired from early childhood, Chorost gets a cochlear implant in his mid thirties. The identity crisis he goes through is unique and reveals how much a hearing-impaired person loses as well as gains when he or she joins the ranks of those who can hear.

Toward the end of her book, Scully raises some issues that most concern me as my body ages and my impairments increase. Slowly I am becoming officially disabled. My body, the generator of my mind, is starting to fail me. Thus, I find it reassuring that Scully does not think I have to play the kind of heroic, larger-than-life roles Linton and Hockenberry respectively play. I don’t have to be a “supercrip” (122) or “feisty disabled activist” when all I want is forgiveness for the fact that gradually, ever so imperceptibly, I am becoming less able to perform the so-called activities of daily living. I also find it important that Scully tells us her position about a unitary “disability identity.” As she sees it, there are

simply too many phenotypic variations (kinds of impairment) in the world for such a mega-identity to exist. Moreover, people with disabilities vary widely with respect to the matter of disablement. Many claim that they are oppressed, repressed, and/or suppressed because of their impairment, but others could not disagree more. Scully compares problems feminists have about the idea of “Woman” with problems people in disability studies have about “Disability.” There is too much difference for any form of essentialism to reign supreme. Yet unless we have some recognition of women as a community (Scully invokes the work of Iris Marion Young) or acknowledgment of disability as a distinct identity, there is little possibility for the kind of purposeful political agendas that improve people’s lives.

After reading Scully’s book, I will never regard bioethics in the same manner. She has convinced me that *bioethics* begins with bodily experiences. With every change of my body, my identity, too, is changing. Moreover, Scully has entirely persuaded me that bioethics has to get beyond asking normative questions about disability. These questions are altogether too limiting and even boring when put beside the always challenging, sometimes tantalizing experiential questions Scully poses. Scully’s book deserves to reach the wide interdisciplinary audience it serves. Bioethics is better for her work.