What Is Disability Studies?

SIMI LINTON
New York, NY

My charge is to talk about what disability studies is. I will do that first and then turn to two areas in theory where I feel some fine-tuning, expansion, and exploration are needed.

Disability studies introduces a disability reading to a range of subject matter. We prod people to examine how disability as a category was created to serve certain ends and how the category has been institutionalized in social practices and intellectual conventions.

Disability studies' project is to weave disabled people back into the fabric of society, thread by thread, theory by theory. It aims to expose the ways that disability has been made exceptional and to work to naturalize disabled people—remake us as full citizens whose rights and privileges are intact, whose history and contributions are recorded, and whose often distorted representations in art, literature, film, theater, and other forms of artistic expression are fully analyzed.

We have enlisted people from a broad range of disciplines in redefining the "problem" of disability. What is the problem? Where is it located? Who can fix it? What scholarship is needed to prepare people to fix the problem?

Here is another way of describing disability studies. I am raising both of my hands in front of me—the right curled in a fist, the left open and ready to receive the fist. Let us imagine the fist as all disabled people and the left hand as society. Everyone might agree, at least publicly, that there should be a good fit—that disabled people should fit in society. What distinguishes disability studies from other approaches to the study of disability is the way we conceptualize the poor fit that generally exists: our explanation of what causes the poor fit and our prescription for change to make for a better fit.

In traditional curriculum and existing courses aimed at intervention, the focus is on individuals—the members of the collective fist. They are the *objects* of study, and the emphasis is on changing them (us) to fit more comfortably in the existing left hand, which is considered for the most part solid and immutable. Disabled people are to be acted on, shaped, and turned out as best as can be done to fit into the existing social structure.

Instead, in disability studies the focus is shifted toward the left hand—the idea that what compromises the fit is the rigidity, faultiness, deficits, and pathological structures in the left hand. In disability studies, the lens is turned toward the representational and institutional structures that constitute the left hand to discover what kinds of analyses and interventions can reconstruct the left hand and make for a better fit. Disability studies also includes the vibrant self-explorations—the right fist turned on itself—that are found in memoir and cultural expressions of various kinds.

We have been working in disability studies and in parallel endeavors in the disability rights movement to bring disability perspectives and voices into the curriculum and simultaneously increase disabled people's participation in society. While none of it has been easy, resistance in the academy comes primarily when the disability perspectives are allowed their full transformative potential and are used to interrogate the traditional curriculum. When they disrupt cherished domains, debunk ideas held sacred, or cost more money than some would like, disability studies encounters resistance. Similarly, outside the academy, resistance to integration and equity comes when standard practices are disrupted, when our presence discomfits the majority, or when the rights we are attempting to exercise are seen as costing too much.

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Here is an example of such disruption. A few years ago, a controversy about the golfer Casey Martin and the golf cart captured a great deal of attention. Martin petitioned the PGA—the Professional Golfers' Association—for permission to ride a golf cart in pro tournaments as an accommodation for a mobility impairment. When the PGA turned him down, Martin took the case to court. It was eventually deliberated in the Supreme Court, where Martin prevailed. The most significant outcome of the debate, I think, is that the discussion came down to the question, What *is* the game of golf? Some people said, If he rides a cart, that's not golf. I'd like to know, then, what golf is and who has decided.

A situation like this presents an opportunity to think not only about disabled people's participation in the social world but also about rules that have typically excluded that participation. It spurs us to ask what is the nature of those rules, who constructed them, and whose interests they serve.

Disabled people continue to test the rules of participation. Just as rules such as "Only men can vote" or "People of African descent can't own property" or "Women can't be police officers or firefighters" or "Two people of the same sex can't marry" have been challenged, the rule that people in professional golf tournaments can't ride in golf carts has been challenged. Throughout the last century, women, African Americans, disabled people, and many others fought to have the rules changed, and we have also had to fight in academic institutions for curricula that examine the politics of the rule structure, consider the social positioning of the rule makers, and analyze representations that reinforce the control and dominance of the rule makers.

That is what disability studies does. Our goal must be to use disability perspectives to ask big questions, such as, What is golf?

I'd like to turn now to two domains where I think there are holes in our language and our formulations. The first domain, loosely, is the disabled-nondisabled configuration and the question of who does and who should do disability studies. The second is the formulation of disability and impairment.

So then, the first domain: disabled and nondisabled people. I've been thinking a lot about nondisabled people lately. Not the ableist ones we rail against, dissect, and skewer regularly but the ones in this room and the ones on the picket lines in front of the Supreme Court. Who are you, I want to know, and—significantly, for the purpose of theory—what are you? What should we call you? *Nondisabled* seems such a nebulous term and, in the context of our theory, an unarticulated term.

I thought about this recently when, for the umpteenth time, someone asked me if I am an atheist. It is a question that always stumps me. I am technically an atheist, but the presumption of theism, the expectation that I must position myself vis-à-vis the universality of theism, hangs me up. My standard answer is that I am a born-again pagan, but it is a silly answer.

Now, I am not positing that disability studies is analogous to theism, although in this room are some pretty saved people who regularly worship at the altar of disability studies. Yet there are some structural elements here that are worth exploring. As an atheist, I have a nonposition. There is no field of study for nontheists; there is only theology, in which I am written off as a nonbeliever. There is no overarching category in which theists and the inadequately named atheists belong. Similarly, there is no overarching named category in which disabled and nondisabled fall. All people? Humanity? Something like that—but we haven't said what it is. Therefore, nondisabled people are positioned only in apposition to disabled people.

It was strategically useful to center disabled people and put nondisabled people off center. Yet nondisabled has become too vague a position, and the term *ally*, while useful in activism, is not adequate here.

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Now, some will be saying, Why is she so concerned about nondisabled people and finding a place for their scholarship? There are reasons. I think it is strategically useful to engage nondisabled people in disability studies but find a way for them to articulate their subject position vis-à-vis the idea of disability. Much as white studies has called attention to the centering of white, in exploring the nondisabled position, we call attention to its centering. Also, these allies are a talented lot, and we need to give them a better space to work.

Ultimately, though, we need to grapple with the absence of an overarching term that subsumes everyone—the vector on which disability falls. The notions of gender, race, sexual orientation, and class, inadequate and faulty as they are, provide a coherence to thinking about these topics.

Having this fault line in our formulation of disability entails a number of consequences. First, it reinforces the idea that the study of disability is particular to those of us identified as disabled, and it leaves dangling everyone else—there is no home in our formulation for them, except as oppressors. Second, it makes it more difficult for people who do not consider themselves disabled to find a location from which to comment on the phenomenon of disability. Third, there is no location from which to comment on the nondisabled center—the default position, similar to the white male heterosexual subject position. There is no white studies opportunity in disability studies.

As an example of the benefits of expanding this concept, consider how gender was long thought a bifurcated category, with male and female the only options. We've moved beyond that to embrace alternative ways of talking about gender and, in the process, sexual orientation, as multiply determined by desire and community and bodies and so on.

In disability studies, we are stuck with disabled and nondisabled. In our past efforts, we worked to debunk the notion of continuum and critiqued the idea that "everyone is disabled in some way." This was a strategic endeavor, and it has been enormously useful. But now we need to find a new way of talking about the place of disabled people in the universe and to find the place of disability in some universal. Maybe the issue is that disability studies needs to decide if it is about the part or about the whole. Yet, either way, the whole remains undefined.

Next, let me address some concerns about the formulation of disability and impairment, with a focus on impairment. *Impairment* is an inadequate term. Nevertheless, I am stuck using it in what I want to say next. I don't have another word to describe the forms our bodies and sensory systems take and the way those forms function.

I want to locate my discussion of the impairment/disability dilemma in the arts, a location at the nexus of impairment and disability. Disabled people's cultural expression provides an opportunity for ideas about disability to be articulated through the body—not just the content of our thoughts, but how the bodies we have can articulate new art forms and new theory.

For instance, a poet I have heard about uses a manual typewriter because it is more workable for him than a keyboard, I assume because of a mobility impairment. On his typewriter, he has the freedom to move the carriage up and down, back and forth, in ways that actively engage his body. As he writes, he manipulates the platen and the carriage and creates poetry with words that splay across the page. His manual typewriter, while ostensibly an accommodation for a mobility impairment, has become an instrument to paint words on the page. In interaction with this technology and with his ideas, his body writes a unique form of poetry.

Getting our bodies to articulate new art forms is very difficult. There are many constraints. Various things hold disabled artists

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back from expressing new forms in art—shame, absence of guideposts and examples, limited opportunity to learn, and so on. Moreover, general social constraints hold us back. Consider how all the so-called minority groups—for instance, African Americans, gays, Latinos, Asian Americans, and disabled people—have been instructed to have our comportment conform to that of the dominant group. We learn that we will be accepted and will succeed to the extent that we move, speak, and look like the majority culture. Don't act too black or too gay. Disabled people are expected to mask the behaviors that would disturb the public and certainly not to exaggerate or call attention to our odd forms or the way our forms function. Yet, in part, the art of our art is to exploit and expand on the quirkiness of our forms and to cultivate the interesting styles such bodies can produce.

One of these dilemmas was recently expressed well by a painter, a dear friend of mine and of a number of us here, Harilyn Rousso. We were talking about how the bodies that we have can articulate new art forms. The subject matter of her paintings often includes images or ideas about disability. Yet, she said, "I find it hard to allow myself to integrate the experience of my body into images. My painting teacher once asked if I could capture my instability and involuntary movements in the brushstrokes and texture of my paintings, and I explained to her, 'I've tried, but I think I've learned to pass too well.'"

What I am going to say next is not a direct answer to the situations and questions raised above. Instead, it is a probe into a way of thinking about our bodies moving in space, about technology, and ultimately about disability.

Let's use a far-flung example as a model of how we might think about bodies in space. The painting style impressionism is defined in various ways, but one definition is as follows: impressionists employ color and visible brushwork to show the dissolution of form in light and atmosphere. One of the many explanations of how impressionism came about is that with the advent of train travel, painters in increasing numbers left Paris to go to the south of France to paint. As the trains moved (more quickly than horse-drawn carriages) and light caught images and fractured those images, painters began to visualize form in more component parts than did earlier painters, who had more static views.

I have thought about this while at the Guggenheim Museum. I doubt that Frank Lloyd Wright conceptualized the grand spiral ramp as a wheelchair-access feature. When I began using a wheelchair in my early twenties, I visited the Guggenheim in a manual chair. The visceral excitement I felt that day when I descended the spiral gave me a pleasure that I had not previously experienced in my disabled state. I returned often. The first time I visited the Gugg in a power chair, about five years ago, reminded me of that initial ride, and gave me the opportunity to compare my experiences in the manual chair and the power chair—and, moreover, my experiences of art at the Gugg in the two chairs.

I am more attentive to art there when I am aboard Rufus (my power chair). In the manual chair, I tend to move more quickly because there is a continual pull downward, it takes effort to slow down and brake, and, significantly, it is great fun to let go and whoosh down the spiral. When I am in Rufus, the experience is quite different. The slope doesn't have any effect on Rufus's movement; the chair moves much as it would on a flat surface. It takes equal effort to go slow or fast, and stopping is easy. When I am moving quickly, I enjoy the building more, I notice the play of light on the walls, and I am attentive to the overall theme of the exhibit or the progression of a single artist's work over time. At a slower pace, I focus more on individual pieces.

At a quick pace, usually in the manual chair, I am less attentive to realistic paintings, particularly ones that have rich detail

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and settings and whose atmosphere and story cannot be absorbed without frontal viewing. Divining hidden meanings or interpreting symbolic elements is nearly impossible at warp speed. What does happen, though, when I coast down the spiral at a fair clip is that my eye captures, for a brief moment, swooshes of color and fragments of form that resemble fireworks exploding and then fading in the night air.

The painters on the first trains going to the south of France and I spinning down the ramp at the Guggenheim are different creatures, and we each have used our velocity for different ends. What ties these two instances together is that each demonstrates how motion affects perception. The ways that our bodies are configured and the ways that our sensory systems function all affect how we move through space and perceive the world.

Art is created by bodies—bodies emitting sounds, wielding brushes, spinning themselves through space, typing words.

I am concerned about the things that constrain our bodies. I want to give disabled people's bodies every opportunity to imprint on the page, on the canvas, on the stage, on mounds of clay—our bodies and senses as they are, making marks.

I began this last section of the paper talking about the inadequacy of the term *impairment*, in the configuration of disability and impairment. And that is where I will end. These bodies, our bodies, need a new name. A new name will give more body to our theory and, if we are lucky, put more bodies in motion.

Disability and Representation

ROSEMARIE GARLAND-THOMSON
Emory University

THE WAY WE IMAGINE DISABILITY IN AMERICA IS changing. The disability rights movement produced civil rights legislation such as the Americans with Disabilities Act of 1990 that mandates full integration and prohibits discrimination. People with disabilities are leaving the closet and the nursing home and entering workplaces, courtrooms, and public debates. Disabled people are now the largest minority group in the United States, constituting twenty percent of the United States population, according to the National Organization on Disability (www.nod.org), and increasing dramatically as baby boomers age. According to the National Center for Education Statistics, eleven percent of college undergraduates reported having a sensory, mobility, or other disability ("Note 11").

Disability permeates our national culture and conversation. A Deaf Miss America reigned; Superman became quadriplegic; Barbie came out as a wheelchair user; Gallaudet University students demanded a Deaf president; Casey Martin accessed golf tournaments with a cart; *Shine*, *Born on the Fourth of July*, *A Beautiful Mind*, *Finding Nemo*, and *Million Dollar Baby* earned Oscars; Heather Mills, an amputee fashion model and disability activist, married the Beatle Paul McCartney. The FDR Memorial in Washington, DC, got a new statue of Roosevelt using his wheelchair. The companies Kohler, Pontiac, and Crown Royal recently captured attention by featuring hip young blind people cleverly promoting sinks, cars, and whiskey. All this suggests that disability is becoming a diversity, inclusion, and civil rights issue rather

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