
Disability and Representation

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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

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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

than simply a medical problem, charity case, or personal misfortune.

Humanities scholarship is discovering disability everywhere as well. For example, the blind, mad, lame, crippled, and unusually embodied have fired the imagination and underwritten the metaphors of classic Western literature. From Sophocles to Toni Morrison, disability confers distinction on protagonists and drives narrative. The West's first literary hero, Oedipus—whose name means “swollen foot” or “injured foot”—begins a tradition of garnering literary meaning from disability that continues through Shakespeare's Richard III, Melville's monomaniacal amputee Ahab, and Faulkner's modernist monologist Benjy Compson. Canonical American literature is rich with disability imagery: Anne Bradstreet, our first poet, imagines her book a deformed child; Nathaniel Hawthorne's revengeful cuckold in *The Scarlet Letter* is disabled; Ralph Waldo Emerson offers the invalid as a contrast to his ideal American individual; Mark Twain uses deafness as humor; the category of illness is fundamental to Walt Whitman's poetic project; Edgar Allan Poe figures the gothic as disability in stories like “Hop Frog.”

To deal in images and narratives—whether they come from literature, art, film, or popular culture—is to focus on issues of representation. I mean here representation in its broadest sense, as a saturating of the material world with meaning. In this sense, disability is a story we tell about bodies. It is a received yet pliable story that changes over time and across place. Representation structures rather than reflects reality. The way we imagine disability through images and narratives determines the shape of the material world, the distribution of resources, our relationships with one another, and our sense of ourselves.

The aim of much disability studies is to reimagine disability, to reveal how the storied quality of disability invents and reinvents the world we share. Disability studies challenges

our collective representation of disability, exposing it as an exclusionary and oppressive system rather than the natural and appropriate order of things.

Let me offer two brief examples of how representations can reimagine disability. Recently I heard a National Public Radio music review of the little-known American composer Thomas Greene Wiggins. Listening to the broad outlines of this composer's life, I recognized that Thomas Greene Wiggins was the proper name of the freak-show performer known as “Blind Tom,” whom I myself had written about because he was the subject of a nineteenth-century sentimental story by Rebecca Harding Davis. What struck me about this respectful review was that the moniker “Blind Tom” was never used, although his slave status, blindness, and apparent cognitive disability were mentioned. Moreover, in all the research I'd done on this disabled performer, I had never read a reference to him as Thomas Greene Wiggins, let alone as an “American composer.” What I realized from this review is that the transformation of knowledge wrought by the civil rights and disability rights movements recast what the nineteenth century imagined as the droll curiosity “Blind Tom” into “an American composer,” one whom the *New York Times* (Riis) called “the most celebrated black concert artist of the 19th century.” This is exactly what disability studies does: it recognizes the contributions of a group of people who have historically been dismissed because of deeply rooted cultural bias—in Wiggins's case, both as a black man and as a person with disabilities.

Here is another story about reimagining disability. Both the impressionist artist Claude Monet and the leader of contemporary photographic realism, Chuck Close, developed significant disabilities later in their careers. Monet became almost blind, and Close became paralyzed. Each artist was forced by his disability to change both the way he painted and the content of his art. Monet's aesthetic

shift from more representational painting to more intensely impressionistic, literally fuzzier, renderings of his famous gardens and bridges resulted from his diminished sight, while Close's celebrated move away from photographic realism toward an almost cubist rendering of his large-scale portraits resulted from his loss of manual dexterity. In other words, disability enabled what we think of as artistic evolution. Monet and Close did not overcome their disabilities, but, rather, they accommodated their disabilities, and their art changed. They were great artists not in spite of disability but because of disability. This is the story we need to understand.

Reimagining disability in this way accomplishes important cultural work. First, it shows disability as a significant human experience that occurs in every society, every family, and most every life. Second, it helps us accept that fact. Third, it helps integrate disability into our knowledge of human experience and history and to integrate disabled people into our culture.

Disability studies points out that ability and disability are not so much a matter of the capacities and limitations of bodies but more about what we expect from a body at a particular moment and place. Stairs disable people who need to use wheelchairs to get around, but ramps let them go places freely. Reading the print in a phone book or deciphering the patterns on a computer screen is an ability that our moment demands. So if our minds can't make sense of the pattern or our eyes can't register the print, we become disabled. In other words, we are expected to look, act, and move in certain ways so we'll fit into the built and attitudinal environment. If we don't, we become disabled.

Disability studies reminds us that all bodies are shaped by their environments from the moment of conception. We transform constantly in response to our surroundings and register history on our bodies. The changes that occur when body encounters world are

what we call disability. The human body varies tremendously in its forms and functions. Our bodies need care; we all need assistance to live. Every life evolves into disability, making it perhaps the essential characteristic of being human.

In spite of or perhaps because of this, the subject of disability both discomforts and compels many people. Even though those of us with disabilities are a visible and vocal constituency, we are also a profoundly economically disenfranchised and excluded group. Thriving alongside the positive images and political empowerment I mentioned earlier are discriminatory attitudes and practices. Our society emphatically denies vulnerability, contingency, and mortality. Modernity pressures us relentlessly toward standardizing bodies, a goal that is now largely accomplishable in the developed world through technological and medical interventions that materially rationalize our bodies under the banner of progress and improvement. We are told that if we buy the right products, cultivate the right habits, pay careful attention, and use the most sophisticated medical technology, we can banish disability from our lives. Strong disincentives such as social stigma and a sense of somehow having failed to "overcome" or "beat" life's inevitable limitations pressure us not to identify ourselves as persons with disabilities. We enact often virulent measures to deny, avoid, and eliminate disability and other forms of human variation we don't value. Despite the popular call for diversity, a deep and seldom-challenged project of creating bodily uniformity marches forward in practices such as genetic engineering, selective abortion, reproductive technology, so-called physician-assisted suicide, surgical normalization, aesthetic-standardization procedures, and ideologies of health and fitness. All these practices are supported by a kind of new eugenics that aims to regularize our bodies. Although we value biodiversity in our environment, we devalue physical and mental variety. In short,

we expect medicine to wipe away all disability. As a consequence, when disability enters our lives, often our only available responses are silence, denial, shame, or determined and desperate vows to “fight it.” Seldom do we imagine disability as an aspect of all lives that our society, government, and community should accommodate and include.

My work is impelled by the question of how representation can affect social justice. What would happen if our society fully recognized and validated human variation? If we cultivated rather than reduced this rich distinctiveness? How would the public landscape change if the widest possible diversity of human forms, functions, and behaviors were fully accommodated? How would such an understanding alter our collective sense of what is beautiful and proper? What would be the political significance of such inclusion? I argue for applying the vibrant logic of biodiversity to humans. Such a logic reimagines a public sphere that values and makes a tenable space for the kinds of bodies variously considered old, retarded, crippled, blind, deaf, abnormal, ugly, deformed, or excessive.

The theologian and sociologist Nancy Eiesland has argued that, in addition to legislative, economic, and social changes, achieving equality for people with disabilities depends on cultural “resymbolization” (98). Eiesland asserts that the way we imagine disability and disabled people must shift for real social change to occur. Whereas Eiesland’s work resymbolizes our conceptions of disability in religious iconography, my current work analyzes representations that resymbolize disability in another cultural arena: that of advertising and fashion photography.

While I can’t detail the complexities of my argument, I want to offer some of these visual reimaginings of disability. Until the civil rights understanding of disability opened the door to political action and consumer culture, the only public images of people with disabilities were medical photographs and pub-

lic charity campaigns. For instance, a 1949 March of Dimes poster shows an appealing little girl stepping out of her wheelchair into the supposed redemption of walking: “Look! I can walk again,” the text proclaims, while also charging the viewers with the responsibility of assuring her future ambulation (fig. 1). A paternalistic sentimentality fuses here with the medicalization of disability to elicit money. The ideology of cure and the mandate for normalcy intertwine, crowding out any possible narrative of accommodating rather than eliminating disability.

In contrast, a post-Americans with Disabilities Act image moves disability from the private medical realm into the public arena of consumer culture (fig. 2). This conventional, stylized, high-fashion shot features a typical female model: slender, white, blond, clad in a black evening gown—and accompanied by her service dog. The juxtaposition of the elite body of a visually normative fashion model

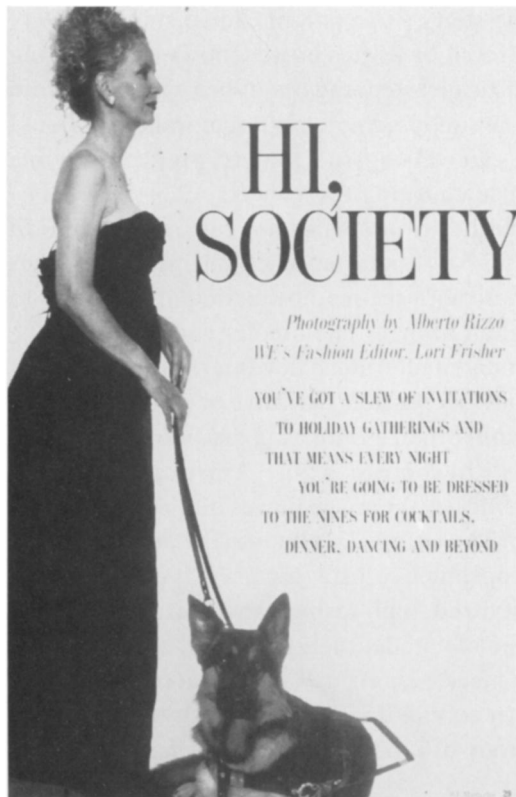
FIG. 1

Reproduced by permission of the March of Dimes Birth Defects Foundation.



FIG. 2

We Magazine.
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permission.

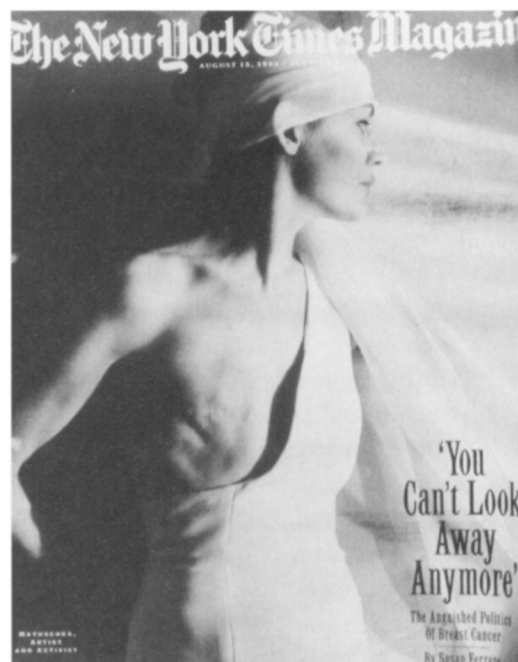


with the mark of disability forces the viewer to reconfigure assumptions about what constitutes the attractive, the desirable, and the livable life. Such images of disabled people as consumer citizens do the cultural work of integrating a previously excluded group into the dominant order. This form of what I call *cripsploitation* may be inadvertently progressive. As one disabled actor quipped, “The Adonis in a wheelchair is better than the whimpering victim in a corner” (qtd. in Haller and Ralph 9–10).

To conclude, I offer two images that visually reimagine disability. Both are covers of the *New York Times Magazine*, and both draw from the visual conventions and contexts of commercial fashion photography to do their cultural work. The first is a 1993 image of the fashion model Matushka, boldly exposing her mastectomy-scarred body as a source of pride and as a display of beauty (fig. 3). The text reads, “You Can’t Look Away Anymore.” This

FIG. 3

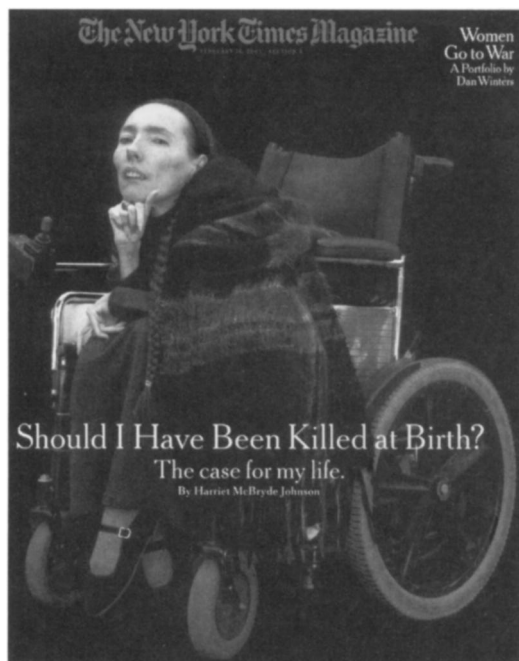
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intrepid portrait is a political act that visually deconstructs the normalized body that ableist beauty culture presents to us. Matushka’s body presents disability as part of the range of human variation and experience, as the typical rather than the atypical, the beautiful rather than the grotesque.

Ten years later, another image of disability appears on the cover of the *New York Times Magazine*. The arresting portrait of Harriet McBryde Johnson, disability rights activist and lawyer, portrays her as charismatic rather than cute, ironic rather than pathetic (fig. 4). And she certainly is not straining to rise out of her wheelchair into an ableist fantasy of ambulation. The photo answers the rhetorical question sprawled across the cover: “Should I Have Been Killed at Birth?” This is what a life worth living looks like, the picture avows.

The shots of Matushka and Johnson refuse the traditional visual rhetorics that present disability as sentimental, inspirational, curable, shameful, or disposable. Instead these photographs evoke the visual conventions of commercial fashion photography to endow their subjects with authority and grace



and to represent disability as a tenable and valued way of being in the world.

Such resymbolization contributes to the project of social justice. Because our pre-

vailing representations constrict disability's complexities, they not only restrict the lives and govern the bodies of people we think of as disabled but also limit the imagination of those who think of themselves as non-disabled. Visual reimaginings such as these begin to fulfill the promise of an egalitarian order.

FIG. 4

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Disability: The Next Wave or Twilight of the Gods?

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IN THE LAST TEN YEARS, DISABILITY STUDIES has become a major field of academic study. Many people are responsible for this happening—people with disabilities, family members and partners, activists and supporters. They have done the hard work to make the issue of disability visible and discussable. While a thriving field of disability studies had been developing since the 1960s (and earlier if we consider the work of considerable numbers of Deaf scholars, educators, and activists from the nineteenth century on), that work was mainly in the areas of the social sciences, applied health sciences, legal rights, and job

discrimination. Disability studies in the humanities is a relatively recent phenomenon.

My aim today is not to rehearse the history of this phenomenon. I am sure many others will discuss the high points and touchstones. I would just add that disability studies seems to have arrived, and this conference is an important event in that arrival. Unlike, for example, the famous Johns Hopkins conference