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## *Disability, Identity, and Representation: An Introduction*

### The Disabled Figure in Culture

In its broadest sense, this book investigates how representation attaches meanings to bodies. Although much recent scholarship explores how difference and identity operate in such politicized constructions as gender, race, and sexuality, cultural and literary criticism has generally overlooked the related perceptions of corporeal otherness we think of variously as "monstrosity," "mutilation," "deformation," "crippledness," or "physical disability."<sup>1</sup> Yet the physically extraordinary figure these terms describe is as essential to the cultural project of American self-making as the varied throng of gendered, racial, ethnic, and sexual figures of otherness that support the privileged norm. My purpose here is to alter the terms and expand our understanding of the cultural construction of bodies and identity by reframing "disability" as another culture-bound, physically justified difference to consider along with race, gender, class, ethnicity, and sexuality. In other words, I intend to introduce such figures as the cripple, the invalid, and the freak into the critical conversations we devote to deconstructing figures like the mulatto, the primitive, the queer, and the lady. To denaturalize the cultural encoding of these extraordinary bodies, I go beyond assailing stereotypes to interrogate the conventions of representation and unravel the complexities of identity production within social narratives of bodily differences. In accordance with postmodernism's premise that the margin constitutes the center, I probe the peripheral so as to view the

whole in a fresh way. By scrutinizing the disabled figure as the paradigm of what culture calls deviant, I hope to expose the assumptions that support seemingly neutral norms. Therefore, I focus here on how disability operates in culture and on how the discourses of disability, race, gender, and sexuality intermingle to create figures of otherness from the raw materials of bodily variation, specifically at sites of representation such as the freak show, sentimental fiction, and black women's liberatory novels. Such an analysis furthers our collective understanding of the complex processes by which *all* forms of corporeal diversity acquire the cultural meanings undergirding a hierarchy of bodily traits that determines the distribution of privilege, status, and power.

One of this book's major aims is to challenge entrenched assumptions that "able-bodiedness" and its conceptual opposite, "disability," are self-evident physical conditions. My intention is to defamiliarize these identity categories by disclosing how the "physically disabled" are produced by way of legal, medical, political, cultural, and literary narratives that comprise an exclusionary discourse. Constructed as the embodiment of corporeal insufficiency and deviance, the physically disabled body becomes a repository for social anxieties about such troubling concerns as vulnerability, control, and identity. In other words, I want to move disability from the realm of medicine into that of political minorities, to recast it from a form of pathology to a form of ethnicity. By asserting that disability is a reading of bodily particularities in the context of social power relations, I intend to counter the accepted notions of physical disability as an absolute, inferior state and a personal misfortune. Instead, I show that disability is a representation, a cultural interpretation of physical transformation or configuration, and a comparison of bodies that structures social relations and institutions. Disability, then, is the attribution of corporeal deviance—not so much a property of bodies as a product of cultural rules about what bodies should be or do.

This socially contextualized view of disability is evident, for example, in the current legal definition of disability established by the Americans with Disabilities Act of 1990. This landmark civil rights legislation acknowledges that disability depends upon perception and subjective judgment rather than on objective bodily states: after identifying disability as an "impairment that substantially limits one or more of the major life activities," the law concedes that being legally disabled is also a matter of "being regarded as having such an impairment."<sup>2</sup> Essential but implicit to this definition is that both "impairment" and "limits" depend on comparing individual bodies with unstated but determining norms, a hypothetical set of guidelines for corporeal form and function arising from cultural expectations about how human beings should look and

act. Although these expectations are partly founded on physiological facts about typical humans—such as having two legs with which to walk upright or having some capacity for sight or speech—their sociopolitical meanings and consequences are entirely culturally determined. Stairs, for example, create a functional "impairment" for wheelchair users that ramps do not. Printed information accommodates the sighted but "limits" blind persons. Deafness is not a disabling condition in a community that communicates by signing as well as speaking.<sup>3</sup> People who cannot lift three hundred pounds are "able-bodied," whereas those who cannot lift fifty pounds are "disabled." Moreover, such culturally generated and perpetuated standards as "beauty," "independence," "fitness," "competence," and "normalcy" exclude and disable many human bodies while validating and affirming others. Even though the law attempts to define disability in terms of function, the meanings attached to physical form and appearance constitute "limits" for many people—as evidenced, for example, by "ugly laws," some repealed as recently as 1974, that restricted visibly disabled people from public places.<sup>4</sup> Thus, the ways that bodies interact with the socially engineered environment and conform to social expectations determine the varying degrees of disability or able-bodiedness, of extra-ordinariness or ordinariness.

Consequently, the meanings attributed to extraordinary bodies reside not in inherent physical flaws, but in social relationships in which one group is legitimated by possessing valued physical characteristics and maintains its ascendancy and its self-identity by systematically imposing the role of cultural or corporeal inferiority on others. Representation thus simultaneously buttresses an embodied version of normative identity and shapes a narrative of corporeal difference that excludes those whose bodies or behaviors do not conform. So by focusing on how representation creates the physically disabled figure in American culture, I will also clarify the corresponding figure of the normative American self so powerfully etched into our collective cultural consciousness. We will see that the disabled figure operates as the vividly embodied, stigmatized other whose social role is to symbolically free the privileged, idealized figure of the American self from the vagaries and vulnerabilities of embodiment.

One purpose of this book, then, is to probe the relations among social identities—valued and devalued—outlined by our accepted hierarchies of embodiment. Corporeal departures from dominant expectations never go uninterpreted or unpunished, and conformities are almost always rewarded. The narrative of deviance surrounding bodies considered different is paralleled by a narrative of universality surrounding bodies that correspond to notions of the ordinary or the supralative. Cultural dichotomies do their evaluative work: this

body is inferior and that one is superior; this one is beautiful or perfect and that one is grotesque or ugly. In this economy of visual difference, those bodies deemed inferior become spectacles of otherness while the unmarked are sheltered in the neutral space of normalcy. Invested with meanings that far outstrip their biological bases, figures such as the cripple, the quadraon, the queer, the outsider, the whore are taxonomical, ideological products marked by socially determined stigmata, defined through representation, and excluded from social power and status. Thus, the cultural other and the cultural self operate together as opposing twin figures that legitimate a system of social, economic, and political empowerment justified by physiological differences.<sup>5</sup>

As I examine the disabled figure, I will also trouble the mutually constituting figure this study coins: the *normate*. This neologism names the veiled subject position of cultural self; the figure outlined by the array of deviant others whose marked bodies shore up the *normate's* boundaries.<sup>6</sup> The term *normate* usefully designates the social figure through which people can represent themselves as definitive human beings. *Normate*, then, is the constructed identity of those who, by way of the bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them. If one attempts to define the *normate* position by peeling away all the marked traits within the social order at this historical moment, what emerges is a very narrowly defined profile that describes only a minority of actual people. Erving Goffman, whose work I discuss in greater detail later, observes the logical conclusion of this phenomenon by noting wryly that there is "only one complete unblushing male in America: a young, married, white, urban, northern, heterosexual, Protestant father of college education, fully employed, of good complexion, weight and height, and a recent record in sports."<sup>7</sup> Interestingly, Goffman takes for granted that femaleness has no part in his sketch of a *normative* human being. Yet this image's ubiquity, power, and value resonate clearly. One testimony to the power of the *normate* subject position is that people often try to fit its description in the same way that Cinderella's stepsisters attempted to squeeze their feet into her glass slipper. Naming the figure of the *normate* is one conceptual strategy that will allow us to press our analyses beyond the simple dichotomies of male/female, white/black, straight/gay, or able-bodied/disabled so that we can examine the subtle interrelations among social identities that are anchored to physical differences.

The *normate* subject position emerges, however, only when we scrutinize the social processes and discourses that constitute physical and cultural otherness. Because figures of otherness are highly marked in power relations, even as they are marginalized, their cultural visibility as deviant obscures and

neutralizes the *normative* figure that they legitimate. To analyze the operation of disability, it is essential then to theorize at length—as I do in part I—about the processes and assumptions that produce both the *normate* and its discordant companion figures. However, I also want to complicate any simple dichotomy of self and other, *normate* and deviant, by centering part 2 of the book on how representations sometimes deploy disabled figures in complex, triangulated relationships or surprising alliances, and on how these representations can be both oppressive and liberating. In part 2, my examination of the way disability is constituted by the freak show, sentimental fiction, and black women's liberatory novels focuses on female figures for two reasons: first, because the links between disability and gender otherness need investigating, and second, because the non-*normate* status accorded disability feminizes all disabled figures. What I uncover by closely analyzing these sites of representation suggests that disability functions as a multivalent trope, though it remains the mark of otherness. Although centering on disabled figures illuminates the processes that sort and rank physical differences into normal and abnormal, at the same time, these investigations suggest the possibility of potentially positive, complicating interpretations. In short, by examining disability as a reading of the body that is inflected by race, ethnicity, and gender, I hope to reveal possibilities for signification that go beyond a monologic interpretation of corporeal difference as deviance. Thus, by first theorizing disability and then examining several sites that construct it, I can uncover the complex ways that disability intersects with other social identities to produce the extraordinary and the ordinary figures who haunt us all.

### The Disabled Figure in Literature

The discursive construct of the disabled figure, informed more by received attitudes than by people's actual experience of disability, circulates in culture and finds a home within the conventions and codes of literary representation. As Paul Robinson notes, "the disabled, like all minorities, have . . . existed not as subjects of art, but merely as its occasions."<sup>8</sup> Disabled literary characters usually remain on the margins of fiction as uncomplicated figures or exotic aliens whose bodily configurations operate as spectacles, eliciting responses from other characters or producing rhetorical effects that depend on disability's cultural resonance. Indeed, main characters almost never have physical disabilities. Even though mainstream critics have long discussed, for example, the implications of Twain's Jim for blacks, when literary critics look at disabled characters, they often interpret them metaphorically or aesthetically, reading

them without political awareness as conventional elements of the sentimental, romantic, Gothic, or grotesque traditions.<sup>8</sup>

The disparity between "disabled" as an attributed, decontextualizing identity and the perceptions and experiences of real people living with disabilities suggests that this figure of otherness emerges from positioning, interpreting, and conferring meaning upon bodies. Representation yields cultural identities and categories, the given paradigms Alfred Schutz calls "recipes," with which we communally organize raw experience and routinize the world.<sup>9</sup> Literary conventions even further mediate experience that the wider cultural matrix, including literature itself, has already informed. If we accept the convention that fiction has some mimetic relation to life, we grant it power to further shape our perceptions of the world, especially regarding situations about which we have little direct knowledge. Because disability is so strongly stigmatized and is countered by so few mitigating narratives, the literary traffic in metaphors often misrepresents or flattens the experience real people have of their own or others' disabilities.

I therefore want to explicitly open up the gap between disabled people and their representations by exploring how disability operates in texts. The rhetorical effect of representing disability derives from social relations between people who assume the normate position and those who are assigned the disabled position. From folktales and classical myths to modern and postmodern "grotesques," the disabled body is almost always a freakish spectacle presented by the mediating narrative voice. Most disabled characters are enveloped by the otherness that their disability signals in the text. Take, as a few examples, Dickens's pathetic and romanticized Tiny Tim of *A Christmas Carol*, J. M. Barrie's villainous Captain Hook from *Peter Pan*, Victor Hugo's Gothic Quasimodo in *The Hunchback of Notre Dame*, D. H. Lawrence's impotent Clifford Chatterley in *Lady Chatterley's Lover*, and Tennessee Williams's long-suffering Laura Wingfield from *The Glass Menagerie*. The very act of representing corporeal otherness places them in a frame that highlights their differences from ostensibly normate readers. Although such representations refer to actual social relations, they do not of course reproduce those relations with mimetic fullness. Characters are thus necessarily rendered by a few determining strokes that create an illusion of reality far short of the intricate, undifferentiated, and uninterpreted context in which real people exist. Like the freak shows that I will discuss in chapter 3, textual descriptions are overdetermined: they invest the traits, qualities, and behaviors of their characters with much rhetorical influence simply by omitting—and therefore erasing—other factors or traits that might mitigate or complicate the delineations. A disability func-

tions only as visual difference that signals meanings. Consequently, literary texts necessarily make disabled characters into freaks, stripped of normalizing contexts and engulfed by a single stigmatic trait.

Not only is the relationship between text and world not exact, but representation also relies upon cultural assumptions to fill in missing details. All people construct interpretive schemata that make their worlds seem knowable and predictable, thus producing perceptual categories that may harden into stereotypes or caricatures when communally shared and culturally inculcated.<sup>10</sup> As Aristotle suggests in the *Poetics*, literary representation depends more on probability—what people take to be accurate—than on reality. Caricatures and stereotypical portrayals that depend more on gesture than complexity arise necessarily out of this gap between representation and life. Stereotypes in life become tropes in textual representation. For example, Marianna Torgovnick describes the trope of the primitive as a discursive construct in the broadest sense, a "world" that has been "structured by sets of images and ideas that have slipped from their original metaphoric status to control perceptions of [actual] primitives."<sup>11</sup> Such portrayals invoke, reiterate, and are reinforced by cultural stereotypes. A highly stigmatized characteristic like disability gains its rhetorical effectiveness from the powerful, often mixed responses that real disabled people elicit from readers who consider themselves normates. The more the literary portrayal conforms to the social stereotype, the more economical and intense is the effect; representation thus exaggerates an already highlighted physical difference. Moreover, Western tradition posits the visible world as the index of a coherent and just invisible world, encouraging us to read the material body as a sign invested with transcendent meaning. In interpreting the material world, literature tends to imbue any visual differences with significance that obscures the complexity of their bearers.

Besides stripping any normalizing context away from disability, literary representation sets up static encounters between disabled figures and normate readers, whereas real social relations are always dynamic. Focusing on a body feature to describe a character throws the reader into a confrontation with the character that is predetermined by cultural notions about disability. With the notable exception of autobiographical texts—such as Audre Lorde's *Zami*, which I address in the last chapter—representation tends to objectify disabled characters by denying them any opportunity for subjectivity or agency. The plot or the works rhetorical potential usually benefits from the disabled figure remaining other to the reader—identifiably human but resolutely different. How could Ahab operate effectively if the reader were allowed to see him as an ordinary fellow instead of as an icon of monomaniacal revenge—if his dis-

ability lost its transcendent meaning? What would happen to the pure pity generated for Tiny Tim if he were portrayed as sometimes naughty, like a "normal" child? Thus the rhetorical function of the highly charged trait fixes relations between disabled figures and their readers. If disabled characters acted, as real people with disabilities often do, to counter their stigmatized status, the rhetorical potency of the stigma would be mitigated or lost. If Hawthorne's Chillingworth made many friends, for instance, or appeared lovable to Hester, his role in *The Scarlet Letter* would be diminished. If Flannery O'Connor's Hulga Hopewell were pretty, cheerful, and one-legged instead of ugly and bitter, "Good Country People" would fail. So, like *tableaux vivants*, beauty pageants, and freak shows—all related forms of representation grounded in the conventions of spectacle—literary narratives of disability usually depend on the objectification of the spectacle that representation has created.

### The Gap Between Representation and Reality

Whether one lives with a disability or encounters someone who has one, the actual experience of disability is more complex and more dynamic than representation usually suggests. Just one example illustrates the skill disabled people often must learn in managing social encounters. Initial or casual exchanges between normate and disabled people differ markedly from the usual relations between readers and disabled characters. In a first encounter with another person, a tremendous amount of information must be organized and interpreted simultaneously: each participant probes the explicit for the implicit, determines what is significant for particular purposes, and prepares a response that is guided by many cues, both subtle and obvious. When one person has a visible disability, however, it almost always dominates and skews the normate's process of sorting out perceptions and forming a reaction.<sup>12</sup> The interaction is usually strained because the nondisabled person may feel fear, pity, fascination, repulsion, or merely surprise, none of which is expressible according to social protocol. Besides the disconcerting dissonance between experienced and expressed reaction, a nondisabled person often does not know how to act toward a disabled person: how or whether to offer assistance; whether to acknowledge the disability; what words, gestures, or expectations to use or avoid. Perhaps most destructive to the potential for continuing relations is the normate's frequent assumption that a disability cancels out other qualities, reducing the complex person to a single attribute. This uncertainty and discord make the encounter especially stressful for the nondisabled person unaccustomed to disabled people. The disabled person may be anxious

about whether the encounter will be too uncomfortable for either of them to sustain and may feel the ever-present threat of rejection. Even though disability threatens to snip the slender thread of sociability, most physically disabled people are skilled enough in these encounters to repair the fabric of the relation so that it can continue.

To be granted fully human status by normates, disabled people must learn to manage relationships from the beginning. In other words, disabled people must use charm, intimidation, ardor, deference, humor, or entertainment to relieve nondisabled people of their discomfort. Those of us with disabilities are supplicants and minstrels, striving to create valued representations of ourselves in our relations with the nondisabled majority. This is precisely what many newly disabled people can neither do nor accept; it is a subtle part of adjustment and often the most difficult.<sup>13</sup> If such efforts at reparation are successful, disabled people neutralize the initial stigma of disability so that relationships can be sustained and deepened. Only then can other aspects of personhood emerge and expand the initial focus so that the relationship becomes more comfortable, more broadly based, and less affected by the disability. Only then can each person emerge as multifaceted, whole. If, however, disabled people pursue normalization too much, they risk denying limitations and pain for the comfort of others and may edge into the self-betrayal associated with "passing."

This is not to suggest that all forms of disability are interchangeable or that all disabled people experience their bodies or negotiate their identities in the same ways. Indeed, it is precisely the variation among individuals that cultural categories trivialize and that representation often distorts. Disability is an overarching and in some ways artificial category that encompasses congenital and acquired physical differences, mental illness and retardation, chronic and acute illnesses, fatal and progressive diseases, temporary and permanent injuries, and a wide range of bodily characteristics considered disfiguring, such as scars, birthmarks, unusual proportions, or obesity. Even though the prototypical disabled person posited in cultural representations never leaves a wheelchair, is totally blind, or profoundly deaf, most of the approximately forty million Americans with disabilities have a much more ambiguous relationship to the label. The physical impairments that render someone "disabled" are almost never absolute or static; they are dynamic, contingent conditions affected by many external factors and usually fluctuating over time. Some conditions, like multiple sclerosis or arthritis, are progressive and chronic; others, such as epilepsy, can be acute. Even seemingly static disabilities like amputation affect activities differently, depending on the condition of the rest of the body.

Of course, everyone is subject to the gradually disabling process of aging.

The fact that we will all become disabled if we live long enough is a reality many people who consider themselves able-bodied are reluctant to admit.<sup>14</sup> As physical abilities change, so do individual needs, and the perception of those needs. The pain that often accompanies or causes disability also influences both the degree and the perception of impairment. According to Elaine Scarry, because pain is invisible, unverifiable and unrepresentable, it is often subject to misattribution or denial by those who are not experiencing it.<sup>15</sup> Disability, then, can be painful, comfortable, familiar, alienating, bonding, isolating, disturbing, endearing, challenging, infuriating, or ordinary. Embedded in the complexity of actual human relations, it is always more than the disabled figure can signify.

That anyone can become disabled at any time makes disability more fluid, and perhaps more threatening, to those who identify themselves as normates than such seemingly more stable marginal identities as femaleness, blackness, or nondominant ethnic identities.<sup>16</sup> In addition, the time and way in which one becomes disabled influence its perception, as do the ways one incorporates disability into one's sense of self or resists it. For instance, the gradual disablement of aging or a progressive illness may not be considered a disability at all. In contrast, a severe, sudden impairment, as from an accident, is almost always experienced as a greater loss than is a congenital or gradual disability, which does not demand adjustment so abruptly. A disability's degree of visibility also affects social relations. An invisible disability, much like a homosexual identity, always presents the dilemma of whether or when to come out or to pass. One must always anticipate the risk of hinting a new relationship by announcing an invisible impairment or the equal hazard of surprising someone by revealing a previously undisclosed disability. The distinction between formal and functional aspects of a disability affects its perception as well. People whose disability is primarily functional but not visible often are accused of malingering or of disappointing expectations about their physical capabilities. Yet those whose disabilities are largely formal often are considered incapable of things they can easily do. Furthermore, formal conditions such as facial disfigurement, scarring, birthmarks, obesity, and visual or hearing impairments corrected with mechanical aids are usually socially disabling, even though they entail almost no physical dysfunction. Moreover, as the history of the freak show that appears in chapter 3 reveals, no firm distinction exists between primarily formal disabilities and racial physical features considered atypical by dominant, white standards.

Although categories such as ethnicity, race, and gender are based on shared traits that result in community formation, disabled people seldom consider themselves a group. Little somatic commonality exists among people with dif-

ferent kinds of disabilities because needs and situations are so diverse. A blind person, an epileptic, a paraplegic, a deaf person, and an amputee, for example, have no shared cultural heritage, traditional activities, or common physical experience. Only the shared experience of stigmatization creates commonality. Having been acculturated similarly to everyone else, disabled people also often avoid and stereotype one another in attempting to normalize their own social identities. Moreover, many disabled people at one time considered themselves nondisabled and may have had very limited contact with disabled people before joining their group. As with all culturally imposed categories extrapolated from biological differences, the identity has a forced quality that levels intragroup variations. For example, the now crumbling institution of "special" education enacts this cultural impulse toward ghettoization by segregating people with disabilities from nondisabled students regardless of individual needs. Finally, most disabled people are surrounded by nondisabled families and communities in which disabilities are unanticipated and almost always perceived as calamitous. Unlike the ethnically grouped, but more like gays and lesbians, disabled people are sometimes fundamentally isolated from each other, existing often as aliens within their social units.<sup>17</sup>

Yet representation frequently obscures these complexities in favor of the rhetorical or symbolic potential of the prototypical disabled figure, who often functions as a lightning rod for the pity, fear, discomfort, guilt, or sense of normalcy of the reader or a more significant character. I intend here to shift from this usual interpretive framework of aesthetics and metaphor to the critical arena of cultural studies to denaturalize such representations. By examining the "disabled figure," rather than discussing the "grotesque" or "cripple" or "deformed," I hope to catapult this analysis out of a purely aesthetic context and into a political one. By opening up a critical gap between disabled figures as fashioned corporeal others whose bodies carry social meaning and actual people with atypical bodies in real-world social relations, I suggest that representation informs the identity—and often the fate—of real people with extraordinary bodies.

### An Overview and a Manifesto

In a sense, this book is a manifesto that places disability studies within a humanities context. Although disability studies has developed as a subfield of scholarly inquiry in the academic fields of sociology, medical anthropology, special education, and rehabilitative medicine, almost no studies in the humanities explicitly situate disability within a politicized, social constructionist