

**CLAIMING DISABILITY**  
KNOWLEDGE AND IDENTITY

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NEW YORK UNIVERSITY PRESS  
NEW YORK AND LONDON

## RECLAMATION

The curriculum is a manifest expression of the cultural values just as laws are manifest expressions of what a society deems to be right or wrong behavior. Kliebard 1992, 199

Our educational institutions . . . are, not alone but preeminently, the shapers and guardians of cultural memory and hence of cultural meanings. Minnich 1990, 12

It was, at one time, seamless. There were no disjunctures between the dominant cultural narrative of disability and the academic narrative. They supported and defended each other. But in the past twenty years, as the flaws in the civic response to disability have been exposed, as changing social structures and legislative victories reassemble that narrative, the academic tale slips further behind. It neither reflects the change that has occurred nor offers the space or the means to think in more progressive ways about disability.

Enter disability studies: a location and a means to think critically about disability, a juncture that can serve both academic discourse and social change. Disability studies provides the means to hold aca-

demics accountable for the veracity and the social consequences of their work, just as activism has served to hold the community, the education system, and the legislature accountable for disabled people's compromised social position.

This book examines disability studies as a field of inquiry, its historical roots, present configuration, and explanatory value. Disability studies takes for its subject matter not simply the variations that exist in human behavior, appearance, functioning, sensory acuity, and cognitive processing but, more crucially, the meaning we make of those variations. "The field explores the critical divisions our society makes in creating the normal versus the pathological, the insider versus the outsider, or the competent citizen versus the ward of the state.

It is an interdisciplinary field based on a sociopolitical analysis of disability and informed both by the knowledge base and methodologies used in the traditional liberal arts, and by conceptualizations and approaches developed in areas of the new scholarship. Disability studies has emerged as a logical base for examination of the construction and function of "disability." These scholarly explorations and the initiatives undertaken by the disability rights movement have resulted in new paradigms used to understand disability as a social, political, and cultural phenomenon.

<sup>†</sup>Disability studies has arisen in the past twenty years to focus an organized critique on the constricted, inadequate, and inaccurate conceptualizations of disability that have dominated academic inquiry. Above all, the critique includes a challenge to the notion that disability is primarily a medical category. Consequently, disability studies contests the current academic division of labor in which the study of the phenomenon rests in the specialized applied fields (rehabilitation, special education, health, and so on) and the rest of the academy is largely exempt from meaningful inquiry into the subject of disability. By refusing the medicalization of disability and by reframing disability as a designation having primarily social and political significance, disability studies points to the inadequacy of the en-

tire curriculum with respect to the study of disability. The fault lines that have been exposed stretch from one end of the curriculum to the other: from cultural studies to American studies, from women's studies to African American studies, from biology to literary criticism, from history to psychology, and from special education to philosophy.

Despite the steady growth of scholarship and courses, particularly in the past five years, the field of disability studies is even more marginal in the academic culture than disabled people are in the civic culture. The enormous energy society expends keeping people with disabilities sequestered and in subordinate positions is matched by the academy's effort to justify that isolation and oppression.

Disabled people, and I will immediately identify myself as one, are a group only recently entering everyday civic life. A host of factors have typically screened us from public view. We have been hidden—whether in the institutions that have confined us, the attics and basements that sheltered our family's shame, the "special" schools and classrooms designed to solve the problems we are thought to represent, or riding in segregated transportation, those "invalid" coaches, that shuttle disabled people from one of these venues to another. The public has gotten so used to these screens that as we are now emerging, upping the ante on the demands for a truly inclusive society, we disrupt the social order. We further confound expectations when we have the temerity to emerge as forthright and resourceful people, nothing like the self-loathing, docile, bitter, or insentient fictional versions of ourselves the public is more used to.

We have come out not with brown woollen lap robes over our withered legs or dark glasses over our pale eyes but in shorts and sandals, in overalls and business suits, dressed for play and work—straightforward, unmasked, and unapologetic.<sup>1</sup> We are, as Crosby, Stills, and Nash told their Woodstock audience, letting our "freak flag fly." And we are not only the high-toned wheelchair athletes seen in recent television ads but the gangly, pudgy, lumpy, and bumpy of

us, declaring that shame will no longer structure our wardrobe or our discourse. We are everywhere these days, wheeling and loping down the street, tapping our canes, sucking on our breathing tubes, following our guide dogs, puffing and sipping on the mouth sticks that propel our motorized chairs. We may drool, hear voices, speak in staccato syllables, wear catheters to collect our urine, or live with a compromised immune system. We are all bound together, not by this list of our collective symptoms but by the social and political circumstances that have forged us as a group. We have found one another and found a voice to express not despair at our fate but outrage at our social positioning. Our symptoms, though sometimes painful, scary, unpleasant, or difficult to manage, are nevertheless part of the dailiness of life. They exist and have existed in all communities throughout time. What we rail against are the strategies used to deprive us of rights, opportunity, and the pursuit of pleasure.

It is our closeted selves that have been naturalized within the academic curriculum. Even a cursory review of the curriculum reveals only patronizing and distorted representations of disability, and these are left largely unexamined and unchallenged. But minor housecleaning will not rid out the deeper structural elements, the scholarly conventions, and theoretical underpinnings within which those representations are deemed valid and useful. A closer look reveals problems in both the structure and content of the curriculum, predicated on a narrowly conceived interpretation of disability.

The field of disability studies is now at a critical juncture; scholars and activists have demonstrated that disability is socially constructed to serve certain ends, but now it behooves us to demonstrate how knowledge about disability is socially produced to uphold existing practices. I attempt to capture this critical moment here in a stop-action photo that reveals that terrain. Yet this is also a strategic endeavor not only to mark the moment and the territory but also to stake out the contested borders where the resistance to the ideas is strongest.

Having appointed myself as navigator, I should comment on my identity as a disabled woman. The particulars of my condition are not of concern. They may impinge on specific pieces of the puzzle I am trying to assemble here, and I will discuss them in that context, but they are of little consequence to this overview. Disabled people, across the broadest spectrum of disability, have solidified as a group. Although this group identity has certainly not been comfortably embraced by all disabled people, a strong disability alliance has led to civil rights victories and the foundation of a clearly identified disabled community. The cultural narrative<sup>2</sup> of this community incorporates a fair share of adversity and struggle, but it is also, and significantly, an account of a world negotiated *from the vantage point of the atypical*. Although the dominant culture describes that atypical experience as deficit and loss, the disabled community's narrative recounts it in more complex ways. The cultural stuff of the community is the creative response to atypical experience, the adaptive maneuvers through a world configured for nondisabled people. The material that binds us is the art of finding one another, of identifying and naming disability in a world reluctant to discuss it, and of unearthing historically and culturally significant material that relates to our experience.

In the absence of the specifics of my condition, and my life, you may find yourself conjuring up some of the readily available images of disabled women, both fictional and real: the beholden Blind Girl in Chaplin's *City Lights*; the shame-riven Laura Wingfield in *The Glass Menagerie*; the doleful poster child gazing up at you from the collection box on the supermarket checkout counter; the defiant disability rights activist arrested for civil disobedience; your neighbor down the hall—or you may see yourself. We all share a cultural space. I don't claim to speak to every person's experience, only to paint myself within this frame. My experience as a disabled subject and my alliance with the community are a source of identity, motivation, and information.

I am also, by discipline, a psychologist, but this essay is informed more directly by women's studies, queer studies, cultural studies, the field of disciplinarity, and, of course, disability studies than by my training. In fact, some basic tenets of psychology run counter to core ideas in disability studies in at least three fundamental ways. First, psychology is responsible for the formulations and research conventions that cement the ideas of "normal," "deviant," "abnormal," and "pathology" in place. The fact that disability is inextricably linked to pathology is problematic, but even more fundamental is psychology's endorsement of the idea of "normalcy," which centers and privileges certain types of behavior, functioning, and appearance. Second, psychology's emphasis on empiricism and its repudiation of standpoint theory or positionality as legitimate starting points for research work against the types of qualitative, interpretive, historical analyses necessary to explicate the social construction of disability, the meanings assigned to disability, and the policies and practices that oppress disabled people. Oliver discusses this issue in a somewhat different way when he notes that the "social relations of research production . . . are built upon a firm distinction between the researcher and the researched" (Oliver 1992, 102). Third, although there are exceptions, psychology primarily trains practitioners to intervene on the personal level rather than intervene to alter the environment. Psychology in general has traditionally focused attention on "the personal qualities of those defined as having or being the problem," and, as a result, the policy derived from that research addresses "person-fixing rather than context-changing" (Trickett, Watts, and Birman 1994, 18). Disability studies, in contrast, focuses on the external variables: the social, political, and intellectual contingencies that shape meaning and behavior.

The questions that psychology and other traditional disciplines ask, and the methods and practices found in those disciplines are insufficient for addressing the problems that disability studies sets out to solve. These limitations aside, I must add that I have found

my clinical training useful not in fostering disability studies but in analyzing the strength of the resistance I've witnessed over the years to disability studies and to disabled people's perspective.

I hope in this book on disability to bring into stark relief, to foreground, the mechanisms by which disability is covered over, layered with meaning and rendered invisible. This book is an effort to turn those processes inside out and reveal them to be not inevitable reactions to human conditions labeled disabilities but devices used to sort human beings according to the social and economic needs of a society. The disability rights movement has paved the way for an investigation of this sort. By calling attention to the patterns of discrimination, by creating unity across previously divided constituencies, and by forging a potent and effective civil rights and social justice movement, it has challenged the academic community to reckon with its own role in this process. The scholarship and curriculum practices housed in academic institutions play a significant role in the perpetuation of a divided and unequal society. The academy has only just begun to examine how its paltry and lopsided vision of disability compromises the knowledge base. Therefore, this book examines the consequences of these constricted views on disabled people's lives and on the knowledge that we impart to students. It uses as its main text the academic culture that constructs that knowledge and participates in the construction of those lives.

#### NOTES

1. The unapologetic stance is given its full recognition in the aptly named book *No Apologies: Making It with a Disability* (Weiner 1986).
2. For further information on ideas on disability as culture see Steve Brown's monograph *Investigating a Culture of Disability* (1994). It is available from the Institute on Disability Culture, 2260 Sunrise Point Road, Las Cruces, New Mexico 88011.

## REASSIGNING MEANING

The present examination of disability has no need for the medical language of symptoms and diagnostic categories. Disability studies looks to different kinds of signifiers and the identification of different kinds of syndromes for its material. The elements of interest here are the linguistic conventions that structure the meanings assigned to disability and the patterns of response to disability that emanate from, or are attendant upon, those meanings.

The medical meaning-making was negotiated among interested parties who packaged their version of disability in ways that increased the ideas' potency and marketability. The disability com-

munity has attempted to wrest control of the language from the previous owners, and reassign meaning to the terminology used to describe disability and disabled people. This new language conveys different meanings, and, significantly, the shifts serve as metacommunications about the social, political, intellectual, and ideological transformations that have taken place over the past two decades.

### NAMING OPPRESSION

It has been particularly important to bring to light language that reinforces the dominant culture's views of disability. A useful step in that process has been the construction of the terms *ableist* and *ableism*, which can be used to organize ideas about the centering and domination of the nondisabled experience and point of view. *Ableism* has recently landed in the *Reader's Digest Oxford Wordfinder* (Tulloch 1993), where it is defined as "discrimination in favor of the able-bodied." I would add, extrapolating from the definitions of *racism* and *sexism*, that *ableism* also includes the idea that a person's abilities or characteristics are determined by disability or that people with disabilities as a group are inferior to nondisabled people. Although there is probably greater consensus among the general public on what could be labeled racist or sexist language than there is on what might be considered ableist, that may be because the nature of the oppression of disabled people is not yet as widely understood.

### NAMING THE GROUP

Across the world and throughout history various terminologies and meanings are ascribed to the types of human variations known in contemporary Westernized countries as disabilities. Over the past century the term *disabled* and others, such as *handicapped* and the less inclusive term *crippled*, have emerged as collective nouns that convey the idea that there is something that links this disparate group of people. The terms have been used to arrange people

in ways that are socially and economically convenient to the society.

There are various consequences of the chosen terminology and variation in the degree of control that the named group has over the labeling process. The terms *disability* and *disabled people* are the most commonly used by disability rights activists, and recently policy makers and health care professionals have begun to use these terms more consistently. Although there is some agreement on terminology, there are disagreements about what it is that unites disabled people and whether disabled people should have control over the naming of their experience.

The term *disability*, as it has been used in general parlance, appears to signify something material and concrete, a physical or psychological condition considered to have predominantly medical significance. Yet it is an arbitrary designation, used erratically both by professionals who lay claim to naming such phenomena and by confused citizens. A project of disability studies scholars and the disability rights movement has been to bring into sharp relief the processes by which *disability* has been imbued with the meaning(s) it has and to reassign a meaning that is consistent with a sociopolitical analysis of disability. Divesting it of its current meaning is no small feat. As typically used, the term *disability* is a linchpin in a complex web of social ideals, institutional structures, and government policies. As a result, many people have a vested interest in keeping a tenacious hold on the current meaning because it is consistent with the practices and policies that are central to their livelihood or their ideologies. People may not be driven as much by economic imperatives as by a personal investment in their own beliefs and practices, in metaphors they hold dear, or in their own professional roles. Further, underlying this tangled web of needs and beliefs, and central to the arguments presented in this book is an epistemological structure that both generates and reflects current interpretations.<sup>1</sup>

A glance through a few dictionaries will reveal definitions of

disability that include incapacity, a disadvantage, deficiency, especially a physical or mental impairment that restricts normal achievement; something that hinders or incapacitates, something that incapacitates or disqualifies. Legal definitions include legal incapacity or disqualification. *Stedman's Medical Dictionary* (1976) identifies *disability* as a "medicolegal term signifying loss of function and earning power," whereas *disablement* is a "medicolegal term signifying loss of function without loss of earning power" (400). These definitions are understood by the general public and by many in the academic community to be useful ones. *Disability* so defined is a medically derived term that assigns predominantly medical significance and meaning to certain types of human variation.

The decision to assign medical meanings to *disability* has had many and varied consequences for disabled people. One clear benefit has been the medical treatments that have increased the well-being and vitality of many disabled people, indeed have saved people's lives. Ongoing attention by the medical profession to the health and well-being of people with disabilities and to prevention of disease and impairments is critical. Yet, along with these benefits, there are enormous negative consequences that will take a large part of this book to list and explain. Briefly, the medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and, significantly, as an individual burden and personal tragedy. Society, in agreeing to assign medical meaning to *disability*, colludes to keep the issue within the purview of the medical establishment, to keep it a personal matter and "treat" the condition and the person with the condition rather than "treating" the social processes and policies that constrict disabled people's lives. The disability studies' and disability rights movement's position is critical of the domination of the medical definition and views it as a major stumbling block to the reinterpretation of *disability* as a political category and to the social changes that could follow such a shift.

While retaining the term *disability*, despite its medical origins, a premise of most of the literature in disability studies is that *disability* is best understood as a marker of identity. As such, it has been used to build a coalition of people with significant impairments, people with behavioral or anatomical characteristics marked as deviant, and people who have or are suspected of having conditions, such as AIDS or emotional illness, that make them targets of discrimination.<sup>2</sup> As rendered in disability studies scholarship, disability has become a more capacious category, incorporating people with a range of physical, emotional, sensory, and cognitive conditions. Although the category is broad, the term is used to designate a specific minority group. When medical definitions of *disability* are dominant, it is logical to separate people according to biomedical condition through the use of diagnostic categories and to forefront medical perspectives on human variation. When disability is redefined as a social/political category, people with a variety of conditions are identified as *people with disabilities* or *disabled people*, a group bound by common social and political experience. These designations, as reclaimed by the community, are used to identify us as a constituency, to serve our needs for unity and identity, and to function as a basis for political activism.

The question of who “qualifies” as disabled is as answerable or as confounding as questions about any identity status. One simple response might be that you are disabled if you say you are. Although that declaration won’t satisfy a worker’s compensation board, it has a certain credibility with the disabled community. The degree and significance of an individual’s impairment is often less of an issue than the degree to which someone identifies as disabled. Another way to answer the question is to say that disability “is mostly a social distinction . . . a marginalized status” and the status is assigned by “the majority culture tribunal” (Gill 1994, 44). But the problem gets stickier when the distinction between disabled and nondisabled is challenged by people who say,

“Actually, we’re all disabled in some way, aren’t we?” (46). Gill says the answer is no to those whose difference “does *not* significantly affect daily life and the person does not [with some consistency] present himself/herself to the world at large as a disabled person” (46). I concur with Gill; I am not willing or interested in erasing the line between disabled and nondisabled people, as long as disabled people are devalued and discriminated against, and as long as naming the category serves to call attention to that treatment.

Over the past twenty years, disabled people have gained greater control over these definitional issues. *The disabled* or *the handicapped* was replaced in the mid-70s by *people with disabilities* to maintain disability as a characteristic of the individual, as opposed to the defining variable. At the time, some people would purposefully say *women and men with disabilities* to provide an extra dimension to the people being described and to decenter the way *the disabled* were traditionally described. Beginning in the early 90s *disabled people* has been increasingly used in disability studies and disability rights circles when referring to the constituency group. Rather than maintaining disability as a secondary characteristic, *disabled* has become a marker of the identity that the individual and group wish to highlight and call attention to.

In this book, the terms *disabled* and *nondisabled* are used frequently to designate membership within or outside the community. Disabled is centered, and nondisabled is placed in the peripheral position in order to look at the world from the inside out, to expose the perspective and expertise that is silenced. Occasionally, *people with disabilities* is used as a variant of *disabled people*. The use of *nondisabled* is strategic: to center disability. Its inclusion in this chapter is also to set the stage for postulating about the nondisabled position in society and in scholarship in later chapters. This action is similar to the strategy of marking and articulating “whiteness.” The assumed position in scholarship has always been the male,



white, nondisabled scholar; it is the default category. As recent scholarship has shown, these positions are not only presumptively hegemonic because they are the assumed universal stance, as well as the presumed neutral or objective stance, but also undertheorized. The nondisabled stance, like the white stance, is veiled. "White cannot be said quite out loud, or it loses its crucial position as a precondition of vision and becomes the object of scrutiny" (Haraway 1989, 152). Therefore, centering the disabled position and labeling its opposite nondisabled focuses attention on both the structure of knowledge and the structure of society.

### NICE WORDS

Terms such as *physically challenged*, the *able disabled*, *handicapable*, and *special people/children* surface at different times and places. They are rarely used by disabled activists and scholars (except with palpable irony). Although they may be considered well-meaning attempts to inflate the value of people with disabilities, they convey the boosterism and do-gooder mentality endemic to the paternalistic agencies that control many disabled people's lives.

*Physically challenged* is the only term that seems to have caught on. Nondisabled people use it in conversation around disabled people with no hint of anxiety, suggesting that they believe it is a positive term. This phrase does not make much sense to me. To say that I am physically challenged is to state that the obstacles to my participation are physical, not social, and that the barrier is my own disability. Further, it separates those of us with mobility impairments from other disabled people, not a valid or useful partition for those interested in coalition building and social change. Various derivatives of the term *challenged* have been adopted as a description used in jokes. For instance, "vertically challenged" is considered a humorous way to say short, and "calorically challenged" to say fat. A review of the Broadway musical *Big* in the *New Yorker* said that the score is "melodically challenged."

I observed a unique use of *challenged* in the local Barnes and Nobles superstore. The children's department has a section for books on "Children with Special Needs." There are shelves labeled "Epilepsy" and "Down Syndrome." A separate shelf at the bottom is labeled "Misc. Challenges," indicating that it is now used as an organizing category.

The term *able disabled* and *handicapable* have had a fairly short shelf life. They are used, it seems, to refute common stereotypes of incompetence. They are, though, defensive and reactive terms rather than terms that advance a new agenda.

An entire profession, in fact a number of professions, are built around the word *special*. A huge infrastructure rests on the idea that *special children* and *special education* are valid and useful structuring ideas. Although dictionaries insist that *special* be reserved for things that surpass what is common, are distinct among others of their kind, are peculiar to a specific person, have a limited or specific function, are arranged for a particular purpose, or are arranged for a particular occasion, experience teaches us that *special* when applied to education or to children means something different.

The naming of disabled children and the education that "is designed for students whose learning needs cannot be met by a standard school curriculum" (*American Heritage Dictionary* 1992) as *special* can be understood only as a euphemistic formulation, obscuring the reality that neither the children nor the education are considered desirable and that they are not thought to "surpass what is common."

Labeling the education and its recipients special may have been a deliberate attempt to confer legitimacy on the educational practice and to prop up a discarded group. It is also important to consider the unconscious feelings such a strategy may mask. It is my feeling that the nation in general responds to disabled people with great ambivalence. Whatever antipathy and disdain is felt is in competition with feelings of empathy, guilt, and identification. The

term *special* may be evidence not of a deliberate maneuver but of a collective “reaction formation,” Freud’s term for the unconscious defense mechanism in which an individual adopts attitudes and behaviors that are opposite to his or her own true feelings, in order to protect the ego from the anxiety felt from experiencing the real feelings.

The ironic character of the word *special* has been captured in the routine on *Saturday Night Live*, where the character called the “Church Lady” declares when she encounters something distasteful or morally repugnant, “Isn’t that special!”

### NASTY WORDS

Some of the less subtle or more idiomatic terms for disabled people such as: *cripple*, *vegetable*, *dumb*, *deformed*, *retard*, and *gimp* have generally been expunged from public conversation but emerge in various types of discourse. Although they are understood to be offensive or hurtful, they are still used in jokes and in informal conversation.

*Cripple* as a descriptor of disabled people is considered impolite, but the word has retained its metaphoric vitality, as in “the exposé in the newspaper crippled the politician’s campaign.” The term is also used occasionally for its evocative power. A recent example appeared in *Lingua Franca* in a report on research on the behaviors of German academics. The article states that a professor had “documented the postwar careers of psychiatrists and geneticists involved in gassing thousands of cripples and schizophrenics” (Allen 1996, 37). *Cripple* is used rather loosely here to describe people with a broad range of disabilities. The victims of Nazi slaughter were people with mental illness, epilepsy, chronic illness, and mental retardation, as well as people with physical disabilities. Yet *cripple* is defined as “one that is partially disabled or unable to use a limb or limbs” (*American Heritage Dictionary* 1992) and is usually used only to refer to people with mobility impairments. Because *cripple*

inadequately and inaccurately describes the group, the author of the report is likely to have chosen this term for its effect.

*Cripple* has also been revived by some in the disability community who refer to each other as “crips” or “cripples.” A performance group with disabled actors call themselves the “Wry Crips.” “In reclaiming ‘cripple,’ disabled people are taking the thing in their identity that scares the outside world the most and making it a cause to revel in with militant self-pride” (Shapiro 1993, 34).

A recent personal ad in the *Village Voice* shows how “out” the term is:

**TWISTED CRIP:** Very sexy, full-figured disabled BiWF artist sks fearless, fun, oral BiWF for hot, no-strings nights. Wheelchair, tattoo, dom. Shaved a + N/S. No men/sleep-overs.

*Cripple*, *gimp*, and *freak* as used by the disability community have transgressive potential. They are personally and politically useful as a means to comment on oppression because they assert our right to name experience.

### SPEAKING ABOUT OVERCOMING AND PASSING

The popular phrase *overcoming a disability* is used most often to describe someone with a disability who seems competent and successful in some way, in a sentence something like “She has overcome her disability and is a great success.” One interpretation of the phrase might be that the individual’s disability no longer limits her or him, that sheer strength or willpower has brought the person to the point where the disability is no longer a hindrance. Another implication of the phrase may be that the person has risen above society’s expectation for someone with those characteristics. Because it is physically impossible to *overcome* a disability, it seems that what is *overcome* is the social stigma of having a disability. This idea is reinforced by the equally confounding statement “I never

think of you as disabled." An implication of these statements is that the other members of the group from which the individual has supposedly moved beyond are not as brave, strong, or extraordinary as the person who has *overcome* that designation.

X The expression is similar in tone to the phrase that was once more commonly used to describe an African American who was considered exceptional in some way: "He/she is a credit to his/her race." The implication of this phrase is that the "race" is somehow discredited and needs people with extraordinary talent to give the group the credibility that it otherwise lacks. In either case, talking about the person who is African American or talking about the person with a disability, these phrases are often said with the intention of complimenting someone. The compliment has a double edge. To accept it, one must accept the implication that the group is inferior and that the individual is unlike others in that group.

The ideas imbedded in the *overcoming* rhetoric are of personal triumph over a personal condition. The idea that someone can *overcome* a disability has not been generated within the community; it is a wish fulfillment generated from the outside. It is a demand that you be plucky and resolute, and not let the obstacles get in your way. If there are no curb cuts at the corner of the street so that people who use wheelchairs can get across, then you should learn to do wheelies and jump the curbs. If there are no sign language interpreters for deaf students at the high school, then you should study harder, read lips, and stay up late copying notes from a classmate. When disabled people internalize the demand to "overcome" rather than demand social change, they shoulder the same kind of exhausting and self-defeating "Super Mom" burden that feminists have analyzed.

The phrase *overcome a disability* may also be a shorthand version of saying "someone with a disability overcame many obstacles."

Tremblay (1996) uses that phrase when describing behaviors of disabled World War II veterans upon returning to the community: "[T]heir main strategies were to develop individualized strategies to overcome the obstacles they found in the community" (165). She introduces this idea as a means to describe how the vets relied on their own ingenuity to manage an inaccessible environment rather than demand that the community change to include them.

In both uses of *overcome*, the individual's responsibility for her or his own success is paramount. If we, as a society, place the onus on individuals with disabilities to work harder to "compensate" for their disabilities or to "overcome" their condition or the barriers in the environment, we have no need for civil rights legislation or affirmative action.

Lest I be misunderstood, I don't see working hard, doing well, or striving for health, fitness, and well-being as contradictory to the aims of the disability rights movement. Indeed, the movement's goal is to provide greater opportunity to pursue these activities. However, we shouldn't be impelled to do these because we have a disability, to prove to some social overseer that we can perform, but we should pursue them because they deliver their own rewards and satisfactions.

A related concept, familiar in African American culture as well as in lesbian and gay culture, is that of *passing*. African Americans who pass for white and lesbians and gays who pass for straight do so for a variety of personal, social, and often economic reasons. Disabled people, if they are able to conceal their impairment or confine their activities to those that do not reveal their disability, have been known to pass. For a member of any of these groups, passing may be a deliberate effort to avoid discrimination or ostracism, or it may be an almost unconscious, Herculean effort to deny to oneself the reality of one's racial history, sexual feelings, or bodily state. The attempt may be a deliberate act to protect oneself

from the loathing of society or may be an unchecked impulse spurred by an internalized self-loathing. It is likely that often the reasons entail an admixture of any of these various parts.

Henry Louis Gates, Jr. (1996) spoke of the various reasons for passing in an essay on the literary critic Anatole Broyard. Broyard was born in New Orleans to a family that identified as "Negro." His skin was so light that for his entire career as "one of literary America's foremost gatekeepers" (66) the majority of people who knew him did not know this. His children, by then adults, learned of his racial history shortly before he died. Sandy Broyard, Anatole's wife, remarked that she thought that "his own personal history continued to be painful to him. . . . In passing, you cause your family great anguish, but I also think conversely, do we look at the anguish it causes the person who is passing? Or the anguish that it was born out of?" (75).

When disabled people are able to pass for nondisabled, and do, the emotional toll it takes is enormous. I have heard people talk about hiding a hearing impairment to classmates or colleagues for years, or others who manage to conceal parts of their body, or to hide a prosthesis. These actions, though, may not result in a family's anguish; they may, in fact, be behaviors that the family insists upon, reinforces, or otherwise shames the individual into. Some disabled people describe how they were subjected to numerous painful surgeries and medical procedures when they were young not so much, they believe, to increase their comfort and ease of mobility as to fulfill their families' wish to make them appear "more normal."

Even when a disability is obvious and impossible to hide on an ongoing basis, families sometimes create minifictions that disabled people are forced to play along with. Many people have told me that when family pictures were taken as they were growing up, they were removed from their wheelchairs, or they were shown only from the waist up, or they were excluded from pictures altogether.

The messages are that this part of you, your disability or the symbol of disability, your wheelchair, is unacceptable, or, in the last case, you are not an acceptable member of the family.

I was recently in an elementary school when class pictures were taken, and I learned that it is the custom for all the children who use wheelchairs to be removed from their chairs and carried up a few steps to the auditorium stage and placed on folding chairs. I spoke with people at the school who said they have thought about raising money to build a ramp to the stage, but in the meantime this was the solution. I wondered, of course, why they have to take pictures on the stage when it is inaccessible. The families of these children or the school personnel might even persist with this plan, believing that these actions have a positive effect on children, that they demonstrate that the disabled child is "just like everybody else." But these fictions are based more clearly on the projections of the adults than on the unadulterated feelings of the child. The message that I read in this action: You are like everyone else, but only as long as you hide or minimize your disability.

Both passing and overcoming take their toll. The loss of community, the anxiety, and the self-doubt that inevitably accompany this ambiguous social position and the ambivalent personal state are the enormous cost of declaring disability unacceptable. It is not surprising that disabled people also speak of "coming out" in the same way that members of the lesbian and gay community do. A woman I met at a disability studies conference not long ago said to me in the course of a conversation about personal experience: "I'm five years old." She went on to say that despite being significantly disabled for many years, she had really only recently discovered the disabled community and allied with it. For her, "coming out" was a process that began when she recognized how her effort to "be like everyone else" was not satisfying her own needs and wishes. She discovered other disabled people and began to identify clearly as disabled, and then purchased a motorized scooter, which meant she

didn't have to expend enormous energy walking. She told this tale with gusto, obviously pleased with the psychic and physical energy she had gained. Stories such as hers provide evidence of the personal burdens many disabled people live with. Shame and fear are personal burdens, but if these tales are told, we can demonstrate how the personal is indeed the political. And further, that the unexamined connections between the personal and political are the curricular.

### NORMAL/ABNORMAL

*Normal* and *abnormal* are convenient but problematic terms used to describe a person or group of people. These terms are often used to distinguish between people with and without disabilities. In various academic disciplines and in common usage, *normal* and *abnormal* assume different meanings. In psychometrics, *norm* or *normal* are terms describing individuals or characteristics that fall within the center of the normal distribution on whatever variable is being measured. However, as the notion of *normal* is applied in social science contexts and certainly in general parlance, it implies its obverse—*abnormal*—and they both become value laden. Often, those who are not deemed normal are devalued and considered a burden or problem, or are highly valued and regarded as a potential resource. Two examples are the variables of height and intelligence. Short stature and low measured intelligence are devalued and labeled abnormal, and people with those characteristics are considered disabled. Tall people (particularly males) and high scores on IQ tests are valued, and, although not normal in the statistical sense, are not labeled abnormal or considered disabled.<sup>3</sup>

Davis (1995) describes the historical specificity of the use of *normal* and thereby calls attention to the social structures that are dependent on its use. "[T]he very term that permeates our contemporary life—the normal—is a configuration that arises in a particular historical moment. It is part of a notion of progress, of

industrialization, and of ideological consolidation of the power of the bourgeoisie. The implications of the hegemony of normalcy are profound and extend into the very heart of cultural production" (49).

The use of the terms *abnormal* and *normal* also moves discourse to a high level of abstraction, thereby avoiding concrete discussion of specific characteristics and increasing ambiguity in communication. In interactions, there is an assumed agreement between speaker and audience of what is normal that sets up an aura of empathy and "us-ness." This process "enhances social unity among those who feel they are normal" (Freilich, Raybeck, and Savishinsky 1991, 22), necessarily excluding the other or abnormal group.

These dynamics often emerge in discussions about disabled people when comparisons are made, for instance, between "the normal" and "the hearing impaired," or "the normal children" and "the handicapped children." The first example contrasts two groups of people; one defined by an abstract and evaluative term (the normal), the other by a more specific, concrete, and nonevaluative term (the hearing impaired). In the second comparison, the "handicapped children" are labeled abnormal by default. Setting up these dichotomies avoids concrete discussion of the ways the two groups of children actually differ, devalues the children with disabilities, and forces an "us and them" division of the population.

The absolute categories *normal* and *abnormal* depend on each other for their existence and depend on the maintenance of the opposition for their meaning. Sedgwick (1990), in *Epistemology of the Closet*, comments on a similar pattern in the forced choice categories homosexual and heterosexual:

[C]ategories presented in a culture as symmetrical binary oppositions—heterosexual/homosexual, in this case—actually subsist in a more unsettled and dynamic tacit relation according to which, first, term B is not symmetrical with but subordinated to term

A; but, second, the ontologically valorized term A actually depends for its meaning on the simultaneous subsumption and exclusion of term B; hence, third, the question of priority between the supposed central and the supposed marginal category of each dyad is irresolvably unstable, an instability caused by the fact that term B is constituted as at once internal and external to term A. (9–10)

Despite the instability and the relational nature of the designations *normal* and *abnormal*, they are used as absolute categories. They have achieved their certainty by association with empiricism, and they suffer from empiricism's reductive and simplifying tendencies. Their power and reach are enormous. They affect individuals' most private deliberations about their worth and acceptability, and they determine social position and societal response to behavior. The relationship between abnormality and disability accords to the nondisabled the legitimacy and potency denied to disabled people. And, central to our concerns here, the reification of *normal* and *abnormal* structures curriculum. Courses with titles such as "Abnormal Psychology," "Sociology of Deviance," "Special Education," and "Psychopathology" assume the internal consistency of a curriculum focused on "the abnormal" and depend on the curriculum of the "normal" being taught elsewhere. In fact, this organization of knowledge implicitly suggests that the rest of the curriculum is "normal."

Rosemarie Garland Thomson (1997) has coined the term *the normate*, which, like *nondisabled*, is useful for marking the unexamined center. "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. The term *normate* usefully designates the social figure through which people can represent themselves as definitive human beings" (8). By meeting *normal* on some of its own terms, *normate* inflects its root, and

challenges the validity, indeed the possibility, of normal. At the same time, its ironic twist gives a more flavorful reading of the idea of normal.

### PASSIVITY VERSUS CONTROL

Language that conveys passivity and victimization reinforces certain stereotypes when applied to disabled people. Some of the stereotypes that are particularly entrenched are that people with disabilities are more dependent, childlike, passive, sensitive, and miserable and are less competent than people who do not have disabilities. Much of the language used to depict disabled people relates the lack of control to the perceived incapacities, and implies that sadness and misery are the product of the disabling condition.

These deterministic and essentialist perspectives flourish in the absence of contradictory information. Historically, disabled people have had few opportunities to be active in society, and various social and political forces often undermine the capacity for self-determination. In addition, disabled people are rarely depicted on television, in films, or in fiction as being in control of their own lives—in charge or actively seeking out and obtaining what they want and need. More often, disabled people are depicted as pained by their fate or, if happy, it is through personal triumph over their adversity. The adversity is not depicted as lack of opportunity, discrimination, institutionalization, and ostracism; it is the personal burden of their own body or means of functioning.

Phrases such as *the woman is a victim of cerebral palsy* implies an active agent (cerebral palsy) perpetrating an aggressive act on a vulnerable, helpless "victim." The use of the term *victim*, a word typically used in the context of criminal acts, evokes the relationship between perpetrator and victim. Using this language attributes life, power, and intention to the condition and disempowers the person with the disability, rendering him or her helpless and passive. Instead, if there is a particular need to note what an individu-

al's disability is, saying *the woman has cerebral palsy* describes solely the characteristic of importance to the situation, without imposing extraneous meaning.

Grover (1987) analyzes the word *victim* as used to describe people with AIDS. She notes that the term implies fatalism, and therefore "enable[s] the passive spectator or the AIDS 'spectacle' to remain passive." Use of the term may also express the unconscious wish that the people with AIDS may have been "complicit with, to have courted, their fate" (29), in which case the individual would be seen as a *victim* of her or his own drives. This is particularly apparent when the phrase *innocent victim* is used to distinguish those who acquire HIV from blood transfusions or other medical procedures from those who contract HIV from sexual contact or shared needles. This analysis is also pertinent to people with other disabilities because a number of belief systems consider disability, or some disabilities, as punishment for sin in this or a former life.

Disabled people are frequently described as *suffering from* or *afflicted with* certain conditions. Saying that someone is *suffering from* a condition implies that there is a perpetual state of suffering, uninterrupted by pleasurable moments or satisfactions. *Afflicted* carries similar assumptions. The verb *afflict* shares with *agonize*, *excruciate*, *rack*, *torment*, and *torture* the central meaning "to bring great harm or suffering to someone" (*American Heritage Dictionary* 1992, 30). Although some people may experience their disability this way, these terms are not used as descriptors of a verified experience but are projected onto disability. Rather than assume suffering in the description of the situation, it is more accurate and less histrionic to say simply that a person *has a disability*. Then, wherever it is relevant, describe the nature and extent of the difficulty experienced. My argument here isn't to eliminate descriptions of suffering but to be accurate in their appointment. It is interesting that AIDS activists intentionally use the phrase *living with AIDS*

rather than *dying from AIDS*, not to deny the reality of AIDS but to emphasize that people are often actively engaged in living even in the face of a serious illness.

The ascription of passivity can be seen in language used to describe the relationship between disabled people and their wheelchairs. The phrases *wheelchair bound* or *confined to a wheelchair* are frequently seen in newspapers and magazines, and heard in conversation. A more puzzling variant was spotted in *Lingua Franca*, which described the former governor of Alabama, George Wallace, as the "slumped, wheelchair-ridden 'Guv'nah'" (Zalewski 1995, 19). The choice here was to paint the wheelchair user as *ridden*, meaning "dominated, harassed, or obsessed by" (*American Heritage Dictionary* 1992), rather than the rider in the wheelchair. The various terms imply that a wheelchair restricts the individual, holds a person prisoner. Disabled people are more likely to say that someone *uses a wheelchair*. The latter phrase not only indicates the active nature of the user and the positive way that wheelchairs increase mobility and activity but recognizes that people get in and out of wheelchairs for different activities: driving a car, going swimming, sitting on the couch, or, occasionally, for making love.

A recent oral history conducted with disabled Canadian World War II veterans and other disabled people who are contemporaries of the vets recounts their memories of the transition from hospital-style wicker wheelchairs used to transport patients to self-propelled, lighter-weight, folding chairs that were provided to disabled people, mostly to veterans, in the years following the war. Prior to the new chairs, one man recalls that "one was often confined to bed for long periods of time. . . . There were a few cerebral palsy chaps there. . . . If they transgressed any rule . . . they'd take their wheelchairs away from them and leave them in bed for two weeks" (Tremblay 1996, 153). In this and other interviews the value of wheelchairs is revealed. A vet described how the medical staff's efforts were geared toward getting veterans to walk with crutches,

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but when the vets discovered the self-propelled chairs they realized “it didn’t make much sense spending all that energy covering a short distance [on crutches] . . . when you could do it quickly and easily with a wheelchair. . . . It didn’t take long for people to get over the idea that walking was that essential” (158–59). Another veteran recalled how the staff’s emphasis on getting the men to walk “delayed our rehabilitation for months and months” (159). The staff obviously understood the value of the wheelchair to disabled people; otherwise they would not have used it as a means of control, yet they resisted purchasing the new self-push chairs for some time after they were made available. It is that type of manipulation and control, along with architectural and attitudinal barriers, that confine people. It is not wheelchairs.

#### MULTIPLE MEANINGS

Are *invalid*, with the emphasis on the first syllable, and *invalid*, with the emphasis on the second, synonyms or homonyms? Does the identical housing of *patient*, the adjective, and *patient*, the noun, conflate the two meanings? Did their conceptual relationship initially determine their uniform casing?

For instance, *invalid* is a designation used to identify some disabled people. The term is seen most prominently on the sides of vans used to transport people with mobility impairments. Disabled people, desperate for accessible transportation, must use vans with the dubious appellation “*Invalid Coach*” printed in bold letters on the side. Aside from this being a fertile source of jokes about the aptness of these notoriously bad transportation services being identified as “not factually or legally valid; falsely based or reasoned; faulty” (*American Heritage Dictionary* 1992), those on the inside of the bus suffer the humiliation of being written off so summarily. Both *invalids* share the Latin root *invalidus*, which means weak. It could be argued that some disabilities do result in weakening of the body, or, more likely, parts of the body, but the totalizing noun,

*invalid*, does not confine the weakness to the specific bodily functions; it is more encompassing.

The homonymic *patient/patient*, is, I think, not coincidental or irrelevant. The noun *patient* is a role designation that is always relational. A patient is understood to belong to a doctor or other health care professional, or more generally to an institution. As a noun, *patient* is a neutral description of the role of “one who receives medical attention, care, or treatment” (*American Heritage Dictionary* 1992). The adjective *patient* moves beyond the noun’s neutral designation to describe a person who is capable of “bearing or enduring pain, difficulty, provocation, or annoyance with calmness” as well as “tolerant . . . persevering . . . constant . . . not hasty” (*American Heritage Dictionary* 1992). The “good” patient is one who does not challenge the authority of the practitioner or institution and who complies with the regimen set out by the expert, in other words a patient patient. Disabled people, who have often spent a great deal of time as patients, discuss the ways that we have been socialized in the medical culture to be compliant, and that has often undermined our ability to challenge authority or to function autonomously. Further, the description of disabled people as patients in situations where we are not, reinforces these ideas.<sup>4</sup>

#### REFLECTIONS ON THE DIS IN DISABILITY

Before discussing the prefix *dis*, let’s examine a similar bound morpheme that conveys meaning and significantly modifies the words it is attached to. The suffix *ette*, when appended to nouns, forms words meaning small or diminutive, as in *kitchenette*; female, as in *usherette*; or imitation or inferior kind, as in *leatherette* (*American Heritage Dictionary* 1992). These various meanings of *ette* slip around in our minds to influence how we interpret other words with the same suffix. So, for instance, although the word *leatherette* is used to tell us it is not the real thing and an inferior version of leather, *usherette* becomes, by association, not only the female ver-



sion of usher but denotes a poor imitation. *Usherette* becomes, like *kitchenette*, the diminutive version. These various meanings tumble into one another, propagating new meanings, unintended and imprecise. I recently met a woman who told me that she had been a Rockette at Radio City Music Hall in Rockefeller Center for twenty years. I realized that this string of high-kicking, synchronized dancing women are perpetually cast as the smaller, imitation, inferior and female counterparts of the great male barons, the Rockefellers.

The prefix *dis*, like the suffix *ette*, has similarly unchecked impulses. Although *ette* qualifies its base and reduces it to the more diminutive and less valid version, a relationship is maintained between the base and its amended version. However, the prefix *dis* connotes separation, taking apart, sundering in two. The prefix has various meanings such as not, as in *dissimilar*; absence of, as in *disinterest*; opposite of, as in *disfavor*; undo, do the opposite of, as in *disarrange*; and deprive of, as in *disfranchise*. The Latin root *dis* means apart, asunder. Therefore, to use the verb *disable*, means, in part, to deprive of capability or effectiveness. The prefix creates a barrier, cleaving in two ability and its absence, its opposite. Disability is the “not” condition, the repudiation of ability.

Canguilhem (1991), in his explorations of the normal and the pathological, recognizes the way that prefixes signal their relationship to the words they modify. He asserts that

the pathological phenomena found in living organisms are nothing more than quantitative variations, greater or lesser according to corresponding physiological phenomena. Semantically, the pathological is designated as departing from the normal not so much by *a-* or *dys-* as by *hyper-* or *hypo-*. . . . [T]his approach is far from considering health and sickness as qualitatively opposed, or as forces joined in battle.” (42)

*Ette*, *hyper* and *hypo*, and *dis* have semantic consequences, but, moreover, each recapitulates a particular social arrangement. The suffix *ette* not only qualifies the meaning of the root word it is attached to but speaks of the unequal yet dynamic relationship between women and men, in which “woman was, as we see in the profoundly influential works of Aristotle, not the equal opposite of man but a failed version of the supposedly defining type” (Minnich 1990, 54). The medical prefixes *hyper* and *hypo* are typically attached to medical conditions that are temporary or circumscribed. People with those conditions are not socially marked and separated as are those with the more pronounced, and long standing conditions known as disabilities. With *hyper* and *hypo* conditions, there is less semantic and social disjuncture. However, the construction of *disability* does not imply the continuum approach Canguilhem finds in diagnostic categories. *Dis* is the semantic reincarnation of the split between disabled and nondisabled people in society.

Yet *women and men with disabilities*, *disabled people*, and the *disability community* are terms of choice for the group. We have decided to reassign meaning rather than choose a new name. In retaining *disability* we run the risk of preserving the medicalized ideas attendant upon it in most people’s idea of disability. What I think will help us out of the dilemma is the naming of the political category in which *disability* belongs. Women is a category of *gender*, and *black* or *Latino/a* are categories of *race/ethnicity*, and it is the recognition of those categories that has fostered understanding of the political meaning of *women* and *black*. Although *race* and *gender* are not perfect terms because they retain biological meanings in many quarters, the categories are increasingly understood as axes of oppression; axes along which power and resources are distributed. Although those of us within the disability community recognize that power is distributed along disability lines, the naming and

recognition of the axis will be a significant step in gaining broader recognition of the issues. Further, it will enrich the discussion of the intersection of the axes of class, race, gender, and sexual orientation, and disability.

Constructing the axis on which disabled and nondisabled fall will be a critical step in marking all points along it. Currently, there is increased attention to the privileged points on the continua of race, gender, and sexual orientation. There is growing recognition that the white, the male, and the heterosexual positions need to be noted and theorized. Similarly, it is important to examine the nondisabled position and its privilege and power. It is not the neutral, universal position from which disabled people deviate, rather, it is a category of people whose power and cultural capital keep them at the center.

In this book, though, disabled people's perspectives are kept central and are made explicit, partly to comment on how marginal and obscure they typically are, and partly to suggest the disciplinary and intellectual transformation consequent on putting disability studies at the center.

#### NOTES

1. Various authors have discussed issues related to definitions of *disability*. See Wendell (1996), Longmore (1985b, 1987), and Hahn (1987), and also the June Isaacson Kailes (1995) monograph *Language Is More Than a Trivial Concern!* which is available from the Institute on Disability Culture, 2260 Sunrise Point Road, Las Cruces, New Mexico 88011.
2. The definition of *disability* under the Americans with Disabilities Act is consistent with the sociopolitical model employed in disability studies. A person is considered to have a disability if he or she:
  - has a physical or mental impairment that substantially limits one or more of his or her major life activities;

- has a record of such an impairment; or
- is regarded as having such an impairment.

Due to the vagaries of this definition, a person may have even if the absence of a substantially limiting impairment, people can be discriminated against. For instance, this may occur because someone has a facial disfigurement or has, or is suspected of having, HIV or mental illness. The ADA recognizes that social forces, such as myths and fears regarding disability, function to substantially limit opportunity.

3. I am indebted to my colleague John O'Neill for his input on these ideas about the use of the term *normal*.
4. See June Isaacson Kailes's (1995), *Language Is More Than a Trivial Concern!* for a discussion on language use.