



The Disability Studies Reader

Second Edition

Edited by Lennard J. Davis

The Disability Studies Reader

Second Edition

Edited by Lennard J. Davis

 **Routledge**
Taylor & Francis Group
New York London

Routledge is an imprint of the
Taylor & Francis Group, an informa business

Routledge
Taylor & Francis Group
270 Madison Avenue
New York, NY 10016

Routledge
Taylor & Francis Group
2 Park Square
Milton Park, Abingdon
Oxon OX14 4RN

© 2006 by Taylor & Francis Group, LLC
Routledge is an imprint of Taylor & Francis Group, an Informa business

Printed in the United States of America on acid-free paper
10 9 8 7 6 5 4 3 2 1

International Standard Book Number-10: 0-415-95334-0 (Softcover) 0-415-95333-2 (Hardcover)
International Standard Book Number-13: 978-0-415-95334-4 (Softcover) 978-0-415-95333-7 (Hardcover)

No part of this book may be reprinted, reproduced, transmitted, or utilized in any form by any electronic, mechanical, or other means, now known or hereafter invented, including photocopying, microfilming, and recording, or in any information storage or retrieval system, without written permission from the publishers.

Trademark Notice: Product or corporate names may be trademarks or registered trademarks, and are used only for identification and explanation without intent to infringe.

Library of Congress Cataloging-in-Publication Data

The disability studies reader / edited by Lennard J. Davis. -- 2nd ed.
p. cm.

ISBN 0-415-95333-2 (hardback : alk. paper) -- ISBN 0-415-95334-0 (pbk. : alk. paper)

1. People with disabilities. 2. Sociology of disability. 3. Disability studies. I. Davis, Lennard J., 1949- .

HV1568.D5696 2006
362.4--dc22

2006007500

Visit the Taylor & Francis Web site at
<http://www.taylorandfrancis.com>

and the Routledge Web site at
<http://www.routledge-ny.com>

Contents

Acknowledgments	ix
Preface to the Second Edition	xiii
Introduction	xv

Part I Historical Perspectives

1	Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century Lennard J. Davis	3
2	Deaf and Dumb in Ancient Greece M. Lynn Rose	17
3	"A Silent Exile on This Earth": The Metaphorical Construction of Deafness in the Nineteenth Century Douglas Baynton	33
4	The Other Arms Race David Serlin	49
5	(Re)Writing the Genetic Body-Text: Disability, Textuality, and the Human Genome Project James C. Wilson	67

Part II The Politics of Disability

6	Construction of Deafness Harlan Lane	79
7	Abortion and Disability: Who Should and Who Should Not Inhabit the World? Ruth Hubbard	93
8	Disability Rights and Selective Abortion Marsha Saxton	105
9	Universal Design: The Work of Disability in an Age of Globalization Michael Davidson	117

Part III Stigma and Illness

10	Selections from <i>Stigma</i> Erving Goffman	131
11	Stigma: An Enigma Demystified Lerita M. Coleman	141

- 12 AIDS and Its Metaphors 153
Susan Sontag

Part IV Theorizing Disability

- 13 Reassigning Meaning 161
Simi Linton
- 14 Disability in Theory: From Social Constructionism 173
to the New Realism of the Body
Tobin Siebers
- 15 On the Government of Disability: Foucault, Power, and the Subject of Impairment 185
Shelley Tremain
- 16 The Social Model of Disability 197
Tom Shakespeare
- 17 Narrative Prosthesis and the Materiality of Metaphor 205
David Mitchell and Sharon Snyder
- 18 The Dimensions of Disability Oppression: An Overview 217
James I. Charlton

Part V The Question of Identity

- 19 The End of Identity Politics and the Beginning of Dismodernism: 231
On Disability as an Unstable Category
Lennard J. Davis
- 20 Toward a Feminist Theory of Disability 243
Susan Wendell
- 21 Integrating Disability, Transforming Feminist Theory 257
Rosemarie Garland-Thomson
- 22 Introducing White Disability Studies: A Modest Proposal 275
Chris Bell
- 23 "When *Black* Women Start Going on Prozac . . .": The Politics of Race, Gender, and 283
Emotional Distress in Meri Nana-Ama Danquah's *Willow Weep for Me*
Anna Mollow
- 24 Compulsory Able-Bodiedness and Queer/Disabled Existence 301
Robert McRuer
- 25 The Vulnerable Articulate: James Gillingham, Aimee Mullins, and Matthew Barney 309
Marquard Smith
- 26 Interlude 1: On (Almost) Passing 321
Brenda Brueggeman
- 27 Deaf People: A Different Center 331
Carol Padden and Tom Humphries
- 28 A Mad Fight: Psychiatry and Disability Activism 339
Bradley Lewis

Part VI Disability and Culture

29	Toward a Poetics of Vision, Space, and the Body: Sign Language and Literary Theory H-Dirksen L. Bauman	355
30	The Enfreakment of Photography David Hevey	367
31	Blindness and Art Nicholas Mirzoeff	379
32	Blindness and Visual Culture: An Eye Witness Account Georgina Kleege	391
33	Disability, Life Narrative, and Representation G. Thomas Couser	399

Part VII Fiction, Memoir, and Poetry

34	Helen and Frida Anne Finger	405
35	Poems Cheryl Marie Wade	411
36	Poems Kenny Fries	413
37	Selections from <i>The Cry of the Gull</i> Emmanuelle Laborit	417
	Contributors	435
	Index	441

Reassigning Meaning

Simi Linton

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 community 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.¹

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.² 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 deneuter 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” (Hara-way 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.

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.

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 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.³

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 individual'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, 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. 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.⁴

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 version 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 intersections 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.

The last two parts of this definition acknowledge that even in 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.

Works Cited

- Allen, A. 1996. Open secret: A German academic hides his past—in plain sight. *Lingua Franca* 6 (3): 28–41.
- American Heritage Dictionary. 1992. 3rd ed. Boston: Houghton Mifflin.
- Cangiuilhem, G. 1991. *The normal and the pathological*. New York: Zone Books.
- Davis, L. J. 1995. *Enforcing normalcy: Disability, deafness, and the body*. London: Verso.
- Freilich, M., Raybeck, D., and Savishinsky, J. 1991. *Deviance: Anthropological perspectives*. New York: Bergin and Garvey.
- Gates, H. L., Jr. 1996. White like me. *New Yorker* 72 (16): 66–81.
- Gill, C. J. 1994. Questioning continuum. In B. Shaw, ed., *The ragged edge: The disability experience from the pages of the first fifteen years of "The Disability Rag,"* 42–49. Louisville, Ky.: Advocado Press.
- Grover, J.Z. 1987. AIDS: Keywords. In Douglas Crimp, ed., *AIDS: Cultural analysis*, 17–30. Cambridge: MIT Press.
- Hahn, H. 1987. Disability and capitalism: Advertising the acceptably employable image. *Policy Studies Journal* 15 (3): 551–70.
- Haraway, D. 1989. *Primate visions: Gender, race, and nature in the world of modern science*. New York: Routledge.
- Kailes, J. I. 1995. *Language is more than a trivial concern!* (Available from June Isaacson Kailes, Disability Policy Consultant, 6201 Ocean Front Walk, Suite 2, Plaza del Rey, California 90293-7556).
- Longmore, P. K. 1985. The life of Randolph Bourne and the need for a history of disabled people. *Reviews in American History* 586 (December) 581–587.
- . 1987. Uncovering the hidden history of people with disabilities. *Reviews in American History* 15 (3) (September): 355–364.
- Minnick, E. K. 1990. *Transforming knowledge*. Philadelphia: Temple UP.
- Sedgwick, E. K. 1990. *Epistemology of the closet*. Berkeley: U of California P.
- Shapiro, J. P. 1993. *No pity: People with disabilities forging a new civil rights movement*. New York: Times Books.
- Steadman's Medical Dictionary. 1976. 23d ed. Baltimore: Williams and Wilkins.
- Tremblay, M. 1996. Going back to civvy street: A historical account of the Everest and Jennings wheelchair for Canadian World War II veterans with spinal cord injury. *Disability and Society* 11(2): 146–169.
- Tulloch, S., ed. 1993. *The Reader's Digest Oxford wordfinder*. Oxford, Eng.: Clarendon Press.
- Wendell, S. 1996. *The rejected body: Feminist philosophical reflections on disability*. New York: Routledge.

"This is an indispensable collection, bringing together foundational arguments in disability studies and provocative new work from emerging young scholars in the field. If you're curious as to why (and how) disability studies has stimulated so much debate in the humanities, *The Disability Studies Reader* is a great place to start finding out."

—Michael Bérubé, Paterno Family Professor in Literature, Penn State University

"There is simply no area of contemporary life—be it medical, economic, educational, juridical, athletic, architectural, culinary, recreation, entertainment—that goes unaddressed in the disability studies literature. Just when you thought that there was nothing new to say about social construction, difference, the performative, the universal, the particular, and the body, disability studies comes along to demonstrate both the theoretical and practical urgencies to which these and other too-often-abstract terms really refer. If you've been hearing about disability studies, but didn't quite know what to make of it, this is the anthology for you."

—Stanley Fish, Davidson-Kahn Distinguished University Professor of Humanities and Law,
Florida International University

"A classic just got even better! Only a few disciplines can claim a founding text. For disability studies, with its far-reaching implications for other fields, this is it. It all starts—and re-starts in a superb second edition—right here."

—David B. Morris, author of *The Culture of Pain*

"This revised edition demonstrates the significant evolution of the field. Greater attention to such vital issues as globalization, gender, critical race studies, and cultural constructions appear in cogent new essays that enhance and complement the collection. As with the original *Disability Studies Reader*, this edition challenges its readers with pioneering studies of theoretical models and the politics of disability."

—Susan Burch, author of *Signs of Resistance: American Deaf Cultural History, 1900 to World War II*

"This collection of scholarly essays strikes at the concept of normalcy and touches us on both personal and societal levels. From an academic perspective, the field of disability studies broadens our race, class, and gender discussions to include layers of identity and moments of connection. *The Disability Studies Reader* challenges us to re-examine human difference."

—I. King Jordan, President, Gallaudet University

Updated to reflect the latest developments in the growing field of disability studies, the new edition of *The Disability Studies Reader* retains the seminal, cutting-edge contributions that made the first edition so groundbreaking, while adding new content to address the contemporary concerns that have arisen since its initial publication. Comprised of experts in cultural studies, literary criticism, sociology, biology, the visual arts, and post-colonial studies, this anthology provides the most comprehensive introduction to disability studies available.

Lennard J. Davis is Professor of English, Disability Studies, and Medical Education at the University of Illinois at Chicago. He is the author of, among other books, *Enforcing Normalcy* and *Bending Over Backwards*.

Cover design: Elise Weinger

Cover image: © Guntmar Fritz/Zefa/Corbis

Printed in the U.S.A.

 **Routledge**
Taylor & Francis Group
an informa business
www.taylorandfrancisgroup.com

270 Madison Avenue
New York, NY 10016
2 Park Square, Milton Park
Abingdon, Oxon OX14 4RN, UK

ISBN 0-415-95334-0

