



Bending over Backwards

*Disability,
Dismodernism &
Other Difficult Positions*

Lennard J. Davis

With a Foreword by Michael Bérubé

BENDING OVER BACKWARDS

CULTURAL FRONT

GENERAL EDITOR: MICHAEL BÉRUBÉ

MANIFESTO OF A TENURED RADICAL

BY CARY NELSON

**BAD SUBJECTS: POLITICAL EDUCATION
FOR EVERYDAY LIFE**

EDITED BY THE BAD SUBJECTS PRODUCTION TEAM

CLAIMING DISABILITY: KNOWLEDGE AND IDENTITY

BY SIMI LINTON

**THE EMPLOYMENT OF ENGLISH: THEORY, JOBS,
AND THE FUTURE OF LITERARY STUDIES**

BY MICHAEL BÉRUBÉ

FEELING GLOBAL: INTERNATIONALISM IN DISTRESS

BY BRUCE ROBBINS

DOING TIME: FEMINIST THEORY AND POSTMODERN CLUTURE

BY RITA FELSKI

MODERNISM, INC.: BODY, MEMORY, CAPITAL

EDITED BY JANI SCANDURA AND MICHAEL THURSTON

**BENDING OVER BACKWARDS: DISABILITY, DISMODERNISM, AND OTHER
DIFFICULT POSITIONS**

BY LENNARD J. DAVIS

BENDING OVER BACKWARDS
DISABILITY, DISMODERNISM, AND OTHER
DIFFICULT POSITIONS

LENNARD J. DAVIS

with a foreword by Michael Bérubé



NEW YORK UNIVERSITY PRESS
NEW YORK AND LONDON

NEW YORK UNIVERSITY PRESS

New York and London

Copyright © 2002 by New York University

This work is licensed under the

Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 license
(CC BY-NC-SA 4.0).

To view a copy of the license, visit

<https://creativecommons.org/licenses/by-nc-sa/4.0>.

Library of Congress Cataloging-in-Publication Data

Davis, Lennard J., 1949–

Bending over backwards : disability, dismodernism, and other difficult positions /

Lennard J. Davis ; with a foreword by Michael Bérubé.

p. ; cm. — (Cultural front)

Includes bibliographical reference and index.

ISBN 0-8147-1949-X (cloth : alk. paper)

ISBN 0-8147-1950-3 (pbk. : alk. paper)

1. People with disabilities—United States. 2. Sociology of disability—United States.
3. Disability studies—United States. [DNLM: 1. United States. Americans with
Disabilities Act of 1990. 2. Disabled Persons—legislation & jurisprudence—United
States. 3. Public Policy—United States.] I. Title. II. Cultural front (Series)

HV1553 . D38 2002

362.4—dc21

2002005282

New York University Press books are printed on acid-free paper
and their binding materials are chosen for strength and durability.

Manufactured in the United States of America

10 9 8 7 6 5 4 3 2 1

CONTENTS

	FOREWORD: SIDE SHOWS AND BACK BENDS	vii
	BY MICHAEL BÉRUBÉ	
	INTRODUCTION	1
	PEOPLE WITH DISABILITY: THEY ARE YOU	
1.	THE END OF IDENTITY POLITICS AND THE BEGINNING OF DISMODERNISM	9
	ON DISABILITY AS AN UNSTABLE CATEGORY	
2.	CRIPS STRIKE BACK	33
	THE RISE OF DISABILITY STUDIES	
3.	DR. JOHNSON, AMELIA, AND THE DISCOURSE OF DISABILITY	47
4.	CRIMINAL STATEMENTS	67
	HOMOSEXUALITY AND TEXTUALITY IN THE ACCOUNT OF JAN SVILT— EIGHTEENTH-CENTURY SHIPWRECKED SAILOR	
5.	WHO PUT THE <i>THE</i> IN <i>THE NOVEL</i>?	79
	IDENTITY POLITICS AND DISABILITY IN NOVEL STUDIES	
6.	THE RULE OF NORMALCY	102
	POLITICS AND DISABILITY IN THE U.S.A. [UNITED STATES OF ABILITY]	
7.	BENDING OVER BACKWARDS	119
	NARCISSISM, THE ADA, AND THE COURTS	

8.	GO TO THE MARGINS OF THE CLASS	145
	DISABILITY AND HATE CRIMES	
9.	A VOYAGE OUT (OR IS IT BACK?)	158
	CLASS AND DISABILITY IN MY LIFE	
	NOTES	165
	INDEX	191
	ABOUT THE AUTHOR	201

FOREWORD

SIDE SHOWS AND BACK BENDS

Michael Bérubé

In 1995, in the opening pages of *Enforcing Normalcy*, Lennard Davis noted that identity politics seemed to have left one form of identity unaccounted for: “there is a strange and really unaccountable silence when the issue of disability is raised (or, more to the point, never raised); the silence is stranger, too, since so much of left criticism has devoted itself to the issue of the body, of the social construction of sexuality and gender.”¹ In the book’s conclusion Davis returned to this theme, at a slightly higher rhetorical pitch: “the concept of disability,” he claimed, “has been relegated to a sideshow, a freak show at that, far away from the academic midway of progressive ideas and concerns.”²

Two years earlier, the late James Tuttleton, writing in *The New Criterion*, had said something similar—not about disability, but about left criticism in toto: “As lit-profs are a national laughingstock,” he cried in a somewhat hysterical review of Gerald Graff’s *Beyond the Culture Wars*, “the only proper response is to ignore the freaks.”³ Freaked out as Tuttleton was by the amiable proposal to “teach the conflicts,” one can only imagine how freaky he would have considered Davis’s exhortation to consider disability as a critical term for the humanities. But what strikes me now about Davis’s claim isn’t the phrase “freak show” but the more innocuous phrase “sideshow.” For as we’ve heard many times in the 1990s, left criticism of the academic variety is itself a sideshow, even to many writers and organizers on the left: the main event is economic inequality, or the main event is the illegitimacy of the impeachment proceedings against Bill Clinton, or the main event is the contested election results in Florida, or the main event is September 11 and its aftermath. Theories of the social construction of sexuality and gender may have relegated disability to the margins, but to the margins of what? Of already socially marginal discourses?

It was not long ago, in other words, that one of the most prominent and prolific writers in the newly emergent field of disability studies could plausibly construe his field as the sideshow of a sideshow, featuring the freakiest of the freaks. The field has grown tremendously since Davis wrote those words, certainly; and yet just as certainly, disability studies has not so transformed the humanities—or the terrain of left criticism—that it is too late to gloss its still-marginal status. In *Time Passages*, George Lipsitz underwrote his forays into the sideshow of cultural politics by quoting jazz saxophonist Rahsaan Roland Kirk’s straight-up denial: “this ain’t no sideshow.”⁴ I could emphatically say the same of *Bending over Backwards*. But I’d like to show another side of the politics of the sideshow, and cite a text that poses the question of its subject’s marginality at the very outset. At the opening of David Lean’s epic *Lawrence of Arabia*, General Sir Edmund Allenby and diplomat Brian Dryden of the Arab Bureau are discussing the recent Arab attack on the city of Medina,

and T. E. Lawrence's consequent request to be reassigned as a military adviser to Prince Feisal:

Allenby: I may as well tell you, it's my considered opinion, and that of my staff, that any time spent on the Bedouin will be time wasted. They're a nation of sheep stealers!

Dryden: They did attack Medina . . .

Allenby: . . . and the Turks made mincemeat of them!

Dryden: We don't know that, sir.

Allenby: We know they didn't take it. A storm in a teacup, Brian! A sideshow! If you want my own opinion, this whole theater of operations is a sideshow. The real war is being fought against the Germans, not the Turks, and not here, but on the Western front, in the trenches! Your "Bedouin army," or whatever it calls itself, would be a sideshow of a sideshow!

Dryden: Big things have small beginnings, sir.⁵

General Allenby's words are true enough if you're thinking, as Allenby is, of a European war being fought in Flanders Fields or the Ypres salient. But as it turned out, the collapse of the Ottoman Empire, the signing of the Sykes-Picot agreement, the end of the caliphate, and the emergence of Arabian nation-states in Southwest Asia wound up being world-historical events after all, in the sense that we could reasonably consider the politics of the Arabian peninsula central to world affairs in the past half-century or thereabouts.

Lean's film (and Robert Bolt's and Michael Wilson's script) knows all this, of course, which is why it says as much. And in the same spirit, I want to suggest, modestly enough, that some sideshows are worth attending to on their own terms, regardless of how far they may seem from the ostensibly main event of the day. For disability studies did not start

to become an important area of study exclusively because of the recent work of Lennard Davis or David Mitchell or Sharon Snyder or Tobin Siebers or Rosemarie Garland Thomson or G. Thomas Couser or Brenda Jo Brueggemann, valuable though all their work has been; rather, disability studies has started to become an important area of study because the long (and largely unheralded) work of disability activists in the past three decades has finally begun to change American law and culture, making disability more visible and thinkable in the midways of American life, and because disability itself is so important to all our lives, so crucial to any account of human embodiment. Disability can be a practical matter of demographics, as Davis reminds us in these pages, or it can be a theoretical matter of deploying the instability of disability as a device for destabilizing all categories of identity, as Davis shows us in these pages. Either way, it doesn't really matter whether anyone thinks of disability as a sideshow; the subject will be central to human existence for as long as humans have bodies—and embodied minds to theorize them with.

The importance of disability as a category of social thought may depend more on the practices and politics of people with disabilities than on the work of academic disability studies, and for now, disability studies may be in the position of finding adequate theoretical concepts with which to describe those practices and politics; but few people in the humanities have done more in recent years to describe those practices and politics than Lennard Davis. Beginning with *Enforcing Normalcy*, which seamlessly blends Davis's earlier work on the history of the novel with his groundbreaking analysis of Adolphe Quetelet's characterization of *l'homme moyen* in the early nineteenth century, Davis has brought post-structuralist cultural history (in the mode of his first book, *Factual Fictions*) to bear on the concept of disability, thereby giving disability studies greater historical and theoretical depth and giving poststructuralism a much-needed specificity with regard to theories of the "normal" body. One measure of Davis's success in moving disability studies from

sideshow to midway is the new *Norton Anthology of Theory and Criticism*, which excerpts Davis's *Enforcing Normalcy* alongside the work of Homi Bhabha, Henry Louis Gates, Dick Hebdige, and Judith Butler; another more immediate measure is the work undertaken and performed by the essays in this volume, essays which demonstrate with eloquence and élan that disability studies is as pertinent to the history of the novel as to the history of the idea of citizenship, as important to the future of genetics as to the history of eugenics, as critical to legal theories of employment as to philosophical theories of embodiment.

For in *Bending over Backwards* Lenny Davis shows once again that the idea of the “normal” citizen was built on, distinguished from, and sustained by countless forms of “abnormal” bodies throughout the past three centuries, as the world's industrialized nations created their new social sciences of population management and figured their new normalities in all manner of social institutions and literary texts. In *Bending over Backwards*, Davis shows that disability simultaneously unsettles the categories of race, gender, class, and sexuality yet cannot be thought of without them, especially (but not exclusively) because disability is so intimately related to poverty, illness, and long-term unemployment. In *Bending over Backwards*, Davis shows us why professors of literature, freaky as they are, should learn to become good close readers of the Americans with Disabilities Act, *Vande Zande v. State of Wisconsin Dept. of Admin.*, and *Sutton v. United Air Lines*. In *Bending over Backwards*, Davis offers us a model of disability studies that points the way to a form of cultural criticism that's every bit as urgent and important as the cultural practices and politics it addresses.

I'm not going to predict—or even try to imagine—that any of the essays in this volume will have the impact of a Supreme Court decision or a vicious executive order directed against the sufferers of repetitive-stress injuries. But I do imagine that these essays will make it still more difficult for teachers and scholars in the humanities to consign disability studies to the margins of theoretical inquiry. And I might even go so far as to predict that in another decade or three, people will look back on Davis's

extraordinary body of work, from *Enforcing Normalcy* to *The Disability Studies Reader* to *My Sense of Silence* to *Bending over Backwards*, and wonder how in the world disability studies could ever have been considered a sideshow in the world of cultural criticism and theory. By that time, no doubt, everyone who works at the intersection of culture and society will know that disability is a pivotal concept for any comprehensive account of culture and society, and they'll assume that the critics of the late twentieth century and the early years of the twenty-first century were simply bending over backwards to avoid the subject—with the salient exception of people like Lennard Davis, and books like *Bending over Backwards*.

INTRODUCTION

PEOPLE WITH DISABILITY: THEY ARE YOU

As this book goes to press, the Supreme Court is considering three cases that will probably determine whether the Americans with Disabilities Act of 1990 will survive. The fate of disability as a legal category is profoundly in jeopardy. While I argue in this book that disability is itself an unstable category, I want to make clear that my argument is not to eliminate the category, as the Supreme Court threatens to do, but to extend the concept so that it applies broadly across society as a civil right for all—the right to be ill, to be infirm, to be impaired without suffering discrimination or oppression.

Most Americans react to the idea of disability with good wishes and a

silent prayer to the effect that “there but for the grace of God go I.” With this level of detachment, few will have noticed a disturbing and seemingly ineluctable trend in which the courts have been whittling away at the provisions of the Americans with Disabilities Act passed with much fanfare and hoopla in 1990 under Bob Dole’s stewardship, George Bush, Sr.’s imprimatur, and bipartisan congressional support. Ten years later, it has been estimated that 95 percent of the cases brought before the courts under the provisions of that act have been lost by people with disabilities.

The Supreme Court has been steadily hacking away at the provisions of the ADA, and the Court will hear cases whose outcomes could completely end the effectiveness of that legislation. The first case currently being heard is one in which an employer wants the right to determine for an employee if the job that employee wants is a danger to his or her health. Chevron withdrew the offer of a refinery job to a man because he tested positive for asymptomatic chronic Hepatitis C. Chevron maintained that the man would be doing possible harm to himself by accepting the position. While the ADA provides that an employer cannot discriminate against someone with a disability, Chevron asks that employers be allowed to discriminate to protect the person from possible harm. In bringing this case, Chevron is appealing a decision of a federal appeals court in San Francisco that rejected “paternalistic rules that have often excluded disabled individuals from the workplace.” If this case is decided in favor of Chevron, it will weaken the ADA by allowing employers, not employees, to decide issues relating to their own health.

The second case will have even more profound consequences in dismantling the ADA. In *Toyota v. Williams*, the auto company argued that Congress has defined disability too broadly. In this case an employee of the company had carpal tunnel syndrome that limited the use of her hands. She was able to perform her job perfectly well until transferred to a different task, which she could not perform. Her employer claimed that she was not disabled because although she could not perform her new task, she could brush her teeth, pick up objects in her home, and so on. Toyota demanded that those claiming coverage under the ADA must

demonstrate that they are “*severely restricted* from using their hands to perform a *broad range of basic functions* needed to meet the *essential demands of everyday life*.” The Supreme Court decided in *Toyota v. Williams* that if a person could carry out tasks at home like tooth-brushing and general chores he or she could not be considered disabled. Despite the fact that Ella Williams, the plaintiff, had carpal tunnel syndrome and could not carry out her job assignment, she would not, for the purposes of the law, be considered a person with a disability. Therefore, her employer could fire her for not doing her job, and she will now have no recourse to legal redress.

The ADA defines disability broadly as a substantial limitation in one or more life activities. In addition, people are considered to be in the protected class not only if they have a disability but also if they are “regarded as” being a person with disabilities. The latitude of this definition has had employers, particularly, up in arms. They fear that they will be beset with requests from their employees for accommodations and will be sued for violations of the Act. This, they say, will reduce employers to poverty. However, recent estimates by small businesses calculate that accommodations cost, on the average, under \$5,000, of which half can be made up by federal credits. The estimated cost per employee with a disability is \$250.

The Supreme Court, with its new activism, has decided a number of previous cases so that states’ rights predominate over federal protections in the area of disability. It has also ruled that people with correctable disabilities, such as hypertension and myopia, are not protected under the law. Even their employer discriminates against them for having such conditions. The net effect of these decisions has been to continue a process of whittling away the protections designed by Congress for people with disabilities.

The lack of knowledge or interest in these developments on the part of nondisabled people is part of a larger picture that the essays in this book address. We have created a firewall between them and us. While many white people have embraced the cause of people of color, and while

many straight people have taken up the cause of gay, lesbian, bisexual, and transgendered people, few “normals” have resonated with people with disabilities. The reasons for this are telling. No whites will become black; few straights will become gay; but every normal person can become disabled. All it takes is the swerve of a car, the impact of a football tackle, or the tick of the clock to make this transformation. Christopher Reeve, one day Superman, next day a quadriplegic, is the most dramatic example of this quick-change act.

The clock tolls for us in a less quirky way than the twist that brought Reeve to his wheelchair. Today’s baby boomer generation is fast heading toward disability. The World Health Organization (WHO) predicts that by the year 2020, there will be more than 690 million people over the age of sixty-five, in contrast with today’s 380 million. Two-thirds of the elderly will be in developing and underdeveloped nations. The increase in the elderly population will cause a major change in the disease patterns of these countries. There will be increasing rates of cancer, kidney failure, eye disease, diabetes, mental illness, and other chronic, degenerative illnesses such as cardiovascular disease.

Although identity politics is popular these days, what people fear is that disability is the identity one may become part of but didn’t want. This is the silent threat that makes folks avoid the subject, act awkwardly around people with disabilities, and consequently avoid paying attention to the current backlash against disability rights. Even without the baby boomers, currently 15 to 20 percent of people in the United States have disabilities. Add to this caregivers and family members, and about half the population is dealing with disability. People with disabilities make up the largest physical minority in our country—too large a group to ignore, and too large a group to roll back the protections afforded to them.

The essays in this book work toward the idea that “them” is actually “us.” If employers are concerned that the protected class is too large, they may have to reconsider their position as more people become disabled. Indeed, most people would be better off identifying with people with disabilities than fearing them. As you begin to notice your hearing going,

your hands stiffening, your eyesight in need of stronger glasses, you may well want to rethink what laws that protect you are being consigned to the dustbin of history. Would it be such a miscarriage of justice if all of us were protected from discrimination and the denial of access, just as all of us are protected from voter fraud and unwarranted search and seizure?

It isn't necessarily bad to be disabled, but it is bad to be discriminated against, unemployed, poor, and blocked by bad laws, architecture, and communication. If there is one thing the essays in this book argue for, it is a reconsideration of the status of disability in the law, in culture, and in society. They are, for the most part, written acts of *esprit d'escalier* following the publication of my *Enforcing Normalcy: Disability, Deafness, and the Body*. Written over the past five years, these essays explore some different terrain than the first book. In general, I wanted to expand my argument to link disability more coherently with politics, to link the disabled subject with the citizen, the governmental structures, and the law.

As with any collection of essays, there is coherence and there is incoherence. Because I've developed some ideas over the past years, most notably the concept of "dismodernism," not all the essays will hang together. But neither will they hang alone. The slow realization that came to me over the past five years, and that perhaps has come to everyone, is that the concept of identity, which served us well for the past twenty years, has been played out. So, while I began by wanting to include disability in the multicultural arena, I've ended by seeing it, along with most identities, as inherently unstable. But rather than jettison disability, I now think that its very difference from traditional identities—its malleable and shaky foundation—can be the beginning of an entirely new way of thinking about identity categories.

I've taken the liberty of placing as the first essay in this collection the one I wrote most recently, "The End of Identity Politics and the Beginning of Dismodernism," which proposes a utopian way of rethinking the body and identity. It contradicts some of the assertions in other essays, and picks up significantly on other assertions. It should be read as a prolegomenon rather than a finished proposal, and it should be read

contrapuntally with the other essays in this collection. Notably, the survey of the field of disability studies, “Crips Strike Back,” will provide a baseline for the interest and resurgence of disability as a subject of contemplation and activism. Two historical essays, “Dr. Johnson, Amelia, and the Discourse of Disability” and “Criminal Statements,” take us back to the eighteenth century and argue for the creation of the modern category of disability, but also remind us of the difficulty of retrieving historical materials about marginalized groups. “Who Put the *The* in *the Novel*?” is my attempt to link up the work I’ve done in disability with the earlier work I’d done on the origins of the novel. In this essay, I attempt to show that we can’t think about the origins of the novel without adding disability to the mix. “The Rule of Normalcy” asks us to think about the very nature of the Enlightenment subject, the individual, the citizen, and to realize how much normalcy and the normal body are involved in any attempt at nation-building and the creation of the modern state. “Bending over Backwards,” the eponymous chapter of this book, is an examination of the rhetoric of recent federal court rulings concerning the ADA, and “Go to the Margins of the Class” continues this discussion under the rubric of hate crimes. The last chapter, “A Voyage Out (Or Is It Back?)” is a more personal, memoirish ending that links me back personally to the materials I have been presenting.

This book is really a series of dialogues with myself and others. Those others are people crucially involved in disability studies who have taught me, counseled me, and allowed me to work with them on this exciting project. My appreciation goes to my colleagues at the University of Illinois at Chicago who have discussed issues with me—David Mitchell, Sharon Snyder, Carol Gill, Susanne Poirier, Sander Gilman, Walter Benn Michaels, Jennifer Ashton, Gerald Graff, Jane Tompkins, Stanley Fish, Brenda Russel, Charles Mills, Dwight McBride, Barbara Ransby, Mary Beth Rose, Michael Lieb, and Chris Messenger. And the many folks around the country and the world who have been my interlocutors: Rosemarie Thompson, Brenda Brueggemann, Rosamaria Lorretelli, Roberto

di Romanis, Michael Bérubé, Jeffrey Williams, Franco Moretti, Edward Said, Dirksen Bauman, Ben Bahan, Houston Baker, Anita Silver, Nancy Armstrong, Douglas Baynton, Ruth Colker, James Trent, Janet Zandy, Sandy Sufian, Julia Rodas, Rich McCoy, Linda Krieger, Theo Steiner, Ian Hacking, and Barbara Katz Rothman. I want to thank Bob Zimmerman for letting me sit in on his philosophy class at Sarah Lawrence during my sabbatical year and for teaching more than I ever thought I could know about Kant and Hegel. And of course deepest thanks to Michael Bérubé, series editor, and Eric Zinner, editor par excellence, who helped me think that this book might be a useful thing.

Finally, to Bella Mirabella, Carlo Emma Mirabella-Davis, and Francesca Mirabella-Davis—all of whom constitute the best editorial collective I'll ever be part of.

For their kind permission to reprint the following essays, thanks to:

Oxford University Press, for “Crips Strike Back: The Rise of Disability Studies,” in *American Literary History* 11:3 (Fall 1999).

University of Michigan Press, for “Dr. Johnson, Amelia, and the Discourse of Disability in the Eighteenth Century,” originally published in *DEFECTS: Engendering the Modern Body*, eds. Felicity Nussbaum and Helen Deutsch (Ann Arbor: University of Michigan Press, 2000).

Peter Lang Publishing, for “Criminal Statements: Homosexuality and Textuality in the Account of Jan Svilt,” in *Narrating Transgression: Representations of the Criminal in Early Modern England* (Frankfurt am Main: Peter Lang, 1999).

NOVEL Corp., for “Who Put the *The* in *the Novel*? Identity Politics and Disability in Novel Studies,” in *Novel: A Forum on Fiction* 31.3 (1998).

Kluwer, for “The Rule of Normalcy: Politics and Disability in the U.S.A. [United States of Disability],” in *Disability, Divers-ability, and Legal Change*, eds. M. Jones and Lee Ann Marks (London: Kluwer, 1999).

University of Michigan Press, for chapter 7, originally published as “Bending over Backwards: Disability, Narcissism and the Law,” in *Backlash against the Americans with Disabilities Act: Interdisciplinary Perspectives*, ed. Linda Kreiger (Ann Arbor: University of Michigan Press, 2002).

Routledge, for “Go to the Margins of the Class: Disability and Hate Crimes,” in *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions*, eds. Leslie Francis and Anita Silvers (New York: Routledge, 2000).

Rutgers University Press, for “The Voyage Out (Or Is It Back?): Class and Disability in My Life,” in Janet Zandy, ed., *Liberating Memory: Our Work and Our Working-Class Consciousness* (New Brunswick, N.J.: Rutgers University Press, 1995).

THE END OF IDENTITY POLITICS AND THE BEGINNING OF DISMODERNISM

ON DISABILITY AS AN UNSTABLE CATEGORY

There are times when the black man is locked into his body. Now, “for a being who has acquired consciousness of himself and of his body, who has attained the dialectic of subject and object, the body is no longer a cause of the structure of consciousness, it has become an object of consciousness.”

—Frantz Fanon, citing Merleau-Ponty,
Black Skin, White Masks

At times we might look back nostalgically to the moment when identity was relatively simple, when it was possible to say that one *was* black or white, male or female, “Indian” or not. It might once have been possible to answer the question that James Weldon Johnson’s narrator in *The Autobiography of an Ex-Colored Man* asks his mother “Are you white?” with her clear reply, “No, I am not white . . .” (8). But the issue of identity by race, gender, or sexual orientation, particularly in America, has become more clouded, fuzzier, grainier than it used to be. And so, the issue of a disability identity has begun to enter murkier grounds.

When I discussed the idea of clouding the issue of disability identity, a prominent disability scholar advised me not to pursue this line of thinking. “We’re not ready to dissolve disability identity. We’re just beginning to form it.” While I agree that there is a strategic kind of identity politics one might want to pursue, especially early on in an academic or political movement, I also think that ignoring the current seismic shifts in identity politics would be equally disastrous and could lead to major instability in the near future. If disability studies were to ignore the current intellectual moment and plow ahead using increasingly antiquated models, the very basis for the study of the subject could be harmed by making its premises seem irrelevant, shoddily thought through, and so on.

In effect, we do have to acknowledge that, unlike race, class, gender, sexual preference, and the like, disability is a relatively new category. Although the category has existed for a long time, its present form as a political and cultural formation has only been around since the 1970s, and has come into some kind of greater visibility since the late 1980s. The political and academic movement around disability is at best a first- or second-wave enterprise. The first wave of any struggle involves the establishment of the identity against the societal definitions that were formed largely by oppression. In this first phase, the identity—be it blackness, or gayness, or Deafness—is hypostasized, normalized, turned positive against the negative descriptions used by the oppressive regime. Thus “Black is Beautiful,” “Gay Pride,” and “Deaf Power” might be seen as mere reappropriations of a formerly derogatory discourse. The first phase also implies a pulling together of forces, an agreement to agree for political ends and group solidarity, along with the tacit approval of an agenda for the establishment of basic rights and prohibitions against various kinds of discrimination and ostracism.

In a second wave, a newer generation of people within the identity group, ones who have grown up with the libratory models well in place, begin to redefine the struggle and the subject of study. They no longer seek group solidarity since they have a firm sense of identity. In a second

wave, the principals are comfortable about self-examining, finding diversity within the group, and struggling to redefine the identity in somewhat more nuanced and complex ways. Often this phase will produce conflict within a group rather than unity. We've seen this most dramatically in the feminist movement when second-wave thinkers like Judith Butler have critiqued earlier essentialist notions that pulled the movement together initially. The conflict can come from differences that have been suppressed for the sake of maintaining a unified front so that the group could emerge in the first place and resist the formerly oppressive categorization and treatment.

Disability studies is, as I have said, a relatively new field of study. Its earliest proponents were writing in the 1970s and 1980s. The second wave of disability writing can be seen as emerging in the 1990s. Both the first and second waves have had a strong interest in preserving the notion of a distinct and clear entity known variously as "people with disabilities" (PWDs) or "Deaf people." In the case of PWDs, the interest has been in creating a collectivity where before there had been disunity. In the past, people with disabilities did not identify as such. Medical definitions of impairments were developed with no need to create unity among diverse patient groups. Wheelchair users saw no commonality with people with chronic fatigue syndrome or Deaf people. Given the American ethic of individuality and personal achievement, there would have been little incentive for PWDs to identify with the "handicaps" of other people. Rather, the emphasis would have been on personal growth, or overcoming the disability, and normalization through cure, prosthesis, or medical interventions. With the return of veterans from the Vietnam war, a movement grew up around civil rights for people with disabilities, which culminated in the Americans with Disabilities Act of 1990. By the beginning of the millennium disability activism, consciousness, and disability studies is well established, although many areas of the ADA are being rolled back in the courts and in the legislature.¹

To begin with, one might want to point out the obvious point that history repeats itself. As Marx wrote about the failed revolution in France,

people tend to model political movements on those of the past. For people with disabilities the civil rights model was seen as more progressive and better than the earlier charity and medical models. In the earlier versions, people with disabilities were seen variously as poor, destitute creatures in need of the help of the church or as helpless victims of disease in need of the correction offered by modern medical procedures. The civil rights model, based on the struggles of African Americans in the United States, seemed to offer a better paradigm. Not plagued by God nor beset by disease, people with disabilities were seen as minority citizens deprived of their rights by a dominant ableist majority.

Along with this model went the social model, which saw disability as a constructed category, not one bred into the bone. This social model is in dialogue with what is often referred to as the British model, which sees a distinction between impairment and disability. Impairment is the physical fact of lacking an arm or a leg. Disability is the social process that turns an impairment into a negative by creating barriers to access. The clearest example of this distinction is seen in the case of wheelchair users. They have impairments that limit mobility, but are not disabled unless they are in environments without ramps, lifts, and automatic doors. So, as long as the minority and/or social model held fast, this model seems to have worked pretty well, or at least as well as the civil rights model itself worked.

Enter postmodernity. The postmodern critique is one that destabilizes grand, unifying theories, that renders problematic desires to unify, to create wholes, to establish foundations. One could fill archives with what has been said or written about the culture wars, the science wars, and whatever other wars. In terms of identity, there has been an interesting and puzzling result. The one area that remained relatively unchallenged despite the postmodern deconstructionist assault was the notion of group identity. Indeed, the postmodern period is the one that saw the proliferation of multiculturalism. One could attack the shibboleths of almost any ground of knowledge, but one could never attack the notion of being, for example, African American, a woman, or gay. To do so would be tanta-

mount to being part of the oppressive system that created categories of oppressed others. One could interrogate the unity of the novel, science, even physics, but one could not interrogate one's right to be female, of color, or queer. Given this resistant notion of identity, the disability movement quite rightly desired to include disability as part of the multicultural quilt. If all the identities were under the same tent, then disability wanted to be part of the academic and cultural solidarity that being of a particular, oppressed minority represented.

Yet, within that strong notion of identity and identity politics, a deconstructive worm of thought began its own parasitic life. That worm targeted "essentialism." Just as no one wants to be a vulgar Marxist, no one wanted to be an essentialist. Essentialists—and there were fewer and fewer of them very soon after we began to hear the word—were putatively accused of claiming in a rather simple-minded way that being a woman or an ethnic minority was somehow rooted in the body. That identity was tied to the body, written on the body. Rather, the way out of this reductionist mode was to say that the body and identities around the body were socially constructed and performative. So while postmodernism eschewed the whole, it could accept that the sum of the parts made up the whole in the form of the multicultural, rainbow quilt of identities.² Social constructionism and performativity seemed to offer the way out of the problem caused by the worm of essentialism, but it also created severe problems in shaping notions of identity.³ If all identities are socially constructed or performative, is there a core identity there? Is there a there?

Disability offers us a way to rethink some of these dilemmas, but in order to do so, I think we need to reexamine the identity of disability, and to do so without flinching, without hesitating because we may be undoing a way of knowing. As with race, gender, and sexual orientation, we are in the midst of a grand reexamination. Disability, as the most recent identity group on the block, offers us the one that is perhaps least resistant to change or changing thoughts about identity. And, most importantly, as I will argue, disability may turn out to be the identity that links

other identities, replacing the notion of postmodernism with something I want to call “dismodernism.”

I am arguing that disability can be seen as the postmodern subject position for several reasons. But the one I want to focus on now is that these other discourses of race, gender, and sexuality began in the mid-nineteenth century, and they did so because that is when the scientific study of humans began. The key connecting point for all these studies was the development of eugenics.⁴ Eugenics saw the possible improvement of the race as being accomplished by diminishing problematic peoples and their problematic behaviors—these peoples were clearly delineated under the rubric of feeble-mindedness and degeneration as women, people of color, homosexuals, the working classes, and so on. All these were considered to be categories of disability, although we do not think of them as connected in this way today. Indeed, one could argue that categories of oppression were given scientific license through these medicalized, scientificized discourses, and that, in many cases, the specific categories were established through these studies.

Postmodernity along with science now offers us the solvent to dissolve many of these categories. In the area of race, we now know, for example, that there is no genetic basis to the idea that race, in its eugenic sense, exists. Thus far, no one has been able to identify a person as belonging to a specific “race” through DNA analysis. In fact, DNA analysis lets us understand that the category of race does not exist in physiological terms. Further, DNA analysis tells us that there is more genetic variation within a group we have called a race than within the entire human gene pool. Indeed, no one is even able to tell us how many races there are, and fine distinctions between phenotypes tend to dissolve the notion of categorical racial identities even further. The Human Genome Project offered up the possibility of mapping with certainty the complete sequence of approximately 3.2 billion pairs of nucleotides that make us human. But the project has left us with more questions than it has answered. For example, scientists are puzzling over the relatively low count of genes in the human genome. It had been estimated that humans would have approx-

imately 100,000 genes, but the study yielded a mere 30,000, putting *Homo sapiens* on par with the mustard cress plant (25,000 genes) in terms of genetic complexity.⁵ More annoying and less known is the fact that the two groups who analyzed the genome, the privately owned Celera group and the government-financed consortium of academic centers, have come up with only 15,000 that they jointly agree on. Fifteen thousand more genes do not overlap in either analysis.⁶ Considerable doubt exists as to whether these genes are “real.”

More to the point, there is considerable confusion over race in relation to genetics. On the one hand, we are told that the mapped human genome, taken from the DNA of one or two individuals, is the same for all humans. We are further informed that there is relatively little diversity in our genetic makeup. But we are also told that various “races” and ethnic groups have differing genetic markers for disability, defect, and disease. The contradiction is one that has been little explored, and those who have pursued the point have come under criticism for racializing genetics.⁷ Central to the confusion is the category of race itself. If we say, on the one hand, that there is no genetic way to ascertain race, and we also say that we have examined certain racial groups and discovered a greater chance of finding a particular gene, then we have indeed mixed our scientific categories.⁸

If we step back from the genetic level, we might want to investigate identity questions at the cellular level. Here, tellingly, we could investigate the HeLa cells widely used in laboratories and schools in what is called an “immortal cell line,” much like the lines developed currently for stem-cell research. These cells all derive from an African American woman named Henrietta Lacks who died in 1951 of cervical cancer. The cells were taken without the permission of Ms. Lacks, and became so widespread as to be ubiquitous. For the point of view of this discussion, the cells were presumed to be universal until 1967, when a geneticist named Stanley Gartler announced that at least eighteen other cell lines had been contaminated by the HeLa cells. He determined this by insisting that the presence of G6PD (glucose-6-phosphate dehydrogenase), an

enzyme which is a factor in red blood cell production, had been a marker in all these lines and that this type of enzyme “has been found only in Negroes” (61).⁹ Thus, during the early period of genetic research previously universal cells were racialized at the cellular level. But the appearance of race at the cellular level is no longer possible or relevant. The markers thought to be of a specific racial group have no validity for that identificatory purpose.

The issue of race is also complicated by the use of *in vitro* fertilization in a recent case of “scrambled eggs,” in which a fertility doctor implanted in a woman’s womb not only her own fertilized embryo but that of another couple as well. The resulting birth was of fraternal twins, one white and the other black.¹⁰ Such complications of reproductive technologies will certainly lead to other kinds of choices being made by parents and physicians, intentional as well as unintentional, with the effect of rendering even more complex racial or even gender identity.¹¹ Finally, the patrolled area of “mixed race” is being interrogated. The fact that multiracial identifications have been prohibited on national censuses is now being challenged. The reasons for keeping single-race checkoff boxes is itself a highly politicized and tactical arena in which, understandably, oppressed groups have gained redress and power by creating a unified subject. Where censuses allow a mixed-race checkoff, the statistical stronghold of race may well become weakened with questionable results.

In the area of gender, we are also seeing confusions in otherwise fixed categories. A culture of transgendered peoples is now being more widely permitted and the right to be transgendered is being actively fought for. The neat binaries of male and female are being complicated by volition, surgery, and the use of pharmaceuticals. Intersexuals, formerly known as hermaphrodites, were routinely operated upon at birth to assign them a specific gender. That move is now being contested by groups of adult intersexuals. Some feel they were assigned the wrong gender, and others feel that they would have liked to remain indeterminate. Transsexuals now routinely occupy various locations along a gender continuum, demarcating their place by clothing and other style-related choices, surgical

corrections, and hormonal therapy. Even on the genetic level, females who are genetically male and males who are genetically female are a naturally occurring phenomenon. The gender determination is suppressed or enhanced in these cases of “Turner Syndrome” or “Klinefelter Syndrome,” so that the genetic markers do not express the expected sexual phenotypes.¹²

Likewise, ethnicity is increasingly seen as problematic. Indeed, writers like Benedict Anderson have shown us that the idea of the nation is formed out of the suppression of ethnicities, although those ethnicities can end up forming new national consciousnesses. Steven Steinberg asserts that ethnicity is only one generation deep, and that all citizens become Americans after that generation, with only a thin veneer of food choices or other accoutrements of their ethnic origin to hold onto.¹³

Sexual orientation, which in the heyday of identity politics had a fairly definitive hold on defining a self, is now being questioned by many under the rubric of “queer studies.” Whereas once the choice of sexual partner indicated who one was—gay, lesbian, heterosexual, or bisexual—now, in an era of dissolving boundaries, sexual orientation has become strangely unhinged, especially with the advent of transgender politics. When a male-to-female transsexual marries a person who defines herself as a woman, should that relationship be called lesbian? If an intersexual person chooses a person of either gender, or another intersexual, how do we define the relationship? In such cases, sexual orientation becomes the only option that does not define the person in all ways as fitting into a discrete category. The change from the expression “sexual preference” to “sexual orientation” serves to indicate something hardwired into a person’s identity.

There has been some suggestion that there exists a “gay” gene, which, if it could be found definitively, would somehow settle the issue of gayness. But what we are seeing in the development of the Human Genome Project is that genetics is not the court of last resort in the story of life. No one gene determines the course of a human life. At this moment, while much good science has gone into the project of genetics, there is

still no gene therapy that works. In addition, the low number of genes in the recent mapping indicates that genes alone will not tell the story. Further, even where genes are shown to contribute to disease, as in for example the case of Jewish women of Eastern European origin who carry a marker for a type of breast cancer, there is no good explanation for why only one-third of all such women will eventually develop breast cancer. If genes were the uncomplicated set of instructions that we are told they are, in a process of scientific grandiosity sometimes referred to as “genohype,” there would be a one-for-one correspondence between the incidence of markers and the occurrence of disease.

Ultimately, if the grounds for an essentialist view of the human body are being challenged, so are the notions that identity is socially constructed. Most coherent of these critiques is Ian Hacking’s *The Social Construction of What?* Hacking shows, to my satisfaction at least, that the idea of social constructionism, while very useful in many regards, is itself tremendously underdeveloped theoretically and methodologically. And it has reached the end of its shelf life. Once shocking and daring, now it has simply become a way of saying that objects in the world have a history of shifting feelings, concepts, and durations. In addition, Walter Benn Michaels has recently said at a public presentation at the University of Illinois at Chicago in March 2001, that if we agree that there is no biological basis for race, then how does it make sense to say there is a social construction of it? Michaels gives the example that if we agree there is no scientific basis for the existence of unicorns, does it make sense to say let’s talk about the social construction of the unicorn?

So, if we follow this line of thinking, joining forces with the major critique of identity, we find ourselves in a morass in terms of identity politics and studies. There are various tactics one can take in the face of this conceptual dead end. One can object vehemently that X does indeed exist, that people have suffered for being X, and still do. Therefore, while there may be no basis in theory for being X, large numbers of people are nevertheless X and suffer even now for being so. Or one can claim that

although no one has been able to prove the biological existence of X, they will be able to do so someday. In the gap between then and now, we should hold onto the idea of being X. Or one could say that despite the fact that there is no proof of the existence of X, one wants to hold to that identity because it is, after all, one's identity. Finally, we can say that we know X isn't really a biologically valid identity, but we should act strategically to keep the category so that we can pass laws to benefit groups who have been discriminated against because of the pseudo-existence of this category.

All these positions have merit, but are probably indefensible rationally. The idea of maintaining a category of being just because oppressive people in the past created it so they could exploit a segment of the population, does not make sense. To say that one wants to memorialize that category based on the suffering of people who occupy it makes some sense, but does the memorialization have to take the form of continuing the identity?¹⁴ Even attempts to remake the identity will inevitably end up relying on the categories first used to create the oppression. Finally, strategic essentialism, as it is called, is based on several flawed premises, most notably the idea that we can keep secret our doubts so that legislators and the general public won't catch on. This Emperor's New Clothes approach is condescending to all parties, including the proponents of it.

Let us pause for a moment here to take into consideration the concept of disability as a state of injury, to use Wendy Brown's term. One of the central motivations for the Human Genome Project is the elimination of "genetic defects." The argument is based on a vision of the "correct" or "real" genome being one without errors or mistakes. Somewhere, in some empyrean there exists the platonic human genome. This genome is a book or text made up of letters sequenced in the right order without "mistakes." As such, it is in fact a sacred text and our correct reading of it is not unlike the vision that the fundamentalist has that his or her sacred text is infallible. However, the problem is that, as it stands now, the human genome is in need of fixing to make it perfect. Errors of transcription have ruined the primal perfection of the text. The problem is

related to exegesis and amanuensis. Thus, people with genetic diseases have “birth defects” and are “defective.”

This explanation, like most, is partial and error-laden. It is based on a pre-postmodern definition of human subjects as whole, complete, perfect, self-sustaining. This is the neoclassical model of Pico della Mirandola, Descartes, Locke, Hume, Kant, and so on. But if we think of cystic fibrosis or sickle cell anemia as “defects” in an otherwise perfect and whole human subject, are we making a grand mistake? Clearly, the people who have such genetic conditions are in grave peril. Few, if any, will live to a ripe old age. Each will have health issues. It would be in the interest of both those people and their physicians to heal their illnesses. Since there is no cure for these diseases at the present time, it seems reasonable to think that we can eliminate the defect by means of genetic medicine. So the idea that one would want to fix these genetic defects seems more than logical.

Yet the model involved in the idea of birth “defect” comes to us direct and unaltered from a eugenic model of the human body. Words like “fit,” “normal,” “degenerate,” “feeble,” “defect,” and “defective” are all interlaced. Their roots lie directly in the “scientific” study of humans that reached its liminal threshold in the middle of the nineteenth century. We now openly repudiate eugenics, mainly because of the Nazis’ use of “negative eugenics,” that is, the direct elimination of “defectives” from the human race. This seems so horrendous to us that the term is no longer used. But organizations in the United States and England have simply morphed their names into ones that use the term “genetics,” preserving the Latin linguistic root in both eugenic and genetic. Now eugenics (or genetics) is carried out through two avenues—prenatal screening, which works some of the time, and genetic engineering, which has not worked on humans so far. In both cases, the aim is to improve the human stock and to remove genetic defects. With the advent of the Human Genome and genetic sequencing projects, the illusion is that single genes will be discovered that can be “fixed” with an improved consequence. There is, of course, the problem of the “single gene” hypothe-

sis, now being hotly debated in the context of the latest claim that there is a single gene for speech.¹⁵

Many would claim that for behaviors like speech, sexual orientation, or intelligence, there can be no single gene or genetic causality. So the premise that we can fix a single gene is itself a problem. Further, the idea of a “mistake” is also problematic. Take the examples I have given of sickle-cell anemia and cystic fibrosis. The genetic markers for both these are recessive, which means that a great number of the population will have genetic information (or misinformation) for these diseases. It turns out that people who carry the trait are resistant to malaria (in the case of sickle-cell anemia) and cholera (in the case of cystic fibrosis). If we posit that other “defects” are also protective against pandemic diseases, we can see that the simple elimination of such defects might be a complicated process with a possibly dubious result. What we are discussing is an algorithm of collective protectivity through genetic diversity versus harm to select individuals. I’m not arguing for a trade-off, but I think evolution has made that trade-off and our genes contain the history of humans and pandemics.

The use of genetic testing to avoid giving birth to children with genetic defects is itself problematic. On a simple statistical level, it can probably only be done in relatively wealthy countries and among middle- and upper-class people. Paradoxically, the effect of doing so may actually serve to increase the incidence of the condition because each time a person is born with the disease, two of the inherited traits end with the person upon his or her death. By bypassing this draconian form of genetic regulation, we may actually be contributing to the increased distribution of the trait in the gene pool, particularly in developing countries. The effect shows us that the simple answer of fixing the defect itself is not simple. Further, we may be tampering with the ability of humans to survive pandemics that we know about and others that we don’t know about. How many people, for example, are now protected against developing active AIDS because they carry a trait for a “defect”?

Another aspect of this “defect” scenario is that a new issue is beginning

to arise in the courts—the right not to be born. French courts recently upheld this idea in regard to women who did not receive genetic testing and who gave birth to children who were, for example, born without an arm. The courts endorsed compensatory payments to such children who had the right to not be born and whose parents were not able to exercise that right because of lack of information. The legislature in a subsequent act voided the court’s ruling. Nevertheless, here indeed is a slippery slope, which many people with disabilities have regarded with suspicion. They rightly claim that their parents might have aborted them had they known of their upcoming impairment as children. On the other side of the disability divide, Deaf parents and parents of small stature have the ability to screen for the birth of a hearing child or a normal-sized child and to abort. And, of course, in countries like India and China, genetic testing is used to abort female fetuses. In the United States, the American Society for Reproductive Medicine, which sets the standards for most fertility clinics, officially stated that it is sometimes acceptable for couples to choose the sex of their children by selecting either male or female embryos and discarding the rest.¹⁶ These cases begin to blur the notion of what a “defect” is and is not. Designer babies, as foreseen in the film *Gattaca*, can begin to be seen as those who will not contain, for example, genes for breast cancer or high blood pressure. The possibilities are limitless.

Some of the issues I’ve outlined here are the result of a destabilization of the categories we have known concerning the body. The body is never a single physical thing so much as a series of attitudes toward it. The grand categories of the body were established during the Renaissance and the Enlightenment, and then refined through the use of science and eugenics. Postmodernism along with science has assaulted many of these categories of self and identity. What we need now is a new ethics of the body that acknowledges the advances of science but also acknowledges that we can’t simply go back to a relatively simple notion of identity. Genetics offers the way back, without, thus far, being able to deliver on that promise.

What I would like to propose is that this new ethics of the body begin with disability rather than end with it. To do so, I want to make clear that disability is itself an unstable category. I think it would be a major error for disability scholars and advocates to define the category in the by-now very problematic and depleted guise of one among many identities. In fact I argue that disability can capitalize on its rather different set of definitions from other current and known identities. To do this, it must not ignore the instability of its self-definitions but acknowledge that their instability allows disability to transcend the problems of identity politics. In setting up this model we must also acknowledge that not only is disability an unstable category but so is its doppelgänger—impairment.

In the social model, disability is presented as a social and political problem that turns an impairment into an oppression either by erecting barriers or by refusing to create barrier-free environments (where barrier is used in a very general and metaphoric sense). But impairment is not a neutral and easily understood term. It relies heavily on a medical model for the diagnosis of the impairment. For example, is Asperger's Syndrome or hysteria an impairment or the creation of the *folie à deux* of the observing physician and the cooperating patient?¹⁷ Is anorexia or ADD an impairment or a disability? Particularly with illnesses that did not exist in the past, the plethora of syndromes and conditions that have sprouted in the hearts and minds of physicians and patients—conditions like attention deficit disorder, fugue states, pseudoneurotic schizophrenia, or borderline psychosis—we have to question the clear line drawn between the socially constructed “disability” and the preexistent and somatic “impairment.” Ian Hacking, in *Mad Travelers: Reflections on the Reality of Transient Mental Illnesses*, points out that fidgety children were not considered to have impairments until ADD began. Is the impairment bred into the bone, or can it be a creation of a medical—technological—pharmaceutical complex?

Further, it is hard if not impossible to make the case that the actual category of disability really has internal coherence. It includes, according to the Americans with Disabilities Act of 1990, conditions like obesity,

attention deficit disorder, diabetes, back pain, carpal tunnel syndrome, severe facial scarring, chronic fatigue syndrome, skin conditions, and hundreds of other conditions. Further, the law specifies that if one is “regarded” as having these impairments, one is part of the protected class.

The perceived legal problem is that the protected class is too large, and that is one of the reasons there is a perceived backlash in the United States against the ADA. In response to initial concerns that too many people with minor conditions were qualifying as disabled, the federal courts have issued very narrow interpretations of disability.¹⁸ While we must deplore the fact that approximately 95 percent of cases brought before the courts are currently decided in favor of employers, we may also understand that some of this backlash is generated by a fear of creating a protected class that is too large. As with affirmative action, there is also general resentment among the populace that certain minority groups have special rights and privileges with regard to college admissions, job hiring, and so on. I want to be clear that I am not arguing against the protection of historically oppressed groups, as I will explain further. But I am calling attention to the increasingly ineffective means of achieving a goal of equality and equity in housing, jobs, and public accommodations.

Indeed, the protected class will only become larger as the general population ages. With the graying of the baby boomers, we will see a major increase in the sheer numbers of people with disabilities. As noted in the Introduction, the World Health Organization (WHO) predicts that by the year 2020, there will be more than 690 million people over the age of sixty-five, in contrast with today’s 380 million. Two-thirds of the elderly will be in developing and under-developed nations. The increase in the elderly population will cause a major change in the disease patterns of these countries. There will be increasing rates of cancer, kidney failure, eye disease, diabetes, mental illness, and other chronic, degenerative illnesses such as cardiovascular disease. Although we may want to call all these senior citizens people with disabilities, what will that mean? Will we have to start making decisions about who is disabled and who is not? What Occam’s razor will we use to hone the definition then? And how

will this majority of older people redefine disability, since they did not grow up with a disability or acquire one early in life? Who will get to claim the definition of disability or the lack of one?

Complicating the issue of disability identity is the notion of cure. Just as people can slip into disability in the blink of an eye or the swerve of a wheel, so too can people be cured. Indeed, although we don't expect this in the near future, it is possible to imagine a world in which disability decreases from 15 to 20 percent of the population to just 2 or 3 percent. Just as we saw a major reduction in infectious diseases in the West over the previous century, so too may we see a decrease in disabilities. Gene therapy, colossally unsuccessful up until this point, could have a major although unlikely breakthrough and become the treatment of choice for many illnesses. Stem cell research could lead to the regeneration of many tissues that are the cause of degenerative and traumatic diseases and conditions. And technological fixes may become much more sophisticated, so that, for example, cochlear implants, now very problematic even if you believe in the concept, could become foolproof. Indeed, this specter is rather terrifying and offensive to many Deaf people, and with good reason. Advances in biotechnology could create natural and effective gaits for paraplegics or useful prostheses that might be virtually indistinguishable from human limbs. Indeed, political issues aside, the possibility does exist of cures for many impairments that now define a group we call "people with disabilities." We must recall though, that cures will of course only be available to people with means in wealthy countries.

What we are discussing is the instability of the category of disability as a subset of the instability of identity in a postmodern era. It would be understandable if one responded to what I've suggested by saying that, notwithstanding this instability, the category must be left alone. It must be maintained for all the reasons I had suggested earlier. Or, as one of my students responded, "What will happen to the handicapped parking space, if what you advocated happens?" True, but I want to propose that the very rationale for disability activism and study is good enough, indeed better than good enough, rationale for many people—people other

than those we now call People with Disabilities. Rather than ignore the unstable nature of disability, rather than try to fix it, we should amplify that quality to distinguish it from other identity groups that have, as I have indicated, reached the limits of their own projects. Indeed, instability spells the end of many identity groups; in fact it can create a dismodernist approach to disability as a neoidentity.

What characterizes the limitations of the identity group model is its exclusivity (which contains the seeds of its own dissolution through the paradox of the proliferation of identity groups). Indeed, you have to be pretty *unidentified* in this day and age to be without an identity. So the very criticism of the category of disability as being too large, as containing too big a protected class, is actually a *fait accompli* with the notion of identity in general. We should not go on record as saying that disability is a fixed identity, when the power behind the concept is that disability presents us with a malleable view of the human body and identity.

Enlightenment thought would have it that the human is a measurable quantity, that all men are created equal, and that each individual is paradoxically both the same and different. Or perhaps, as Kierkegaard put it, “the single individual is the particular that has its *telos* in the universal.”¹⁹ In the past much of the paradoxical attitude toward citizens with disabilities arose from the conflict between notions of the equality of universal rights and the inequality of particular bodies.²⁰

For all the hype of postmodern and deconstructive theory, these intellectual attempts made little or no impression on identity politics. Rather, those who pushed identity had very strong Enlightenment notions of the universal and the individual. The universal subject of postmodernism may be pierced and narrative-resistant but that subject was still whole, independent, unified, self-making, and capable. The dismodern era ushers in the concept that difference is what all of us have in common. That identity is not fixed but malleable. That technology is not separate but part of the body. That dependence, not individual independence, is the rule. There is no single clockmaker who made the uniform clock of the

human body. The watchword of dismodernism could be: Form follows dysfunction.

What dismodernism signals is a new kind of universalism and cosmopolitanism that is reacting to the localization of identity. It reflects a global view of the world. To accomplish a dismodernist view of the body, we need to consider a new ethics of the body. We may take Kierkegaard's by-now naïve belief in the universal and transform it, knowing that this new universalism cannot be a return to Enlightenment values. Rather it must be a corrective to the myths not only of the Enlightenment but of postmodernism as well.

A new ethics of the dismodernist body consists of three areas: The first concerns the official stance—care *of* the body is now a requirement for existence in a consumer society. We are encouraged and beseeched to engage in this care; indeed, it is seen as a requirement of citizenship. This care of the body involves the purchase of a vast number of products for personal care and grooming, products necessary to having a body in our society. Although we are seen as self-completing, the contemporary body can only be completed by means of consumption. This is the official stance: that the contemporary human body is incomplete without deodorant, hair gel, sanitary products, lotions, perfumes, shaving creams, toothpastes, and so on.²¹ In addition, the body is increasingly becoming a module onto which various technological additions can be attached. The by-now routine glasses, contact lenses, and hearing aids are supplemented by birth-control implants, breast implants, penile implants, pacemakers, insulin regulators, monitors, and the like. Further work will also intimately link us to more sophisticated cybertechnology. All this contributes to what Zygmund Bauman calls “the privatization of the body,” which he sees as the “primal scene of postmodern ambivalence.” The aim and goal, above all, is to make this industrial-modeled, consumer-designed body appear “normal.” And even people with disabilities have to subscribe to this model and join the ranks of consumers.²²

Another official area pertains to care *for* the body, an area that also links the economy with the body. Here we must confront an entire

industry devoted to caring for the human body. We are discussing the healthcare industry and the dependent care industry. Included here are physicians' private practices, clinics, medical insurance companies, medical laboratories, hospitals, extended-care facilities, hospitals, hospices, nursing homes, in-home caregivers, pharmacies, manufacturers of assistive devices, and organizations that promote the research, development, and care of certain kinds of illnesses and conditions. In most countries, this industry makes up the largest sector of the economy. There are obviously huge economic advantages to the creation and maintenance of the disability industry. It is important to recall that since huge financial commitments are being made to the abnormal body, the ethics involved in the distribution of resources and the shaping of this industry is a major part of our approach to an ethical society. By and large, this industry is controlled and dominated by people who are not people with disabilities.

Finally, to secure a dismodernist ethics, in opposition or in some cases in alliance with the official stance, we need to discuss caring *about* the body. This is the area I would most like to emphasize. If we care about the body, that is to say care about the issues I have raised, we finally begin to open up and develop a dismodernist discourse of the body and the uses of bodies. This area begins with attention paid to human rights and civil rights that have to be achieved to bring people with disabilities to the awareness of other identity groups. Here we must discuss the oppression of so-called abnormal bodies, and the treatment of the poor with disabilities. Class again becomes an issue in identity. We must focus on the poor, since by all estimates the majority of people with disability are poor, unemployed, and undereducated. In the United States, only one-third of people with disabilities are employed, versus upward of 70 percent of "normal" workers. Indeed, many people with disabilities end up in prisons—particularly those with cognitive and affective disabilities. A *New York Times* article (August 7, 2000) pointed out that one in ten death row inmates are mentally retarded. Since the majority of people in the United States become quadriplegic or paraplegic from gunshot wounds, a disproportionate number of African American males are so impaired. And

therefore a large number of these males with disabilities are also in prisons, often without adequate accommodations.

On an international level, land mines create impairments on a daily basis, and this fact combined with other technologies of war and extremely poor working conditions in sweatshop environments creates a level of disability in so-called developing countries that requires attention and thought. The treatment of women and female babies—including the abortion of female fetuses, the use of clitorectomies, the oppression of gay, lesbian, bisexual, and transgendered people—often intersects in familiar and unfamiliar ways with the mechanisms of disablement. It can be said that the most oppressed person in the world is a disabled female, Third World, homosexual, woman of color. In addition, the absence of adequate wheelchairs in poor countries, along with inadequate street and public accommodation facilities create a virtually inaccessible world for people with mobility impairments.

My point is that with a dismodernist ethic, you realize that caring *about* the body subsumes and analyzes care *of* and care *for* the body. The latter two produce oppressive subjection, while the former gives us an ethic of liberation. And the former always involves the use of culture and symbolic production in either furthering the liberation or the oppression of people with disabilities.

An ethics of the body provides us with a special insight into the complex and by now dead end of identity politics. The problem presented to us by identity politics is the emphasis on an exclusivity surrounding a specific so-called identity. Writers like Kenneth Warren, K. Anthony Appiah, Paul Gilroy, Wendy Brown, Walter Benn Michaels, Thomas Holt, and others are now critiquing the notion of a politics based on specific identities and on victim status. Disability studies can provide a critique of and a politics to discuss how all groups, based on physical traits or markings, are selected for disablement by a larger system of regulation and signification. So it is paradoxically the most marginalized group—people with disabilities—who can provide the broadest way of understanding contemporary systems of oppression.

This new way of thinking, which I am calling dismodernism, rests on the operative notion that postmodernism is still based on a humanistic model. Politics have been directed toward making all identities equal under a model of the rights of the dominant, often white, male, “normal” subject. In a dismodernist mode, the ideal is not a hypostatization of the normal (that is, dominant) subject, but aims to create a new category based on the partial, incomplete subject whose realization is not autonomy and independence but dependency and interdependence. This is a very different notion from subjectivity organized around wounded identities; rather, *all* humans are seen as wounded. Wounds are not the result of oppression, but rather the other way around. Protections are not inherent, endowed by the creator, but created by society at large and administered to all. The idea of a protected class in law now becomes less necessary since the protections offered to that class are offered to all. Thus, to belatedly answer my student, normal parking becomes a subset of handicapped parking.

The dismodernist subject is in fact disabled, only completed by technology and by interventions. Rather than the idea of the complete, independent subject, endowed with rights (which are in actuality conferred by privilege), the dismodernist subject sees that metanarratives are only “socially created” and accepts them as that, gaining help and relying on legislation, law, and technology. It acknowledges the social and technological to arrive at functionality. As the quadriplegic is incomplete without the motorized wheelchair and the controls manipulated by the mouth or tongue, so the citizen is incomplete without information technology, protective legislation, and globalized forms of securing order and peace. The fracturing of identities based on somatic markers will eventually be seen as a device to distract us from the unity of new ways of regarding humans and their bodies to further social justice and freedom.

We can thus better understand how the by now outdated postmodern subject is a ruse to disguise the hegemony of normalcy. Foucault is our best example. His work is, as Edward Said has noted, in *Power, Politics and Culture: Interview with Edward W. Said*, a homage to power, not an

undermining of it. Said calls Foucault a “scribe” of power because of his fascination with the subject. For Foucault the state is power and citizens are docile bodies. This overtly sadomasochistic model is one that is part of a will-to-power, a fantasy of utter power and utter subjection. That model appeared to be postmodern, but was in fact the nineteenth century of Freud, Sacher-Masoch, and imperialism writ large. Instead, dismodernism doesn’t require the abjection of wounds or docility to describe the populace, or the identity groups within. Rather it replaces the binary of docility and power with another—impairment and normalcy. Impairment is the rule, and normalcy is the fantasy. Dependence is the reality, and independence grandiose thinking. Barrier-free access is the goal, and the right to pursue happiness the false consciousness that obscures it. Universal design becomes the template for social and political designs.

The rhizomatic vision of Deleuze’s solution to the postmodernist quandary presented by power, with its decentered, deracinated notion of action, along with the neorationalist denial of universals, leaves us with a temporary, contingent way of thinking about agency and change. The dismodernist vision allows for a clearer, more concrete mode of action—a clear notion of expanding the protected class to the entire population; a commitment to removing barriers and creating access for all. This includes removing the veil of ideology from the concept of the normal, and denying the locality of identity. This new ethic permits, indeed encourages, cosmopolitanism, a new kind of empire, to rephrase Hardt and Negri, that relies on the electronic senses as well as the neoclassical five. It moves beyond the fixity of the body to a literally constructed body, which can then be reconstructed with all the above goals in mind.

Clearly, what I am describing is the beginning of a long process. It began with the efforts of various identities to escape oppression based on their category of oppression. That struggle is not over and must continue. While there is no race, there is still racism. But dismodernism argues for a commonality of bodies within the notion of difference. It is too easy to say, “We’re all disabled.” But it is possible to say that we are all disabled

by injustice and oppression of various kinds. We are all nonstandard, and it is under that standard that we should be able to found the dismodernist ethic.

What is universal in life, if there are universals, is the experience of the limitations of the body. Yet the fantasy of culture, democracy, capitalism, sexism, and racism, to name only a few ideologies, is the perfection of the body and its activities. As Paul Gilroy writes, “The reoccurrence of pain, disease, humiliation, grief, and care for those one loves can all contribute to an abstract sense of human similarity powerful enough to make solidarities based on cultural particularity appear suddenly trivial.”²³ It is this aspect of experience, a dismodern view, that seems suddenly to be, at the beginning of the twenty-first century, about the only one we can justify.

CRIPS STRIKE BACK

THE RISE OF DISABILITY STUDIES

In the 1932 film classic *Freaks*, there is a grisly scene of revenge in which a posse of microcephalics, dwarves, midgets, conjoined twins—described by MGM’s publicity as “creatures of the abyss,” “strange children of the shadows,” and “nightmare shapes in the dark”—mutilates the beauty queen who has swindled and poisoned her midget husband. Transformed from beauty to freak, she is exhibited in the final scene of the movie as the grotesque “chicken woman.”

This scene of retribution, the feverish fantasy of the “normal” director Todd Browning, comes up frequently in current writings on disability. It does so, for example, in Joan Hawkins’s essay in an anthology

entitled *Freakery: Cultural Spectacles of the Extraordinary Body* (1996). Of course, the scene serves as a perfect example of the imagined bitterness and resentment nondisabled people project onto people with disabilities, But it also provides a leitmotif for the newly emerging discourse in recent American writing and scholarship on disability. One can see this imagery at work in Simi Linton's book, *Claiming Disability: Knowledge and Identity* (1998), in which she describes the liberation of disabled people from "the institutions that have confined us, the attics and basements that sheltered our family's shame": "We have come out, not with those brown wool lap robes over our withered legs, or dark glasses over our pale eyes, but in shorts and sandals . . . —straightforward, unmasked, and unapologetic. . . . We are everywhere these days, wheeling and loping down the street, tapping our canes, sucking on our breathing tubes. . . . We may drool, speak in staccato syllables, wear catheters to collect our urine, or live with a compromised immune system."¹

While Linton's description is short of a revenge scenario, it reveals something of the specter haunting normality in our time. That specter may be crippled, deaf, blind, spasming, or chronically ill—but it is clearly no longer willing to be relegated to the fringes of culture and academic study. This defiant tone emerges in Kenny Fries's title *Staring Back: The Disability Experience from the Inside Out* (1997), an anthology of disability writing, and in his introduction to the volume: "Throughout history, those who live with disabilities have been defined by the gaze and the needs of the nondisabled world. Many times, those who live with disabilities have been isolated in institutions, experimented upon, exterminated. We . . . have been silenced by those who did not want to hear what we had to say."² Like Browning's freaks, disability activists and scholars are returning the Medusa gaze of the "normals" in action and in print.

Within the past five years, articles and news stories about the academic study of disability have appeared with regularity in the *New York Times*, the *Chronicle of Higher Education*, the *Hastings Center Report*, and other publications. New scholarly analyses, as well as anthologies, memoirs, journals like *Disability Studies Quarterly* (the periodical of the Society for

Disability Studies), and slick disability-related magazines like *We* and *Poz* are appearing and disappearing with the speed of a wheelchair racer. The University of Michigan Press has discerned the potential of a new market and has initiated a series on disability studies, while editors at scholarly presses such as Routledge, Chicago, Rutgers, Duke, Illinois, and NYU recruit books on this subject. And disability studies was seen as threatening enough to warrant a right-wing attack in an article entitled “Disability Chic,” which appeared in the *New York Press* in February 1998.

Despite this recent increase in publications on disability, however, the majority of academics do not consider disability to be part of their social conscience. As Michael Bérubé, author of *Life as We Know It: A Father, a Family, an Exceptional Child* (1996), his essay and memoir of parenting a son with Down Syndrome, notes: “I did not see what ‘disability studies’ might have to do with me. I had what I thought was a liberal, open-minded attitude toward mental and physical disabilities . . . but when it came to whether disability should be a major academic subject, I just couldn’t see the point of one more ‘additive’ studies program” (qtd. in Linton 1998:2–3). Bérubé thinks of his resistance to disability studies as “a piece with a larger and more insidious cultural form of resistance.”³ He calls this “the politics of disavowal” which he links to “the psychological distance most people put between themselves and disability.”⁴ Disability scholars locate that distance in social constructions such as “the stare,” that telling glance directed toward people with physical differences; in the omission of disability culture from anthologies, curricula, and conference topics; in the barriers placed before Deaf and disabled scholars who do attempt to attend academic conferences that make no provision for them.⁵ The distance Bérubé refers to is called “ableism,” an equivalent to better known terms like racism or sexism.

But despite some similarities to other forms of identity politics, disability studies is not just the new multicultural kid on the block. Rather, the discussions interrogate many truisms of the field. Most noteworthy is the rather impermeable barrier that each patch of the multicultural quilt sets up between itself and others. To be African American is not to be

white; to be gay is not to be straight. But the category of disability is permeable—anyone can become disabled, and in fact, most people will develop impairments with age (according to a recent report, between 40 and 80 percent of people sixty-five and older are disabled.⁶ Indeed, the acronym TAB (Temporarily Able-Bodied) serves to remind us of the shaky footing on which normalcy rests. This point is brought home by Paddy Masfield, a British theater director and playwright, who became disabled at forty-four: “If I had gone to sleep a man and woken up a woman, or gone to sleep white and woken up black, I might have had some understanding of my new situation. After all, more than half my world were women, I was born in Africa and I had many black professional colleagues, personal friends, teachers. . . . Had I really in forty-four years, never thought of disability, never worked with disabled colleagues, never travelled, holidayed, shopped or partied with disabled people?”⁷ Given that people with disabilities compose 15 percent of the population—the largest physical minority in most countries—and that the likelihood that many of the nondisabled today will become the disabled of tomorrow, it is strange that most people are more willing to identify with the struggles of African Americans or gays and lesbians, each of whom comprise a smaller percentage of the total population. As Michael Bérubé asks, “Why isn’t disability seen as a potentially universal condition—as it most assuredly is?”⁸

Because disability is an amorphous identity with porous boundaries, other identity groups in the United States have had difficulty incorporating it into their goals. Previously legitimized groups such as Latinos or African Americans have been reluctant to admit disability into the multicultural arena. For example, in 1996 a disabled, white assistant professor at a historically black university found that the chair of the department and the dean of the school had recommended against tenure, saying that any analogy between disability and race was both methodologically unsound and insulting to the unique history of African Americans. For them, the categories of oppression were mutually exclusive and should not be mixed. After much public outcry from the disability

community, the president of the university decided to award tenure to the assistant professor. Nevertheless, the issue of an identity defined by impairment as opposed to one defined by race or ethnicity is a sticking point for some. When some faculty members at Hunter College in New York City tried to include disability studies as part of the requirement for a multicultural curriculum, they were opposed by many of the ethnic and national groups that usually make up the progressive wing of the university. Hunter ended up deciding to omit disability from the curriculum.

Even within the disability rights movement itself, notions about who falls into the category of the “disabled” are unclear. For example, many Deaf activists do not consider themselves disabled. Rather, the Deaf think of themselves as a linguistic minority like Latinos or Asians, who are defined by their use of a language other than the dominant one in the United States. Deaf advocates such as Paddy Ladd, Tom Humphries, and MJ Bienvenue claim they have nothing in common with amputees, paraplegics, or people with mental retardation. Nor do they wish to be included in a group of people who are seen as “incapacitated.” This was the case with the 87 percent of respondents to *Deaf Life’s* questionnaire who said they did not consider themselves handicapped, and the eight out of ten deaf people who said they did not want cochlear implants to help them hear.⁹ Deaf scholars argue that their “problem” is not that they are deficient, but that the society at large does not know, nor does it care to know, how to speak American Sign Language. Harlan Lane, in his article in *The Disability Studies Reader*, criticizes the disability movement for making the category of disability “universal” and including every disability under its umbrella, although deafness is culturally and structurally very different from many other disabilities. Likewise, the Deaf and the disabled do not see eye-to-eye on the issue of mainstreaming. Disabled people want to be mainstreamed into the “normal” educational system rather than be segregated in often inferior schools. But for the Deaf, mainstreaming is seen as cultural genocide since residential schools are the breeding ground of Deaf culture. Further, the Deaf want to be in a

setting where their language, ASL, is used as the primary teaching and social language.

The fact is that disability disturbs people who think of themselves as nondisabled. While most liberals and progressives would charitably toss a moral coin in the direction of the lame, the blind, or the halt, few have thought about the oppression committed in the name of upholding the concept of being “normal.” Consequently, one of the major tasks of this new field is to determine why this “fact” of disturbance exists, is accepted, and is promulgated. Disability scholars want to examine the constructed nature of concepts like “normalcy” and to defamiliarize them. David Pfeiffer writes that “normal behavior is a statistical artifact which encourages people with power and resources to label people without power and resources as abnormal.”¹⁰ Rosemarie Garland Thomson coins the term “normate” to make us think twice about using the term normal: “The term normate usefully designates the social figure through which people can represent themselves as definitive human beings. Normate, then, is the constructed identity of those who, by way of the bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them.”¹¹

Normates thus enforce their supposed normality by upholding some impossible standard to which all bodies must adhere. To further demystify such terms, disability activists have called attention to the routine ways in which language is used to describe people with disabilities. Such activists refer to themselves as “crips,” as in the video documentary by David Mitchell and Sharon Snyder called *Vital Signs: Crip Culture Talks Back*, and choose words like *gimp*, *geek*, *deaf*, and *blind* over more polite euphemisms. Expressions like “confined to a wheelchair” are being replaced by the more active “wheelchair user.” And expressions that use impairments metaphorically to convey a negative sense—such as “a lame idea,” “turn a deaf ear,” or “morally blind”—are being seen as the equivalent of racial epithets.

This obsession with being normal has a history, as I attempt to show in my book *Enforcing Normalcy*.¹² The use of the word normal in refer-

ence to physical bodies appeared in English merely one hundred fifty years ago, coinciding with the birth of statistics and eugenics. Before the nineteenth century in Western culture the concept of the “ideal” was the regnant paradigm in relation to bodies, and so all bodies were less than ideal. The introduction of the concept of normality, however, created an imperative to be normal, as the eugenics movement proved by enshrining the bell curve (also known as the “normal curve”) as the umbrella under whose demanding peak we should all stand. With the introduction of the bell curve came the notion of “abnormal” bodies. And the rest is history, including the Nazis’ willing adoption of the state-of-the-art eugenics funded and developed by British and American scientists, as Martin Pernick points out in *The Black Stork*.¹³ The devastating result was the creation of procedures for exterminating deaf and disabled people, procedures which were later used on the Jews, gypsies, and other “degenerate” races. But the Nazis were only the most visible (and reviled) tip of an iceberg that continues quite effectively to drive humans into daily frenzies of consuming, reading, viewing, exercising, testing, dieting, and so on—all in pursuit of the ultimate goal of being considered normal.

Disability studies demands a shift from the ideology of normalcy, from the rule and hegemony of normates, to a vision of the body as changeable, unperfectable, unruly, and untidy. Philosopher Susan Wendell sounds a clarion call that in the end provides a rationale for the disability perspective: “Not only do physically disabled people have experiences which are not available to the able-bodied, they are in a better position to transcend cultural mythologies about the body, because they cannot do things the able-bodied feel they must do in order to be happy, ‘normal’ and sane. . . . If disabled people were truly heard, an explosion of knowledge of the human body and psyche would take place.”¹⁴

This cult of the normal is linked to a myth that people with disabilities are better off in the twentieth century than they were in the past. There is an open debate on whether life was better or worse for people with disabilities in the past—an area of study that is only beginning to be researched and analyzed. Moreover, the history of disability is crucial not

only to an understanding of what constitutes “disability,” but also to current attempts to formulate theories of the modern “body.” For example, many disability historians, including Michael Oliver, see a profound change in conceptions of normalcy and the body when industrialization made the standardized body necessary for both the factory line and its products, while relegating the “abnormal body” to the welfare rolls.¹⁵ Other scholars, like Martha Edwards in her essay, “Deaf and Dumb in Ancient Greece” in *The Disability Studies Reader*, see preindustrial communities as being more accepting of people with disabilities. Edwards’s revisionist history of the ancient world shows that disability was often prized in classical Greece, particularly because so many people with disabilities received their impairments in war or artisan activities, gaining marks of honor in a warrior culture that also valued the aesthetic. In another article, Edwards debunks the “truism” that the Greeks routinely practiced infanticide on children with disabilities. In disproving this assumption, Edwards points out the underlying biases of classical scholars who assume that it is self-evident that a “perfect” society like the Greeks would want to kill less than perfect babies.¹⁶

Other historians, such as James Trent, have shown that mental retardation was regarded as “an expected part of rural and small town life,” with “simpletons” and “fools” kindly regarded, even romanticized by the likes of William Wordsworth, and cared for by family members and the community.¹⁷ This inclusion changed during the nineteenth century when “feeble-mindedness” was invented and pathologized, shifting society’s role from education to custodianship. Likewise, historian Douglas Baynton reveals that the deaf were pathologized and controlled by hearing “educators” who banned sign language and forced Deaf people to speak orally during the same period.¹⁸

The fact that disability and normality can be looked at as sociohistorical concepts is crucial to disability studies, since the alternative paradigms—the medical and rehabilitation models—presume that disability is a universal constant. These models have been operating (literally) on disabled people for more than a hundred and fifty years. The medical

model treats disability as a disease in need of a cure, while the rehabilitation model sees it as a body in need of repair, concealment, remediation, and supervision. The results of these two models are activities like implanting cochlear devices in the deaf, forcing mobility-impaired people to use prosthetics to walk “normally,” or performing painful and invasive corrective surgery for cosmetic purposes. Likewise medical people have, until recently, been the sole publicists for issues around disability; consequently, the ableist prognosis for medical interventions in the twentieth century has been glowing. As opposed to the medical model, the constructionist model sees disability as a social process in which no inherent meanings attach to physical difference other than those assigned by a community. This model condemns the medical establishment for its single-minded reliance on technology, institutionalization, and remediation.

In a constructive mode first articulated by the late Irving Kenneth Zola of Brandeis University, disability scholars make the distinction between impairment and disability. An impairment involves a loss or diminution of sight, hearing, mobility, mental ability, and so on. But an impairment only becomes a disability when the ambient society creates environments with barriers—*affective, sensory, cognitive, or architectural*. For example, a person using a wheelchair is only disabled if there are no ramps; a Deaf scholar is only disabled if there is no interpreter provided at a conference; a blind scholar is disabled in the absence of large-type or Braille texts, or a computer and scanner.

In addition to the constructivist model, a model of the disabled person as oppressed minority-group member, articulated by Harlan Hahn in several articles,¹⁹ Harlan Lane,²⁰ and James Charlton,²¹ sees a capitalist, imperialist power structure as one that needs to create an exploited and exploitable minority. Hahn articulates an analysis of capitalism and consumerism that creates ideal bodies for advertising and publicity by casting out various minorities as abnormal—including minority ethnic groups and people with disabilities. Lane, writing specifically about the Deaf, makes analogies between the way colonialists described “natives”

and the way the audist establishment describes Deaf people. Charlton looks at the disability rights movement in the United States and throughout the world, seeing in globalization, imperialism, and colonialism the seeds of a worldwide oppression of people with disabilities. Charlton also focuses on the issue of human rights, noting that the right to a wheelchair is a basic human right—virtually ignored by organizations like Human Rights Watch, Oxfam, or Amnesty International.

Like African American studies or queer studies, disability studies got its biggest impetus and rationale from political struggles in the United States and abroad. As with the civil rights movement or Act Up, political movements such as protests surrounding the Jerry Lewis Telethon and the Deaf President Now movement at Gallaudet University, galvanized interest and created a political context for academic research. These activities first appeared in the United States after World War II, when wounded veterans organized for healthcare and social compensation for their war injuries.

The first major legislation, the Architectural Barriers Act (1968), required all buildings constructed with federal funds to be accessible to people with disabilities. Several acts through the 1970s and 1980s laid the legal foundations for the civil rights of people with disabilities, culminating in the Americans with Disabilities Act of 1990 (ADA). None of this legislation would have been possible without the activism of people with disabilities, described in journalistic detail by Joseph Shapiro.²² More recently, disability activists have been focusing on enforcing the provisions of the ADA, trying to change the pictorial representation of Franklin Roosevelt in the new Washington, D.C., memorial so that it includes graven images of the former president using a wheelchair.

The work of these activists has challenged received categories and politics. For example, a woman's right to have an abortion is nonnegotiable in much of the liberal to leftist community. But disability scholars like Adrienne Asch and Ruth Hubbard, investigating prenatal screening, question the use of abortion as a "solution" to the "problem" of bearing a baby with a disability.²³ People with disabilities are aware that they them-

selves might not have been born had such technology been available to their parents. While not questioning the abstract prerogative of a woman to have an abortion, these scholars worry that since society is ableist and since genetic counselors share this bias, women will abort fetuses simply because they do not want a child who is deaf, blind, missing a limb, or who has some anomalous but not life-threatening condition. Likewise, deaf parents could abort hearing fetuses in the desire to have babies who are also deaf.

Another hot-button issue comes over right-to-die legislation favored by most liberals and progressives. However, to disability activists and scholars, people like Jack Kevorkian are executioners in the service of an ableist medical establishment. During Supreme Court hearings on this issue, television images showing wheelchair users wearing “Not Dead Yet” T-shirts flooded the media. These activists point out that most physician-assisted suicide is performed on depressed people with chronic disabilities—particularly multiple sclerosis. Rather than provide psychological counseling, peer-group support, social services, and governmental subsidies, the death option seems much simpler. Activists and scholars are concerned about giving so much power to doctors and hospitals, particularly since people with disabilities have many horror stories about their own treatment by the medical rehabilitation system. They foresee a managed-care future in which chronically ill people will be encouraged by cost-conscious doctors to end their lives based on a biased notion of “quality of life.”

One more area of potential friction in disability studies is between the humanists and the social scientists. Since the 1980s, disability studies had been the domain of political scientists and sociologists. The Society for Disability Studies (SDS) and its publication, *The Disability Studies Quarterly*, along with the British journal *Disability and Society*, were dominated by social scientists. But recently disability studies has taken a new direction, given a boost by cultural studies, and has veered toward the humanities, popular culture, literary theory, and so on. Books like *The Body and Physical Difference: Discourses of Disability in the Humanities* (1997),

edited by David Mitchell and Sharon Snyder, are beginning to appear. Younger scholars more familiar with French feminists than with American sociologists are trying to gain a foothold in the academic world of disability. Yet there is resistance. At the May 1997 meeting of SDS in Minneapolis, only one session out of many was slated for the humanities—and it was buried in the graveyard slot of 8:30 A.M. on a Sunday morning. Only active lobbying by the humanists shifted the session at the last minute to a more accessible time. The 1998 conference was chaired by a humanities-oriented scholar, and there are signs that some better accommodation may be reached between the social sciences and the humanities in the future.

All said and done, why should anyone care about disability studies? What could the viewpoint or fate of the man using the wheelchair or the woman with a cane have to do with the great issues of our time? Why should it matter that Alexander Pope was a hunchback or that Chuck Close is a paraplegic? What difference does it make that all three films nominated for an Academy Award in 1997 featured disability prominently? To disability scholars, it matters very much. For scholars of literary history, disability is beginning to provide a new lens through which perceptions can be refracted in a different light.

Yet it is also fair to say that at this point in history most scholars still consider disability an anamorphic lens displaying distorted or grotesque subjects who are rather more “them” than “us.” In other words, ableism is still operative in the academic world as well as in the world at large. This distancing of the subject is a familiar defensive tactic similar to that taken by “outsiders” at the inception of African American, Latino, feminist, and other identity studies. But over time many scholars have come to see that the “them” of these identity studies is ultimately the social collectivity of “us.” As I have become involved in the study of disability, I have had the experience, as have many of my students, of seeing what appears to be a narrow subject expand to include almost all of literary studies. I can only give a brief view of this expansion here.

First, much of literature is part of a national project in which repre-

sentative character types are emplotted into narrative situations. These characters, whether Robinson Crusoe, Captain Ahab, or Lily Bart, are embodied in specific bodies, unlike heroic bodies of the epic or the idealized bodies of poetry. These specific bodies are seen through the lens of normality as either disabled or nondisabled. Protagonists are almost always defined as having normal bodies, the default setting of physicality in novels. When characters have disabilities, the novel is usually exclusively about those qualities. Yet the disabled character is never of importance to himself or herself. Rather, the character is placed in the narrative “for” the nondisabled characters—to help them develop sympathy, empathy, or as a counterbalance to some issue in the life of the “normal” character.

Even “normal” bodies signify moral traits as well as the traits ascribed to disabled characters. Beautiful (and noble, gentle, or bourgeois) characters should be morally virtuous; crippled or deformed people are either worthy of pity or are villains motivated by bitterness or envy. Disability studies interrogates the formation of bodies, the signification of bodies, and the national interest in producing templates for bodies and souls. That non-nationals, women, and minorities are seen as sharing the traits of the disabled, and that disabled people are feminized or racialized, also complicates the explication of bodies in narrative forms.

Second, the very mode that is privileged in literary endeavors, oral language, is interrogated by recent theoretical work on sign language and deafness. Extending the work of critics like Jacques Derrida, who find problematic Western society’s reliance on the spoken word, disability and Deaf studies scholars can open up the inherent prejudices of a given mode of representation. Some scholars have developed analyses of modernist poetry, for example, by looking at American Sign Language poetry. Others have questioned the linearity of Western prose and used disability as a theoretical construct to question such phallogentrism. Others have used Jacques Lacan to examine the misperception that constructs the normal, coherent, unified body and likewise the elaboration of language that is tied to that view. And still others have examined how that

communication and rhetoric can be interrogated by the premises of sign language and deafness.

The study of literature, literary history, and theory have only begun to fall under the sway of disability studies. The grotesque, the gaze, the dialogic, visual theory, the law, and so on—all are beginning to be broached by interrogations of disability. The exciting thing is the emergence of a whole new field in literary studies at the moment when many felt that there was nothing new under the hermeneutic sun. The survival of literary studies may well belong not to the fittest, but to the lame, the halt, and the blind, who themselves may turn out to be the fittest of all.

DR. JOHNSON, AMELIA, AND THE DISCOURSE OF DISABILITY

[I]t was requisite to a Whore to be Handsome, well shap'd, have a good Mien, and a graceful Behaviour; but that for a Wife, no Deformity would shock the Fancy

—Daniel Defoe, *Moll Flanders*

Samuel Johnson was a person with multiple disabilities. He was blind in one eye and had poor vision in the other. He was also deaf in one ear. These disabilities were the result of childhood tuberculosis of the lymphatic system then known as “scrofula.” In addition, he had prominent scars on the neck from incisions of his lymph nodes in treatment of this tubercular attack.¹ His face was further ravaged extensively by smallpox.

Johnson was also intermittently mentally ill, suffering from profound, often debilitating depression with suicidal impulses. In addition, he evidenced what might be diagnosed as an obsessive-compulsive

disorder that manifested itself in hypochondria, phobic and ritualistic behaviors,² compulsive picking of the skin on his hands, crushing anxiety attacks, and so on. Perhaps related were the physical tics and convulsive actions he manifested. As described by Boswell,

He commonly held his hand to one side towards his right shoulder, and shook it in a tremulous manner, moving his body backwards and forwards, and rubbing his left knee in the same direction, with the palm of his hand. In the intervals of articulating he made various sounds with his mouth, sometimes as if ruminating, or what is called chewing the cud, sometimes giving a half whistle, sometimes making his tongue play backwards from the roof of his mouth, as if clucking like a hen, and sometimes protruding it against his upper gums in front, as if pronouncing quickly under his breath, *too, too, too*.³

When Hogarth first met Johnson, he remarked that he saw a man “shaking his head and rolling himself about in a strange, ridiculous manner” and concluded that Johnson “was an ideot, whom his relations had put under the care of Mr. [Samuel] Richardson” (1:147). Alexander Pope wrote that his attempts to get Johnson a job as tutor failed because Johnson had “an infirmity of the convulsive kind, that attacks him sometimes, so as to make him a sad Spectacle” (1:143). Johnson’s tics and throat cluckings, as well as other behaviors, were almost certainly symptoms of what is now called Tourette syndrome.⁴

In his early twenties as well as in his fifties, Johnson suffered severe mental breakdowns and depressions so total that often he could not get out of bed. He became paranoid during these times, refusing to see people he did not trust. A contemporary described him during one of his breakdowns sitting in silence: “[He] looked miserable; his lips moved, tho he was not speaking; he could not sit long at a time. . . . [He] walked up and down the room, sometimes into the next room, and returned immediately dreadful to see.”⁵ In later life, he suffered a stroke that caused

aphasia and agraphia, congestive heart failure, kidney disease, severe arthritis that made it difficult to walk, emphysema, and increasing deafness, as well as a hydrocele of the testes.

If Johnson had lived during the twentieth century, he most probably would have been institutionalized, given shock therapy, or more recently put on a regimen of antidepressants. Without treatment, he might well have ended up on the streets. More tellingly for our purposes, his biography would have focused on these ailments, disfigurements, and so on. He would have become his illnesses and deformities. While his contemporaries clearly note his eccentricities, Johnson is not pathologized.

The question I wish to explore is why his contemporaries refer to his disabilities only in a casual and literary manner⁶—tending to see him as a brilliant man who had some oddities rather than as a seriously disabled person. As Julia Epstein asks, did Johnson never write about his own mannerism when he did write about other aspects of his illness?⁷ On the other hand, why do we know about these disabilities at all? Shakespeare, for example, lived fewer than two hundred years earlier, yet we have almost no knowledge of his appearance, let alone whether he had disabilities. His body is not a factor in our thinking about his subjectivity, and standards of normality do not apply to our judgment. John Milton wrote about his blindness in his poetry, but our detailed knowledge of the medical issues is limited. Clearly, standards of biography change, and one can point to an increasing interest in the individual and the author. But I think there are more factors at work than simply the growth of individualism.

I would argue that this evolving interest in disability, and the paradoxical aestheticizing of it in Johnson's life, is actually part of a historical and cultural transition in which the modern discourse of disability became consolidated. In this liminal period, we can see traces of both earlier and later formulations of disability. In other words, we can see the contradiction of an earlier sense in which disability per se did not exist and of a later one in which disability became a modality used to explain a great deal.

In order to understand this phenomenon better, let us look at the reception of disability in this period and earlier. To do this I need to qualify what I mean by disability. Disability is not so much the lack of a sense or the presence of a physical or mental impairment as it is the reception and construction of that difference. Contemporary theoreticians of disability distinguish between an impairment and a disability. An impairment is a physical fact, but a disability is a social construction. For example, lack of mobility is an impairment, but an environment without ramps turns that impairment into a disability. In other words, a disability must be socially constructed; there must be an analysis of what it means to have or lack certain functions, appearance, and so on.

For the sake of this argument, I define physical disability as a disruption in the sensory field of the observer.⁸ Disability, in this sense, is located in the observer, not the observed, and is therefore more about the viewer than about the person using a cane or a wheelchair. The term disability is tied to the development of discourses that aim to cure, remediate, or catalog variations in bodies. Thus, disability is part of a continuum that includes differences in gender, as well as bodily features indicative of race, of sexual preference, and even of class.⁹

Notably, researchers in disability have a difficult time documenting disability before the mid-eighteenth century. Obviously this is not because persons with disabilities were lacking. Indeed, it is probable that the figure of 15 percent, now generally accepted as the percentage of people with disabilities in the United States and throughout the world, would have held in the past.¹⁰ In fact we might estimate that upward of 25 percent of the population was disabled, given the lack of modern medicine and so on. It is now estimated that in some Third World countries upward of 50 percent of the population is either disabled or cares for people with disabilities. This figure would have held true as well for countries like England before the advent of modern medicine. In short, disability affects a very large number of people now and in the past.

Although there may have been a great number of people with disabilities, one must, however, assume that disability was not an operative cat-

egory before the eighteenth century. Some researchers have made the point that in preindustrial countries disability is not as relevant a category as it is under factory conditions where the interchangeability of standardized workers is paramount. People with differences in visual, auditory, or mobile ability can be incorporated into a preindustrial society. Thus, in some sense, their disabilities are not remarkable. One has only to think of Nora Groce's account of deafness on Martha's Vineyard, in which few contemporary informants could recall which citizens of the island in the past had been deaf since the entire community had learned sign language to accommodate extensive hereditary deafness.¹¹

To make the historical point, let us consider King James I. Almost no one knows or mentions, even in his lifetime, that he was a person with disabilities. His public representations and other documents almost never cite or represent what apparently only two contemporaries noted. Anthony Weldon, a contemporary Englishman and critic of James, writes that

his tongue [was] too large for his mouth, which ever made him speak full in the mouth, and made his drink very uncomely, as if eating his drink, which came out into the cup of each side of his mouth. . . . his legs were very weake, having had as was thought some foul play in his youth, or rather before he was born,¹² that he was not able to stand at seven years of age, that weaknesse made him ever leaning on other mens shoulders; his walke was ever circular, his fingers ever in that walke fiddling about his cud-piece.¹³

M. de Fontenay, a French ambassador and one of the few writers to confirm this observation, wrote that "his carriage is ungainly, his steps erratic and vagabond, even in his own chamber. . . . he is feeble in frame, and . . . he cannot work for a long time at business."¹⁴

One would assume that such debilities would have been noted by other writers, but in most descriptions of James I, no mention is made of

such, and other contemporary accounts read like that of the ambassador from Venice: “He is sufficiently tall, of noble presence, his physical constitution robust, and he is at pains to preserve it by taking much exercise at the chase.”¹⁵ This lack of attention to James’s ambulatory difficulties and to his somewhat convulsive behavior gives us some indication that this type of disability was not seen as remarkable, mentioned by only two of scores of contemporary historians.

Rather than disability, what is called to readers’ attention before the eighteenth century is *deformity*. The word seems to have been in use since the beginning of print, according to the *Oxford English Dictionary*, and is the operative word in defining some aspects of physical disability. Disability as the observation of the absence of a sense, a limb, or an ability is much less remarked on than deformity as a major category, a dramatic physical event or bodily configuration like giantism, dwarfism, or hunchback formations. Even so, only a few writers comment on the subject at all—notably Castiglione, Montaigne, and Bacon, writing briefly on “deformity” and “monsters.” And of course we have Shakespeare’s *Richard III*. Castiglione, in *The Courtier*, stresses that physical ugliness or deformity, while not necessarily a punishment by Nature, is often seen as such.

Thus everyone tries hard to conceal his natural defects of mind or body, as we see in the case of the blind, the lame, the crippled and all those who are maimed or ugly. For although these defects can be imputed to Nature, yet no one likes to think he has them, since then it seems that Nature herself has caused them deliberately as a seal and token of wickedness.¹⁶

Thus Castiglione ends up ratifying the notion that deformity is a sign of evil. Montaigne in his essays seems mainly interested in the idea that deformed people, particularly women with crooked spines or lame men like Hephaestus, are hypersexual, and that deformity often occurs because the pregnant mother’s imagination is shocked by some event into producing a marked or deformed child. Montaigne also sees monstrous births as

signs of divine intention,¹⁷ as Castiglione sees physical defects as punishments by Nature. Meanwhile, Bacon, as a rationalist, sees deformity “not as a sign” of divine intervention or marking of the body, but as a “cause” of personality and behavior. For Bacon, deformed people are ambitious, “void of natural affection,” good spies, and advantaged in “rising” in court.¹⁸ Shakespeare, clearly holding to all these opinions, depicts Richard III as a crooked-backed, limping sexual villain, a spying, usurping plotter. His behavior is a result of his appearance, as he says, “since I cannot prove a lover, . . . I am determined to prove a villain.”¹⁹

While references to deformity are sporadic, they tend to uphold certain time-honored beliefs, such as the notion that deformity can be traced to a moment in utero. Without a genetic explanation for the birth of people with disabilities, the Empedoclean paradigm, which attributed birth defects to the mother’s imagination, held sway, as Marie-Hélène Huet has painstakingly documented.²⁰ Thus deformity is caused by a moment, an instance, as when Richard describes himself as “deformed, unfinish’d, sent before my time / Into the breathing world, scarce half made up.”²¹ His self-image is of a loaf half-baked, deformed by not enough time in the womb.²²

While not much attention was paid to people with disabilities, during the late seventeenth and early eighteenth centuries an inordinate amount of attention was paid to natural “wonders,” that is, to dramatic instances of deformity. These wonders tended to fall into the category of *lusus naturae*, including giants, dwarfs, hermaphrodites, Siamese twins, hirsute women, and other kinds of anomalous births. While we now tend to consider any anomalous birth as part of the category of disability, this grouping together of birth anomalies and disability did not exist much before the nineteenth century. Our modern concept of normality requires that all deviations from the norm be treated equally. But under the previous discursive grid, anomalous, strange births were distinguished from disabilities that were acquired, particularly through disease.

But even dramatic deformities, such as those exhibited for example at Bartholomew Fair and other locations which tended to capture the

attention of writers, were met with a strangely calm affect. Montaigne's accounts of monsters in his essay on the subject are written laconically.²³ Those who saw monsters in the seventeenth and eighteenth centuries did not spell out their reactions in any great emotional detail. A Mr. Hooke, seeing a female giant wrote, "saw the Dutch woman in Bartholomew fair, very strange"; a Mr. Thoresby writes, "After dinner with Mr. Gale, walked into Southwark to see the Italian gentleman with two heads; that growing out of his side has long black hair."²⁴ Dennis Todd attributes this blasé tone to the fact that these "are records of men imbued with the spirit of Baconian science." But, given that these reactions are the rule over time rather than the exception, I think a better explanation is required. We want to recall, for example, that Jonathan Swift, upon hearing of Mary Toft's giving birth to rabbits, sent the following letter to Mrs. Howard:

I have been five days turning over old Books to discover the meaning of those monstrous Births you mention. That of the four black Rabbits seems to threaten some dark Court Intrigue, and perhaps some change in the Administration [,] for the Rabbit is an undermining animal that loves to work in the dark. The Blackness denotes the Bishops, whereof some of the last you have made, are persons of such dangerous Parts and profound Abilities. Rut Rabbits being clothed in Furs may perhaps glance at the Judges.²⁵

While Swift, that man of reason, may be mocking an irrational tradition here, he signals its continuing strength by referring to the notion of monstrous births as signs from heaven. Two hundred years earlier Montaigne did the same, commenting on seeing a monstrous child with a headless twin years earlier that this occurrence "might well furnish a favorable prognostic to the king that he will maintain under the union of his laws these various parts and factors of our state."²⁶ These two approaches—the deformed as creatures of their mother's imagination or as signs of divine intention—were the regnant paradigms for the category of the births of

people with disabilities. These ways of thinking about people born with disabilities seem to be the operative explanatory devices through the middle of the eighteenth century. Thus the blandness we see is a function of the unremarkable, common quality of most physical differences.

What we do see in the second half of the eighteenth century is the remarkable appearance of the disabled person in print as author and character. Deafness, particularly, seems to be discovered as a discrete category of disability. We can track this interest by noting that the number of schools for the deaf increases from zero at the beginning of the century to a dozen in 1789, to sixty in 1822.²⁷ Deafness and blindness become the subject of study by philosophers, linguists, and educators. Even the category of “monster” becomes refined and delineated into a discourse, finally arriving at Saint Hilaire’s founding of the science of teratology and the attempt to produce monsters through teratogeny in the nineteenth century. These events are tied up with the development of the concepts of the normal, the abnormal, the anomalous, and so on.

William Hay’s publication of *Deformity: An Essay* may be used to mark this watershed. Hay, a member of Parliament, had spinal deformities and described himself as “scarce five Feet high,” with a “Back [that] was bent in my Mother’s Womb.”²⁸ Hay’s work, although influential, does not do much to reform the concepts of deformity that preceded his work. Rather, Hay ends up reiterating (although humanizing and questioning to a degree) stereotypes about people with disabilities, including the notion that the disability results from an extraordinary shock or event during gestation. He also maintains the distinction between deformity and disability, seeing spinal deformity and the accompanying dwarfism as fitting into the remarkable or even wondrous category more than blindness, deafness, or lameness. As he writes, “it is not easy to say why one Species of Deformity should be more ridiculous than another, or why the Mob should be more merry with a crooked Man, than one that is deaf, lame, squinting, or purblind.”²⁹ Here Hay makes distinctions between types of deformity, rather than seeing blindness, for example, as linked to spinal deformity. He also notes that the mob will mock a birth deformity like

his more than degenerative disabilities that might, for example, accompany old age. Hay appears to occupy a liminal position in his analysis between discourses of wonder and deformity and a discourse of disability.³⁰

In regard to Dr. Johnson we can see better how this tension between older systems of classification and newer ones plays out. In the *Life of Johnson* Boswell simultaneously mentions and then downplays Johnson's disabilities.³¹ For example, while Boswell does note Johnson's scrofulous childhood, he takes great pains to point out that Johnson could see very well and that though he was blind in one eye "its appearance was little different from that of the other" (1:41). Hester Thrale echoes this point, saying of his blind eye that "this defect however was never visible, both Eyes look exactly alike."³²

Given the extent of Johnson's multiple disabilities, relatively little mention is made of them even by Boswell and his contemporaries. For example, portraits of Johnson edit out his disabilities; only his death mask shows the rather dramatic scars on his neck. In the *Life of Johnson*, at Boswell's first meeting with Johnson, the biographer mentions his "slovenly" dress and "uncouth" surroundings, but nothing else. Tellingly, however, the first discussion between the two of them is about madness and Christopher Smart, the poet who had been confined to a madhouse. Of Johnson's eyesight, Boswell writes, "How false and contemptible then are all the remarks which have been made to the prejudice either of his candour or of his philosophy, founded upon a supposition that he was almost blind" (*Life*, 1:42).³³ Of Johnson's depression, hypochondria, and paranoia, Boswell says that "there is surely a clear distinction between a disorder which affects only the imagination and spirits, while the judgement is sound, and a disorder by which the judgement itself is impaired." Boswell is in part defending Johnson against "those who wish to depreciate him . . . since his death" by laying hold of "this circumstance" (1:66). Johnson himself seemed to be of the opposite opinion, often fearing himself mad.³⁴ This fear is perhaps closer to the truth than Boswell's protective defense. Although Boswell wants to make a distinction between impairment of the "imagination and spirit" and impairment of "judge-

ment,” traditional categorizations of the mentally ill were not so discerning. As Jonathan Andrews notes, “Early modern writers made little distinction between idiocy and chronically progressed conditions of mental enfeeblement.”³⁵ Andrews points out that while the term “idiot” and “fool” were used in the country parishes, the same terms in metropolitan parishes were equivalent to “distracted” and “lunatic.”³⁶ Johnson himself must have been aware of the slippage possible between his condition of profound bouts of distracted depression and the degenerative possibilities inherent in that condition.

What we may be observing here are the effects of the formation of a new discursive category of disability. With it go several contradictions. This new category is seen as continuous, running the gamut from physical impairments to deformity to monstrosity to madness. Linked to this development is an institutional, medicalized apparatus to house, segregate, isolate, or fix people with disabilities. Part of this fixing involves the clinical gaze that replaces the stare of wonder. The disabled person is now seen, drawn, illustrated, dissected, legally placed, morally and ethically determined. Mental illness is categorized into types and subtypes. The concept of normality is invented, along with the bell curve and statistics.³⁷

As Huet points out, once disability is linked to genetics, we see a shift in the way people with disabilities are categorized. No longer is disability something tied to an individual event, like the mother’s witnessing of a violent crime, but to a genetic entity or a group defect—ethnic, racial, national, or class-related. Women continued to be blamed for birth defects, particularly those from undesirable socioeconomic groups. Further, in terms of cultural symbolic production, images of the disabled person are linked to specific kinds of moralized narrative. People with impairments are now seen as deserving or undeserving. The undeserving disabled are the villains, the poor who develop disabilities through their laziness or lack of care, fakes, and the like. Among these are the literary villains, limping, one-eyed, one-armed evil men. The deserving literary disabled are often women, children, or older people, sickly and struggling to triumph over their disability.

This contradiction is built into the literary discourse of disability. Disability implies weakness or evil as well as personal culpability and the effect of divine justice, but it is also random, impersonal, and something over which the individual sufferer triumphs. In some sense this contradiction is a pentimento of the two opposing, historically divergent readings of disability-deformity as sign or punishment versus disability as impersonal affliction randomly assigned throughout the population. In the earlier version, unless the deformity is wondrous, it is ignored or erased. In the latter, it must be commented on, noted, treated, and inscribed into an economy of bodily traits.

In the case of Dr. Johnson, we can see both systems in action. On the one side Boswell and Thrale note his disabilities, but on the other they forget them, as do Sir Joshua Reynolds and other portrait painters. For example, Thrale talks of Johnson's mentioning "the Evil which greatly afflicted him in his Childhood, & left such Marks as even now greatly disfigure his Countenance."³⁸ But in another place she writes of "his appearance":

His Stature was remarkably high, and Limbs exceedingly large; his Strength was more than common I believe & his Activity was greater than his Size gave one Cause to expect, his Features were strongly marked, though his Complexion was fair, a Circumstance somewhat unusual.³⁹

And in another:

Mr. Johnson's bodily Strength & Figure has not yet been mentioned; His Height was five Foot eleven without Shoes, his Neck short, his Bones large & His Shoulders broad; his Leg and Foot eminently handsome, his hand handsome too, in spite of Dirt, & of such Deformity as perpetual picking his fingers necessarily produced: his Countenance was rugged.⁴⁰

Remarkably, the description of his person never mentions its facial disfigurements detailed earlier. This description and erasure are done under the pressure of the new injunction, as it were, to include disability or normality as a functional category in the formation of the subject. Indeed, we know more about Dr. Johnson's health than almost anyone before him. According to one physician-scholar, "we can follow his case history from before birth through his autopsy two days after death."⁴¹ We even know about the abscess Dr. Johnson had on his buttock three weeks after he was born, as well as the swollen testicle he had to have drained in his last month.

This incredible level of intimacy with his body, demanded by a new standard of biography and a new attitude toward disability, must also be disavowed or resisted. Hence the erasure and the contradictions by Boswell of the symbolic significance of blindness or insanity. In other words, given the ideology of normality and the hypersignification of images of disability, Johnson must not and cannot be allowed to signify as would a character in a novel if he or she were blind, deaf, or physically impaired in some way. Narrative must not be allowed to transubstantiate the physical into the moral, both because of Boswell's respect for Johnson and because the discourse of disability is not fully in place to transmute the physical into the medical.

But by the nineteenth century, when Macaulay writes of Johnson, he can permit this narrative transformation. He writes clinically of Johnson as a child:

The boy's features which were originally noble and not irregular, were distorted by his malady. His cheeks were deeply scarred. He lost for some time the sight of one eye; and he saw but very imperfectly with the other. But the force of his mind overcame every impediment. Indolent as he was, he acquired knowledge with such ease and rapidity that at every school to which he was sent he was soon the best scholar.⁴²

Here we see the appearance of the familiar narrative trope of disability—the triumph over adversity. Macaulay develops this trope further, detailing Johnson’s mental illness, now seen as genetic, hereditary. I will quote at length to show the extent of the commentary on disability. Macaulay describes “the sufferings of an unsound body and an unsound mind”:

Before the young man left the university, his hereditary malady had broken forth in a singularly cruel form. He had become an incurable hypochondriac. He said long after that he had been mad all his life, or at least not perfectly sane; and, in truth, eccentricities less strange than his have often been thought grounds sufficient for absolving felons, and for setting aside wills. His grimaces, his gestures, his mutterings, sometimes diverted and sometimes terrified people who did not know him. At a dinner table he would, in a fit of absence, stoop down and twitch off a lady’s shoe. He would amaze a drawing-room by suddenly ejaculating a clause of the Lord’s Prayer. He would conceive an unintelligible aversion to a particular alley, and perform a great circuit rather than see the hateful place. He would set his heart on touching every post in the streets through which he walked. If by any chance he missed a post, he would go back a hundred yards and repair the omission. Under the influence of his disease, his senses became morbidly torpid, and his imagination morbidly active. At one time he would stand poring on the town clock without being able to tell the hour. At another, he would distinctly hear his mother, who was many miles off, calling him by his name. But this was not the worst. A deep melancholy took possession of him, and gave a dark tinge to all his views of human nature and of human destiny.⁴³

Macaulay goes on to describe Johnson’s depression. What should impress us about his account is the extensive detail of the consideration. Johnson

is narrativized into his disability.⁴⁴ Yet the operative trope remains his triumph over disability: “With such infirmities of body and mind, this celebrated man was left, at two-and-twenty, to fight his way through the world.”⁴⁵ Fight he does, as do all deserving people with disabilities, and the fight becomes emblematic for all of us, just as the league of dying or disabled characters from Tiny Tim in “A Christmas Carol” to Philip Carey in *Of Human Bondage* to Christy Brown of *My Left Foot* serve the cause of society, in this way.⁴⁶

I want to turn now from Dr. Johnson to a literary character with a disfigurement—Fielding’s Amelia. In so doing, I am retreating to midcentury in order to provide an example that represents both a literary disability as well as a physical one. When Henry Fielding published *Amelia* in 1751, he expected a huge success. So did many others who bought the book, having read *Joseph Andrews* and *Tom Jones*. But the bawdiness, humor, and satire were missing. In fact, the novel became the laughing-stock of the general public. But the greatest ridicule sprung from one minor point. The eponymous heroine of the book was introduced as having little or no nose. Mr. Booth, her husband, says of her:

However it was, I assure you, the accident which deprived her of the admiration of others, made the first great impression on my heart in her favour. The injury done to her beauty by the overturning of a chaise, by which, as you may well remember, her lovely nose was beat all to pieces, gave me an Assurance that the Woman who had been so much adored for the Charms of her Person, deserved a much higher Adoration to be paid to her mind.⁴⁷

Amelia’s noselessness is brought to the attention of the reader as well as of other characters in the beginning of the novel. In particular, Amelia is ridiculed by other young ladies who “have turned their heads aside, unable to support their secret triumph, and burst into a loud laugh in her hearing.” Jokes are made at her expense: “she will never more turn up her

nose at her betters.” Her loss of nose is also seen as a “loss of exquisite beauty,” which is the same as “the loss of fortune, power, glory” (67). Yet Mr. Booth, her husband-to-be, is taken with her, although—or because—she wears a mask. He begs her to show him her face, and when she does he says, “Upon my Soul, Madam you never appeared to me so lovely as at this Instant” (68).

Amelia is a long-suffering wife to an errant and problematic husband. Her facial mutilation is in keeping with a moral trope of Griselda-like affliction. The problem with her lack of a nose, however, arose specifically because, as is well known, in the first edition Fielding does not mention Amelia’s nose being repaired. Yet Amelia is treated as if she were beautiful throughout the rest of the novel. The reviewer for *London Magazine* pointed out that an “imperfection” of the novel “in our opinion, is, that the author should have taken care to have had Amelia’s nose so completely cured, and set to rights, after its being *beat all to pieces*, by the help of some eminent surgeon, that not so much as a scar remained, and that she shone forth in all her beauty as much after that accident as before.”⁴⁸ Many reviewers attacked Fielding for this point alone. In France the following year, Matthew Maty’s review in *Journal Britannique* noted, “It is not made clear how she recovered a member so essential to a beautiful face; but apparently a clever surgeon fixed it because after her marriage there is hardly a man who does not become amorous with her or a woman who does not envy her.”⁴⁹ Bonnel Thornton wrote a parody of the novel in his *Drury-Lane Journal*. In it Booth comes home to his Amelia, but this time with his nose flattened as well:

She then clap’d him down upon a chair, and was going to wipe his mouth with her muckender: but what was her consternation, when she found his higharch’d Roman Nose, that heretofore resembled the bridge of a fiddle, had been torn all to pieces! As herself had before lost the handle of her face, she now truly sympathis’d with him in their mutual want of snout.⁵⁰

In William Kenrick's parody of *Macbeth*, the three Weird Sisters throw various texts into the pot, including *Amelia*, saying, "To add to these and to make a pois'nous Stench, Here take 4 Ounces of a *noseless wench*"⁵¹ Samuel Foote, an old adversary of Fielding, inserted a frontispiece to the published version of his play *Taste*, which ridiculed Fielding at several points, portraying the bust of Praxiteles's Venus of Paphos, a statue whose nose has been destroyed. Fielding, in defense of his novel, staged a mock-trial in the *Covent Garden Journal* in which he has a prosecutor address an imaginary court with a list of accusations that ends with "Lastly, That she is a Beauty WITHOUT A NOSE, I say again, WITHOUT A NOSE. This we shall prove by many Witnesses."⁵²

I have taken much time to review what many already know—that this little detail was not a flash in the pan but a sustained issue. Contemporaries were aware that "his fair heroine's nose has, in my opinion, been too severely handled by some modern critics,"⁵³ or that "Amelia's Nose, was an Omission of the Author's which has occasioned a vast deal of *low wit* and has been a standing Joke here."⁵⁴ Why should Fielding's career have tottered on the bridge of Amelia's nose?

Perhaps the issue was intensified by people's knowledge of Fielding's personal life. Fielding's heroine is based on his first wife, Charlotte Craddock. He took the name Amelia from his deceased daughter. This much Samuel Richardson recognized in a letter in which he deprecated Fielding for lack of invention: "Amelia, even to her noselessness, is again his first wife."⁵⁵ Charlotte had suffered the same accident in a chaise and had her nose fixed by a surgeon. As Johnson commented, when

the Town had found out that Amelia had performed all her Wonders with a broken Nose, which Fielding had forgotten to cure, & had broken indeed for no other Reason than to impress himself with an Idea of his favourite Wife, who had once met with a similar Accident, & whose Character he had meant to exhibit under the Name of Amelia; thus did this oddity

spoil the Sale of one of the first Performances in the World of its Kind.⁵⁶

So, what was the joke all about? There was evident glee that Fielding had inadvertently forgot to fix his fictional character's nose. The contrast between a woman who deserved praise, especially for beauty, and the fact of noselessness was clearly too much of a contradiction, too risible. Fielding changed his text in the second edition, clearly smarting under the critique, by adding a physician who repairs Amelia's nose.

But the issue, as with the case of Johnson, involves a complex clashing of paradigms. If noselessness, or disability, represents or signifies a failing or a lack, then Amelia becomes, through this signification, an example of deformity—a deformed character. Indeed, perhaps not so strangely, Fielding begins his novel with the appearance of a noseless woman who encounters Booth when he arrives in prison:

The first Person who accosted him Was called *Blear-Eyed Moll*; a Woman of no very comely Appearance. Her Eye (for she had but one) when she derived her Nick-name was such, as that Nick-name bespoke. . . . Nose she had none, for *Venus*, envious perhaps of her former Charms, had carried off the gristly Part and some earthy Damsel, perhaps from the same Envy, had levelled the Bone with the rest of her Face: Indeed it was far beneath the Bones of Cheeks, which rose proportionally higher than is usual. (28)

Blear-Eyed Moll is punished by both goddess and mortal with disfigurement—punished because of her sexual charms, and in reality punished by the retributive force of syphilis. Noselessness is a common image for the effects of venereal disease, as Ned Ward indicates when he points out “the abundance of both Sexes had sacrificed to the God *Priapus*, & had unluckily fallen into Aethiopian Fashion of Flat Faces.” He lists in this “Noseless Society” many “poor scarify'd Bawds.”⁵⁷ Not only is Moll

noseless, but she is distorted as well. Her remaining eye is crossed and yellowed, and “About half a dozen ebony Teeth fortified that large and long Canal, which Nature has cut from Ear to Ear, at the Bottom of which was a Chin, preposterously short, Nature having turned up the bottom, instead of suffering it to grow to its due Length.” Her corpulence is mentioned along with the fact that “her vast Breasts had long since forsaken their native Home, and had settled themselves a little below the Girdle” (28).

How odd that this novel should have two noseless women, when most novels do not have even one. Moll seems in some sense the necessary repressed Other of Amelia. She too is noseless, but her noselessness is made to signify in a narrative sense, in the sense in which such details in a novel should. And, as with Amelia, Moll’s noselessness is tied up with the issue of feminine envy. For Fielding, the iconography of the deformed, grotesque, morally and physically corrupt female is perfect. Yet, though he tried to isolate this negative picture from the idealized Amelia, his textual parapraxis opened the floodgates of ridicule, revealing the necessity of the imposed binary of good-bad, beautiful-deformed, in the regulation of female bodies. The danger of the uncontrolled female body, expressed in the uncontrollable nature of deformity, is the punishment meted out to Moll in the projection of female envy. Hence, Moll exists as the grotesque, deformed female, so that Amelia can remain pure. The problem was that Fielding violated the mutually exclusive categories by “forgetting” to fix Amelia’s nose.

But how accidental is this forgetting? All critics have seen Fielding’s parapraxis as an unmotivated event; something that simply slipped his mind. But would it not be much more canny to see Fielding’s slip as revealing a repressed fact about femininity under patriarchy and disability under ableism. In the latter case, what we see is the slippage from the earlier, still persisting, model in which deformity reflects inner vice or divine judgment, to the latter one in which disability is seen as moral virtue, especially in its overcoming. Novels of the second half of the eighteenth century begin to take up the role of enforcing normalcy by producing

images of the perfect and disabled body.⁵⁸ Here in the world of fiction, or cultural symbolic production, the disability signifies.

Amelia was not the only novel in which female characters were depicted as becoming facially disfigured. Sarah Scott, who herself had smallpox, features two major heroines—Harriot Trentham in *Millenium Hall* and Louisa Tunstall in *The History of Sir George Ellison*—who lose their beauty to facial scarring. Frances Burney presents Eugenia in *Camilla* also as disfigured in childhood by smallpox and a fall. However, these women, in the new pattern, may find the disfigurement a blessing rather than a curse. For example, Harriot Trentham “became perfectly contented with the alteration this cruel distemper had made in her. . . . She has often said she looks on this accident as a reward for the good she had done.”⁵⁹ In effect, disfigurement and disability become a positive virtue, particularly in women, children, and the elderly, that signals spiritual and moral dignity achieved through suffering. This trope continues through the nineteenth century, for example, with Esther Summerson in *Bleak House*, disfigured by smallpox, not as punishment for her sins, but as a mark of female suffering and spiritual transcendence over the body.⁶⁰

So Amelia and Dr. Johnson, caught between these two paradigms, are described with their disabilities, but not really allowed to have them. Their bodies bear the mark but not the sign. They are neither normal nor abnormal. They signify, and yet they do not. Their message is written on the flesh and yet, in some sense, more aptly written on the page. Looking backward from the eighteenth century, we see an absence of a discourse of disability—a world of variously marked unexceptional bodies amid a Bartholomew Fair of signs and wonders. Looking ahead, we see the systematized, divided structure of normal and abnormal bodies whose various disabilities are to be institutionalized, treated, and made into a semiology of metonymic meanings. Dr. Johnson, Amelia, and many others suffer that moment where paradigms clash at night.

CRIMINAL STATEMENTS

HOMOSEXUALITY AND TEXTUALITY IN THE ACCOUNT OF JAN SVILT—EIGHTEENTH-CENTURY SHIPWRECKED SAILOR

If on a winter's night a professor sees a large envelope fall through the mail slot in his door, it would be logical that he would retrieve the envelope and open it. This was such a night, grim and dark. It was the kind of night in New York that made the city look like a prize-fighter who had gone too many rounds. I picked up my bourbon, walked over to the door, and inspected the envelope.

It was addressed to Lennard Davis, Book Review Editor, *Radical Teacher Magazine*. It was entitled *The Queer Dutchman: True Account of a Sailor Castaway on a Desert Island for "Unnatural Acts" and Left to God's Mercy*, edited by Peter Agnos.¹ The book had a look of transgressivity, set in IBM typeface with no margin justification.

I took another drink of bourbon and squinted at the print. The book was published by Green Eagle Press with a date of 1993, although the indication of copyright was 1978 by C. Adler. The Preface by Peter Agnos began, “Four winters ago, while browsing in Mendoza’s Bookstore on Anne Street in lower Manhattan, I chanced upon a curious old book written in Dutch.” After buying the book, Peter Agnos, talks about it to a Dutch friend, Michael Jelstra, who tells him that “the old volume was a copy of sea adventures published in Amsterdam in 1762.” Jelstra is described as translating the original journal into English. The Preface is signed Peter Agnos, Sonora, Mexico, May 1977. We are told on a subsequent page that “this book is based upon a journal kept by Jan Svilt who in 1725 was forcibly marooned on the deserted island of Ascension. Svilt’s journal was found by Captain Mawson, Commander of the British ship Compton, homeward bound from India. Mawson had stopped at Ascension to turn turtles.”

The phone rang with a shrill electronic keening, but I ignored it. I began to read the story of Jan Svilt’s voyage, trial, marooning, and death. Svilt, thirty-four, bookkeeper on the Dutch East India Company ship the *Geertruyd*, was married and had two daughters. In 1725, he was detected by two other sailors, Johan Eckoff and Nicholas Fockema, who testified: “we made out two men with their shirts off sitting close to each other. They seemed to be looking out at the moon. The bigger man, who was Jan Svilt, had his arm about the waist of the smaller man, Bandino Frans. We saw them turn their heads towards each other, put their mouths together and engage in a long and passionate kiss.” The observers’ response was “to hoot and giggle. We jeered at Svilt and Bandino. We called them buggers and queers and said that they must squat to piss” (1978:12). Svilt responded by calling them “syphilitic boors, pimp-bait, drunken louts, and other unkind names” (1978:13).

Captain Dirk van Kloop convened a trial heard by a council of ship’s officers because, as he testified, “the abominable sins of homosexuality, as attested in the Bible, bring ruination to our community, as they brought down the wrath of God on Sodom and Gomorrah” (1978:13). At the trial,

Bandino, sixteen, the captain's mess boy, "appeared flustered, blushed, and said little" (1978:13). Svilt did not deny having his arm around Bandino or kissing him, but argued that "Bandino has been like an adopted son to me since he came aboard in Batavia. I promised his uncle that I would look after the boy until he reached Holland. My affection towards him has been as a father to his son, and in no way improper" (1978:13).²

The ship's council doubted Svilt and decided to use torture to "delve for the true facts" (1978:13). The method used was the "water cure" in which a canvas sheet was tied around his neck, and water was poured into the sheet until it covered his mouth and nose. Only by drinking could he breathe. He is described as swallowing "considerable amounts of water for the first hour of torture. His belly distended enormously, but he kept declaiming that he was a God-fearing man, and that he was innocent. At the urging of the officers, however, more water was poured around his head until he fainted. When he revived he confessed." As the captain noted, Svilt admitted "to having had abominable sexual relations with Bandino—the recitation of his confession caused us to shrink from him in horror."

Weighing the options for punishment, the officers felt that only death could prevent future misbehavior on the part of the sailors and might prevent terrible plagues on the ship. Captain van Kloop testified, "We might have punished both wrongdoers by tying them together and tossing them into the sea—a just and proper reward for Sodomites." But because of Bandino's youthfulness, and because they were near Ascension Island, they decided to maroon Svilt there and "let God punish him as He would." Svilt was left on Ascension Island on May 5, 1725, and he wrote in his journal, which he had been keeping all along his trip, that he was "struck with great dread and dissatisfaction" (1978:17). He decided to "keep a strict calendar and journal so that I may know the sabbath and the holy days."

In reading this text, I was intrigued at having what seemed to be an actual journal of a castaway, not like the fictional journal of Crusoe, and intrigued by the addition of Svilt's homosexual interest or accusation

thereof. But I was also a little dubious about the provenance of this book. After all, the preface claims the work is translated from the Dutch edition of sea adventures of 1762, but the actual printed material is supposed to be a text of Svilt's journal. We are told that a mutilated copy of the journal is in the Rare Book Room of the New York Public Library. That book is actually entitled *The Just Vengeance of Heaven exemplified in a journal lately found by Captain Mawson (Commander of the ship Compton) on the island of Ascension; as he was Homeward-Bound from India. In which is a full and exact relation of the author's being set on shore there, for a most enormous crime he had been guilty of and the extreme and unparall'd hardships, sufferings, and misery he endur'd, from the time of being left there, to that of his death. All wrote by his own hand and found lying near his skeleton*. The publication information for this book says that it was printed in New York by James Parker at the New Printing Office in Beaver Street in 1747. This book in turn was a reprint of the 1730 British book of the same name published in London.³

A Just Vengeance is a book written in English and originally published in England. Although it purports to be based on Svilt's journal written in Dutch, this fact of translation is nowhere indicated as a problem. Further, the purport of the title is clearly hortatory and admonitory. In other words, this is a book with a purpose—to show that God sees homosexuality as criminal and justly avenges homosexual activity with suffering and death. In this sense, it is in the tradition of fictional criminal narratives, like those of Defoe, whose central drama acts out a fall from grace and an eventual repentance. Finally, the “all wrote by his own hand” bears the ritualistic marks of the news/novels discourse and raises the issue of whether the work is fact or fiction.⁴ The metonymy of Svilt's skeleton and found text suggests a problem. If Mawson actually found Svilt's skeleton next to the book, how did the journal manage to survive while Svilt's body had been picked clean by rats, seabirds, or the elements?

The 1993 edition clearly takes a different tack, since its title refers to “God's mercy” rather than “a just vengeance of heaven.” Because I was dubious about the provenance of the 1993 edition, I called the publisher.

His telephone indicated that this was not a business but a private home. I left a message on the answering machine and a Charles Adler returned my call. He was somewhat suspicious of my motives. He was evasive when I asked him how he got the manuscript, how I could contact Peter Agnos, and if the book was authentic. Adler claimed only to have printed it, having received the manuscript by mail from Agnos, whom Adler claimed he had never met.

I realized that even if the 1993 book *The Queer Dutchman* could be authenticated as accurately drawn from the 1730 edition, I still could not prove that Mawson's book was accurate—wholly or partially. This point raises an issue about criminal biography, memoir, or journal. While the subject matter concerns criminals, homosexuals, whores, or whomever, the very idea of publishing a coherent, chronological, organized, and teleological work itself can be seen as a criminal activity, in the sense that the critic engages in some level of falsification in arriving at a coherent story. The lacunae in the text are inevitably filled in by the historical process of reconstruction. Was there a Captain Mawson? We do not have more than his last name. Did someone invent this work or did they take Mawson's find and interpolate material to strengthen the notion of a "just vengeance"?⁵

One can easily imagine that sailors would be particularly prone to homosexual activity, and some recent scholarship has been devoted to this point.⁶ We may recall Churchill's famous statement that the British navy was well known for three things: "rum, sodomy, and the lash"; and more recently Hans Turley has shown us the close connection in eighteenth-century writing between piracy and homosexuality. Svilt's tale may have been created or elaborated by a desire to create a cautionary tale to British seamen; a sort of "Don't act or we'll tell" policy.⁷ Indeed, the number of editions and reprints in the United States indicates the antigay purpose of *A Just Vengeance*. This eighteenth-century text was not reprinted so that contemporaneous readers might sympathize with Svilt, but so that his life might serve as a moral warning to others.

But then another question occurs: does it matter at all whether Svilt's

narrative is factual or fictional? Since this text presents us with a level of uncertainty, the reality is that we may never know if the work is authentic. What, then, is to be done with it? Is it criminal, to shift the burden to the critic, to do anything with this text? Which is more or less transgressive: to think of the text as fictive, and by so doing deny the constitutive experience of queerness that is preserved there for us, or to think of it as factual, and in so doing cover up the problems of provenance?

To answer this question, we need to look at some aspects of the text—but what is the text? In the following sections I will be using the 1993 version, having corroborated parts of it with the 1748 Philadelphia edition, and I will indicate when there is a variance between texts. One of the first things the text presents us with is the question of Svilt's guilt. In the terms of the work *A Just Vengeance*, we have to ask whether or not Svilt is guilty of having had homosexual encounters with Bandino. This decision again puts us in an ambivalent relation to the text—if we see homosexuality as part of a continuum of human experience, then the desire to decide Svilt's guilt is suspect. On the other hand, if we don't care to discover the "truth" of the accusation, then can we regard Svilt as a "hero" in the repressed history of sexual intolerance?

The text is not so clear either. In the testimony of the trial, which has been taken (presumably) from Dutch records, one can see that Svilt confesses only at the extreme of torture. We are told that he has a wife and two children whom he expresses the desire to see and be with. In his first entry he writes, "God has punished me for returning to sea. How have I sinned?" (1978:19) The question seems open—on the one hand acknowledging that he is being punished, but then adding puzzlement as to what his sin was. It is not until seventeen days later that Svilt returns to the issue of his guilt or innocence when he tells how he marched on the beach, singing a hymn with the words

What if men assail me?

What if men assail me?

God, my Lord will break their sword;
He will never fail me. (1978:34)

And he adds, “I well know the wages of sin are death, but I could not possibly form an idea in my mind of a punishment that could justly atone for my offence” [not in the 1748 version]. The hymn implies that he is unjustly accused, but the following statement is quite ambiguous, implying either that death is too great a punishment or not a great enough punishment.

Not until a month later does Svilt come back to the issue of his innocence or guilt. After a night of being plagued by the apparitions of devils who lash his face with their tails and curse at him saying, “Queer, Asshole fucker, Asshole fucker!” (1978:52) [“Bouger” in 1748 edition], Svilt laments that:

I would not be in this miserable state if Captain van Kloop had not subjected me to the water cure. After hours of drowning and gasping for breath in his hellish contraption, I would have confessed to bugging not only his darling cabin boys, but the whole Dutch navy. I am innocent before the Lord. (1978:52) [not in 1748]

Does that mean that Svilt is innocent—or innocent before the Lord? He goes on to assert:

my affection for Bandino perhaps went beyond that of an older friend. When a man is at sea for two years, away from the love of his family, is it not natural that he should wish to give and take affection to his companions, especially when they are friendly and shaped like a young maiden, as is the beautiful Bandino. And did I not promise his uncle that I would care for him? (1978:53) [not in 1748]

Here Svilt speaks, in seeming opposition to what he has said before, expressing at least a desire for Bandino, whom he sees as having the form of “a young maiden.” But quickly after this he adds:

Alas! how wretched is that man whose bestial pleasures have rendered him odious to the rest of his fellow-creatures and turned him loose on a barren island, Nebuchadnezzar like, to herd and graze with beasts, till, loathsome to himself and spurned by man, he prays to end his wretched days! (1978:54)

This theme suddenly continues after a bad night of being thrown around by devils. “I then began to hope that if Heaven did not think fit to end my torments these punishments would serve as an atonement for my desire to make use of man to satisfy my lust, despising woman, which His hand had made a far more worthy object” (1978:55). This self-abasement motif reaches a climax in the final entry when Svilt, dying of thirst, dreams he is walking through a wilderness. He falls asleep in a cave where he dreams, within his dream, that he was “sadder than at any time in my life; all my sin and vileness appeared before me great and consuming. I saw that I was fit for nothing but hell and for the everlasting damnation of my soul [. . .]” (1978:118). Suddenly he sees Christ who tells him to believe, and he shall be saved. Svilt replies, “I am a great, a monstrous sinner.” But Jesus assures him he will reach the Celestial City, which Svilt enters with golden raiment. He awakes from this dream “to find two rats nibbling at my sandals” (1978:118). Within a month and only a few lines of the journal, he is apparently dead.

How do we read these excerpts? If we see the text as accurate, we can view Svilt as acknowledging homoerotic desires, rationalizing them, but then coming to condemn them with his increasing duress on the island and a sense of God’s judgment.

If we see the text as containing interpolations, we can parse out the ambiguities by saying that when Svilt is defending himself and saying he is innocent, we are seeing the text doctored by a twentieth-century gay

writer, while the condemnatory passages are no doubt written in by an early moralizer. But the fictionalizing twentieth-century writer may in fact be expressing Svilt's true text, in spirit if not in the letter of his original text, and the writer of *A Just Vengeance* may have added the condemning passages to make sure eighteenth-century readers were hyper-aware of God's punishment of Svilt. A third possibility is that if we see the text as totally constructed, then the whole work follows a predictable pattern in which the guilty man comes to accept his guilt, repent, and be forgiven by Christ. If this were the case, even the name of Ascension Island could be seen as deliberately part of a narrative design rather than simply being the place in which Svilt happened to find himself.⁸

Likewise, we have the problem of Svilt's memories, dreams, and observations. The work has a very anti-Dutch flavor to it, particularly criticizing the Dutch East India Company. Would this be because Svilt is disgusted with his compatriots and employers for putting him on Ascension Island, or is it because the original publication was British, and the Dutch had been their long-standing rivals in trade and foreign affairs?⁹ For example, in two instances he describes members of his crew, including the captain, selling contraband and illegal items. Svilt says he is "saddened by the thought of the men who had died, and who would die to enrich the Company. Many of its employ would die so that the spices and the gold would continue to flow to Holland. Many poor natives would be sold into slavery and many more would waste away their lives so that silks would grace the fine women of the Heeren XVII" (1978:55). Can we read this prescient condemnation of colonialism as conditioned by Svilt's outsider subject position made possible by his queerness, or is it rather the myopic jingoism of a British chauvinist criticizing the evil manichaeen Other of Dutch colonialism? Or is this a twentieth-century fictionalizer's obvious and rather pedestrian condemnation of colonialism and slavery? We need Borges's Pierre Menard here to help sort things out.

Religion, nationalism, and sexual preference come together in the bodies of Dutch sailors. They are seen as less than human, fouling the

ship's hold with their excrement in violation of Company policy, and lambasted by a Muslim in Capetown who observes the sailors at a brothel and says: "The Calvinists are, to hear them, the salt of the earth with God-given morals." He pointed to the line of drunken sailors, "Look at how you really are. You behave like swine, like drunken, whoring pigs. I would never allow my daughter to marry a Dutchman. I would break her neck first."¹⁰ Svilt guides Bandino through the lust-filled streets of Capetown and Batavia as if he were carrying his chalice through the crowd. When Bandino and Svilt refuse to avail themselves of prostitutes, they are mocked. The ever witty Nicholas Fockema shouts, "What's the matter boys, no balls? Do you squat to piss?"

As opposed to the syphilitic, debauched sex offered by the Dutch sailors is the rather elevated, poetic relation between Bandino and Svilt. Bandino Franz is described when Svilt meets him in Batavia as "a slight, strangely beautiful boy with the skin and eyelashes of a Javanese Houri, tinged with wisps of blond hair. He moves his small, delicate hands and feet with great deliberation. He is thin, spry, and well-proportioned" (1978:75). He recites Indian and Arabic poetry, and says things like, "love is the water, if not the wine of life." His stepfather feels he is "peculiar" and that he will grow worse if he stays in Batavia, where "voluptuous and lascivious women walk the streets" (1978:74). So Svilt agrees to take him to the Netherlands and protect him. Indeed, Svilt's homosexuality is linked to his abhorrence of the behavior of his fellow Dutch sailors. They are drunken louts debauching with lascivious women. On the other hand, Bandino and Svilt tend to have rather lush, oriental encounters in gardens.

We must ask ourselves, is this a twentieth-century queer pastiche of Khalil Gibran, or is it an eighteenth-century writer's evocation of early orientalism, or is it really Svilt's idyllic recollection?

There are some rather striking motifs that go through the work, particular an obsession with the mouth, with drinking, with being forced to drink, being unable to find water to drink, and ending up with Svilt reduced to drinking his own urine mixed with turtle blood. The 1748 edi-

tion I was able to consult had the last third of its pages torn out.¹¹ These are the ones recording Svilt's drinking of urine and blood and his ensuing death. Or another motif of cursing demons and rats threads through the book. But, were these motifs deliberately put there by a designing author, or are they the unconscious collection of details by this queer Robinson Crusoe?

It may be possible to find, through further research, that some of the texts are more authoritative than others. But I think it will be impossible to ascertain if there was a Jan Svilt, and there was a journal, whether any printed version is an accurate document concerning what happened. In addition, since Svilt was considered queer, it is unlikely that his journal would have been preserved with any reverence. An object like this one is itself unstable and unreachable by historical inquiry, part of a deeply political and psychological repression. As such, its status raises serious questions about the recuperability of history, particularly of repressed history, the culpability of writers and historians, and the transgressive role of interpretation.

The act of criminality may indeed be the act of narrative, of putting events into a continuous history in time. I have tried to resist the temptation to make this account a seamless whole. I bear in mind Adomo's statement that "the whole is a lie." What then must be said of the desire to place events in a chronotope, to render an officiated, reified scholarly version of a series of past moments defined as criminal into a discourse which, while perhaps claiming to be transgressive, is actually the legitimated discourse of academic documentation? In this mystery narration of mine, who is the criminal? Is it Svilt? The Dutch East India Company? The tribunal that wrote up the narrative of inquest? Captain Mawson? The editor of *A Just Vengeance*? The author of the Dutch book of "sea adventures"? The translator? The new "editor" Agnos? The publisher Adler? Are some of these people creations of yet others? Or is the criminal myself, implicated by reading, conspiring in writing, made guilty by research, unconsciously or consciously fictionalizing and narrativizing what I am claiming as fact? Or perhaps the guilty party is the reader—

who follows along with various motives, unknown intentions, unquiet thoughts?

The figment of Jan Svilt, a corpse, a corpus, a body of knowledge or of misinformation still lies at the center of the story. Is the center a heart of darkness, an aporia, a blind spot, or a recuperable being who, having lived, if he lived, left his legacy through the queer fact of his having been? And what is the strange connection between myself, randomly chosen as the explicator or mystifier of his life, and this man who lived almost three hundred years ago, perhaps, or some other man or woman who invented him? What bonds are forged by the writing, the telling, the warning, the retelling of his putative existence? In the end, the only answer is the set of implications that entrap and draw the reader, the critic, and the character together in this set of criminal statements.

APPENDIX: PUBLICATION CHRONOLOGY RELATING TO JAN SVILT

May 2, 1725—Report from Dutch East India Company by Algemeen Ryksar-chief (translated by M. Jelstra).

May 5, 1725—Jan Svilt marooned on Ascension Island.

1730—Captain Mawson, *A Just Vengeance of Heaven*. London.

1747—*A Just Vengeance of Heaven*. New York: James Parker at the New Printing Office in Beaver Street.

1748—*A Just Vengeance of Heaven*. Philadelphia: sold by William Bradford, at the Sign of the Bible, on Second Street.

1762—Dutch edition of *Sea Adventures*, Amsterdam (the “source” for the 1993 edition then translated by Michael Jelstra for Peter Agnos).

1993—P. Agnos, ed., *The Queer Dutchman: True Account of a Sailor Cast-away on a Desert Island for “Unnatural Acts” and Left to God’s Mercy*, trans. M. Jelstra. New York: Green Eagle Press (copyright 1978, C. Adler).

WHO PUT THE *THE* IN *THE NOVEL*?

IDENTITY POLITICS AND DISABILITY IN NOVEL STUDIES

We are unknown, we knowers, ourselves to ourselves.

—Friedrich Nietzsche, *The Genealogy of Morals*

Who put the *bop* in the *bop shoo bop*?

Who put the *ram* in the *ram a lam a ding dong*?

Who was that man? I'd like to shake his hand.

—Bobby Vee

In the past few years, there has been much discussion, from a post-modern perspective, concerning the ontological status of the novel that challenges the very category of “the novel” as a discrete form or genre. For example, the editors of the collection *Cultural Institutions of the Novel*, Deirdre Lynch and William Warner, ask whether we can talk about “the” novel without using conceptual quotation marks. “[W]e project a form of novel studies that would take as its object the semantic and social contests through which *the* novel keeps hold of its definite article and stakes a claim to cultural capital.”¹ Clifford Siskin prefers to replace “the novel” with the term “novelism,” which he defines as “the now

habitual subordination of writing to the novel” (qtd. in Lynch and Warner 1996:423). For these critics and others, the novel is not so much a knowable thing as it is a constructional process, a prejudice in writing that privileges certain power relations in the interests of cultural capital, national sovereignty, domestic domination, and racial, gendered, and class-based positionality.

At the end of the late twentieth century, one has little choice but to highlight the “the” in the novel. After all, this is the century that saw the removal of the “the” from such places as Ukraine, Congo, and Sudan (but not yet from the place where I write this essay—the Bronx) in a surge of identity politics characterized by postcolonial consciousness and a sense of the power of linguistic collusion in structures of power. The “the” in the Levant, the Sudatenland, as well as the Congo, seems to convey a notion of possession, a signification of country as a thing to be had. Like previously unquestioned categories of bourgeois thought, the novel is now seen as a term that claims a space, marks a domain, but is not and can never be a thing. Gone is the myth of *the* novel, a discrete form, a knowable practice, that arose at a specific time for a specific purpose. We run Ian Watt from pillar to postmodern. He made some really big mistakes—he thought there was “a” novel; he thought it had a beginning; he assumed it was a narrative fiction that displaced previous narrative fictions and had a “rise” located in metropole England.² In doing so, he was naive, sexist, racist, Anglophilic, logocentric, essentialist, positivist, vulgarly materialistic, and probably homophobic. But nobody is perfect.

Witness most of the critical works on the novel written since the 1980s, including work by Nancy Armstrong, John Bender, Michael McKeon, Catherine Gallagher, Janet Todd, Ian Watt, and others, including myself—all can be faulted along some, if not most, of these lines. At the end of the twentieth century, a new reckoning has begun to take place. This reckoning is being made by a conceptual tribunal of academic representatives of the disenfranchised and the marginalized—people of color, queers, indigenous and colonized peoples, feminists, to name a few, and the presiding judge has a mask whose features morph alternately

into those of Derrida, Foucault, Irigaray, Baudrillard, Butler, Said, and Lacan.³

When the novel takes its place in the docket, a central issue before the tribunal is whether those who wrote about it and claimed a European, or even a British, origin for it were in the right. This discussion depends, as does all cosmogony, on a rather simple idea: either the novel is a form with a beginning, or it is a form that has always been around. If the novel has always been around in the form of prose storytelling, then any attempt to see it as a “new” form is biased against indigenous peoples, against non-European cultures, and so on. If the novel does have a big-bang beginning, there arises the question of “when” and “where” it began. One could divide the critical world into “originists” and “antioriginists.” If, as some have done, the origin of the novel is placed in eighteenth-century England, then criticism can be leveled that such a claim is motivated by an Anglocentric, colonialist, metropolitan bias. I would agree that highlighting something called “the novel,” which in its name implies a new and dominant form, requires a certain act of national and cultural bravura. It is clear that when Clara Reeve in 1785 has one of her characters in *The Progress of Romance*, say “[T]he word *Novel* in all languages signifies something new,”⁴ she is striking a blow for early modernity and for England as well. Indeed, her title implies progress in narrative forms and in civilization. In this sense, Clara Reeve is an originist, although in a different sense than contemporary critics.

Many of the now critiqued “originists” who have written since the 1980s about the origin of the novel in the eighteenth century have been leftists and progressives of various stripes. The aim of placing the origin of the novel in eighteenth-century England and not at the dawn of human consciousness or in a country other than England was to claim that the novel was historically an early modern form dependent on early modern technologies which participated, both collusively and transgressively, in the transformation of the social, political, and cultural life produced by capitalism as an economic system and bourgeois liberalism as its concomitant political ideology. Since most can agree that industrial-

ization and capitalism began in England specifically and quickly spread through Europe, this originary discussion is driven by a historically necessary logic.

This approach varied from earlier materialist explanations of the novel by its use, in many cases, of the work of Michel Foucault. The theoretical sophistication of Foucault's analysis of discourse gave critics an instrument with which they might perform analyses that did not rely on a simple exegesis of themes relating to class and exploitation. But Foucault's work, while eminently suited for this kind of analysis, was not without its political pitfalls. As Wendy Brown has recently summarized the critique of Foucault:

In his concern with disciplinary power, in his articulation of how certain discourses are forged into regimes of truth, and in his formulation of power as that which produces subjects rather than simply suppressing or positioning them, Foucault conjures a political field with relatively little open space and none of the tricks of self-overcoming, of forward motion, contained in Marxist historiography.⁵

In a sense, the revision of an older materialist vision of history and subjectivity was certainly long overdue. But, like any historically determined practice, Foucault's work was also grounded in its time. In the sixties and seventies, radical movements found themselves virtually without a political model for social change. In the tradition of the Frankfurt School, Foucault offered a largely intellectual model instead. For Foucault, power in its micro-dissemination is to be found, like background noise in the cosmos, equally distributed through all societies, not simply in capitalist formations. Power may ultimately trace its origins back to some head of government or sovereign entity, but it has a life of its own. It operates discursively, which means that it can only be opposed discursively.

Furthermore, with Foucault's refutation of the "repression theory," an identifiable political force oppressing citizens cannot be located and

therefore opposed. Political compliance is achieved without repression through the willing cooperation of a populace. Thus, Foucault's thought, while suiting a Marxist or leftist critique, undermines, or revises, some very fundamental political notions. Agency becomes problematic, and political change becomes confusing since, like Oakland to Gertrude Stein, there is no "there" there; identity becomes fraught, since to "be" someone involves being a subject whose existence depends on engaging in the common discourse. All this leads to a critique of the novel that can be carried out in the university without an allied political struggle, without models of what a society or cultural production would look like in a progressive setting, and without the need for any articulation other than an individual one written at night in the glow of the computer screen.

Along with this formation in leftist thought came the beginning of identity politics in the form of the feminist and civil rights movements. Because this history is well known, I do not need to trace these developments and their subsequent proliferation through a variety of further identities—national, ethnic, somatic, sexual, and so on. But what is clear is that our current critical sensorium must necessarily include the sense of identity, and many articles on the novel see identity as a key for understanding this literary form or nonform. Linked with and overlaying this notion of the primacy of identity is a postmodern paradigm or antiparadigm that questions the nature of meaning and categories. This interrogation exists in a difficult and tense relation to the idea of identity. However, one relatively untroubled way that postmodern thought has entered into the identity debate, primarily through the work of Lacan and Derrida, has been in problematizing essentialism. By raising doubts about the ontology of meaning, the view that things unproblematically signify, that objects are, that genders exist, postmodern theorists have helped create the notion that identity is not a given but a construction. However, the very permission given to think of identity as a complex construction also serves to undermine the notion of identity, as theorists like Judith Butler have pointed out by asking, "[w]hat can be meant by 'identity,' then, and what grounds the presumption that identities are

self-identical, persisting through time as the same, unified and internally coherent?”⁶ Identity has the paradoxical virtue of being socially defined yet synonymous with individual integrity. Or, to paraphrase the Firesign Theater, “how can you have an identity that is in two places at once when you’re nowhere at all?”

One might understand the current primacy of identity as a function of the postmodern moment by historicizing this set of interests. Wendy Brown postulates that identity politics arose in coordination with the late-twentieth-century liberal state:

On the one side, the state loses even its guise of universality as it becomes ever more transparently invested in particular economic interests, political ends, and social formations. On the other side, the liberal subject is increasingly disinterred from substantive nation-state identification, not only by the individuating effects of late-twentieth-century economic and political life: deterritorializing demographic flows; the disintegration from within and invasion from without of family and community as (relatively) autonomous sites of social production and identification; consumer capitalism’s marketing discourse in which individual (and subindividual) desires are produced, commodified, and mobilized as identities.⁷

Unlike Foucauldian analysis, which is a largely academic affair, identity politics is linked to a larger array of political movements, sometimes referred to in the United States as the Rainbow Coalition, to use Jesse Jackson’s term for the coalition that supported his presidential bid. But in reality that coalition has been one in name only, with the different identity groups clashing on tactics and agendas, offering a fantasy of cohesion without actually creating one. The one thing these groups have in common is the wish for its constituency to have the full rights of any citizen. Indeed, in a bourgeois democracy, the issue of rights is paramount.

But a rights-based approach, connected with empowerment, will necessarily lead to the quite limited and conservative goal of making sure that each disenfranchised group has the rights of white, middle-class males. This goal, according to Brown, “only preserves capitalism from critique [and] sustains the invisibility and inarticulateness of class.”⁸ Although a truly just government should establish parity of interests for all identity groups, the larger goal would be to place the bar rather higher than the projected fantasy of the “middle class” in bourgeois democracies. Indeed, one can argue that historically the emphasis on rights as opposed to economic inequalities was ideologically coterminous with the foundation of Western democracy.⁹

I do not wish to convey the idea that I am against identity politics, nor that I think the issues it raises in regard to the novel are invalid. Indeed, my own work for the last few years has involved the identity of disability, and I have been an active proponent of the notion that the tribunal bench needs to be redesigned so that people using wheelchairs, and other people with disabilities, as well as the Deaf and the blind, can be accommodated. My concern is that the model we have of identity politics has some problems, and my advocacy on behalf of people with disabilities has shown me the shortcomings of such a praxis. One must ask the question: is identity the sharpest instrument to allow analysis and understanding of the novel?

To focus this question, let us consider the demand that disability should be included in the roster of the disenfranchised. The tendency is to see disability as “another” identity to be added to an existing welter of identities. Thus, one simply adds to the list of outrages committed by a dominant majority. By this standard, if I want disability to be recognized as part of the general outrage against the excluded and marginalized, I must develop a body of knowledge elucidating those injuries. Part of the project, then, is to turn to the novel and show how people with disabilities have been constructed historically and by and large negatively depicted by the dominant culture. I can run through the many characters in novels who are depicted as having disabilities, and I can show that

often they are seen as villains, bitter and warped, or as innocent victims, good and kindly, although desexualized and devitalized.¹⁰ They range from Quilp to Tiny Tim, from Ahab to Esther Summerson, from Quasimodo to Clifford Chatterly.

But disability is somewhat different from other identities and subjects them to a kind of scrutiny. Disability is an identity divorced from family, nation, ethnicity, or gender. It is not a discrete but rather a porous category. Anyone can become disabled, and it is also possible for a person with disabilities to be “cured” and thus become “normal.” Furthermore, race, nationality, and ethnicity have in effect been considered biological disabilities in an eugenic culture. Because the category of disability is porous, its contingent nature is all the more challenging to identities that seem fixed. In some sense, disability is more like class, which is constructed but is not biologically determined. We might say that disability is a postmodern identity because, although one can somatize disability, it is impossible to essentialize it the way one can the categories of gender or ethnicity. That is, although disability is “of” the body, it is much more “of” the environment which can create barriers to access and communication.¹¹ Also, since the category of disability casts quite a wide net according to definitions provided by the Americans with Disabilities Act of 1990—including in the same grouping obesity, carpal tunnel syndrome, AIDS, deafness, dyslexia, attention-deficit disorder, Down syndrome, and many other diverse conditions—it is hard to imagine any one person as a “representative” for this group or as a “representative” character in a novel. And this very fact engenders a deconstructive potential that undermines any individual’s claim to represent the totality of an identity.¹²

More tellingly and to my point, the identity community, if one can call it that, has been very slow to recognize disability as a legitimate member. Perhaps because of the ambiguities I just related, disability is seen as in some sense “spoiling” the neatness of the categories of oppression, victim, and victimizer. Anyone working in the field of disability studies will know that disability, despite the legislative accomplishments achieved in its name, is generally seen as having a less legitimate minority status than

other more high-profile identities.¹³ Indeed, in multicultural curriculum discussions, disability is often struck off the list of required alterities because it is seen as degrading or watering down the integrity of identities. While most faculty would vote for a requirement that African American or Latino or Asian American novels should be read in the university, few would mandate the reading of novels about people with disabilities. A cursory glance at books on diversity and identity shows an almost total absence of disability issues. The extent to which people with disabilities are excluded from the progressive academic agenda is sobering, and the use of ableist language on the part of critics and scholars who routinely turn a “deaf ear” or find a point “lame” or a political act “crippling” is shocking to anyone who is even vaguely aware of the way language is implicated in discrimination and exclusion.

These acts of omission and commission are all the more scandalous since people with disabilities make up 12 to 15 percent of the population—a greater proportion than that of any other minority. This statistic can be increased for people in poorer countries. Likewise, about 15 percent of the population has hearing loss and another 15 percent has impaired vision. With an aging baby boomer population, the number of people with disabilities will only increase. In the Third World, poor nutrition, land mines, war, and disease increase the numbers of people with disabilities. And let us not forget children, particularly those of the Third World, who are the primary victims of discrimination, with 90 percent dying before they reach twenty, and 90 percent of children with mental disabilities dying before they reach five. In the United States, 66 percent of people with disabilities are unemployed, while half the people with disabilities live on or near the poverty line. A recent Modern Language of America survey showed that there were twice as many members with disabilities as there were African American members. Yet, by and large, there is scant attention paid to disability in the identity politics market, particularly in regard to novel studies. Certainly, disability studies is beginning to reverse this trend. Its status, at this point, resembles that of African American studies in the early 1960s.

The lack of attention paid to disability by those in the forefront of identity and multicultural studies shows dramatically that the Occam's razor employed to evaluate critical works—does it focus on race, gender, or sexual orientation?—is a dull razor indeed. Rather, one can say that identity politics as a method of literary analysis will necessarily reflect the biases of its own time. While our consciousness of some selected and canonized identities has certainly been raised, the biases of those within the confines of the canon remain confirmed by their invisibility. Identity studies is no more value-free and objective than hermeneutics, structuralism, or any other applied discourse. Perhaps critics of the future will be astounded, puzzled, and disturbed that works by scholars like Eve Sedgwick, Judith Butler, Henry Louis Gates, bell hooks, and others managed to steer so completely away from any discussion of disability.

I should make clear that my solution to the problem of identity is not the inclusion of disability on the roster of favored identities. Rather, the point is that identity studies itself is limited by the necessarily taxonomic peculiarity of its endeavor. The list of identities will only grow larger, tied to an ever-expanding idea of inclusiveness. After all, when all identities are finally included, there will be no identity. When studies focus on alterity, and when alterity must be included, then, in the full plenum of inclusion, alterity ceases to be Other. Identity becomes so broad a category that it cannot contain identity. In other words, identity politics has reached a paradoxical resolution to a problem that started as a logical extension of a discussion about rights. It is Wendy Brown's point, citing Foucault, that "the universal juridical ideal of liberalism" combined with "the normalizing principle of disciplinary regimes conjoined and taken up within the discourse of politicized identity" yields a new kind of subject, "reiterative of regulatory, disciplinary society . . . which 'ceaselessly characterizes, classifies, and specializes,' which works through 'surveillance, continuous registration, perpetual assessment, and classification,' through a social machinery 'that is both immense and minute.'"¹⁴ In other words, the classificatory and judgmental system inherent in an identity critique of novels will necessarily end up surveying texts through

an ever-expanding and therefore increasingly imprecise grid. This framework will therefore yield less and less information about more and more works and become a system that explains everything, thus ultimately explaining nothing.

I want to complicate this already complicated critique further by pointing to the inability of identity politics to include disability under its tent in some way other than with second-class status. My point is to question how effective an antidiscriminatory stance, based on identity politics, can be when the watchman always needs to be watched. No coalition of identity-based activists or scholars will ever be able to avoid marginalizing and minoritizing *some* group. Bosnian mothers, Albanian Serbs, or Ethiopian Jews will always be out of favor, and if not them, then tribal peoples of northern India or indigenous rebels in Sri Lanka. An inherent limitation of permitted or favored identities is built into the definition of the project. The contradiction becomes more acute when we realize that much of identity politics is a reaction to a rights-based model rather than to an economically egalitarian, political one.

From this perspective, we can see that the necessity for identity is actually a compromise formation in theory, tailored to a largely middle-class, First World audience seeking reassurance about the parameters of liberal thought and politics. The interest in identity in novel criticism is a ratification of this reassurance. If one can say, for example, that women are depicted in a binary way in novels as either madwomen or angels, the alternative to either of these roles is held out as a norm. What is that alternative but some superscription of the ideal of white, middle-class men with full rights? Likewise, the benchmark for people of color is the depiction of the middle-class or gentry as full-fledged members of society. As Brown writes, “without recourse to the white masculine middle class ideal, politicized identities would forfeit a good deal of their claims to injury and exclusion, their claims to the political significance of their difference.”¹⁵

What relevance could this discussion have to the novel and novel studies? First, I think the current caution against thinking of “the” novel

is an effect of a more general tendency to think of identity as multiple on the one hand and resistant on the other. The novel must be an effect of power in the same sense that identity is both the result of power and a resistance to it. As in the case of human identities, the identity of the novel is postulated as covering many instantiations of narrative. But, unlike materialist explanations, identity critique tends toward ahistoricism by postulating a timeless category of identity, transferred from the present to the past, and then defining origins by postulating that identity is anterior to the origin. So the origin of the novel, for example, is clearly preceded by the category of “feminine” or “colonial.” This circularity of thinking defines the moment of origin as causally related to the category of identity so chosen. The flaw in this argument is that if an originary moment is sufficiently originary, it will participate in a redefinition of the identity that is supposed to have created it. In a cosmological sense, the world can’t be created without the creation of the creator.

In this sense, I hope that by questioning the foundation of identity politics, I can raise the case for a reading of the origin of the novel that is not totally dependent on what must be considered a bias of contemporary criticism—the demand that all explanations must satisfy an insistence on tracing a nondominant, non-Western, non-European, non-British origin of the novel. So, I now wish to perform a paradoxical proof of the points I have been making by attempting to develop a theory of the origin of the novel that is solely based on the concept of disability. In other words, I want to prove that I can justify a disability-centered identity politics the way that others have done, for example, in establishing feminist, ethnic, or class-based models. In doing so, my aim is twofold: I want to show that disability is a viable identity, and, paradoxically, I want to demonstrate the limitations of an identity-based explanation for the origin of the novel. In other words, I want to show that disability can and should sit on the tribunal of identity politics, but I also want to show that including disability will not solve the problems inherent in the tribunal in the first place.

What are the possibilities for a disability-centered discussion of the novel? Initially, one would want to rethink the nature of the novel. An early definition of the novel, by Clara Reeve in 1785, states,

the Novel is a picture of real life and manners, and of the times in which it is written. The novel gives a familiar relation of such things, as pass every day before our eyes, such as may happen to our friend, or to ourselves; and the perfection of it, is to represent every scene, in so easy and natural a manner, and to make them appear so probable, as to deceive us into a persuasion (at least while we are reading) that all is real.¹⁶

Some fifty years later, John Dunlop defined novels as “agreeable and fictitious productions, whose province it is to bring about natural events by natural means, and which preserve curiosity alive without the help of wonder—in which human life is exhibited in its true state, diversified only by accidents that daily happen in the world.”¹⁷

According to these relatively contemporary accounts, a new literary form with links to previous fictions like the romance, tales, the epic, and so on, had appeared on the scene in England and France. And what characterizes this form is some notion that it treats “real” life in a “familiar” way that appears to be “true” without the intrusion of the elements that do not appear “natural.” This technique, most familiarly called “realism,” is so much a part of our critical vocabulary that perhaps we have reified it somewhat. What is realism, in fact? If novelists tried to create a real effect, does that mean that earlier writers did not attempt to portray the real? The implication is that earlier writers of the romance and epic wrote imaginary tales or at least tales involving the supernatural, the realm of gods, witches, monsters, classical heroes and heroines, and so on. But is realism any more “real” than other types of narrative? Is a representation of the real any more real than “the real”? And is the concept of what is real absolute? Why should realism have arisen in this particular period? Did novelists and readers just decide to get real?

Ian Watt, as one of the early exponents of the origin-of-the-novel paradigm, explains rather glibly that “[m]odern realism, of course, begins from the position that truth can be discovered by the individual through his [*sic*] senses: it has its origins in Descartes and Locke.”¹⁸ Watt further explains realism as part of the middle class’s interest in the individual and his or her perceptions of reality. His notion of “formal realism” is defined as such “because the term realism does not here refer to any special literary doctrine or purpose, but only to a set of narrative procedures which are commonly found together in the novel.”¹⁹ This definition owes much to the period in which Watt’s book was written, and his debt to formalism and New Criticism are obvious. So for Watt realism is not about the subject matter of the novel, but more about the way the story is told and the consciousness that apprehends the story. But why does interest in the individual have to take the form of realism? Why could not the same interest take the form of rampant egocentric fantasy or one-sided, biased memoir (which seems to be the form realism takes in our own time)? Indeed, individual perception should lead more to individualist, sensory-based texts, more like twentieth-century literature, and not necessarily toward narratives about groups, social classes, and communities.

Instead of looking toward this explanation of realism, why not look elsewhere? The growing body of literature on disability indicates to us that part of the formation of the modern subject was tied up with the creation of the disabled object. Characteristic of the split between the “normal” and the “abnormal” which arose during the formative period of the novel (as we know it) is a distinction between normal bodies and abnormal bodies, between normal minds and abnormal minds, between normal environments and abnormal environments, and so on. The normal-abnormal dichotomy displaced an earlier paradigm based on a notion of the ideal.

This notion of the ideal seems to have been the general rule in Western society and was linked ideologically to structures of kingship and feudal society. In this paradigm, an ideal person or institution (ruler, form,

palace, god) occupied the pinnacle of a social-cultural triangle, and all other instantiations were by definition below the ideal. The transition to ideological forms of government that would legitimate the change from feudalism and mercantilism to capitalism required new forms of subjectivity and symbolic production. Since the fundamental paradox of bourgeois society as it evolved was between the concentration of power and money in the hands of a relatively few and the ideological claim that all men [*sic*] were created equal, forms of symbolic production that glorified the ideal and placed all citizens below that ideal person were no longer appropriate.

Yet, at the same time, a citizenry that was truly equal in the economic sense, as depicted in literature, was also prohibited. In order to bridge the gap between the obvious social and economic inequality in bourgeois democracies and the notion that all citizens are equal, there emerged that most perfect of subjects—the average citizen, “*l’homme moyen*,” described by Adolphe Quetelet at the beginning of the nineteenth century. Quetelet took physical bodily measurements in order to determine the proportions of the average man. Of this man Quetelet wrote, “If one seeks to establish, in some way, the basis of a social physics, it is he whom one should consider.”²⁰

The necessity for the average citizen in social thought was paralleled by the need for the average citizen in ideology. How do we think of this average citizen? Symbolically. Thus symbolic production on the ideological level aimed at the creation of average, that is, nonheroic, middle-class, “real” citizens. In this sense, real means average. It is no coincidence that for the next hundred years or more, bourgeois society spent much of its culturally productive time trying to find out exactly what average meant. This was done largely with the aid of the new science of statistics, initiated by Quetelet and others, in conjunction with the new science of eugenics.²¹ The word and concept of “normal” entered the English and French languages at this time. Novels were novel precisely because they were a form engaged in depicting this average or normal life, as Reeve and Dunlop noted in their own time. Indeed, the project

of creating “realistic” heroes and heroines was the aim of novel writing from the mid-eighteenth to the end of the nineteenth centuries.

The word repeatedly and regularly used in conjunction with character in eighteenth-century discussions of the novel was “virtue.” Novels were judged to be good depending on the extent to which the story inspired virtue and the protagonists were virtuous. Virtue implied that there was a specific and knowable moral path and stance that a character could and should take. In other words, a normative set of behaviors were demanded of characters in novels. Characters had to be “exemplary.”²² We can see in works like *The Progress of Romance* that novels were judged mainly on two criteria—their realism or probability and their attitude toward virtue, which “should always be represented in the most beautiful and amiable light.”²³ Both these criteria, as we can see, are really measures of normativity. If readers disagreed about the worth of a novel during this period, the argument revolved around whether an author had depicted “human nature as *it is*, rather than as *it ought to be*.”²⁴ or around whether the events of the story were “probable” or “improbable.”²⁵ Thus, the question for the eighteenth century centered on the extent to which the novelist conformed to a cultural norm, not, as Watt suggests, the formal aspects of the writing or the perception of the truth of an individual.²⁶ In fact, it is virtually impossible to find a discussion about the “formal” aspects of novel writing in this period.

Furthermore, the main characters of novels, in their virtuous incarnations, were national types. The requirement that they be “realistic” and “virtuous” was in effect a requirement that they be typical. There are few novels from 1720 to 1870 whose main characters, the ones with whom we identify and sympathize, are not national stereotypes. And, as such, these characters also have bodies and minds that signify this averageness. The protagonists of British novels are British, look typical, and embody the virtues that England values.²⁷ Love stories may offer a cross-national or class liaison but usually end up ratifying the norm.

This project of cultural typicality has to be seen for what it is—the inchoate impulse of a tendency that would later be called eugenics. It is in-

structive that one of the founders of eugenics was Sir Francis Galton, a cousin of Charles Darwin, who embarked on a project similar to that of the novel when he began photographing different racial and ethnic peoples in order to create composite photographs of the physiognomies of each type. So, for example, he photographed Jewish citizens of England and overlaid their photographic images to create the composite (or in some sense) typical Jew. He also photographed mental and tubercular patients to see if he could arrive at the physiognomies of the diseased.²⁸ This attempt to create typical images of racial and disabled Others in photography must be seen as linked to the attempt to do likewise in novels. The investigations of race and nationality in nineteenth-century novels demonstrate this linked interest.

There is virtually no major protagonist in a novel written during the eighteenth and nineteenth centuries who is in some way physically marked with a disability.²⁹ Indeed, realism, with its emphasis on probability, is bound to present normative characters and situations. Think of the physical typicality of Robinson Crusoe, Tom Jones, Joseph Andrews, Clarissa Harlowe, Becky Sharp, Emma Woodhouse, David Copperfield, Julian Sorel, and the hundreds of other physically able and typical protagonists from novelistic central casting. This is so much the case that E. M. Forster, in the course of *Aspects of the Novel*, sees the inclusion in a novel of a character with disability as unrealistic. He says that readers will protest deviations from a norm: “‘One knows a book isn’t real,’ they say, ‘still one does expect it to be natural, and this angel or midget or ghost—no, it is too much.’”³⁰ The midget is “too much” because midgets do not walk into one’s bourgeois house any more than do Africans or angels.³¹

So, on some profound level, the novel emerges as an ideological form of symbolic production whose central binary is normal-abnormal. This dialectic works in a fundamental way to produce plots. Often a “normal” character is made “abnormal” by circumstance. The most familiar of these has to do with that character’s loss of social class, social milieu, family lineage, or money. So the very normal Robinson Crusoe is made

abnormal by unusual circumstance. The very normal Tom Jones is made abnormal by a ruse that deprives him of his noble birth. The very normal Pamela or Clarissa are made abnormal by abduction and the threat of, or the act of, rape. Ironically, these rather unusual abnormalities in the life of a character are seen as “probable,” given the novel’s own rules of realism, when, in fact, it is rather unlikely that a bourgeois person will lose all his or her money, social status, or personal freedom. Indeed, social class is defined by its persistence and interlocking guarantees.

Another variation on this theme is that the protagonist is made “abnormal” by a certain trait or habit that, while not a disability, acts as a disability in contrast to the expectations of readers concerning the conventions of character in the novel. So Jane Eyre is plain, which is quite normal, but it is rendered abnormal by the convention of novels, which insists that heroes and heroines be physically attractive, presumably since the national type is projected to be well-proportioned in face and limb. Or someone like Evelina is made abnormal by her lack of proper parenting, which renders her socially maladroit.

In the realm of social class, the norm is typically not the mean but the ideological fantasy of the mean. This fantasy is an ideological necessity if bourgeois capitalism is to project a positive vision of its operative world as free, prosperous, and coherent. Not so strangely, the “average” novel hero of the mid-eighteenth to the mid-nineteenth centuries more often than not moves through the world not of the bourgeoisie, but of the upper gentry and lower nobility. This netherworld of upper gentry and lower nobility elevates the tone and vision of bourgeois existence much in the way that contemporary television shows that present upper-middle-class interiors as the norm do, even while the majority of viewers are from a much less privileged class.³² To be deprived of this fantasy norm is considered a disabling event for someone like Oliver Twist, Jane Eyre, David Copperfield, or Gwendolyn Harleth. Even for someone like Jude Fawley, the realistic norm of the rural peasantry is a disabling situation, although, unlike many of the earlier heroes, he will never achieve the desired state of comfort.

So, to consolidate the national norm, the major characters in novels must somehow confront the disabling of their character. For the norm to be established, the abnormal must also appear. The abnormal appears in all kinds of ways in the realms of the social and financial, as I have indicated, as the unvirtuous, the mentally ill, the racial Other, as well as simply in the appearance of characters with physical disabilities. In the eighteenth century, for the most part, normal characters with virtues are set off by abnormal characters with vices. Most often, the vice is sexual license in the behavior of a debauched, upper-class libertine or seductress, or, in rarer cases, greedy and unprincipled parvenus. A simple Manichean battle ensues, and ultimately either the virtuous character triumphs or, in some cases, dies.

Later, as a culture of the norm becomes fully operative in the nineteenth century, the immoral or negative is often depicted as having a physical disability. Here begins the novel with a recognizable villain who is often one-eyed, one-legged, walks with difficulty, stutters, manifests compulsive tics, and so on. The flip side of this character is the utterly innocent character with a disability, most often a child, a childlike person, a woman, or an aged character. Interestingly, this dichotomy can work in many other multicultural analyses, since race, gender, and class were also integrally part of the eugenic analysis. In other words, moral characteristics become increasingly somatized, particularly as eugenics begins to codify physical, mental, and ethnic traits. Under this imperative, Zola and the Neo-Realists are able to formulate a theory of the novel in which inheritable family traits determine character and behavior, thus institutionalizing the “scientific” work of eugenics in the very fabric of novel making.

Plot in the novel, then, is really a device to turn what is perceived as the average, ordinary milieu into an abnormal one. Plot functions in the novel, especially during the eighteenth and nineteenth centuries, by temporarily deforming or disabling the fantasy of nation, social class, and gender behaviors that are constructed as norms. The *telos* of the plot aims to return the protagonists to this norm by the end of the novel.³³ The end

of the novel represents a cure, a repair of the disability, a nostalgic return to a normal time. René Girard points to Stepan Trofimovitch's quotation of the New Testament at the end of Dostoevski's *The Possessed*, "But the sick man will be healed and 'will sit at the feet of Jesus,' and all will look upon him with astonishment." Girard says Stepan "is this sick man who is healed in death and whom death heals."³⁴ This notion of cure as closure is the rule in novels in which the end represents the plot as strategic abnormality overcome, or, as Girard puts it, "an obsession that has been transcended."³⁵

In this sense, the identity of the novel, if we can see the novel as having an identity, revolves around a simple plot. A normal situation becomes abnormal and, by the end of the novel, normality or some variant on it is restored. We can put this simplistic paradigm into the language that Wendy Brown uses, and say that the identity of the novel is therefore a "wounded identity." Like Philoctetes, the novel must have a wound. And like that of Philoctetes, this wound is necessary, since without it the novel would not be able to perform its function. Yet, also like that of the mythical character, the wound must be healed or cured.

I return to the notion of identity because I want to tie the novel, disability, and identity politics together around the issue of cure. The novel as a form relies on cure as a narrative technique. Protagonists must "change," we are told, for their characters to be believable. Interestingly, this aspect of believability flies in the face of probability, since most "real" people do not change easily, if at all. When characters change, they undergo a kind of moral or perceptual transformation that cures them. So Emma is cured of her self-centeredness and D'Arcy is cured of his pride. Likewise, the plot is cured of its abnormal initiating events. The narrative, at its end, is no longer disabled by its lack of conformity to imagined social norms. The process of narrative, then, serves to wound identity—whether individual, bourgeois, national, gendered, racialized, or cultural. Readers read so that they can experience this wound vicariously, so they can imagine the dissolution of the norms under which they are expected to labor. As a temporarily wounded person, the reader can see the way

that society disavows various categories of being and at the same time can rejoice in the inevitable return to the comfort of bourgeois norms, despite the onus that these norms place on its beneficiaries as well as on those excluded from the benefits of bourgeois identity.³⁶

But the desire for a cure is also the desire for a quick fix. The alterity presented by disability is shocking to the liberal, ableist sensibility, and so narratives involving disability always yearn for the cure, the neutralizing of the disability. This desire to neutralize is ironic, since in a dialectic sense the fantasy of normality needs the abjection of disability to maintain a homeostatic system of binaries. But, since this desire is premised on the denigration of disability, it will of course be invisible to the normal³⁷ readers who prefer the kindly notion of cure to the more dramatic notion of eradication. Likewise, the quick fix presented by issues concerning race, class, and gender are equally characteristic of the bourgeois imagination. Class conflict can be nicely reconciled by novels like *North and South*, where a kind of utopian factory emerges that bypasses unions and is achieved by rerouting surplus value through the benevolence of a female captain of industry in the form of Margaret Hale, or *Hard Times*, where the working-class struggle is seen as a “muddle” only soluble by Christian charity toward the poor who “will always be with you.”

All these cures are placebos for the basic problem presented to capitalism and its ideological productions in the form of modern subjectivity, which dons the form of the normal, average, citizen protagonist—that bellcurve-generated, fantastic being who reconciles the promise of equal rights with the reality of an unequal distribution of wealth. But the quick fix, the cure, has to be repeated endlessly, like a patent medicine, because it actually cures nothing. Novels have to tell this story over and over again, as do films and television, since the patient never stays cured and the disabled, cured individually, refuse to stop reappearing as a group. Indeed, modern subjectivity is a wounded identity that cannot cure itself without recourse to cure narratives, which means that it cannot cure itself at all, since the disability of modern subjectivity is inherent in the environment, not in the subject.

The problem with the notion of wounded identities, as Brown postulates, is that the ontology of their coming into being is best characterized by Nietzsche's notion of *ressentiment*, an "effect of domination that reiterates impotence, a substitute for action, for power, for self-affirmation that reinscribes incapacity, powerlessness, and rejection."³⁸ Thus, identity is dependent for its motivation and existence on remembering and reinvoking the pain caused by oppression. Politicized identity "installs its pain in the very foundation of its political claim, in its demand for recognition as identity by entrenching, restating, dramatizing, and inscribing its pain in politics."³⁹ Like the novel, identity is rooted in its wounds, and plot is a form of pain control. Thus, its solution must be to heal the wound, end the pain. However, just as the cure offered in novels spells closure for the text, the cure offered to wounded identity spells the end of identity, since identity is created by the initializing wound. The answer to novels is only more novels, not a cure offered for the actual ills of society. Likewise, the proliferation of politicized identities is symptomatic of the problem, and the inclusion of more identities in our norm will no more solve the problem of oppression than the proliferation of novels will.

I have tried to make the case that disability, as an identity, can legitimately be seen as the foundational model that situates the origin of the novel in eighteenth-century England and France. If disability is such an origin, I can argue that all other identities—class, race, gender, sexual preference—should be subsumed under the hegemonic identity category of disability. In other words, I contend that the "the" in the novel belongs to a history of ableist domination. If I do that, I place myself in the line of critics who have argued for the centrality of their identities as foundational for the creation of modern subjectivity. By doing so, I can now make two observations. First, I clearly have not solved the problem of identity politics. By adding my identity to the roster, and even by claiming foundational status for my identity (which can be seen as including and therefore superseding other identities), I have rearranged the chessboard without creating a strategy for winning the battle. Second, my

writing of this piece, its subsequent publication in 1998 in *Novel*, and even a chorus of supporting voices from other scholars involved in disability studies who may read this work, will not propel disability into the forefront of identity politics for the simple reason that the other identity groups will not cede their place of priority. The reason for this reluctance is also relatively simple—to truly acknowledge the existence of another identity dilutes the general category of identity, and to prioritize identities places some identities further down the line of significance. Disability will have difficulty being seen as having a primary place in identity politics because most academics are deeply implicated in ableism without, of course, realizing it. Disability is still routinely ignored, marginalized, or patronized by the very people most active in identity politics.

As for *the* novel, the attempt to deabsolutize the form will in fact yield far less than the attempt to keep the form unitary. Pluralities of narrative-things-in-prose, rather than epics, romances, novels, and short stories, may provide a deconstructive breathing space apart from the rigidities of genre, but it also risks a certain hyperventilation of categories that prevent political analysis altogether. If we simply say that humans have told stories throughout the ages, we run the danger of making an observation no more trenchant than the kind of opening paragraph first-year students write in English 1 classes. If we follow this “throughout the ages” mode, we risk abolishing history in the endeavor to pluralize.

No one is suggesting a glib, monolithic view of the novel’s history, and it is better for us to argue over terms, moments, directions, and implications than it is to be content with quick and dirty hegemonic meta-narratives. But, without an acknowledgment that narrative forms arise from historical moments, speak to those moments, enforce powerful interests while also resisting them, we come up with a fairy tale about empowerment, multiple voices, liberatory discourse, and so on that belies the difficult work of cultural-political practice. And we all know that fairy tales “which treat of fabulous persons and things,” as Clara Reeve wrote, are the things of romance, while the novel “is a picture of real life and manners.”⁴⁰

THE RULE OF NORMALCY

POLITICS AND DISABILITY IN THE U.S.A.
[UNITED STATES OF ABILITY]

When my book *Enforcing Normalcy* was published in 1996, it received a positive review in an English periodical, but the reviewer did raise an Anglo-eyebrow at my use of the word “normalcy,” noting that the word “normality” was preferred in England. Indeed, of “normalcy” *Fowler’s* comments that it is “a word of the ‘spurious hybrid’ class . . . and seems to have nothing to recommend it.”¹ Blanching at this degree zero of recommendation, I consulted my American reference works and found to my relief that although in some dictionaries “normality” was the preferred usage, “normalcy” was acceptable, and in others there was no distinction made between the two words.² I found out

that President Harding was rumored to have coined the word in a speech entitled “Return to Normalcy,” for which neologism he was much ridiculed, although *Fowler’s* notes “there is no ground for the charge made against President Harding of having coined it; others had used it long before he did.”³ And after he did, one might add.

While I was relieved not to have made such a noticeable, front-page lexical blunder, nevertheless, like any obsessive academic, I got to thinking. I realized that my horror of appearing in print with a grammatical “error” was accentuated by my awareness of my working-class origins, my low-budget Bronx public school education, and my fear of being “outed” as a nonstandard English speaker, branded with the dreaded “[sic]” trailing after my solecisms like a tin can maliciously tied to a dog’s tail. Although I have generally “passed” in a world of largely middle- and upper-class academics, I still bear the hidden injuries of class. Then, of course, I had to factor in my parents’ deafness, and my “passing” in a hearing world which by and large, until I began to write about this part of my life, had no idea that I was in fact culturally Deaf. Further, I had to acknowledge that I am, like my son, somewhat dyslexic, at least in the realm of spelling and mathematics.

In other words, this near-slip in usage made me realize that something as superficial as the choice of a word in a title had a whole legacy tied up with disability and normalcy. Thinking more on it, I began to realize that a notion of correct and incorrect language usage, the notion of a preferred word—“normality” over “normalcy”—was after all a linguistic aspect of the very normalizing process I had been exposing in *Enforcing Normalcy*, the same book that was now being accused of abnormal forms of the word “normal.”

When we say that “normality” is preferred over “normalcy,” what exactly do we mean? We mean that some or a preponderance of experts in the field have agreed that a certain word is more “normal” than another word. How is the norm determined? By usage, to an extent. By logic, to an extent. By reference to grammatical patterns worked out from other languages like Latin and Greek. In other words, by social convention. For

example, since “normalcy” is credited by the *Oxford English Dictionary* as having an American origin, we can imagine that the neologism would be discounted by some British lexicographers as a colonial malapropism, only another example in the decline of the empire’s standards.

If we think of the distinction between prescriptive grammar, the body of didactic rules that tells us how to write and speak, versus descriptive grammar, which aims to describe how language is used in a variety of settings, we can understand how truly socially constructed are grammatical “norms.” Prescriptive grammar arose in the seventeenth and eighteenth centuries in an attempt to regularize the English language, which had no grammar, to the level of the revered Latin and Greek, which being dead languages had to have grammars and rules so that they could be taught in schools. Scholars at the time had fretted over the fact that English had no grammar, so the grammatical conventions of Latin were applied in a procrustean way to English, whether they fit or not.⁴ During this time, the first English dictionaries were compiled, so that spelling and meaning could be normalised, and so that printers could standardise their productions. In other words, language was regularized, and the effort of speaking and writing came under the jurisdiction and control of a class of scholars, men and women of letters, and other professionals who tried to make spoken language, in its transformational complexity, fit into rather arbitrary, logical categories. As Georges Canguilhem wrote, when French grammarians of the Enlightenment “undertook to fix the usage of the French language, it was a question of norms, of determining the reference, and of defining mistakes in terms of divergence, difference.”⁵

Why I am mentioning grammar and language usage in the context of a discussion of disabled or abnormal bodies is worth considering. When we think about normality, people in disability studies have generally made the error, I would say, of confining our discussions more or less exclusively to impairment and disease. But I think there is really a larger picture that includes disability along with any nonstandard behaviors. Language usage, which is as much a physical function as any other somatic activity, has become subject to an enforcement of normalcy, as have

sexuality, gender, racial identity, national identity, and so on. As Canguilhem writes, “there is no difference between the birth of grammar . . . and the establishment of the metric system. . . . It began with grammatical norms and ended with morphological norms of men and horses for national defense, passing through industrial and sanitary norms.”⁶

Let me backtrack here for a moment and rehearse the argument I made in *Enforcing Normalcy* so that I can make clear to readers of this essay the direction in which I am going. In that book, I claimed that before the early to mid-nineteenth century, Western society lacked a concept of normalcy. Indeed, the word “normal” only appeared in English about a hundred and fifty years ago, and in French fifty years earlier. Before the rise of the concept of normalcy, I argued, there appears not to have been a concept of the normal, but instead the regnant paradigm was one revolving around the word “ideal.” If one has a concept of the “ideal,” then all human beings fall below that standard and so exist in varying degrees of imperfection. The key point is that in a culture of the “ideal,” physical imperfections are not seen as absolute but as part of a descending continuum from top to bottom. No one, for example, *can* have an ideal body, and therefore no one has to have an ideal body.

Around the beginning of the nineteenth century in Europe, we begin to see the development of statistics and of the concept of the bell curve, called early on the “normal” curve. With the development of statistics comes the idea of a norm. In this paradigm, most bodies fall under the main umbrella of the curve. And those that do not are at the extremes—and therefore are “abnormal.” Thus, there is an imperative on people to conform, to fit in, under the rubric of normality. Rather than being resigned to a less-than-ideal body in the earlier paradigm, people in the past hundred and fifty years have been now encouraged to strive to be normal, to huddle under the main part of the curve.

Is it a coincidence, then, that normalcy and linguistic standardization begin at roughly the same time? If we look at that confluence in one area in particular, we see that language and normalcy come together under the rubric of nationalism. As Benedict Anderson has pointed out, the rise of

the modern nation took place largely in the eighteenth and nineteenth centuries when the varieties of polyglotism that had made up a politically controlled area were standardized into a single “national” language. Without this linguistic homogeneity, a notion of the modern nation-state would have had great difficulty coming into being. In addition, national literatures, both in prose and poetry, were made possible through the standardization of languages, the prescriptive creation of “normal” language practices.⁷

While few now object to Anderson’s thesis that language practices had to be standardized, homogenized, and normalized to allow for the creation of the modern nation-state, I think that the next step, which I want to propose in this essay, might be more objectionable. I would claim that for the formation of the modern nation-state not simply language but bodies and bodily practices also had to be standardized, homogenized, and normalized.⁸ In this sense, a national physical type, a national ethical type, and an antinational physical type had to be constructed. Here we see much work done in the nineteenth century on racial studies, studies of pathology, deviance, and so on—all with the aim of creating the bourgeois subject in opposition to all these abnormal occurrences.

This is where I want to return to my putative linguistic solecism. In thinking about the difference, or lack of difference, between normalcy and normality, I began to think of the suffixes which make all the difference in those two words. “-cy” seems to indicate a state of being, as does “-ity,” but there are resonating differences. Both “-ity” and “-cy” turn adjectives into nouns—as “sexuality,” “ethnicity,” “formality,” as well as “malignancy,” “pregnancy,” “immediacy.” However, I would suggest, without insisting absolutely, that the use of “-cy” seems more strongly to denote a permanent state, as it does in “idiocy,” “complacency,” “malignancy.”⁹ But interestingly enough, many words that describe not simply a corporeal state but a political state use the suffix—“democracy,” “autocracy,” “plutocracy,” or “aristocracy.”¹⁰ My thought, then, was to salvage my own oversight by making a valid distinction, much in the way that Jacques Derrida talked about “difference” and “differance.” I would

call “normality” the alleged physical state of being normal, but “normalcy” the political-juridical-institutional state that relies on the control and normalization of bodies, or what Foucault calls “biopower.” Thus, like democracy, normalcy is a descriptor of a certain form of governmental rule, the former by the people, the latter over bodies.

This distinction allows us to think through ableism in a somewhat different way than we have in the past. Rather than conceptualizing ableism as a trait or habit of thought on the part of certain somatically prejudiced people, we can consider ableism to be one aspect of a far-ranging change in European and perhaps global culture and ideology that is part of Enlightenment thought and part of modernization. Further, and I think this is important, we can begin to move away from the victim-victimizer scenario with which ableism, along with racism, sexism, and the other “isms” have been saddled and which leaves so little room for agency. Instead, one can see ableism as an aspect of modifications of political and social practice that have both positive and negative implications and that can be changed through a political process.

Let us look at the development of bourgeois representative democracy as an example of how ideological structures can shape notions of the body. The feudal model of society encouraged, for its own ends, the notion of inequality, a notion that the king or queen represented an ideal below which all subjects fell. The feudal system was based on a hierarchical notion of perfection, power, and wealth massed at the top of the social and political pyramid, less perfection, power, and wealth in the aristocracy, and even less in the peasantry. This model seeks to justify such inequality through the institutions of religion, of the patriarchal family, and of the violence inherent in the visible trappings of the state. Enlightenment writers like Jean-Jacques Rousseau, Voltaire, Adam Smith, and Thomas Jefferson rejected the concept of an idealized ruler holding all the power and wealth in favor of a representative government that postulates individuals who are equal to all other individuals. Thus the ruling entity, whose power derives from a social contract, is theoretically made up of individuals no different in kind from any other

individual. Thus it can be, for example, that a well-known statue of George Washington can show a button missing on his coat without fear of diminishing his authority, which does not derive from his embodying an ideal but from the delegated power of a social contract.

Yet, such a notion of an individual equal to other individuals, as expressed in the phrase of the Declaration of Independence of the United States of America that “all men are created equal,” has at base several contradictions. First, how is it possible that someone can be an individual and yet be the same as other individuals? This paradox is contained in the word “identity,” which signifies both individual existence and similarity with others. In order to postulate a government, at least theoretically, in which citizens are individuals equal to other individuals, one needs a notion of the average citizen. This being is seen as representative of all citizens. Likewise, in a representative democracy, one has to postulate that the elected officials “represent” each of these equal individuals.

The word “represent” conveys a further paradox. If the elected representative is a stand-in for any citizen, then he or she must act to convey the opinion of that individual. So the representative must both convey and literally “be” or represent the existence of the citizen. But to be truly representative, a government would have to have one elected official for each citizen. The notion of an individual representative representing groups of citizens contains the fundamental paradox of representative democracy: how is it possible to represent an individual citizen when one is elected by a majority or plurality of a segment of voters?

None of these issues was a problem for feudal or monarchical governments, since no representation of citizens had to take place. One did not have to postulate individuals but rather groups, classes, realms of control. Yet in order to represent, as a painter would for example, one has to visualise, create, postulate a simulacrum of a citizen.

This is where we see the development of the average citizen, “*l’homme moyen*,” by Adolphe Quetelet at the beginning of the nineteenth century. As noted in the previous chapter, Quetelet physically measured people’s bodily dimensions in order to come up with the proportions of the aver-

age man. He wrote, "If one seeks to establish, in some way, the basis of a social physics, it is he whom one should consider."¹¹ Thus, the average citizen is constructed to dissolve difference and hierarchy, all of which is reconciled in this statistical figure of equality. But the average citizen, like the average family with 2.5 children, is a kind of fiction, a created character that fits the national mold.

During the same period, statisticians began to come up with the concept of the norm and the normal. We may say of the norm, as a concept, that it is the perfect ideological and technical solution to the paradox of the individual. The norm provides an efficient explanation that reconciles the contradiction required in representative democracy concerning the notion of the represented individual. The paradox of how it is possible to be an individual equal to other individuals, and the further paradox of how to represent such individuals, is taken care of through the concept of the norm and the bell curve. Individual instantiations become statistically possible. Each entry has an existence and integrity, each person is an individual with his or her place on the bell curve. Yet, at the same time, each person is part of a continuum and fits into the whole. In addition, there is an average, a normal citizen who can be described. These are the hypothetical people whose cumulative characteristics fall under the center of the curve. Thus, the concept of the norm permits the idea of individual variation while enforcing a homogeneous standard or average.

Further, with the concept of a norm, representation is made possible, since the average citizen can be seen, postulated, and consulted in this way. Individuals can be represented in government as a collective. Indeed, the very idea of voting in an election for a representative has much to do with the formulation of an ideology of the norm. A collective voting decision can be thought of as nothing more than the tabulation of individual variations, and the result is the election of a person who is supposed to represent a norm of opinion or sentiment. Especially in a parliamentary election with many parties contending, the results can describe a kind of bell curve of opinion. The House of Representatives in the United States was conceived as a kind of living embodiment of this sense

of the norm. Thus, representative democracy is normalcy or, to try another neologism, normocracy.

The point I am trying to make is that bourgeois, representative democracy implies normalcy—that the two are really one form of government. As Canguilhem writes, “Between 1759, when the word ‘normal’ appeared [in French], and 1834 when the world ‘normalized’ appeared, a normative class had won the power to identify . . . the function of social norms, whose content it determined, with the use that that class made of them.”¹² Democracy needs the illusion of equality, and equality needs the fiction of the equal or average citizen. So with the creation of representative democracy comes the need for an ideology that will support and generate the aims of normalcy.

If democracy fosters notions of individualism, equality, and liberty, it also requires an ideology that reconciles those aims with the aims of capitalism, under whose watchful eye bourgeois democracy has been shaped. Capitalism conceptualizes equality as equality among workers rather than financial equality—since the latter would eliminate the differences in capital between ruling classes and workers and therefore eliminate capitalism. As philosophers like Jurgen Habermas have pointed out, there is a fundamental paradox in Enlightenment thinking. Enlightenment philosophers have argued for equality, freedom, and liberty in an ethical sense, hoping to have a society in which all people are theoretically free as regards rights. However, the unequal distribution of wealth required by capitalism seems a stark contradiction to these ethical goals.

So capitalism must explain logically or through ideology why it is just and fair that some people should have so much wealth and by virtue of that wealth, so much power to influence government. The concepts behind normalcy allow for such an explanation. If one takes the bell curve as a model, one notices that all variations fall into the unremitting logic of this distribution. Indeed, even random instantiations fall into a bell curve, as Francis Galton demonstrated through his construction of the *quincunx*, a device which allowed steel balls to fall randomly through a series of pegs and accumulate at the bottom of the device. Galton could

demonstrate that, because the balls always accumulated in a bell curve pattern, the normal curve was in effect a law of nature. Therefore, it is logical to say that something like individual wealth will conform to the curve of normal distribution—on the one side will be the poor, in the middle people of means, and on the other extreme the very wealthy. So the very theory that allows the individual to be instantiated in the collective on an equal basis also allows for wealth to be unequally distributed. Equality and normalcy demand, by the unbending laws of mathematics, that there will always be inequality.

Equality among citizens is therefore not based on an ethical notion of equality but on a quasi-scientific one. Once the ethical notion is reconditioned by the statistical one, the notion of equality is transformed. Indeed, the operative notion of equality, especially as it applies to the working classes, is really one of interchangeability. As the average man can be constructed, so can the average worker. All working bodies are equal to all other working bodies because they are interchangeable. This interchangeability, particularly in nineteenth-century factories, means that workers' bodies are conceptualized as identical. So the term "able-bodied" workers came to be interchangeable with able-bodied citizens. This ideological module has obvious references to the issue of disability. If all workers are equal, and all workers are citizens, then all citizens must have standard bodies to be able to fit into the industrial-political notion of democracy, equality, and normalcy. Clearly, people with disabilities pose problems to work situations in which work is standardized and bodies are conceptualized as interchangeable.¹³

Up to this point, I have been discussing what might be regarded as political considerations with reference to their implications for disability issues. But I hope that this discussion makes clear that there is no neat division between the world of the body and the world of the body politic. Indeed, what I have been stressing is that the rather neat divisions made between the technologies of the body and the machinations of the political world are ones that serve the very interests and ideologies being critiqued. So it is possible to talk about the way that medical discussions of

illness and disability can partake of political and ideological imperatives as well.¹⁴ One of the striking issues that comes up in looking at early medical conversations around the concept of normality is the way these conceptualizations dovetail with the political issues already discussed.

A major change in medical discourse occurred between about 1750 and 1850 around the definition of the normal and the pathological, as Georges Canguilhem details in his book *On the Normal and the Pathological*. The change was essentially from one system in which health and illness fought in a Manichean way over a body to another system in which disease and health were not seen as opposed forces but were conceptualized as part of a continuum. In the former, health and disease were sharply demarcated. In the latter, disease or health was measured by a lack or an excess. As the French physician Broussais writes, “the phenomena of disease coincided essentially with those of health from which they differed only in terms of intensity.”¹⁵ So disease becomes associated with prefixes like “hyper” or “hypo,” becoming in essence an extreme of normal health. According to John Brown writing in the 1780s, “it has been proved that health and disease are the same state depending upon the same cause, that is excitement, varying only in degree.”¹⁶

In other words, a theory of a norm extends to and develops within medicine. In this theory, disease is actually a significant deviation from a moderate norm. Words like “intensity” or “excitement” connote disease, whereas health has been described by René Leriche as “the silence of the organs.”¹⁷ That disease can be quantified is illustrated by Samuel Lynch, who created a “veritable thermometer of health” which rated excitability in terms of the numbers zero to eighty, with perfect health in the middle at forty.¹⁸

Since the norm implies a theory of moderation, and since, as we have seen, this theory arose during the ascendancy of the middle classes and the rise of bourgeois democracy in the Western world, it makes sense to look carefully at the rhetoric of medicine here. In that formulation, the normal tranquil body is silent, operating with its moderate methods. Disease involves excess, excitability, noise, attention, irritation, stimulation.

One can see in this rhetoric, as Susan Sontag saw in the metaphors surrounding illness, that a parallel is being drawn between the human body and the body politic. Perhaps it is no coincidence that this theory underlying normalcy, the rule of the norm, occurred exactly when Europe was trying to assimilate the specter of violent revolutions and insurrections.

Indeed, Auguste Comte saw such a parallel and thought approvingly that Broussais's ideas concerning medicine could be extended to "moral and intellectual activities" and applied to "the collective organism," which can use it "to confirm or perfect sociological laws."¹⁹ Comte, too, emphasized that "the analysis of revolutions could not illuminate the positive study of society without the logical initiation resulting, in this respect, from the simplest cases presented by biology."²⁰ As Canguilhem observes, "[by] stating in a general way that diseases do not change vital phenomena, Comte is justified in stating that the cure for political crises consists in bringing societies back to their essential and permanent structure, and tolerating progress only within limits of variation of the natural order defined by social status."²¹

The conclusion then becomes quite clear. If the norm regulates society by creating equal bodies, then medical theory, following suit, defines disease as a lack of regulation, an excess, that must be returned to a silent norm. The theory then can work back to politics, so that a revolution is an excess, an excitability, in society, causing disease, that must be returned to a state of health, which implies moderation, silence, and invisibility. Broussais's formulation that irritation is "normal excitation transformed by its excess,"²² is a telling remark made in 1822, just after the excessive excitation of the revolutionary and republican period had ended in France and the stability of the monarchy had been restored.

It is important to see that ideological ways of thinking about social unrest and physical health have the power to shape the perception of each other. If we think of hysteria, mental illness, mental retardation, blindness, deafness, or physical deformity during this period, we can see that there are often political valences attributed to such conditions. Certainly, books like James Trent's *Inventing the Feeble Mind*, David Rothman's *The*

Discovery of the Asylum, Douglas Baynton's *Forbidden Signs*, and Martin Pernick's *The Black Stork*, among many others, show us how physical conditions are attributed political significance. Further, issues of national identity and allegiance are tied to physical issues, as we see in many of the eugenic discussions concerning the poor, women, foreigners, people of color, Jews, the Irish, Italians, gypsies, and so on.

A related consequence of this model of health, in which disease is linked to excesses or lacks, is that the patient, the person with an illness, is no longer a valuable reporter of somatic information. Rather, an individual's disease is determined in the laboratory by the expert. Levels of chemicals in the blood, urine, or tissue tell the expert whether the patient is in good health or not. Likewise, it is the laboratory that determines the norms to which the individual patient's body chemistry should match. Since these quantitative measures are not available to the patient, the patient is in no position to evaluate himself or herself. Likewise, statistics measure the invisible numbers of the state and determine the health or illness of the economy, the national debt, employment, and so on. In the case of the state, a new generation of specialists can determine, better than can an individual, how the collectivity is performing. In the case of the patient, the doctor, with the help of the laboratory, takes on the function of informing the patient whether she or he is or is not healthy.

In either of these scenarios, the autonomy of the individual is weakened, as is any sense of agency. The results are by now familiar to most of us. In the case of the state, although we individually may be financially strapped, we are told that the economy is doing well. The average citizen is made to feel that statecraft is too specialized for ordinary people to do anything about, and complacency and resignation is the proper role of the citizen. In this sense the citizen becomes the citizen-patient who must silently submit to the role of the specialist—medical or bureaucratic. In medicine, the case is similar. Although an individual is feeling fine, a doctor can alert the patient to a dangerously high level of cholesterol or estrogen or a lack of thyroid hormone. These ideologies fit nicely together to make both medically and socially compliant bodies—both of which

are necessary for a rule by normalcy whether in the physician's office, the workplace, or on the streets.²³

It may not be so far-fetched to claim even further that representative bourgeois democracy requires a consistent and controlled level of institutionalization for bodies. Foucault's work has shown us the extent to which the medical, institutional, personal, and political realms are all blurred under forms of enforced compliance. One of the side effects of the creation of norms in medicine is the need for each person to be linked to a doctor. Under the rule of normalcy, each person must have a physician who can monitor the hidden levels of health or illness in his or her body. Thus the physician becomes instrumental in determining whether each citizen is "normal" or "abnormal."

Individuals cannot self-report on their participation in the bell curve, since much of the data and the analysis of the data will be unavailable to him or her. For example, how can you know if your height or weight are normal? You must first have experts determine the normal height or weight in your particular nation. If you are, as I am, a 5'7" male living in the United States, then you will discover you are below average in height. If you are the same height in Mexico, you will discover you are above average. But you cannot determine this yourself with any accuracy. Nor can you determine whether you have prostate cancer or high blood pressure by yourself. Diagnosis and care become part of one's individual social identity. Each citizen must be part of a cradle-to-grave health care system in order to participate in the collectivity.²⁴

An interesting situation arises with the necessity of the one-doctor-per-person model. The problem of representation is inverted. While we saw that it was really not possible to have an elected official represent each person, it is however possible for each person to be administered by a single doctor. Here, representation is not adequate, since no collectivity can replace the individual's medical history or identity. While I can elect a representative to stand in for me, I cannot choose a medical representative to act in the place of my body. Yet when patients are treated, they are not treated as individuals but as instantiations of norms. If my

blood sugar rises above a certain measurable level, I am a diabetic; if below a certain level, I am hypoglycaemic. If I don't experience symptoms, I still violate the norm. So while normalcy requires that I appear in person, as an individual, before my healthcare giver, I am treated by reference to a laboratory and statistically determined medical norms. Thus the paradox of the normal curve—that it contains equal individuals, yet groups them into a collective based on statistically based similarities—continues in force.

Linked to this is the imperative to be normal in health matters. The major drugs and therapies today are aimed at bringing abnormal bodies, as defined by quantitative measures, into line with agreed upon norms. A good deal of the energy of being alive becomes devoted to this imperative to conform physically. Through exercise, dieting, corrective surgery, the use of prostheses, and so on, contemporary citizens use up the hours left over from work and leisure activities, which can be seen simply as a prolongation of the workday,²⁵ so that there is no time or energy to engage in activity or analysis. In other words, the hegemony of normalcy creates compliant and disciplined bodies, to use Foucault's terms, which meet the needs of a bureaucratic, corporate state.

The fact that medical costs now make up the largest area of entitlements in the United States indicates that the relation between the medical and the political is not simply academic. Healthcare, as Bill Clinton discovered, is about much more than health—it is about money, business, trade, and power. Indeed, the overlap between the institutions of government and the medical system becomes more profound each day. A new entity—the patient-citizen—is now a reality. The patient-citizen, governed by the norm of representation and by the hegemony of normalcy, passes in one lifetime through a series of institutions—day care, primary, secondary, and higher educational facilities, corporate employment, managed care, hospitals, marriage and family, and finally nursing homes—all of which are based around legal, juridical, medical, and cultural normalizing concepts. The interlocking demands of these normalizing institutions are overwhelming and even totalitarian. Has there ever

been such a total control of people in history? Arguably even in the most unfair feudal rule by a single all-powerful despot the ability to control all aspects of the mind and body seem trivial compared to the rule of normalcy as it has developed over the past two hundred years.

In the midst of this system, the person with disabilities is only one casualty among many. Under normalcy, the fact is that no one is or can be normal, as no one is or can be equal. Everyone has to work hard to make it seem that they conform, and so the person with disabilities is singled out as a dramatic case of not belonging. This identification makes it easier for the rest to think they fit the paradigm.

As the media unfolds endless tales of their version of people with disabilities—take the three Academy Award nominees for 1997 alone, *Shine*, *The English Patient*, and *Slingblade*, all disability films—for the examination and comfort of people who believe themselves to be able-bodied, society groans on in singling out disability as the Other by which it defines itself. Whether we are talking about AIDS, low birth weight babies, special education issues, euthanasia, and the thousand other topics listed in the newspapers every day, the examination, discussion, anatomizing of this form of “difference” is nothing less than a desperate attempt by people to consolidate their normality. As Leriche suggests, the sick person must be studied to “advance knowledge about the normal,”²⁶ or, one might add, to create the normal person. Indeed, Freud’s fascination with psychopathology laid the foundation for a superstructure describing mental health. Freud’s interest in deviant minds created the framework for his psychology of the normal mind.

At the same time, the move of people with disabilities to frame the struggle in terms of civil rights and equality is something one might want to question. Obviously, a civil rights paradigm is better than one that relies on pity, the reverse side of discrimination. However, if, as I have been arguing, normalcy and equality go together, then a critique of normalcy that does not critique ideological notions of equality will end up falling prey to the same problems experienced by all who are oppressed by the rule of normalcy. In other words, people with disability may get their

equal rights in their respective United States of Ability and join the ranks of the “privileged” normals (or normates, to use Rosemarie Thomson’s term), but with that will come the repercussions of that complex agenda. To become part of the solution, one may become part of the problem. Equal access and equal rights are certainly important, but equality is a two-edged sword that carves out ethical space but also cuts down bodies to convenient and usable size. It should be the goal of a liberating movement based on disability rights to know the way in which rights create disability and how disability can help find a way to solve the problem posed by bourgeois definitions of rights.

BENDING OVER BACKWARDS

NARCISSISM, THE ADA, AND THE COURTS

I am not a lawyer. But when I was a child growing up in the Bronx, my Deaf mother highly recommended that I become one because I was so good at arguing for my position against my parents' accusations. Instead, I became an English professor and now spend much of my time arguing for my interpretations against those of others. So perhaps things are not so different.

I began this presentation with a brief story about myself. In the previous statement, I allowed a snippet of biographical detail that would permit readers to make certain judgments about me. As a result of those few words, those readers who are lawyers probably feel they can let me off the

professional hook. Such readers are probably now settling back, putting their pens down, and expecting a literary jaunt, a kind of breezy, erudite entertainment rarely found in legal books or journals. In making such judgments, readers are relying on stereotypes about English professors arrived at by interpreting my tone and my style of writing, and they are indexing their expectations from previous life events that were similar. In other words, such readers are interpreting me as they might any text or person, and my meager narrative has provided some grist for their mill.

I too am interpreting texts—in this instance, some legal cases concerning people who have brought suits under the Americans with Disabilities Act. Before I do that, I need to justify the value of having an English professor read through some of these cases. It has been established by many in the relatively new endeavor of critical legal studies that cases are forms of narrative that can therefore be subject to the same kind of analysis that we tend to employ on novels or poetry.¹

A second point involves the understanding that such cases are far from objective. Although cases are written in a style that suggests objectivity, impartiality, and authority, they are, after all, simply the written words of people. That style of writing, described by one scholar as comprising a “profoundly alien linguistic practice, . . . an archaic, obscure, professionalised and impenetrable language,” which judges use to decide cases,² is simply a literary style like any other. Because words are part of language and language is a communal practice, there can be no use of language that transcends the sociability and biases of any linguistic community. It might therefore make sense for a literary critic to analyze the way legal language is used to create the illusion of objectivity, impartiality, and so on. In this sense, the role of the critic is that of unmasking the underlying reality, an attempt to show how many factors contribute to the writing of a case, just as many strands of culture come into the making of a novel or an opera.

A third and related point is that, because cases are both analyzable and instantiations of a larger culture, they are therefore ideological by definition. By ideological I don’t mean that they are polemical, but rather that

they contain the predilections, politics, nuances, and biases of their authors' particular culture or class within that culture. It is the job of a critic to tease out those predilections and nuances.

Having justified, however sketchily, the claim that legal cases are narratives in need of interpretation by literary critics, among others, I need to make another assertion. Cases involving disability, because they are often not so much about fact as they are about personal and social attitudes, tend to involve the states of mind of the various players in the story. We are asked, for example, to imagine the state of mind of a potential employer who faces an obese job applicant and tries to decide whether or not to hire her,³ or the state of mind of a supervisor who fires an employee who happens to have nonsymptomatic AIDS.⁴ When judges and juries rule on such cases, they have to perform a complex and creative act of identification. Since the Supreme Court advises us to consider trial participants not as "members of a faceless, undifferentiated mass," but as "uniquely individual human beings,"⁵ we have an obligation to imagine and bring to life these individual states of mind through an act of what Martha Nussbaum calls "the literary imagination."⁶ When we follow the narrative of the alleged crime, we must be readers, and as readers, we must be willing to enter the state of mind of the players involved.

Two kinds of people do this for a living. One group is composed of dramaturges, directors, actors, and literary critics. The other group is composed of psychologists, psychoanalysts, or therapists. Therefore, along with saying that we need to know something about narrative to analyze these cases, we also need to know a lot about psychology. Indeed, a judge in writing such cases and resolving the questions they raise is acting as a kind of analyst, both literary and psychological. He or she will have the same problems psychotherapists have—problems of interpretation, transference, and so on. However, as judges do not seem to be very good at reflecting on these problems, it will be the job of someone like me to do that for them.

We might begin with the first judge of psychoanalysis, Sigmund Freud. In his analysis of Shakespeare's *Richard III*, Freud identifies the

deformed or disabled person as a characteristic personality type met in psychoanalysis.⁷ Freud begins by reading Richard's well-known opening soliloquy in which the would-be king explains his character by saying:

But I, that am not shaped for sportive tricks,
Nor made to court an amorous looking-glass;
I, that am rudely stamp'd, and want love's majesty
To strut before a wanton ambling nymph;
I, that am curtail'd of this fair proportion,
Cheated of feature by dissembling Nature,
Deform'd, unfinish'd, sent before my time
Into this breathing world, scarce half made up,
And that so lamely and unfashionable,
That dogs bark at me as I halt by them;
...
And therefore, since I cannot prove a lover,
To entertain these fair well-spoken days,
I am determined to prove a villain,
And hate the idle pleasures of these days.⁸

According to Freud, Richard's soliloquy would serve to alienate the audience if Richard were merely saying: "I find this idle way of life tedious, and I want to enjoy myself. As I cannot play the lover on account of my deformity, I will play the villain."⁹ This is the case, according to Freud, because "[s]o wanton a cause of action could not but stifle any stirring of sympathy in the audience, if it were not a screen for something much more serious."¹⁰ Freud's point is that audiences generally tend to identify with a sympathetic rather than a villainous character, as the most elementary screenplay manual will inform the neophyte writer. If we remove the "screen" and reveal the "something much more serious," Freud tells us that the "wantonness vanishes" and what remains is the "bitterness and minuteness with which Richard has depicted his deformity."¹¹

Here Freud begins to act like the judge in a disability case. He is penetrating beneath the words of the plaintiff's complaint to the intent behind it. Freud explains Richard's real motive by reanalyzing the soliloquy, pointing to Richard's true message:

Nature has done me a grievous wrong in denying me that beauty of form which wins human love. Life owes me reparation for this, and I will see that I get it. I have a right to be an exception, to overstep those bounds by which others let themselves be circumscribed. I may do wrong myself, since wrong has been done me.¹²

In this explanation, we begin to see how the analyst—and we might add the judge and even the jury—begins to perceive people with disabilities. Such disabled people claim that Nature has done them a wrong, and for this wrong they seek reparation. This reparation is really an attempt to claim that they are an exception to the rules of society, which allows them to overstep the bounds assigned to normal people. Thus, they see themselves as entitled to do a wrong to correct a wrong—thereby violating two universal imperatives taught by parents to their children: “Two wrongs don’t make a right,” and “If I make an exception for you, I have to make an exception for everyone else.” But just as children remain unconvinced by such parental logic, so it is with audiences. As Freud writes:

Richard is an enormously magnified representation of something we can all discover in ourselves. We all think we have reason to reproach nature and our destiny for congenital and infantile disadvantages: we all demand reparation for early wounds to our narcissism, our self-love. Why did not nature give us the golden curls of Balder or the strength of Siegfried or the lofty brow of genius or the noble profile of aristocracy? Why were we born in a middle-class dwelling instead of a royal palace?¹³

Freud tells us that as members of the audience we can put ourselves in Richard's position and identify with his sense of injustice, since all of us are deprived of something physical, mental, or economic that we might wish to have redressed. Freud further tells us that the core of these feelings of deprivation is "early wounds to our narcissism, our self-love."¹⁴

An application of Freud's theory thus characterizes people with disabilities as narcissists, particularly when evaluated in psychoanalysis, as Tobin Siebers has recently pointed out.¹⁵ According to psychoanalytic theory, people with disabilities inherently view themselves as "exceptions" to the rule. Freud says as much when he talks about a woman with "organic pain" and a man who was accidentally infected by his wet nurse.¹⁶ He describes these patients' personalities as "deformities of character resulting from protracted sickness in childhood."¹⁷ In his work *On Narcissism*, Freud again refers to the "familiar egoism of the sick person."¹⁸ Siebers points out that current psychoanalytic theory continues this tradition, citing William G. Niederland's assertion that "minor physical anomalies or imperfections" are associated with "compensatory narcissistic self-inflation."¹⁹

An analyst, or in our case a judge or jury, may find that the narcissism of the person with disabilities spills over to the observer. For example, Siebers cites analyst Kenneth R. Thomas who states that, in treating a patient with a disability, "therapists may experience a variety of reactions including 'imaginary' pangs of pain in the genital area, headaches, dizziness, or other physical symptoms."²⁰ This psychoanalytic theory further argues that such reactions are a sign that the therapist "has identified with the patient" and is "mirroring what the patient is feeling."²¹ In other words, the narcissistic attitude of the person with disabilities is catching, and the observer can mimic or acquire the symptoms like a kind of non-birth-related couvade.

Such insights or prejudices carry over into the judicial realm. For example, in the quest to identify with the state of mind of the plaintiff with disabilities, the judge may find him- or herself reacting much in the same way that Freud and others suggest the culture demands "normal" people

react to people with disabilities. This reaction causes the judge to see the disabled plaintiff as first and foremost narcissistic and egoistic. By definition, a concern for one's disability is seen as a self-concern rather than a societal concern. One of the major struggles of the disability rights movement has been to create public awareness that the problem of disability is not solely located in the individual using a wheelchair or in the Deaf person, but rather that the problem resides in the society that does not mandate curb cuts or allow American Sign Language to satisfy foreign language requirements in high schools and colleges.²²

Many people with disabilities can testify to this general reaction in the areas of accommodation and employment. When "special needs" (and let us notice the valence of that term) are required, too often the person making the request is seen as overly self-concerned, overly demanding. Indeed, this attitude is evident in the case of *DeSario v. Thomas*,²³ recently vacated by the Supreme Court in *Slekis v. Thomas*,²⁴ in which the Second Circuit Court of Appeals had ruled that states could refuse to provide equipment that met the medical needs of a small number of people as long as the state's plan for "home health services" provided adequately for "the needs of the Medicaid population as a whole."²⁵ In vacating that lower court ruling, the Supreme Court countermanded the notion expressed by the lower court that people with unusual needs "will have to look for other sources of assistance."²⁶ This lower court ruling saw people with even more specialized needs as overly demanding beyond the regular needs of people with disabilities. Because they are regarded as narcissists, people with disabilities are seen as demanding exceptions for themselves that overstep what employers can or should provide.

This theory of narcissism is further elaborated when we consider the very particular nature of many cases brought under the ADA. The Act defines a disability as a physical or mental impairment that substantially limits one or more of the major life activities, a record of such an impairment, or being regarded as having such an impairment.²⁷ The ADA also bars discrimination against a person with a disability who can perform a job with reasonable accommodation.²⁸ But the Act has not speci-

fied the range of definitions. For example, the Supreme Court in 1999 decided that a correctable disability is not a disability under the ADA in three cases which involve correctable vision in airline pilots and truck drivers and high blood pressure in a mechanic.²⁹ A second area of ambiguity is the nature of reasonable accommodation, and a third is the very gray area which asks whether the impairment is such that it interferes with the employee's ability to perform the job. This last issue is almost the litmus test for many of these cases because, if a person claims to have been discriminated against on the basis of disability, the accuser must establish that, although she is disabled, she is not so disabled as to warrant that the employer was correct in either not hiring her or in dismissing her.

In all these instances, the claimant must rely on very fine distinctions. In other words, these are not cases in which the matters of fact are clear. Of course, many cases revolve around such ambiguities, but it is fair to say that in disability cases these ambiguities abound. For example, to argue that one was discriminated against because a potential employer thought the claimant was obese is to make a strident claim about a subtle thing. To claim that an employer did not provide reasonable accommodation because it installed ramps and provided many other structural changes, but did not lower a sink, is to make a strident claim about a subtle thing. Indeed, it almost seems that, in some cases, the claimant is biting the hand that feeds her, is unappreciative of what has been done for her, or is acting in a paranoid manner. In other words, the claimant is being self-centered and narcissistic.

There is a phrase for the attempt to accommodate this narcissistic demand for exceptions made by employees, one which occurs in the language of legal cases: "bending over backwards." Take, for example, *Vande Zande v. State of Wisconsin Dept. of Admin.*, a case I will analyze in greater depth later in this chapter, wherein the court describes the employer as one who "bends over backwards to accommodate a disabled worker."³⁰ The metaphor of "bending over backwards" to accommodate a disabled worker is worth considering. The *Dictionary of English Colloquial Idioms* defines the phrase as to "go to extreme limits to try and satisfy some-

one.”³¹ The implication is that to redress a problem, the redresser must engage in a painful, extreme action. Indeed, the image is somewhat contradictory, since by bending over backwards in an awkward position, how can one help anybody? The meaning, perhaps, is that the contortion is out of the ordinary, since normally we bend forward. Bending backwards is distinctly uncomfortable for most people, except perhaps those in circuses or on videos that feature “abs of steel.” The implication of this legal usage seems to be that the pain felt by the person with a disability, as a result of either being disabled or being discriminated against on account of the disability, is now felt by the employer seeking to provide reasonable accommodation.³² This sense of parity between the feelings of both employer and discriminated-against-employee creates the sense that justice has been served.

The concept of parity or equivalence in the law is expressed by Friedrich Nietzsche in *The Genealogy of Morals* when he describes “the notion that for every damage there could somehow be found an equivalent, by which that damage might be compensated—if necessary in the pain of the doer.”³³ Nietzsche goes on to speak of “that ancient, deep-rooted, still firmly established notion of an equivalency between damage and pain.”³⁴ In essence, the judge in this case is telling us that the pain felt by the employee is weighed against the compensatory pain felt by the employer. In this equation one pain is equivalent to the other, and the scales of justice are balanced by this awkward bending. But further, the compensatory pain is like a referred pain, in that the judge feels the pain much as does the therapist who experiences in transference the pain of the narcissistic, disabled person. In fact, the judge and the employer, as observers, have to take “pains” to accommodate a narcissistic plaintiff.

A recent episode in *Ally McBeal* serves to illustrate this point as it exists in popular culture and consciousness. A man who claimed to be a sex addict argued that his marital contract was invalid because he married his wife in a state of lust that was close to insanity. In other words, he argued that his sexual addiction constituted a disability that should get him out of his marriage vows. Although this case is clearly invented, the television

audience was meant to see that his claim to disabled status was the ultimate claim of a narcissistic personality. Although marriage vows are considered universally binding, the plaintiff wanted to make an exception for himself based on his disability and receive legal and financial rewards for behavior for which even the president of the United States could not expect recompense.

Returning to Shakespeare for a moment, let us consider his other outcast villain, Shylock. While he is not a person with disabilities, there are certainly parallels between Shylock and Richard III. There is much historical and sociological work to indicate that European gentile society considered Jews to be disabled or physically inferior.³⁵ As a Jew and an “alien,”³⁶ Shylock inhabits a body that is scorned by the general Christian populace, and he specifies this perceived physical inferiority in the now famous “Doth not a Jew have eyes?” speech. Shylock turns hateful and demands his pound of flesh in court specifically because of his treatment as an outcast, much as Richard seeks his revenge for his treatment by others. Moreover, Shylock is perceived by the characters in the play as not being “touched with human gentleness and love”³⁷ when he insists on “the due and forfeit of my bond.”³⁸ Shylock, like the claimants in a disability case, must counter, “I stand here for law.”³⁹ But Portia’s responsive speech on the “quality of mercy” asks Shylock to “mitigate the justice of thy plea.”⁴⁰ Shylock is thus made to seem the self-centered, irrational, vengeful claimant who is redressing past wrongs through his legal suit. He demands his pound of flesh for no reason other than that “it is my humor.”⁴¹ In this sense, he provides yet another instance of a narcissistic person with wounds demanding his right to receive redress.

Let us now take a case not from the court of television or the stage but rather from the annals of the law: *Vande Zande v. State of Wisconsin Department of Administration*,⁴² in which the judge⁴³ felt that the employer had “bent over backwards.” Lori Vande Zande was a thirty-five-year-old paraplegic woman who used a wheelchair. She developed pressure ulcers from time to time that made it difficult for her to work in the office. Ms. Vande Zande worked for the housing division of the state of Wisconsin

for three years as a program assistant, which involved her preparing information, attending meetings, typing, mailing, filing, and copying. The state made modifications at her request, including improving bathroom access, providing adjustable furniture, paying one-half the cost of a cot, and changing plans for a locker room in a not-yet-constructed building. Ms. Vande Zande complained that the state did not accommodate her requests to work full-time at home during an eight-week bout of pressure ulcers and to provide a laptop computer during that period. Instead, she was told she would have to make up the difference between a reduced schedule and a full-work week by subtracting days from her accumulated sick leave.

Ms. Vande Zande had also requested that a sink in the office kitchenette be lowered to accommodate her wheelchair. If the building had been constructed after the passage of the ADA, accessible facilities would have been required; however, since the planning had occurred prior to 1990, no such requirement existed. The plaintiff did not argue that the failure to include 34-inch high sinks violated the Act, but she did argue that once she had brought the complaint to the attention of her supervisors, they should have made the alteration as a reasonable accommodation. Her employer claimed that it agreed to lower a counter in the kitchenette but could not lower the sink because the plumbing was already in place. However, that repair would have cost only \$150, or \$2,000 if the employer lowered similar sinks on every floor of the building. The employer argued that Ms. Vande Zande could use the sink in a nearby accessible bathroom. Ms. Vande Zande claimed that being forced to use the bathroom sink “stigmatized her as different and inferior.”⁴⁴

By nature, these cases tend to be about rather small matters. A series of small matters may add up to a large matter, but each individual request—cot, ramp, sink, shelf, and so on—seems rather insignificant and petty. Indeed, the plaintiff in this case appeared to violate a series of agreed-upon behaviors for team players, stoical American individualists, and generally agreeable people. Rather than take the self-abnegating road and wash her coffee cup out in the bathroom sink, Ms. Vande Zande

protested the indignity of having to use a bathroom to fill a drinking cup. Also, rather than just accept the donation of her time, and therefore money, from accumulated sick leave, she contested such a quid pro quo. Plaintiffs making these types of claims will, by definition, seem to be bad sports, whiners, and, most of all, self-centered.

Ms. Vande Zande ultimately violates the understanding that people should be self-sufficient, and, in a culture based on independence rather than interdependence, she appears to be asking for too much. Indeed, the Seventh Circuit Court of Appeals notes as much when it critiques her demand to have a laptop at home: “Most jobs in organizations . . . involve team work . . . rather than solitary unsupervised work.”⁴⁵ Thus, the court’s attitude is dismissive, because it envisions the plaintiff to be asking for an even more narcissistic accommodation—to work at home as a solitary player, rather than as part of a team. Next, the court implies, she’ll be asking for massages and cappuccinos. The court further states that “[i]t is plain enough what ‘accommodation’ means.”⁴⁶ This appeal to common sense is then belied by the court’s next sentence, “The difficult term is ‘reasonable.’”⁴⁷ Signaling a profound lack of knowledge about current nonableist terminology, the court notes that the plaintiff “is confined to a wheelchair.”⁴⁸ So the analysis begins immediately with a central paradox. Accommodation is seen as a limpid category, while reasonableness in accommodation is not clear. Meanwhile, the court’s ableist phraseology indicates that issues around disability are not, in fact, “plain enough” to those unfamiliar with these issues.

The court refers to the fact that even if the employer is large or wealthy (or a state bureaucracy, as in this case) and cannot plead undue hardship, “it would not be required to expend enormous sums in order to bring about a trivial improvement in the life of a disabled employee.”⁴⁹ The point here is that, although the court does not know what “reasonable” accommodation may be, it feels comfortable judging whether a particular accommodation is “trivial” or not. Therefore, as I have suggested, most of complaints made in such cases are going to be seen by people without a disability consciousness as “trivial.” At this point, an analogy to

earlier civil rights struggles might be instructive. For example, one can easily envision a Southern judge in a 1960s civil rights case concluding that lack of access to a drinking fountain when another by its side was made available would be trivial, or that being seated in one seat versus another on a bus would be trivial. In cases of discrimination and civil rights, however, attention to the trivial is precisely the way to stop discrimination, because discrimination often operates on a trivial level or on many trivial levels, all of which add up to a substantial level of discrimination in the aggregate.

The court then fashions a *reductio ad absurdum* argument, saying that “if the nation’s employers have potentially unlimited financial obligations to 43 million disabled persons, the Americans with Disabilities Act will have imposed an indirect tax potentially greater than the national debt.”⁵⁰ Considering that the national debt is in the trillions of dollars, this assertion is clearly an overstatement. The court balances on one side of the scales trivial improvements and on the other side the imposition of crushing taxes equaling the national debt. In an employer-centered, pro-tax cut world, the decision is suddenly made easy: tax the engine of prosperity or indulge the narcissistic whiners.

The court adds another color to its discussion by noting that “[w]e do not find an intention to bring about such a radical result in either the language of the Act or its history.”⁵¹ The new color is clearly “red”—that is, the desire to avoid going into the red because of “radical” reinterpretations of the ADA. The court’s statement further suggests another kind of “red” threat, because it contains an implication that leftist radicals may be trying to use the ADA to attack the very nature of capitalism itself. It is important for the court that the history of activism that led to the passage of the ADA not be seen as radical in nature, nor the effect become radical in intent or action.

Thus, the court cites the preamble of the ADA as something that “‘markets’ the Act as a cost saver, pointing to ‘billions of dollars in unnecessary expenses resulting from dependency and nonproductivity.’”⁵² This move is important because it casts the ADA as a putatively prag-

matic, but fundamentally conservative, statute that appears to espouse cost saving as its main goal. Seizing that Occam's razor, the court slices through the complex issue of civil rights, proclaiming: "The savings will be illusory if employers are required to expend many more billions in accommodations than will be saved by enabling disabled people to work."⁵³ So, on a simple cost basis, employing a reductionist double-entry book-keeping model, accommodation on a "trivial" level is a tax on businesses and does not live up to the cost-saving goal of the drafters of the ADA.

It is important to note the court's premise that the accommodation of removing barriers would be, on a national scale, too costly to enforce. So costly, in fact, that it would—and here I choose my words carefully—cripple the national economy. Again, we see the transference inherent in the analytic relation between the disabled person and the nondisabled observer—the observer feels the pain. If one weighs the discomfort of the trivializing narcissist against the crushing anguish of the crippled national economy, the former inevitably loses to the latter. Yet the government's own statistics show that the costs of removing barriers are relatively low. In fact, tax credits give employers back at least 50 percent of barrier removal expenses: the IRS figures for 1993 indicate that small businesses (defined as those making less than \$1 million in gross receipts and employing thirty or fewer employees) taking advantage of the Disabled Access Tax Credit spent on the average \$3,327 for such accommodations, half of which was reimbursed for expenditures up to \$10,250.⁵⁴ For individually owned businesses the average expenditure for accommodations was lower, about \$2,500 per employer.⁵⁵ Clearly, the national economy can handle and will more than benefit from these improvements, but the Seventh Circuit Court of Appeals has unfortunately not taken even the basic steps to ascertain the nature of the expenditure on which it predicates the fall of America.

To put the final touch on this argument, and completely eviscerate any notion of civil rights inherent in the ADA, the Seventh Circuit in *Vande Zande* states that the district judge had granted summary judgment to the defendants because they "had gone as far to accommodate the plaintiff's

demands as reasonableness, in a sense distinct from either aptness or hardship—a sense based, rather, on considerations of cost and proportionality—required.”⁵⁶ Although the Seventh Circuit critiques the district court’s analysis, it ultimately accepts the lower court’s conception of what makes an accommodation “reasonable.” The Seventh Circuit states:

The employee must show that the accommodation is reasonable in the sense of both efficacious and of proportional to cost. Even if this *prima facie* showing is made, the employer has an opportunity to prove that upon more careful consideration the costs are excessive in relation either to the benefits of accommodation or to the employer’s financial survival or health.⁵⁷

In accepting the lower court’s reasoning, the Court of Appeals has reinstated the “bending over backwards” test in what appears to be a supreme act of logic. Although the court allows that “reasonable” is a loaded word, it decides that reasonableness is based on common sense. And what constitutes that common sense? Cost and proportionality. Cost is put into a proportional equation with accommodation, while rights are magically left out of the equation.

Thus, the court concludes in effect that almost no accommodation except one that is deemed not trivial could be considered reasonable. Employers who grant any accommodations whatsoever, then, are seen as the ones who “bend over backwards.”⁵⁸ That is, this defendant employer “goes further than the law requires—by allowing the worker to work at home.”⁵⁹ How exactly compliance in regard to the ADA is seen as “going further” than the law requires is an interesting turn of phrase. If the law requires reasonable accommodation, and reasonable accommodation might require allowing the employee to work at home, then how is this “going further”? The court implies that workers with disabilities are approaching asymptotically that classic stereotype of the worker who fakes a disability to shirk work. It notes, “An employer is not required to allow disabled workers to work at home, where their productivity inevitably

would be greatly reduced.”⁶⁰ In this deteriorating chain of pseudologic, the court now sees the disabled employee as seeking institutionally sanctioned absenteeism as a way of life. Such absenteeism is automatically assumed to be linked to reduced productivity, which the court sees as an inevitable consequence of working at home (where, by the way, I am currently unproductively writing this essay). Thus, the largesse of the accommodating employer is placed in stark contrast with the trivializing, unproductive shirker using the ADA as convenient shield to cover basic laziness.

Notice how this way of putting things leads to the court’s next conclusion. The employer “must not be punished for its generosity by being deemed to have conceded the reasonableness of so far-reaching an accommodation.”⁶¹ Compliance is now seen as an act of “generosity” with all its resonance of charity, almsgiving, philanthropy, and altruism—that general attitude that disability activism and laws have sought to change into a discussion of rights, fairness, and equity. In the court’s scenario, though, the employer is generous to a fault, while the disgruntled, disabled employee is faulted for lacking the same generosity and team spirit. In a complete reversal of intention and logic, the court concludes that to punish such a generous employer “would hurt rather than help disabled workers.”⁶² Now, the notion of enforcing compliance with the ADA is seen as something that would paradoxically injure disabled employees. This argument brings to mind the old slogan, “What’s good for General Motors is good for America!” and implies that, if we impede the function of industry by insisting that it comply with the provisions of reasonable accommodations, we will reduce cash flow and thus limit industry’s ability to pay for the costly barrier removal insisted on by the law.

This logic is so apparently clear to the court that it comments, “we therefore do not understand what she [Vande Zande] is complaining about.”⁶³ It is no wonder that the court is in such a state of incomprehension; it has so mangled the intent of the ADA that the transformed Act now seems merely to amount to a governmental injunction for business to cut unnecessary costs. Under that set of misapprehensions, we

should not be surprised that the Seventh Circuit cannot understand the discrimination about which Vande Zande is complaining. Neither could slave owners understand why slaves were carrying on so insistently about freedom.

The court's lack of comprehension becomes obvious in its analysis of the issue of the sink in the kitchenette. The court notes that Vande Zande complains about having to use the bathroom sink to wash out her coffee cup or fill a glass with water. She claims that this situation "stigmatized her as different or inferior."⁶⁴ The court notes that "she seeks an award of compensatory damages for the resulting emotional distress."⁶⁵ Here we have the crux of the Richard III or Shylock problem. The aggrieved disabled party is injured by the way people treat him or her; the person with disabilities is therefore distressed and embittered, seeks revenge or compensation, and will not be deterred. Vande Zande wants her pound of flesh, only she'll take cash to soothe her emotional distress. Its perception of how trivial and narcissistic this claim is causes the court to respond in measured, objective cadences completely devoid of understanding. The specific ways in which disability operates within the culture and throughout the economy are a mystery to the court.

Of Vande Zande's claim that she is "stigmatized," the court responds "[t]hat is merely an epithet."⁶⁶ This parsing of the word is particularly strange. The court's statement that being stigmatized is merely an "epithet," which the dictionary defines as "a disparaging or abusive word or phrase,"⁶⁷ without further examination of the concept of stigmatization is itself no more than an epithet. In fact, the Vande Zande court pays only lip service to the concept of stigmatization. For example, while the court is willing to assume that "emotional as well as physical barriers . . . are relevant in determining the reasonableness of an accommodation,"⁶⁸ the very next sentence of its opinion discounts the emotional barrier by retreating to the earlier cost-saving argument: "But we do not think an employer has a duty to expend even modest amounts of money to bring about an absolute identity in working conditions between disabled and nondisabled workers."⁶⁹

Here, the court seeks to attack the claim of being stigmatized, by presenting it in turns as merely emotional and at the same time as impossible to fix by economic means. But it must be pointed out that, although the stigmatization at issue may have caused emotional distress, the basic act of stigmatization is not so much an emotional issue as it is a sociological one. The term was virtually coined for use in relation to disability by Erving Goffman in his classic book *Stigma*, which focuses not on emotional distress but on a pattern of behavior inherent in ableist society.⁷⁰ To link emotion with stigma is to denigrate the rationality inherent in the study of stigma and to negatively feminize it, as it were, since women are perceived in patriarchal society to be “emotional” rather than “rational.” Further, taking the complex concept of stigma and reducing it to a simple and absurd claim that any attempt to remove or lessen a stigma requires creating an “absolute identity in working conditions between disabled and nondisabled workers,”⁷¹ eviscerates any notion that stigma can ever be lessened or neutralized because employers would be forced to such lengths of bending over backwards that they would end up virtually upside down. Under these circumstances it is no wonder the *Vande Zande* court thinks that stigmatizing is “merely an epithet.”⁷²

Under this logic, the court can likewise conclude that *Vande Zande* could not have experienced a “pattern of insensitivity or discrimination,”⁷³ as she had claimed. First, all the events in question are “minor incidents,”⁷⁴ too trivial to rise to the level of a pattern of discrimination. Second, the experiences of stigma and emotional distress are not possible since these words are merely epithets. Third, this stigma can never be removed, since removal requires “an absolute identity in working conditions.”⁷⁵ Finally, all accommodations made by an employer are reasonable, and reasonableness is a cost-related concept determined by the employer’s and the nation’s economic ability to pay. Even if an employer can afford an accommodation, the national economy cannot afford such remedies because it will be devastated by the exponential expenditures of millions of employers. Thus, there can never really be a pattern of insensitivity or discrimination sufficient for redress. The logic of the court be-

comes consistent and impeccable, with only the minor failing of being completely wrong.

If my reading of the case is at all accurate, then it is necessary to try and specify how we can fix the court system, if possible, to decrease the likelihood that decisions like this one will continue to appear throughout cases related to the ADA. Certainly, it would be grandiose, to say the least, for me to claim that I had the broom that could clean out these Augean stables, or that this essay could even begin to provide the impetus for that housecleaning. Nonetheless, and because my mother was probably right about my argumentative nature, I will make the first attempts at housecleaning measures.

The first point that needs to be acknowledged is that the general public, including those members of it in the judiciary and on juries, is by and large ableist. I don't mean to use this brush to tar the good people of America. I am sure that each and every person, when asked, "Are you biased against people with disabilities?" will proclaim, one more loudly than the other, that they are as likely to be biased in that regard as they would be biased against mothers or national heroes. Yet my experience, and I am sure the experience of most people who work in disability studies, sheds a different light.

The point is not that rampant, overt prejudice abides in the hearts of citizens. Rather, the discrimination I am speaking about appears to be, to choose *le mot juste*, trivial. The ordinary encounter, the glancing gaze, the innocent observation are the stock-in-trade of this kind of discrimination. We are not speaking of people with tattoos that say, "I hate cripples" or "Death to Deaf." What we are speaking of is well-meaning people who simply do not have progressive information and education, in part because we do not teach disability in the public schools and colleges as we now teach race and gender. Few educated people nowadays would dare say that African Americans are not good long-distance runners but are good basketball players and dancers; yet such observations were commonplace twenty years ago and were thought to be simple observations of fact. A friend of mine who trained as a lifeguard in the 1950s was told

in a matter-of-fact way by his instructor not to save African Americans if they were drowning because “they’re sinkers.” This wasn’t deemed to be a racist comment, but rather a simple bit of fact passed on by one life-guard to another to avoid being pulled down to one’s death. But, thanks to an educational policy that recognized the injustices being done to minorities by well-meaning folks, racism—while hardly eliminated—has been highlighted and discouraged. Sexism is also dying a slow and protracted death.

Ableism, on the other hand, is alive, well, and playing in your local theater, if you judge by the never-ending roster of movies filled with stereotypical disabled people triumphing over their afflictions. During the period in which this essay has been written, I have also been trying to place an op-ed piece in the *New York Times* and *The Nation*, both rather progressive newspapers. My piece is about the dragging death of James Byrd, Jr., in Jasper, Texas, a subject much covered in the news. I point out that Byrd, in addition to being an African American, was also a person with disabilities, and I question why that fact was essentially suppressed in the news. I also discuss the long history of people with disabilities who have been abused and murdered. In trying to place this essay, I spoke with an editor at *The Nation* who immediately said, “but there’s a long history of blacks being murdered and abused.” When I said that there was also a history of such abuse toward people with disabilities, she was surprised. Having absolutely no knowledge of that history, she nonetheless presumed to tell me there was no such history. Likewise, when I spoke to a member of the editorial board of the *New York Times*, he protested that although the issues about which I spoke were valid, it was wrong perhaps to link them to the Byrd story. “People will see you as an opportunist trying to promote a cause that’s unrelated to the story.” I replied, “Oh, yes, because people are ‘ableist,’” and he immediately shot back, “Not at all. It just seems like one thing has nothing really to do with the other.” *The Nation* had agreed to publish the piece, but several months later has not yet done so because of the more “pressing” nature of other issues.

I give these examples not to grind personal axes, but rather to show

how intelligent progressives simply do not see a connection between racism and ableism. Further, and this is a telling point, many people don't realize that there is a history or a politics to disability. There is nothing to be learned that an ordinary, sensitive person (and aren't we all?) can't simply intuit in the "I-feel-your-pain" scenario I laid out earlier. Just as anyone can go to the cinema and be moved by a story about a mentally retarded woman or a blind man, so too anyone, judge or jurist, can sympathize with the plight of a person with disabilities. Empathy is cheap and there's plenty to go around. But, as many of us know, there is more to disability than meets the eye (if yours happen to be able to see).

Indeed, the aim of disability studies and disability activism has been to fight commonsense notions of disability such as these. Much of this knowledge is counterintuitive and for this reason especially needs to be taught in organized curricula and through the media in special series on radio and television, parallel to those multipart extravaganzas on the oppression of other groups. To counter the notion that disability is a personal tragedy, we propose the conception that disability is a social and political problem. To counter the stereotype that people with disabilities are either bitter, lustful, and resentful, or else innocent, asexual, and resigned, we propose very different ways of thinking. To the idea that language is neutral, we expose the lexicon that contains moralized and demoralizing words associated with impairment. And so on. The answer is a radical project of education on a national level. How we could achieve this cannot be addressed in this essay, but it is clear to me that the backlash against the ADA will not be halted by legal measures alone. The people that make up the court system need more knowledge.

Thus, it should come as no surprise that legal cases are filled with such a lack of knowledge and understanding. Let me take a few concrete examples. In the case of *Runnebaum v. Nationsbank*,⁷⁶ there are a host of uneducated assumptions concerning homosexuality and disability. The court notes as an example of Runnebaum's "inappropriate" behavior that "[h]e brought his gay lover to the reception and introduced him . . . as his 'boyfriend.'"⁷⁷ This example, among others, is seen as "failing

to present a professional image.”⁷⁸ I won’t go into more detail about this issue, except to say that the court never questions its own attitudes toward homosexuality.

The same is true of the court’s attitudes toward disability. In order to determine whether Runnebaum’s asymptomatic HIV is an “impairment” and, thus, a disability covered under the ADA, the court’s first recourse is to look up the word “impair” and “impairment” in *Webster’s Ninth New Collegiate Dictionary*. What it finds is that “impair” means to “make worse by or as if by diminishing in some material respect” and that “impairment” means a “decrease in strength, value, amount, or quality.”⁷⁹ While I understand that this refreshing approach to language is characteristic of such progressive judges as Richard Posner, who would prefer to use the plain or common meaning of words, it is a uniquely inappropriate strategy for dealing with words like “disability” or “impairment,” which are in the process of being defined and redefined in complex ways to combat the kind of ableism one might indeed find in a dictionary.

In this case, the judge acts like a mediocre student attempting to write a freshman essay without doing much research. He simply reaches over to the shelf and selects a dictionary, and one indeed that was published in 1986, four years before the ADA was passed and eleven years before the case was heard. To beef up the serious scholarship inherent in this cantilevered swivel from desk to shelf, the court also cites two other *Webster’s* dictionaries of the same era, and concludes that “under these definitions, asymptomatic HIV infection is simply not an impairment.”⁸⁰ The court cites an earlier case *de la Torres v. Bolger*⁸¹ which states, “the term ‘impairment,’ as it is used in the Act, cannot be divorced from its dictionary and common sense connotation of a diminution in quality, value, excellence or strength.”⁸² Yet, the “Act” referred to in this citation obviously cannot be the ADA because *de la Torres* was written four years before the passage of the ADA.

The point here is that the *Runnebaum* court, precisely because it has no knowledge of disability history or terminology and doesn’t care to find out, deems that the only recourse is to a dictionary. Dictionaries, how-

ever, frequently contain antiquated and inappropriate definitions, particularly with regard to terms relating to race and disability. For example, had the court looked up the word “nigger” in a *Merriam-Webster’s Collegiate Dictionary*, it might have found the definition “a black person,” which definition has recently been protested and will be removed in subsequent editions.⁸³ Likewise, “blind” would have yielded among its definitions “defective” and “unable or unwilling to discern or judge.”⁸⁴ By that usage, the statement “justice is blind” would come out “justice is defective, unable or unwilling to discern or judge.” Actually, not a bad definition given these cases. Furthermore, the word “Deaf” would produce “unwilling to hear or listen,”⁸⁵ and the word “lame” hobbles in as “weak.”⁸⁶ What all this proves is that you don’t go to the dictionary to find out about constructions within society that undergird prejudice, because the language itself will necessarily contain or reflect that prejudice.

But the bigger misapprehension in *Runnebaum*, found both in the majority and minority opinions, is that the term “impairment” is a specific term, like “stigma,”⁸⁷ that relates to the history and conceptualization of disability as it developed within disability activism and scholarship since the 1980s. I am speaking of the distinction, widely known and no doubt used by the drafters of the ADA, between “impairment” and “disability.” The previously used term “handicapped” did not allow a distinction between the physical condition and the barriers that cause that condition to become a problem. As a result, disability activists came to define “impairment” as the physical limitation of a particular illness or a chronic physical limitation, while defining “disability” as the social and political conditions that place barriers in the way of that “impairment,” thereby creating a disabling condition.⁸⁸

Thus, an impairment might be anything from HIV to paraplegia, and the disability anything from targeted discrimination to the absence of curb cuts or ramps. Since the peculiar history of the passage of the ADA included the input of many disability activists in the actual wording of legislation, particularly in the sense of encouraging civil rights-associated wording in the Act, the folly of looking up the meaning of the word

“impairment” in *Webster’s* is obvious. The equivalent would be to look up the meaning of “atom” and “bomb” in the dictionary in an attempt to understand how to build a tactical nuclear weapon. Instead, the judge should have looked up works about the drafting of the ADA and about the history of disability rights in the United States, works such as those by Paul Longmore, David Pfeiffer, Irv Zola, and many others.⁸⁹ But that would require what we might call “disability literacy,” something that the courts don’t seem to demand of the citizens who occupy the bench.

Indeed, one case shows us by its metaphors how foreign a country disability is for many judges. In *Cook v. State of Rhode Island, Dept. of Mental Health, Retardation, and Hospitals*,⁹⁰ the judge describes the case as one that “calls upon us to explore new frontiers.”⁹¹ He therefore embarks on “our journey into the terra incognita of perceived disabilities [which] requires us to explore”⁹² the subject. The metaphor is of the pith-helmeted adventurer going into the heart of darkness to bring light. At another moment, the court describes a consideration of evidence as “[t]he next stop on our odyssey.”⁹³ The pith helmet is now replaced by battle helmet and shield as the judge continues as an epic hero wandering through the Scylla and Charybdis of disability. And a final determination is referred to as “[o]ur last port of call.”⁹⁴ Now the errant nautical type, like Odysseus, and even a bit like Lord Jim or Marlowe, travels from one insecure port to another across ever more treacherous seas. At the conclusion of the decision, the judge announces, “We need go no further.”⁹⁵ The journey of exploration need go on no more, as the judge brings light and security to the chaotic world of disability claims.

The plaintiff, on the other hand, is described as one who “did not go quietly into this dark night” of discrimination.⁹⁶ But the plaintiff, to make her case, must “prove each element of her chain,” and the court must “turn, then, to the remaining links that forge the chain.”⁹⁷ So, while the court is the active explorer, out in the dangerous world of disability, the plaintiff is much more stationary. She doesn’t go into “this dark night” but stays at home forging chains like a blacksmith to make her own case.

While the plaintiff in *Cook* ultimately prevailed amid this orgy of purple prose and the journey of the court led to an enlightened land, the metaphors used still tell us that the court is out there in the dark. Despite the heroic efforts of this decision and the self-referential congratulations for this exploration and bringing of light to the darkness, which perhaps comprehendeth it not, the basic problem remains. For intelligent and just decisions to be made, decisions based on knowledge and rationality rather than impulsive tropisms, bad faith, common sense, stereotyping, and a patronizing condescension to the issues, the judiciary will have to learn a lot more. Law schools should certainly teach courses on disability, and K-12 as well as college courses need to be developed. All of us will have to do much more to educate America.

Here are some suggestions:

1. Write op-ed pieces and articles for local and national magazines and newspapers;
2. Create a demand for radio and television documentaries, and help to develop these.
3. Set up a public relations bureau that will make information available to the entertainment industry. Such entities already exist for other identity groups and foreign nationals.
4. Actively protest targeted legal cases, as for example ADAPT did on May 12, 1999 before the *Olmstead* case was decided by the Supreme Court,⁹⁸ and coordinate such demonstrations with educational outreach programs.

These are only a few suggestions among many. But we will never see a reversal in the backlash against the ADA until the majority of Americans, or at least what pollsters call “the opinion makers,” are educated on this subject, or until enough of these opinion makers are themselves people with disabilities. The new millennium may see the number of people with disabilities rise to 20 or 25 percent of the population as the baby

boomers age and if the trend of increasing disabilities among the young continues. But short of sheer numbers, we need to let the world know that people with disabilities who become whistle-blowers aren't trivializing narcissists who are just whistling "Dixie." In fact, they are really whistling "The Star-Spangled Banner."

GO TO THE MARGINS OF THE CLASS

DISABILITY AND HATE CRIMES

With great ceremony, the press reported the February 1999 conviction of white supremacist John William King for the kidnapping and murder of James Byrd, Jr., who had been chained to a truck in Jasper, Texas, dragged two miles, and dismembered. Likewise, the conviction of coconspirator Lawrence Russell Brewer in September 1999 seemed to imply that justice had been done. If justice in a broader sense is to be served, however, another fact of the case deserves attention. Byrd was not only black and the victim of race hatred; he was also disabled. The press has noted this so casually that few people realize it; those who do, including myself, found out that Byrd was severely arthritic and

subject to seizures. This information was ferreted out only after extensive searches of news reports.

Indeed, I myself was uncertain that Byrd was a person with disabilities. I recalled reading, on the day the crime was first reported, that a disabled African American had been brutally murdered. Since I was interested in disability, the article caught my eye. Yet when the story reappeared days, weeks, and months later, Byrd was simply referred to as African American. Almost all the news stories contained this simplification. Indeed, when I decided to write a piece on the subject for *The Nation*, I at first thought I might have made an error in thinking that Byrd was a person with disabilities. When I went to the library to look up the articles on microfilm, I found that the *New York Times* mentioned only twice, in the first two reports, that Byrd was a person with disabilities. Any newspaper story I checked tended to follow that pattern.

I decided that in order to write this essay, I had to find out what Byrd's disability was. When I called the sheriff's office, the local newspaper, the district attorney's office, Byrd's family and lawyers, no one could or would tell me. Finally, fact checkers at *The Nation* managed to discover that Byrd was severely arthritic. When I wrote the article for *The Nation*, the war in Kosovo was beginning. Because of the journalistic space taken up by the war, my article kept being delayed and then further delayed. Finally, the story was no longer current, so the editors and I decided we would aim to publish it when the second defendant went on trial. By the time that happened, the immediacy of the issue had faded. Perhaps the rather complex notion of identity made the piece seem less of a priority, and *The Nation* decided in the end to cancel the story. The reason I am telling this tale, no anomaly in the annals of journalism, is that it signals the difficulty of talking about the issue of disability in the face of race.

At the risk of being overly anecdotal, let me add another bit in the biography of this article. Initially, I wanted to write this story as an op-ed piece for the *New York Times*. An acquaintance who is on the editorial board of the paper read my initial article and responded in a somewhat condescending and negative way. He asked me if I seriously thought that

race could be equated with disability, whether the history of lynching and slavery could be meaningfully equated with occasional violence against people with disabilities. The editors for both these progressive journals saw race as the primary category and disability as a poor third cousin of race. Their assumption was that violence toward a person of color with disabilities is primarily the result of the color and much less the result of the disability.

But disability is hardly a minor category. Approximately 16 percent of Americans have a disability and, as such, they comprise a significant minority group with an inordinately high rate of abuse.¹ According to the Center for Women's Policy Studies, disabled women are raped and abused at a rate more than twice that of nondisabled women.² The risk of physical assault, robbery, and rape, according to researcher Dick Sobsey, is at least four times as great for adults with disabilities as for the general population.³ In February 1999, for example, a mentally retarded man in Keansburg, New Jersey, was abducted by a group of young people who tortured, humiliated, and assaulted him.⁴ In March 1999, advocates for another mentally retarded man filed a lawsuit against a group of Nassau County, New York, police officers who beat him while he was in custody.⁵

People with disabilities and deaf people report that they are routinely harassed verbally, physically, and sexually in public places. In private institutions or group homes, they are often the prime victims of violence and sexual abuse; in their own homes, they are subjected to sexual abuse, domestic violence, and incest, preyed upon by family members, family "friends," and "caretakers."⁶ So the question remains, why is American society largely unaware of or indifferent to the plight of people with disabilities? Is it because as an ableist society, we do not really believe that disability constitutes a serious category of oppression? Whenever race and disability come together, as in the King case, ethnicity tends to be considered so much the "stronger" category that disability disappears altogether.

As a society, we have long been confronted by the existence of discrimination against people of color. Students pour over the subject of

race in their textbooks and read the work of multicultural writers in high school and college. Martin Luther King Day and Kwanzaa raise our consciousness, and the heroic tales of people like Rosa Parks inspire us.

But while we may acknowledge we are racist, we barely know we are ableist. Our schools, our textbooks, our media utterly ignore the history of disability; the dominant culture renders invisible the works of disabled and deaf poets, writers, and performance artists. The closest we have come to a national media engagement is the 1998 six-part NPR radio series *Beyond Affliction* and a few references to deafness in the TV series ER. Motion pictures still largely romanticize or pathologize disability; there is not much else to make the experience of 16 percent of the population come alive realistically and politically.

Yet 72 percent of people with disabilities are unemployed, and their income is half the national average.⁷ Among working-age adults with disabilities, the poverty rate is three times that of those without impairments. One-third of all disabled children live in poverty;⁸ and despite the Americans with Disabilities Act, a judicial backlash has been under way ever since its passage in 1990. From 90 to 98 percent of discrimination cases brought under the ADA by people with disabilities have been lost in court. Immigration policy with respect to the disabled emulates the restrictive 1920s naturalization policies aimed at other “undesirable” groups.⁹

With the aging of the baby boom generation, there will be a disability boomlet in the near future. But children constitute the fastest growing segment of the disabled population. From 1990 to 1994 the number of children and young adults with disabilities rocketed to 1.5 million and 1.9 million, respectively—largely due to rising rates of asthma, mental disorders, mental retardation, learning disabilities, and spinal cord injuries.¹⁰ The last of these result mostly from sports and automobile accidents among whites and from gunshot wounds among African Americans.

Legal theorists have a term for the way that race eclipses disability—intersectionality. Kimberly Crenshaw, writing about the way that color

obliterates gender, notes that antidiscrimination law rotates around “a single-axis framework.”¹¹ Thus people who do not fit clearly into a recognized minority status are marginalized. Crenshaw makes this case for African American women who are, according to her analysis, edited out of civil rights and employment decisions which tend to focus more on the issue of race than the combination of race and gender. For example, in *De Graffenreid v. General Motors*, five African American women brought a suit against General Motors, claiming that the seniority system perpetuated the effects of past discrimination against African American women. Although evidence adduced at trial revealed that General Motors engaged in discriminatory activities against such women, the district court granted summary judgment for the defendant, stating: “[P]laintiffs have failed to cite any decisions which have stated that Black women are a special class to be protected from discrimination.”¹² Because GM had hired women, no sex discrimination was found; the court thought the issue should have been pursued on the basis of race alone. The idea that race and gender could create a special category or have negative synergistic effects seems to have eluded the court entirely.

Anita Silvers notes this fact when she writes: “the courts tend to implement prohibitions against discrimination so as to favor paradigmatic members of the protected class. In doing so, they propel individuals whose experiences diverge from those of the class’s prototypes, but who are equally at risk, to the class’s margins.”¹³ Thus when disability meets race, disability is propelled to the margins of the class.

From a legal perspective, one wants to make sure that members of a historically unprotected class receive proper justice and consideration under the law. Thus in America, women and minorities have been the focus of antidiscrimination law. There has been much cultural work done to make it acceptable at the end of the millennium for such groups to have public respect and sympathy. Countless novels, movies, and plays have accomplished this goal over the course of the twentieth century. It is unimaginable that a film could be made now that would present African Americans, Native Americans, or women as members of a

deservedly subordinate, disenfranchised group. Thus the courts will, in the most obvious cases, uphold the right of members of such groups to redress wrongs in housing, employment, discrimination, and so on.

However, disability occupies a different place in the culture at this moment. Although considerable effort has been expended on the part of activists, legislators, and scholars, disability is still a largely ignored and marginalized area. Every week, films and television programs are made containing the most egregious stereotypes of people with disabilities, and hardly anyone notices. Legal decisions filled with ableist language and attitudes are handed down without anyone batting an eyelid. It is telling that a professor who is perceived to take an openly antidisability stance was hired in 1999 by Princeton University to fill a prestigious chair over the protests of leaders of the disability community.¹⁴ Such a hire would have been impossible for someone who harbored racist or sexist views. Newspapers and magazines barely notice the existence of disability and largely use ableist language and metaphors in their articles. In other words, disability may be the last significant area of discrimination that has not yet been resolved, at least on the judicial, cultural, and ethical levels, in the twentieth and twenty-first centuries. Likewise, there are no nationally known advocates of disability rights or scholars of disability studies who have anything remotely like the visibility of scholars who deal with race, gender, and postcoloniality.

This lack of visibility and of widespread legitimation through cultural and pedagogical institutions has left disability the weaker term. Further, the way that disability has been constructed as an identity category in the popular imagination leads to a lower status in a pecking order of abuses. Tobin Siebers has written about the way that people with disabilities will necessarily be regarded as narcissists, and I have taken his insight and written about the way that legal cases tend to view people with disabilities.¹⁵

Because of the nature of disability discrimination, plaintiffs will often protest rather large claims based on rather small infractions. That is, if a particular stairway is not ramped or an employer provides an accessible

sink for drinking water in a bathroom but not in the kitchen, a plaintiff can claim violations of the ADA. However, the issue around lack of access can often seem to be minor and trivial, and at the same time the plaintiff will appear overly concerned about such details, petty, narcissistic, and not a good sport or team player.

The issue of the water fountain, which is one of the violations cited in *Vande Zande v. State of Wisconsin Dept. of Admin.*, seems incredibly trivial. Lori Vande Zande, a paraplegic who uses a wheelchair, worked for the State of Wisconsin, and complained about a pattern of discrimination, one aspect of which involved the state's agreeing to make a bathroom accessible but not a kitchen. As noted in the previous chapter, Vande Zande had to fill her drinking cup, clean her dishes, and so on in the bathroom while her coworkers used the kitchen. Vande Zande claimed that being forced to use the bathroom sink "stigmatized her as different and inferior."¹⁶ Such a claim appears narcissistic in the setting of the office when the category of disability is considered. However, when placed in a setting concerning race, the nature of the claim changes. An African American who had to use a separate, although equal, water fountain in public accommodations because of his or her identity, would more clearly be an obvious victim of civil rights violations. From the point of view of a white Southerner in the 1960s the person using the fountain was still able to drink the same water and only the location of the fountain was at issue. But from the point of view of the late twentieth century, such segregated drinking fountains are unjust-unless the person is one with disabilities and the employer, not the state, has to provide the accommodation.

Since much of the substance in legal cases is based on the state of mind of the plaintiff and the defendant rather than on any major egregious wrong done, these cases seem all the more ephemeral and trivial. If an obese woman claims that she was not hired because the manager thought she was too fat,¹⁷ the case rises or falls on one's assessment of various internal states of mind. Often, to a judge or jury unfamiliar with disability, the claimant can seem paranoid, self-centered, whiny, or overly dramatic. Such ideological obstructions stood in the way of earlier cases in which

race or gender were considered, but now these categories are so well established that the claimants will not seem petty in asserting discrimination based on these issues.

So when it comes to violence against people with disabilities, several factors intervene. Although many states have statutes that describe disability in a list of categories that are protected under hate crime legislation, the actual enforcement of such policies may be muted by the intersectionality I have been describing. The Violent Crime Control and Law Enforcement Act of 1994 defines a hate crime as one “in which the defendant intentionally selects a victim, or in the case of a property crime, the property that is the object of the crime, because of the actual or perceived race, color, religion, national origin, ethnicity, gender, disability or sexual orientation of any person.”¹⁸ The following states include disability in their hate crime law, although not all these states have actually passed this legislation: Alaska, Arkansas, Arizona, California, the District of Columbia, Delaware, Illinois, Iowa, Louisiana, Maine, Minnesota, Nebraska, Nevada, New Hampshire, New Jersey, New York, Oklahoma, Rhode Island, Vermont, Washington, and Wisconsin.

Tellingly, though, a distinction is often made in this legislation. For example, previously under California’s hate crime law, a murder committed because of the victim’s race, color, religion, ancestry, or national origin could bring the death penalty or life in prison without parole. However, the maximum penalty for a murder based on gender, sexual orientation, or disability was twenty-five years to life in prison. A new bill signed in September 1999 increases the maximum in those latter categories to life in prison without parole. Federal efforts to prevent hate crimes, however, are now restricted to race, color, religion, and national origin.

Several U.S. senators have sponsored legislation to extend protections to gender, disability, and sexual orientation. But this idea ultimately did not pass into law and, even if it had, hate crimes based on disability are unlikely to carry as stringent a penalty as crimes based on hate for race, color, religion, or national origin. In September 1999, the National Organization for Women (NOW) and other advocacy groups met with key

senators to urge that prohibitions against sex-based and disability-based hate crimes be retained in the Hate Crimes Prevention Act (S. 622, HCPA). But senators opposed to including the new categories prevailed, and the extension of the Act's protection to disability, as well as to sex, was defeated in October 1999.

The hierarchy of hate in such legislation is telling. The general idea behind hate crime legislation, ratified in *Wisconsin v. Mitchell*¹⁹ and up to this point without significant appellate action, is that a crime is committed whenever the defendant, in the words of the Wisconsin statute: “[i]ntentionally selects the person against whom the crime . . . is committed . . . because of the race, religion, color, disability, sexual orientation, national origin or ancestry of that person.”²⁰ Although the Wisconsin statute includes disability on par with other identity categories, California and other states consider that to be a victim because of one's race or religion is substantially more troubling than being a victim because of one's gender, disability status, or sexual preference.

But how do we determine, in any philosophical sense, that one kind of identity is more important than another? Historically, although the United States was founded on a separation of church and state, religion has been seen as a “holy” category certainly higher in status than, for example, one's sexual orientation; race, so embroiled in the nation's history, must be more important than something like disability; and so on—the arguments are based more on ad hoc judgments about the viciousness of different kinds of prejudice than on any principle one can articulate. This seems to be the same unreflective influence that gives priority to race over gender or disability in the intersectionality argument.

We can see this contradiction in another arena. The FBI is required to keep track of hate crimes. It has produced a report that found that of the 8,049 incidents of hate crime reported to police in 1997, 12 were motivated by bias based on disability; of these, 9 were based on the victim's physical condition and 3 were based on the victim's mental condition. These numbers seem shockingly low when compared to other studies such as Dick Sobsey's tabulations.²¹ Sobsey also notes that when a person

with disabilities is a victim of crime, it tends to be a violent crime rather than a property crime.

With women who are disabled, according to the Center for Women's Policy Studies, the fact of disability raises the chances that a woman will be the victim of a crime, and women of color even more so. The Colorado Department of Health estimates that at least 85 percent of women with disabilities are victims of domestic violence, compared with 25 to 50 percent of nondisabled women.²² Most crimes against women with disabilities go unreported and are substantially higher than the mere 20 percent of rapes of nondisabled women that are reported. Given these special considerations, is it any wonder that the FBI has such low statistics? The answer must be that when confronted with hate crimes, the FBI, like the journalists reporting on Byrd's case, will often tend to look for the bigger category.

Indeed, I am sure that when it comes time for the FBI to list the report on Byrd, they will file it under racial hate crime rather than a disability-related crime. Also, many of the crimes against people with disabilities will simply be seen as ordinary rather than hate crimes. So the rape or murder of a mentally ill resident of a sheltered facility will be seen as a rape or murder, not as one motivated by the status of the person involved. Indeed, one of the arguments used by opponents of hate crime legislation, particularly as it applies to gender or disability, is that crimes such as rapes will have to be investigated by the FBI, putting an undue burden on that organization. Since such crimes are daily occurrences, and since it could be argued that rape itself is a hate crime against women, the FBI will be taxed to the utmost in trying to detail all these acts of violence.

Intersectionality argues that individuals who fall into the intersection of two categories of oppression will, because of their membership in the weaker class, be sent to the margins of the stronger class. What these statistics suggest is that the category of disability, while a weak one to judges or legislators, is a powerful one to those who seek to victimize. Rather than minimizing an identity, victimizers are drawn to the double or triple

categories of race, gender, and disability. Each of these categories enhances the opportunity for hate and the likelihood that the crime will go unnoticed, unreported, or disbelieved. For example, the Center for Women's Policy Studies reports that virtually half of the perpetrators of sexual abuse against women with disabilities gained access to their victims through disability services, and that caregivers commit at least 25 percent of all crimes against women with disabilities.²³ In other words, the dependency of such women, compounded by their lower economic status, ethnicity, and diminished mobility or ability to communicate to authorities is an enticement to victimizers.

Not only do authorities pay less heed to people with disabilities with diminished capacities who are dependent, but they do so because they are unaware, for the most part, of the way that ableism is built into the social, physical, and ideological environment. It has only been through the work of disability scholars in the recent past that this situation has come to be articulated in a public and widespread way. As Harlan Hahn observes, the public paternalistically imagines that people with disabilities are usually treated with kindness.²⁴ This rationalization is then used to invoke happenstance to explain practices that harm people with disabilities. For example, a 1999 lawsuit by students and the California Faculty Association against San Francisco State University was prompted by such conditions as the university's disregard of the safety of blind people and mobility-impaired people during a period when campus paths of travel were disrupted by construction. Although the student newspaper ran a front-page story and students with disabilities petitioned the university president, the university did not respond. This public university exacted bodily injury as the price students with disabilities had to pay for their education, but deflected its responsibility by construing the dangerous conditions as accidental.²⁵

Hahn criticizes the tendency of the justice system to fail to come to grips with the fact that much injurious conduct toward people with disabilities is knowingly imposed. The doctrine of benign neglect which suffuses the judicial interpretation of disability discrimination law denies

that overt bigotry is the cause of inequities in the protection of people with disabilities. Instead, as Justice Thurgood Marshall insisted in 1985: “discrimination against the handicapped . . . is most often the product, not of invidious animus, but rather of thoughtlessness and indifference—of benign neglect.” As Hahn comments in a footnote, Justice Marshall may have invoked the phrase “benign neglect” ironically, but the other justices did not appear to recognize it.²⁶

The point here is that the general climate of ableism makes it comfortable for us to regard systematic violence against people with disabilities as accidental. Could one claim that the university’s policy of negligence toward students with disabilities, especially after being forewarned, was a willed act of violence? The consciousness of the general public and the legal system would have to undergo a dramatic change for the truth of such a claim to be obvious.

Likewise, the definition of “hate” has to change as well. One of the reasons there is resistance to calling attacks against people with disabilities “hate” crimes is because the general ideology toward people with disabilities rules out hate as a viable emotion. In our culture, it is permissible to “pity” or even “resent” people with disabilities. It is sometimes loosely permitted to make fun of some disabilities (stutters, mental retardation, age-associated deafness, myopia, and the like), but one is generally not supposed to “hate” disabled people. Thus the idea that crimes against people with disabilities might be a result of “hate” seems to most people somehow wrong. Who would act violently toward a person using a wheelchair merely because that person could not walk? But the “hate” against people with disabilities is a much more subtle and ingrained hatred. It is a hatred of difference, of the fact that someone cannot see a clearly posted sign, cannot walk up unblocked stairs, needs special assistance above what other “normal” citizens need. This kind of hatred is one that abhors the possibility that all bodies are not configured the same, that weakness and impairment are the legacy of a cult of perfection and able embodiment. When the law begins to catch on to this level of hatred, justice will be served.

Considering that we are entering a new millennium when people with disabilities may make up 20 percent or more of the population, as a society we ought seriously to set about educating ourselves, just as we have on issues of race, gender, and sexual preference. Let us never forget that the deaf, the feeble-minded, and other “defectives” were the first to be rounded up by the Nazis and sent to the death camps. Only when the camps had consumed people with disabilities did the Nazis begin to bring in the racial undesirables. Disability is not a category that should be obliterated by race or gender. Rather, all these forms of oppression should walk, or wheel, side by side.

A VOYAGE OUT (OR IS IT BACK?)

CLASS AND DISABILITY IN MY LIFE

“Only connect,” says E. M. Forster, and we all try. But the “only” is misleading. Is it as simple as “only”? Are these connections arbitrary? Made after the fact? Are they easily made? Too easily? For these purposes, I would like to think that there were connections, continuities between my upbringing, my politics, my work, my life. Only connect. But there may not be, other than as a fantasy of orderliness. Noam Chomsky has always struck me as an interesting case in point because he has steadfastly claimed that there is no connection between his linguistic work and his political work. Perhaps he is right. Perhaps he just could not see.

If I want to web my life with connective strands, I would draw them out beginning with my family's deafness. To me, my parents' deafness will always be inseparable from our social class. There are now greater opportunities for the deaf, but when I was growing up in the 1950s, the deaf were usually factory workers. My mother was an "alteration hand" in a department store and my father was a "sewing machine operator" who sewed in the garment district of New York. The grind and rhythm of their work was to me part of their deafness, and their deafness was part of their work. I can say that I am who I am because of that conjunction.

I cannot say that everything about that conjunction was enabling. Life for me as a child was spare, depleted, gray. My parents, exhausted by their work, had little time to enrich my life. Their deafness added a greater barrier between me and any world outside. My mother took me to a museum just once in my entire childhood; we never dined out; occasionally we went to the park. My only enriched life was lived at school. Home meant boredom, television, and family squabbles. But school meant excitement, knowledge, harmony. Small wonder I became a teacher.

From my father and mother, I learned to survive. They had survival skills that most ordinary people can only imagine. My mother survived an early childhood attack of meningitis in which she lost her hearing, and my father survived an impoverished childhood and his own infant deafness. Survival is a double-edged form of salvation—you learn to tolerate high degrees of frustration and disappointment, but you forget how to regret and mourn the loss of what you might have had. You make do; you get by. My childhood felt like that of Dickens's orphan; I was old before my time, but I was wise.

My father tried to win at a life that others would have considered a failure. He came back each day from his menial job and told about his work in such a way that he made it seem to us that he was a gifted artisan—a Daedalus forging his inventions in a dingy sweatshop. And then on the weekends, he would don his athletic shorts and shoes and train for his walking races. He had been a race walker since his twenties, and he raced his last race when he was eighty. He even held the American record for

twenty-five miles. His goal in life was to beat the odds, beat his lot in life, beat his deafness. His motto was: "Never say die." So he gave me a feisty raised fist that I still hold onto to this day. I think of it as a fist raised against the forces of injustice.

It was really at school, though, that my life opened. My father inspired me, but like many children from dysfunctional homes, I found my real mentors outside my family life. The principal of my public school, Sidney N. Levy, adopted me, gave me books to read, and once a telescope to study the stars. Kindly teachers took me under their wings. In my settlement-house summer camp, counselors talked to me of philosophy, life, ideas, and radical politics. In junior high school, an English teacher, Peter Poulakis, introduced me to George Orwell and Aldous Huxley. In high school, another English teacher, Ronald Greenhouse, nudged me into the world of bebop and the beatnik culture of the early sixties. School was always a place of wonder for me. I learned, I thrived, and through the genuine interest of others, I managed to get myself into Columbia University.

I was a kid from the slums for whom the system worked. The public schools and the private charities like the Jewish Federation of Philanthropies, who ran my summer camp, seemed to produce people who took the time to teach me. And I was a willing learner. Moments of learning were organic, like the time that Sidney, the high school math teacher who lived in my building, sat me down on the curb by the abandoned lot and explained to me that the whole was greater than the sum of its parts. He was reaching for a metaphor, perhaps about our lives. He also told me to question authority; he said just because a teacher tells you something, doesn't mean it's right.

So, I was, as Antonio Gramsci called the likes of me, an organic intellectual, being taught not necessarily in the schools, but on the streets, articulating the issues of my class. There were many sages amongst us in the Bronx. Mr. Zuckerman, the podiatrist who lived across the hallway, had a run-down office a few blocks away. The back rooms of that office were filled with a visual cacophony of scientific equipment—oscilloscopes,

Van de Graff generators, electrical receivers and transceivers. Mr. Zuckerman let me wander through these rooms, hooking up one thing to another. I built my science projects back there, under his guiding hand. The Bronx was and is filled with people like him, with their local wisdom tucked into back rooms, so that an outsider who walked down the derelict streets would have no idea that behind these drab buildings were scientists as smart as Niels Bohr or Albert Einstein who just happened to be podiatrists by day. And there were poets, and painters, and geniuses of all sorts.

It is a contradiction of our culture that organic intellectuals who speak and articulate positions for their class frequently get tracked out of their milieu as quickly as society can arrange it. Of course, not all do, but I, for one, went to Columbia University, got my Ph.D., and taught for many years in elite institutions. In essence, I abandoned my class, and I fled from deafness. This was my voyage out. Most of my students would have little idea of the kind of world in which I grew up. But from time to time, I see someone like myself. Often they have rough edges and can come across as obnoxious or aggressive (I was) as they work out their awkward and contentious relation to the establishment; but other times they are shy and quiet. I always know their secret and their route, and share my story with them. Teaching, for me, has much to do with these moments of connection and revelation.

One student comes to mind. William Michaels (let us call him) was an African American young man who lived in Harlem and each day climbed the fortresslike steps of Morningside Park, the geographical boundary that separates the ghetto from the university, to come to my humanities class in the early 1970s. He was a really smart student, and I was drawn to him. I was probably only five years older than he was. William's financial aid was inadequate, so he sold drugs to keep himself in college. One day he told me that he was quitting because his seventeen-year-old girlfriend was pregnant. Obviously the contradictions in his life were too great to stay in this elite institution. I called his mother and we both lamented his decision. I tried to get him to remain, but he had made up

his mind. We stayed in touch for a while, but I always felt his loss, I felt the guilt of a survivor for having made it through college.

Having taught at state universities, I am often surrounded by students who are the organic intellectuals of their age; some have even come from my old neighborhood. Forty to seventy percent of the incoming students are the first people in their families to go to college. When I see a student with a bright eye and a quick tongue, I feel the deep connection of those moments when life and work make sense on the most profound level.

When I think of my work, I see myself as the doer of many things. What did they call Ulysses—the man of many ways? Perhaps I am trying to avoid the limiting trajectory of my parents' work, or perhaps I am acting out my father's attempt to break from that trajectory through his semi-career of race walking. I think of myself as a teacher, as a writer—but I write many things, and each of them makes sense to me in terms of my upbringing. As an academic, I have written two books on the novel that attempt to place the “high” culture of literature in a political and social context that shows how such artifacts come from and affect the lives of less elite peoples. This was my mandate to show the effect of lower-class culture on consciousness. *Left Politics and the Literary Profession*, the anthology I coedited with M. Bella Mirabella, attempts to place the achievements of progressive politics in the analysis of literature since the 1980s. I know that my class position motivated my point of view.

More recently, in addition to connecting with class issues, I have reconnected with the issue of deafness. This was my voyage back. For me deafness had been something I associated with my parents, and despite all my interest in race, class, and gender, it never occurred to me to write about deafness in an academic setting. In 1997 I joined an organization called Children of Deaf Adults (CODA) and met many professionals in the field of deafness. From them, I learned that there was an academic discourse about deafness, and after reading extensively, I have written a few articles on deafness, and am working on a book attempting to theorize deafness and by extension disability. Recently, I have been at work on a memoir, *The Sense of Silence*.

I also do a fair amount of popular journalism—a kind of writing I always appreciate because it is popular. I would not want to write exclusively for the academic elite, and so *Redbook* or *McCalls* is as much a part of my sphere as is *In These Times*, *The Nation*, or *The Eighteenth Century: Theory and Interpretation*. I recently wrote an article about how the deaf are abused by the legal and mental systems. This kind of reportorial journalism feels right—as I attempt to point out to society what wrongs it has inflicted on the deaf, who are for the most part poor and in these cases African American or Latino.

So, in essence, my working-class experience has been a guide to my life. It probably is no accident that my wife is also from the same background—both academics, we found each other and reconnected with our past while forging a present. But like my various working-class students, I know that, having left physically, I will never be part of the working class. Of course I am not part of the ruling class. I am one of those who belong to that tricky, in-between grouping known as intellectuals.

I wanted very much by the time I was in high school to be an intellectual. I remember that a fellow student wrote in my high school yearbook, “One day we will run into each other in Central Park. I will be a music critic and you will review books for the *New York Times*.” This was a wish to be part of the intellectual world that seemed fantastically out of our reach. When I finally came to write some reviews for the *New York Times Book Review*, I remember the feelings of cognitive and affective dissonance. But what would have surprised my high school self was the fact that the books I reviewed were on leftist art forms in the 1920s and the autobiography of a deaf actor. The pleasure of being myself at midlife is the pleasure of realizing that I no longer have to flee from my working-class self and my deaf self; that the very issues of my upbringing—the Bronx, deafness, class position—are capacious enough for me to make my work.

I have not forgotten what it means to be working class. I would say that not a day passes by but that something reminds me of my origins. Being a professor connects me with issues, and even people, but it does

not reintegrate me to my class in the way that my parents and my childhood self experienced the resentment of class humiliations, the lived experience of class injustice, and class pride. I can remember and I can tap into these memories, but I think it would be disingenuous to claim that I am still working class. There is a dialectic between the past and the present. The past is never effaced by the present. And like the unconscious, my class experience is perhaps the background radiation that informs daily action. But I do feel that I can never fully return to those origins. In the same way, I connect with deafness, but I am not deaf. Part of my consciousness is and always will be deaf; I am structured by deafness as I am by class. But I am not fully that which I write about. Perhaps it is true that the outsider is fully the only one who can write. And perhaps writers are never fully part of that which they write about. Writers are more often than not the silent observers of their culture; the spies in their families who take notes for future novels and poems.

For me such disjunctions get worked out in writing, in narrative, in articulation and teaching, and in struggling for a more just political process. I even live in a blue-collar neighborhood in the Bronx, but I am still an outsider—the professor. The voyage out may contain a return, but it is never entirely a voyage back. And the desire to connect is often more about desire than connection, despite the will for desire and the will to connect.

NOTES

NOTES TO FOREWORD

1. Lennard Davis, *Enforcing Normalcy: Disability, Deafness and the Body* (London: Verso, 1995), 5.
2. Davis, *Enforcing Normalcy*, 158.
3. James Tuttleton, "Back to the Sixties with Spindocter Graff," *The New Criterion* 11.7 (1993): 28–34. Quotation on 28.
4. George Lipsitz, *Time Passages: Collective Memory and American Popular Culture* (Minneapolis: University of Minnesota Press, 1991), 3.
5. *Lawrence of Arabia*, dir. David Lean, screenplay by Robert Bolt and Michael Wilson, perf. Peter O'Toole, Alec Guinness, Anthony Quinn, Jack Hawkins, and Omar Sharif (Columbia, 1962).

NOTES TO CHAPTER 1

1. For more on this, see a special issue of the *Berkeley Journal of Employment and Labor Law* 22:1 (2000), and also Leslie Francis and Anita Silvers, eds., *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions* (New York: Routledge, 2000).
2. I have written more about this aspect of identity and disability in chapter 5.
3. See Ian Hacking, *The Social Construction of What?* (Cambridge: Harvard University Press, 1999; rpt. 2001).
4. I have made this point elsewhere. See Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (London: Verso, 1995) for greater exposition.
5. Let us not even consider the further problem that in order to locate a gene, we have to cordon off “good DNA” from “junk” DNA. Now, with the advent of relatively low numbers of genes for humans, scientists are beginning to posit that so-called “junk” DNA may have a role to play in “influencing” the good DNA. Thus the exact science of genetics begins to resemble other explanatory systems requiring influence based on humors, astrological causes, and so on. Indeed, many human traits are polygenic, involving several different genes working in coordination with each other and with other processes.
6. Raymond Bonnier and Sarah Rimer, *New York Times* (August 24, 2001), A13.
7. See Steve Olsen, “The Genetic Archeology of Race,” *Atlantic Monthly* (April 2001).
8. See works like Tukufo Zuberi, *Thicker than Blood: An Essay on How Racial Statistics Lie* (Minneapolis: University of Minnesota Press, 2001).
9. For the most complete discussion of HeLa cells in regard to racial politics, see Hannah Landecker, “Immortality, In Vitro: A History of the HeLa Cell Line,” in *Biotechnology and Culture: Bodies, Anxieties, Ethics*, ed. Paul E. Brodwin (Bloomington: Indiana University Press, 2000), 53–72.
10. Dwight Garner, *New York Times Sunday Magazine* (March 25, 2001).
11. Although, as Dorothy Roberts has pointed out, prenatal technology is still

- very much a site of racial discrimination. See her “Race and the New Reproduction,” *Hastings Law Journal* 47:4 (1996).
12. For more on this subject, see Leslie Feinberg, *Transgender Warriors: Making History from Joan of Arc to Dennis Rodman* (Boston: Beacon Press, 1996). Also see Bob Beale, “New Insights into the X and Y Chromosomes,” *The Scientist* (July 23, 2001) 15(15):18.
 13. Steven Steinberg, *The Ethnic Myth* (Boston: Beacon Press, 2001).
 14. See Wendy Brown, *States of Injury: Power and Freedom in Late Modernity* (Princeton: Princeton University Press, 1995).
 15. Nicholas Wade, *New York Times* (October 4, 2001), .
 16. Gina Kolata, *New York Times* (September 28, 2001), A14.
 17. See Ian Hacking’s discussion of transient mental illnesses in *Mad Travelers: Reflections on the Reality of Transient Mental Illnesses* (Charlottesville: University of Virginia, 1998).
 18. For an extensive discussion of the legal issues around disability, see a special issue of the *Berkeley Journal of Employment and Labor Law* 21:1 (2000). For background on many of these issues, see Ruth O’Brien, *Crippled Justice: The History of Modern Disability Policy in the Workplace* (Chicago: University of Chicago Press, 2001).
 19. Soren Kierkegaard, *Fear and Trembling*, trans. Alastair Hanney (London: Penguin, 1985), 83.
 20. See my chapter, “The Rules of Normalcy,” in this volume.
 21. As an assignment, I ask my students to tally up the cost of all the products they buy for their bodies. The annual cost is astounding.
 22. Magazines like *We* and *Poz* generate income by selling trendy and sexy wheelchairs and other equipment for people with disabilities. Of course, the routine body care products are called for here as well.
 23. Paul Gilroy, *Against Race: Imagining Political Culture beyond the Color Line* (Cambridge: Harvard University Press, 2000), 17.

NOTES TO CHAPTER 2

1. Simi Linton, *Claiming Disability: Knowledge and Identity* (New York: NYU Press, 1998), 3–4.
2. Kenny Fries, *Staring Back: The Disability Experience from the Inside Out* (New York: Plume, 1997), 1.

3. Michael Bérubé, *Life as We Know It: A Father, a Family, an Exceptional Child* (New York: Pantheon, 1996), 4.
4. Michael Bérubé, "The Cultural Representation of People with Disabilities Affects Us All," *Chronicle of Higher Education* (May 1997): 85.
5. I follow the usage that spells "Deaf" with a capital "D" to indicate the culturally Deaf and with a lower-case "d" to indicate the physical impairment (loss of hearing).
6. H. Stephan Kaye, *Disability Watch: The Status of People with Disabilities in the United States* (Volcano: Disability Rights Advocates, 1997), 41.
7. Paddy Masefield, Preface, *Framed: Interrogating Disability in the Media*, ed. Ann Pointon and Chris Davies (London: BFI, 1997), viii.
8. Bérubé, "Cultural Representation," 85.
9. Lennard Davis, ed., *The Disability Studies Reader* (London: Routledge, 1997), 16.
10. David Pfeiffer, "Similar and Different?" Unpublished ms., no page number.
11. Rosemarie Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997), 8. Also see Rosemarie Garland Thomson, *Freakery: Cultural Spectacles of the Extraordinary Body* (New York: NYU Press, 1997).
12. Lennard Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (London: Verso, 1995).
13. Martin Pernick, *The Black Stork: Eugenics and the Death of "Defective" Babies in American Medicine and Motion Pictures since 1915* (New York: Oxford University Press, 1995).
14. Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996), 274. Also see Susan Wendell, "Towards a Feminist Theory of Disability?" In Davis, *Disability*, 260–78.
15. Michael Oliver, *The Politics of Disablement: A Sociological Approach* (New York: St. Martin's Press, 1990).
16. Martha Edwards, "The Cultural Context of Deformity in the Ancient Greek World?" *Bulletin of Ancient History* 10.3–4 (1996): 79–92.
17. James W. Trent, Jr., *Inventing the Feeble Mind: A History of Mental Retardation in the United States* (Berkeley: University of California Press, 1984), 7.

18. Douglas C. Baynton, *Forbidden Signs: American Culture and the Campaign against Sign Language* (Chicago: University of Chicago Press, 1996).
19. See, e.g., Harlan Hahn, "Can Disability Be Beautiful?" *Social Policy* 18 (1988); "Disability and Capitalism: Advertising the Acceptably Employable Image," *Policy Studies Journal* 15 (1987): 551–70; "Disability and the Reproduction of Bodily Images: The Dynamics of Human Appearances?" *The Power of Geography: How Territory Shapes Social Life*, ed. I. Wolch and M. Deor (Boston: Unwin, 1989), 370–88.
20. Harlan Lane, *The Mask of Benevolence: Disabling the Deaf Community* (New York: Knopf, 1992).
21. James Charlton, *Nothing about Us without Us: Disability Oppression and Empowerment* (Berkeley: University of California Press, 1998).
22. James Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Times Books, 1993).
23. Adrienne Asch and Michelle Fine, "Shared Dreams: A Left Perspective on Disability Rights and Reproductive Rights," in *Women with Disabilities: Essays in Psychology, Culture, and Politics*, eds. Adrienne Asch and Michelle Fine (Philadelphia: Temple University Press, 1988), 297–305; Ruth Hubbard, "Abortion and Disability?" In Davis, *Disability*, 187–200.

NOTES TO CHAPTER 3

1. Mrs. Thrale writes that the childhood tuberculosis, known as scrofula or "The King's Evil," "left such Marks as even now greatly disfigure his Countenance, besides the irreparable damage it has done to the Auricular Organs; & I suppose 'tis owing to that horrible disorder too that he never could make use of one Eye, this defect however was never visible, both Eyes look exactly alike." Hester Thrale, *Dr. Johnson by Mrs. Thrale: The "Anecdotes" Mrs. Piozzi in Their Original Form*, ed. Richard Ingrams (London: Chatto and Windus, 1984), 5.
2. His compulsive behavior included activities such as "touching the posts as he passed, and going back if he missed one; adjusting his steps so that his foot would touch a threshold at a particular moment; blowing out his breath loudly like a whale when he finished a lengthy remark or a dispute, as if to punctuate it and give it finality; treading the floor as if measuring it and also testing its firmness or stability; or making patterns with his

- heels and toes, as Miss Reynolds said, ‘as if endeavoring to form a triangle or some geometrical figure.’” W. Jackson Bate, *Samuel Johnson* (New York: Harcourt Brace Jovanovich, 1978), 382.
3. James Boswell, *Life of Samuel Johnson*, ed. George Birkbeck Hill, rev. by L. F. Powell (Oxford, 1934–50), 1:485. All subsequent references are to this edition and are given in the text.
 4. This thesis is discussed by Julia Epstein in *Altered Conditions: Disease, Medicine, and Storytelling* (New York: Routledge, 1995), 65–66. The syndrome was first reported in 1885 by Dr. Gilles de la Tourette, a French physician interested in neurology. It is characterized by uncontrollable facial and bodily tics, compulsive grunting vocalizations, in some cases profane verbalizations, and incessant, obsessive exploration of the environment.
 5. James Boswell, *Correspondence and Other Papers of James Boswell Related to the Making of the Life of Johnson*, ed. Marshall Waingrow (New York: McGraw-Hill, 1951), 24.
 6. Julia Epstein in *Altered Conditions* makes this point, stressing that Johnson’s literary fame is linked to the aestheticization of Johnson’s maladies (1995:67). She comments on and notes the difference between this kind of writing which serves to monumentalize Johnson’s body and mental prowess, and later clinical writings (or pathographies) which treat the physical difference as symptoms. While I agree with Epstein’s notion of a split between an earlier nonmedicalized way of seeing the body and the later discourses which medicalize disability, I want to point out that the aesthetic impulse Epstein describes is not simply a literary tendency but part of a larger cultural way of regarding disability.
 7. Epstein, *Altered Conditions*, 67.
 8. William Hay defines disability in a similar way: “Bodily deformity is visible to every Eye.” *Deformity: An Essay* (London: R. and J. Dodsley, 1754), 2.
 9. It is important that we not cut off disability from these other manifestations. The connections are not obvious initially, but consider Aristotle’s dictum that women are deformed males (*Generation of Animals*, trans. A. L. Peck [Cambridge: Harvard University Press, 1944], 4:104). Later versions have it that women are disabled men. Or add to this the idea that

non-Europeans were “monsters” that could be exhibited in fairs along with dwarfs and giants, that homosexuality could be regarded as a medical disability, and that lower-class workers could be seen as physically imperfect, deformed by work, or working at such jobs because they were deformed.

10. Adrienne Asch and Michelle Fine, “Disability beyond Stigma: Social Interaction, Discrimination, and Activism,” *Journal of Social Issues* 44:1 (1988): 5.
11. Nora Ellen Groce, *Everyone Here Spoke Sign Language: Hereditary Deafness on Martha’s Vineyard* (Cambridge: Harvard University Press, 1985).
12. This alludes to the murder of David Rizzio in the presence of a pregnant Mary Stuart, reflecting the classical belief that deformities were caused by the mother’s looking on something disturbing or impressive during her pregnancy. See Marie-Hélène Huet, *Monstrous Imagination* (Cambridge: Harvard University Press, 1993); and Julia Epstein, *Altered Conditions*.
13. Robert Ashton, ed., *James I by His Contemporaries* (London: Hutchinson and Co., 1969), 12.
14. Ashton, *James I*, 2–3.
15. Ashton, *James I*, 8.
16. Baldesar Castiglione, *The Book of the Courtier*, trans. George Bull (London: Penguin, 1967), 289.
17. Michel de Montaigne, *The Complete Essays of Montaigne*, trans. Donald Frame (1958; rpt. Stanford: Stanford University Press, 1965), 539, 791.
18. Francis Bacon, *A Selection of His Works* (New York: Odyssey, 1965), 158–59.
19. William Shakespeare, *The Complete Works*, ed. Alfred Harbage (London: Penguin, 1969), 1.1.28–30.
20. Huet, *Monstrous Imagination*.
21. Shakespeare, *Richard III*, 1.1.20–21.
22. The baking analogy appears with a somewhat different spin in an eighteenth-century work:

As when the Wheaten Mass is work’d to Dough,
Or swells with Leaven in the Kneading-Trough,

It takes whatever Marks the Maker gives,
And from the Baker's hand its Form receives.
So works the Fancy on the Female Mold,
And women shou'd beware what they behold.

Claude Quillet, *Callipaedia; or, The Art of Getting Beautiful Children: Done into English Verse by Several Hands* (1708–10; rpt. Philadelphia: American Antiquarian Publishing Company, 1872), 53–54.

More recently, scientists have lent some credence to the notion of the mother's diet or cravings having an effect on the adult child's health or physical well-being. The *New York Times* reported that adults with heart disease may have developed the disease not because of hereditary influences but rather as a result of their mothers' diet during pregnancy (October 10, 1996, C1).

23. Montaigne, *Complete Essays*, 538–39.
24. Dennis Todd, *Imagining Monsters: Miscreations of the Self in Eighteenth-Century England* (Chicago: University of Chicago Press, 1995), 154.
25. Todd, *Imagining Monsters*, viii.
26. Montaigne, *Complete Essays*, 539.
27. Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (London: Verso, 1995), 52.
28. Hay, *Deformity*, 4.
29. Hay, *Deformity*, 34.
30. The remarkable aspect of his work is that it is one of the first written by a person with disabilities about disabilities. Pierre Desloges, a deaf person, some fifteen years later writes a book about his deafness. In other words, although persons with disabilities may still uphold stereotypes about disability, they nevertheless are speaking themselves.
31. Boswell's motivation in countering other critical versions of Johnson's life is clearly operative here. Unfortunately, I cannot deal with Boswell's motivation in detail here; neither do I include research concerning the telling revisions that Boswell made in his manuscript or varying accounts of Johnson given in Boswell's journal versus his public accounts.
32. Thrale, *Dr. Johnson*, 5.
33. He might be referring to a book interestingly entitled *Deformities of Dr.*

Samuel Johnson. The author, James Thomson Callender, attacks not the physical deformities of Johnson but his literary ones. The book includes eighty-nine pages of line-by-line corrections of Johnson's putative errors. Callender refers to Johnson's physical condition only twice, quite indirectly. Callender states that "his personal appearance cannot much recommend him" and refers to "the weakness of his vision." James Thomson Callender, *Deformities of Dr. Samuel Johnson* (1782; rpt. Los Angeles: William Andrews Clark Memorial Library, 1971), iv.

34. I am operating under the assumption that madness is a disability. It is so defined, for example, in the Americans with Disabilities Act of 1990. However, it is entirely possible that in the eighteenth century madness was considered completely differently from disability. If Foucault is correct in *Madness and Civilization: A History of Insanity in the Age of Reason*, trans. Richard Howard (New York: Random House, 1973), madness was considered a defect in reasoning power or rationality. This defect might be ascribed an epistemological rather than a physical basis—and so might not be considered a "defect" or "disability." For more recent work on this subject, see David Wright and Anne Digby, *From Idiocy to Mental Deficiency: Historical Perspectives on People with Learning Disabilities* (London: Routledge, 1996).
35. Jonathan Andrews, "Identifying and Providing for the Mentally Disabled in Early Modern London," in Wright and Digby, *From Idiocy to Mental Deficiency*, 70.
36. Andrews, "Identifying and Providing," 71.
37. For more on this, see my *Enforcing Normalcy*, 23–49; Rosemarie Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1994); Harlan Lane, *When the Mind Hears* (New York: Random House, 1984); Douglas C. Baynton, *Forbidden Signs: American Culture and the Campaign against Sign Language* (Chicago: University of Chicago Press, 1996); Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception*, trans. A. M. Sheridan (New York: Pantheon, 1973).
38. Thrale, *Dr. Johnson*, 5.
39. Thrale, *Dr. Johnson*, 68.
40. Thrale, *Dr. Johnson*, 47.

41. Peter Pinco Chase, "The Ailments and Physicians of Dr. Johnson," *Yale Journal of Biology and Medicine* 23:5 (April 1951): 370.
42. Thomas Babington Macaulay, *Life of Samuel Johnson* (Boston: Atheneum, 1904), 4–5
43. Macaulay, *Life of Samuel Johnson*, 4–5.
44. Rather than dismissing or apologizing for Johnson's Tourette syndrome, a disability studies approach might show how the syndrome enabled Johnson to compile his dictionary. The obsessive-compulsive behavior would aid him in the repetitive activities required.
45. Macaulay, *Life of Samuel Johnson*, 5.
46. Alternatives to the "triumph over disability" scenarios are ones in which the morality and uplift is not built in a mandatory way into the story. Contemporary memoirs and fiction by authors like Nancy Mairs, *Remembering the Bone House* (New York: Harper and Row, 1989); Kenny Fries, *Body Remember* (New York: Dutton, 1997); Anne Finger, *Basic Skills* (Columbia: University of Missouri Press, 1986); Michael Bérubé, *Life as We Know It* (New York: Random House, 1996), and others provide us good examples.
47. Henry Fielding, *Amelia* (Oxford: Oxford University Press, 1983), 66. Subsequent references are given in the text.
48. Ronald Paulson and Thomas Lockwood, eds., *Henry Fielding: The Critical Heritage* (London: Routledge and Kegan Paul, 1969), 303.
49. Paulson and Lockwood, *Henry Fielding*, 327.
50. Paulson and Lockwood, *Henry Fielding*, 323.
51. Paulson and Lockwood, *Henry Fielding*, 333.
52. Paulson and Lockwood, *Henry Fielding*, 315.
53. Paulson and Lockwood, *Henry Fielding*, 349.
54. Paulson and Lockwood, *Henry Fielding*, 348.
55. Paulson and Lockwood, *Henry Fielding*, 335.
56. Thrall, *Dr. Johnson*, 102–3.
57. Cited in Philip Stevick, "The Augustan Nose," *University of Toronto Quarterly* 34:2 (1965): 111.
58. See my *Enforcing Normalcy* for a fuller development of these ideas, as well as my "Who Put the *The* in the Novel? Identity Politics and Disability in Novel Studies," chapter 5 in this book.

59. Sarah Scott, *Millenium Hall* (Harmondsworth, England: Penguin, 1986), 199.
60. It is possible that disability served some positive, adaptive function for eighteenth- and nineteenth-century women. As invalids or “sick” women, females could avoid undesirable aspects of caregiving and attain greater privacy, perhaps even a sickroom of their own, which would permit concentrated, uninterrupted intellectual and creative work.

NOTES TO CHAPTER 4

1. *The Queer Dutchman: True Account of a Sailor Castaway on a Desert Island for “Unnatural Acts” and Left to God’s Mercy*, ed. P. Agnos, trans. M. Jelstra (New York: Green Eagle Press [copyright 1978 C. Adler], 1993), p. 12. For the sake of clarity, since there are several versions of Svilt’s story, I will use publication dates along with page references.
2. We might want to compare this statement to the statement of the eponymous hero of Defoe’s *Captain Singleton* who describes his own boyhood, “a Master of a ship . . . took a Fancy to me . . . I lived well enough, and pleased my Master so well, that he called me his own Boy; and I would have called him Father, but he would not allow it, for he had Children of his own” (p. 3).
3. I was able to read a partially mutilated copy of this pamphlet, printed in Philadelphia in 1748. It differs somewhat from the text I received in the mail but the language was close enough to be similar. The striking difference is that many sections have been added in the 1993 edition. Were these excised in the English version? Or were they added by Agnos, who might be fictionalizing Svilt’s life?
4. See chapter 1 of my *Factual Fictions: The Origins of the English Novel* (New York: Columbia University Press, 1983; rpt. Philadelphia: University of Pennsylvania Press, 1997), for more on the idea of authorial assertions of a text’s veracity.
5. Whenever I have presented this paper at academically oriented venues, the universal response from my colleagues has been that I should engage in further research. People have suggested I go to Holland and track down shipping records, or that I go to England and find out if there was a Captain Mawson. Such helpful suggestions come from a profound feeling that

history can be recovered if we try hard enough and are scholarly enough. I do not wish to contravene such ideas, and clearly much valuable revisionist history comes from such archival work. But what I want to suggest in this essay is that there are limits to our ability to recover the past—particularly when we are dealing with marginal groups like homosexuals, criminals, slaves, people with disabilities, and so on. Even those remaining documents may, like *A Just Vengeance*, be so imbricated in an ideology of repression and concealment that the notion of a clear reality that can be recovered has to be rethought and retheorized.

6. See, for example, B. R. Burg, *Sodomy and the Pirate Tradition: English Sea Rovers in the 17th-century Caribbean* (New York: New York University Press, 1984), or A. N. Gilbert, “Buggery and the British Navy,” *Journal of Social History* 10:1 (fall 1976): pp. 72–98.
7. For readers not familiar with my refashioning of a phrase here, I am referring to the U.S. Army’s policy toward homosexuality which is known as the “don’t ask, don’t tell” policy.
8. Other names might then be seen as embodying authorial intent. Is Svilt’s name supposed to be close to the English internally rhyming “guilt”? Does Bandino’s name imply a reference to the French vulgarity for “erection”? And does Bandino’s name, with its Mediterranean suggestivity, imply a meridional passionate nature or else a notion of abandonment?
9. How perfect for the English writer, if there was one, to have placed queerness in a Dutch figure, imputing moral degradation to the archival country.
10. Compare this condemnation with the statement in Defoe’s Captain Singleton that “Thieving, Lying, Forswearing, joined to the most abominable Lewdness, was the stated Practice of the Ship’s Crew.” *Captain Singleton*, ed. S. K. Kumar (New York: Oxford University Press, 1990), 6.
11. None of the Capetown or Batavia episodes are in the 1748 edition, although they may have appeared in that edition in the sections contained in the missing pages.

NOTES TO CHAPTER 5

1. Deirdre Lynch and William B. Warner, eds., *Cultural Institutions of the Novel* (Durham: Duke University Press, 1996), 2.

2. Ian Watt, *The Rise of the Novel: Studies in Defoe, Richardson and Fielding* (Berkeley: University of California Press, 1967).
3. An illustrative quotation:

I hope to have avoided the onesidedness that structures many noteworthy approaches to eighteenth-century prose fiction, such as John Bender's, Lennard Davis's, and Michael McKeon's highlighting of male writers in their studies of the origins of the novel, or, conversely, Catherine Gallagher's, Jane Spencer's, and Janet Todd's corrective examinations of the history of fiction in which the works of female writers are separated from those of their male counterparts.

Christopher Flint, *Family Fictions: Narrative and Domestic Relations in Britain, 1688–1798* (Stanford: Stanford University Press, 1998), 23.

4. Clara Reeve, *The Progress of Romance* (New York: The Facsimile Text Society, 1930), 2 vols., 1:110.
5. Wendy Brown, *States of Injury: Power and Freedom in Late Modernity* (Princeton: Princeton University Press, 1995), 117.
6. Judith Butler, *Gender Trouble: Feminism and the Subversion of Identity* (New York: Routledge, 1990), 16.
7. Brown, *States of Injury*, 57–58.
8. Brown, *States of Injury*, 61.
9. See the following chapter in this book, “The Rule of Normalcy: Politics and Disability in the U.S.A. [United States of Ability],” which argues that the disabled citizen was created concomitantly with a rights-based political system in Europe during the eighteenth century.
10. Such work has been done by many disability scholars, including Rosemarie Thomson, Leonard Kriegel, and Paul Longmore. See Rosemarie Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997); Leonard Kriegel, “The Cripple in Literature,” in *Images of the Disabled, Disabling Images*, eds. A Ian Gartner and Tom Joe (New York: Praeger, 1987); Paul Longmore, “Screening Stereotypes: Images of Disabled People in Television and Motion Pictures,” in *Images of the Disabled, Disabling Images*, eds. A Ian Gartner and Tom Joe (New York: Praeger, 1987), 65–78.

11. The notion of disability as created by barriers rather than inherent inabilities is the hallmark of recent thinking about the subject. For further information, see chapter 1 of Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness and the Body* (London: Verso, 1995). Also see Lennard J. Davis, *Factual Fictions: The Origins of the English Novel* (Philadelphia: University of Pennsylvania Press, 1996), and “The Rule of Normalcy: Politics and Disability in the U.S.A. [United States of Disability],” in chapter 6.
12. Indeed, the universal sign symbol for disability—the wheelchair—is the most profound example of the difficulty of categorizing disability, since only a small minority of people with disabilities use that aid.
13. We saw this denigration of disability’s minority status in the 1996 presidential election when Bob Dole tried to use his status as a person with disabilities to forge a connection with African Americans and Latinos. Many in these groups doubted his genuine minority status and thought of his claims as mere politicking, which they no doubt were. However, the rapidity with which his claims were dismissed by the media and the public was telling. Clearly, having lost the use of an arm is downplayed in an ableist culture, although becoming a quadriplegic, as Christopher Reeve did, is a more acceptable basis for claiming disability.
14. Brown, *States of Injury*, 65.
15. Brown, *States of Injury*, 61.
16. Reeve, *The Progress of Romance*, 1:111.
17. John Dunlop, *The History of Fiction*, 3rd ed. (London: Longman, Brown, Green, and Longmans, 1845), 362.
18. Watt, *The Rise of the Novel*, 12.
19. Watt, *The Rise of the Novel*, 32.
20. Theodore M. Porter, *The Rise of Statistical Thinking, 1820–1900* (Princeton: Princeton University Press, 1986), 52.
21. For more on the conjunction of statistics and eugenics, see chapter 2 of my *Enforcing Normalcy*.
22. Reeve, *The Progress of Romance*, 1:139.
23. Reeve, *The Progress of Romance*, 2:27.
24. Reeve, *The Progress of Romance*, 1:141. Emphasis in the original.

25. The French romance was based on the idea of *vraisemblance* which may at first seem to be similar to notions of realism, normality, and the average. But actually this concept simply involved the notion that characters should not be invented but rather have some basis in history—mainly classical history. By severing themselves from the romance notion of *vraisemblance*, that is, from having their characters be historical, novels had the newer and more complex task of making characters believable by making them conform to normative behaviors by which people “ought” to act.
26. Clearly, as the culture moved from the concept of the ideal to that of the norm, this question concerning character became moot in novel criticism. No one in the late nineteenth century expected a character like Jude or Verloc to be the embodiment of “human nature as it ought to be.”
27. In the most egregious examples like those of Kim or Tarzan, Britishness is so firmly a part of the character that it is impervious to cultural assimilation. And this impervious quality is inscribed in terms of social class as well. Consider the likes of Tom Jones or Oliver Twist.
28. Mark Booth, Sandra Phillips, and Carol Squires, *Police Pictures: The Photograph as Evidence* (San Francisco: Chronicle Books, 1998), 55.
29. Statements like this one cry out for readers to provide exceptions. I am willing to concede that readers may find exceptions to my statement but believe that the rule in general holds. For example, to cite one exception myself, Esther Summerson in *Bleak House* is facially marked by smallpox. However, the exception of this case is so jarring that by the end of the book Dickens has virtually erased the markings. Where a character like Captain Ahab in *Moby Dick* is so marked, he becomes his disability and is not in the proper sense a hero like Ishmael, who is unmarked. Indeed, like many disabled characters, he is seen in negative terms and is ultimately punished by the mechanism of the novel. Far fewer main characters can be found who are born disabled, although the literature is rife with minor disabled characters whose disability serves various moral or comic purposes.
30. E. M. Forster, *Aspects of the Novel* (Harmondsworth: Penguin, 1968), 114.
31. Presumably, Forster felt the same way about homosexuality, considered to

be a medical disability during this period, since he refused to publish *Maurice* in his own lifetime.

32. Since, in fact, the mean annual income of a family of four in the United States hovers around \$37,000, the spacious suburban and urban interiors of most sitcoms hardly resemble the interiors from which most of America watches these shows.
33. Mitchell and Snyder refer to the use of disability in novels as “narrative prosthesis.” For them,

a narrative issues to resolve or correct—to “prostheticize” in David Wills’s sense of the term—a deviance marked as abnormal or improper within the social context. A simple schematic of narrative structure might run: first, a deviance or marked difference is exposed to a reader; second, a narrative consolidates the need for its own existence by calling for an explanation of the deviation’s origins and formative consequences; third, the deviance is brought from the periphery of concerns to the centerpiece of the story to come; and fourth, the remainder of the story seeks to rehabilitate or fix the deviance in some manner, shape, or form. This fourth step of the repair of the deviance may involve an obliteration of the difference through a “cure,” the rescue of the despised object from social censure, the extermination of the deviant as a purification of the social body, or the revaluation of an alternative mode of being.

David Mitchell and Sharon Snyder, “Narrative Prosthesis: The Materiality of Metaphor,” SDS Conference, June 1997.

34. René Girard, *Deceit, Desire, and the Novel: Self and Other in Literary Structure*, trans. Yvonne Freccero (Baltimore: Johns Hopkins University Press, 1965), 290.
35. Girard, *Deceit, Desire, and the Novel*, 300.
36. Obviously, I am speaking about middle-class readers, who traditionally made up the bulk of the reading public. But within this category, various identities, most notably feminine ones, had the complex task of seeing their social setting as residing both within and outside the norm. This dialectic is explored in many studies, notably the work of Nancy Armstrong,

Mary Poovey, Catherine Gallagher, Janet Todd, and Ruth Perry, among others.

37. To use the term coined by Thomson in *Extraordinary Bodies*.
38. Brown, *States of Injury*, 69.
39. Brown, *States of Injury*, 74.
40. Reeve, *The Progress of Romance*, 1:111.

NOTES TO CHAPTER 6

1. R. W. Burchfield, *Fowler's Modern English Usage* (Oxford: Oxford University Press, 1965), 395.
2. Ironically, the person who made the first dictionary in English, Samuel Johnson, was himself a very nonstandard human. He had many disabilities, including Tourette Syndrome, which may have accounted for his obsessive behavior in compiling words. See chapter 3.
4. See also H. Aarslef, *The Study of Language in England, 1780–1860* (Princeton: Princeton University Press, 1967); and Murray Cohen, *Sensible Words: Linguistic Practice in England, 1640–1785* (Baltimore: Johns Hopkins Press, 1977).
5. Georges Canguilhem, *On the Normal and the Pathological*, trans. R. Fawcett (New York: Zone Books, 1991), 150.
6. Canguilhem, *On the Normal*, 150.
7. Benedict Anderson, *Imagined Communities: Reflections on the Origin and Spread of Nationalism* (London: Verso, 1983).
8. I am following Foucault's lead in this claim. Foucault talked about the control of deviant bodies—criminal, sexual, and medical. In some sense, Foucault never fully accounted for why these bodies were considered deviant. He never really explained the ontology of deviance. My emphasis here is on deviance as pressured by concepts of the norm. In other words, the creation of the modern sense of deviance for bodies is located in the work of statisticians, medical doctors, and eugenicists attempting to norm physical variation.
9. I am sure that one can find many examples in which “-cy” does not express a permanent state. One could argue that “immediacy” can hardly be permanent or that “pregnancy” is certainly a state that has an end. But one could counterargue that each of these is an absolute state. A malignancy

- generally does not become benign, and one cannot be a little pregnant. So that while time can end the “-cy” state, it does not diminish it. In any case, as will be seen, my definition here serves propaedeutic and hortatory purposes more than linguistic ones.
10. I would be the first to recognize that my philology is probably spurious. The “-cracy” in these terms derives from *kratein*, “to rule.” But for my polemical purposes, I will equate the “-cy” in “democracy” with that in “normalcy.”
 11. Theodore M. Porter, *The Rise of Statistical Thinking, 1820–1900* (Princeton: Princeton University Press, 1986).
 12. Canguilhem, *On the Normal*, 151.
 13. It is interesting that this formulation of an average worker is not only a necessity for capitalism, but is so for socialism or communism as well. Marx, for example, used Quetelet’s idea of the average man to come up with his formulations of labor value or average wages. For more on this, see my *Enforcing Normalcy*, 28–29.
 14. What follows are largely some thoughts on and reactions to my reading of Georges Canguilhem’s book *On the Normal and the Pathological*, which I had failed to read when I wrote *Enforcing Normalcy*. This book is central to any study of normality, and the fault is clearly mine for having omitted it in my study. However, I would add that no conclusion I reached would have been altered by reading Canguilhem’s work. If anything, my book would have been strengthened by the observations of this writer.
 15. Canguilhem, *On the Normal*, 18.
 16. Canguilhem, *On the Normal*, 24.
 17. Canguilhem, *On the Normal*, 46.
 18. Canguilhem, *On the Normal*, 25.
 19. Canguilhem, *On the Normal*, 18.
 20. Canguilhem, *On the Normal*, 18.
 21. Canguilhem, *On the Normal*, 28.
 22. Canguilhem, *On the Normal*, 22.
 23. A larger point to made, and one that is far beyond the scope of this essay, is that in effect holistic, traditional practices of medicine based on accumulated experience, such as the traditions of Native American, Chinese,

or Maori medicine, has been eliminated by this new kind of practice in which treatment can only be accomplished after laboratory work which isolates specific locations of disease. The suppression of indigenous medical practice in favor of a rationalized medical discourse can certainly be analyzed as an aspect of the suppression of indigenous people, colonial subjects, and women.

24. One has only to look at the social pressures forcing one to “have” a doctor; to “have” regular checkups; to find the hidden diseases that may be incipiently growing without one’s knowledge. The ideological impulse is to place the responsibility for one’s health on the individual rather than the community. Diet rather than control of pesticides, regular checkups rather than reduction of pollution, sunscreen rather than ozone-saving measures, cochlear implants rather than the widespread use of sign language and interpreters—are examples all of which point to the way ideology functions on the patient-citizen.
25. Max Horkheimer and Theodor W. Adorno, trans. John Cumming, *Dialectic of Enlightenment* (New York: Herder and Herder, 1972), 137.
26. Canguilhem, *On the Normal*, 52.

NOTES TO CHAPTER 7

1. See, e.g., WAI CHEE DIMOCK, RESIDUES OF JUSTICE: LITERATURE, LAW, PHILOSOPHY (1996); STANLEY FISH, DOING WHAT COMES NATURALLY: CHANGE, RHETORIC, AND THE PRACTICE OF THEORY IN LITERARY AND LEGAL STUDIES (1989); PATRICIA WILLIAMS, THE ALCHEMY OF RACE AND RIGHTS (1991).
2. PETER GOODRICH, LEGAL DISCOURSE: STUDIES IN LINGUISTICS, RHETORIC AND LEGAL ANALYSIS 1 (1987).
3. See *Cassista v. Community Foods*, 5 Cal. 4th 1050 (1993).
4. *Runnebaum v. Nationsbank of Maryland, N.A.*, 123 F.3d 156 (4th Cir. 1997).
5. *Woodson v. North Carolina*, 428 U.S. 280, 304 (1976).
6. MARTHA C. NUSSBAUM, POETIC JUSTICE: THE LITERARY IMAGINATION AND PUBLIC LIFE 1–4 (1995).
7. See SIGMUND FREUD, CHARACTER AND CULTURE 158–62 (Philip Rieff ed., 1963).

8. *Id.* at 160–61 (quoting WILLIAM SHAKESPEARE, RICHARD THE THIRD, act 1, sc. 1).
9. *Id.* at 161.
10. *Id.*
11. *Id.*
12. *Id.*
13. *Id.*
14. *Id.*
15. Tobin Siebers, *Tender Organs, Narcissism and Identity Politics*, in *DIS-TURBING DISCOURSES: A DISABILITY STUDIES SOURCE-BOOK* (Brenda Jo Brueggemann et al. eds., New York: Modern Language Association Press, 2002).
16. FREUD, *supra* note 7, at 159–60.
17. *Id.* at 160.
18. Sigmund Freud, *On Narcissism*, in 14 *THE STANDARD EDITION OF THE COMPLETE PSYCHOLOGICAL WORKS OF SIGMUND FREUD* 82 (James Strachey ed. and trans., 1974).
19. Siebers, *supra* note 15.
20. *Id.*
21. *Id.*
22. Lennard J. Davis, *The Linguistic Turf Battles over American Sign Language*, *CHRON. HIGHER EDUC.*, June 5, 1998, at A60.
23. 139 F.3d 80 (2nd Cir. 1998).
24. 119 S. Ct. 864 (1999).
25. Linda Greenhouse, “*Three Strikes*” Challenge Fails, but Others Are Invited, *N.Y. TIMES*, Jan. 20, 1999, at A12.
26. *Id.*
27. The Americans with Disabilities Act of 1990, 42 U.S.C.A. § 12102(2) (1994).
28. *Id.* at §§12112(a), 12112(b)(5)(A).
29. *Murphy v. United Parcel Serv., Inc.*, 527 U.S. 516, 119 S. Ct. 2133 (1999) (high blood pressure controllable by medication does not constitute a disability under the ADA); *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 119 S. Ct. 2139 (1999) (correctable myopia does not constitute a disability under the ADA); and *Albertson’s, Inc. v. Kirkingburg*,

- 527 U.S. 516, 119 S. Ct. 2162 (1999) (individuals with monocular vision are not per se “disabled” within the meaning of the ADA, but must prove on a case-by-case basis that their conditions substantially limit a major life activity).
30. 44 F.3d 538, 545 (7th Cir. 1995).
 31. FREDERICK T. WOOD, *DICTIONARY OF ENGLISH COLLOQUIAL IDIOMS* 30, 191 (1979).
 32. The original meaning of “bend” is actually “to bind,” related to the use of the noun “band,” as in “fettters.” *OXFORD ENGLISH DICTIONARY* 104 (2d ed. 1989). Thus the original meaning of the word implied coercion and imprisonment, and “bend” derived from the sense of binding something by twisting it into an unnatural position, similar to forming a knot. *Id.* Therefore, it is possible that our phrase “to bend over backward” was originally to “to bind over backward,” indicating an even greater degree of suffering, pain, and deformation. However, the phrase is also found in the form of “lean over backwards.” In any case, the notion of pain is now retained in the current expression.
 33. Friedrich Nietzsche, *The Genealogy of Morals, in THE BIRTH OF TRAGEDY AND THE GENEALOGY OF MORALS* 195 (Francis Golffing trans., 1956).
 34. *Id.*
 35. *See, e.g., SANDER GILMAN, THE JEW’S BODY* (1991).
 36. William Shakespeare, *The Merchant of Venice, in WILLIAM SHAKESPEARE: THE COMPLETE WORKS* 238 (Alfred Harbage ed., 1969).
 37. *Id.* at 234.
 38. *Id.*
 39. *Id.* at 235.
 40. *Id.* at 236.
 41. *Id.* at 234.
 42. 44 F.3d 538 (7th Cir. 1995).
 43. Fans of legal theory might be interested to note that Judge Posner was the judge who ruled in this case.
 44. 44 F.3d at 546.
 45. *Id.* at 544.

46. *Id.* at 542.
47. *Id.*
48. *Id.* The preferred phrase among people with disabilities is “uses a wheelchair,” rather than “confined to a wheelchair.”
49. *Id.* at 542–43.
50. *Id.* at 543.
51. *Id.*
52. *Id.*
53. *Id.*
54. See H. STEPHEN KAYE, DISABILITY RIGHTS ADVOCATES, DISABILITY WATCH: THE STATUS OF PEOPLE WITH DISABILITIES IN THE UNITED STATES 54 (1997).
55. *Id.*
56. *Vande Zande*, 44 F.3d at 543.
57. *Id.*
58. *Id.* at 545.
59. *Id.*
60. *Id.*
61. *Id.*
62. *Id.*
63. *Id.*
64. *Id.* at 546.
65. *Id.*
66. *Id.*
67. WEBSTER’S NINTH NEW COLLEGIATE DICTIONARY 419 (1983).
68. *Vande Zande*, 44 F.3d at 546.
69. *Id.*
70. ERVING GOFFMAN, STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY (1963).
71. *Vande Zande*, 44 F.3d at 546.
72. *Id.*
73. *Id.*
74. *Id.*
75. *Id.*

76. *Runnebaum v. Nationsbank of Maryland, N.A.*, 123 F.3d 156 (4th Cir. 1997).
77. *Id.* at 162.
78. *Id.* at 163.
79. *Id.* at 168.
80. *Id.*
81. 781 F.2d 1134 (5th Cir. 1986).
82. *Runnebaum*, 123 F.3d at 168.
83. *Dictionary Will Revise Definitions of 200 Slurs*, N.Y. TIMES, May 3, 1998, at 34.
84. WEBSTER'S NINTH NEW COLLEGIATE DICTIONARY 159 (1983).
85. *Id.* at 327.
86. *Id.* at 671.
87. And one wouldn't want to look up "stigma" in *Webster's Ninth New Collegiate Dictionary* because the definitions provided therein do not adequately describe the sociological term. Out of seven definitions, all but one are about marks, scars, or spots on the skin; only "a mark of shame or discredit: STAIN" comes close to the currently accepted sociological meaning. *Id.* at 1158.
88. See Tom Shakespeare, *What Is a Disabled Person?* in DISABILITY, DIVERS-ABILITY AND LEGAL CHANGE 25–34 (Melinda Jones and Lee Ann Basser Marks eds., 1999).
89. There are cases that trace disability history such as *Cassista v. Community Foods*, 5 Cal. 4th 1050 (1993), although that case ends up using a kind of spurious continuity between older and newer legislation insofar as the distinction between disability and impairment is concerned.
90. 10 F.3d 17 (1st Cir. 1993).
91. *Id.* at 22.
92. *Id.* at 25.
93. *Id.* at 26.
94. *Id.* at 28.
95. *Id.*
96. *Id.* at 21.
97. *Id.* at 22.

98. *ADAPT Anticipates Affirmation of Housing Rights of the Disabled*, U.S. NEWSWIRE, May 12, 1999, available in LEXIS, News Group File, at A11. The case at issue, *Olmstead v. L.C. ex rel. Zimring*, was ultimately decided at 527 U.S. 581, 119 S. Ct. 2176 (1999).

NOTES TO CHAPTER 8

1. H. Stephen Kaye, *Disability Watch: The Status of People with Disabilities in the United States* (Oakland, Calif.: Disability Rights Advocates, 1997), 11.
2. Barbara Waxman, "Fact Sheet: Violence against Disabled Women," Center for Women's Policy Studies, e-mail document.
3. Private communication.
4. "9th Is Charged in Torture Case as Prosecutors Look for Bias," *New York Times*, February 18, 1999, B8.
5. David M. Halbfinger, "Man Says Union Chief Beat Him in Jail," *New York Times*, February 24, 1999, B5.
6. Waxman, "Fact Sheet."
7. Kaye, *Disability Watch*, 31.
8. Kaye, *Disability Watch*, 18.
9. Susan Sachs, *New York Times*, February 18, 1999, B1.
10. Kaye, *Disability Watch*, 16.
11. Kimberly Crenshaw, "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory, and Antiracist Politics," in *Living with Contradiction: Controversies in Feminist Social Ethics*, ed. Allison Jagger (Boulder: Westview, 1994), 40.
12. De Graffenreid, 413 F Supp at 143.
13. Anita Silvers, "The Unprotected: Constructing Disability in the Context of Antidiscrimination Law," in *Americans with Disabilities: Exploring the Implications of the Law for Individuals and Institutions*, eds. Leslie Pickering and Anita Silver (New York: Routledge, 2000).
14. Katha Pollit, "Peter Singer Comes to Princeton," *The Nation* 16 (May 3, 1999), 10.
15. Tobin Siebers, "Tender Organs, Narcissism and Identity Politics," in *Disturbing Discourses: A Disability Studies Sourcebook*, eds. Brenda Jo Brueggemann et al. (New York: Modern Language Association Press, 2002).

- Lennard J. Davis, “Bending over Backwards: Narcissism, the ADA, and the Courts,” in this volume.
16. *Vande Zande v. State of Wisconsin Dept. of Admin.* 44 F. 3d 538, 545 (7th cir. 1995).
 17. *Cassista v. Community Foods*, 5 Cal. 4th 1050 (1993).
 18. Pub. L. No. 103–322, 108 Stat. 1815 (Sept. 13, 1994).
 19. 508 U.S. 476 (1993).
 20. Wisc Stat. § 939.645.
 21. Dick Sobsey, *Violence and Abuse in the Lives of People with Disabilities* (Baltimore: Paul Brookes Press, 1997).
 22. Waxman, “Fact Sheet.”
 23. Waxman, “Fact Sheet.”
 24. Harlan Hahn, “Disputing the Doctrine of Benign Neglect: A Challenge to the Disparate Treatment of Americans with Disabilities,” in *Americans with Disabilities: Exploring the Implications of the Law for Individuals and Institutions*, eds. Leslie Pickering and Anita Silver (New York: Routledge, 2000), 45.
 25. Carolyn Thompson, “Special Report, Disabled Students Settle Lawsuit against San Francisco State University,” KGO-TV (ABC affiliate). Eleven O’Clock News, November 5, 1999.
 26. *Alexander v. Choate*, 469 U.S. 287 (1985) at 296.

INDEX

- Ableism: in academia, 44, 87; awareness of, 148–50; and benign neglect, 155–56; definition of, 35; and hate crimes, 155–56; language of, 87; in legal cases, 137–38, 155–56; nationalism and, 107; racism and, 137–39, 146–48
- Abnormal. *See* Normal
- Abortion, prenatal screening and, 22, 42–43
- Academy Awards, 117
- Accommodations: cost of, 3, 131–36; reasonable, 125–26, 127, 130, 133; tax credits for, 132; trivial, 130–31; in Vande Zande case, 129–36
- Action, in dismodernism, 31
- ADA. *See* Americans with Disabilities Act
- ADAPT, 143
- ADD. *See* Attention deficit disorder
- Adler, C., 68, 71
- African American(s): cellular identity of, 15–16; and disability identity, 36–37; prevalence of disabilities among, 28–29; women, 149. *See also* Race; Racial discrimination
- Agnos, Peter, 67, 68, 71
- Ally McBeal* (TV show), 127–28
- Amelia* (Fielding), 61–66
- American Sign Language (ASL), 37, 45
- American Society for Reproductive Medicine, 22

- Americans with Disabilities Act (ADA) of 1990: accommodations required by (*See* Accommodations); backlash against, 24, 139, 143, 148; compliance with, 134; cost of, 131–36; definition of disability in, 2–3, 23–24, 86, 125–26; drafting of, 141, 142; enforcement of, 134; impairment in, 139–42; legal foundations for, 42; litigation under, 1, 2–3, 24 (*See also* Legal cases); on madness, 173n. 34; number of people protected under, 24; Supreme Court on, 1, 2–3
- Ancient world, disability in, 40
- Anderson, Benedict, 17, 105–6
- Andrews, Jonathan, 57
- Anorexia, 23
- Appiah, K. Anthony, 29
- Architectural Barriers Act of 1968, 42
- Aristotle, 170n. 9
- Armstrong, Nancy, 80
- Asch, Adrienne, 42
- ASL. *See* American Sign Language
- Aspects of the Novel* (Forster), 95
- Asperger's Syndrome, 23
- Assisted suicide, 43
- Attention deficit disorder (ADD), 23
- Autobiography of an Ex-Colored Man, The* (Johnson), 9
- Bacon, Francis, 52–53
- Barriers: emotional, 135–36; removal of (*See* Accommodations)
- Bartholomew Fair, 53
- Baudrillard, 81
- Bauman, Zygmund, 27
- Baynton, Douglas, 40, 114
- Behavior, genetics and, 21
- Bell curve, 39, 105, 109, 110–11, 115
- Bender, John, 80
- “Bending over backwards”: in legal cases, 126–27, 133; meaning of, 126–27, 185n. 32
- Benign neglect, doctrine of, 155–56
- Bérubé, Michael, 35, 36
- Beyond Affliction* (radio series), 148
- Beyond the Culture Wars* (Graff), viii
- Bhabha, Homi, xi
- Bienvenue, MJ, 37
- Biotechnology, 25
- Birth defects: before mid-eighteenth century, 52–55, 171n. 12, 171n. 22–172n. 22; as genetic defects, 57; prenatal screening for, 20–22, 42–43
- Black Americans. *See* African American(s)
- Black Skin, White Masks* (Fanon), 9
- Black Stork, The* (Pernick), 39, 114
- Bleak House* (Dickens), 66, 179n. 29
- Blood pressure, high, 126, 184n. 29
- Body(ies): average, 93; care for, 27–28, 29; care of, 27, 29; caring about, 28–29; deviant, 181n. 8; in dismodernism, 27–32; essentialist view of, 13, 18; ideal, 39, 105; identity and, 13, 18, 22–23; of literary characters, 44–45; nationalism and, 106–7; new ethics of, 22–23, 27; normal, rise of concept of, 39, 40, 106; in representative democracy, 107–11, 115–16; vs. rights, equality of, 26; standardization of, 40, 51, 106, 111; technological additions to, 27
- Body and Physical Difference: Discourses of Disability in the Humanities, The* (Mitchell and Snyder), 43–44
- Bolt, Robert, ix
- Boswell, James, 48, 56–57, 58, 59
- Brewer, Lawrence Russell, 145
- British model of disability, 12
- Broussais, François-Joseph-Victor, 112, 113
- Brown, John, 112
- Brown, Wendy, 19, 29, 82, 84, 85, 88, 89, 98, 100
- Browning, Todd, 33
- Brueggemann, Brenda Jo, x
- Burney, Frances, 66
- Bush, George, 2
- Butler, Judith, xi, 11, 81, 83–84, 88
- Byrd, James, Jr., 138, 145–46
- California, hate crime law in, 152, 153
- California Faculty Association, 155
- Callender, James Thomson, 172n. 33–173n. 33
- Camilla* (Burney), 66
- Canguilhem, Georges, 104, 105, 110, 112, 113
- Capitalism: and democracy, 110; equality in, 110; and origin of novel, 81–82, 93
- Captain Singleton* (Defoe), 175n. 2
- Carpal tunnel syndrome, 2–3
- Cases. *See* Legal cases
- Cassista v. Community Foods*, 187n. 89
- Castiglione, Baldesar, 52–53
- Celera, 15
- Cellular level, identity at, 15–16
- Censuses, national, multiracial identifications in, 16

- Center for Women's Policy Studies, 147, 154, 155
- Characters, literary, 94–97; audience identification with, 122; average citizens as, 93–94; bodies of, 44–45; change enacted by, 98–99; with disabilities, 44–45, 61–66, 95; eugenics and, 94–95, 97; moral element of disability in, 45, 57–58, 66; as national/cultural norm, 94–97; plot and, 95–98; virtue of, 66, 94, 97
- Charlton, James, 41, 42
- Chevron, 2
- Children of Deaf Adults (CODA), 162
- Children with disabilities, number of, 148
- China, prenatal screening for sex in, 22
- Cholera, 21
- Chomsky, Noam, 158
- Chronicle of Higher Education*, 34
- Churchill, Winston, 71
- Citizen(s), average: bodies of, 93, 111; emergence of, xi, 93, 108–9; ideology of, 93
- Citizen(s), patient, 116
- Civil rights model: problems with, 117–18; rise of focus on, 11–12
- Civil rights movement, trivial accommodations in, 131
- Claiming Disability: Knowledge and Identity* (Linton), 34
- Clarissa* (Richardson), 96
- Class, social: deafness and, 159; disability as, 86; fantasy norm of, 96, 99; in identity, 28; in novels, 96, 99; passing, 103
- Clinton, Bill, 116
- Close, Chuck, 44
- Cochlear implants, 25, 37
- CODA. *See* Children of Deaf Adults
- Colleges, disability studies at, 36–37, 87
- Colorado Department of Health, 154
- Commonality, difference as, 26–27
- Common sense: notions of disability, problems with, 139; and reasonable accommodations, 133
- Communism, 182n. 13
- Comte, Auguste, 113
- Consumption, care of body through, 27
- Cook v. State of Rhode Island, Dept. of Mental Health, Retardation, and Hospitals*, 142–43
- Correctable disability, Supreme Court on, 126, 184n. 29–185n. 29
- Cosmopolitanism, of dismodernism, 27, 31
- Courtier, The* (Castiglione), 52
- Couser, G. Thomas, x
- Covent Garden Journal*, 63
- Craddock, Charlotte, 63
- Crenshaw, Kimberly, 148–49
- Crime. *See* Hate crimes
- Criminality, in literature, 71, 77–78
- Crips, 38
- Cultural Institutions of the Novel* (Lynch and Warner), 79, 80
- Cure: and disability identity, 25; instability of, 99; in medical model of disability, 41; in novels, 98–100
- Cystic fibrosis, 20, 21
- Damage, pain and, in legal cases, 127
- Daniel Deronda* (Eliot), 96
- Darwin, Charles, 95
- David Copperfield* (Dickens), 96
- Deaf: cochlear implants for, 25, 37; culturally vs. physically, 168n. 5; as disabled, 37; education for, 37–38; history of treatment of, 40; as linguistic minority, 37, 41–42
- “Deaf and Dumb in Ancient Greece” (Edwards), 40
- Deaf Life*, 37
- Deafness: history of, 40, 55; in late-eighteenth century, 55; in literature, 45–46; and social class, 159
- Deaf President Now movement, 42
- Declaration of Independence, 108
- Defectiveness, genetic, 19–22. *See also* Birth defects
- Defoe, Daniel, 47, 70, 175n. 2
- de Fontenay, M., 51
- Deformities of Dr. Samuel Johnson* (Callender), 172n. 33–173n. 33
- Deformity, 52–56; dramatic, 53–54; history of word, 52; writings on, 52–56, 58
- Deformity: An Essay* (Hay), 55–56
- De Graffenreid v. General Motors*, 149
- de la Torres v. Bolger*, 140
- Deleuze, Gilles, 31
- Democracy. *See* Representative democracy
- Dependent care industry, economics of, 28
- Derrida, Jacques, 45, 81, 83, 106
- DeSario v. Thomas*, 125
- Descartes, René, 20, 92
- Desloges, Pierre, 172n. 30
- Developing countries, 29, 50, 87
- Deviant bodies, 181n. 8
- Diagnosis, medical, 114–16
- Dickens, Charles, 66

- Dictionary(ies): “bending over backwards” in, 126–27, 185n. 32; “deformity” in, 52; first English, 104, 181n. 2; inadequacy of, 141–42; in legal cases, 140–42; “normalcy” in, 104; prejudice of, 141; “stigma” in, 187n. 87
- Dictionary of English Colloquial Idioms*, 126–27
- Difference, as commonality, 26–27
- Disability(ies): current prevalence of, 4, 36, 50, 87, 148; definition of, 50; historical prevalence of, 50; instability of concept, 1, 23–26, 86; models of, 10–13; projected prevalence of, 4, 24–25
- Disability and Society* (journal), 43
- “Disability Chic,” 35
- Disability studies, 33–46; aim of, 139; first and second waves of, 11; historical, 39–40; humanities vs. social sciences in, 43–44; language and, 38–39; political activism and, 42–43; publications in, 33–35; rise of, viii, x, 11; at universities, 36–37, 87. *See also* Literature
- Disability Studies Quarterly* (periodical), 34–35, 43
- Disability Studies Reader, The* (Davis), 37, 40
- Disabled Access Tax Credit, 132
- Discovery of the Asylum, The* (Rothman), 113–14
- Discrimination. *See* Ableism; Racial discrimination
- Diseases: diagnosis of, 114–16; disability as, in medical model, 41; as excess, 112–14; pandemic, genetic resistance to, 21; political revolution as, 113–14; projected patterns of, 4, 24–25
- Dismodernism: body in, 27–32; identity in, 14, 26–32
- DNA: good vs. junk, 166n. 5; and race, 14
- Doctors: diagnostic power of, 114–15; representation and, 115–16
- Dole, Bob, 2, 178n. 13
- Domestic violence, 147, 154
- Dostoevski, Fyodor, 98
- Drinking, in *The Queer Dutchman*, 76–77
- Drinking fountains, 131, 151
- Drury-Lane Journal*, 62
- Dunlop, John, 91, 93
- Dutch East India Company, 75
- Economy: accommodations and, 132, 136; care for body and, 27–28; diagnosis of, 114
- Education: for Deaf, 37–38; disability studies in, 36–37, 87; in legal cases, need for, 139–43; mainstreaming in, 37–38; suggestions for, 143
- Edwards, Martha, 40
- Elderly population, projected growth of, 4, 24–25
- Emotional barriers, 135–36
- Empedoclean paradigm, 53
- Enforcing Normalcy* (Davis), vii, x, xi, 38, 102, 103, 105
- England, as origin of novel, 81–82
- English Patient, The* (film), 117
- Enlightenment thought, 26, 27, 107, 110
- Epstein, Julia, 49, 170n. 6
- Equality: average citizens and, 110; in capitalism, 110; in democracy, 107–8, 110, 111; ethical vs. scientific notions of, 111; in feudalism, 107; normalcy and, 117–18; of rights vs. bodies, 26
- ER* (TV show), 148
- Essentialism: on body and identity, 13, 18, 19; criticism of, 13, 83; strategic, 19
- Ethnic identity, 17
- Eugenics: and birth defects, 20; and literary characters, 94–95, 97; Nazi, 20, 39, 157; and normality, 39; and racial identity, 14
- Euthanasia, 43
- Evelina* (Burney), 96
- Facial disfigurement, in literature, 61–66
- Factories, standardization of body for, 40, 51, 111
- Factual Fictions* (Davis), x
- Fanon, Frantz, 9
- Federal Bureau of Investigations (FBI), 153, 154
- Feminist movement, second-wave conflicts in, 11
- Feudalism, 92–93, 107
- Fielding, Henry, 61–66
- Films, viii–ix, 22, 33–34, 117
- Firesign Theater, 84
- Foote, Samuel, 63
- Forbidden Signs* (Baynton), 114
- Forster, E. M., 95, 158, 179n. 31
- Foucault, Michel: on control of bodies, 107, 115, 116, 181n. 8; and literary criticism, 81, 82–83; on power, 30–31, 82
- Fowler’s Modern English Usage* (Burchfield), 102, 103

- France: language norms in, 104; novels of, 179n. 25; right not to be born in, 22
- Frankfurt School, 82
- Freakery: Cultural Spectacles of the Extraordinary Body* (Thomson), 34
- Freaks* (film), 33–34
- Freak show, disability as, vii, viii
- French language, 104
- Freud, Sigmund, 117, 121–24
- Fries, Kenny, 34
- Gallagher, Catherine, 80
- Gallaudet University, 42
- Galton, Francis, 95, 110–11
- Gartler, Stanley, 15–16
- Gattaca* (film), 22
- Gates, Henry Louis, xi, 88
- Gender: as disability, 170n. 9; as genetic defect, 22; genetics of, 17; hate crimes based on, 152–53, 154, 155; race and, intersectionality of, 149
- Gender identity, 16–17
- Genealogy of Morals, The* (Nietzsche), 79, 127
- General Motors, 149
- Genetic(s): behavior and, 21; of gender, 17; of homosexuality, 17; and identity, 14–16, 17–18; of race, 14–16
- Genetic defects: and abortion, 22; birth defects as, 57; elimination of, 19–22; sex as, 22
- Genetic engineering: cures through, 25; and genetic defects, 20–21
- Genetic testing. *See* Prenatal screening
- Genome, human: defects in, 19–22; and identity, 14–15, 17–18; mapping of, 14–15, 17–18; number of genes in, 14–15
- Gilroy, Paul, 29, 32
- Girard, René, 98
- Glucose-6-phosphate dehydrogenase (G6PD), 15–16
- Goffman, Erving, 136
- Graff, Gerald, viii
- Grammar: prescriptive vs. descriptive, 104; standardization of, 103–5
- Gramsci, Antonio, 160
- Greece, ancient, disability in, 40
- Greek language, 103, 104
- Greenhouse, Ronald, 160
- Groce, Nora, 51
- G6PD (glucose-6-phosphate dehydrogenase), 15–16
- Guilt, in *The Queer Dutchman*, 72–75, 77–78
- Habermas, Jurgen, 110
- Hacking, Ian, 18, 23
- Hahn, Harlan, 41, 155–56
- Harding, Warren, 103
- Hard Times* (Dickens), 99
- Hardt, Michael, 31
- Harm, protection from, 2
- Hastings Center Report*, 34
- Hate crimes, 145–57; definition of, 156; disability-based, 147, 152–57; gender-based, 152–53, 154, 155; intersectionality and, 152; legislation on, 152–53; race-based, 145–47; sexual orientation-based, 152, 153; tracking of, 153–54
- Hate Crimes Prevention Act (HCPA), 153
- Hatred, of disabled people, 156
- Hawkins, Joan, 33–34
- Hay, William, 55–56
- HCPA. *See* Hate Crimes Prevention Act
- Health: diagnosis of, 114; harm to, decisions about, 2; as norm, 112–14, 116
- Healthcare industry, economics of, 28, 116
- Hebdige, Dick, xi
- HeLa cells, 15–16
- Hepatitis C, 2
- Hermaphrodites. *See* Intersexuals
- Hilaire, Saint, 55
- History of disability, 47–66; ancient, 40; before mid-eighteenth century, 50–55; in mid-eighteenth century, 55, 61–66; in nineteenth century, 40, 59–61; debate over, 39; Johnson and, 47–49, 56–57, 58–61
- History of Sir George Ellison, The* (Scott), 66
- HIV, 140
- Hogarth, William, 48
- Holistic medicine, 182n. 23–183n. 23
- Holt, Thomas, 29
- Homosexuality: genetics of, 17; hate crimes based on, 152, 153; in legal cases, 139–40; in literature, 67–78
- hooks, bell, 88
- House of Representatives, 109–10
- Hubbard, Ruth, 42
- Huet, Marie-Hélène, 53, 57
- Human Genome Project, 14–15, 17–18, 19
- Humanistic model in postmodernism, 30
- Humanities, in disability studies, 43–44
- Hume, David, 20
- Humphries, Tom, 37
- Hunter College, 37

- Huxley, Aldous, 160
 Hysteria, 23
- Ideal, vs. normal, 39, 92–93, 105
- Identity, 9–32; biases in studies of, 88; birth defects and, 20–22; body and, 13, 18, 22–23; at cellular level, 15–16; cure of disabilities and, 25; in dismodernism, 14, 26–32; essentialism and, 13, 18, 19; establishment of, stages in, 10–11; ethnic, 17; exclusivity of, 26; foundation of, disability as, 100–101; gender, 16–17; genetics and, 14–16, 17–18, 19–22; instability of, 5, 9–10, 23–26; intersectionality and, 154–55; memorialization of, 19; models for, 10–13; multiracial, 16; and novel studies, 83, 85–86, 88–90, 98–100; obsolescence of, 5; pain as root of, 100; paradoxical inclusiveness of, 88–89; political movements and, 84; postmodernism and, 12–13, 83–84; power and, 90; racial, 14–16, 36–37; as sense, 83; sexual, 17; wounded, 30, 98–100
- Idiocy, 57
- Immigration, 148
- Impairment(s): definition of, 12, 23, 41, 50, 140, 141; vs. disability, 12, 23, 41, 50, 141; in legal cases, 140–42; as rule, 31; in social model, 12, 23, 41
- Imprisonment, 28–29
- India, prenatal screening for sex in, 22
- Individual(s): litigants as, Supreme Court on, 121; norm and, 109; representation of, 108–9, 115–16
- Individualism, and realism, 92
- Industrialization: and origin of novel, 81–82; and standardization of body, 40, 51
- Innocence, in *The Queer Dutchman*, 72–75, 77–78
- Intersectionality: and hate crimes, 152, 154–55; in legal cases, 148–49
- Intersexuals, 16, 17
- Inventing the Feeble Mind* (Trent), 113
- In vitro fertilization, and racial identity, 16
- Irigaray, Luce, 81
- Jackson, Jesse, 84
- James I, King, 51–52
- Jane Eyre* (Brontë), 96
- Jefferson, Thomas, 107
- Jelstra, Michael, 68
- Jerry Lewis Telethon, 42
- Jewish Federation of Philanthropies, 160
- Johnson, James Weldon, 9
- Johnson, Samuel: on Amelia, 63–64; descriptions of, 48, 49, 56–57, 58–61, 66; dictionary by, 181n. 2; disabilities of, 47–49, 169n. 2–170n. 2
- Journal Britannique*, 62
- Judaism, 128
- Jude the Obscure* (Hardy), 96
- Just Vengeance, A*, 70, 71
- Kant, Immanuel, 20
- Kenrick, William, 63
- Kierkegaard, Soren, 26, 27
- King, John William, 145
- Kirk, Rahsaan Roland, viii
- Klinefelter syndrome, 17
- Laboratories, disease diagnosis by, 114
- Lacan, Jacques, 45, 81, 83
- Lacks, Henrietta, 15
- Ladd, Paddy, 37
- Land mines, 29
- Lane, Harlan, 37, 41–42
- Language: ableist, 87; correct vs. incorrect usage of, 103–6; for descriptions of disabled people, 38; genetics of, 21; grammatical norms in, 103–5; of legal cases, 120–21, 126–27, 140–42; of literature, 45–46; of medicine, 111–17; nationalism and, 105–6; normalcy and, 105–6; sign, 37, 45; standardization of, 103–6
- Latin language, 103, 104
- Law(s). *See* Legislation
- Lawrence of Arabia* (film), viii–ix
- Law schools, courses on disability in, 143
- Lean, David, viii–ix
- Left criticism, vii, viii
- Left Politics and the Literary Profession* (Davis and Mirabella), 162
- Legal cases, 119–44; ableism in, 137–38, 155–56; education needed in, 139–43; ideology of, 120–21; intersectionality in, 148–49; language of, 120–21, 126–27, 140–42; literary analysis of, 120–21; narcissism in, 124–28, 150–51; objectivity in, 120, 137; outcome of, 2, 24, 148; parity in, 127; perception of disabilities in, 123–24; psychological analysis of, 121–24; states of mind in, 121, 124–25, 151. *See also specific cases*
- Legislation: on hate crimes, 152–53; political activism and, 42. *See also specific laws*
- Leriche, René, 112, 117
- Levy, Sidney N., 160

- Life as We Know It: A Father, a Family, an Exceptional Child* (Bérubé), 35
- Life of Johnson* (Boswell), 56–57
- Linguistic minority, Deaf as, 37, 41–42
- Linton, Simi, 34, 35
- Lipsitz, George, viii
- Literacy, disability, 142
- Literature: mid-eighteenth century, 61–66; disabled characters in, 44–45, 61–66, 95; homosexuality in, 67–78; language of, 45–46; moral element of disability in, 45, 57–58, 66. *See also* Novel(s)
- Litigation. *See* Legal cases
- Locke, John, 20, 92
- London Magazine*, 62
- Longmore, Paul, 142
- Lynch, Deirdre, 79, 80
- Lynch, Samuel, 112
- Macaulay, 59–61
- Madness, as disability, 173n. 34
- Mad Travelers: Reflections on the Reality of Transient Mental Illnesses* (Hacking), 23
- Mainstreaming, 37–38
- Malaria, 21
- Marshall, Thurgood, 156
- Marx, Karl, 11
- Mary Stuart, Queen of Scots, 171n. 12
- Masefield, Paddy, 36
- Maty, Matthew, 62
- Maurice* (Forster), 179n. 31
- McKeon, Michael, 80
- Media, 117, 139, 145–46, 148
- Medical model of disability: cure in, 41; vs. social model, 40–41
- Medicine: before mid-eighteenth century, 112; costs of, 116; diagnosis in, 114–16; government institutions and, 116–17; holistic, 182n. 23–183n. 23; normalcy in, 111–17; treatment in, 116
- Mental retardation, history of treatment of, 40
- Merchant of Venice, The* (Shakespeare), 128
- Merleau-Ponty, Maurice, 9
- Merriam-Webster's Collegiate Dictionary*, 141
- Michaels, Walter Benn, 18, 29
- Millennium Hall* (Scott), 66
- Milton, John, 49
- Mines, land, 29
- Minority: disabled people as, 41–42, 86–87; linguistic, Deaf as, 37, 41–42
- Mirabella, M. Bella, 162
- Mitchell, David, x, 38, 44, 180n. 33
- Moby Dick* (Melville), 179n. 29
- Moderation, disease and, 112–14
- Modern Language of America, 87
- Moll Flanders* (Defoe), 47
- Monocular vision, 185n. 29
- Montaigne, Michel de, 52–53, 54
- Moral traits, of literary characters, 45, 57–58, 66
- Movements, social, stages of, 10–11
- Multiculturalism: disability in, 13, 36–37, 87; postmodernism and, 12–13
- Multiracial identifications, in censuses, 16
- Myopia, correctable, 184n. 29
- Narcissism, 124–28, 150–51
- Nation, The* (newspaper), 138, 146
- Nationalism: and linguistic standardization, 105–6; and normalcy, 105–7
- National Organization for Women (NOW), 152
- Nazi eugenics, 20, 39, 157
- Neglect, benign, doctrine of, 155–56
- Negri, Paoli, 31
- New Criterion, The*, viii
- New York Press*, 35
- New York Times* (newspaper), 28, 34, 138, 146–47, 172n. 22
- New York Times Book Review*, 163
- Niederland, William G., 124
- Nietzsche, Friedrich, 79, 100, 127
- Normal: vs. ideal, 39, 92–93, 105; origin of word, 38–39, 93, 105
- Normalcy, 102–18; definition of, 107; equality and, 117–18; as fantasy, 31; industrialization and, 40; and linguistic standardization, 105–6; in medicine, 111–17; nationalism and, 105–7; vs. normality, 102–4, 106–7; origin of word, 104, 105; representative democracy and, 107–10; rise of concept of, 105–6; suffix of, 106, 181n. 9–182n. 9
- Normality: definition of, 107; vs. normalcy, 102–4, 106–7; origin of concept, 39; suffix of, 106, 181n. 9–182n. 9
- Normate, 38
- Normocracy, 110
- North and South* (Gaskell), 99
- Norton Anthology of Theory and Criticism*, xi
- Noselessness, 61–66
- Novel(s), 79–101; critiques of, 80–81, 82–83, 88–90; cure as closure in, 98–100; definitions of, 91; disability-centered reading of, 90–100; identity and, 83, 85–86, 88–90,

- Novel(s) (*continued*)
 98–100; origins of, 81–82, 90–100; plot of, 95–98; realism in, 91–97, 98; “the” in, 79–80, 100–101; virtue in, 66, 94, 97; wounded identity in, 98–100. *See also* Characters
- Novelism, 79–80
- NOW. *See* National Organization for Women
- NPR radio, 148
- Nussbaum, Martha, 121
- Oliver, Michael, 40
- Oliver Twist* (Dickens), 96
- Olmstead v. L.C. ex rel. Zimring*, 143
- On Narcissism* (Freud), 124
- On the Normal and the Pathological* (Canguilhem), 112
- Orwell, George, 160
- Oxford English Dictionary*, 52, 104, 185n. 32
- Pain: damage and, in legal cases, 127; identity and, 100
- Pamela* (Richardson), 96
- Pandemic diseases, genetic resistance to, 21
- Parity, in law, 127
- Parker, James, 70
- Pathology, 112
- Patient-citizens, 116
- People with disabilities (PWDs), preservation of identity for, 11
- Performativity, and essentialism, 13
- Pernick, Martin, 39, 114
- Pfeiffer, David, 38, 142
- Philoctetes, 98
- Physicians: diagnostic power of, 114–15; representation and, 115–16
- Pico della Mirandola, Giovanni, 20
- Piracy, and homosexuality, 71
- Pity, 117
- Plot, literary, 95–98
- Poetry, 45
- Politic(s): and disability studies, 42–43; of identity, 84–85; and legislation, 42; and literary criticism, 82–83; and medicine, 113–17; and origins of novel, 92–93
- Political revolution, as disease, 113–14
- Pope, Alexander, 44, 48
- Posner, Richard, 140, 185n. 43
- Possessed, The* (Dostoevski), 98
- Postcolonial consciousness, 80
- Postmodernism: dismodernism as replacement for, 14; humanistic model in, 30; and identity, 12–13, 83–84; and multiculturalism, 12–13; subject in, 14, 26, 30–31
- Poulakis, Peter, 160
- Poverty: and caring about body, 28–29; among disabled people, 148
- Power: Foucault on, 30–31, 82; and identity, 90; and novels, 90; in postmodernism, 30–31
- Power, Politics and Culture: Interview with Edward W. Said*, 30–31
- Poz* (magazine), 35, 167n. 22
- Prenatal screening: and abortion, 22, 42–43; for birth defects, 20–22, 42–43; and right not to be born, 22; for sex, 22
- Pride and Prejudice* (Austen), 98
- Princeton University, 150
- Prisons, 28–29
- Progress of Romance, The* (Reeve), 81, 94
- Psychology, in legal cases, 121–24
- PWDs. *See* People with disabilities
- Queer Dutchman, The* (Agnos), 67–78; criminality in, 71, 77–78; drinking in, 76–77; guilt and innocence in, 72–75, 77–78; provenance of, 70–72
- Queer studies, 17
- Quetelet, Adolphe, x, 93, 108–9
- Quincunx*, 110
- Race: at cellular level, 15–16; and disability identity, 36–37; genetics of, 1416; mixed, in censuses, 16
- Racial discrimination: ableism and, 137–29, 146–48; awareness of, 147–48; and hate crimes, 145–47; intersectionality and, 148–49; in reproductive technologies, 166n. 11–167n. 11; trivial levels of, 131
- Racial identity, 14–16, 36–37
- Radio, NPR, 148
- Rainbow Coalition, 84
- Rape, 154
- Realism: formal, 92; individualism and, 92; in novels, 91–97, 98; realness of, 91, 98
- Reeve, Christopher, 4, 93, 178n. 13
- Reeve, Clara, 81, 91, 94, 101
- Rehabilitation model of disability, 40–41
- Representation: of disability identity, 86; of individuals, 108–9, 115–16; in medicine, 115–16; norm and, 109
- Representative democracy: average citizens in, 108–9, 110, 111; equality in, 107–8, 110, 111; medicine in, 115–17; and normalcy, 107–10; paradox of, 108–9
- Repression theory, 82–83

- Reproductive technologies: and birth defects, 20–22; racial discrimination in, 166n. 11–167n. 11; and racial identity, 16
- Revolution, as disease, 113–14
- Reynolds, Joshua, 58
- Richard III* (Shakespeare), 52, 53, 121–24, 128
- Richardson, Samuel, 48, 63
- Right(s): to die, 43; disability created by, 118; in identity politics, 84–85; not to be born, 22; of states, 3; to wheelchair, 42. *See also* Civil rights movement, trivial accommodations in; Equality
- Rizzio, David, 171n. 12
- Roberts, Dorothy, 166n. 11–167n. 11
- Robinson Crusoe* (Defoe), 95–96
- Roosevelt, Franklin, 42
- Rothman, David, 113–14
- Rousseau, Jean-Jacques, 107
- Runnebaum v. Nationsbank*, 139–42
- Said, Edward, 30–31, 81
- Sailors, homosexuality among, 71
- San Francisco State University, 155
- Scott, Sarah, 66
- SDS. *See* Society for Disability Studies
- Sedgwick, Eve, 88
- Sense(s): in dismodernism, 31; identity as, 83
- Sense of Silence, The* (Davis), 162
- Sex: prenatal screening for, 22. *See also* Gender
- Sexual abuse, 147, 154, 155
- Sexual orientation: hate crimes based on, 152, 153; and identity, 17; in legal cases, 139–40; in literature, 67–78; vs. sexual preference, 17
- Shakespeare, William, 49, 52, 53, 121–24, 128
- Shapiro, Joseph, 42
- Shine* (film), 117
- Sickle cell anemia, 20, 21
- Sideshow, disability as, vii, viii
- Siebers, Tobin, x, 124, 150
- Sign language, 37, 45
- Silvers, Anita, 149
- Singer, Peter, 188n. 14
- Single gene hypothesis, 20–21
- Siskin, Clifford, 79–80
- Slekis v. Thomas*, 125
- Slingblade* (film), 117
- Smart, Christopher, 56
- Smith, Adam, 107
- Snyder, Sharon, x, 38, 44, 180n. 33
- Sobsey, Dick, 147, 153–54
- Social class. *See* Class, social
- Social constructionism, essentialism and, 13, 18
- Social Construction of What?, The* (Hacking), 18
- Social contract, 107–8
- Socialism, 182n. 13
- Social model of disability: impairment in, 12, 23, 41; vs. medical model, 40–41
- Social movements, stages of, 10–11
- Social sciences, in disability studies, 43–44
- Society for Disability Studies (SDS), 34–35, 43, 44
- Sontag, Susan, 113
- Speech, single gene for, 21
- Staring Back: The Disability Experience from the Inside Out* (Fries), 34
- States' rights, 3
- Statistics, and concept of norm, 39, 105, 109
- Stein, Gertrude, 83
- Steinberg, Steven, 17
- Stem cell research, 25
- Stigma* (Goffman), 136
- Stigma, definitions of, 187n. 87
- Stigmatization, 135–36
- Suicide, assisted, 43
- Supreme Court: on ADA, 1, 2–3; on definition of disability, 3, 126; on litigants as individuals, 121; on special needs, 125
- Svilt, Jan, 67–78
- Swift, Jonathan, 54
- TAB (Temporarily Able-Bodied), 36
- Taste* (Foote), 63
- Tax credits, for accommodations, 132
- Television shows, 127–28, 148
- Temporarily Able-Bodied (TAB), 36
- Teratology, 55
- Teratology, 55
- Third World countries, 29, 50, 87
- Thomas, Kenneth R., 124
- Thomson, Rosemarie Garland, x, 38, 118
- Thornton, Bonnel, 62
- Thrall, Hester, 56, 58, 169n. 1
- Time Passages* (Lipsitz), viii
- Todd, Dennis, 54
- Todd, Janet, 80
- Toft, Mary, 54
- Tom Jones (Fielding), 96
- Tourette syndrome, 48, 170n. 4, 174n. 44
- Toyota v. Williams*, 2–3
- Transgender identity, 16–17
- Transsexuals, 16–17
- Treatment, medical, 116
- Trent, James, 40, 113

- Turley, Hans, 71
 Turner Syndrome, 17
 Tuttleton, James, viii
- Unemployment, 28
 Unicorns, social construction of, 18
 Universalism, of dismodernism, 27, 32
 Universality: of disability, 36; of wounded identity, 30
 Universities, disability studies at, 36–37, 87
 University of Michigan Press, 35
- Vande Zande, Lori, 128–37, 151
Vande Zande v. State of Wisconsin Dept. of Admin., 126, 128–37, 151
 Vee, Bobby, 79
 Veterans, 11, 42
 Violence. *See* Hate crimes
 Violent Crime Control and Law Enforcement Act of 1994, 152
 Virtue: disability as, 66; in literature, 66, 94, 97
 Vision disabilities, correctable, 126, 184n. 29–185n. 29
Vital Signs: Crip Culture Talks Back (documentary), 38
 Voltaire, 107
 Voting, 109–10
Vraisemblance, 179n. 25
- Ward, Ned, 64
 Warner, William, 79, 80
 Warren, Kenneth, 29
- Water fountains, 131, 151
 Watt, Ian, 80, 92, 94
We (magazine), 35, 167n. 22
 Wealth, distribution of, in capitalism, 110–11
 Webster's dictionaries, 140, 141, 187n. 87
 Weldon, Anthony, 51
 Wendell, Susan, 39
 Wheelchair users: impairment vs. disability in, 12; language used to describe, 38, 186n. 48; rights of, 42; as universal sign for disability, 178n. 12
 WHO. *See* World Health Organization
 Williams, Ella, 3
 Wills, David, 180n. 33
 Wilson, Michael, ix
 Wisconsin, hate crime law in, 153
Wisconsin v. Mitchell, 153
 Women: and birth defects, 52, 53, 55, 57, 171n. 12, 171n. 22–172n. 22; as disabled men, 170n. 9; hate crimes against, 152–53, 154, 155
 Women's rights movement, second-wave conflicts in, 11
 Wordsworth, William, 40
 World Health Organization (WHO), 4, 24
 Wounded identity: cure for, 100; in novels, 98–100; universality of, 30
- Young adults with disabilities, number of, 148
- Zola, Irving Kenneth, 41, 97, 142
 Zuckerman, Mr., 160–61

ABOUT THE AUTHOR

LENNARD J. DAVIS is a Professor in the English Department at the University of Illinois at Chicago where he is also Professor of Disability Studies and Human Development, and Professor of Medical Education. His books include *Enforcing Normalcy: Disability, Deafness, and the Body* and *My Sense of Silence: Memoirs of a Childhood with Deafness*.

