

Lynn Z. Bloom

Able, Disabled, Enabled: Mainstreaming the Disability Course

Why I Taught a Disability Course

I WAS IMPELLED, IN A WORD, BY PAIN. THREE ROTATOR CUFF SURGERIES in two years oblige me to live for six weeks each time in another country I have previously only glimpsed briefly while speeding past. *Pain* so searing that I can't move, accompanied by nausea and vertigo from an allergic reaction to the prescribed opiate. Pain leaking from beneath the edges of the Aleve, the only painkiller I can tolerate. Pain in staccato bursts from the tough but necessary physical therapy exercises. *Discomfort* throughout the forty-one long nights of trying to sleep upright in a recliner chair because the bulky sling-and-pillow apparatus necessary to hold the shoulder in place prevents lying down. *Disorientation* from having to do things with one hand that ordinarily require two—buttoning buttons, washing my hair, writing on the computer—and writing with the wrong hand when the right is immobilized by a sling. *Fatigue*. Everything I can in fact do takes twice as long, showering, getting dressed, mincing across the icy campus sidewalks for fear of falling. Even thinking. *Dependency* on my husband—I can't drive, tie my shoes, cut up my meat, trust myself to hold a hot heavy frying pan. *Indifference* from the world at large. The only acceptable answer for people who ask, "Hi, how are you?" is "Fine," even when they see the sling. But fellow sojourners in the land of joint repair show me slides of their journeys; on the scale of recuperative pain, rotator cuffs trump hips and knees. *Blame*. I am labeled "noncompliant" when I follow the physical therapist's exercise directions to the letter, tearing out all the stitches and the screws and thus requiring surgery #2. If this is all my fault, the doctor and therapist are exempt. *Guilt*. It could be worse; I don't complain. There will be no pity parties on my watch. *Humor*, preferably self-deprecating. "Ambulatory surgery," as I explain in "(Im)Patient," my essay on this experience, "strikes me as an oxymoron. Are patients—as an impatient person I think of us as scarcely patient at all—expected to walk around while the doctor operates on the run?" (187).

My experiences could be anyone's, I realized. There is ample corroboration—and more—not only in the locker room at the gym where I go every post-op day even if only to stagger a few laps around the track—but in nonfiction, my professional specialty. There are

numerous distinguished autobiographies by people with disabilities, caregiver narratives, physicians and science writers exploring issues of health and medicine for a general readership. Because these works are nonfiction, written by people with firsthand, real-life experience of the topics they address, they possess the authority and credibility necessary to compel conviction from readers accustomed to either hyperbolic or sentimental presentations of disability in fiction and the mass media. (This is not to deny the validity of fiction by such masters ranging from Dostoevsky, *The Gambler*, to David Lodge, *Deaf Sentence*—both writing from personal experience—but to justify the choice of the generous range of nonfiction genres.) A growing body of theoretical, literary, and pedagogical scholarship undergirds the burgeoning field of disability studies (discussed elsewhere in this issue). These materials, in combination with easy access to the news online—particularly the *New York Times*—make it possible to teach literature courses to a mainstream audience. Why not bring disability out of the closet and into the classroom, not only for students expecting to work in therapeutic professions but also for all students?

What I Taught

So I developed a course, “Able, Disabled, Enabled: Disability in American Literature and Culture,” which I hoped would transform, utterly, the students’ understanding of the world. They develop—to the extent that this is possible in fourteen fleeting weeks—an insider’s knowledge of an entire realm of information and fresh points of view that had hitherto been hidden in plain sight. As new, enthusiastic advocates for disability rights and recognition, the students, I think, feel as if they’ve joined a secret club, even though millions of people worldwide may actually share their understanding.

This nutshell overview of the course is proffered in hopes that this model may provide a useful template for innumerable variations—as many versions of a course as there are variations among people with a particular disability. For instance, Brenda Brueggemann’s “An Enabling Pedagogy” and various configurations discussed in Lewiecki-Wilson and Brueggemann’s *Disability and the Teaching of Writing* offer possibilities undergirded by the perspectives historical, political, cultural, theoretical, and experiential in Lennard Davis’s *The Disability Studies Reader*.

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The **course description reads:** “In a society that values high-level functioning from all its members, what does it mean to be able-bodied? disabled? Is disability a state of body, mind, (in)ability to perform, social attitude? Is *disability* itself even an appropriate term, in a world where surgery, genetic engineering, drugs, and other means can repair, alter, and create bodies—and minds—to order? Who makes decisions over people’s bodies, who holds the power, who is empowered—and to do what? There are no simple, easy, finite, even “right” answers to these controversial hot button questions, which we will examine from many perspectives, each and all subject to change” (Bloom, “Able” 1). So, through excellent works by and about disability by autobiographers, physicians, scientists, social commentators, essayists, artists, the course explored the changing and contested meanings of key concepts, such as able/ability, disabled/disability from multiple perspectives: physical, intellectual, emotional, psychological, ethical, social, political, economic, medical and more.

Course Topics. The following topics and core works address the course aims.

Definitions: What is “normal”? What is disability? What does it mean to be able bodied? To have “a sound mind in a sound body”? (Frederick Douglass, *Narrative*; all the other core works before the authors became ill or disabled)

Social and political perspectives: Stigma, shunning, and some consequences. The normative standard—and personhood. In what ways the person’s social, political, legal status affect these conceptions? (Again, Douglass, *Narrative*; and all works.)

Historical: The default representation of disability in 20th-century America before 1985. (Helen Keller’s *The Story of My Life*.)

Representational: Representations of disability: in theory, sports, law, the media, and in—gasp—real life. (John Hockenberry, *Moving Violations* (paraplegia); Kay Jamison, *An Unquiet Mind* (bipolar disorder); Marisa Marchetto, *Cancer Vixen* (cancer and body images).

Ethical: Matters of quality of life, education, social life, professional opportunities and ethical issues. (All works. Ethics for professional practitioners: mental health: psychiatrist, Kay Jamison; physician, Atul Gawande, *Complications*.)

Medical and Public Health: Ethical Issues and medicine. Public health; Disability, disease and public policy. (Jamison, Gawande.)

Caregivers and family perspectives: Keller. When parents take (or try to take) control. (Short readings by Sea, Sanders, Hall, Martensen, McKibben.)

These are huge topics; they interweave, overlap, and embed a host of auxiliary issues, particularly when the assigned readings are augmented by updates from the *New York Times* du jour. It may be presumptuous for an English professor/course to take on these topics—after all, I’m not a real doctor, even though my first post-dissertation book was *Doctor Spock: Biography of a Conservative Radical*. (I wrote about America’s most widely consulted

mid-century pediatrician, author of the bestselling *Baby and Child Care*, to understand biographical method and the author's creative process (my dissertation topic), not pediatrics.) Yet disability studies extends so comprehensively beyond the borders of a single discipline that it would be both impossible and mistaken—even unethical—to try to restrict this (or, I would argue, any) literature course only to the texts at hand. Disability studies has too many real world implications to confine it to the classroom, and it is these that make the course so exciting for the students.

What the Students Read

To further these aims, the students read distinguished autobiographies and creative nonfiction that largely provide a social activist rather than a medical model, which, as Tobin Siebers says, “defines disability as an individual defect . . . that must be cured or eliminated if the person is to achieve full capacity as a human being.” Disability is instead “a cultural and minority identity . . . not a biological or natural property but an elastic social category both subject to social control and capable of effecting social change” (3-4). I chose works that represent common disabilities, all except the cartoon *Cancer Vixen* available in audio as well as print versions. Except for Frederick Douglass, the authors—white, well-educated, upper middle class professionals—are typical of the authors of disability autobiography, but not typical of people with disabilities. For, as Couser observes, autobiography “is not a universal human endeavor.” It is “confined to particular cultures . . . characterized by literacy, individuality, and the valorization of particular life scripts” (“Signs” 227)—in general, positive, triumphant accounts by successful people. The works that are published in paperback by mainstream presses are thus written by authors who demonstrate—in the mode established by Helen Keller—how to prevail over disability and lead fulfilling, mainstream lives. Nancy Mairs's 1986 essay, “On Being a Cripple,” about confronting MS head-on, determines the predominant stance and the appropriate, defiant language: “People—crippled or not—wince at the word ‘cripple,’ as they do not at ‘handicapped’ or ‘disabled.’ Perhaps I want them to wince. I want them to see me as a tough customer, one to whom the fates/gods/viruses have not been kind, but who can face the brutal truth of her existence squarely. As a cripple, I swagger” (9). Thus as core works I chose the following:

Frederick Douglass *Narrative of the Life of Frederick Douglass An American Slave* (1845 edition). Douglass's *Life* is an example of the profound effects—social, political, economic, ethical—of stigma on the lives of an entire class of people. His superlative physical and mental capabilities enabled him to become a 19th-century phenomenon, an African-American model of a paradigmatic American success story. There are significant analogies between the historically stigmatizing treatment of slaves and the treatment of people with

disabilities to warrant reading this American classic in a disabilities studies course.

Helen Keller, *The Restored Classic: The Story of My Life* (1903, 2003). This remains the 20th-century default disability autobiography, the single disability autobiography that students know, even though they are more likely to have encountered Keller through *The Miracle Worker* than her own work, and thus regard the author as a young child whose moment of triumph occurred when she learned to spell “w-a-t-e-r” after a tremendous struggle with her teacher, Anne Sullivan. In fact much of the autobiography itself focuses on Keller’s education—classical, sophisticated, and rigorous—during her college prep and work at Radcliffe. Her defense against accusations of plagiarism and dishonesty reflects a cultural suspicion of the learning and ethical capacities of the blind or deaf. Like Douglass’s *Life*, Keller’s *Story* is an exemplary model of the power of intelligence, perseverance, and hard work that can also be read through the lenses of class, gender, collaborative learning, and social leadership.

John Hockenberry, *Moving Violations: War Zones, Wheelchairs, and Declarations of Independence* (1996). A paraplegic since his auto accident at 19, Hockenberry is the very model of a modern major disability rights advocate, feisty and funny. He describes his career as an NPR reporter at Mt. St. Helen’s eruption, in Chicago, Washington DC, and in the Middle East; his finish-line race to be the first journalist in space; his love affairs; and his loathing of sentimentalizing and stereotyping of people with disabilities. “I’m a cripple for life,” he says, “I cannot walk. I have ‘lost the use of my legs.’ I am paralyzed from the waist down. I use a wheelchair. . . . I am a paraplegic. I require ‘special assistance for boarding.’ I am a gimp, cripple, physically challenged, differently abled, paralyzed. I am a T-5 para. I am sick. I am well. I have a T4-6 incomplete dural lesion, a spinal cord injury, a broken back, ‘broken legs’” (87).

Marisa Acocella Marchetto, *Cancer Vixen: A True Story* (2006). Here Marchetto, a cartoonist, narrates in pictures the story of her discovery of breast cancer three weeks before her marriage, at 43, to Silvano, a Prince Charming restaurateur. Her mantra: “Cancer, I am going to kick your butt . . . and I’m gonna do it in killer 5-inch heels!” Her “(s)mother,” her friends, and especially her fiancé—whose wedding gift is health insurance that absorbs much of the \$192,720.04 cost of the eleven-month treatment—rally round to defeat the enemy, not only cancer but jealous female rivals. Although this book fits the medical model of **a**: discovery of disease **b**: treatment **c**: cure, its upbeat fashionista central character serves as an activist, aspirational model for the book’s target female audience.

Kay Redfield Jamison, *An Unquiet Mind: A Memoir of Moods and Madness* (1995). From the dual perspectives of a clinical psychologist and someone with bipolar disorder, Jamison writes “to change public attitudes about psychiatric illnesses in general and

manic-depressive illness in particular” (7). Because “the student years represent the age of greatest risk” of suicide, she also writes to encourage “students who struggle with mental illness” to fight against “the lack of understanding [of] professors and . . . administrators; the lack of adequate health insurance; their fears about being asked to go on medical leave and not . . . being allowed to return to campus” and other life-and-death aspects of discrimination (*Nothing*, 47-48).

Atul Gawande, *Complications: A Surgeon's Notes on an Imperfect Science* (2002). This collection of Gawande's *New Yorker* essays discusses how doctors learn, work, make life-and-death decisions dependent on intuition, ethical and technical judgments, collegiality—and sanitation; ways of dealing with obesity, pain; and medical errors and mistakes. Gawande himself represents the, yes, cutting edge of contemporary medical writing, humane, unsentimental, exemplifying medicine's high-stakes paradox of expertise and uncertainty, “doubts and missteps,” “failures as well as the successes,” “messy, uncertain . . . surprising” (4).

All these authors' dynamic lives and work confront and contradict the social stereotype that having an “able body and mind determines whether one is a quality human being” (Siebers 4). Their versatile works may also be read through a variety of lenses emphasizing ethical, political, economic, social, legal, technological, medical, and/or religious concerns. Thus they speak to one another and provide many points of entrance to the ongoing conversation.

Additional material. The core autobiographies can be augmented by films (such as *The Diving Bell and the Butterfly*; *Sicko*), articles on health and medicine from the *New York Times*, and, when available, outside speakers, and other writings categorized here.

Theory, though difficult for the students, provides a necessary underpinning, as addressed in such articles as Tobin Siebers's “Disability in Theory,” Lerita M. Coleman's “Stigma: An Enigma Demystified,” Simi Linton's “Reassigning Meaning.”

Science and medicine. A wealth of writings exists, readily accessible to the general public, and stimulating to the science students as well. Bill McKibben's “Designer Genes” offers a chilling, clearheaded analysis of what could happen if aspiring (and wealthy) parents employ genetic engineering to create new and ever-newer models of superior children in a “biological arms race.” He warns, “Suppose parents could add thirty points to their child's IQ? . . . Deciding not to soup them up . . . well, it could come to seem like child abuse” (Bloom, *Essay* 576). Charles G. Mann's “The Coming Death Shortage” addresses the ethical and social inequities that will result from increasingly long life expectancy, rising from age 47 in 1900 to 77 in 2000: “a tripartite society: the very old and very rich on top . . . a mass of the ordinary old . . . and the diminishingly influential young” (Bloom, *Essay* 427).

Caregiver and family narratives. Some families must play the cards fate has dealt.

Scot Sea's "Planet Autism" snapshots the bleak alternative universe where Sea and his wife have been on duty for the fifteen years of their autistic daughter's life, no time out, no days off: "Shit everywhere. Splashes of blood glistening like paint, black clots, yellow-brown feces, and a three-foot-diameter pond of vomit that your daughter stands in the middle of" (208). In "Under the Influence: Paying the Price of My Father's Booze," Scott Russell Sanders speaks for the families of the "ten million victims, fifteen million, twenty" million alcoholics in the United States who share the "family secret": "You swallow the bitter quinine of knowledge, and you learn to feel pity and compassion toward the drinker. Yet the shame lingers in your marrow, and, because of the shame, anger" (20, 8). People suffer from others' decisions. Meredith Hall's "Shunned" excoriates the social mores of the 1960s in a searing account of the "deep and scarring depression" she experienced at 16 as an unwed and therefore "dirty pregnant girl hiding upstairs in a cold, lonely house," shunned by her parents and exiled from the previously embracing society. In "Reflections on the Plight of Sick Children," Dr. Robert Martensen raises questions of bioethics in which federal policy and parents' wishes conspire to keep painfully ill children alive: "too little treatment has given way to too much" (122).

Privacy policy. "Able, Disabled, Enabled" by its very nature encourages telling and trading personal stories, a potentially great disclosure of intimate information. So from day 1 the privacy policy is in effect: "If you don't want others to read your work, simply label it 'Private.'" This is particularly important in a disability studies class where students may have, as E. B. White says, "secret reasons" for taking the course and for not wanting to disclose those reasons (425). Even though with time and comfort most students open up, they have a right to remain silent.

What the Students Wrote

Major papers. Of the three major papers, two were on the readings, one was a personal essay on "My Intimate Understanding of Disability" (for assignments, email Lynn.Bloom@UConn.edu). "The first two papers," I tell the students, "are to fulfill university requirements. The personal essay is for you." Thus students wrote about caring for relatives with cancer, AIDS, diabetes, and other complications of obesity; growing up with siblings with Tourette's syndrome, eating disorders, drug and alcohol abuse and the consequent family devastation; dealing with their own Chron's disease, chronic pain, broken bones, cleft lip, mysterious fevers, fibromyalgia, cutting, depression, attempted suicide.

The revisions were, for many, as important as the initial drafts; they needed freedom to approach the tough topics obliquely, to gradually understand the embedded issues, to change their minds if necessary, and above all, to be honest with themselves. As an English professor, I am not practicing therapy without a license, but I am providing a context for

growth. This may be the only opportunity students have in four undergraduate years to examine aspects of their own lives, the lives of their families and friends, from a long-term perspective governed by values and ethical principles, fears—and hopes. These are the papers, I like to believe, they will never forget.

Brief writings. To each class meeting the students brought a brief writing to jump start the day's discussion. Refined, revisited, and revised throughout the semester, they provided a cumulative dialogue on the topic at hand.

1. Unpack and compare the meanings of a variety of definitions of disability on the Internet from websites such as the Americans with Disabilities Act of 1990, the World Health Organization, Women's Health Zone, and others.
2. List ten aspects of your ability to function physically that you take for granted. Rank order these with the most important ones first.
3. List ten aspects of your ability to function mentally and/or psychologically that you take for granted. Rank order these with the most important ones first. Identify negatives as well as positives, if you wish. For instance, are you a chronic procrastinator (how far in advance do you study for an exam? mind/psychology? ability to function)?
4. Get dressed using your dominant arm/hand only and write an analysis of your experience.
5. Now get dressed using your less dominant arm/hand. Analyze your experience and compare this with your dominant handed dressing.
6. Spend an hour blindfolded. Analyze your experiences, reactions, others' behavior toward you during this time. [I share in advance with my students the common Disability Studies critique of such role playing—that because this activity is transient, not genuine, and casual it cannot possibly replicate the authentic experience; all true. Nevertheless, however superficial, the students find these brief experiences are illuminating and moving.]
7. Map your typical campus route. How would you have to alter it if you were traveling by wheelchair? Is our campus truly “accessible”? If not, what could make it so?
8. Analyze a charitable appeal (I distributed mail solicitations for medical, health, and humanitarian organizations), noting its language, illustrations, and the nature of its appeals. Check its claims against the evidence in Charity Navigator. On the basis of what you've found, would you contribute to this charity?
9. Reaction papers to films (*The Diving Bell and the Butterfly*; *Sicko*) and the out-

side speaker (Elie Wiesel, Nobel Peace Prize recipient; a speaker discussing her altered career and life expectations throughout a decade of breast cancer with a myriad of complications, positive yet realistic in confronting an anticipated early death.

Although these writings represented a lot of work, no one complained. Indeed, the students seemed energized by their variety and breadth, and discussed them with enthusiasm.

What We Learned (Students and Instructor Alike)

A lot, all of us. Among other things, as student final exams revealed, the complexity of disability extending far beyond medical issues: “I was [now] able to see the ethical, social, and psychological sides, among many others.” The myriad of opportunities for people with disabilities to lead full and varied lives, at work and play, love and marriage, in sickness and in health, however compromised: “Disability can affect you only as much as you let it.” Disability, concludes another, “should not be seen as negative but a special uniqueness. If disability were eliminated a lot of character would be eliminated as well.” Moreover, writing about disability can effect positive transformation, providing a new “outlook and understanding that change the person you are now and will continue to be.”

“Able, Disabled, Enabled” could have lapsed into solipsism, narcissism, or self-pity, but it didn’t. The students were inspired by the readings, exhilarated by their writing—particularly the short assignments and the “Intimate Understanding of Disability” papers: “I am incredibly appreciative that I was able to write about this experience”; “It was an important piece for me to write personally.” In addition to accomplishing the course aims, unique in their college experience, the course encourages students to use their writing and reading for self-understanding and—when possible—the resolution of personal problems. If the students’ enhanced personal awareness leads to greater social awareness and potential political activism, so much the better. Above all, however, what we all learned, with every reading, every writing, every experience with disability in and out of class was to see the world with new eyes, a world in which disability is made visible and ordinary, an integral part of everyday life.

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