Couser, G. Thomas

DISABILITY AS DIVERSITY: A DIFFERENCE WITH A DIFFERENCE G.
Ilha do Desterro: A Journal of English Language, Literatures in English and Cultural Studies, núm. 48, enero-junio, 2005, pp. 95-113
Universidade Federal de Santa Catarina
Florianópolis, Brasil

Available in: http://www.redalyc.org/articulo.oa?id=478348686004
DISABILITY AS DIVERSITY:
A DIFFERENCE WITH A DIFFERENCE

G. Thomas Couser
Hofstra University

Abstract
Disability is a fundamental facet of human diversity, yet it lags behind race, gender, ethnicity, sexual orientation, and class in recognition inside and outside the academy. Disability has its own history (or histories) and culture(s) which deserve to be studied in their own right. Disability Studies is not limited to the study of disabled people as a distinct population, however; rather, it involves the comprehensive investigation of disability as a cultural construct that undergirds social practices and cultural representations. As contemporary Disability Studies scholars view it, then, disability is a significant and powerful cultural category; like race and gender, disability is a cultural construct that assigns traits to individuals—and discriminates among them—on the basis of bodily differences. Today, disabled people, long vulnerable to prejudicial representation in high and low culture, are challenging conventional assumptions by representing themselves in memoir and autobiography.

Keywords: disability; diversity; Disability Studies; impairment; narrative; representation; memoir.

Resumo
A deficiência física é uma faceta fundamental da diversidade humana, porém ela geralmente só é reconhecida dentro e fora da academia depois de raça, gênero, etnia, orientação sexual e classe. A diferença física tem
sua(s) própria(s) história(s) e cultura(s) que merecem estudo específico. A área de estudos sobre diferença (construída como deficiência) física não se limita a estudar pessoas incapacitadas como uma população distinta; ao contrário, ela pretende a investigação ampla da deficiência como um construto cultural que circunda as práticas sociais e as representações culturais. Como defendem atualmente os estudiosos dessa área, a deficiência física é uma categoria cultural significativa e poderosa; assim como ‘raça’ e ‘gênero’, ela é um construto cultural que marca os indivíduos—e os discrimina—com base em diferenças físicas. Atualmente as pessoas com alguma deficiência ou incapacidade, que sempre foram vulneráveis a representações preconceituosas tanto na dita ‘alta’ quanto ‘baixa’ cultura, estão desafiando tais pressupostos convencionais através das representações que fazem de si principalmente em textos autobiográficos e de memórias.

**Palavras-chaves:** deficiência; diversidade; estudos da diferença física e mental; incapacidade; narrativa; representação; memórias.

Disability is an inescapable element of human experience. Although it is rarely acknowledged as such, it is also a fundamental aspect of human diversity. It is so, first, in the sense that, world-wide, an enormous number of people are disabled. (The proportion of people who are disabled in different national populations varies significantly with economic development, health care, and other factors, of course, but in the United States, at least, people with disabilities make up the population’s largest minority.) Furthermore, because of the way this minority is constituted, it is arguably more heterogeneous than those of race, gender, class, and sexual orientation. Disabilities may affect one’s senses or one’s mobility; they may be static or progressive, congenital or acquired, formal (affecting the shape of the body) or functional, visible or invisible.

All these differences create potential fault lines within the whole; far from monolithic, then, the category of disabled people is inflected with differences that profoundly affect identity politics. For example, people with congenital disabilities are far more likely to identify as disabled and to express pride in their anomalous bodies. Indeed, most people who were born deaf and whose first language is American Sign
Language do not consider themselves disabled at all; rather, the Deaf think of themselves as akin to an ethnic minority set off from the mainstream by their language and culture. In contrast, individuals with acquired disabilities are more likely to resist or even reject identification as disabled and more likely to invest, financially and emotionally, in the quest for cure or rehabilitation. In any case, the border between the disabled and the non-disabled is less permanent and more permeable than those between races and genders. On the one hand, with the help of biomedicine or rehabilitation, individuals may pass from the status of disabled to that of nondisabled; on the other hand, anyone can become disabled at any time, and, barring sudden or accidental death, most people will eventually become disabled to a significant degree. So as a form of diversity, disability is distinct in its variability, contingency, and extent.

Disability is fundamental also in that it may “trump” other minority statuses. That is, for people who differ in more than one way from the hegemonic identity (middle-class white male heterosexual normate), certain impairments—such as blindness or deafness—may function as their “master” status, their primary defining characteristic. Similarly, and not coincidentally, physical and mental impairments often underpin constructions of gender, race, and ethnicity. I am referring here to the way in which, for example, women have traditionally been viewed as defective males, people of color as deficient whites, and “ethnic” groups as pathologically deviant from majority populations.

This phenomenon is most evident (and most disturbing) in the eugenics movement during the first half of the twentieth century in the U.S., Britain, and, climactically, in Nazi Germany. In subtler form, however, it is also evident in other historical events and movements. In the United States, Douglas Baynton has shown that

not only has it been considered justifiable to treat disabled people unequally, but the concept of disability has been used to justify discrimination against other groups by attributing
disability to them. Disability was a significant factor in the three great citizenship debates of the nineteenth and early twentieth centuries: women’s suffrage, African American freedom and civil rights, and the restriction of immigration. When categories of citizenship were questioned, challenged, and disrupted, disability was called on to clarify and define who deserved, and who was deservedly excluded from, citizenship. Opponents of political and social equality for women cited their supposed physical, intellectual, and psychological flaws, deficits, and deviations from the male norm. . . . Arguments for racial inequality and immigration restrictions invoked supposed tendencies to feeble-mindedness, mental illness, deafness, blindness, and other disabilities in particular races and ethnic groups. (33-34)

Defenders of minority groups addressed the prejudices against them only at the surface level, decoupling them from “ableist” prejudice.

Such arguments took the form of vigorous denials that the groups in question actually had these disabilities; they were not disabled, the argument went, and therefore were not proper subjects for discrimination. Rarely have oppressed groups denied that disability is an adequate justification for social and political inequality. (34)

As these debates suggest, disability may be a more fundamental form of human diversity than differences in race, ethnicity, and gender.

In part because of its seeming elementality—it still seems intuitive to many that disability is a natural form of human inequality—disability has escaped critical scrutiny until quite recently. But like Poe’s purloined letter, disability has been hidden in plain sight all along. That is, even as disability lies below the surface and serves to rationalize various discriminatory practices, it has had a remarkably high profile in both high and popular culture. Thus, while in the U.S. it is often
said that oppressed groups have been under-represented, the opposite is true of people with disabilities: both high and popular culture are saturated with images of disability. Unlike other minorities, then, disabled people have been hyper-represented in mainstream culture; they have not been marginalized so much as they have been subjected to perpetual inspection in the form of mediated (and thus vicarious) staring.

In *Narrative Prosthesis: Disability and the Dependencies of Discourse*, David T. Mitchell and Sharon L. Snyder have demonstrated how Western culture has persistently, even obsessively, deployed disability both as a *prompt* and as a crutch-like *prop* for narrative. The tradition stretches from Sophocles’s Oedipus through Shakespeare’s Richard III and Melville’s Ahab to Faulkner’s Benjy and beyond. As a trope, disability serves to conflate narrative and character; even when it does not generate narrative, it may imply a back story. A crippled or scarred character, for example, may be assumed to have been traumatized and embittered in the manner of Ahab. (Not coincidentally, such characters are often put to death, lending force to the impression that disabled people are doomed, if not cursed.)

In film, a medium that puts a premium on appearance and the body, disability is, if anything, even more prominent than in literature. In *The Cinema of Isolation*, his survey of the representation of physical disability in film, Martin Norden observes that disability was featured prominently in some of the very first films: “One subject area [early film makers] found fertile with possibility was a major social concern on both sides of the Atlantic: beggars, especially those with fake disabilities” (14). Further, the first wave of films established many of the preoccupations and conventions of the cinematic representation of disability that persevere to this day:

stereotypes so durable and pervasive that they have become mainstream society’s perception of disabled people and have obscured if not outright supplanted disabled people’s perception of themselves. . . . Its more common representations
include extraordinary (and often initially embittered) individuals whose lonely struggles against incredible odds make for what it considers heart-warming stories of courage and triumph, violence-prone beasts just asking to be destroyed, comic characters who inadvertently cause trouble for themselves or others, saintly sages who possess the gift of second sight, and sweet young things whose goodness and innocence are sufficient currency for a one-way ticket out of isolation in the form of a miraculous cure. (3)

Quite early on in the history of film, too, prominent scarring or deformity became a standard way of quickly and economically establishing villainy. (This practice continues in “B” films, most obviously in the horror genre.)

In apparent contrast, contemporary American feature films often focus on sympathetic protagonists who have significant disabilities, and the actors who play them are favored candidates for Academy awards. (The disabled characters are never played by actors with the disability in question, of course.) While we might applaud this trend as a belated honorific “recognition” of disability, the Oscar phenomenon suggests that disability is so alien a form of existence that for a nondisabled actor to simulate it is a professional achievement of the highest order.

For better or worse (mostly worse), disability has been an extremely valuable cultural commodity for thousands of years—literally as well as figuratively. In spite of its fundamental status and its high visibility, however, disability has lagged behind other aspects of diversity (race, gender, ethnicity, sexual orientation, and class) in recognition both inside and outside the academy. Various reasons might be advanced to account for this. For one thing, in some quarters there is reluctance to add yet another element to the diversity formula—as though the notion of diversity gets progressively diluted as more constituents of it are recognized. (This phenomenon is most obvious in curriculum and “turf” conflicts.) But disability may also lurk beneath
Disability as diversity:... the critical radar in part for a reason suggested already: precisely because disability constitutes the one minority anyone can join, it may be the form of diversity that generates the most anxiety and discomfort in others. Many people prefer to avert their eyes and their attention from what registers, if only unconsciously, as deeply threatening to their sense of identity, agency, and autonomy.

This neglect and aversion have begun to be addressed and rectified by the field of Disability Studies, which is now well established in Britain and in North America. There are at least two distinct but related projects to be advanced. One is the investigation of the history and culture of particular disabilities or conditions—blindness, deafness, mobility impairments, mental illness, etc.—all of which deserve to be studied in their own right. Such research is labor intensive, and, as with other such groups, the very marginalization of the population in question often impedes the project by limiting, obscuring, or dispersing sources. A notable exception occurs in the case of distinct populations, like the mentally ill or mentally retarded, that have been literally marginalized—sequestered in institutions; the archives of these institutions often represent rich, untapped databases (Foucault, Trent). Although these groups may be represented only anonymously and as aggregates rather than as distinct individuals, some populations may have left ample traces because of their segregation.

Disability Studies is not limited to the study of disabled people as a distinct population (or populations), however; another major project involves the comprehensive investigation of disability as a construct that undergirds social practices and cultural representations. As contemporary Disability Studies scholars view it, then, disability is a significant and powerful system of representation, like race and gender, that assigns traits to individuals, and discriminates among them, on the basis of bodily differences. Until recently, however, disability has been understood primarily through the symbolic or the medical paradigms. Under the first of these, whose origins are ancient but which continues powerfully to shape language and culture, particular conditions are read as signs or metaphors of moral, spiritual, or emotional conditions.
The convention of the crippled villain referred to earlier is an obvious example of this paradigm at work. It offers writers and film makers a narrative shorthand that inscribes internal traits onto the very body of a character; it offers readers and filmgoers a code that can be understood instantly, unambiguously, and without conscious effort. This phenomenon operates in an even more fundamental and pervasive way in the form of dead metaphors, which are unconsciously decoded; consider the idiomatic expressions “lame argument,” “upstanding character,” “crook,” and so on.

With the birth of the clinic and the growth of biomedicine, disability could be viewed in a very different way. By locating disability in particular malfunctions of individual bodies, Western medicine generated a new paradigm of disability as a discrete somatic dysfunction to be prevented, rehabilitated, cured, or corrected. The medical paradigm has the advantage of naturalizing or demystifying disability; it promises to remove the stigma from impairment. Thus, individuals who once might have been persecuted—even executed—for being possessed by demons may now be regarded as afflicted with particular mental illnesses. (Despite the efforts of physicians and advocates, mental illness has retained a substantial degree of stigma.) Because of its naturalizing tendency, the medical paradigm is of little value in cultural representation; under this paradigm, a limp is just a limp—perhaps the residue of an illness or accident—not a sign of twisted character.

But while the medical paradigm does not treat impairments as representing moral or spiritual conditions, it perpetuates the notion that they are located entirely in the individual body. It is therefore up to individuals to address and resolve the problems of their disabilities; otherwise, they may justifiably be excluded from education, employment, and the public sphere generally. So the medical model may be complicit in the marginalization of the disabled. (At worst, of course, it creates its own set of stigmas; consider the pathologizing of homosexuality as a mental illness, which was all the more insidious for claiming the authority of science.)
In contrast, contemporary Disability Studies seeks to explore, expose, and reconstruct the ways in which disability is socially and culturally constituted, usually at the expense of the individuals designated as disabled. One move made by contemporary theorists is to distinguish “impairment” (a physical or functional anomaly) from “disability” (restrictions imposed on those with impairments). By analogy with gender and sex, the argument is made that cultures map personal and moral traits arbitrarily onto somatic anomalies and reserve certain privileges and rights for those deemed normal. The new paradigm of disability as a construct, rather than a natural or moral phenomenon, shifts the onus of accommodation away from the individual and onto the environment—social, cultural, and political. As a recent Supreme Court case involving the Americans with Disabilities Act, Tennessee v. Lane, determined, it is not the responsibility of paraplegics to find a way of ascending the courthouse stairs; it is the responsibility of the state to provide an elevator or ramp to accommodate their wheelchairs. Not to provide such access is to discriminate on the basis of disability.

Considered as a discriminatory system of representation, disability has historically functioned at the expense of people with disabilities in part because they have not controlled their own representation within it. Thus, while they may have been in some sense over-represented, they have not been fairly, diversely, and complexly portrayed; most important, they have not often been self-represented. My own point of entry into Disability Studies, however, was through an antithetical phenomenon: namely, late 20th-century life writing in which, in unprecedented ways and to an extraordinary degree, disabled people have initiated and controlled their own representation. Indeed, I would argue that one of the most significant developments—if not the most significant development—in life writing in North America over the last three decades has been an upsurge in the publication of book-length accounts—from both first- and third-person points of view—of living with illness and disability. Whereas in the 1970s it was difficult to find any representation of most disabling conditions in life writing, today one can find multiple representations of many conditions. Equally
significant, and more remarkable, one can find autobiographical accounts of conditions that would seem to preclude first-person testimony altogether—for example, autism and (early) Alzheimer’s disease.

A comprehensive history of disability life writing has yet to be written, but it is safe to say that there was not much in the way of published autobiographical literature in the United States—and probably elsewhere—before World War II. War both produces and valorizes certain forms of disability, and the availability of new antibiotics enabled many combatants in World War II to survive wounds that would have been fatal in earlier conflicts. Not surprisingly, then, disabled American veterans produced a substantial number of narratives after the Second World War. Polio generated even more narratives; indeed, polio may be the first disability to have engendered a substantial autobiographical literature—in part because it was primarily a disease of middle-class children (Wilson). In the 1980s and 1990s, HIV/AIDS and breast cancer provoked significant numbers of narratives; many of these challenge cultural scripts of the conditions—such as that AIDS is an automatic death sentence or that breast cancer negates a woman’s sexuality (Couser). Thus, one major post-World War II cultural phenomenon was the generation of large numbers of narratives about a small number of conditions.

A complementary phenomenon has been the production of small numbers of narratives about a large number of conditions, some quite rare and some only recently recognized. Among these conditions are (in alphabetical order) ALS, or Lou Gehrig’s disease (Robillard); Alzheimer’s (DeBaggio, McGowin); aphasia (Wolf); Asperger’s syndrome (Willey); asthma (Brookes); autism (Grandin, Williams); cerebral palsy (Sienkiewicz-Mercer); chronic fatigue syndrome (Skloot); cystic fibrosis (Rothenberg); diabetes (Roney); disfigurement (Grealy); Down syndrome (Kingsley and Levitz); epilepsy (Robinson, Slater); locked-in syndrome (Bauby); multiple sclerosis (Mairs); obesity (Kuffels, Wilensky); obsessive-compulsive disorder (Wilensky); stuttering (Jezer); stroke (McCrum, Robinson, Sarton); and Tourette syn-
drome (Handler). As the 20th century drew to a close, then, many disabilities came out of the closet into the living room of life writing.

Like life writing by other marginalized groups—women, African-Americans, and gays—life writing by disabled people in North America and Britain is a cultural manifestation of a human rights movement; significantly, the rise in personal narratives of disability roughly coincides with the disability rights movement, whose major legal manifestation in the United States is the Americans with Disabilities Act, which was passed in 1990. The first flowering of disability autobiography is also part of a broader disability renaissance that involves other arts and media. Disability autobiography should be seen, then, not as spontaneous self-expression but as a response—indeed a retort—to the traditional misrepresentation of disability in Western culture generally.

Just as disability is a difference with a difference (and in some ways more fundamental than differences in race, ethnicity, and genre), it stands in a unique relation to life narrative. One way of understanding this special relation between somatic variation, on the one hand, and life narrative, on the other, is through a common phenomenon: the way deviations from bodily norms often provoke a demand for explanatory narrative in everyday life. Whereas the unmarked case—the “normal” body—can pass without narration, the marked case—the scar, the limp, the missing limb or the obvious prosthesis—calls for a story. People presenting unexpectedly anomalous bodies are often called upon to account for them, sometimes explicitly: “What happened to you”? (Illustrating and responding to this cultural practice is a collection of life writing by women with disabilities called What Happened to You? [Keith].) One of the social burdens of disability, then, is that it exposes affected individuals to inspection, interrogation, and violation of privacy.

In effect, people with extraordinary bodies are held responsible for them, in two senses. First, they are required to account for them, often to complete strangers; second, the expectation is that their accounts should relieve their auditors’ discomfort. Despite the request
for impromptu narration, often the answer to the question—“what happened to you?”—is pre-determined. The elicited narrative is expected to conform to, and thus confirm, a cultural script. For example, people diagnosed with lung cancer or HIV/AIDS are expected to admit to behaviors that have induced the condition in question—to acknowledge having brought it upon themselves. Thus, one fundamental connection between life writing and somatic anomaly is that to have certain conditions is to have one’s life written for one. For people with many disabilities, culture inscribes narratives on their bodies in a way or to a degree not true of other minority populations.

One can see, then, why autobiography is a particularly important form of life writing about disability: written from inside the experience in question, it involves self-representation by definition and thus offers the best-case scenario for revaluation of that condition. Disability autobiographers begin from a position of marginalization, belatedness, and pre-inscription. Long the objects of others’ classification and examination, disabled people have only recently assumed the initiative in representing themselves. In autobiography, disabled people counter their historical subjection by occupying the subject position. In approaching this literature, then, one should attend to the politics and ethics of representation, for the “representation” of disability in such narratives is a political as well as a mimetic act—a matter of speaking for as well as speaking about. Indeed, disability autobiography may be regarded as a post-colonial (which is to say, an anti-colonial) phenomenon, a form of autoethnography, as Mary Louise Pratt has defined it: “instances in which colonized subjects undertake to represent themselves in ways that engage with [read: contest] the colonizer’s own terms” (7).

With severe or debilitating conditions, particularly those affecting the mind or the ability to communicate, the very existence of first-person narratives makes its own point, that people with that condition are capable of self-representation. Even or perhaps especially when the text is collaboratively produced, the autobiographical act models the agency that the disability rights movement has fought for. One notable example is *Count Us In: Growing Up with Down Syndrome*, a
collaborative narrative by two young men with the syndrome in question. Not only is the title cast in the imperative mood—“count us in”—the subtitle puns on “up” and “down” in a way that challenges conventional ideas about mental retardation, such as that those with it never really mature. Another well known narrative emanating from an unlikely source is The Diving Bell and the Butterfly, Jean-Dominique Bauby’s memoir of locked-in syndrome, a condition of near-total paralysis and thus of utter dependency. Bauby laboriously “eye-typed” his brief narrative, blinking to select each letter as an amanuensis recited the alphabet over and over. Autobiography, then, can be an especially powerful medium in which disabled people can demonstrate that they have lives, in defiance of others’ perceptions of them.

A text that vividly demonstrates the post-colonial impulse is Susanna Kaysen’s Girl, Interrupted, an account of the author’s sojourn in a mental hospital. Kaysen astutely avoids ready-made narrative formulas and plots; instead of offering a linear account of her experience, she produces a collage of short chapters of distinct and very disparate types. Some offer brief vignettes of herself or other patients; others are meditations on the inadequacy of medical terminology and hence the diagnosis of mental illness. Still others incorporate and interrogate the actual documents that effected her diagnosis, admission, supervision, and discharge. One of the strengths of the book is its persistent interrogation of medical discourse in order to undermine its definition of her. One strategy here is to offer an array of diagnoses that might have been applied to the “same” condition in different eras and cultures; a chapter titled “Etiology” consists of the prompt—“This person is [blank]”—followed by multiple-choice answers ranging from the condemnatory—“possessed,” “bewitched,” “bad”—to the clinical—“ill”—to the romantic—“sane in an insane world.” Kaysen thus suggests the persistence of psychiatric disorder, its historical contingency, and the arbitrariness of the discourses of madness. To put it in terms of my discussion earlier, Kaysen demonstrates, by rehearsing the progressive constructions of mental illness (juxtaposing the symbolic with the medical paradigms) that it is to some extent a cultural construction.
Another of her strategies, in the more essayistic chapters, is to adapt existing scientific terms (such as “topography,” “viscosity,” and “velocity”) and/or to invent her own pseudo-scientific terms (like “stigmatography”) to challenge the authority of biomedical discourse. She avoids romanticizing her condition, acknowledging that she was troubled and benefitted from her retreat from the world, but implying that her condition was mostly an extreme version of the confusions of adolescence, perhaps exacerbated by the turbulence of the late sixties. As she sees it, she was perceived as deviant or delinquent because she attempted to make a life out of the only two things that truly engaged her, boyfriends and books. As testimony that she was never crazy she asserts that in the twenty-five years since her discharge she has made a successful life out of precisely those same two elements; in Freud’s terms (not hers) these are two of life’s fundamental concerns, love and work. She was then, she implies, not so much delinquent as precocious.

Some of the most effective parts of the book are those in which she contextualizes her medical records in such a way as to reveal the contingency of diagnosis and, more generally, the difficulty of drawing a clear line between mental illness and mental health—or mental illness and disaffection.

Kaysen is fortunate to have been able to document, reclaim, and recast her sojourn in a mental hospital. Other people with disabilities may find themselves quite literally at the mercy of their families. My last example is intended to suggest that even in best-case scenarios, prejudice against disability can literally be life-threatening. Richard Galli’s _Rescuing Jeffrey_ is a father’s account of coping with his teen-aged son’s sudden paralysis. When Jeffrey Galli, a seventeen-year-old high school student emerging from a deep depression, was suddenly rendered quadriplegic by a diving accident, his father’s almost immediate response was to explore the possibility of “killing” (his word) his son by removing his life support. Because Jeffrey was not yet legally an adult, his parents did have the power to determine his fate, and despite the fact that he was conscious and competent, they decided not only that his life was no longer worth living but that they should
have his ventilator disconnected without consulting him. In the end, for reasons that are left implicit, they changed their minds, and Jeffrey survived. (He finished high school and went on to university.) But it is clear that their initial decision was driven by their literal inability to imagine their son having a meaningful life as a quadriplegic.

What goes unquestioned in his parents’ deliberations is the proposition that quadriplegia is a fate worse than death. Galli declares to his wife: “I try to believe that helping Jeffrey live is the right thing to do, but I can’t believe it. If I were in his position, I know what I would want him to do for me. And I know I should do the same thing for him. I’m sure of it” (36-37). Here he seems to be projecting his own desires onto his son—that is, substituting his own judgment for Jeffrey’s. The decision is rationalized at other times by an intuitive utilitarian calculus of the cost of his disability to Jeffrey: “I still believed that the pain of Jeff’s diminishment exceeded the value of living the lesser life of a quadriplegic” (167). When the Gallis eventually reverse course, the shift is somewhat anti-climactic; indeed, the crucial shift is less a decision, which suggests conscious choice, than a surrender—not to resistance from physicians or hospital staff, although there is some of that, but to what Galli refers to as “the wave” or “the river,” a groundswell of sentiment for Jeffrey’s survival among family, friends, acquaintances. As Jeffrey weathers some crises, and as support from others buoys his parents up, they find themselves swept along by unfolding events. Thus, they opt finally in favor of the uncertainty of Jeffrey’s survival over the certainty of his death.

Acquaintance with disability—or, lacking first-hand acquaintance, the ability to view it in a certain light—may literally be life-saving; destigmatizing disability may make the seemingly unendurable endurable. Richard Galli touches upon the issue of his pre-existing attitude toward disability in the following passage:

“I have never been in a situation where there was no out,” I told [my wife]. . . .
But now this situation had only two possible outcomes: Jeff would die or he would live trapped in his quadriplegia. I couldn’t imagine that, couldn’t visualize it... 

I suffered from a failure of the imagination. Paralysis was repugnant to my imagination. (italics mine, 171)

Richard Galli’s inability to imagine his son as a quadriplegic needing help with toileting is not surprising or blameworthy; previous to Jeffrey’s accident, he had no need to imagine such a situation. Presumably Jeffrey also struggled to imagine living with disability. The narrative affords us little insight into his thought processes, but it is a good sign when he asks his father whether, once he is able to resume his education, he “will have to go to a school for cripples” (159). In this brief comment, he reveals both a prejudice against disabled people and an incipient ability to imagine living as one. There are two important things about the answer to this question. First, for a young man in his father’s generation, the answer would have been the one Jeffrey fears: that he would henceforth have to attend a different school from his friends. The second is that the actual answer to his question—no, he could rejoin his classmates in his old school—is a function of public policy and not his degree of impairment. That is, this reassuring answer is a function of the social/cultural paradigm of disability, which locates disadvantage in the cultural and physical environment and legislates the right of access to education accordingly.

Much disability life writing can be approached as quality-of-life writing because it addresses questions discussed under that rubric in philosophy, ethics, and especially biomedical ethics. As such, disability life writing should be required reading for citizens of societies with underfunded, often inadequate, health care, with enormous technological capability to sustain life and repair bodies in the case of acute illness and injury but with very little commitment to accommodate and support chronic disability. Among forms of human diversity, disability is perhaps the most fundamental; it is in many parts of the world the
Disability as diversity:... 111

least acknowledged, the least celebrated, and the most life-threatening. Even where, as in the U.S., people with disabilities are increasingly visible in public spaces and open about their disabilities, their physical presence in public life represents only a rather limited kind of access. Indeed, visibility has its disadvantages and dangers as well as its advantages for minority groups, and the mapping of the human genome threatens to revive and rehabilitate eugenicism. Properly conceived and carried out—admittedly, a large qualifier—life writing can play a crucial role by providing the reading public with mediated access to a kind of diversity that might otherwise remain opaque, exotic, and threatening to them.

Works cited


112  G. Thomas Couser


