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JOHN HOCKENBERRY

VED MEHTA

ADRIENNE RICH

AND 30 OTHER WRITERS WITH DISABILITIES

Staring Back



THE
DISABILITY
EXPERIENCE
FROM THE
INSIDE OUT

EDITED BY KENNY FRIES

STARING BACK

The Disability Experience
from the Inside Out



E D I T E D B Y

Kenny Fries



A PLUME BOOK

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Introduction



K E N N Y F R I E S

I — “*You would have been better off dead.*”

We’ve been shadow spirits lost between our nondisabled (for most of us) upbringing and our Disability lessons in life.

—Carol Gill, Ph.D.

Throughout history, people with disabilities have been stared at. Now, here in these pages—in literature of inventive form, at times harrowingly funny, at times provocatively wise—writers with disabilities affirm our lives by putting the world on notice that we are staring back.

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 who live with disabilities have been silenced by those who did not want to hear what we have to say. We have also been silenced by our own fear, the fear that if we told our stories people would say: “See, it isn’t worth it. You would be better off dead.”

Seven years ago, I began searching for the words with which to begin speaking about my own experience living with a congenital physical disability, a disability I was born with for no known scientific reason, a disability with no medical name except the generic “congenital deformities of the lower extremities”—one way of saying I was missing bones in both legs. In the summer of 1989, I took the initial steps of finding the language, unearthing the images, shaping

the forms with which I could express an experience I had never read about before, so that my experience as a person with a disability could become meaningful to others.

What I remember most about that summer is wanting to throw all those drafts away, not thinking them poems. Not having a role model in whose steps I could follow, unsure of my own identity as both a writer and a person who lives with a disability, I felt like one of those “shadow spirits” Carol Gill writes about, unable to successfully meld on the page the nondisabled world I lived in with my experience of being disabled in that world.

I also felt afraid. I felt a fear that Anne Finger was writing about at almost the same time in *Past Due: A Story of Disability, Pregnancy and Birth*. In *Past Due* Finger recounts her experience at a feminist conference when she talked about her inhumane treatment as a child in the hospital because of complications from polio. After Finger publicly shares her story, a colleague says: “If you had been my child, I would have killed you before I let that happen. I would have killed myself, too.” Finger reacts:

My heart stops. She is telling me I should not be alive. It is my old fear come true: That if you talk about the pain, people will say, “See, it isn’t worth it. You would be better off dead.”

If this was a friend’s response to Finger’s experience, how would my friends, not to mention those who did not know me, react to what I had to say? And, after knowing what I had gone through how could they believe there was so much more to living with my disability than pain?

All the work in *Staring Back* speaks of the disability experience from the inside out. At Gallaudet College, when the hearing majority on its board rejected two qualified deaf educators for president to select yet another hearing candidate, student-government president Greg Hilbok asked, “Who has decided what the qualifications for president should be?” And historian Paul K. Longmore similarly asks: “Who should have the power to define the identities of people with disabilities and to determine what it is they *really* need?”

The work in *Staring Back* not only shows that pain is but a small part of living life as a person with a disability. It also challenges us to look anew at the disabilities of FDR and Matisse (Doris Baizley and Victoria Ann-Lewis’s “P.H.*reaks”), the lives of Helen Keller and

Frida Kahlo (Anne Finger's "Helen and Frida"), and the work of Stephen Hawking (Mark O'Brien's "The Unification of Stephen Hawking"); to redefine what is meant by cure (Marilyn Hacker's "Cancer Winter"); to understand hidden disabilities (Edward Nobles's "Heart Ear"); to expand definitions of cross-cultural identities (Nancy Mairs's "Carnal Acts," Lynn Manning's "The Magic Wand," David Manuel Hernández's "Back Problems," Johnson Cheu's "Banana Stealing"); to reimagine the reality and symbol of a wheelchair (Katinka Neuhof's "Blue Baby"); to become familiarized with other ways to speak (Elizabeth Clare's "Learning to Speak"); to hear (Raymond Luczak's "Ten Reasons Why Michael and Geoff Never Got It On," Terry Galloway's "The Engines Are Roaring"); to see (Nancy Scott's "Hearing the Sunrise"); and to read (Stephen Kuusisto's "Learning Braille at 39," Ved Mehta's "Bells"); to realize we are all part of one world (selections from John Hockenberry's "Walking with the Kurds," Adrienne Rich's "Contradictions: Tracking Poems"), not as separate and disparate as we might think.

If asked what, besides the fact that all the work in *Staring Back* has been written by a writer who lives with a disability and that I chose each piece first and foremost for its literary merit, binds together this work, I must reply it is the theme of human connection—connection with the past, connection with one another, connection with our bodies, connection with our selves.

II — ". . . lost to the *crip* world, like Mayan dialects and Incan shopping lists."

Disabled characters shaped by the old moral and medical models of representation have filled the stage for generations. . . . Consider the ease of signaling Good vs. Evil by the addition of a hook, peg leg, or eye patch. Introductory guides to screenwriting actually counsel fledgling authors to give their villain a limp or an amputated limb. The seductive plot possibilities of the medical model with its emphasis on overcoming and cures are irresistible in creating conventual dramatic structure. . . . The medical model also serves as terrific PR for one of the most powerful American myths: the rugged individual who pulls himself up by his own bootstraps. . . . We Americans want our characters to exist outside the forces of history and economics, making it easier to fix things and achieve a happy ending, which, in the case

of disabled depiction, translates into the cheerful cripple who overcomes all obstacles by sheer willpower.

—Victoria Ann-Lewis

Jessica Hagedorn, editor of *Charlie Chan Is Dead*, an anthology of contemporary Asian-American fiction, lists “the demeaning legacy of stereotypes” that is ingrained in American popular culture. She lists Fu Manchu, Stepin Fetchit, Sambo, Aunt Jemima, Amos ’n Andy, Speedy Gonzalez, Tonto, and Little Brown Brother. She discusses how the stereotypical images of Asian-Americans have now evolved into subtler stereotypes such as “the greedy, clever, Japanese businessman, and the Ultimate Nerd, the model Asian-American student, obsessed with work, excelling in math and computer science.”

Those of us who live with disabilities have seen ourselves represented in a similar fashion. As Leonard Kriegel points out in his essay “The Wolf in the Pit of the Zoo,” “images of disability have always been important in Western myth and literature. Probably all cultures link physical handicap to moral culpability. Stigmatization, one suspects, is prehistorical.” For Kriegel, “the classical world saw the cripple as the man defined by others (Hephaestus) and the man defined by his own excess (Oedipus). They balanced the cripple as cuckold with the cripple who goes beyond the boundaries acceptable to the ‘normal.’ ”

In a statement remarkably similar to that of Hagedorn, Kriegel writes: “For generations, blacks were asked to see their lives in the comic obsequiousness of Butterfly McQueen and Stepin Fetchit. An image can become so pervasive that its consequences are swallowed up by the welter of moralistic judgments it calls forth.”

And so it has been for the representation of people with disabilities in literature. The “Demonic Cripple” (Shakespeare’s Richard III, Melville’s Ahab, Mary Shelley’s Frankenstein, the villains in James Bond films) is “not merely physically crippled. . . . He is crippled in the deepest spiritual sense. His injury subsumes his selfhood.” David Hevey, the British disabled photographer and disability theorist, points out, “As these stories unfold, the antihero’s limited and semi-human consciousness glimpses their tragic existence through the cracked mirror of their hatred for themselves. They all live bitterly, with the festering sores of their loss, until their self-destructive rage explodes on to the world.”

The Demonic Cripple inspires fear. Whereas the Demonic Crip-

ple's spiritual opposite, the "Charity Cripple" (Dickens's Tiny Tim, Melville's Black Guineau), according to Kriegel, functions "to perpetuate in his audience the illusion of its own goodness." These characters "charm because they relieve guilt. The Charity Cripple, ever evident on telethons, inspires pity." Kriegel points out that both the Demonic Cripple and the Charity Cripple define the disabled person from outside their existence, "one image reflecting the culture's fears and taboos, the other its sentimentality and aspirations."

The onset of the Civil War and society's increasing industrialization, with its demands made by the more rapid pace of machines and production lines geared to nondisabled norms, both gave rise to an increase in the population of those who live with disabilities. In fact, Victor Finkelstein, the first disabled social scientist to put forth a theory that shifts the discussion of disability away from the personal tragedy and medical view of disability, persuasively argues that it is with industrialization that the disabled for the first time began to be segregated out into the class of "deserving poor," as opposed to the "undeserving poor" (those who were physically able but did not work). This segregation was often literal, as asylums, hospitals, and segregated schools were created to deal with the disabled who were excluded from what Hevey calls the "time-as-money norm."

Both Finkelstein and Hevey point out that it was during this phase that the relationship between the disabled and society becomes a paradox of mutual dependency—the disabled dependent upon the "impairment specialists workers" or "the disability professions" that were geared to either care or cure; and the institutions and their employees now capitally dependent on those who depend on them.

But after industrialization, even with the advent of the Realist novelists such as William Dean Howells, those in the United States were still not forced by their literature to look at the actual lives of those who were disabled. Nor were these new social relationships dealt with in our novels and on our stages as the nineteenth century expired.

It is not until the 1930s and 1940s that we see a change in the attitude of American writers. But once again, as Kriegel points out, instead of the actual lives of the disabled being examined and portrayed, in work by writers such as Nathanael West, Dalton Trumbo, Nelson Algren, and Carson McCullers, we see depictions of the dis-

abled, though still horrific, “come increasingly to reflect the values of being an outsider for writers who have growing doubts about the society spawned by insiders.” In other words, the reality of living with a disability is not depicted, but disability becomes a stand-in, a metaphor, for the social outcast, who is marginalized, misunderstood.

Kriegel ends “The Wolf in the Pit of the Zoo” with a look at the “by no means central character” of William Einhorn in Saul Bellow’s *The Adventures of Augie March*. In Einhorn, Kriegel identifies another literary classification of the disabled: the Survivor Cripple, “who is stronger than those on whom he is dependent.” Bellow writes: “He wouldn’t stay a cripple, Einhorn; he couldn’t hold his soul in it.”

Looming behind the Survivor Cripple is the image of Franklin Delano Roosevelt, who has arguably done more than anyone else to put forth the image of the disabled person who succeeds despite his disability, by overcoming it. With this image of FDR we are firmly rooted in the medical model of disability. According to this model, disability is defined by the impairment and how an individual deals with the impairment, as opposed to the more current notion that disability be seen as a category defined by a social structure that does not allow full participation of the disabled in the life of the culture.

To most, FDR is viewed as overcoming his disability because he went to great lengths to keep the true nature of his disability hidden. But to John Hockenberry, a fellow wheelchair user, FDR “was the champion self-loather who was never photographed in a chair during his lifetime and made a deal with the press corps that he was never to be even seen in crutches.”

Hockenberry points out that if “FDR had done wheelies or had worked out advanced transferring techniques on the White House furniture, that information is lost to the cripp world, like Mayan dialects or Incan shopping lists.” To this day, as evident in the decision not to show FDR in his wheelchair in the original design for the memorial currently being built on The Mall in Washington, D.C., details of history have been, “put out with the trash,” suppressed to disabled and nondisabled alike.

The damage done by this medical model of disability has been considerable. If an individual is defined by his or her ability to overcome a disability, he or she is viewed as a failure if unable to do so. Instead of seeing the forces outside the body, outside the impair-

ment, outside the self, as essential to a disabled person's successful negotiation with an often hostile society (whether the barriers be financial, physical, or discriminatory), this view of disability, where cure and eradication of difference are the paramount goals, puts the blame squarely on the individual when a physical impairment cannot be overcome.

Historian Longmore, echoing Finkelstein, points out that this medical model also provides for great economic benefit to those interests which include "vendors of over-priced products and services; practitioners who drill disabled people in imitating the 'able-bodied' and deaf people in mimicking the hearing; a nursing-home industry that reaps enormous revenues from incarcerating people with disabilities." This model creates a class of "incurable" persons with disabilities who are "confined within a segregated economic and social system and to a socioeconomic condition of childlike dependency."

But that's not all. The defining of the disabled individual by what he or she can and cannot physically achieve, how productive he or she might or might not be, comes with great psychic cost. When the only choices deemed viable—kill it or cure it—are choices that would erase the disability, what does this say about how society disvalues disabled lives?

As we move away from viewing disability within the confines of the moral and medical models, we are moving toward a social definition of disability. As Finkelstein so concisely states, whereas in the medical model the "focus of attention is firmly on the physically impaired individual," now it shifts to where "the focus is the nature of society which disables physically impaired people."

That the disability experience is not solely rooted in bodily impairment is evidenced by how the definition of disability changes from society to society. What is considered a disability in some societies, for example club- or flatfeet, is not considered a disability in others. And what was considered a disability in our culture years ago would no longer be considered a disability today. Consider poor eyesight before eyeglasses. For example, in a preliterate, agrarian society, visual acuity, the need to read print or traffic signs, was not necessary or could be compensated for.

Viewed from this perspective, it is clear that it is the barriers, both physical and attitudinal, that need to be changed, not the impairments or the bodies with which we live. I have asked many dis-

abled persons what causes them more difficulty, the disability itself or the discriminatory barriers put in their way. The answer is overwhelmingly the latter.

The experiences of those with disabilities prove there are countless different and effective ways of moving through the world. But old models die hard. Literature, which reflects the richness of the different ways we conceptualize how we live within the world and the ways the world lives within us, thankfully does not, and should not, conform to the dictates of current political or social discourse. In *Staring Back*, along with the literature that clearly espouses the social model of looking at disability, can be found vestiges of the moral and medical models of disability that have been internalized. We come up against these habits of thinking in ourselves as much as we actually come up against them in our daily lives.

However, what distinguishes the creative nonfiction, poetry, fiction, and drama in *Staring Back* is that each work chosen is the product of a disabled writer's encounter with his or her disability experience. Whether it be reflected in the poems of Larry Eigner, whose disability profoundly affected the work's actual composition, or the fiction of Marcia Clay, whose experience as a young woman with cerebral palsy is strikingly rendered in "Wolf," at the center of each work is an experience told from the perspective of a writer who lives with a disability. (This is so even when the work's central focus is not disability or a disabled character, as in Andre Dubus's luminous "Dancing After Hours.")

What differentiates the oppression and discrimination of the disabled from other traditionally marginalized groups is that in one quick instant—a slip in the bathtub, a virus-borne disease—anyone can join us, the disabled (currently estimated at 49 million in the United States). In fact, at some point in our lives, each and every one of us, sooner or later, will be, whether for short term or long, in some way disabled. Because of this fact, those of us who live with disabilities are viewed with a fear, though irrational, that is perhaps too easy to understand. (And if there's one thing those who live with disabilities understand it is change; e.g. Barbara Rosenblum's "Living in an Unstable Body.") Ultimately, those of us who live with disabilities are too often treated as unwelcome reminders of the mortality that is the fate of us all.

III — “*The task is to explore or create a disability culture*”

Beyond proclamations of pride, deaf and disabled people have been uncovering or formulating sets of alternative values derived from within the deaf and disabled experience. . . . They declare that they prize not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community.

—Paul K. Longmore

A lot has happened during the seven years since I first began to write about my experiences living with a disability. In 1990, the process, which began in 1968 with the Architectural Barriers Act and sections 504 and P.L. 94–162 of the Rehabilitation Act of 1973, culminated in the passage and signing into law of the Americans with Disabilities Act, called the most far-reaching civil rights legislation since the Civil Rights Act of 1964. As historian Longmore points out, with the ADA’s passage, even as the “quest for civil rights, for equal access and equal opportunity, for inclusion” continues, we have moved on to a second phase, which he defines as “a quest for collective identity” in which “the task is to explore or to create a disability culture.”

In many ways, *Staring Back* mirrors this very quest. In 1994, I was invited to and participated in the historic “A Contemporary Chautauqua: Disability and Performance,” organized by Victoria Ann-Lewis, director of Other Voices, at the Mark Taper Forum in Los Angeles. That April weekend, prominent artists with disabilities gathered from all across the United States to perform, read, teach, learn, talk, and get to know one another. That we had something valuable to offer was evidenced not only by an audience hungry to share our work, not only by the overcrowded classes, the sold-out performances, the TV camera crews from CNN and WNET, but also by the lasting nurturing relationships forged by many of the participant artists.

When leaving Los Angeles, I did not know the writing I was exposed to that weekend would eventually form the core of this anthology. But returning home, I knew I was not alone in my struggle to give voice to the disability experience, an experience which throughout history has been marginalized or coopted, if not ignored. It is my hope that *Staring Back* is just one step in an ongoing effort to bring the lives of those of us who live with disabilities closer

to the center where a truer understanding of the richness of our lives can be forged.

Kenny Fries
Northampton, Massachusetts
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