Meditation, Disability, and Identity
Susan Squier

Since we are all Crips in one way or another, it is well worth learning the truth of what must befall us some day, even if it hasn’t already started (it has).

Lorenzo Milam, *CripZen*

After all, when all identities are finally included, there will be no identity.

Lennard Davis, *Bending Over Backwards*

[C]lassifications should be recognized as the significant site of political and ethical work that they are. They should be reclassified. . . . There is no simple unraveling of the built information landscape, or, *pace* Zen practice, of unsettling our habits at every waking moment.

Bowker and Star, *Sorting Things Out*

I have practiced Zen meditation for a number of years now. Maybe that is why, when I noticed that a number of disabled people have taken up meditation and written narratives about it, I became interested in what meditation has to teach us about disability (and vice-versa). Seated meditation, or *zazen*, involves learning to “think not-thinking,” according to Zen Master Dogen.1 Zazen consists of the moment-to-moment encounter with *what is*: the thoughts that flow through the mind; the feelings that pass through the body; and the occurrences in one’s surroundings as they come into being, and fade away.

An examination of three narratives written by disabled meditators reveals how Zen meditation might illuminate the relationship between disability and identity, as well as what Buddhism might learn from the experience of disability. Lorenzo Milam writes *CripZen: A Manual for Survival* from the perspective of a postpolio paraplegic.2 Joan Tollifson,
whose right hand was severed in utero by a strand of amniotic tissue, traces her journey from alienated marginality through disability activism to committed meditation practitioner in her *Bare-Bones Meditation*.3 Finally, in *The Zen Path through Depression*, Philip Martin investigates the value of meditation to a social worker and psychotherapist suffering from major depression, a disability generally situated on the other side of the mind/body divide from the experiences of Milam and Tollifson.4 In these three narratives, Zen insight is modified by disability insight, so that meditation acts as a survival aid for the disabled person at the same time as the experience of disability modifies the notion of meditation, introducing itself as a new form of Zen practice. But what of narratives written not by disabled meditators, but by those who treat the disabled? If we examine two recent studies by medical and psychological professionals who use meditation as a mode of treatment, we can see that the two-way traffic between meditation and disability is given another twist in clinical texts written from the point of view of the practitioner.5 As I will explore, the result is a paradoxical identity position with challenging implications for disability studies.

Milam, Tollifson, and Martin arguably have very different experiences of body and mind, given their very different disabilities, but through meditation they learn the inadequacy of any simple construction of the disabled identity, whether universalizing or minoritizing.6 To frame a universalizing view of disability would be to say, with Lennard Davis, “People with disability: they are you.”7 Such a view extends disability from a narrow category of difference to a broad category with, sooner or later, universal applicability. Viewed this way, the identity category of disability is porous; as it reconceptualizes ability, it decenters the norm. Philosopher Eva Kittay makes strategic use of this position when she argues that disability is characterized by the dependency that all human beings share at least twice in our lives: when we are infants, and when we are very old.8 The minoritizing view retains the concept of “normal” and holds that only the person with a disability has the right to represent the disabled. As James Charlton puts it in his study of disability rights activists around the world, “This is a militant, revelational claim aptly capsulized in ‘Nothing About Us Without Us.’”9 The slogan asserts marginality in order to claim representation as disabled Others, a strategy distinct (in philosophy and in historical use) from the universalizing claim that disability is an inevitable life experience.10

These narratives by disabled meditators point to an epistemological or representational gap between the embrace of disability as a
collective constructed identity and the Zen-influenced surrender of any notion of identity at all. This gap is reflected in the uncertain genre of these texts, all of which offer what might be called the “situated knowledges” made possible by meditating with a disability. This term, which has a Zen-like paradox at its core, I draw from Donna Haraway, who describes it as “an ungraspable middle space”: “even the simplest matters in feminist analysis require contradictory moments and a wariness of their resolution, dialectically or otherwise. ‘Situated knowledges’ is a shorthand term for this insistence.”

Lorenzo Milam’s *CripZen: A Manual for Survival*

Lorenzo Milam contracted polio in 1952, as an eighteen-year-old Yale undergraduate. His dazzling, angry memoir, *The Cripple Liberation Front Marching Band Blues* (1984), recounts how he fell ill with polio just two weeks after his twenty-nine-year-old sister did.12 (She would soon die of the disease.) A pioneer organizer of nonprofit radio stations, Milam wrote the classic handbook, *The Original Sex and Broadcasting: A Handbook on Starting a Radio Station for the Community*. Under the pseudonym Carlos Amantea he published *The Blob That Ate Oaxaca*, which was nominated for the Pulitzer Prize in 1992, while as “Pastor A. W. Allworthy,” he investigated the tensions between the views on disability articulated in the Bible and Zen Buddhism. Milam abandoned the play with alternate identities in *CripZen*, however, which was published under his own name in 1993. He gave it the subtitle *A Manual for Survival* and addressed it to “those of us who have lost the use of part or all of our bodies. . . . With or without a label,” he says, “we know who we are” (vii).

A compilation of pieces Milam wrote when he was “disability-sexuality columnist” for *Independent Living*, articles for other disability periodicals, reviews, and National Public Radio broadcasts, *CripZen* offers its readers a way of getting free “of the prisons: those we build for ourselves, and those created by people trying to help us” (171). Milam introduces the reader to a range of strategies including psychotherapy, hallucinogens, yoga, forms of sexuality ranging from sex surrogacy and masturbation to celibacy, and, in the title chapter, training in Zen meditation. All of these methods spring from what Milam calls his “two articles of faith.” The first article is that each person with a disability will one day experience not just the revelation of “our new life” as disabled people, but what he calls the “Second Revelation”: the
realization that “our great bravery, our seeming acceptance of fate, the splendid triumph of spirit over physical self—these were all put-up jobs” (x). Milam explains that the pain of this discovery is almost overwhelming: “Once we come to the knowledge of the deception we have imposed on ourselves and on others, we find ourselves immersed in a new pain, and a bitter, bitter sadness. This can be fatal, as fatal as our first grief-at-loss” (xi). Milam suggests that the Second Revelation is responsible for the “possible fifty percent suicide rate” among “Crips. You and me” (ix). To combat that threat, Milam responds with mordant humor by modifying Kubler-Ross’s five stages of dying to produce “five stages leading to CripZen”:

Stage I. I am not a Crip;
Stage II. I’m a Crip and I can’t take it;
Stage III. I’m a Crip, but I can beat it;
Stage IV. I’m a Crip, I can beat it—but I am Still a Crip and I can’t take it;
Stage V. I am that I am. (223)\(^{13}\)

“How to get from I to V without going under is the subject of this book,” he explains (xii). That the Second Revelation “doesn’t have to kill you,” Milam offers as his “second article of faith.” “Once you stumble across the truth of your being, . . . [it] will become part of your survival mechanism, one that even you won’t be able to take from you. With it you can forge a powerful new system for dealing with a new world” (xi).

CripZen does more than explore what meditation can do for the disabled; it demonstrates what disability consciousness can do for meditation, and then it goes beyond that to demonstrate the limitations of both. While his CripZen dharma recalls the traditional, repetitive, oral form of Buddhist sutras, it also subverts the authority of traditional Buddhism, challenging its normalizing foundations. Milam critiques Buddhist teachings for their ableist assumptions: “Some masters tell us that we can only do meditation in the lotus position. Obviously, they haven’t gone through Rehab” (192). With his ironic refrain, “You and I might be in an especially good position to study this,” he asserts that the disabled meditator holds a privileged position as dharma student.

Milam’s survival guide for the new world of disability has a central paradox: it simultaneously celebrates and relinquishes the body, mourning and embracing the disablement that is central to its loss. As he explains in the book’s preface: “I must accept reluctant responsibility
for the contradiction of CripZen—that is, that I offer a plea for Good Sex and Good Mental Health while at the same time offering a Zen model of Forget-The-Body Quiet-The-Mind” (viii). Notice the two-way traffic here. Zen meditation modifies the experience of disability, while disability modifies Zen practice.

While the book’s title chapter opens with the assertion that “CripZen begins the day you wake up and know that you no longer own your body,” Milam is far from arguing that when disablement occurs the longing for an able body has vanished, or even should vanish. Rather, Milam harnesses the paradoxical perspective of Zen doctrine to the goal of disability equity, offering in the concluding chapter a comic vision of the embodiment he would choose if he were reincarnated:

I would still like to have the chance to work out with someone else’s body for a change. Jane Fonda’s, say. . . . Or the dusky, sunny fisher-lad we saw . . . in Puerto Perdido. . . . The one with the great sloe eyes, and the body like chocolate glaçé, and the great quadriceps. . . . If they want me to come back with any real enthusiasm they’ll have to stuff me into a body like that . . . I simply refuse to come back as a Crip gringo anymore, with all that dysfunctional plumbing, arms and legs that don’t work worth shit, ridiculous aches and pains that take up too much of my days and nights. (250)

Milam imagines persuading the divine powers to give him a beautifully functioning body by promising that he will “give up everything when I get through with the usual teen-age indiscretions. After just a few short years, I’ll become a holy man, a wandering saddhu.”14 To some readers of this essay, Milam’s articulation of the yearning for a nondisabled body suggests that he is stuck at stage four of the five stages leading to CripZen: “I’m a Crip, I can beat it—but I am Still a Crip and I can’t take it.” Yet I read this somewhat differently. Milam’s text both challenges and affirms the meditation-born insight that we truly do not own or control our own body. Whether we are disabled or able, the physical pleasures of our existence are transient, with pain being a recurrent, inevitable reality. Milam makes the universality of this Zen insight explicit in a footnote: “It’s a Western concept that we can wage a war with the body and—with sufficient determination—win. The truth is that none of us can triumph in a battle with our own mind, body, or soul” (x). In fact, the very notion of life as an attempt to triumph over the mind, body, or soul is beside the point, as absurd as the advertising slogan I have taped to my file cabinet: “In 28 minutes
you’ll be meditating like a zen monk!” Time is not our enemy, but the very condition of our being, to be accepted, even celebrated.

Joan Tollifson’s *Bare-Bones Meditation*

The power of meditation as an alternative to doing battle with the body or the mind is also central to the disability narrative of Joan Tollifson. Born without a hand, Tollifson grew up with a sense of herself as damaged, a construction of her identity reinforced by physicians, family, and strangers alike. Right after her birth, her doctors engaged in a curious performance:

Newborn, I was brought to a room where there was a large pillow. My father was called out of the waiting area and taken to this room by the doctor. My father was left alone in there with me and the large pillow. He understood finally that he was being given the chance to smother me. But he didn’t do it.

The doctor knocked. “Are you finished yet?” (1)

As a child, she says, she felt like “a kind of oxymoron. Sometimes strangers on the street would tell my mother that we were being punished by God. . . . The central theme of my life was thus in place early: I was different, asymmetrical, imperfect, special. . . . When I was very small and first heard about death, I dreamed recurrently about a person whose arm fell off, then the other arm, then each leg, until nothing was left. I was already on my way toward this mysterious disappearance” (2). Starting with that core sense of herself as imperfect but “special,” Tollifson gradually took on other identifications: as lesbian, as alcoholic, and finally as disability activist, one of over a hundred people who in 1977 occupied the San Francisco Federal Building for a month in support of civil rights for the disabled. The experience taught her that, “In the same way that gay people automatically understand that gender roles are mostly an arbitrary construction, disabled people automatically understand something about the illusory nature of our attachment to the body, and our ideas about what’s normal” (21). After the Federal Building occupation ended, Tollifson found a copy of Shunryu Suzuki’s classic, *Zen Mind, Beginner’s Mind*, and began to meditate, an experience that confirmed the way she had already come to understand her identity, as that of a disabled person. As she explains, her childhood dream of the person losing body parts,
working her way “toward this mysterious disappearance,” anticipated the encounter with “no-self” that is central to Zen practice.

Yet Tollifson’s experiences as a disability activist and a lesbian woman made this kind of surrender of self (and of the fantasized control over the self) problematic, for reasons she was helped to understand by Mel Weitsman, abbot and teacher of the Berkeley Zen Center: “He said that Zen practice is perhaps particularly challenging and difficult for people like blacks or gays who are working on finding their identity in a certain sense, or regaining it, because this practice is about having no identity at all” (90). Moving beyond static categories, the practitioner of meditation encounters a time that is no time (and all time), a self that is no self (and all selves), and a space that is both no space and unlimited space. The very concept of identity, as the embodied union of a finite discrete mind and a finite discrete body, is revealed as an inadequate model for the richly complex perspective and experience meditation brings into being. In her memoir, Tollifson articulates this transformed understanding of identity in a way that reflects the influence of her teacher, Toni Packer, who after studying with Roshi Philip Kapleau at the Rochester Zen Center eventually abandoned the formal trappings of Zen practice, stripping meditation down to its bare bones. Packer’s modification of Buddhist dharma converges productively with Tollifson’s own phenomenological understanding of physical disability in a metaphor at once whimsical and ironic. Tollifson explains:

Toni’s work is like realizing that we’re all put here in various bizarre costumes: black skin, white skin, amputations, old age, cerebral palsy, Down’s syndrome. Some people get more bizarre costumes than others, but everyone gets one, without exception. And then no one really sees anyone else. We see the costume. We can’t get past it. Some people never even realize they’re at a costume party. (91)

Tollifson explains how her metaphor of life as a costume party articulates the reconfigured notion of identity as “no-self” that Zen meditation teaches:

I experience myself as a regular person who happens to be wearing this strange costume without a right hand. (A friend of mine in California calls her German shepherd the one in the dog suit, and that’s sort of how I feel, like the one in the amputee suit.) (91)

Tollifson’s metaphor not only builds on Packer’s work as a meditation teacher, but critiques it as well, talking back to Buddhism by challeng-
ing what lies beneath the metaphor of life as a costume party. Her
image offers a disability-based reformulation of the Zen practice of no-
self, by revealing the unexamined *normate* assumptions of Zen doctrine.
The term is Rosemarie Garland-Thomson’s, and it refers to “the con-
structed 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.”16

Garland-Thomson connects the binary oppositions that structure
normate and non-normate identities to the binary oppositions unhelpfully
structuring homo/heterosexual identities: “Naming the figure of the
normate is one conceptual strategy that will allow us to press our
analyses beyond the simple dichotomies of male/female, white/black,
straight/gay, or able-bodied/disabled so that we can examine the subtle
interrelations among social identities that are anchored to physical
differences.”17 While meditation may afford the valuable insight that
we’re “all put here in various bizarre costumes,” that metaphor for the
disabled identity is minoritizing at its core, and the internalized normate
self on which it relies has a high cost for a disabled person. If he or
she accepts that notion of being a “regular person” just *disguised* as
disabled, the result is a failure to be recognized—either by others or
even by oneself—as fundamentally human in one’s disability.18

If a fundamental principle of sitting meditation is continual refusal
of all categories and judgments in service of a return to an embodied,
present experience, this practice cannot be complete if the embodied self
is assumed to be normate. In “Unspeakable Conversations Or How I
Spent One Day as a Token Cripple at Princeton University,” Harriet
McBryde Johnson recounts her debate with Peter Singer over assisted
suicide and euthanasia of disabled newborns. Johnson is a disability
rights activist and attorney; Singer is a philosopher whose appointment
to the faculty of Princeton University stirred controversy because he
advocates both animal rights and the euthanizing of disabled newborn
human beings. The article juxtaposes a detailed narrative of the physical
obstacles Johnson must overcome to deliver her lecture at Princeton
(repairing her wheelchair when it is damaged in transit, finding an
accessible hotel room, arranging for food she can swallow, navigating
an inaccessible college campus, and so on) with a minutely observed
response to Singer himself. She concludes with the surprised awareness
that she doesn’t hate Singer or find him repellent. The cost would be
too great: “If I define Singer’s kind of disability prejudice as an ultimate
evil, and him as a monster, then I must so define all who believe
disabled lives are inherently worse off . . . I can’t refuse the monster-
majority basic respect and human sympathy.”19
Disability activist James Overboe challenges Johnson’s refusal to condemn Singer: “As a sociologist my work centers on how humanism continues to devalue the vitalism of physical, emotional, intellectual and psychiatric disabilities in the name of a ‘common sense’ and normality. And Singer’s position, along with other forms of humanism that promise a better world like eugenics, the human genome project all point to a conflation of liberal individualism (choice) and the longing for a nostalgic ‘normal’ community.” Overboe’s point is that the attempt to achieve inclusion in the human community produces a repression of the phenomenological presence of disability, and at a cost: “I have been accepted by others because of my intellectual ability, but at a cost—I cannot embrace my cerebral palsy and its spasms that are a central part of me. . . . When I am caught up in the ‘madness’ of humanism by someone allowing me to join them I defer to them and humanism and continually find myself censoring my disabled vitality and losing my authentic voice and presence.”

Overboe argues, “Our experience of disability must be embraced in order for there to be the creation of a new meaning of life.” The phrase recalls Milam’s fifth stage of the CripZen experience, the paradoxical “I am that I am,” as well as Tollifson’s insight on her last meditation retreat: “Somehow for me these days there’s a much more profound power in allowing things not to be okay. . . . These specters that we think will be the death of us turn out to be straw tigers in the end. What we are fundamentally does not get hurt, rejected, or killed” (202–3). By the conclusion of Bare-Bones Meditation, Tollifson has moved beyond the notion that she has a “regular self” beneath her “bizarre costume.” Instead, she embraces her most stigmatized self, asking “Is it so terrible, really, to be an ugly, depressed cripple?” (203).

There are some problematic implications for disability activism in this embrace of what is—“allowing things not to be okay”—associated with the meditative encounter with emptiness. While the affirmation of her most socially discredited self signals Tollifson’s acceptance of disability on an individual level, she does not move to the next level, to realize that human consciousness is relational, “immanent in the living body and the interpersonal social world.” This realization of interbeing—the term used by Vietnamese Buddhist teacher Thich Nhat Hanh—gives rise to the political and ethical understanding that all human experience, including the experience of disability, incorporates, implicates, and exists in relation to both the natural environment and human society. Tollifson’s use of Buddhist dharma to achieve personal peace in the face of pain is heartening. Still, how much more would she have benefited
from the teachings of engaged Buddhism, which might have shown her a way to reclaim the activist passion that led her to disability consciousness in the first place?

The Zen Path through Depression

Can an exploration of the temporal and spatial qualities of depression also serve as a disability narrative? We can explore this question by considering the memoir of Philip Martin, who found himself at age thirty-seven unexpectedly struggling with a severe depression. A psychotherapist and psychiatric social worker who had devoted “over a decade working with people dealing with mental illness, including a great number with depression,” Martin did not initially even have a name for what he was feeling. Nor could he find for himself the compassion and understanding he displayed towards his clients, whom he “encouraged . . . to keep an open mind about things such as counseling and medication” (87). Instead, he reports, “I felt that surely my own depression was the result of some weakness on my part, and that I did not need any outside help” (87). Although people tried to confront him with “what was obvious to everyone else,” it was not until his three-year-old son asked him simply “Daddy, are you not happy?” that he finally broke through his isolation and denial (11). Only then could Martin draw on his years of Buddhist meditation and respond to his depression with what is called “beginner’s mind”: not categorizing it or attempting to fix it, but simply experiencing it as it was in the moment.

In The Zen Path through Depression, Martin recounts the experience of becoming lost while on a canoe trip with two friends, in the wilderness of Northern Ontario, Canada, when he was seventeen years old. “A long rapids and waterfall were not where they were supposed to be, and there seemed to be a lake where one shouldn’t have been. We were lost in unfamiliar territory, and our maps, and all the other resources we depended on within ourselves, were useless” (xi). At thirty-seven, depression plunged him in an experience of isolation, disorientation, and inability to rely on and control his own resources that reminded him of that camping trip. Indeed, Martin suggests that his depression may have resulted from a survival mechanism first developed by that teenaged self, a philosophy he had hoped “would shield me from pain in my life. . . . I called mine the Outward Bound approach to life. Like the people in those solo survival exercises,
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outfitted only with a fishing line, a safety pin, and a match, I resolved to make it through life entirely on my own. I would depend on nothing and no one except myself” (58).

*The Zen Path through Depression* is a map to a territory that is both specific to one disability—the psychological and psychiatric disorder that is major depression—and also characteristic of the universal challenge articulated in the couplet from Dante that serves as Martin’s epigraph: “in the middle of the path through life, / I suddenly found myself in a dark wood” (xi). While his book can be appreciated by anyone who has experienced depression, it draws specifically on the conceptual and emotional structure of Zen Buddhism. Martin studied at the Minnesota Zen Center with Dainin Katagiri Roshi, the Dharma successor to Shunryu Suzuki. *The Zen Path through Depression* consists of a series of “explorations” of the experiences of pain, impermanence, death, fear, desire, doubt, grief, the desire for escape from pain, the habit of discrimination, and anger. Martin establishes a theme for each meditation session based on one of the “Four Noble Truths,” the fundamental teachings about the nature of all human experience: the existence of suffering, the origin of suffering, the cessation of suffering, and the path to the cessation of suffering.24 Each chapter addresses the role the specific experience (of pain, of impermanence, of awareness of death, for example) plays in depression and offers a suggestion for “further exploration” that consists in merely observing the experience without judging, fighting, or attempting to control it. Modeling the encounter with depression on the encounter with no-self that is the core of meditation, Martin presents exercises through which the meditator can explore the psychic, physiological, social, and spiritual territory that depression reveals, *before* moving into any explanatory or curative response.

Perhaps because Martin is dealing not with the visible physical immobility, pain, and sexual isolation of postpolio paralysis, or the visual difference and stigma of Tollifson’s missing hand, but rather the invisible mental immobility, pain, stigma, and social isolation of depression, he does not explicitly use the term “disability” to characterize his depression. Unlike Milam and Tollifson, Martin never explicitly self-identifies as disabled. Rather, he turns to the Buddhist notion of the “middle path” as a useful model for his condition: “the middle path walks the line between . . . seeing existence as real and seeing it as an illusion. This middle path is a difficult path to follow, because it is utterly dynamic. It often requires us to hold two contradictory ideas in our minds at the same time. It means balancing on the razor’s edge,
and avoiding the temptation of easy answers” (81). As Martin applies the concept of the middle path to his depression, it produces consequences that are material, social, and medical:

In our struggle with depression, this can mean standing in the midst of uncertainty. The uncertainty between solving all our problems with medication, and refusing to consider medication as an option. The uncertainty between viewing depression as merely a physical illness, and viewing it as a condition brought on by psychological conditions and poor coping skills. The uncertainty between working hard to heal, and just letting go and giving up trying to force a solution. (82)

How do we understand Martin’s reluctance to identify as disabled? We could understand it as residue of his chosen identity as a therapist—someone who helps others rather than being helped—as well as a symptom of the shock of loss of mastery entailed by the forced surrender of such an identity. Certainly when Baba Ram Dass (Richard Alpert) had a stroke in his sixties, he felt discomfort at being forcibly evicted from the helping role, as he acknowledges in his memoir, Still Here. Yet the significance of that experience, Ram Dass argues, lies in exploring what the transition from helper to helped can teach one.25 For Martin too, I would argue, his previous role as therapist coupled with his present experience of depression enables a release from recourse to labels, whether to pathologize or to normalize.

Despite their different levels of identification as disabled, however, all three writers use the experience of meditation to move from a specific focus on their impairment to a broader understanding that physical vulnerability is fundamental to all lives. As Tobin Siebers puts it: “The cycle of life runs in actuality from disability to temporary ability back to disability, and that only if you are among the most fortunate, among those who do not fall ill or suffer a severe accident. . . . It has often been claimed that the disabled body represents the image of the Other. In fact, the able body is the true image of the Other.”26 What their narratives do not seem to explore fully, however, is the means by which an encounter with one’s own vulnerability and connectedness to others can provide a position from which to launch a critique of the social construction of disability as well as a program for remediating social action.
What if we turn from the perspective of disabled people to the perspective of those Others—the medical and psychological personnel who treat the disabled, using meditation to that end? From examining how the practice of meditation reconfigures and illuminates the nature of disability as identity, I now ask how the therapeutic use of meditation shifts the conception (and experience) of identity (in particular, the response to difference) deployed in medical practice. I make this move, from memoir to medical treatment narrative, deliberately in order to resist the belief that experience figures as a category worth exploring only in pathographies or disability memoirs, whereas medical treatment narratives are objective and nonexperiential.

Two recent studies reporting on the use of meditation as the core of a medical treatment program for illnesses ranging from psoriasis, cancer, heart conditions, and rheumatoid arthritis to asthma and major depression demonstrate that the identity of the medical practitioner undergoes a reformulation as marked as that we found with disabled meditators. These texts, Jon Kabat-Zinn’s *Full Catastrophe Living* (1990) and the less evocatively titled *Mindfulness-Based Cognitive Therapy for Depression: A New Approach to Preventing Relapse*, by Zindel V. Segal, J. Mark G. Williams, and John D. Teasdale (2002), demonstrate a new mode of medical practice much more responsive to (and respectful of) a wide range of cultural and biological differences. They also embody the beginnings of a hybrid textual genre yoking a scientific presentation of protocol for medical treatment to a more diverse aesthetic and performative narrative of individual and even collective identity transformation.

Where does difference fit into this new paradigm for health care? Difference of all kinds is understood as a crucial, and previously unacknowledged, factor in illness causation. “There are many diseases whose origins . . . are intimately linked to social factors such as poverty and social exploitation, dangerous working conditions, stressful and poisonous environmental conditions, and culturally entrenched habits, all of which are outside the direct influence of medicine and science as they are presently organized.” Indeed, Kabat-Zinn’s book can be understood as a boundary object between the worlds of mindfulness meditation training and clinical medicine, as evidenced by the mix of professionals whose praise is quoted on the back cover: four physicians (one on the faculty of Harvard Medical School), the director of an addictive behavior research center, and the founding head of the Insight
Meditation Society (Barre, Massachusetts). A new openness to difference extends to discursive conventions, too. Both the texts of Kabat-Zinn and Segal et al. combine the reevaluation of categories with what I have called discursive hybridity. By this I do not mean that they co-opt Eastern spirituality into the Western medical paradigm, although that is arguable, but rather that they incorporate aspects of traditionally literary and humanistic discourses into the framework of medical science. So Kabat-Zinn’s book transcends the cultural and disciplinary boundaries that have allocated medicine to the realm of positivist instrumentality while confining literature to the realm of aesthetic value enhancement, from its title Full Catastrophe Living, drawn from Zorba the Greek, to its concluding citation of Pablo Neruda’s poem “Keeping Quiet.” Moreover, the generic hybridity is intimately related to the reversal of perspective that the book advocates. Just as the disability narratives discussed earlier portray how the experience of disability has—through the practice of meditation—opened out to an understanding of the impermanence, vulnerability, and dependency central to all lives, so here the use of meditation as a medical treatment opens out from the narrow focus on illness, pain, and loss of control to a broader project of integrating the vicissitudes inevitable in life within an experience of health and well-being.

Similarly, Mindfulness-Based Cognitive Therapy for Depression by Segal, Williams, and Teasdale reveals both medical and discursive innovation. The three cognitive psychologists who wrote the study made the specific decision to depart from the standard scientific publication format. Instead they recount the following:

The story of their own learning in encountering and then testing a very different paradigm from that in which they were trained professionally and in which they were recognized as experts. This is an unusual approach for a scientific text, as the authors themselves acknowledge, and one that . . . is, in this instance, both admirable and totally appropriate to accomplish their professional purposes given the subject matter.

This work echoes the generic hybridity of Full Catastrophe Living, being both commercially and formally innovative. In addition to including the charts, tables, and handouts accompanying the eight sessions of therapeutic exercises used in the clinical trial, it even grants the purchaser a “Limited Photocopy License,” specifying that those pages, tables, and charts may be reproduced by “qualified mental health professionals” for
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use with their own clients and patients (copyright page). Then, in a move beyond the disciplinary exclusivity of that limited license, the authors introduce poems, autobiographical narratives, Middle-Eastern teaching stories, and what might be called a scientific parable, as well as an extremely accessible popular science explanation of “the power of randomization” and the procedure they followed in their randomized clinical trial, to broaden its address beyond clinicians to a general audience.

As a result of those scaled innovations, what begins as a distinctly minoritizing construction of disability develops into a universalizing one. Or, to put it another way, what began as a text addressed to physicians and psychologists for treating patients and clients becomes a text addressing anyone who has experienced a life reorientation leading to a broader sense of self. Beginning with the desire to help their clients, previously disabled by depression, from experiencing a relapse, the three psychologists explain how they became motivated to change their own professional and personal practices, not only applying a meditation model drawn from Eastern religion to their Western medical practices, but taking up mindfulness meditation themselves. Though we are now in the realm of clinical case study rather than pathography or disability narrative, once again we find the focus on mindfulness catalyzes the transcendence of specific identity categories. As Segal et al. observe, “A commonality of experience crosses the usual boundaries between researchers, clinicians, and patients. Each has made discoveries from which he or she learned. . . . As it turns out, the wisdom that helps us to deal with tragedies and disappointments is the same wisdom that sees, in the ordinary and everyday things of life, how things change from one moment to the next, often in surprising ways.”

The insight that meditation enables is thus inherently political. Not only does meditation challenge what Lennard Davis has characterized as “the fantasy of culture, democracy, capitalism, sexism, and racism, to name only a few ideologies, [that one can attain] the perfection of the body and its activities,” but when linked to a socially engaged Buddhism it can also support work to eradicate the social and political oppression bred by such ideologies. Of course, as we move from the inevitably limited individual body to those large institutions aspiring to its improvement (and fantasizing its perfection), just as we ask questions about the context in which impairment becomes disability, so too we must ask questions about the context in which meditation becomes medicine. Eve Kosofsky Sedgwick has eloquently traced the paradox inherent in the affective embrace of Buddhist thinking:
The Western reader drawn to Buddhist pedagogical thinking may be most at risk of decontextualizing and misrecognizing it, riding roughshod over its cultural difference, even recasting it in her own image—the worst Orientalizing vices identified by recent critical scholarship—just to the degree that she can apprehend it through a Buddhist sense of knowing rather than a Western one. Conversely, from within the framework of the Buddhist respect for realization as both dense process and active practice, a theorized scholarly skepticism as to whether Buddhism can be known by Westerners may reveal its own dependence on an eerily thin Western phenomenology of “knowing.”

Thus a westerner who feels drawn to Buddhism may be deeply realizing Buddhist dharma precisely by seeing it “as not other than oneself,” even when such an act of recognition seems like the most blatant sort of cultural appropriation. Following that insight, I am more interested now in the instrumental, scientific deployment of meditation in medicine than in making the obvious point about its cultural decontextualization.

As Davis’s reference to broader institutional and ideological forces indicates, we stop short if we focus only on meditation’s effect on individuals, whether the disabled individual seeking relief from her/his disability, or the able physician or psychologist seeking to provide that relief. There will be limitations to the identity transformations enabled by Zen meditation precisely because of its position within a sociocultural and economic field. The multiplication of for-profit alternative medicine centers testifies to the fact that meditation, like medication, is increasingly commodified. Because the work of Segal et al. is informed by a public health perspective, its use of meditation must be considered in that context. Meditation is targeted to a specific population: people who have suffered at least one episode of major depression (or as many as three) and who are at risk of a relapse. The authors comment explicitly on the cost- and time-effective nature of group instruction in meditation, yoga, and other body-based mindfulness technique methods, which can treat a large number of people for the cost and time that would otherwise be used for one person in individual psychotherapy. They offer little space for the explicitly individually oriented perspectives familiar from the narratives by Milam, Tollifson, and Martin. Nor do they adopt a broader systemwide perspective that might be critical of a society that relies on mindfulness training to repair the damages wrought by demanding, high-intensity careers focused on personal or collective productivity rather than personal or collective meaning.
Similarly, Philip Martin’s exploration of the efficacy of meditation is shaped and constrained by the broader institutional structures of disciplinary and professional identity and commodification. Martin’s brave assertion of a liminal identity as a person with depression and as a therapist is enabled by his encounter with Zen meditation only to be undercut by the publisher’s defensive marketing department, which emphasizes Martin’s professional status in its choice of book design. While the text of Martin’s book maps the middle path between a minoritizing and a universalizing view of depression, the publication format ultimately closes off that productive liminal zone with a preface disclaimer firmly resituating Martin in the position of health-care provider, subjecting his reader to the regulatory discourses of medicine and law: “While the techniques described in this book may alleviate symptoms of depression in some individuals, depression is a serious illness that may in some cases require medical treatment by a licensed health-care professional, and readers are encouraged to seek such advice. Neither the author nor the publisher assumes any liability for any injury that may be suffered by any person applying the techniques set forth in this book” (vi).

The impairment/disability system—“the process by which biological impairment is transformed into cultural disability”—plays out very differently in Martin’s narrative than it does in Tollifson’s gradual encounter with the psychic and social meaning of her missing hand and Milam’s furiously funny acknowledgement of his battle with his own self-pity and the condescension of others. The crucial difference between them is the degree to which they are willing to identify as disabled. Ironically, it is precisely Martin’s professional ability as a psychotherapist that may make him unwilling to claim identity as disabled, or to take refuge in the privilege of the physician. The normalizing model still available (in fantasy) to those like Milam and Tollifson who suffer from bodily impairment is not accessible to those who, like Martin, suffer from mental impairment. The prefatory proviso with its careful attention to the potential medical and legal implications of Martin’s advice is “symptomatic of a larger, cultural anxiety surrounding mental illness” that produces materially different identity positions for the mentally and the physically disabled. This is not to argue that mental and physical disabilities are so easily disentangled, of course. All too often people with physical disabilities are treated as though they are cognitively or psychologically impaired as well. Yet to the extent that we can tease them apart, it is worth considering the different social stigma attached—particularly in a clinical or therapeutic
setting—to mental disability. Not only does the discourse of the democratic citizen privilege the intact and autonomous self, but the discourse of medicine figures mental illness as an irreparable, symbolically freighted breach in self-determination. In order for Martin’s book to be of use to the reader desiring clinical guidance, it must be written by someone in command of his faculties.

Disability Koans

This brings me back to the questions with which I began: What experience of identity does meditation catalyze, and what are the implications for disability studies? As I mentioned at the outset, I practice meditation. I began meditating over five years ago, as a way of traversing territory similar to the wilderness that Philip Martin mapped in *The Zen Path through Depression*. In my case the depression followed a painful illness and surgery; through it I have come to know well the genetic and psychic pathways that Martin charts. Do I identify as disabled? That identity oscillates for me, mirroring my changing meditation spaces: in Pennsylvania, a corner in my study; in New York City, a closet in a small apartment. At times, I certainly have so identified: when I have been unable to think clearly because of depression and uncertainty, or when my passion for adventure and play has fizzled out in a drab calm. But at other times, that label has seemed not only incomplete but actually unhelpful because it truncates the sense of spacious possibility that I experience in meditation. And in those times, with Lorenzo Milam, I resist any label at all, preferring perhaps “I am that I am,” even as I laugh or wince at the echo of the Old Testament in the phrase.

Moreover, the indeterminate or variable construction of identity links my experience to the texts I have been considering. Though Tollifson, Milam, and Martin may have turned to meditation as a relief from the pain of their disability, and though Kabat-Zinn and Segal et al. may have deployed meditation as a form of medical treatment, what each group found was less a confirmation of the identity position with which they began (as disabled individuals or as medical practitioners) than a dissolution of that identity, an understanding of its inherent impermanence. To put it another way, the lesson I learned through illness, surgery, and depression was the same one that both the disabled meditators and the meditation-based medical practitioners learned, and
articulated, in the course of their narratives. Lennard Davis expresses the insight as follows: “What is universal in life, if there are universals, is the experience of the limitations of the body.” Because of my experiences with meditation, I note and surrender the identity of disability, understanding it as both characterizing and escaping the moment-to-moment experience of being myself.

What does that oscillating affiliation with disability identity signify, in social and intellectual terms? I would venture first that it marks a high-stakes conflict in disability studies between a rejection of the normate when it is framed as morphological and a privileging of the normate when it is framed as psychological. To put the issue bluntly, if a scholar claims mental disability, and identifies as mentally disabled, can he or she still work as effectively in disability studies? As a scholar? As an activist? Will the university and publishing apparatus within which her/his claims must be made value them commensurately to those of a mentally able, or at least effectively closeted, individual? As one scholar with Tourette’s syndrome said to me, “If I came out as having Tourette’s, the legitimacy of all of my work would be called into question.”

What price disability identity, when the disability is psychological, in a profession that so highly values intellectual clarity and rationality? However, what of Kay Redfield Jamison, the clinical psychologist who has written so bravely and insightfully about her own bipolar disorder? One reader of this essay suggested that Jamison’s successful career proves that such a dual identification—as mentally disabled person and as professional practitioner/scholar—is viable. In contrast, I would argue that Jamison’s iconic status as what some call a “Supercrip” (that is, someone who although disabled performs better than a nondisabled, “normal” person) is the exception that proves the rule. Her fame testifies to the difficulty of drawing on one’s professional authority in service of a devalued and discredited social position. Moreover, physician Steven Miles’s experience of investigation by his professional licensing board following his disclosure that he suffered from “type II bipolar disorder, a mainly depressive disorder, unaccompanied by life-disrupting mania” reveals that non-psychiatrist medical practitioners are similarly jeopardized.

Yet if it is professionally risky to come out as a psychologically or cognitively disabled person, there are dangers lurking in the closet as well. If a disability studies scholar remains closeted as someone who has experienced mental illness (be it depression, schizophrenia, obsessive compulsive disorder, bipolar disorder), how authoritative or legitimate can that disabilities scholarship be? What are the gains and losses
in that act of closeting for those in the disability studies community? What is the ethical and political significance of that choice?

Perhaps we shouldn’t dismiss the example of Kay Jamison. What if we think of it not as enabling an affirmation of disability identification, but as unsettling the stark binary nature of any identity at all? To frame the choice for those who experience psychological disability as a simple binary one—stay closeted as a person with a disability or “come out” as mentally disabled—may be to miss the point. If we expand the disability studies paradigm to reincorporate the insights that Zen meditation has made possible, we can ask ourselves what the implications are of categorizing ourselves in terms of any aspect of mind-body experience.

What do we lose when we refuse our encounter with the imperfect, disabled, physically and/or mentally limited aspects of our embodied selves—those aspects that are necessarily part of living as temporal beings? What “important political and ethical work” do we dodge when we refuse that encounter? Conversely, when we use those aspects to define ourselves, how have we silenced our experiences as selves that are strong, able, and richly alive? What is the personal, even spiritual price of that tactically important political and ethical act? What moments of meaning, what encounters with wisdom do we thus forgo when we accept the stasis of a label? Conversely, what are the effects of that refusal on our scholarship, whatever our identification? How might that refusal be of a piece with the motive to normalize and pathologize, or to cling to the fantasy of a perfect self by positing a rejected, physically and/or mentally imperfect Other? These are not so much questions to answer, or even problems to solve, than they are koans: intellectual, social, legal, and ethical paradoxes, arising from the experience of disability, that merit our collective meditation.

NOTES

My thanks to Jonathan Metzl and Suzanne Poirier, to the readers for Literature and Medicine, and to the Six Rings Sangha.

1. According to Zen Master Dogen, when one learns the “essential art of zazen” then the “body-mind of itself will drop off and your original face will appear.” Zen Master Dogen, “Recommending Zazen to All People,” in Enlightenment Unfolds: The Essential Teachings of Zen Master Dogen, ed. Kazuaki Tanahashi (Boston: Shambhala, 2000), 32–3. In her discussion of the issue of surgical modification of the faces of children with Down’s syndrome, Janet Lyon has identified another site where a conversation between Buddhism and disability would be illuminating. There is important tension between the Zen model of seeing one’s original face and the “long historical effort on the part of normative culture to avoid ethical contact with the face of disability, with the face of the other . . . with the face of ‘irrevocable difference.’”
Janet Lyon, “About Faces and Down Syndrome,” forthcoming manuscript courtesy of the author.


6. An issue that requires an essay to itself is the role meditation plays in negotiating the identities of disability and race. One might compare to these three narratives by white disabled meditators a recent surge in meditation narratives by African American authors, most notably Alice Walker and bell hooks. Walker began studying TM (Transcendental Meditation) when she was living in New York City after a divorce. She went on to study tonglen (the Tibetan Buddhist practice of meditation) with teacher Pema Chodron, with whom she has engaged in many public dialogues, including the audiotape *Pema Chodron and Alice Walker in Conversation: On the Meaning of Suffering and the Mystery of Joy*. hooks, whose *All About Love: New Visions* came out in 2000 and *Salvation: Black People and Love* in 2002, has been a practicing Buddhist since she was an eighteen-year-old Stanford undergraduate. In a recent interview with *Tricycle: The Buddhist Review*, hooks articulated a concept of identity with remarkable resonances to the argument I am making here: “If I were really asked to define myself, I wouldn’t start with race; I wouldn’t start with blackness; I wouldn’t start with gender; I wouldn’t start with feminism. I would start with stripping down to what fundamentally informs my life, which is that I’m a seeker on the path. I think of feminism, and I think of anti-racist struggles as part of it. But where I stand spiritually is, steadfastly, on a path about love.” Helen Tworkov, “Agents of Change: An Interview with bell hooks,” *Tricycle: The Buddhist Magazine* 2, no. 1 (1992): 48–57. For the disabled meditators I discuss in this essay, as for hooks, this is a love that extends not only to others but to the self in its embodied and experienced specificity.


8. Eva Kittay, “Caring for the Vulnerable by Caring for the Caregiver: The Case of Mental Retardation,” (paper, Rock Ethics Institute, Penn State, University Park, PA, March 15, 2002).


13. Milam references Appendix II, where he glosses this phrase, which in the Book of Exodus is the name of God: “I-am-that-I-am. A statement directly out of Buddhism: paradoxical, saying everything and nothing, leaving us to contemplate the
glorious contradictions that are as much the problem of our lives as our unstable reliance on words” (223).

14. The full passage is comically paradoxical:

“I really don’t care what they give me for a body, as long as they don’t make me come back as me any more,” I said. “You know I like myself well enough, have had fairly good times with me (some bad times, too). . . .

“I’ve done with that one,” I’ll tell them. ‘You want me to be divine don’t you? Well, give me something nice to be divine in for a change.” . . .

“I’ll be good, I promise you,” I’ll tell them. “I’ll give up everything when I get through with the usual teen-age indiscretions. After just a few short years, I’ll become a holy man, a wandering saddhu. I promise faithfully: I’ll spend the rest of my years cheerfully walking the land, delivering Lordly messages, eating bark and drinking nothing stronger than leaf tea and branchwater, pausing only briefly near the beaches to look . . . at the figure I once was, the one I once wanted to be.

“I am sure that after they hear my plea,” I tell her, “they’ll be more than willing to trust me with a new, powerful, lithe body—so I can have some fun for the first few years of my new return, before I turn into the saint they (and all of us) can be so proud of.” (250–1)

15. Her California friend’s joke about her German shepherd as “the one in the dog suit” suggests the potentially profound reframing of identity that meditation enables, challenging not just the categories for human beings (race, age, sex, ability) but the category of species as well.


17. Ibid.

18. Paradoxical indeed that we would actually prefer to maintain our human privilege by disavowing aspects of human behavior that are not rational or under our control than to extend our sense of fellow feeling to members of other species.


21. Ibid.


29. I am borrowing the term “boundary object” from Geoffrey C. Bowker and Susan Leigh Starr, who use it to refer to “objects that both inhabit several communities of practice and satisfy the informational requirements of each of them . . . [are] plastic enough to adapt to local needs . . . yet robust enough to maintain a common identity across sites.” Sorting Things Out: Classification and Its Consequences (Cambridge: MIT Press, 1999), 297. Of course, attention to cultural differences has also provided a rich reservoir of alternative healthcare practices. See Lynn Payer, Medicine & Culture (New York: Henry Holt, 1988). Moreover, while so-called “New Age” approaches to medicine can at times be reductive, culturally sensitive approaches to medicine can affirm the complex identities and practices of non-Western medical traditions. For a discussion of the need for such new approaches to medical care, see Anne Fadiman, The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures (New York: Farrar, Straus and Giroux: 1997), and for a discussion of the reductionism of a specific New Age treatment, see Jackie Stacey, Teratologies: A Cultural Study of Cancer (London: Routledge, 1997).


31. Ibid., 329, 332.

32. Davis, 32. For an example of how socially engaged Buddhism can take on the intersecting experiences of disability and the history of oppression based on race and gender, see Michelle T. Clinton, “Breathing Through History: A Dark Reflection on Zen,” Turning Wheel: The Journal of Socially Engaged Buddhism, Summer 2003: 34–6.

33. Sedgwick, 168.

34. For the most powerful recent intervention in this area, see the “Take Back Your Time” movement, a project of the Center for Religion, Ethics and Social Policy at Cornell University, http://www.simpleliving.net/timeday (accessed on December 5, 2003).


36. Ibid., 113.

37. Davis, 32.

38. In focusing on psychological disability I am not addressing the related, but distinctly different, issues posed by cognitive disablement. See Kate Lindemann, “Persons with Adult-Onset Head Injury: A Crucial Resource for Feminist Philosophers,” Hypatia 16, no. 4 (Fall 2001): 105–23. I also do not consider the difficulty of being closeted with a mental disability, whether it is depression, bipolar disorder, or schizophrenia. Although morphologically invisible impairments, such illnesses produce significant—and thus often socially perceptible—distortions of one’s ability to function well in community. However, that is for another essay.

