



# Whose Line Is It, Anyway?: Doing Harm in Disability Memoir

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During the past four decades, memoirs written by disabled individuals have gained attention in the literary world. Many of these works are accomplished narratives that are intensely personal, unabashedly political, heart-wrenching, triumphant, and everything in-between. Yet while these stories reveal that disability is an individual experience, the impulse of many readers is to consider one story as representative of all disabled people with that particular impairment. The flaw in this reasoning is highlighted by Thomas Couser, who argues that we must be aware of the internal politics and diversity of opinions within any disability community, particularly in regards to the nature of disability itself. As Couser explains, individuals' sentiments may vary based on whether their disability was congenital or acquired, their attitude toward rehabilitation, and internalized ableist ideas, among other factors (*Signifying Bodies* 90 – 91). It is critical to realize this range of attitudes, since disability biography and autobiography often ask difficult questions about the nature of human life: What is a meaningful life? If someone is seriously disabled, how does their quality of life change? How should they deal with adaptation? How should disability be represented to those who do not share that disability? Couser argues that people writing about disabled individuals have the potential to cause them harm by misrepresenting or appropriating their stories, so writers must consider these ethical repercussions (*Vulnerable Subjects* x). Yet we must also note that such harms may be perpetrated by disabled writers themselves.

Given the political and social implications of memoir writing, some disability scholars have critiqued disabled memoirists for not addressing how various facets of intersectional identity play into the lived experience of disability, thereby writing exclusionary texts that fail to mention important problems within some disability communities. Ellen Samuels criticizes Nancy Mairs for neglecting to include disabled people of color and those who lack sufficient economic resources, since Mairs's memoir focuses on a white heterosexual middle-class perspective (198-200). Similarly, Chris Bell faults Disability Studies as a discipline for excluding narratives by people of color, since one cannot generalize about the African-American disability experience (or the experience of any other minority group) (407-11). Victoria Brownsworth is critical of how

disabled individuals have often been excluded from LGBTQ communities, and how the historical medicalization of queerness has had detrimental effects for those who need mental health care (xix).

Still other forms of harm may be posed when disabled writers disparage the state of being impaired. While these sentiments may be true to their personal experiences, such writings can risk repeating stereotypes that devalue the worth and personhood of people with disabilities. This is a crucial issue, since during the past few decades there have been several court cases in which a person with quadriplegia filed a petition for the right to commit suicide, a request that has been met with disturbing acceptance on the part of courts. These cases reflect a mainstream cultural assumption that using a wheelchair must be a miserable existence, and that people with disabilities have no value to society (Longmore 157-8, 165-7).

Memoirs can do harm to people with disabilities when they reinforce these kinds of stereotypes, as Cristina Crosby does in her book *A Body, Undone*. Crosby focuses on her loss of ability, sexuality, and gender, while disavowing notions that disability could be anything less than heartbreaking. Other memoirists such as Shane Burcaw, who uses a wheelchair for mobility, display creative adaptations to their shifting embodiment, yet reflect horizontal hostilities against people with other kinds of impairments. In Burcaw's case, he lobs hurtful comments at people with intellectual disabilities, detracting from respect for their personhood.

While Crosby and Burcaw are true to their own reflections, we must take into account how their memoirs may reinforce negative perceptions of disability, since their writings implicate others. As Arthur Frank notes, an individual's tale can potentially speak for many people: "In stories, the teller not only recovers her voice, she becomes a witness to the conditions that rob others of their voices, when any person recovers his voice, many people begin to speak through that story" (xx-xxi). Yet this "mass speaking" is inherently problematic, since we must ask how many people any individual can speak "for." While individuals with disabilities may share spaces of agreement, they may also have a wide range of impairment levels, frustrations, thoughts on the idea of "cure," and notions of bodily "fitness" (*Vulnerable Subjects* 31). Any writer of a disability narrative must realize it is an act of political representation. Disability stories are not all the same, nor can we expect writers to tease out all the differences, but how do we reconcile this complexity with the idea that individuals could do harm to other disabled people in memoir?

Memoir itself may help pose an answer to this question, since the genre can be an important means to share personal experiences, and find connections and community with others. Memoir writing can work against doing harm if writers use the form not only to reflect on personal experience, but on the interconnectedness of people and stories. Further, in exploring the ideas of harm and connection as they relate to disability memoirs, we can also ponder similar issues in other minority groups.

## DEFINING DISABILITY, COMMUNITY, AND THE DISABILITY MEMOIR

As disability scholar Alison Kafer points out, the definition of disability is ever-widening and subject to shift. It has come to include the visible and invisible: physical disabilities that affect mobility, sight, and hearing; invisible disabilities such as diabetes, asthma, chronic fatigue syndrome and lupus; intellectual disabilities such as Downs Syndrome; and mental disabilities such as depression and anxiety. Intersectional identities must also be taken into account when discussing disability, since facets of one's identity like race, class, and gender affect how one's body and disability are interpreted by others, and the quality of care one can access and afford (Kafer 12). Kafer also argues that it is crucial to realize that disability is not only a political identity but can be a lived experience of pain, leading some individuals to "simultaneously [desire] to be cured of chronic pain and be identified and allied with disabled people" (6).

While disability communities encompass a diverse group of individuals, Kafer suggests they can find common ground through "collective affinity," since many have "faced discrimination as a result [of disability]" (11). Along similar lines, disability scholar Petra Kuppers notes that trying to merge the various identities and embodiments of disabled people into one cohesive "unit" is a daunting and perhaps impossible task, yet she suggests that being part of a community is to "understand that solidarity can be found – precariously, in improvisation, always on the verge of collapse" (109). But not everyone may want to claim disability as an identity, or have membership in a disability community. While some may want to assert a political disability identity, others wish to pass as nondisabled, and still others seek a cure for their disability (Shuttleworth and Meekosha 186).

Regardless of whether someone wants to claim a disability identity, whether a book is classified as a disability memoir may depend more on how the reader interprets the text, and the prominence of impairment as an issue within the book. The texts I selected for my analysis involved memoirists who were confronting shifting levels of ability and impairment, and who had a wide range of relationships to claiming a disability identity and feeling affiliated with other disabled people.

While some of my chosen texts are recent and others are considered part of the canon of disability writing, these are important memoirs to address for the range of intersectional identities, acquired versus congenital disabilities, and relationships to disability communities that they represent. Cristina Crosby and Lucia Perillo both acquired their disability in mid-life and do not identify with disability communities, while Terry Galloway and Audre Lorde have congenital and acquired disabilities that grew more severe over time, yet they found community and ways to adapt to their embodiment. Ruth Mercer, Shane Burcaw, and Eli Clare have congenital disabilities, but aspects of their disability and intersectional identities affect how they relate to others within disability communities.

While we cannot hope to encompass entire disability communities under the umbrella of one memoir, we can examine how relationships to disability identity and communities move these writers toward or away from a more inclusive and complex accounting of disability, and affect the risk of doing harm to others.

## THE TEXTS – CROSBY’S CHAOS NARRATIVE

Christina Crosby’s memoir *A Body, Undone*, highlights intersectional aspects of disability such as race, gender, and sexual orientation, yet Crosby does harm to other disabled people by depicting disability as a wholly negative and desexualizing state of embodiment. The physical and emotional trauma she experienced reveals the inherent conflict between an individual writing what they feel is the truth of their disability, but doing so in a manner that may detract from the idea that disabled people have lives worth living. Further, Crosby does not seem to have integrated with members of disability communities, and found strategies for being in the world with her new embodiment.

Crosby is white, identifies as lesbian, and openly acknowledges that her racial and economic privilege have benefited her as a disabled person, allowing her to get the care and equipment she needs to live at home, and continue her university teaching job. She also admits to deeply grieving her body status after being partially paralyzed in an accident while bicycling, and needing to use a wheelchair for mobility. Her narrative often focuses on experiences that she feels have been forever lost, and that “The more mundane enjoyments of everyday life—making a peach pie in August, feeling sexy in leather pants and silver jewelry—are also gone, because they depended on a body radically different from mine now” (12). A reader might ask if Crosby is limiting her exploration of new life experiences, such as why she can no longer feel sexy in silver jewelry or derive pleasure from peach pie, even if she might not be able to wear leather pants. Crosby anticipates these arguments, writing that “To focus on intractable pain, then, or grief at the loss of able-bodiedness, as I do here, may be thought to play into a pathologizing narrative that would return disability to ‘misshapen’ bodies and ‘abnormal’ minds” (7). But Crosby asserts that she must address the pain and grief that were part of her accident, since she feels these issues are too often ignored by disability studies.

Her argument shares ground with Kafer’s assertion that disability studies must incorporate the lived experience of pain, yet Crosby focuses the majority of her narrative on loss, and not adaptation. We cannot deny the reality of her pain as she describes how medications offer little relief. Even at her most comfortable she feels like there is an electric current coursing through her body, and leg spasms can make it difficult to sleep (28). This commitment to one’s truth is an important part of storytelling, as Frank writes, “The good story refuses denial, and thus stands against social pressures,” including the pressure to tell a story that focuses on positivity, and becomes a trite overcoming narrative (63). Yet this space is where the complexity of memoir writing becomes clear, because while we don’t wish to deny an individual’s experience, we also do not want to let one story misrepresent the bodies of others.

One part of Crosby’s narrative that is troubling in terms of reflecting stereotypes of disability is her assertion that “I no longer have a gender. Rather, I have a wheelchair. I’m entirely absorbed into its gestalt. I’m now misrecognized as a man more often than ever before.” Crosby laments how her breasts are pressed to her chest by a restraint that keeps her in her chair, which she feels is a masculine object. To further erase herself, she dresses in black “to make my body disappear as much as I can”

(60-1). While before her accident she had identified as a butch lesbian who also reveled in her femininity, Crosby's treatment of disability represents it as a mournful and genderless state, with no hint to how other disabled people have decorated or customized their wheelchairs and incorporated them into their (often gendered) identities. She writes "How can I settle for a life with deadened sensations that decree I'll never again have an orgasm? How can I live on with profoundly compromised strength and tactile perception, especially in my hands? How I miss the way sex used to feel!" (118-9). Crosby does not allow that some people with disabilities have lived their entire lives in bodies that may feel similar to hers, and how her narrative may devalue their experiences. Renegotiating sexuality with a new form of embodiment poses a challenge to many people who acquire disabilities, yet as disability studies scholar Tobin Siebers writes, "The sexual activities of disabled people do not necessarily follow normative assumptions about what a sex life is. Neither fact means that people with disabilities do not exist as sexual beings" (138). Crosby's views on gender and sexuality reveal an ableist viewpoint that she has not been able to shake since becoming impaired, and that may be detracting from her ability to revise her sense of a sexual self, and find alternate models of thinking about sexuality.

Crosby's memoir also has aspects of a chaos story, which Frank characterizes as one that imagines "never getting better" (97). While these are difficult narratives to hear, Frank suggests we must not deny someone the experience of chaos since we need "an enhanced tolerance for chaos as part of a life story" (111). But Crosby refuses the idea that there could be a disability story other than the chaos story, writing that disability narratives too often "[carry] the troubled subject through painful trials to livable accommodations and lessons learned, and all too often sounds the note triumphant. Don't believe it" (116). Crosby implies that there is no way of making disability a "livable" much less a pleasurable experience. While the standard "overcoming" narrative of disability deserves the critique of being too easy and ignoring the complexity of living with disability, Crosby's condemnation of disability is likewise a monochromatic representation that does not allow for the idea of adapting to the disabled body and new joys, pains, and ways of being.

Crosby also portrays other disabled people she has encountered after her accident as being dismissive of disability, perhaps justifying why she has not joined or does not see herself as a member of a disability community. While she acknowledges that she and her lover Janet have been supported by a strong system of friends and family, she does not include other disabled people in that community, and depicts at least one of them as being rather hostile. Crosby explains "When I presented some of this work to a study group, one guy in a wheelchair more or less told me to 'man up' and get on with my life—after all, that's what he had done decades ago, before the ADA even" (7). With this line, she suggests other disabled people have shrugged off as opposed to empathized with her pain. For her, the chance of solidarity within community that Koppers suggests has already collapsed. While there is no imperative that states Crosby must associate with a wider range of disabled people, there is a distinct lack of such interactions in her memoir. In turn we must wonder if having such exchanges would shift her perspective on her embodiment, and the potentially harmful stereotypes her memoir persists in spreading.

## PERILLO'S ADAPTIVE NATURE ODYSSEY

Along with avoidance or affiliation to disability communities, memoir can reflect an author's change in thinking about disability and embodiment. Lucia Perillo's book *I've Heard the Vultures Singing*, focuses on her adjustment process to having multiple sclerosis (MS), a much more gradual process than Crosby's sudden impairment. At times Perillo does harm to her own body through disparaging her limitations, but she also describes new ways of existing in the world as she adapts to her changing ability levels. She is white, educated, middle-class, and her husband has a steady job, so she does not have to work outside the home. While the reader should not ignore this level of privilege since it affects the mobility she is able to achieve, Perillo makes clear how difficult it is to confront her changing embodiment, since she had previously enjoyed being alone in nature and taking long mountain hikes. Similar to Crosby, she resents her body status and rejects the idea of belonging to a disability community.

Perillo is direct about her frustrations, revealing her discomfort and anxiety when looking at other wheelchair users: "I'm not immune to a hitch in my swallow when I cross paths with the likes of me" (24). She is leery of being lumped together with other disabled people, and rejects terms such as "cripple" that are used by some disability community members with a certain affection. She notes, "To make the label more aggressive and maybe chummier, the brotherhood of those foiled by bad body luck sometimes shortens it crip, as in the crip community" (Perillo 27). Perillo refers to her "bad body-luck" at several points in the memoir, a term that devalues the disabled body, and points to Couser's suggestion of how individuals with disabilities often internalize ableist notions. An example of her disenchantment arises when Perillo tells her "cute" wheelchair salesman:

"I would rather kill myself than go back to dating,"

He offers helpfully, 'There are computer dating sites for people in wheelchairs.'

'That's just it!' I say. 'I'd kill myself if I had to date me'" (Perillo 59).

While it isn't clear if Perillo means she would kill herself if she had to date herself, or if she had to date another disabled person, either interpretation is fairly damning in its assessment of disabled people as desexualized and date-less individuals. Further, Perillo's statement also connotes doing literal harm to her own body, even if in the context of a dark joke.

Perillo recalls her past in a more able body with a nostalgia similar to Crosby's, including episodes of shoplifting meat and a life of petty pseudo-crime. She laments, "Now that I'm feeble...I'll not easily be offered the opportunity to be bad...This physical dilapidation only makes the outlaw more cherished, seeing as she is so improbable" (Perillo 130-1). Yet because Perillo has rejected involvement in disability communities, she may grossly underestimate the creative potential of its members, and outlets for "bad" behavior and resistance strategies. Since she has cut herself off from spaces in which people may exchange ways to be diabolical, she has also limited her view of the possibilities to be found in

disability. For example, it might have been instructive for Perillo to read of the adventures of amputee Kafer and friends when they defaced an ableist bulletin board:

Although we had not discussed it in advance, we each took on the task best suited to our impairments: Ellen Samuels served as lookout, because her EI required her to stay a distance from the paint; my limited hand control made wielding the spray paint impossible, so I held the stencil in place, blocking the sign from public view with my body; and Anne Finger transformed the original caption ‘Lost Leg, Not Heart: Overcoming’ into ‘Lost Leg, Not Rights: Overcoming Pity.’ Ellen snapped a quick picture of the sign with her phone and we hurried away. (101-2)

Yet while disability community membership may advance the potential for this kind of activism, Perillo does start to reshape her views of herself and her relationship to her disability, locating spaces of adaptation. She relates that one turning point came when she abandoned the idea of finding a cure for her MS, and “[felt] unburdened, lighter strangely giddy as I float” (Perillo 141). Not only does she discover an emotional release, the process restores an element of her sexuality that she felt was lacking: “There is an erotic component to the surrender—it comes from the self relinquishing control, throwing itself away. That body is offered to whatever seizes possession of it—whether the seizer be disease or time or a human lover” (Perillo 141). By reframing her submission as a sexual act, she can reclaim herself as a sexual being and find different ways of expressing those sensibilities. This is an example of Siebers’s call to for disabled people to “think expansively and experimentally about what defines sexual experience for them,” and find new ways to embrace the disabled self as a sexual being (151).

Perillo also starts reassessing her relationship to nature and determining her place in it, negotiating ways to be in the outdoor “community” that is all around her. She goes to the seashore to study and identify various species of gulls, and joins an evening neighborhood excursion to look for bats. She calls her research “knowledge games,” and uses them to “plug the holes where I’ve been torn... bats are supposed to make me not resent my friends who head off to camp in the mountains” (Perillo 112). At the same time, she struggles to find self-validation when she gets up in the morning to identify bird calls in her backyard, while watching her neighbors go to work. She wonders if her knowledge games can truly make her happy, “And the answer is: *No, no, you will never be happy, Best you can do is fill yourself with the clutter of these distractions*” (Perillo 160-1). While her resentment is clear as she parks her chair on the concrete block in her driveway that she refers to as her “habitat,” she also becomes cognizant of the multiple ways she can “access” the ecosystem around her: “The advantage of sound is the way it pervades space,” she notes, realizing that she can still identify birds without seeing them because she has paid such careful attention to their distinct songs (Perillo 162-4). “Then it starts to seem that by listening for their songs I’m causing birds to appear, that this game has the power to pull substance from the air, and I don’t know why it ever made me sad” (Perillo 173). In learning how to pay attention to her surroundings, Perillo creates an experience that is different from the one she had before her disability, but fulfilling in its own way. She is still frustrated by having to stay on the boardwalk when going to the beach, but she finds a new way to fit within the ecosystem and natural

community around her and enjoy what it has to offer. Perillo's narrative is complex in that it at times does harm to disabled bodies through discounting them, yet it is a journey in which she redefines what it means to be in her body, and interact with familiar spaces and communities in new ways. In essence, her memoir is a story about fitting her new body back into old spaces, and shaping a different kind of place for herself.

### **SIENKIEWICZ-MERCER'S MEMOIR OF INTERDEPENDENCE**

Other disability memoirs share this combination of violence and validation, such as Ruth Sienkiewicz-Mercer's *I Raise My Eyes to Say Yes*. Sienkiewicz-Mercer is a wheelchair user due to cerebral palsy, and has a nuanced attitude toward her body and individuals with disabilities. She explains that her limited mobility was frustrating throughout childhood because she could not walk and speak like other children. At the same time, her family respected her intelligence and she developed a system for saying "yes" and "no" when she was four, adding emphasis using facial expressions and verbal sounds (Sienkiewicz-Mercer 2-6). Her intersectional identity greatly affected her educational path, since she is white but came from a family with few economic resources. Her parents were able to send her to an out-of-state school for children with disabilities when she was young, so Sienkiewicz-Mercer developed a strong affiliation with other disabled kids. When she was twelve, however, her parents lost their educational financial aid, so Sienkiewicz-Mercer was admitted to the Massachusetts state school. She did not know that to be accepted, someone had to be classified as intellectually disabled. During her physical exam, the doctor decided Sienkiewicz-Mercer was an "imbecile" since she could not talk and didn't seem to respond to him. For the next several years the medical staff treated her as intellectually disabled, though she tried to make her cognitive skills and understanding clear (Sienkiewicz-Mercer 35-8). Relating these stories fulfills Samuels's call for disability memoir to examine the crucial effects of class on the experience of disability. Disabled people without economic means have often been shunted to similar institutions and treated very poorly. Sienkiewicz-Mercer's recollections of her abuse, and defense of the personhood of non-verbal people, make her memoir an important voice for those in similar situations.

During her emotionally taxing period in the state school, Sienkiewicz-Mercer made friends with a woman named Theresa when she noticed Theresa's sounds were responses to things going on in their ward. Though sound and facial expressions they devised a means to communicate, noting change in pitch and tone so they could talk softly at night without disturbing the staff (Sienkiewicz-Mercer 62-5). She developed a great appreciation for the intelligence and ingenuity of others in her disability community, and how people with serious physical impairments could still express themselves. Yet while Sienkiewicz-Mercer was able to make breakthroughs and befriend other patients, she feared for her safety around some of the intellectually disabled patients who she worried would treat her like a doll (76-9). She was grateful that even if she could not control her body, she had a "sound mind" and control of her

senses (Sienkiewicz-Mercer 80-1). Sienkiewicz-Mercer's sense of a disability hierarchy is apparent in these passages, although this admission is not uncommon in disability memoirs. Other writers such as Anne Finger have expressed similar ambivalent sentiments in regards to preferring physical over intellectual disabilities. Finger wrestled at length with these feelings when she feared that her infant son may have an intellectual disability, and how it seemed so much "worse" than the physical disability she had lived with for years (137, 143). At the same time, we can relate Finger's struggle with this issue to her increasingly complex understanding of disability, and her realization that she is part of a larger disability community and engaged in the continual fight to have her personhood recognized.

Similarly, Sienkiewicz-Mercer is cognizant of some of her prejudices, since she knew that others might not believe her life was worth living. That realization of how easily disabled people could be devalued lead her to be more careful not to make such determinations about about any other girl in her ward. Her own experiences had shown that she couldn't know what was going on in anyone else's head, and sometimes a great deal of patience was required to recognize someone else's means of communication in a diverse disability community (90-2). It took years before Sienkiewicz-Mercer had sympathetic attendants who were willing to devote this kind of attention to noting her reactions. By laughing at their jokes and understanding their sarcastic humor, Sienkiewicz-Mercer communicated her intelligence and introduced her caretakers to her way of "speaking" (Sienkiewicz-Mercer 103-9). That recognition granted Sienkiewicz-Mercer the personhood and respect she hadn't experienced for years, and allowed her to further develop her communication skills using word boards. Later, she and other disabled adults from the state school were able to move into independent living apartments, with full-time attendants and responsibility for their own budgeting, meal planning, and making appointments (Sienkiewicz-Mercer 202-3). At the end of her memoir Sienkiewicz-Mercer finds happiness in this interdependent community, marries one of her friends from the state school, and explores her sexual self. She also gains respect in nondisabled communities where she becomes a spokesperson for other people who were confined to state institutions.

Sienkiewicz-Mercer's memoir stands in stark contrast to Crosby's narrative in terms of its defense of people with limited mobility and verbal capacity as having enjoyable lives worth living. While Sienkiewicz-Mercer's thoughts on intellectual disability could be critiqued as doing harm to some disabled people, her fear is understandable since she saw how easily her personhood was denied by her care providers when she was assumed to be intellectually disabled. Even when her intelligence was recognized, her fight for independence was a drawn-out battle carried over several years. Thus it is important to note that when a memoir writer does harm to themselves, their disability communities, or another group of disabled people, this could be due not only to internalized stereotypes and prejudices, but fears and life experiences.

## BURCAW'S COMEDY AND COMMENTARY

In his memoir *Laughing at My Nightmare*, Shane Burcaw reflects on many of the social anxieties that people with disabilities may feel in how they are regarded by temporarily able-bodied people. Burcaw uses a motorized wheelchair due to a degenerative muscle condition, and much of his writing focuses on the humor he's found in his disability identity, and how he's used joking to help negotiate relationships with temporarily able-bodied people. He has had similar economic privileges to Crosby and Perillo, since he is white and grew up in a middle-class household, with parents who had the means to buy a power chair. He was mainstreamed in school, but realized the importance of appearance to how people with disabilities are treated when he went to a summer camp for disabled kids. Burcaw saw how many other kids who were wheelchair users did not wear shoes and had atrophied feet. That small detail seemed to make a difference in whether they were treated like a mature teenager or a little kid, and lead him to focus on how important appearance was to fitting in socially (84-5). While Crosby dresses in black to try to disappear, Burcaw focuses on dressing and doing his hair like other kids his age, and doing his best to have the life of a "normal" teenager.

Burcaw reflects that he was terribly worried about making friends in middle school since he needed help to get books out of his backpack and do other small tasks. He knew other kids were just as worried about having friends, but "in my mind, my wheelchair and disease would be the cause of never making friends." Since image was important, he "practiced asking for help in cool ways that didn't sound pathetic and annoying" (Burcaw 76-8). He realized that when other people saw his chair, they would think they know everything about him. He wanted to present himself to this community as "just another guy" but admits his disability was an underlying tension.

While Burcaw is adept at negotiating the chaotic social world of junior high and high school, his memoir does not avoid deriding other people with disabilities. Like Sienkiewicz-Mercer, he integrates himself with some disability communities, while distancing himself from others. Burcaw explains that he had to ride the "short bus" to school because it was the only one with a wheelchair lift. Most of the other passengers were intellectually disabled kids, and Burcaw often made fun of them, including Skunk, who was proud of the fact he never took a shower. Skunk spent a lot of time playing with his penis and waving it at other people until Burcaw yelled at him to stop (Burcaw 98-100). Burcaw also remembers Brandon, a kid in his twenties who still went to the high school and smelled bad, "like he always had a large pile of poop in his pants, which might have been because he always had a large pile of poop in his pants" (103). This "Short Bus" chapter may be indicative of how Burcaw was annoyed to be lumped together with the intellectually disabled students, something he alludes to at other points in the memoir when he explains his extreme frustration at how often adults assumed he was intellectually disabled. At the same time, the chapter serves little function other than doing harm to intellectually disabled individuals. Burcaw does not recognize the points of solidarity he may have with them, so their chance for community has already collapsed. The fact that Burcaw feels he has the right to mock

these individuals also hints to his own sense of internalized ableism, supporting a disability hierarchy. This derision may also spring from Burcaw's realization of the commonalities he shares with intellectually disabled people, particularly in terms of how they are both discounted by temporarily able-bodied individuals and vulnerable to being considered not fully human.

As Eli Clare argues, mocking intellectually disabled people does harm to them because it puts their personhood at risk. Clare observes that prejudice tends to focus on a particular group's intelligence as lacking (such as with racism, sexism, classism, and homophobia), but when individuals in targeted groups use their intelligence to defend their personhood, "we come close to disowning intellectually disabled people," ultimately devaluing those who think or understand things differently (*Brilliant Imperfection* 157-8). As Clare suggests, the end effect of doing harm to someone else may be disqualifying them as a person, a tension that some individuals feel as a constant threat. He writes, "Some of us are granted personhood as our birthright, but others are required to prove and defend it every day. And when we fail this perverse test, we're in trouble" (*Brilliant Imperfection* 28). With his use of the pronoun "we," Clare is implicating other people with a range of disabilities, suggesting the interconnectedness of disabilities, disability communities, and the fragility of personhood itself. In essence, needing to have a "personhood" test at all means that one's personhood is continually at risk of being damaged, further suggesting how derision is a treacherous path.

### GALLOWAY'S ACTING OUTSIDE THE BOX

Another function of disability memoirs may be to reflect the memoirist's developing realization of the interconnectedness of disability communities. Deaf actor and writer Terry Galloway spent much of her life through her early twenties passing as hearing and straight, as she explains in her book *Mean Little deaf Queer*. Her intersectional identity and shifting affiliation with various communities is part of the overriding theme of this book, relating the many ways in which she was closeted, and how she feared rejection from friends and family. This text is also notable since it not only recognizes commonalities among people with disabilities, but makes a space for specific marginalized voices to be heard. While Galloway lends her voice to deaf queer individuals and allows group members to feel less isolated (Moges 220-1), she simultaneously engages with issues of disability community affiliation and validation without having to sacrifice one for the other.

Galloway started losing her hearing in childhood, and resented the huge, cumbersome hearing aids she was supposed to wear. The first time she was allowed to be in a disability community was when she went to a summer camp for kids with disabilities, and like Burcaw it lead her to focus on appearances. While she made friends, she also felt a separateness from other children as she realized "I had a talent they did not—I could pass for normal" (49). Galloway mourned her old body, but also desired to protect her parents from her disability and difference. While part of her wanted to learn sign language

and join a larger Deaf community, she knew that would set her apart from others and she just wanted to “appear whole again. I already knew how to do that—act cool and pretend that all was well” (76).

Galloway birthed a love of acting in high school after learning lip-reading and going to a speech therapist, but when she went to university to prepare for an acting career, she was told she could be of service in costuming. The head of the acting department gave her a “stare...that, even as it presumes to know all about you, really just intends to put you in your place, to remind you of your unworthiness” (Galloway 98). Galloway persisted however, and found a place acting with an eccentric local performance group. Years later, after she had started to accept her lesbian and deaf identities, she was asked to do an acting workshop on performing with disabilities. Galloway felt like she had been burdened with an “inferior” group, yet planned to do physical theater exercises with the participants. After everyone had assembled, she realized that individuals who used wheelchairs and those who had Downs Syndrome couldn’t do things she thought were “essential” to acting (149).

Galloway had a good conversation with the participants, but only weeks later did she reflect on the workshop and her own experiences of disability prejudice, recognizing she had internalized those same ableist stereotypes about the limitations of disabled people. Too late, she realized the potential those workshop members had to be great performers, and that since the summer camp she’d attended decades earlier, she hadn’t made an effort to find disabled friends (158). The fact she had stayed in a more “traditional” theater community meant she hadn’t been able to think more expansively about performance and see her workshop participants and herself outside the “standard” theater box (162). In this way, Galloway’s memoir suggests how opportunities for community may collapse only to be resurrected and reformed in different ways. Like disability itself, the notion of community is not a fixed entity, but can be subject to change. As Galloway notes, she later helped to found an acting troupe for people with disabilities, and had workshops in which people could feel free to ask questions like “What the hell happened to you?” She developed creative ways to allow participants to tell their stories, and brainstorm how to translate those tales to the stage: “after we started playing with our differences and became captivated by them, we started making them part of the script, part of the performance itself” (Galloway 209-11). It is this kind of re-thinking of disability and community, one that allows the writer to see their body and the bodies of other disabled people as different yet united by common concerns and desires, that can allow a new sense of community to form and thrive.

### **LORDE’S LETTERS OF BODY-LOVE**

It is difficult to find many writers like Audre Lorde whose books embrace intersectionality so overtly and unabashedly. In *The Cancer Journals*, she addresses aspects of disability, queerness, blackness, gender, and economic privilege in relating her experiences with breast cancer and having a mastectomy. As Moya Bailey and Izetta Mobley note, one of the most important aspects of Lorde’s book is her

attention to complexity of identity, and why it is important for individuals in disability communities to consider both identity specificity and commonalities (20-1).

From the outset, the reader has a sense that Lorde is writing to a collective. As Jennifer Barager notes, community and collaboration are key facets of Lorde's book and her path to survival, since she continually refers to the threads that draw people together, and the societal structures that discourage forming those ties (7). While her story is particular to her experiences, she knows many elements are held in common with "other women of all ages, colors, and sexual identities who recognize that imposed silence about any area of our lives is a tool for separation and powerlessness" (7). As Frank suggests, Lorde offers her voice to those who have not been able to speak, particularly about the physical and emotional pain of having a life-threatening illness, and needing to confront a changed body that other people want to re-shape. Her work is devoted to forming community where such has been prohibited in the past, and realizing the power of collectives in which people share common experiences, goals, and understandings.

Lorde speaks to this need for empathy when she explains how she was visited by a woman who suggested that she use a lambswool prosthesis, but "Her message was, you are just as good as you were before because you can look exactly the same...and nobody'll ever know the difference. But what she said was, 'You'll never know the difference,' and she lost me right there, because I knew sure as hell I'd know the difference." Lorde wants to talk with someone who understands her sentiments, someone who is clearly not this woman who assumes Lorde is heterosexual (42). As Moya and Mobley note, Lorde composed *The Cancer Journals* since she "lamented that she had no writing to turn to that described the experiences of a Black lesbian woman surviving cancer" (22). At the same time, Lorde makes her prose accessible through her attention to sensory detail. Similar to Crosby, Lorde addresses anxieties about her changed body in language that focuses on her lesbian identity, yet her prose connects with the reader in its embodied sensations and sense of longing:

"I was thinking, 'What is it like to be making love to a woman and have only one breast brushing against her?'"

I thought, 'How will we fit together so perfectly ever again?'"...

My right breast represented such an area of feeling and pleasure for me, how could I bear never to feel that again?" (43) Lorde reveals she has periods in which her story is a chaos narrative, but the difference between her story and Crosby's is that she does not remain in those spaces for the long-term.

Lorde also addresses her racial and intersectional identity when determining that the prosthesis will not find a home on her body: "It perched on my chest askew, awkwardly inert and lifeless, and having nothing to do with any me I could possibly conceive of. Besides, it was the wrong color, and looked grotesquely pale through the cloth of my bra" (44). While her narrative highlights these specifics of embodiment, Lorde is also an example of Kafer's call to think about the collective affinities and

struggles that may be shared by many people with disabilities. She extends her community to include a wide swath of women who have been through a similar painful experience, only to have their emotions disregarded by doctors and nurses who maintain a shallow focus on women looking just as they had before surgery. Lorde argues that women are not allowed to mourn for their changed bodies and learn how to live in them. As Frank would suggest, they are not allowed a period of chaos. Instead, Lorde writes, a cancer survivor “must mourn the loss of her breast in secret, as if it were the result of some crime of which she were guilty” (58). Her narrative of illness has endured as a seminal text because she highlights her own identity and periods of disarray, yet shapes her community to be ever-expanding, including “The women who sustained me through that period...black and white, old and young, lesbian, bisexual, and heterosexual, and we all shared a war against the tyrannies of silence” (19). As Elizabeth Alexander notes, Lorde suggests that strong communities can also be diverse communities, a facet that should not be ignored: “Lorde argues difference within the self is a strength to be called upon rather than a liability to be altered. She exhorts her readers to realize how each of them is multifarious and need never choose one aspect of identity at the expense of others” (695). Her memoir is a letter to the diverse community of cancer patients and survivors, as well as their friends and lovers and family members, suggesting how this collective includes people who have been deeply affected by disability, even though they have not become disabled themselves.

Far from doing harm, Lorde seeks to help others re-see their bodies and reclaim a sense of wholeness. She is clear that her journey was not easy, and that she encountered many social road blocks on the way, but she writes of these barriers to acknowledge that others in her community will face them as well, and to encourage those individuals to push through as she did, Lorde notes, “Right after surgery I had a sense that I would never be able to bear missing that great well of sexual pleasure that I connected with my right breast, that sense has completely passed away, as I have come to realize that that well of feeling was within me. I alone own my feelings” (79). A blend of the communal and the deeply personal, Lorde’s memoir reminds other women of their right to their feelings, the right to define their sexuality, and the right to fall back in love with themselves.

### CLARE’S MEDITATIONS ON COMPLEXITY

Eli Clare’s book *Exile & Pride* also speaks to the notion of enlarging our sense of disability communities, and the complex relationship between race, disability, gender, class, and sexuality. Clare identifies as a white transgender person with cerebral palsy, and begins his memoir by relating a time when he went mountain climbing with a friend. He struggled on the hike due to his cerebral palsy, and while he addresses his own disability in this anecdote, he also situates himself in a larger collective of marginalized people. Clare describes how all of them must climb metaphorical mountains, and “every time we look ahead we can find nothing remotely familiar or comfortable” (*Exile & Pride* 1). These climbers must ask if getting to the summit is worth the cost, which is why some people decide to stop climbing.

Just as Lorde describes the particulars of her situation but also her place in a larger struggle, Clare is careful to foreground his work with an image of a wider community engaged in the same trying task.

His book continues in that collective vein as he examines social problems that affect people with a range of physical and mental disabilities. He writes of so-called “supercrip” narratives, stories of disabled people who achieve great athletic feats, or simply live what mainstream society would consider a “normal” life. Clare argues that all people with disabilities are victims of such tales, since they “focus on disabled people ‘overcoming’ our disabilities. They reinforce the superiority of the nondisabled body and mind. They turn individual disabled people, who are simply living their lives, into symbols of inspiration” (*Exile & Pride* 2). Clare suggests that supercrip stories not only devalue disability, but ignore the complexity of social problems faced by many people in disability communities, including “material, social, legal conditions...lack of access, lack of employment, lack of education, [and] lack of personal attendant services” (*Exile & Pride* 2). In this manner, Clare again echoes Lorde in the idea that people with a range of body types and identities can find common ground in similar experiences of oppression, since the same social factors come into play.

His attention to widening the scope of disability communities also examines the ways that people can feel divorced from their bodies, and how the body can be precious and yet vulnerable to disability due to outside forces: “The body is home, but only if understood that bodies and can be stolen, fed lies and poison, torn away from us...bodies stolen by hunger, war, breast cancer, AIDS, rape, the daily grind of the factory” (*Exile & Pride* 12). Clare suggests how easily individuals can become members of disability communities due to economic and social situations outside of their control. His writing alludes to the fact that the boundaries of such communities are permeable and porous, and most people will become a member at some point in their lives.

While Clare continually refers to his own experiences growing up as a white transgender person in a rural Oregon logging town, his memoir also reflects on his ties to “redneck” loggers, queer people, and people with disabilities. Clare not only reminds the reader of the numerous communities to which he feels an affiliation, but asks how these seemingly disparate groups can be united by their common problems and concerns surrounding social justice and economic inequality (*Exile & Pride* 37-41). It makes logical sense for people to form larger communities based on shared interests, but often other political beliefs and preconceptions get in the way of recognizing their many overlapping interests.

Clare also recognizes the diversity of individuals within communities, and how as Koppers suggests, that factor can place solidarity “on the verge of collapse.” Clare writes about the conflict around representing marginalized identities that have been stigmatized in the past, reflecting on terms such as “queer “ and “cripple” that “are cousins; words to shock, words to infuse with pride and self-love, words to resist internalized hatred.” He recognizes that “crip, queer, and freak have come to sit on a cusp. For some of us, they carry too much grief. For others, they can be chosen with glee and pride” (*Exile & Pride* 70). While Clare uses the term “crip,” he is uncomfortable with the term “freak,”

pointing to problems any individual may experience in trying to speak for the group. As word choice can be a space of heated debate, Rebecca Garden notes that “Clare’s analysis reveals the instability of representation...the danger also involves misrepresentations, getting the other’s meaning or story wrong, or even claiming the power of that story for one’s own purposes or benefit” (79). Clare’s memoir reveals how speaking will always pose the problem of mis-speaking, since forming larger communities means widening the potential for disagreement. At the same time, his arguments regarding social injustice make a case for needing to widen our scope of community. Similar to Lorde, he continually highlights points of “collective affinity,” expanding not only the notion of disability communities, but the very idea of community and the number of people his narrative is meant to address. It is this kind of creative community formation that makes Clare’s memoir a vibrant piece of literature, and an example of the ways to avoid doing harm through identifying spaces of collective resonance.

Clare, Lorde, and Galloway’s memoirs seek to broaden the definition of one’s community, and connect communities with similar interests. Widening the definition of community reveals how these authors are cognizant of the many groups to which they belong, the diversity of voices within their communities, and the need to respect a variety of viewpoints.

For any storyteller, it is far easier to focus on the communities that you know, and the experiences with which you are familiar, than try to project your understanding into communities in which you don’t see yourself as a good “fit.” This narrowing of one’s sense of community could explain the exclusion of, or harm against, people of various sexualities, classes, races, and kinds of embodiment in disability memoirs. The lack of inclusiveness also reveals how it is disturbingly simple to reproduce the harm of denying personhood to someone else, even after your own personhood has been threatened.

In disability memoir, as in memoirs by members of other marginalized groups, writers must acknowledge their intersectional identity, including social position and/or privilege, to clarify how their experiences may differ from others in the same group. Yet writers also have a responsibility to understand the possible repercussions of memoir writing, and ways in which they may do harm by perpetuating negative stereotypes, denying others their personhood, or otherwise questioning their social worth. Whether or not they intend to be a voice for a larger group, memoirists must balance the need to tell a personal story and relate their own truth, with an acknowledgment that writing is a political act.

By the same token, as readers we must realize that to understand the many facets of disability and other minority experiences, we must peruse a wide variety of books. This can lead us to a range of memoirs that explore both pain and privilege, and focus on disabled people and disability communities as spaces of creativity, resilience, and interdependence, spaces where people continually negotiate with their embodied selves, and with what it means to live a “good” life in bodies that are ever-shifting.

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