"From the Periphery Towards the Center"¹: Locating An Alternative Genealogy for Disability Studies in Audre Lorde’s *The Cancer Journals*

As a white feminist, I come to Audre Lorde’s work with humility and trepidation, aware of my own privileged position within the field of gender studies and cautious of the risks of appropriation. I discovered her memoirs and poetry while coming out as a teenager, and have continually returned to her work for inspiration and guidance—as a feminist queer-identified woman with a learning disability survivor of an invasive surgery daughter of a disabled parent. Lorde’s writings have not only provided a resource for my own healing and resistance, but have also inspired a lifelong commitment to antiracist activism and education, which informs my current academic work in disability studies.

*The Cancer Journals* is a collection of essays, journal entries, and poems Lorde wrote in the late 1970s reflecting on her diagnosis with breast cancer, mastectomy, and recovery. In the first essay of the journals, which she originally delivered as a speech at the MLA convention in 1979, Lorde opens with a challenge to her audience: “I am myself, a black woman warrior poet doing my work, come to ask you, are you doing yours?” (21).

I hear Lorde’s question—directed at feminists—echoed in the work of Chris Bell and members of the People of Color Caucus of the Association of Disability Studies. They have in recent years criticized the field of disability studies for its narrow focus on the experiences of *white* subjects with disabilities. Bell contends that, “Disability Studies has a tenuous relationship

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to race and ethnicity: while the field readily acknowledges its debt to and inspiration by inquiries such as Black Studies, its efforts at addressing intersections between disability, race, and ethnicity are, at best, wanting” (278). Inspired by Bell and others, I pose the question: What if we moved the theoretical insights of women-of-color feminists “from the periphery towards the center” of disability studies? In particular, what if we located a figure such as Audre Lorde among the current canon of disability studies theorists such as Michel Foucault, Rosemarie Garland Thomson, and Lennard Davis? My goal in this paper is not to discredit the significant insights that white disability scholars, artists, and activists have contributed thus far, or to discount the genuine experiences of suffering and oppression that white people with disabilities face in our society. However, Audre Lorde’s theoretical insights in *The Cancer Journals* provide an alternative map for disability studies scholarship that might help to remedy the field’s current neglect of race.

I. The first theme I highlight from Lorde’s work is intersectionality, a concept introduced by critical race theorist Kimberlé Crenshaw to draw attention to those subjects—particularly women of color—who exist at the margins of both mainstream feminist and civil rights organizations. An intersectional approach recognizes that a person’s identity is not the sum total of the pain of each separate form of marginalization, but that, for example, Blackness is lived differently by women than by men, and being female is not a uniform experience across race, class, age, or disability.

Much scholarship in disability studies tends to discuss disability as a discrete identity or experience that is *analogous* to but separate from racial identity. This approach neglects the complex interrelation of oppressions experienced by *people of color* with disabilities, as well as
the ways in which racism and able-ism are linked but not always analogous. Is this perhaps a legacy of the landmark Americans with Disabilities Act of 1990? In this legislation, Congress declares that “individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society” (U.S. Congress Section 12101). According to the U.S. legal system, one must be recognized as having a distinct—and injured—identity before discrimination can be recognized, but this formal recognition obscures the many differences among people with disabilities and defines them as sharing a coherent and fixed identity based around the experience of “powerlessness” (U.S. Congress Section 12101). It thus contributes to what Wendy Brown—influenced by Michel Foucault’s notion of disciplinary power—describes as a disciplinary “configuration” of a minority subject (Brown 65). In doing so, it forecloses the possibility that the “injured” have at times enacted forms of resistance and not been entirely “powerless.” And it presumes that disability is the primary or only site of oppression for its subjects, a presumption more likely to be true of white subjects with disabilities. Finally, it affirms “participation” in liberal capitalist society as the goal of the legislation (U.S. Congress Section 12101), seemingly negating a more radical “critique of capitalism” (Brown 61).

An intersectional approach to disability is especially urgent, in my view, considering that numerous studies have shown that poor people and people of color are often at greater risk for developing disabilities as a result of limited access to health care and exposure to environmental toxins and hazardous workplace conditions. Ruth Wilson Gilmore defines racism as “the state-sanctioned and/or extra-legal production and exploitation of group-differentiated vulnerabilities to premature death, in distinct yet densely interconnected political geographies” (247). While her
definition emphasizes premature *death*, it implies vulnerability to premature disability as well—an important feature of racism that disability scholars tend not to discuss. “The machine will try to grind you into dust” (22), writes Audre Lorde, an observation echoed 25 years later by Lupita, a factory worker and labor activist in Tijuana interviewed in the documentary *Maquilapolis*: “Under globalization, a woman factory worker is like a commodity,” quickly used up and discarded, she explains. “Our labor / has become more important / than our silence,” concludes Lorde (19).

In the introduction to *The Cancer Journals*, Lorde models intersectionality when she asks, “How do my experiences with cancer fit into the larger tapestry of my work as a Black woman, into the history of all women?” (16-17). Her question reminds us that for many women of color, disability may occur within (and sometimes as a result of) a larger history of racism, sexism, classism, and other forms of violence and oppression. “Growing up Fat Black Female and almost blind in america requires so much surviving that you have to learn from it or die,” she explains (40). Faced with a cancer diagnosis, Lorde summons internal and community resources for survival forged from her earlier experiences of oppression, including the marginalization she experienced as a vision-impaired child.

Lorde’s work inspires many “intersectional” lines of inquiry in disability studies, including but not limited to

--An exploration of the many and diverse contributions of activists, artists, performers, and theorists of color who also have disabilities . . . an exploration that should result in more than a passing reference or token gesture.
Another avenue would be to analyze how disability has served as a literary device for representing racially marginalized subjects. Ato Quayson calls this literary strategy “disability as the interface with otherness (race, class, sexuality, and social identity)” (52).

A third line of inquiry might explore the philosophical connections between racial and disability discourses throughout Western history, including but not limited to biological racism.

And a fourth line of inquiry would examine how discourses of disability have been used historically to justify discrimination against subjects of color, for example, in the United States in the context of immigration policies in the early 20th century and in the context of public education in the post-World War II era.

These lines of inquiry have been pursued by disability scholars such as Quayson, Rosemarie Garland Thomson, and Douglas Baynton, as well as by disability activists such as Eli Clare and Anne Finger, but they represent the minority of disability studies scholarship.

II. The second theme I draw attention to in Audre Lorde’s text is institutionalization. In The Cancer Journals, Lorde expresses her loathing for the hospital where she spends weeks undergoing testing, surgery, and recovery, subjected to the condescension of medical experts and aides who prescribe a normalizing agenda for healing: “It was an erotically blank environment within whose undifferentiated and undemanding and infantalizing walls I could continue to be emotionally vacant” (46), she explains. But, she admits, the hospital also provides “a kind of protection, a welcome insulation within which I could continue to non-feel” (46). Lorde’s ambivalence toward the medical institution is perhaps one we might carry over to the academic institutions from which we disability studies scholars seek recognition and reward.
What are the risks of institutionalizing disability studies? For example, disability has in previous generations been institutionalized in the academy as a medical problem to be remedied by the “helping professions” such as audiology and physical therapy. It has also been institutionalized in university offices of disability services, which purport to provide support to students with disabilities but which often seem designed to protect the university against ADA lawsuits. Each semester I am presented by one or more students with letters that verify their disabilities and list accommodations such as note-takers and extended time on exams. Yet the Disability Services office has not fundamentally challenged the university to rethink the way it delivers education to a student population with a wide variety of learning and physical differences. Might education for all be improved if universities placed the needs of its marginalized students first?

Further, are there advantages to exploring disability from the peripheries of other programs—especially ethnic studies? Several pivotal anthologies in disability studies—such as Disability Studies: Enabling the Humanities, the Disability Studies Reader, and "Defects": Engendering the Modern Body, co-edited by Prof. Deutsch—have done an amazing job of fostering a collaborative conversation across disciplines such as literature, gender studies, history, anthropology, urban planning and beyond. But we need to make an effort to open that dialogue with our colleagues in ethnic studies programs and departments. Without such connections and conversations, “disability studies” as a stand-alone academic enterprise risks institutionalizing a restricted definition of disability identity and in turn producing scholarly work that reaffirms that perspective.
III. This brings me to the final theme I wish to highlight, which concerns the importance of community and collaboration. Of her experience with cancer, Lorde writes, “The women who sustained me through that period were black and white, old and young, lesbian, bisexual, heterosexual, and we all shared a war against the tyrannies of silence” (20).

My own work in disability studies is deeply indebted to and informed by the insights of my colleague and friend Laura Fugikawa in the American Studies and Ethnicity Department at USC. We did not meet in a disability studies seminar because no such thing exists at USC; our common ground has been courses in gender studies and comparative ethnic studies, which have provided the intellectual foundation for a shared—often intersectional—conversation including but not limited to disability. While collaboration is a basic condition of social justice activism, it is a practice that continues to be at odds with the standards of individual academic success imposed on all scholars—disability and otherwise—by the university.

IV. “It is not difference that immobilizes us, but silence” (23) declares Lorde, words that should encourage each of us to extend ourselves beyond the comfortable boundaries of our own personal experience and disciplinary training. I close with a quote from Lorde:

We must each of us recognize our responsibility to . . . not hide behind the mockeries of separations that have been imposed on us and which so often we accept as our own (23).


