PREFACE

WRITING (WITH) A MOVEMENT FROM BED

When I moved to Oakland in 2007, I started writing from bed. I wrote in old sleep pants, lying on a heating pad, during the hours I spent in my big sick-and-disabled femme of color bed cave. I wasn't alone in this. I did so alongside many other sick and disabled writers making culture. Writing from bed is a time-honored disabled way of being an activist and cultural worker. It's one the mainstream doesn't often acknowledge but whose lineage stretches from Frida Kahlo painting in bed to Grace Lee Boggs writing in her wheelchair at age ninety-eight.

I had very good timing. I moved to Oakland just as disability justice was birthing itself as a movement. "Disability justice" is a term coined by the Black, brown, queer, and trans members of the original Disability Justice Collective, founded in 2005 by Patty Berne, Mia Mingus, Leroy Moore, Eli Clare, and Sebastian Margaret. Disabled queer and trans Black, Asian, and white activists and artists, they dreamed up a movement-building framework that would center the lives, needs, and organizing strategies of disabled queer and trans and/or Black and brown people marginalized from mainstream disability rights organizing's white-dominated, single-issue focus. Sins Invalid[1], the disability justice performance collective cocreated by Patty Berne and Leroy Moore, was based in Oakland and was shaking things up with its large-scale, beautifully produced performances about Black and brown queer disabled sex, bodies, and struggles, its use of culture as a weapon to reshape people's dreams, nightmares, and future visions of disabled Black and brown queer liberation. The

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[1] For more about Sins Invalid's vibrant history as a performance collective, see http://sinsinvalid.org/ or https://youtube.com/CripJustice.

writing of disabled queer Black and brown writers and activists like Mia Mingus, Stacey Milbern, Aurora Levins Morales, and Billie Rain was shaking things up online and in print, their pieces being passed from hand to hand in communities I was part of. I was reading them over and over again, silently in my room, my brain breaking open. I had never seen disabled queer and trans Black, Indigenous, and people of color (QTBIPOC) writers talking about the nitty-gritty facts of our lives out loud before, without apology. It felt like queer crip of color writers were creating space for sick and disabled queer and trans people of color to name ourselves as disabled, our kind of disabled, for the first time, and talk about the shit we'd only whispered before. We were finding ourselves, and each other, and making sick and disabled QTBIPOC space that held our desires and our stories. It felt like some non-disabled queers and activists were paying attention, being forced to deal with ableism, and with us, whether or not they were thrilled about it.

As disability justice was giving birth to itself as a movement, I got to be part of it as a cultural worker, often working from bed. As I was able to perform with Sins Invalid and experienced its exquisitely high level of access for disabled artists, that experience refused to stay in one little corner of my life—I wanted all the QTBIPOC cultural spaces I took part in to be that accessible, that whole. I wrote pieces about cross-disability access that were tools I and other disabled BIPOC queers and allies used to help create the first Creating Collective Access network[2], an experiment in access made by and for QTBIPOC disabled people at the 2010 Allied Media Conference (AMC) and US Social Forum (USSF) that broke away from traditional formats of "access as service begrudgingly offered to disabled people by non-disabled people who feel grumpy about it" to "access as a collective joy and offering we can give to each other." Finding other disabled QTBIPOC creators and building with them prompted me to write about what it meant to create performing arts spaces where access was a central part of the performance, not an afterthought. As queers and femmes in my communities, particularly queer femmes of color and multiply marginalized femmes, continued to kill themselves, I wrote about suicidality as an ever-present reality in our communities. As I finally finished my first memoir after ten years of work, I wrote about what it takes to write femme of color disabled trauma stories and how survivorhood is part of disability justice.

I wrote these pieces not out of a desire for fame or cultural capital but to be useful. Culture makes culture. When there's no space to talk about disability in art—when people at the poetry slam respond to your crip poem with "How touching" and give you sad face, or just look confused—disabled artists of color won't make disabled art. When there are few QTBIPOC arts spaces, QTBIPOC tend to think art isn't a viable career option. Disability justice allowed me to understand that me writing from my sickbed wasn't me being weak or uncool or not a real writer but a time-honored crip creative practice. And that understanding allowed me to finally write from a disabled space, for and about sick and disabled people, including myself, without feeling like I was writing about boring, private things that no one would understand.

This is a big deal. Because, while I got sick with fibromyalgia and chronic fatigue immune deficiency syndrome (CFIDS)[3] in 1997, and have been a neurodivergent survivor of violence with complex PTSD all my life, I didn't write or publish anything about disability until *Bodymap*, my third book of poetry, came out in 2015. It was almost twenty years

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[2] For more information about the CCA, check out https://creatingcollectiveaccess.wordpress.com/. I talk in more detail about the CCA in "Care Webs: Experiments in Creating Collective Access" (see p. 32).

[3] The term most commonly used now, like on official websites and the like, is "Chronic Fatigue Immune Dysfunction," but I learned it as "chronic fatigue immune deficiency syndrome," and that's what I've been using for twenty-plus years, so I think we'll stick with it.

since I'd first become chronically ill and a decade into my publishing books. Before I had the great good fortune to run into Sins Invalid and other queer people of color talking and writing about disability, I, like many other QTBIPOC I knew, thought of disability as something that you weren't allowed to talk or write about in QTBIPOC culture. Nowhere in the QTBIPOC politicized spoken word communities I was part of (or wanted to be cool enough to be part of) in the early 2000s do I remember anyone ever doing poetry about disability or thinking about access at all. (Do you remember any poems about disability justice making it onto *Def Poetry Jam*? I don't.) And that state of affairs continued into my adult life in the able-bodied QTBIPOC artist community. It's not like anyone came right out and said they hated disabled people. But disability was depressing or embarrassing to write about, or just something that "most people wouldn't be able to relate to as a subject." There was a huge echoing silence in POC and/or queer activist communities. I had a few friends who whispered to each other about our chronic illnesses—but the most we could say was "It sucks, right?" We had no idea we could be part of a community, a history, a movement.

But in the past decade, disability justice culture has bloomed, through the hard work of disabled people who are also queer feminists of color, and it's not like that anymore—at least, not all of the time. It's not that ableist disregard for crip lives, both in the mainstream and inside our movements and communities, doesn't still exist. But I no longer worry that every single person I encounter at an event will be awkward or pity me or just not get it. I do not feel like I am the only person I know who is talking about disability justice. I no longer feel like one of a tiny handful of people talking about access or worry that if I produce a crip show of course no one will come to it. I think more people know that not all disabled people are white. When I first started offering sick and disabled writing workshops for queer and trans people of color around 2010, sometimes no one would come out, or just a few people, or the idea would be shot down because the organizers were sure no one would come. But when I went on tour with *Bodymap* in 2015 and read explicitly disability-focused work, almost all of my gigs were standing and sitting room only. When I did a writing workshop by and for sick and disabled people of color at the 2015 Queer Students of Color Conference, the room was spilling over with queer people of color who wanted to talk and write about everything from pesticide exposures they had received doing farm work to intergenerational trauma. Disabled Black and brown queer voices are no longer uncommon on popular feminist and queer blogs like *The Body Is Not an Apology*, *Everyday Feminism*, *GUTS*, and *Autostraddle*, and I see articles including and thinking about ableism instead of forgetting about it. The Disability Visibility Project, Wear Your Voice, the Spoonie Collective, the Deaf Poets Society, Autistic Hoya, Krip-Hop Nation, and many other sites by and for intersectional disabled people are live. Everywhere people are talking about care work, emotional labor, femme emotional labor, access, and crip skills and science.

None of this happened because the able-bodied people decided to be nice to the cripples. It happened because disabled queer and trans people of color started organizing, often with femme disabled Black and brown queer people in the lead. Much of that work has been done through writing, storytelling, and art as activism. Much of our coming together has been through zines, online disabled QT/POC communities, Tumblr and blog and social media posts, or through three people getting together at a kitchen table or a group Skype call to start to hesitantly talk about our lives, organize a meal train, share pills and tips, or post the thoughts about activism and survival we have at two in the morning. It is underdocumented, private work—work often seen as not "real activism." But it is the realest activism there is. This is how disability justice art and activism change the world and save lives.

In writing this book, I wanted to capture some of this history as it is being made and dreamed.

CONCRETE TOOLS, LIBERATION POLITICS, AND POETRY

THIS IS DISABILITY JUSTICE

I'd like to offer a quick definition and history of what we mean when we say the words "disability justice." This is important for so many reasons but especially because our work and terminology are in danger, now and always, of having the fact that they were invented by Black, Indigenous, and people of color erased and their politics watered down. There is a specific danger in that happening with disability justice, as disabled Black and brown creators face a specific invisibilization and erasure of our political and cultural work. I want to both give the Black and brown people and femmes who invented the term credit and be clear about what DJ means and what it doesn't.

In the words of Sins Invalid cofounder and executive director Patty Berne,

> While a concrete and radical move forward toward justice for disabled people, the Disability Rights Movement simultaneously invisibilized the lives of peoples who lived at intersecting junctures of oppression—disabled people of color, immigrants with disabilities, queers with disabilities, trans and gender non-conforming people with disabilities, people with disabilities who are houseless, people with disabilities who are incarcerated, people with disabilities who have had their ancestral lands stolen, amongst others ... Disability Justice activists, organizers, and cultural workers understand that able-bodied supremacy has been formed in relation to other systems of domination and exploitation. The histories of white supremacy and ableism are inextricably entwined, both forged in the crucible of colonial conquest and capitalist domination. One cannot look at the history of US slavery, the stealing of indigenous lands, and US imperialism without seeing the way that white supremacy leverages ableism to create a subjugated 'other' that is deemed less worthy/abled/smart/capable ... We cannot comprehend ableism without grasping its interrelations with heteropatriarchy, white supremacy, colonialism and capitalism. Each system benefits from extracting profits and status from the subjugated 'other.' 500+ years of violence against black and brown communities includes 500+ years of bodies and minds deemed 'dangerous' by being non-normative.
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> A Disability Justice framework understands that all bodies are unique and essential, that all bodies have strengths and needs that must be met. We know that we are powerful not despite the complexities of our bodies, but because of them ... Disability Justice holds a vision born out of collective struggle, drawing upon the legacies of cultural and spiritual resistance within a thousand underground paths, igniting small persistent fires of rebellion in everyday life. Disabled people of the global majority—black and brown people—share common ground confronting and subverting colonial powers in our struggle for life and justice. There has always been resistance to all forms of oppression, as we know through our bones that there have simultaneously been disabled people visioning a world where we flourish, that values and celebrates us in all our myriad beauty.[4]

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[4] Patty Berne, "Skin, Tooth, and Bone—The Basis of Our Movement Is People: A Disability Justice Primer," *Reproductive Health Matters* 25, no. 50 (May 2017): 149–50.

To me, disability justice means a political movement and many interlocking communities where disability is not defined in white terms, or male terms, or straight terms. Disability justice is to the disability rights movement what the environmental justice movement is to the mainstream environmental movement. Disability justice centers sick and disabled people of color, queer and trans disabled folks of color, and everyone who is marginalized in mainstream disability organizing.

More than that, disability justice asserts that ableism helps make racism, christian supremacy, sexism, and queer- and transphobia possible, and that all those systems of oppression are locked up tight. It insists that we organize from our sick, disabled, "brokenbeautiful" (as Alexis Pauline Gumbs[5] puts it) bodies' wisdom, need, and desire. It means looking at how Indigenous and Black and brown traditions value sick and disabled folks (not as magical cripples but as people of difference whose bodyspirits have valuable smarts), at how in BIPOC communities being sick or disabled can just be "life," and also at how sick and disabled BIPOC are criminalized. It means asserting a vision of liberation in which destroying ableism is part of social justice. It means the hotness, smarts, and value of our sick and disabled bodies. It means we are not left behind; we are beloved, kindred, needed.

When we do disability justice work, it becomes impossible to look at disability and not examine how colonialism created it. It becomes a priority to look at Indigenous ways of perceiving and understanding disability, for example. It becomes a space where we see that disability is all up in Black and brown/queer and trans communities—from Henrietta Lacks to Harriet Tubman, from the Black Panther Party's active support for disabled organizers' two-month occupation of the Department of Vocational Rehabilitation to force the passage of Section 504, the law mandating disabled access to public spaces and transportation to the chronic illness and disability stories of second-wave queer feminists of color like Sylvia Rivera, June Jordan, Gloria Anzaldúa, Audre Lorde, Marsha P. Johnson, and Barbara Cameron, whose lives are marked by bodily difference, trauma-surviving brilliance, and chronic illness but who mostly never used the term "disabled" to refer to themselves. Many of us rely on state funding and services to survive and fight for things like the Affordable Care Act (ACA) and the Americans with Disabilities Act (ADA) to remain protected and expanded. But our focus is less on civil rights legislation as the only solution to ableism and more on a vision of liberation that understands that the state was built on racist, colonialist ableism and will not save us, because it was created to kill us. A movement where, in the words of Sins Invalid, "we move together, with no body left behind."

To me, one quality of disability justice culture is that it is simultaneously beautiful and practical. Poetry and dance are as valuable as a blog post about access hacks—because they're equally important and interdependent. This book is an example of that both/and. In this mosaic, you will find pieces of personal testimony and poetry, meditations on Gloria Anzaldúa and Prince as disabled queer Black and brown figures, grassroots intellectual examinations of accessible performance spaces as prefigurative politics—and tips for how to tour as a chronically ill artist and notes on where to get accessible fragrance-free POC hair products.

That is not usual, and that is on purpose. Like disability justice itself as a framework and culture, this book is a mix of very concrete tools and personal essays. I hesitated a bit to include the former. Serious cultural work isn't supposed to include lists of fragrance-free curly hair products or instructions about how to tour while sick and hurt less, right? But—*fuck that.* The making of disability justice lives in the realm of thinking and talking and knowledge making, in art and sky. But it also lives in how to rent an accessible porta potty for an accessible-except-the-bathroom

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[5] Alexis Pauline Gumbs, brokenbeautiful press, https://brokenbeautiful.wordpress.com, accessed May 28, 2018.

event space, how to mix coconut oil and aloe to make a fragrance-free hair lotion that works for curly and kinky BIPOC hair, how to learn to care for each other when everyone is sick, tired, crazy, and brilliant. And neither is possible without the other.

CARE WORK IN THE APOCALYPSE

When I began working on this book in July 2016—right after I quit the job at a giant corporate university that I had hoped would be an accessible way of making a living but ended up giving me pneumonia for three months—I thought I'd just slap together a collection of all the pieces of writing I'd done over the past decade: essays about curating QTBIPOC performance art, the *Femme Shark Manifesto*. But as I edited this book over the summer of 2017, I realized that the pieces that were the most prominent were all ones that I'd written about disability justice and care labor in many forms.

The theme of care work, as a place where disability justice and queer femme emotional labor intersect, came to me. "Nothing about us without us" is a disability rights slogan that was created by South African disability rights groups in the 1980s. A more recent disability justice slogan I have heard, that I first saw on an image Sins Invalid created in protest of the killing intersections of racism and ableism in the Israeli bombardment of Gaza in the summer of 2014, is "To exist is to resist." This phrase speaks to the ways in which the everyday struggles to live and survive by sick and disabled QTBIPOC are "real" activism—when you are lying in bed trying to breathe or talking someone through a panic attack or fighting Medicaid or the queer club to let you in, that is resistance. And in this political moment, where Trump is attempting to kill sick and disabled people by ending Medicaid, the Affordable Care Act, and the ADA, and where the things that do save us—emergent airport demonstrations against Trump's Islamophobic and racist travel and immigration bans, care webs where we raise money for medical and housing surpluses—are so clearly not the state, this book feels timely.

I also wrote this book with a lot of anxiety. I was very conscious during the process of compiling and editing this book that it would be the first on disability justice by a queer writer of color that was not self- or micropress-published. This is huge, and telling: that the racism and ableism of the publishing industry mean there are barely any popular books out there on disability, and the vast majority of them are written by white, disabled people. Like every other disabled writer I know, I have been asked if I think "readers will really know what ableism is." I have had pieces about disability politics be read with incomprehension by editors who said, "Don't you want to say more about your illness?" and were confused that I am not telling the only disabled story they can comprehend—a simple, tragic yet uplifting tale where I talk about my "illness" and how I have "overcome" it—but a story of collective struggle, community building, love and luck and skills. Like every disabled Black and brown writer I know, I have fought to get anyone to give a shit or not just throw up their hands at how way too complicated my story is—can't I just focus on my brownness or ableism?

Because I am a cultural worker who is one disabled femme of color writer in a collective movement of many, I was clear about what I did and did not want this book to be. For the past year, I have thought a lot about what I wanted to do to intervene in the very likely reality that, as I am a light-skinned, non-Black, ambulatory, often verbally communicative person, mainstream media would want to cast me as "the face of disability justice" and thrust into the spotlight as the one "expert" on this wacky new movement—erasing all of my comrades and fellow artists, thinkers, and organizers, particularly those who face certain kinds of ableism that are more overt and killing than some that I face. This fear didn't come from nowhere: I had one offer to publish this book that meant very well in talking about how "the time had come for a big book on disability justice" but then admitted that in mainstream publishing, unless you're willing to pitch yourself as "the expert," essay books don't sell.

I am and want to be very clear: I am one writer and performer in a sea of sick and disabled QT/BIPOC people who are doing work in many ways all the time—as writers and activists, and as everyday folks who are keeping themselves and other people alive. I do not want this to be "the" book on disability justice. This book is one in a garden of books that I invoke to become more abundant. Please check out the books, authors, websites, and zines in the Further Reading and Resources section for a complete view of what this world is.

But for now, please come into this one. And write your own.

10 PRINCIPLES OF DISABILITY JUSTICE

by Patty Berne, edited by Aurora Levins Morales and David Langstaff, on behalf of Sins Invalid

From my vantage point within Sins Invalid, where we incubate both the framework and practice of Disability Justice, this burgeoning framework has ten (10) principles, each offering new opportunities for movement builders:

1. INTERSECTIONALITY. We know that each person has multiple identities, and that each identity can be a site of privilege or oppression. The mechanical workings of oppression and how they output shift depending upon the characteristics of any given institutional or interpersonal interaction; the very understanding of disability experience itself is being shaped by race, gender, class, gender expression, historical moment, relationship to colonization, and more.

2. LEADERSHIP OF THOSE MOST IMPACTED. We know ableism exists in the context of other historical systemic oppressions. We know to truly have liberation we must be led by those who know the most about these systems and how they work.

3. ANTI-CAPITALIST POLITIC. We are anti-capitalist, as the very nature of our mind/bodies often resists conforming to a capitalist "normative" level of production. We don't believe human worth is dependent on what and how much a person can produce. We critique a concept of "labor" as defined by able-bodied supremacy, white supremacy, and gender normativity. We understand capitalism to be a system that promotes private wealth accumulation for some at the expense of others.

4. CROSS-MOVEMENT SOLIDARITY. Necessarily cross movement, Disability Justice shifts how social justice movements understand disability and contextualize ableism, lending itself towards a united front politic.

5. RECOGNIZING WHOLENESS. We value our people as they are, for who they are, and understand that people have inherent worth outside of capitalist notions of productivity. Each person is full of history and life experience. Each person has an internal experience composed of their own thoughts, sensations, emotions, sexual fantasies, perceptions, and idiosyncrasies. Disabled people are whole people.

6. SUSTAINABILITY. We pace ourselves, individually and collectively, to be sustained long term. We value the teachings of our lives and bodies. We understand that our embodied experience is a critical guide and reference pointing us toward justice and liberation.

7. COMMITMENT TO CROSS-DISABILITY SOLIDARITY. We value and honor the insights and participation of all of our community members.

We are committed to breaking down ableist/patriarchal/racist/classed isolation between people with physical impairments, people who identify as "sick" or are chronically ill, "psych" survivors and those who identify as "crazy," neurodiverse people, people with cognitive impairments, and people who are of a sensory minority, as we understand that isolation ultimately undermines collective liberation.

8. INTERDEPENDENCE. Before the massive colonial project of Western European expansion, we understood the nature of interdependence within our communities. We see the liberation of all living systems and the land as integral to the liberation of our own communities, as we all share one planet. We attempt to meet each other's needs as we build towards liberation, without always reaching for state solutions that inevitably then extend its control further over our lives.

9. COLLECTIVE ACCESS. As brown/black and queer crips, we bring flexibility and creative nuance to engage with each other. We create and explore new ways of doing things that go beyond able-bodied/minded normativity. Access needs aren't shameful—we all have various capacities which function differently in various environments. Access needs can be articulated within a community and met privately or through a collective, depending upon an individual's needs, desires, and the capacity of the group. We can share responsibility for our access needs, we can ask that our needs be met without compromising our integrity, we can balance autonomy while being in community, we can be unafraid of our vulnerabilities knowing our strengths are respected.

10. COLLECTIVE LIBERATION. How do we move together as people with mixed abilities, multiracial, multi-gendered, mixed class, across the orientation spectrum—where no body/mind is left behind?

This is Disability Justice, an honoring of the long-standing legacies of resilience and resistance which are the inheritance of all of us whose bodies or minds will not conform. Disability Justice is not yet a broad-based popular movement. Disability Justice is a vision and practice of a *yet-to-be*, a map that we create with our ancestors and our great-grandchildren onward, in the width and depth of our multiplicities and histories, a movement towards a world in which every body and mind is known as beautiful.