Introduction


3 I use (dis)ability to designate the overarching social system of bodymind norms that creates categories of disability, impairment, able-bodiedness, and able-mindedness, producing privilege for some and oppression for others in dynamic, intersectional, and context-based ways. I use the terms disability and ability to designate the specific marginalized and privileged positions within the (dis)ability system as a whole. For more on the rationale behind this language choice, see Schalk, “Critical Disability Studies as Methodology”; and Schalk, Bodyminds Reimagined, 6.

4 In addition to the individuals named thus far, additional examples of important Black disability studies scholarship include Samuels, “Examining Millie and Christine McKoy”; Samuels, Fantasies of Identification; Bailey, “Race and Disability in the Academy”; Boster, African American Slavery and Disability; Barclay, “’The Greatest Degree of Perfection’”; Barclay, “Mothering the ‘Useless’”; Knadler, “Dis-Abled Citizenship”; Jarman, “Dismembering the Lynch Mob”; Jarman, “Coming Up from Underground”; and Jarman, “Cultural Consumption and Rejection of Precious Jones.”


6 Berne, “Disability Justice.”

7 Berne, “Disability Justice.”


9 See McRuer, Crip Theory; and M. Johnson and McRuer, “Cripistemologies.”
11 Kafer, Feminist, Queer, Crip, 10.
12 Kafer, Feminist, Queer, Crip, 12.
13 See Schalk, “Interpreting Disability Metaphor and Race.”
14 For more on the history of the disability rights movement, see Charlton, Nothing about Us without Us; Fleischer and Zames, Disability Rights Movement; and Shapiro, No Pity.
15 For the historical evidence of Black disability politics prior to the 1970s, see, for example, Tyler, “Jim Crow’s Disabilities”; Waggoner, “‘My Most Humiliating Jim Crow Experience’”; Knadler, “Dis-Abled Citizenship”; Knadler, Vitality Politics; and Barclay, Mark of Slavery.
17 Kafer, Feminist, Queer, Crip, 153.
18 Given the limited scholarly work on the specific approaches to disability politics within particular racialized communities thus far, I cannot say how much Black disability politics overlaps with Indigenous and Native disability politics, Asian/American disability politics, or Latinx disability politics, but I am certain future research will trace the connections among these approaches as each group further develops and articulates their specific disability politics.
19 An important example of this work occurring among other racialized groups is the 2013 special issue of Amerasia Journal 39, no. 1, titled “The State of Illness and Disability in Asian America,” and the Asian American Literary Review’s 2016 special issue “Open in Emergency: A Special Issue on Asian American Mental Health.”
20 I acknowledge the scholarly debates around the term intersectionality, but following the lead of Jennifer Nash, I aim to disrupt Black feminist defensiveness and protectiveness of the term by simply defining and using an intersectional framework rather than spending extensive time defending it. The term works for me and may not work for others, and that is okay. See Nash, Black Feminism Reimagined.
21 For scholarship on the complicated relationships of people of color to disability identity, see Day, “Resisting Disability, Claiming HIV”; Nishida, “Understanding Political Development through an Intersectionality Framework”; Erevelles, Disability and Difference in Global Contexts; Erevelles, “Crippin’ Jim Crow”; and Puar, Right to Maim.
24 See J. Livingston, Debility and the Moral Imagination in Botswana.
25 Puar, Right to Maim, xiii.
26 Puar, Right to Maim, xv.
Notes to Chapter one

27 Price, “Bodymind Problem and the Possibilities of Pain”; and Schalk, Bodyminds Reimagined.


29 For examples of the range of issues addressed by Black feminists, see Hull, Bell-Scott, and Smith, All the Women Are White; Combahee River Collective, “The Combahee River Collective Statement”; B. Smith, Home Girls; or Guy-Sheftall, Words of Fire. For a scholarly analysis of this broad range of Black feminist issues, see Springer, Living for the Revolution, 91–93.

30 All participants were paid for their time, and interviews ranged from thirty minutes to just under two hours. I asked participants the same series of eight questions but informed them that they were allowed to skip any questions or come back to them later. I asked:

1 How do you identify or describe yourself?
2 How did you become politicized in your identities or become an activist?
3 What activist work have you done? What are you most proud of in that work?
4 How do you think Black activists and Black communities have addressed or avoided disability as a political concern?
5 How do you think the mainstream disability rights movement has addressed or avoided race as a political concern?
6 How do you see race and disability (or racism and ableism) interacting in the lives of Black people historically and/or in the present?
7 How would you describe Black disability politics or Black disability activism? What are important qualities or aspects of Black disability political work?
8 Is there anything else I should know about you, your work, or Black disability politics?

After the interviews, I sent transcripts to participants to allow them to review them and edit or change anything they wanted. Later I sent the first draft of chapter 5 to the participants to again get their approval and feedback on how I am representing them and their ideas.


Chapter One: “We Have a Right to Rebel”

1 The original image caption misidentified Dennis Phillips as Dennis Billips, but he is mentioned and quoted in other articles under his proper name.

2 Huggins and LeBlanc-Ernest, “Revolutionary Women, Revolutionary Education,” 165. Ericka Huggins and Angela D. LeBlanc-Ernest argue that Panther women are represented less in the literature in part because they wrote less and worked more than leading men in the BPP. They write, “BPP women did
not have time to reflect and write while they were active in the Party. Most Party members worked twenty hours per day, seven days per week. Women’s activism was central to Party success. Indeed, women’s work in the Party was not separate work. It was seamlessly intertwined with the Party’s leadership and activities. Due to the daily trauma women in the BPP experienced from external oppressive forces such as harassment from local law enforcement, shootings, assassinations, arrests, and imprisonment, all of which often caused women to be separated from their children, many privately processed the complexities of being women and mothers, Black critical thinkers, and revolutionary activists.” Huggins and LeBlanc-Ernest, “Revolutionary Women, Revolutionary Education,” 166.

3 Bloom and Martin, Black against Empire, 2.
5 Rhodes, Framing the Black Panthers, 292–93.
6 For more extended histories of the BPP, see Bloom and Martin, Black against Empire; and Spencer, Revolution Has Come.
7 Austin, Up against the Wall, xviii.
9 See A. Nelson, Body and Soul; and R. Spencer, The Revolution Has Come.
10 Hilliard, Black Panther Party, 3; see also Austin, Up against the Wall.
12 “History of the Black Panther Party”; emphasis added.
13 “History of the Black Panther Party.”
14 Bloom and Martin, Black against Empire, 56.
15 Spencer, Revolution Has Come, 192–94.
16 “Innerparty Memorandum #24,” series 2, box 4, folder 10, Dr. Huey P. Newton Foundation Inc. Collection, M0864, Department of Special Collections, Stanford University Libraries, Stanford, CA.
17 Rhodes, Framing the Black Panthers, 308–9.
18 For example, see Fleischer and Zames, Disability Rights Movement, 54; Shaw, Activist’s Handbook, 240; Shapiro, No Pity, 67; Longmore, Why I Burned My Book, 107; Meade and Serlin, “Editors’ Introduction,” 2; and Scotch, From Good Will to Civil Rights, 115.
20 Groups who provided support for the 504 protesters “included the Butterfly Brigade, ‘a group of gay men who patrolled city streets on the lookout for gay violence,’ who smuggled walkie-talkies into the occupied building; Glide Church; local and national labor organizations; members of Delancey Street, the famous grassroots rehab program for substance abusers and former felons, who brought breakfast into the building each day; the Chicano group Mission Rebels, who also provided food; and the Black Panthers.” Schweik, “Lomax’s Matrix.”


22 D’Lil, *Becoming Real in 24 Days*, 56. Based on the location of this quote in the book, it’s unclear if the quote comes from White’s rally speech on April 5 or from later, most likely on April 8, the fourth day of the protest, which is the chapter in which this quote and White’s photo (captioned as an image from his rally speech) both appear.


24 In a footnote Schweik includes informal communication with Fultz in which he recalls organizing the Panthers’ delivery of food and giving an “extemporaneous” speech at the protest because Elaine Brown, leader of the BPP at that time, was unable to attend. I have been unable to locate any transcript or date of Fultz’s speech. D’Lil lists Brown as “outside support.” D’Lil, *Becoming Real in 24 Days*, 58.


30 Report by Brad Lomax, September 3, 1977, series 2, box 5, folder 8, Dr. Huey P. Newton Foundation Inc. Collection, MO864, Department of Special Collections, Stanford University Libraries.

31 The second half of the report briefly discusses conflict with “Chuck,” likely Chuck Jackson from the previously discussed cover-story image. Lomax states, “I have criticized Chuck constantly on the house condition: floor waxing, kitchen cleaning, washing the dishes, and washing my clothes. These criticisms

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seem to have no effect.” Lomax then notes that he told Jackson that if the issues continued, he would “take it too [sic] a higher level.” Lomax concludes by stating that he would like to go swimming in an indoor pool because “it would help my speech, organize my thoughts etc.” Archival records by and about Lomax are extremely limited, and at least one document from or about Lomax and Jackson has been removed from the Dr. Huey P. Newton Foundation Inc. Collection for “confidential” reasons. However, given this report and the fact that Jackson accompanied Lomax throughout the protest events, including the trip to DC, it seems reasonable to infer that Jackson acted as Lomax’s roommate in shared BPP housing and as his personal care assistant as part of his duties as a Panther. It’s hard to say much more about their relationship without further evidence, but Lomax’s report suggests that care work for disabled members (in addition to the care work provided by the clinics and the children’s programs) was part of the labor Panther members were expected to take on to sustain the work of the collective. Report by Lomax, September 3, 1977.

37 O’Toole, Fading Scars, 60.
38 Quoted in Pelka, What We Have Done, 273; emphasis added.
41 The number of people who received or read the paper can only be estimated. In May 1978, the editor of the Black Panther estimated they printed approximately 5,500 copies of the paper per issue. Spencer, Revolution Has Come, 192. It is
reasonable to assume, therefore, that about that number were being printed and distributed during the period discussed here.

43 “Rights for Disabled at Issue,” 20.
44 A version of the social model was explicitly included in a quote from a protestor who stated, “If they’d take away the handicaps (like stairs, and other barriers for wheelchair-confined and otherwise disabled people), then we wouldn’t be handicapped.” “Rights for Disabled at Issue,” 20.
45 Shakespeare, “Social Model of Disability.”
46 Quoted in “Rights for Disabled at Issue,” 20.
47 See “Medical Malpractice as Methods of Torture at Niantic State Farm for Women,” Black Panther, November 21, 1970, 17.
48 Quoted in “Pressure Forces Califano,” 6.
49 For more on oppression analogies, see Schalk, “Interpreting Disability Metaphor and Race”; Sherry, “(Post)Colonising Disability”; and Samuels, “My Body, My Closet.”
52 “Comment: The Harder You Look,” 12.
53 “Comment: The Harder You Look,” 2.
54 “BPP Members Interviewed,” 5, 8.
55 “BPP Members Interviewed,” 8; and “Delegation to Go to Washington,” 12.
56 “BPP Members Interviewed,” 5.
57 Beal, “Double Jeopardy”; and Bambara, Black Woman.
59 K.-Y. Taylor, How We Get Free, 8.
60 Phillips, “Feminist Leadership of Ericka Huggins.”
61 “Carter, HEW Secretary Califano Snub,” 10; “Delegation to Go to Washington,” 4; and “Pressure Forces Califano,” 6. Across the ten articles (approximately ten thousand words total) covering the 504 demonstration in the Black Panther, the words inspiring or inspiration were used six times total, the word poignant was used twice, and the words victimized or victim were used four times (all four in reference to Lomax’s multiple sclerosis).
62 Schweik, “Lomax’s Matrix.”
63 For more on this argument, see Schalk, “Black Disability Gone Viral.”
64 “Carter, HEW Secretary Califano Snub,” 10; “Editorial: What Price Freedom,” 2; and “BPP Members Interviewed,” 5.
65 “Pressure Forces Califano,” 1.
66 Shapiro, No Pity, 66.
For more on the history of the Intercommunal Youth Institute and its evolution into the ocs, see C. Jones and Gayles, “‘The World Is a Child’s Classroom’”; and Williamson, “Community Control with a Black Nationalist Twist.”


Huggins and LeBlanc-Ernst, “Revolutionary Women, Revolutionary Education,” 177.

In an audio interview, former ocs teacher M. Gayle “Asali” Dickson provides an anecdote about a preschool-aged girl who was “very hard to understand” in her verbal communication excitedly using clearer language with her mother after Dickson created a large-scale visual representation of a class field trip. This is potentially another example of a student with a disability at the ocs. Tammerlin Drummond, “Black Panther School a Legend in Its Time,” East Bay Times, October 6, 2016, https://www.eastbaytimes.com/2016/10/06/black-panther-school-ahead-of-its-time/.

Huggins and LeBlanc-Ernst, “Revolutionary Women, Revolutionary Education,” 172, 177; emphasis added.

Huggins and LeBlanc-Ernst, “Revolutionary Women, Revolutionary Education,” 176.

Huggins and LeBlanc-Ernst, “Revolutionary Women, Revolutionary Education,” 162.


Chapter Two: Fighting Psychiatric Abuse


2 Steiner, “Principles of Radical Psychiatry,” 6.

3 See the following *Black Panther* articles: “NY’s Tombs of Torture,” August 30, 1969, 8; “Queens Copy Acquitted in Murder of 10-Year-Old; Brooklyn Officer Indicted for Killing Sickle Cell Victim,” June 22, 1974, 7; and “Blowing Off Steam—a Necessity for Good Health,” March 10, 1980, 7.

4 Steiner, “Principles of Radical Psychiatry,” 6.


8 Occasionally, the *Black Panther* misnamed the NAPA in articles as the Network against Psychiatric Abuse. For more on the NAPA, see their website: http://networkagainstpsychiatricassault.org.


10 For more on the history of the deinstitutionalization movement, see Grob, *From Asylum to Community*.


13 J. Johnson, *American Lobotomy*, 2; see also Pressman, *Last Resort*.
16 As mentioned in the previous chapter, in the 1970s approximately 5,500 copies
of the paper were being printed per issue and were distributed primarily in Cali-
ifornia but also in select cities nationwide. Spencer, *Revolution Has Come*, 192.
17 See Ben-Moshe and Carey, *Disability Incarcerated*; and the following *Black
Panther* articles: “San Quentin Prisoners Kept Heavily Drugged,” February 9,
1974, 3; “Regional Prisons for Disruptive Inmates Planned,” February 9, 1974,
7, 10; “Inmates Expose Forced Drug Treatments,” August 7, 1976, 9; “Forced
Drugging of Mentally Ill California Inmates Probed,” November 6, 1976, 10;
18 “Vacaville—America’s Headquarters for Medical Genocide,” *Black Panther*,
June 26, 1971, 14. For historical context, Harriet A. Washington explains, “Dur-
ing World War II, prisoners had been commonly used as research subjects, and
after the war, the United States was the only nation in the world continuing
to legally use prisoners in clinical trials. Federal, pharmaceutical, and cosmetic
companies’ money catalyzed a thirty-year boom in research with prisoners”
(*Medical Apartheid*, 249). These experiments occurred despite the American
Medical Association’s 1952 public disapproval of such practices. Washington
writes that news coverage of prison medical, pharmaceutical and cosmetic
research was generally lauded in the US until the reforms were passed in the
1970s (256, 265). By the time the Panthers were writing on the subject, prison
research was supposed to be limited to therapeutic medical treatments with
minimal risk, but as their articles suggest, even purportedly therapeutic medi-
cine, especially psychiatric drugs, can be abused, especially when specifically
applied to incarcerated racialized populations.
19 See, for example, “New Federal Prison for ‘Behavior Modification’ to Open,”
*Black Panther*, July 6, 1974, 5, 6.
20 For more on the concept of able-mindedness and its racial, gender, and class
norms, see A. Taylor, “Discourse of Pathology”; or Schalk, *Bodyminds Re-
imagined*, chap. 2.
21 “Right to Refuse Psychosurgery Promoted,” *Black Panther*, March 13, 1976,
7; and “Psychosurgery Given Ok,” *Black Panther*, September 18, 1976, 7.
Johnson provides more detailed information about the psychosurgery laws
eventually passed in California and Oregon as well as on the congressional
22 Kevin Crockett, “Patients Legal Defense Protests Forced Medication,” *Black
25 Note that in the first letter the author is listed as Kevin Crockett, and in the
second letter the author is listed as Calvin Crockett. It is unclear which
of these is correct, though it is reasonable to assume, given the content and origin of both letters, that the author is the same in each case, but the name was mistyped in one of the printings of the letters (which were likely handwritten).


31 Crockett specifically mentions reading another issue of the *Black Panther* and requests additional political education materials in his January 24, 1976, letter.

32 For example, Judi Chamberlin’s foundational 1978 book, *On Our Own: Patient-Controlled Alternatives to the Mental Health System*, mentions the presence of a Black woman on a psychiatric ward with her but does not engage the intersection of race and psychiatric disability (44). The most robust example I could find is an extended quote from an interview with Jennifer Reid, a mixed-race Black and Native lesbian, in which Reid explicitly discusses the intersection of the prison industrial complex, racism, and the psychiatric industrial complex based on her experiences in Canada. Everett, *Fragile Revolution*, 83–87.

33 Morrison, *Talking Back to Psychiatry*, 78–79.

34 For more on Black experiences with psychiatric institutions, see Vanessa Jackson, “In Our Own Voice: African-American Stories of Oppression, Survival and Recovery in Mental Health Systems.”

35 For more on race and disability metaphors and oppression analogies, see either Schalk, *Bodyminds Reimagined*, chap. 1; or Schalk, “Interpreting Disability Metaphor and Race.”

36 “History of the Black Panther Party”; emphasis added.


42 In addition to “Burn Your Brains Out,” see also “On Eldridge Cleaver by Kathleen Cleaver,” *Black Panther*, August 9, 1969, 5.

43 Hilliard and Cole, *This Side of Glory*, 356.


46 “Tearing Out Our Thoughts,” 13; emphasis added.

48 A. Nelson, Body and Soul, 161–73.


50 Quoted in “Brain Operation Performed without Permission,” 10.


52 “Brain Operation Performed without Permission,” 10.


54 “Brain Operation Performed without Permission,” 10.


56 “Brain Operation Performed without Permission,” 12.

57 “Brain Operation Performed without Permission,” 12.


60 Utsey et al., “Cultural, Sociofamilial, and Psychological Resources”; and Kwate and Goodman, “Cross-Sectional and Longitudinal Effects of Racism on Mental Health.”


62 Washington, Medical Apartheid, 349.


65 Rhodes, Framing the Black Panthers.


See Nelson, Body and Soul; Spencer, The Revolution Has Come; Huggins and LeBlanc-Ernest, “Revolutionary Women, Revolutionary Education”; and Bloom and Martin, Black against Empire.

Federal Bureau of Investigation, Counterterrorism Division, Black Identity Extremists Likely Motivated to Target Law Enforcement Officers, 2.

Praxis Interlude One

2 Jennett and Plum, “Persistent Vegetative State after Brain Damage.” See also Jennett, Vegetative State.
3 Examples of this early use of vegetable or human vegetable to describe the effects of psychosurgery are cited in J. Johnson, American Lobotomy, 96; and Diefenbach et al., “Portrayal of Lobotomy in the Popular Press.”
4 Interestingly, vegetable is an example of how the social reception and use of medical language can result in changes to medical terminology and practices. This has occurred previously in regard to words like idiot, imbecile, moron, and retarded, which were all at one time official medical terms for what we would now call developmental or intellectual disabilities but are no longer used as such, in part owing to how these words were taken up as insults in wider society. Tammy Reynolds, c.e. Zupanick, and Mark Dombeck, “History of Stigmatizing Names for Intellectual Disabilities,” accessed December 18, 2017, https://www.mentalhelp.net/intellectual-disabilities/history-of-stigmatizing-names/.

In regard to vegetable and vegetative state, in 2010 a group of doctors affiliated with the European Task Force on Disorders of Consciousness argued for changing the name of this condition to unresponsive wakefulness syndrome. In their rationale for why the name should be changed, Steven Laureys and colleagues provide both social and medical reasons, arguing that for “most of the lay public and media vegetative state has a pejorative connotation” that reduces the humanity of the person involved, and that vegetative state as a descriptor misrepresents the condition in multiple ways.
The misleading nature of the term *vegetative state*, the authors argue, can potentially lead to a misunderstanding of prognosis by loved ones (because *state* implies permanence) and/or misrecognition of consciousness and awareness in patients “without behavioral responses to command.” So although part of the rationale for changing the term *vegetative state* to *unresponsive wakefulness syndrome* is based in medical practice and diagnosis, a significant portion is also based on the negative social connotations of the term and its derivative social insult of *vegetable*, which was used in the Panthers’ articles on psychiatric abuse and continues to be used today. Laureys et al., “Unresponsive Wakefulness Syndrome,” 711.

5 “Tearing Out Our Thoughts,” 13.

6 *Vegetable* continues to be used today as an ableist term to disparagingly describe people with a number of disabilities, particularly those with limited movement and communication capacities. The top two definitions for *vegetable* on the Urban Dictionary website in 2017, for example, were “a person who is brain-dead” and “something that is living, but their brain is not working, they have no personality, they’re stupid.” Urban Dictionary, s.v. “vegetable,” accessed December 14, 2017, https://www.urbandictionary.com/define.php?term=vegetable. The latter definition also includes the hashtags “#coma #stupid #retard #no-lifer.”

7 Increasingly, the disabled poster child in US, Canadian, and European contexts is becoming the “foreign” racialized disabled poster child for charity and nonprofit organizations. For more on this particular use of disabled bodyminds for supposedly positive social justice purposes, see Barker, *Postcolonial Fiction and Disability*, 7–15; and Talley, *Saving Face*, chap. 5.


9 Clare, *Brilliant Imperfection*, 56.


11 Erevelles, *Disability and Difference in Global Contexts*, 17. See also Puar, *Right to Maim*.

12 Clare, *Brilliant Imperfection*, 62.


15 Blake, ”Jacob Blake Speaks Out”; and Jefferson, “7 Shots in the Back.”

17 Blake, “Jacob Blake Speaks Out.”
18 During the Kenosha protests, two men, Joseph Rosenbaum and Anthony Huber, were shot and killed by Kyle Rittenhouse, a white teenager from Illinois. Rittenhouse was found not guilty of all charges on November 19, 2021 by a nearly all white jury.
19 Morales, “What We Know.”
20 Jefferson, “7 Shots in the Back.”
23 Ben Crump (@AttorneyCrump), “#JacobBlake released this powerful video message from his hospital bed today, reminding everyone just how precious life is. #JusticeForJacobBlake,” Twitter, September 5, 2020, 7:11 p.m., https://twitter.com/AttorneyCrump/status/1302398977938161667?ref_src=twsrc%5Etfw%7Ctwcamp%5Etweetembed%7Ctwterm%5E1302398977938161667%7Ctwgr%5E%7Ctwcon%5Eest_&ref_url=https%3A%2F%2Fwww.news8000.com%2Fnothing-but-pain-jacob-blake-speaks-about-shooting-from-hospital-bed%2F.
28 “Mother of Psychosurgery Victim,” 12; and “v.a. Hospital Pays for Human Guinea Pigs,” 7.
30 “Mother of Psychosurgery Victim,” 12; and “v.a. Hospital Pays for Human Guinea Pigs,” 7.
Chapter Three: Empowerment through Wellness

1. Black Women’s Health Project, “First National Conference on Black Women’s Health Issues,” 1983, 8, 10, 14, 19, Black Women’s Health Imperative Records, Sophia Smith Collection, Smith College, Northampton, MA. Unless otherwise noted, all documents by the NBWHP are from this collection.


3. Valerie Boyd describes the workshop as follows: “The ‘Black & Female’ workshop seeks to help us recognize and purge ourselves of internalized oppression. The workshop teaches us to engage in confirmation rather than in condemnation. To appreciate our diversity rather than scorn our differences. To validate our own beauty, our own strength, our own ability and right to give and take. The workshop teaches us to overcome fear of relationships that require genuine self-exposure. To pursue our longing for each other/ourselves.” Boyd, “Where Is the Love?,” 2.

4. For histories of progressive health movements generally, see Hoffman, Politics of Knowledge; Dittmer, Good Doctors; and Loyd, Health Rights Are Civil Rights. For histories of feminist health activism, see Ruzek, Women’s Health Movement; Morgen, Into Our Own Hands; and J. Nelson, More Than Medicine. For histories of Black health activism, see S. Smith, Sick and Tired of Being Sick and Tired; and A. Nelson, Body and Soul.

5. Avery, “Empowerment through Wellness.”


8. NBWHP, Lasting Legacy, 30.


13. For more on Avery’s personal history, see Hart, “Building a More Inclusive Women’s Health Movement.”


15. Quoted in NBWHP, Lasting Legacy, 8.

17 For instance, the 1991 evaluation report of the Center for Black Women’s Wellness states “that all staff members are expected to participate in the self-help group process,” and the 1996 national organization bylaws require that 51 percent of the board members be active members of a self-help group in good standing with the organization. NBWH, “Center for Black Women’s Wellness Evaluation Report,” 1991, vol. 4; and NBWH, “Amended and Restated Bylaws of the National Black Women’s Health Project, Inc.,” 1996, vol. 5.


20 NBWH, “Eight Week Self-Help Group Meeting Guide Draft,” ca. 2000, 24. This sentiment is also expressed earlier in the organization’s history in the 1989 annual report, which states, “Self-help groups provide a supportive environment for women to build self-esteem and develop coping and problem-solving skills, the basis for a commitment to wellness. Groups raise awareness about controllable factors associated with major health problems, and offer basic information on family life and educational skills within a framework of empowerment. Self-help groups create a bridge to community resources, new pathways for referrals that have the potential to significantly improve a member’s quality of life and, by extension, her family and community…. NBWH self-help groups provide a time and place for Black women to come together to talk openly and honestly, to be validated for their historic ability to survive despite assaults to self-esteem and self-worth, and to collectively develop solutions to our poor health status. By breaking the conspiracy of silence that threatens individual health, NBWH self-help groups enable each participant to analyze her life and understand her decision-making within a social context. The empowerment process encourages personal responsibility and a commitment to changing one’s life and community for the better.” NBWH, “Annual Report,” 1989, 3.


26 Villarosa and NBWH, Body and Soul, xvii.

27 See also Boykins, “Wellness Not Medicine, Safeguard for the Year 2000,” 16, 63.


29 Harriet A. Washington writes that “African Americans also suffer far more devastating but equally preventable disease complications, such as blindness,”
confinement to wheelchairs, and limb loss. Studies continue to demonstrate that, far from sharing in the bounty of American medical technology, African Americans are often bereft of high-technology care, even for life-threatening conditions such as heart disease.” Washington, Medical Apartheid, 20. See also Smedley, Stith, and Nelson, Unequal Treatment.

30 Shakespeare, “Social Model of Disability,” 199; and Kafer, Feminist, Queer, Crip, 6–10.

31 See Wendell, “Unhealthy Disabled”; Deal, “Disabled People’s Attitudes toward Other Impairment Groups”; and Shakespeare, Disability Rights and Wrongs, 75.


34 See, for example, Wilson, “Reclaiming Our Spiritual Health”; Crichlow, “Queen Afua”; Estes, “Choosing to Live in a Time of AIDS”; and Helem, “Little Pentecostal Lesbian That Sat on the Pew.”

35 Villarosa and NBWH, Body and Soul, 395.

36 Villarosa and NBWH, Body and Soul, 397.


38 See Cort, “Spiritual Sexuality”; or Avery, “Self-Help Is the Best Help.”

39 See, for example, the articles in the “Religion and Spirituality” themed section of Disability Studies Quarterly 26, nos. 3 and 4 in 2006; as well as Avalos, Melcher, and Schipper, This Abled Body; and Olyan, Disability in the Hebrew Bible.

40 See, for example, King, “Beam in Thine Own Eye”; or Rogers-Dulan and Blacher, “African American Families, Religion, and Disability.”

41 Tinu Abayomi-Paul, interview by Sami Schalk, September 12, 2019.

42 T. S. Banks, interview by Sami Schalk, October 29, 2019.

43 Minich, Accessible Citizships, 99–104.


46 Minich, Accessible Citizships, 104.

47 NBWH, “Project Proposal to Ford Foundation,” 10. The phrase conspiracy of silence is used frequently as a shorthand for the effects on Black women of
internalized oppression that keeps us silent about our experiences and separate from one another. As Valerie Boyd explains, “When we dare to break the conspiracy of silence, we begin our journey back to connectedness, our journey back to our self. When we dare to break the conspiracy of silence, we allow ourselves to provoke and cherish each other’s rich, uninhibited laughter. When we dare to break the conspiracy of silence, we allow ourselves with curious minds, responsive eyes and slightly timid hearts, to revel in self-revelation. When we dare to break the conspiracy of silence, we allow ourselves, with little surprise, to recognize each other as the treasures that we are.” Boyd, “Where Is the Love?,” 2.

49 Moreau, “If Looks Could Kill.”
50 Richardson, “My Life with Lupus,” 4.
51 NBWH, “A Proposal for Consideration for Program Funding Continuation,” 11.
54 For more on the strong Black woman stereotype, see Wallace, Black Macho and the Myth of the Superwoman; Beauboeuf-Lafontant, Behind the Mask of the Strong Black Woman; and Parks, Fierce Angels.
58 See, for example, Davis, “Roots of Black Women’s Oppression”; Braxton, “And a Little Child Shall Lead Us”; and Villarosa and NBWH, Body and Soul, 429–32.
59 Villarosa and NBWH, Body and Soul, 115.
60 Villarosa and NBWH, Body and Soul, 119–20.
61 Villarosa and NBWH, Body and Soul, 115. Simi Linton’s Claiming Disability: Knowledge and Identity, first published in 1998, is an example of where the mainstream movement was in terms of language around disability in the 1990s, particularly in regard to what she terms “nice words” like physically challenged, which were used in Body and Soul alongside the more commonly accepted terms of the period, disability and handicapped. Linton, Claiming Disability, 9–14.
62 Bell, “Introducing White Disability Studies.”
64 I use the term fat as opposed to obese or overweight in alignment with the politics of the body positivity, Health at Every Size, and anti-fatphobia movements, in which fat is a neutral description of bodyminds that are above the average size or above the social ideal/norm. I do not use fat as an insult or as an indicator of health and well-being. For more information, see Kirkland, Fat Rights; or Rothblum and Solovay, Fat Studies Reader. For the specific relationship of fatphobia, anti-Black racism, and ableism, see Mollow, “Unvictimizable.” Notably,
the NBWHP’s approach to fatness varied widely, sometimes acknowledging fatphobia and at other times seeming to perpetuate it. See, for example, Janice S. Vaughn, “Obesity and the Black Woman,” in First National Conference on Black Women’s Health Issues, 1983, Atlanta Lesbian Feminist Alliance Archives, Duke University Libraries, Durham, NC, box 8; and Hoytt, Beard, and Black Women’s Health Imperative, *Health First!,* 193–95, 198, 258–59.

65 Avery, “Breathing Life into Ourselves,” 150.
67 See, for example, Spoonie Living (http://www.spoonieliving.com/) or the Chronic Illness Bloggers Directory (https://chronicillnessbloggers.com/bloggerdirectory/).
68 NBWHP, “National Black Women’s Health Project Information Sheet.”
72 NBWHP, *Our Bodies, Our Voices, Our Choices,* 5.

### Chapter Four: More Than Just Prevention

3 New York NBWHP, “Untitled,” 1; emphasis added.
6 US Department of Health and Human Services, “Timeline of HIV and AIDS.”
9 US Department of Health and Human Services, “Timeline of HIV and AIDS.”
10 Cohen, Boundaries of Blackness, 21–22.
12 Shapiro, No Pity, 136–37; and Colker, Disability Pendulum, 41, 51, 53–54.
13 Colker, Disability Pendulum, 65.
14 For more on the role of HIV/AIDS in the development of the ADA, see Colker, Disability Pendulum, 26–68.
16 For existing disability studies scholarship on HIV/AIDS, see R. McRuer “Critical Investments”; and A. Day “Resisting Disability, Claiming HIV.”
17 Kafer, Feminist, Queer, Crip, 12; and Minich, “Enabling Whom?”
19 For instance, almost all of the histories of HIV/AIDS I’ve read for this research don’t even include disability as an index keyword, let alone as a political issue or intellectual/theoretical perspective.
22 See, for example, Washington, Medical Apartheid; Kline, Building a Better Race; and Stern, Eugenic Nation.
23 Clare, Brilliant Imperfection, 76.
24 For examples of work in disability studies that explore pain or push against simplistic approaches to cure and prevention, see Wendell, “Unhealthy Disabled”; and Price, “Bodymind Problem and the Possibilities of Pain.”
25 In the many social, cultural, and political histories of the AIDS crisis, there are many other organizations, such as SisterLove, with whom the NBWHP partnered or with whom their work overlapped or intersected. I am not aiming to present the project’s work as wholly unique; rather, I intend to highlight how their approach can be understood as a Black disability political one that is applicable beyond HIV/AIDS specifically.
28 See, for example, the chapter on HIV/AIDS in Villarosa and NBWHP, Body and Soul, 535–54.
29 Avery, “A Question of Survival/a Conspiracy of Silence,” 79. The concept of “the conspiracy of silence” is related to Darlene Clark Hine’s “culture of dissemblance.” See Hine, “Rape and the Inner Lives of Black Women in the Middle West”; and Schalk, “Contextualizing Black Disability and the Culture of Dissemblance.”
35 NBWHP, “From Cries and Whispers to Action,” 11; and Villarosa and NBWHP, Body and Soul, 544–45.
36 NBWHP, “From Cries and Whispers to Action,” 11.
38 Potcat, “AIDS and Black Lesbians,” 8, 44.
39 NBWHP, “From Cries and Whispers to Action,” 1.
40 NBWHP, “From Cries and Whispers to Action,” 10.
41 NBWHP, “From Cries and Whispers to Action,” 10.
42 Lorde, Cancer Journals, 42–44.
43 Lorde, Cancer Journals, 49–51, 56–57.
46 Andresen, “Public Health Education, Research, and Disability Studies.”
47 Hayward, “Slowly Evolving Paradigm of Disability in Public Health Education.”

Praxis Interlude Two

1 NBWHP, Lasting Legacy, 28.
5 NBWHP, “Social Security Disability and HIV.”
6 See, for example, Thomas, “Socializing in the Age of HIV/AIDS”; and Parker, “Emotional Aspects of Chronic Illness.”
7 Banks, interview, 2019. Unless noted otherwise, all quotes from Banks in this interlude are from this interview.
8 Lewis, interview, 2019. Unless noted otherwise, all quotes from Lewis in this interlude are from this interview.
Chapter Five: Black Disability Politics Now


2 According to the Harriet Tubman Collective, the Movement for Black Lives did not connect with many self-identified Black Disabled/Deaf advocates, community builders, or organizers in the drafting process. “This led to the Movement’s overall failure to adequately address the disparities and specific violence and oppression that exist at the intersection of Blackness and Disability/Deafness.” Harriet Tubman Collective, “Disability Solidarity: Completing the ‘Vision for Black Lives,’” Medium, September 7, 2016, https://medium.com/@harriettubmancollective/disability-solidarity-completing-the-vision-for-black-lives-119ec03e982.

3 In my 2019 interview with Dustin Gibson, he explained that the phrase disability solidarity originated in 2014 with Ki’tay D. Davidson, Táliá “TL” Lewis, and Allie Cannington as a hashtag on Twitter “just a few weeks after Mike Brown was killed as a call for the disability community to be in solidarity.
with folks fighting for racial justice” and has continued to be used to call for disability communities to be invested in intersectional, collective liberation. Davidson, Lewis, and Cannington hosted a Twitter chat on August 22, 2014, where hundreds of people joined to discuss. At the time, Davidson said, the three defined disability solidarity as that which holds the disability community accountable for intersectional justice and holds all communities accountable for disability justice. See Talila “TL” Lewis (@talilalewis), “@ KitayDavidson, @AllieCannington & I hosted the 1st #DisabilitySolidarity chat,” Twitter, August 22, 2019, 9:14 p.m., https://twitter.com/talilalewis/status/1164722603619160064.

4 Audism is discrimination against people who are D/deaf or hard of hearing, which includes devaluing or discriminating against D/deaf modes of communication and literacy (such as banning sign language) and overvaluing hearing and hearing people’s methods of communication and literacy. Audism also includes lack of recognition of Deaf cultures and languages as distinct cultures and languages.

5 HTC, “Disability Solidarity.”

6 HTC, “Disability Solidarity.”

7 The names of the people on the HTC’s “Disability Solidarity” statement are Patricia Berne, Kylie Brooks, Neal Carter, Patrick Cokley, Candace Coleman, Dustin Gibson, Timotheus Gordon Jr., Keri Gray, Christopher DeAngelo Huff, Cyree Jarelle Johnson, Lorrell D. Kilpatrick, Carolyn Lazard, Talila A. Lewis, Leroy F. Moore Jr., Vilissa Thompson, Alexis Toliver, and Heather Watkins.

8 I am unable to find out the exact date of the changes or if the changes occurred over time.


12 Coleman, interview, 2019. Unless noted otherwise, all quotes from Coleman in this chapter are from this interview.


15 Gibson, interview, 2019. Unless noted otherwise, all quotes from Gibson in this chapter are from this interview.

16 Cokley, interview, 2019. Unless noted otherwise, all quotes from Cokley in this chapter are from this interview.

17 Lewis, interview, 2019. Unless noted otherwise, all quotes from Lewis in this chapter are from this interview.


19 Thompson, interview, 2019.


21 Banks, interview, 2019. Unless noted otherwise, all quotes from Banks in this chapter are from this interview.

22 Sins Invalid, Skin, Tooth, and Bone, 16.

23 For more on care webs, including within organizing spaces, see Piepzna-Samarasinha, Care Work.

24 Lorrell Kilpatrick, interview by Sami Schalk, July 31, 2019. Unless noted otherwise, all quotes from Kilpatrick in this chapter are from this interview.

25 Participants identified a wide range of issues as Black disability political concerns. The most commonly named issues (mentioned by at least three of the eleven interviewees) were health care/medicine, education, police violence, and incarceration/institutionalization. Other issues mentioned include economics/employment, housing, sexual violence, and environmental racism.

26 In the interview, for example, Lewis noted that in the work of HEARD, lawyers often want to go in and sue for accommodations like TTY telephones and interpreting services for Deaf and disabled people but that lawsuits often result in punishment and retaliation against Deaf and disabled inmates; therefore, attempting to bring about change without a lawsuit is often what most benefits the people most impacted by this particular injustice of the prison industrial complex.


(Not a) Conclusion

1 Shout-out to my Twitter followers, who donated over $20,000 in a month to allow these supplies to be freely provided to so many people, as well as to the many Madison locals who donated supplies and made masks.