EMPOWERMENT THROUGH WELLNESS

Black Disability Politics
in the National Black
Women’s Health Project

Politics do not stand in polar opposition to our lives. Whether we desire it or not, they permeate our existence, insinuating themselves into the most private spaces of our lives.


On June 24, 1983, the National Black Women’s Health Project (NBWHP), at the time a new program under the auspices of the National Women’s Health Network, hosted the First National Conference on Black Women’s Health Issues at Spelman College, a historically Black college for women. The conference organizers expected a few hundred Black women to register and attend. In the end, nearly two thousand attendees showed up from across the country. The conference focused broadly on Black women’s health, from stress management, diabetes, mental health, and self-esteem to domestic violence, sexual health, aging, and cancer. In addition to more traditional plenary sessions, keynote lectures, and academic presentations, the conference also included health screenings, group exercise opportunities, a concert by Sweet Honey in the Rock, and interactive workshops, several of which directly engaged with disability, such as “The Mask of Lupus,” “Dispelling the Myths of Mental Illness,” “Health Concerns of the Physically Disabled,” and “Diabetes.” The conference’s most popular workshop, however, was Lillie Allen’s “Black and Female: What Is the Reality?,” which was reserved
exclusively for Black women only to discuss what being a Black woman has meant for them, to discuss the impact of history on Black women, and to begin to face and deconstruct internalized oppression. As Allen writes in a reflection on the workshop, “We have internalized too long the lies and myths which taught and preached to black women self-invalidation, self-doubt, isolation, fear, feelings of powerlessness and despair that led us to say ‘I don’t think I’m good enough.’ … Internalized oppression exists anytime you feel intolerant or, irritated by, impatient with, embarrassed by, ashamed of, not as black as, blacker than, better than, not as good as, fearful of, not cared about by, unable to show support or not support by another black woman.”

The workshop encouraged Black women to tell their stories and to truly listen to other Black women in order to bear witness to both the similarities and differences between their lived experiences.

As this brief overview of the organization’s first conference suggests, the NBWHP engaged in a multifaceted, comprehensive, intersectional, and explicitly political approach to health that built on the legacies of previous health activism in feminist, civil rights, and other progressive movements.

The NBWHP, however, enacted a specifically Black feminist form of health activism that focused on improving the health of Black women holistically in order to gain, in NBWHP founder Byllye Avery’s words, “empowerment through wellness.”

Black women have long been central in health activist movements although the term feminist has not always been applied to this work. Black women served Black communities as midwives and later, when medicine became a more formalized profession, as nurses, fundraisers, and volunteers in Black hospitals. More recently, Black women were the majority of the “health cadre” members who ran the Black Panther Party’s free clinics, and many Black women, such as Byllye Avery, played major roles in feminist health organizations like the National Women’s Health Network. Women, however, are not automatically feminists, and feminists are not exclusively women. I use the term Black feminist health activism, therefore, to refer to health activism by Black people that is critically attuned to intersectional gender, race, and class politics, whether or not the word feminist was used by the organizations or activists involved. Although in the case of the NBWHP, the vast majority of members and all of its leaders were Black women, it is certainly possible to call work by other, more mixed-gender Black organizations Black feminist health activism.
The NBWHP was the first organization to focus exclusively on the health of Black women and the first of many women-of-color-specific health organizations that eventually emerged within the feminist health movement. The many women involved in the NBWHP, from doctors, nurses, therapists, and social workers to academics, politicians, writers, mothers, and teens, did not all necessarily identify as feminists, but their advocacy, writing, and organizing on Black women’s health was undoubtedly grounded in the legacies of Black feminist theorizing and activism. This is particularly evident in the fact that several major Black feminist scholars such as Angela Davis, Beverly Guy-Sheftall, and Dorothy Roberts each at one point served on the NBWHP board.

The NBWHP was a grassroots Black feminist activist organization that sought to reduce health disparities and instances of preventable diseases/conditions while simultaneously insisting on the political nature of health and disability. In this chapter, the first of two on the organization, I analyze the NBWHP’s Black feminist health activism as another prime example of Black disability politics. More specifically, I assess how disability was explicitly and implicitly included within its organizational mission, self-help philosophy, and holistic, cultural, and political approaches to health and wellness. Importantly, this chapter explores how spirituality was incorporated into this public health work, providing a needed intervention and invitation to further explore the intersections of race, disability, and spirituality, faith, or religion in both Black studies and disability studies. Overall, I argue that the NBWHP consistently addressed disability and took anti-ableist stances but did so within a Black feminist health activist framework rather than under the banner of disability rights. Although explicit engagement with disability as a term, let alone disability rights, is rare within the NBWHP’s publications and archival documents, the politics expressed are nonetheless anti-ableist and critical to advancing our understanding of the common qualities of Black disability politics. In what follows, I first provide an overview of the organization’s history, including its primary mission and central self-help philosophy, before delving into a more detailed analysis of disability politics within the NBWHP’s holistic, cultural, and political approaches to health. This chapter argues that the NBWHP’s general Black feminist health activism was Black disability politics in order to then perform a close analysis of the organization’s disability-specific work on HIV/AIDS in the next chapter.
A Brief History of the NBWHP

The NBWHP was started in 1981 as a project within the National Women’s Health Network to focus on the specific health needs of Black women. Following the success of and excitement from its first conference, the NBWHP was incorporated into an independent nonprofit organization in 1984 with its base in Atlanta, Georgia. Early organizational documents define the NBWHP as

a health education, advocacy and empowerment project designed and directed by Black women to critically examine the health care concerns and issues pertinent to the lives of all Black women and their families…. The Project sees its mission as empowering Black women to take an active part in the decisions that govern our lives—and teaches us to seek affirmation, validation and support within ourself first, and then within the network of our “sisters.” Only through an analysis of the forces that have shaped our lives as Black women, through the telling of our life stories, does the NBWHP believe that we can regain and control the quality of our lives, and future generations.9

From its inception the NBWHP promoted an intersectional and specifically Black feminist approach to addressing health disparities and health crises for Black women with the aim of improving health across Black communities in general.

The NBWHP was founded by Byllye Avery. Although many Black women health activists, particularly Lillie Allen, were involved in shaping the organization from the start, Avery was the consistent face of the organization. She served as executive director from 1981 to 1989 and as president from 1990 to 1995 before shifting into a more honorary role as “founder,” writing pieces for annual publications and speaking at events but no longer involved in the day-to-day workings of the NBWHP. As a result of Avery’s importance in the organization, a brief discussion of her personal history, especially in relationship to disability, is pertinent to my analysis of disability politics within the NBWHP.

Before working in health activism, Avery had personal and professional experience with people with disabilities that may have influenced the NBWHP’s approach to disability politics. On a personal level, Avery’s brother had multiple sclerosis, and according to her, “he suffered with it for a long time, a long time before it was ever diagnosed.”10 Avery also lost her husband to a heart attack when he was thirty-three years old. In an oral
history interview, she states, “He was hypertensive. We didn’t know it. He had had a couple of exams earlier that should have let us know… [T]he doctor told him that his pressure was high and that he needed him to exercise and to diet to bring his pressure down. But that was all that was told to him. It wasn’t put into a way that he would have known that it had the dangers that it carried.” Avery describes the death of her husband as “truly a radicalizing experience,” which, combined with the lack of diagnosis and intervention for her brother and the effects of heart disease and diabetes on multiple members of her extended family, made her realize that “it doesn’t really matter how much formal education you have. If you don’t know how to take care of yourself, you’re still basically in a state of ignorance.”¹¹ These personal experiences with loved ones with disabilities and disabling diseases were foundational to Avery’s activism and her emphasis on self-help, education, and empowerment around health issues in Black communities.

On a professional level, Avery earned a degree in psychology from Talladega College in 1959 and then worked for six years at the North Florida State Mental Hospital. After her first child was born, she worked for a few years at “a school program for emotionally disturbed children” before going on to get a master’s degree in special education. In October 1970 she took a new job at a “university-based children’s mental health unit.”¹² These educational and professional experiences inside of programs and institutions for people with disabilities, particularly people with mental disabilities, likely influenced Avery’s consistent emphasis within the NBWHP on the importance of mental and emotional health and well-being. Avery eventually moved from practitioner to organizer and activist via the women’s health movement and her work with multiple women’s health and birthing centers in Florida and Georgia.¹³ This work led her to become an active member of the National Women’s Health Network, within which she initiated the NBWHP after discovering the dearth of health research specific to Black women and the dire nature of the findings of the limited existing research at the time.

Under Avery’s leadership, the NBWHP undertook a wide variety of programs to address and improve the health and wellness of Black women. The NBWHP’s activities ranged from national conferences and leadership institutes to the Walking for Wellness program to encourage more physical activity and the Plain Talk program for creating dialogue between Black mothers and daughters about sex and sexuality. Additionally, the NBWHP produced policy briefs, sponsored and published research, and developed programming on HIV/AIDS, diabetes, hypertension, and substance abuse in Black communities. From 1988 to 1996, the NBWHP operated the Center for
Black Women’s Wellness in Atlanta, a wellness center and clinic in a public-housing neighborhood that provided free health screenings, vocational training, self-help support groups, and more. The NBWHP also published Vital Signs, the organization’s official newsletter, which grew and changed over time from a quarterly eight-page newsletter to an annual sixty-page color magazine with advertisements.

While the Black Panther Party’s work described in the previous two chapters was intersectional but centered on race, the NBWHP’s work was intersectional but centered on race and gender, as a specifically Black feminist health activist organization. Publications and internal documents from the NBWHP always name racism and sexism as major factors in Black women’s health with fairly consistent mention of classism and frequent mention of homophobia. Other forms of oppression, such as the oppression of elders, people with disabilities, and fat people, are only occasionally mentioned in some documents and publications.\(^{14}\) The NBWHP was not a disability rights organization but a health organization that frequently acted in solidarity with disabled people in much of its work and included disabled people in leadership positions, such as Deborah Williams-Muhammed, a Black woman with multiple sclerosis and sarcoidosis who served on the NBWHP board. Williams-Muhammed claims that the self-help skills, knowledge, and support network she obtained through the NBWHP helped her get out of a nursing home where she was overmedicated and under-cared-for, stating, “If it were not for my sisters at NBWHP, I might still be in the nursing home or I might not be alive.”\(^{15}\) The NBWHP’s self-help philosophy and practices, which Williams-Muhammed credits for her wellness, were the foundation of the organization’s central programming and the context in which the NBWHP’s disability politics become more apparent.

Self-help, as a philosophy and a practice, was for many years the core program of the NBWHP. The organization fostered the development of self-help support groups across the country, which were intended to provide sustained supportive environments for Black women, teens, and girls in which to tell their stories, address their health concerns, learn about and combat internalized oppression, and connect with other Black women. This self-help philosophy combined Lillie Allen’s expertise in reevaluation counseling and the legacies of self-help and consciousness-raising groups in the women’s liberation movement while also prioritizing the cultural and social contexts of Black women’s lives.\(^{16}\)

The NBWHP self-help groups ranged from three to ten women who would meet on a regular, typically weekly, basis for two to three hours. Self-help
groups sometimes formed around specific health issues but more often were based on existing social networks, meeting in women’s homes, community centers, or churches. Groups were led and organized by codevelopers who received training and leadership development three times a year from the organization. The importance of self-help to the NBWHP is illustrated not only by how much of the organization’s time and resources went into developing and supporting self-help groups nationwide but also by the fact that leaders and employees of the organization were encouraged or even required to participate in the self-help process. While the exact numbers of women who attended these groups are difficult to ascertain—an issue that eventually became a problem for the organization when seeking funding—in 1989 the organization estimated that two thousand women were participating in a NBWHP self-help group each month, and in 2000 they estimated that over thirty thousand women had participated since the organization’s founding.

While self-help groups may not seem like the most radical grassroots activity, the philosophy undergirding the creation and maintenance of these groups was explicitly political and praxis focused. A 1989 annual report explains the political potential envisioned for these groups: “NBWHP self-help group development is predicated on the realization that an increased health consciousness and personal commitment to wellness for Black women require an environment of understanding and support. Through sharing collective experiences and a validation of our individual efforts in the unique struggles to overcome racism, sexism and class elitism, our members learn that our health problems are part of a larger picture. We learn that physical health, emotional health and spiritual health are all linked and that the empowerment of individuals can transform a distressed community.”

The NBWHP’s self-help groups combined political education with public health education in a nonmedical, explicitly Black- and woman-centered setting. In groups, Black women gained self-empowerment through telling their stories and connecting with others with similar experiences in a free, nonjudgmental space. This self-empowerment was then intended to help women to take action regarding their health and the health of others in their communities. As one self-help meeting guide explains, “The goal is to develop a sense of empowerment and activism to take actions…. The Self-Help Group is not the action or organizing group, but is the place where women develop a greater sense of capacity to be able to make change.” The NBWHP therefore envisioned self-help groups as a means to impact Black women’s and Black communities’ health at the micro (individual and family) and macro (community and nation) levels.
The self-help philosophy of the NBWHP, which undergirded most of its work for over a decade, can be interpreted within a Black disability political framework. For instance, while self-help groups occasionally formed around specific disabilities or diseases, such as diabetes, the groups were neither based in disability identity nor segregated by disability or health status, and they strongly encouraged women with and without disabilities and diseases to participate and understand their bodyminds as impacted by the histories and politics of race, gender, class, and sexuality. As a Center for Black Women's Wellness funding proposal to the Kellogg Foundation states, “Self-help groups do not stigmatize their members because of health or social conditions; they may therefore have as members women who are single parents, chronic disease sufferers, homeless persons, and so forth, as well as career and professional women, and women of varied educational backgrounds, health challenges, and ages.”21 This is an example of Black disability politics because it is explicitly inclusive of Black disabled women without being dependent on a disability identity.

The NBWHP self-help groups also moved away from a strictly medical model of disability, health, and disease by emphasizing the need to address internalized oppression and to have a broad network of emotional and material support. Organizational materials repeatedly make clear that self-help groups were not therapy—not because therapy was bad or to be avoided but because therapy typically involves an expert and a recipient of expertise, along with payment. As one self-help manual for codevelopers states, “No one person is the expert. It is a relationship between peers/equals. All the members of the group use the expertise gained from their lives to help self and each other…. No one pays or gets paid. No medical tools are used…. The goal is wellness—not elimination of symptoms! Professional therapy may be used in conjunction with self-help to augment and accelerate the healing process.”22 This quote suggests that the NBWHP fully embraced the need for quality medical care, including psychotherapy, while simultaneously believing that providing access to and improving the quality of medical care alone was not enough to fully address the legacies of racism and sexism that shape Black women’s experiences of disability and disease. In this way, the NBWHP remained vigilantly focused on contextualizing and historicizing Black women’s health, broadly construed, in a fashion that I argue constitutes Black disability politics.

As the NBWHP grew, becoming increasingly reliant on major federal and foundation funding and putting more efforts into policy briefs, lobbying, and research—emphasizing macro- more than microlevel change—self-help became far less central to its work. In an organizational brief in 2000, the
NBWHP states, “Although self-help provides a philosophical richness and is the ‘brick’ in our foundation, NBWHP has been unable to measure its effectiveness nor have we been able to replicate the model for use by larger groups of women…. It was acknowledged that self-help is no longer the cutting edge technology that it was in the 1980s and now there is a proliferation of self-help models.”²³ By the turn of the century, self-help groups were mentioned less and less in organizational materials, before disappearing entirely. In 2002 the organization officially changed its name to the National Black Women’s Health Imperative. This name change was long overdue, marking not only the organization’s move away from the self-help philosophy and practices on which it was founded but also other major organizational shifts that had been slowly occurring since 1996, when the organization relocated its headquarters to Washington, DC, and ceased its operation of the Center for Black Women’s Wellness (which continues to operate independently today). As a result of these major shifts between 1996 and 2002, for the purposes of this and the next chapter, I focus on the disability politics of the NBWHP’s work in the 1980s and 1990s.

In the next section, I demonstrate how the NBWHP’s holistic, political, and cultural approaches to health and wellness are emblematic of Black disability politics. This section’s discussion of how the NBWHP articulated Black disability politics provides the framework for analyzing how the organization actually enacted these politics in its work regarding HIV/AIDS in the next chapter.

Holistic, Cultural, and Political Approaches to Health and Wellness

The NBWHP’s approach to defining and addressing health was very different from that of typical public health organizations. The NBWHP’s materials typically define health as “not merely the absence of illness, but the active promotion of physical, spiritual, mental, and emotional wellness of this and future generations.”²⁴ This definition draws largely from the definition of health by the World Health Organization (WHO), first published in 1948, which “defines health positively, as complete physical, mental and social well-being, not merely negatively as the absence of disease or infirmity.”²⁵ There are, however, a few key differences. First, the NBWHP’s definition drops mention of infirmity, which suggests the inclusion of the elderly and/or the disabled within states of health. Second, the NBWHP’s definition of health includes spiritual and emotional wellness in an attempt to account for the
role of spirituality in the lives of Black women as well as the need to tend to emotional well-being, particularly stress and relationship dynamics. The terms *emotional* and *mental* are used in different ways over the course of the organization’s history; sometimes both appear in the same document, and sometimes one or the other, but at least one of these terms (*emotional* or *mental*) always appears along with physical and spiritual well-being. Last, the NBWHP’s definition of health emphasizes action in “the active promotion of” wellness and the need to think communally and long term in the phrase “this and future generations.” These differences between the NBWHP and the WHO definitions of health begin to show how the NBWHP’s work as an explicitly Black feminist public health organization differed ideologically from that of more general public health organizations.

The related terms *wellness* and *well-being* appear in both the NBWHP and the WHO definitions of health and therefore warrant additional comment. Although both terms are used often in NBWHP publications, they are never explicitly defined. However, one undated pamphlet in the organization’s archive, titled *Black Women Helping Ourselves*, provides some insight. It states, “Our Self-Help Groups are a model for Black women to create the space and take the time to define wellness for ourselves in the context of the larger social forces that impact our lives.” The suggestion here is that wellness can be self-defined in the context of one’s wider social and political world. This sentiment, though not explicitly stated elsewhere, is reflected in the holistic, cultural, and political approaches to health undertaken by the NBWHP. Wellness includes things not directly of the bodymind, such as finances and housing, which nonetheless have a real impact on physical, mental, and emotional health. Wellness must be self-defined, therefore, because it is about one’s own needs, desires, capabilities, and norms. What is necessary for one person’s wellness may be unnecessary for another. Furthermore, in both the NBWHP and WHO definitions of health, wellness and well-being are understood as foundational to health, as part of its definition. As a result, health within the NBWHP can also be understood as deeply personal and contextual rather than merely medical and objective, as health is dependent on wellness, which is self-defined. This personalized and contextualized approach to health and wellness is evident, for instance, in the introduction to the NBWHP’s self-help health book, *Body and Soul: The Black Women’s Guide to Physical Health and Emotional Well-Being*, which states, “Good health is about intuition. That means being in tune with everything and everyone around us. In this scientific world, we don’t give credence to the idea that our intuition can lead us to the right place. When faced with health
challenges, we must collect all the information, talk to all the doctors, and then go inside ourselves and take direction from our inner voices. We have to believe in ourselves and believe in our ability to make the decision that will lead to healing.”

Here it is clear that rather than understanding health and well-being as self-evident, medically determined, objective states of being, the NBWHP understood these terms to be deeply personal and contextual.

These broad, individualized, and overlapping understandings of health and wellness are important not only for understanding the Black disability politics of the NBWHP specifically but also for understanding Black disability politics in general. Expressions of a desire for wellness or healing by Black and other racialized groups are sometimes construed within disability studies and disability rights circles as (internalized) ableist expressions of desire for able-bodiedness and able-mindedness when that is not inherently the case. As the discussions of language and ableism in chapter 2 and praxis interlude 1 make clear, a major task for disability studies scholars as well as for disability activists working among racialized populations is to resist impulsive knee-jerk reactions to language that is often, but not always, used in ableist ways. To analyze and explore how Black activists have engaged with disability means understanding the purpose and intention with which people use certain words, such as wellness and healing, assessing how such discourses do or do not reflect solidarity with disabled people in general.

In this case, the NBWHP was a Black feminist public health organization that was not simply interested in improving physical health or reducing instances of preventable disease among Black people. Instead, the NBWHP was invested in a holistic, cultural, and political approach to health and wellness that would ensure long-lasting positive effects on generations of Black people. The NBWHP definitions of health and wellness do not exclude disabled people nor fixate on cure; rather, the organization sought wellness, broadly and individually defined, for all people regardless of health or (dis)ability status. As the next chapter details more specifically in relationship to HIV/AIDS, throughout its work, the NBWHP sought to reduce instances of preventable disabling diseases and conditions among Black people while also advocating for improved personal, social, and material supports for existing disabled or chronically ill Black women, including the right to intangible aspects of wellness such as dignity and joy. Interpreting the Black disability politics of the NBWHP’s work means holding this latter solidarity with disabled people in tension with the former desire to reduce the number of Black disabled people overall through disease prevention and treatment.
As discussed in praxis interlude 1, it is possible to fight disabling violence and oppression without using disability as a pathetic or terrifying symbol of such harm by instead emphasizing the mutual constitution of oppressions and supporting people disabled by social injustice and violence. The NBWH, I contend, did just that. In its work the NBWH articulated and enacted Black disability politics, refusing to stigmatize or shame Black women for their health and promoting wellness for all. In the following sections, I further detail how the NBWH approached health and wellness in holistic, culturally attuned, and politicized ways. In each of these three overlapping approaches, we can further understand the Black disability politics of the organization.

Holistic Approaches to Health

As the above-discussed definition of health suggests, the NBWH took a holistic approach to health that included physical, mental/emotional, and spiritual well-being. The NBWH believed that one could not address physical symptoms or concerns alone without addressing and caring for the mental/emotional and spiritual elements of a person, which would equip them with the knowledge, support, skills, and confidence to attend to their physical health. This holistic approach meant that although the NBWH often created disease/condition-focused programming around common health concerns among Black women, such as HIV/AIDS, diabetes, and hypertension, its work addressed a wide variety of health and wellness topics. This is most apparent in its major publications in the 1980s and 1990s: Vital Signs, the organizational newsletter/magazine, and Body and Soul: The Black Women’s Guide to Physical Health and Emotional Well-Being, a self-help health book published by the NBWH in 1994 and edited by Linda Villarosa.

In each of these two major publications, there is consistent recognition of and attention to all of the NBWH’s major aspects of health and wellness. Issues of Vital Signs consistently include articles attending to physical, spiritual, and mental/emotional health. In particular, from 1993 to 1995, when the publication briefly changed from a simple eight-to-twenty-page photocopied or newsprint quarterly newsletter to a forty-to-sixty-page quarterly magazine before shifting to an annual publication, Vital Signs contained a regular section called “Well Woman,” which included the tagline “Empowerment through Wellness: Mental, Physical and Spiritual,” with typically thematically related columns addressing each part of holistic health in the section in every issue. An example of this section is shown in figure 3.1. Similarly, the NBWH’s self-help health book, Body and Soul, while heavily focused on physical (especially reproductive) health in its first seventeen chapters, also
contains in its second half chapters on emotional health, self-help, spiritual health, self-love, relationships and sex, domestic violence, incest and child abuse, HIV/AIDS, and workplace and environmental health hazards. These latter chapters in more and less explicit ways address both mental/emotional and spiritual health.

The NBWHP understood the physical, mental/emotional, and spiritual aspects of health to be overlapping and mutually dependent. That is, one’s mental/emotional well-being could impact one’s physical and spiritual well-being and vice versa. This is evident, for example, in a 1986 Vital Signs article titled “Emotional Aspects of Chronic Illness,” which begins with the statement “Emotional aspects of chronic illnesses are real and often long-lasting” and then provides examples of how chronic illness emotionally impacts people, such as grief or shame produced by loss of the ability to work or maintain levels of productivity, changes in self-esteem as a result of changes in physical appearance, and feelings of being objectified and denied privacy within the medical industrial complex.28 Here and in other articles and publications, it is clear that the NBWHP understood and promoted a

**FIGURE 3.1** Example of a “Well Woman” page from Vital Signs.
holistic version of health that was dynamic and interconnected. Importantly, unlike many holistic approaches, which tend to understand whole bodyminds as including the physical and mental/emotional, the NBWHP explicitly included the spiritual in its conceptualization of holistic health. The inclusion of spirituality, faith, and religion in the NBWHP’s work is an example of its cultural approach to health, which I address further below.

By taking such a holistic approach to defining and understanding health, the NBWHP’s publications and activities, like the work of the Panthers in the previous two chapters, regularly addressed a broad range of health topics and concerns, which vary in their proximity to disability as typically defined medically or legally. For instance, Vital Signs issues include articles on the following conditions, diseases, disabilities, and health concerns: lupus, HIV/AIDS, kidney disease, fibroids, diabetes, rheumatoid arthritis, depression, chronic illness, cancer (especially breast and ovarian), sickle cell anemia, hypertension, stress, toxic shock syndrome, suicidal ideation, and sexually transmitted diseases. Body and Soul similarly addresses addiction, heart disease, cancer, diabetes, lupus, sarcoidosis, sickle cell anemia, asthma, chronic fatigue syndrome, Alzheimer’s disease, arthritis, osteoporosis, anxiety disorders (phobias, panic disorder, post-traumatic stress syndrome, and obsessive-compulsive disorder), depression, bipolar disorder, and schizophrenia. The wide variety of illnesses, diseases, conditions, and disabilities on these two lists is typical of much Black health activism, which tends to be inclusive of disability but not primarily focused on it. This broadness in particular reflects the reality that Black people are more likely to be disabled by secondary health effects of otherwise nondisabling and/or preventable illnesses as a result of a lack of educational, social, and financial access to preventative care and early treatment as well as of environmental racism, medical racism, and racist violence.29

Historically, the relationship of and differences between disability on the one hand and illness, disease, and other health concerns on the other has been contentious within disability studies and the disability rights movement, demonstrating that the boundaries of what constitutes disability have been challenged even within white and mainstream disability communities. The disability rights movement, for example, has been criticized for developing platforms and activist concepts like the social model of disability based primarily on the bodyminds and experiences of white, heterosexual, wheelchair-using disabled men.30 Disability rights activists have also identified intracommunity hierarchies of disability in which those with chronic illnesses, mental disabilities, and intellectual and developmental
disabilities are devalued, marginalized, and even excluded from activist work.\textsuperscript{31} Relatedly, the field of disability studies has been critiqued for focusing heavily on physical and sensory disabilities as the basis for theorizing disability generally.\textsuperscript{32} More recently, the term \textit{disability/disabled} itself has been critiqued as being overdetermined by whiteness, wealth, and rights-based political platforms. Jasbir Puar in particular argues for using the term \textit{debility} to discuss those whose bodyminds are purposefully, slowly, worn down by the violence of capitalism, racism, colonialism, and other forms of oppression but who are denied access to the label of disability and the small amount of resources begrudgingly provided to those legally and medically recognized as disabled.\textsuperscript{33} All these critiques and arguments demonstrate that even within existing disability studies and disability activism, there are disputes about the appropriate boundaries of the word \textit{disability} and its related academic and activist discourses. What becomes apparent in studying Black disability politics historically, however, is a frequent lack of investment in disability as a clearly defined and politicized identity and instead an investment in an umbrella approach to health activism that is inclusive of disability broadly defined. This has increasingly changed over time, and I say more about the role of disability identity in contemporary Black disability politics in praxis interlude 2.

For the \textit{NBWH}, a holistic approach to health meant addressing physical, mental/emotional, and spiritual well-being and engaging with a wide variety of disabilities as well as potentially disabling illnesses, diseases, and health conditions. As will become further evident in my discussion of the cultural and political aspects of the \textit{NBWH}’s approaches to health, the organization’s engagement with disability was consistently grounded in the real experiences of Black women. The \textit{NBWH}’s holistic approach was less invested in legal and medical definitions of disability and more concerned with the material impact of oppressions on the health and well-being of Black women and their communities. Nonetheless, the \textit{NBWH}’s approach was inclusive and supportive of Black disabled women, as is further reflected in the cultural and political aspects of its philosophical approach to health and health activism.

Cultural Approaches to Health

The \textit{NBWH}’s approach to health and wellness was influenced by African diasporic cultures and rooted in the lived experiences of Black women. This cultural aspect of the \textit{NBWH}’s approach to health is emblematic of the contextualized and historicized approach to disability typical of Black disability politics. At its core, the \textit{NBWH} believed in the need for health
initiatives created for us, by us. This culturally contextualized approach to health is primarily represented in, first, its inclusion of spirituality; second, its emphasis on the importance of telling and listening to Black women’s health stories; and, third, its promotion of culturally informed public health initiatives.

The NBWHP recognized the need to value and include spiritual health within Black feminist health activism in order to reach their intended audience. The NBWHP did this, importantly, without promoting any particular religious and spiritual beliefs, even as individual members discussed their specific faith practices and experiences—both good and bad—in articles for Vital Signs. The chapter on spirituality in Body and Soul asserts that “the spirit” can mean God, Allah, ancestors, or one’s own spirit. The book further explains that “spirituality has been a part of African tradition since long before the birth of Christianity” and is especially present in Black resistance traditions, such as using spirituals to send messages during slavery and singing spirituals during civil rights marches, largely because of the religious roots of leaders like Dr. Martin Luther King Jr., Malcolm X, and Fannie Lou Hamer. The chapter then includes stories of “how three Black women find sustenance through spirituality,” including the narrative of a woman who used Yoruba traditions to help her with depression after a suicide attempt. Spirituality within the NBWHP therefore encompassed a wide range of practices and beliefs that allow individuals to attend to their inner life and feel connected to a larger system or purpose in ways that shape their behaviors in the world. For example, in a Vital Signs article about her experience with dialysis, Berlinda Hawkins writes, “I had kidney failure, and my only survival depended upon being hooked to a machine three times a week. I learned to cope by praying to God for the strength to adjust to my sickness. With the help of God and my family, I made up my mind that I wanted to live.” This is one example of how Black women members of the NBWHP incorporated spirituality into their understandings and experiences of disability, illness, and disease. The NBWHP understood, therefore, that including spirituality in its Black feminist health activism was essential to reaching and empowering Black women, though this did not, importantly, prevent critique of the oppressive role religion and the church have played in the lives of many Black women as well.

Spirituality is not a common element of disability studies or public health work, and yet spirituality, faith, and religion are major parts of Black culture and are therefore critical to interpreting Black disability politics. Disability studies scholars have engaged with religion primarily through discussions
of ableism in Christian churches, critiques of faith or prayer healing, and challenges to notions that disability is either a gift or curse from God.\textsuperscript{39} There is limited work on the relationship of disabled people to spirituality and religion, much of which focuses on families of disabled people and on Christian churches specifically.\textsuperscript{40} While many Black people identify as Christian and the \textit{nbwhp} often partnered with Black Christian churches as locations for programming, the organization’s cultural approach to health conceived of spirituality much more expansively, often explicitly discussing non-Christian African and Caribbean spiritual practices.

The issue of religion and spirituality for disabled people came up multiple times in my interviews with contemporary Black disabled cultural workers. Several participants mentioned the tendency in Black communities to believe that (some) disabilities and illnesses can be treated with faith and prayer alone—potentially because of Black people’s negative experiences with the medical and psychiatric industrial complexes. This emphasis on religion over medicine sometimes leads to blaming and shaming of Black disabled people, particularly those who reject faith healing and laying on of hands as well as those who openly prioritize treatments and medication, especially for psychiatric disabilities. As Tinu Abayomi-Paul explains, “People seem to try to, you know, throw God at it … [but] it’s not, you know, something that I’m praying away. I’m treating it. God made the doctors, and the doctors are treating me … you have people [who] feel like you haven’t prayed hard enough … [who want to] lay hands on you without your permission … to basically erase part of your identity and swap it out for whatever identity they think that you should have…. [They accuse the disabled person] of being a faker or being not religious or not being strong enough.”\textsuperscript{41} T. S. Banks echoes this sentiment, stating that when he told loved ones about needing help for mental disabilities, he was told that “you should pray things away or that more church … more scripture” would help, but Banks explains that as a Black disabled person of faith, he believes in “Jesus and medication, Jesus and therapy.”\textsuperscript{42} While religion did not come up in every interview, the insights provided by those who did discuss religion, faith, or spirituality within Black communities make clear that there is still much work to be done to better integrate disability justice into Black faith communities. Our communities, especially our Black liberation movement communities, need to be holistically supportive of wellness and healing without overemphasizing cure or shaming Black disabled people for the choices they make to care for their bodyminds in a racist and ableist world. The \textit{nbwhp} modeled some of the ways this work could occur.
The NBWH’s inclusion of spiritual practices also intersects with its engagement with alternative and non-Western healing practices. Julie Avril Minich discusses the importance of cultural healing practices, such as the botánica in Latinx communities, which supplement or provide alternatives to medical and social systems that have failed, excluded, or harmed marginalized communities. The botánica is typically a small store that sells herbal medicines, oils, and teas as well as religious candles, crystals, incense, and other products for spiritual, magical, or ancestral practices. Similar types of alternative healing practices, many with spiritual or ancestral roots, are represented in Vital Signs articles and advertisements as well as within Body and Soul, often with discussion of the history of these practices in Black diasporic cultures. Versions of these practices appear contemporarily among antiracist, feminist activist organizations, such as Harriet’s Apothecary, Kindred Southern Healing Justice Collective, and BadAss Visionary Healers, who use the concept of healing justice as a revolutionary practice that does not equate healing with cure or able-bodiedness and able-mindedness. Minich argues that a disability studies perspective can help us interpret representations of and engagement with alternative healing practices among low-income and racialized communities as both evidence of the need for an improved health-care system and an indication of how “bodily difference can have diverse social and cultural meanings.” Although the ableism of some religious, spiritual, and alternative healing communities is undeniable and worthy of critique, critical race and disability studies scholars must balance such critique with attention to the racism and classism that shape interpretations of what spiritual and healing practices are deemed acceptable and explore what such practices bring to the lives of disabled people of color. The NBWH’s cultural approach to health provides a model for leaving space for spiritual and alternative healing practices within Black feminist health activism and Black disability politics.

A second aspect of the NBWH’s cultural approach to health is the valuing of personal stories from members of the organization. A major and regularly asserted goal of the NBWH was to fight against “the conspiracy of silence” among Black women and Black communities regarding health, especially sexual and reproductive health. In an article for the organization’s publication Sister Ink, JoAnne Banks-Wallace draws from a number of Black feminist writers to explore “the power of storytelling as a tool for health and healing from whatever ails us,” as well as “the value of storytelling as a tool for self-definition and self-determination.” The NBWH’s self-help
groups and “Black and Female: What Is the Reality?” workshops were
the primary venues in which the NBWHP facilitated the sharing of stories
among Black women. Additionally, however, organization publications
regularly included personal narratives submitted by members about their
health concerns, struggles, and victories alongside more traditional health
information and education.

The value of storytelling within the NBWHP reflects its emphasis on the
importance of cultural context in understanding Black women’s experiences
of disability, illness, and disease. This is evident, for example, in Vital Signs
articles on lupus. In one article A. D. Moreau-Morgan describes seeing a
public health awareness poster for lupus featuring a white woman’s face and
then details some of the medical research that shows Black women are actu-
ally three times more likely to have lupus than white women and that flare-
ups are often stress induced.49 In another article Angela Ducker Richardson
discusses how the particular stresses of her life, such as planning a wedding
and trying to find a job after college, led to lupus symptoms, which were
consistently misdiagnosed and therefore mistreated by doctors as nerves
and allergies. For a long time, Richardson simply lived with pain, itchiness,
and swelling throughout her body, explaining, “I didn’t immediately go to
the doctor because I thought I would once again be told that it was all my
nerves, and treated like some first-class hypochondriac.”50 In multiple issues
of Vital Signs over the years Black women with and without lupus discuss
how various factors—including lack of research into the racial and gendered
aspects of lupus, the high stress of many Black women’s lives, and the sex-
ism and racism of medical professionals which facilitate misdiagnosis—all
impact Black women’s specific racialized and gendered experiences of the
disease. These and other stories published by the NBWHP illustrate its at-
tempt as a Black feminist health activist organization to promote prevention
and/or awareness of specific illnesses and diseases for those not yet affected
while also providing advice to and from women already impacted by dis-
ability, illness, and disease in order to help them care for themselves, be self-
advocates, and manage their health as well as possible. The stories shared in
NBWHP publications are immensely valuable in that they collectively help
articulate some of the cultural norms and expectations of Black women that
impact their physical, mental/emotional, and spiritual health. By reading
about and sharing these themes, individual women could feel less alone and
more empowered with knowledge and resources, while public health workers
and researchers partnering with and learning from the NBWHP were better
able to develop programs drawing from the actual experiences, desires, and needs of Black women. These culturally based initiatives are the third aspect of the NBWHP’s cultural approach to health.

In addition to attending to spirituality and valuing personal narratives, another way the NBWHP took a cultural approach to health is through the promotion and creation of culturally based public health initiatives. The NBWHP was explicitly critical of public health programs developed for communities by people outside of those communities. NBWHP members instead promoted and created programming that met people where they were, understood their life situations intersectionally and holistically, and took a community’s own desires and needs into account. This aspect of the NBWHP’s cultural approach to health, like the inclusion of spiritual and alternative healing practices, reflects how organization leaders adapted their Black disability politics to the specific needs of communities of Black women.

The NBWHP was explicit and insistent about the need for public health officials and researchers to learn about, honor, and incorporate cultural perspectives and values into the development and implementation of programming because public health initiatives that do not account for the lived realities, priorities, and desires of the targeted population are destined to fail. This explicit insistence is evident, for example, in a funding proposal for the NBWHP’s Center for Black Women’s Wellness, which states:

We respect the opinions and recognize the dignity and the personal resources of persons in this population [of Black women living in public housing in Atlanta]. We recognize that the people most affected by a problem and who live with it daily often carry the solutions within themselves. Health educators, medical providers, and service program planners can benefit greatly from the involvement of people as active participants in their own health care rather than as passive recipients of services. Indeed, the success of these services depends on the acceptance and active involvement of the people expected to benefit from them.51

Here the organization makes clear, even in a request for funding, that its work will center the recipients of health education and health-care programs. The NBWHP’s tactic for culturally based public health initiatives involved asking Black women what they wanted and needed to attend to their health rather than telling them what to do or developing programs without regard to how such programs would be interpreted and experienced by the populations supposedly being helped.
When I refer to these programs as *culturally based* or *culturally informed* here, I am not equating culture with race. The NBWHP’s public health initiatives understood culture broadly as encompassing a variety of social factors such as race, class, gender, religion, and geography. There is not, therefore, one Black culture to which the NBWHP adjusted its goals but rather a variety of Black cultures that influence individual Black women in various ways. This is why, for example, in addition to partnering with subsidized-housing projects and churches, the NBWHP also developed programming that targeted students at historically Black colleges and universities. Each of these communities required an adaptation of tactics as more information was obtained through programmatic successes and failures. Gwen Braxton, a leader of the New York City chapter of the NBWHP, addresses the possibility of failures, in multiple senses, within the organization’s culturally based public health work. She writes:

> For you and I to assist others in reclaiming their power means we do whatever is necessary for them to make the best decisions that they can make for themselves with the resources that they have or have the ability to develop. This means that you and I have to accept that they might not make the decision that we want. They will make mistakes despite our advice and learn from their mistakes. I haven’t met anyone who wanted to get AIDS, but because their priorities are different, their decisions will be different than our decisions for them. The program may not achieve its measurable objective, and may lose its funding.52

Braxton acknowledges that part of a culturally based initiative means trusting and empowering people to make their own decisions about their health and bodyminds based on their individual priorities, needs, and abilities, with the recognition that such an approach also allows individuals to make mistakes. Importantly, Braxton also highlights that this approach challenges traditional models of public health program funding from private foundation and government grants because the impact may not be immediate, obvious, or easily measured in a fashion that can be exhibited for funders.

Overall, the NBWHP’s cultural approach to health, which includes recognition of spirituality, valuing of personal narratives, and development of culturally based public health initiatives, is an example of how Black cultural workers articulate Black disability politics in very contextualized ways that account for the way race, gender, class, and culture intersect with experiences of disability, health, and disease. This cultural approach to health,
which builds on the holistic approach, also necessitated engagement with the broader politics and history of Black women’s health. Above all, the NBWHP emphasized that health is inherently political, and the organization sought to draw attention to and change the conditions that damage Black women’s health.

Political Approaches to Health

The NBWHP tackled a wide variety of health issues from an explicitly political, antiracist, and feminist perspective. In a meeting guide for self-help groups, the organization asserts:

> Our commitment to our health includes understanding the umbrella of oppression that hovers over us and the reality for all Black women of the pervasiveness of oppressive conditions in our lives. These oppressions are interlocking and affect us in all areas of our lives, even when we believe ourselves to be surviving and thriving in our personal and occupational lives. By better understanding the ways in which these interlocking oppressions affect health status we can look at our wellness within the broader social/political/economic context that is our reality. In this way, our efforts to promote our health are clearly political in nature as we take control of our lives and support each other to do the same.53

Politics were consistently at the center of the NBWHP’s work at all levels, as is likely already evident from my discussion of its holistic and cultural approaches. However, in this section I aim to highlight not only how the NBWHP positioned health as a political issue—that is, as something that is both experienced within larger contexts of oppression and directly impacted by political policy—but also how it sought to raise political consciousness and political engagement among its membership. There are two aspects of the NBWHP’s political approach to health that I highlight here: historicizing and contextualizing Black women’s health and providing political education, empowerment, and training for Black women. These aspects of the NBWHP’s political approach to health are examples of two trends in Black disability politics: taking a contextualized and historicized approach to disability in Black communities and simultaneously seeking both micro- and macrolevel change.

The first way the NBWHP took a political approach to health is by historicizing and contextualizing Black women’s health within the legacies of racism, sexism, and classism in the United States. In a Vital Signs article titled “Slavery Still in Effect: Lamentables of a Women’s Health Advocates
Marlene Braxton Fisher confronts the strong Black woman stereotype and its impact on Black women’s physical, mental/emotional, and spiritual health. She begins, “I always believed that African American women were physically, emotionally, and spiritually the strongest women in the world who could endure any hardship without lamentation. We are often encouraged to persevere [through] sickness and social ills by recanting the mythical stories of Amazon women of African descent.” Fisher details how the strong Black woman myth negatively impacted her own health and then returns to slavery, stating, “I learned a few facts about my mythical ancestors. Instead of being the inherently healthy, physically capable women I thought they were, female slaves were never even half as healthy as white women. How could they be healthy as malnourished and battered as they were?” She follows this rhetorical question with details about the life span and health trends of enslaved Black women before making direct connections to health-care systems in the present, including the lack of inclusion of Black women in pharmaceutical trials. She concludes, “Medicine practiced to heal the masses does not take into account the tremendous pressure imposed on African Americans by poverty, racism and environmental stress. We need attention that is real, constant and understands our culture.” This article is particularly emblematic of all three of the NBWHP’s approaches to health—holistic, cultural, and political—in that Fisher includes her personal narrative, historical information, contemporary health statistics, pharmaceutical research information, and calls for political change all in one piece.

The historicizing of Black women’s health continues in other articles and publications, which address how slavery, medical abuse, forced sterilization, and environmental racism have negatively impacted Black health for generations. The NBWHP worked to trace and highlight these impacts in order to position health as always already a political issue for Black women. The organization, through publications, self-help groups, and workshops, sought to link histories of racialized and gendered violence to contemporary health concerns, including the impact of internalized oppression on individual Black women’s health.

Importantly, although the primary focus of the NBWHP was addressing racial and gender oppression, in Body and Soul there is also brief engagement with the impact of ableist oppression on disabled Black women, though the term ableism is not used. The text contains five paragraphs on physical disability generally (mental disability is addressed separately later), including the story of a Black disabled woman named Janice Jackson. These paragraphs conclude the chapter on diseases most common among Black women, in
which specific disabilities and potentially disabling diseases and conditions, including hypertension, cancer, diabetes, lupus, sickle cell disease, asthma, and chronic fatigue syndrome, are each provided lengthier and more focused discussion than physical disability as a whole. This general physical disability section places disabled people within the context of oppression, stating, “Having a disability of any kind can be difficult, especially in a world that generally ignores the physically and mentally challenged…. Ignorance of the differently abled extends beyond personal interactions. The rights of the blind, deaf, those who use wheelchairs, who speak different or are mentally challenged are too often disregarded.” The text then emphasizes intersectionality, stating, “And the situation is worse for Blacks who are physically challenged: A recent congressional study reported that for the past thirty years African-Americans have been much more likely than whites to be rejected for benefits under Social Security disability programs. But many folks like Janice are forming support groups and fighting back against the insensitivity and discrimination so common in the ‘abled’ world.” The section concludes with a list of relevant books and organizations, ranging from national advocacy groups like the American Council of the Blind to more charity-oriented groups like the National Easter Seal Society and smaller support groups like the Black Women with Disabilities Alliance. The engagement with physical disability in this section of the book reflects a clearly political understanding of disability and an acknowledgment of ableism. The language, however, runs the gamut from “confined to a wheelchair” and “physically and mentally challenged” to “differently abled” and “handicapped,” which suggests that the leaders of the organization and the book editor were not well connected to or inclusive of disability rights activists in the 1990s, who had by that time moved to predominantly using disability over all of these other terms. I provide further critique of the NBWHP’s lack of engagement with contemporaneous disability rights movement work in praxis interlude 2.

The language used in the Body and Soul section on physical disability is another example of how Black disability politics have often emerged independently from mainstream disability rights even as the intent may be anti-ableist solidarity with disabled people. Scholars researching disability politics among Black and other marginalized groups typically excluded from the priorities and activities of the mainstream movement must not allow the use of outdated or ableist language alone to be the barometer of disability politics. As this chapter has already shown, the NBWHP was clearly invested in a social and political model of health that included disability.

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Its political model of health has much in common with the social, political, and relational models of disability common in disability studies and disability activism today, but it is grounded in holistic and cultural approaches that strongly differentiate their approach from mainstream disability rights at that time. Part of my work here is not to claim that the NBWHP was perfect in its articulations and enactments of disability politics but rather to demonstrate that the organization is part of a legacy of Black disability politics that has been overlooked, ignored, misunderstood, and dismissed because of how it presents itself as race centered and not based in disability identity, thereby utilizing frameworks and language that sometimes conflict with standard practices in the white mainstream movement and “white disability studies.”

The second aspect of the NBWHP’s political approach to health and well-being was its investment in political education, empowerment, and training, which included patient rights education, policy briefs, and training for political engagement through leadership institutes. In the organization’s own words, “NBWHP works at the primary prevention level, with individuals and groups; at the community action level, where groups influence local health policies which affect them; and at the national policy level, where the perspectives of African American women influence policy makers and the public.” This part of the NBWHP’s political approach to health demonstrates a commitment to both micro- and macrolevel change and an understanding of how progress at one level necessitates and encourages continued progress at the other. The NBWHP believed the adage that knowledge is power, but it also asserted that knowledge without the empowerment, means, and skills to use it is of little value to Black women. This sentiment is reflected in founder Byllye Avery’s often shared experience early in her health activism of running a support group for fat Black women in which she realized that the women all understood what diet and exercise regimes were considered healthy, but the material circumstances of their lives made perfectly executing such regimes impossible. In the end, Avery realized “that it’s not just about giving information; people need something else,” and this need for “something else” helped launch her vision for the NBWHP. Throughout their work the NBWHP’s political approach aimed to connect individual health education to individual and collective empowerment with the goal of widespread political and social change.

One way the NBWHP sought to empower Black women with knowledge and skills was via patient rights education. The organization believed in the need to be knowledgeable about one’s own bodymind as well as about
one’s rights within the medical industrial complex. *Body and Soul*’s chapter 19, “Dealing with Doctors and Hospitals,” enacts this combination of patient rights education and empowerment. The chapter provides questions to ask when choosing a new doctor; advice on how to prepare for a doctor’s appointment; information on what to ask, expect, and do during a doctor visit; a descriptive list of medical specialists one might encounter in a hospital; and an example of a patient bill of rights from a Brooklyn hospital. Similarly, the NBWHP published *Vital Signs* articles in 1993 and 1994 that detailed how Black women with HIV/AIDS could qualify for Social Security disability benefits and gave instructions on how to apply.\(^{66}\) By including such detailed information, the NBWHP taught Black women how to advocate for themselves and their loved ones within the medical-industrial complex. This information is particularly invaluable for Black disabled women and nondisabled Black women serving as caretakers for loved ones, as they are likely to have above-average amounts of interaction with medical professionals and are more likely to experience combinations of racism, sexism, ableism, and classism within medical interactions, which necessitates knowing one’s rights. Patient rights education occurs similarly within disability activism and communities of people with similar disabilities, such as the contemporary chronic illness “spoonie” digital community, in which people share life hacks and tips on how to navigate complicated, bureaucratic, and oppressive health-care systems.\(^{67}\)

In addition to the more individual, microlevel political education and empowerment of patient rights education, the NBWHP also sought to use a political approach to health to enact more macrolevel change via policy briefs and updates and training for political engagement. By encouraging Black women to be aware of planned policies that would impact their health and well-being and by teaching them how to respond to and impact local and national politics, the NBWHP not only supported Black women’s politicized awareness of health but also provided training and support for them to take action. The majority of this more formal legislative and lobbying work occurred in the 1990s after the establishment of the NBWHP’s Public Policy and Public Education Office in Washington, DC, which worked to disseminate “information, data and perspectives of Black women and the NBWHP Self-Help Network … to broaden the national Reproductive Health/Rights Agenda; and to promote public policies for the improved health status of Black women, their children and communities.”\(^{68}\)

From 1991 to 1999, the NBWHP regularly published a featured section called “Public Education and Policy” in *Vital Signs*. This section contained
position statements, policy briefs, and legislative updates on topics such as health-care reform, abortion, birth control, welfare reform, family and medical leave, and sexual and domestic violence. This was part of the organization’s new policy committee, which, according to a *Vital Signs* update on organizational governance, aimed to “bring to the membership major policy statements about positions affecting ourselves, our families and our communities” while also “testifying in Congress, allied with other women’s organizations in the struggle for change, and empowering our membership through education and information exchange.”

The NBWHP did not, however, simply provide this information to the membership. As this quote suggests, the NBWHP aimed to empower members to do something in response to local, state, and federal policies impacting their health by publicizing political-action events such as marches, demonstrations, and days of solidarity as well as by creating institutes and trainings to develop individual Black women’s health activist skills and engagement.

Early in the organization’s history, the NBWHP established ways for members, particularly self-help group leaders, to come together for community and education. This occurred through the Self-Help Developers Task Force meetings, annual conferences, retreats, and leadership institutes. The meetings and institutes for self-help group developers and local NBWHP chapter leaders were intended “to increase skills; identify problems; share information regarding the status of the self-help group process; identify emerging health trends and developments among the membership; discuss and evaluate the effectiveness of various program models that are being used and tested in the field; discuss national public policy issues; and develop strategies for more effective utilization of social service and preventive health resources at the local and national levels.”

Additionally, Black women not yet established as leaders of self-help groups or local chapters could develop their own leadership skills through workshops at annual conferences. For example, the 1993 conference included one workshop on public policy that aimed to teach attendees “how to become an active participant in health advocacy at the local, national, and global level”; and another workshop for general leadership training sought to show participants “how to become an effective leader in your community through ‘grassroots’ organizing, networking, and coalition building.” These multiple leadership development opportunities, combined with the patient rights and policy education provided through NBWHP publications, sought to ensure that Black women had the information, confidence, skills, and support to enact change in their local communities as well as at the state and national levels if they so desired.
The two major aspects of the NBWH’s political approach to health, historicizing Black women’s health in the context of oppression and providing political education, empowerment, and training, are perhaps best summarized by the organization’s health information booklet *Our Bodies, Our Voices, Our Choices*. The booklet states that the NBWH operates on the “fundamental belief” that “every woman—whether heterosexual, bisexual, or lesbian—may substantially increase her chances of achieving overall health and well-being if: She is knowledgeable about her body; she is aware of her rights and empowered to ask necessary questions; and she knows that she is entitled to information and services that are delivered with dignity and respect. We also believe that when women appreciate how history and contemporary events combine to impact our ability to make decisions and to have choices, they will want to get politically involved on matters close to home, across the nation, or around the world.”

Here it is clear how the multiple tactics within the NBWH’s political approach to health and wellness come together into a single Black feminist health activist mission that sought radical and revolutionary change. Although the organization became less grassroots oriented over time, focusing more on policy, lobbying, and research funding, this eventual organizational transformation does not negate the important intersectional, multimodal work it performed in the 1980s and 1990s to improve health outcomes for Black women and their communities.

Conclusion

Together, holistic, cultural, and political approaches to health shape the way the NBWH articulated and enacted its particular form of Black disability politics. The individual aspects of each of these three approaches illustrate all of the common qualities of Black disability politics generally. The NBWH’s approaches to health were intersectional but race centered, not based in disability identity, historicized and contextualized, and holistic. Understanding the history and mission of the organization and its holistic, cultural, and political approaches to health allows us to trace how the NBWH engaged with disability in politicized ways.

There are several important lessons to be drawn from the Black disability politics of the NBWH. First, the organization’s work clearly demonstrates how health activism can be inclusive of disability politics even as the work may emphasize concepts of health, wellness, and healing typically considered antithetical to disability inclusion and acceptance. Indeed, it is critical that scholars take culturally contextualized approaches to analyzing health
activism and engagement with alternative healing practices, especially spiritual ones, within racialized, poor, and otherwise marginalized communities in order to understand the place of disability and disabled people within such work. I want to emphasize again here that the role of spirituality in the NBWHP’s health triad is important, and yet disability studies has few to no frameworks for discussing the spiritual beliefs and practices of disabled people, particularly disabled people of color. This is work that needs to be taken up by Black studies and Black theology scholars in conversation with existing work in disability studies.

This chapter has provided an overview of the history of the NBWHP, followed by a detailed analysis of how the organization engaged with disability and included disabled Black women within its holistic, cultural, and political approaches to health. My aim here has been to highlight the varied ways disability is included, engaged with, and politicized within the NBWHP’s publications, programming, and overall Black feminist health activist philosophy in order to frame the organization’s work as engaged in Black disability politics. This broader overview of the NBWHP’s engagement with disability lays the foundation for the next chapter, which takes a more focused look at the organization’s work regarding HIV/AIDS specifically. This second chapter on the NBWHP allows for a deeper understanding of how the holistic, cultural, and political approaches to health discussed here played out in programming and publications aimed at supporting Black women with disabilities and chronic diseases. In particular, I build on the framework-oriented work of this chapter to specifically engage with how health activist work that promotes prevention or reduction of potentially disabling diseases and conditions can still be anti-ableist when it is combined with work to support existing disabled people.