MORE THAN JUST PREVENTION

The NBWHP and the Black Disability Politics of HIV/AIDS

In an informational packet for potential new members, the New York chapter of the National Black Women’s Health Project (NBWHP) asserts, “The complexity and diversity of health problems experienced by Black women requires a comprehensive plan of action with strategies designed to identify and eliminate root causes, promote prevention and wellness by creating new healthy ways of living and relating, early diagnosis, treatment and follow-up, and maintenance of life with as much comfort, independence, dignity and joy for everyone, including those who have severe disabilities, or are chronically or terminally ill.” This statement reflects how the organization’s holistic, political, and cultural approach to health was not focused on prevention alone; rather, the NBWHP’s Black feminist health activism also sought to support people with disabilities.

There are three main parts of the “comprehensive plan of action” articulated by the New York chapter’s informational packet. First, “to identify and eliminate root causes” of health problems, as the previous chapter discussed, meant dealing with all of the larger social and political issues that shape and limit life choices for Black women. Second, “to promote prevention and wellness” through “new healthy ways of living, and relating” included regular engagement with the medical industrial complex to receive early diagnoses and treatment if necessary. Here I emphasize new and relating because although the NBWHP promoted typical public health agendas, such as receiving regular checkups and understanding basic health practices regarding eating and exercise, the organization also addressed mental, emotional, and spiritual wellness in a politicized
fashion that changed the way Black women related to themselves and to other Black women, particularly via understanding the role of oppression in their lives. Third, and most important for the purposes of this chapter, the New York chapter of the NBWHP argues here that the final part of a comprehensive health activist action plan is to help people, including disabled and chronically ill people, maintain their lives with “as much comfort, independence, dignity and joy” as possible.4 The explicit inclusion of disabled and chronically or terminally ill people in this action plan is indicative of how the organization understood health activism to be about not only prevention and awareness but also material support for people with disabilities, illnesses, diseases, and other health concerns. This chapter explores how the NBWHP balanced prevention and public health education with support for disabled people, specifically in its Black feminist health activism on HIV/AIDS.

In addition to the ways Black disability politics were articulated generally in the philosophy and mission of the NBWHP, as discussed in the previous chapter, the organization also enacted Black disability politics in its work on HIV/AIDS. The NBWHP addressed HIV/AIDS in a dual-pronged fashion that aimed simultaneously to reduce the number of new HIV infections and provide material and social support for Black women living with HIV/AIDS. I use the NBWHP’s HIV/AIDS work to demonstrate how health activism that attempts to reduce the incidence or severity of disability, illness, and disease can nonetheless participate in disability politics by aligning with and supporting those already disabled, sick, or ill. The NBWHP illustrates how public health initiatives can work in antiracist, feminist, and anti-ableist ways when grounded in the experience and expertise of multiply marginalized people. Further, the approaches the NBWHP used in this work model central qualities of Black disability politics by connecting the racial disparities of the AIDS epidemic at the time to racism, sexism, classism, and ableism within public health and medicine in the United States. This politicized prevention work emphasized how the racism, sexism, and classism undergirding mainstream American understandings of and approaches to sexual health actually exacerbated the prevalence and severity of sexually transmitted infections and diseases in Black communities. The NBWHP argued for, and at times created, culturally specific approaches to education, prevention, and support in regard to HIV/AIDS. As a result, the NBWHP’s HIV/AIDS work is another example of how Black disability politics often operate differently from white mainstream disability rights work by necessity.

In what follows, I first provide a historical and theoretical overview of the AIDS crisis in the 1980s and 1990s, with an emphasis on the role of race,
gender, and disability within the medical, cultural, and activist discourses at that time. I then provide analysis of the NBWHP’s work on HIV/AIDS, demonstrating how its Black feminist health activism balanced prevention with support. This work was intersectional but centered on race and gender, contextualized, and holistic. More specifically, the NBWHP’s Black feminist health activism on HIV/AIDS models how Black disability politics can fight the ways racism and ableism intersect and collude in the lives of Black people without distancing them from disabled people or using disability as a static symbol of violence, trauma, or neglect.

**HIV/AIDS: Historical and Theoretical Overview**

There are numerous useful and important histories of the AIDS epidemic from various social, political, medical, activist, and identity perspectives. For the purposes of my arguments here, I want to briefly cover the specific racial, gendered, and disability history of the epidemic to provide the cultural backdrop against which the NBWHP was performing its work regarding HIV/AIDS among Black women. This section therefore provides a historical and theoretical overview of the relationship of HIV/AIDS to disability, womanhood, and Blackness in the United States in the 1980s and 1990s, the period of the NBWHP’s work on HIV/AIDS under discussion in this chapter.

In 1981 AIDS first became a medical epidemiological concern when hundreds of predominantly white gay men had documented cases of severe immune deficiency. Initially, medical professionals and laypeople alike assumed that the disease occurred primarily or even exclusively among gay men, who were also at the forefront of early activism around the disease. In addition to gay men, in the first few years of the US epidemic, HIV infection was also associated with intravenous drug users. In fact, the first documented cases of HIV in women occurred in 1982, primarily among intravenous drug users and sexual partners of intravenous drug users. Despite these early cases, it was not until 1995 that women were more fully recognized as part of the epidemic and that symptoms more common among women with HIV, such as chronic yeast infections, were added to the list of AIDS symptoms. In a similar fashion, although there are early documented cases of AIDS among people of color, particularly among Haitians and gay men of color, it wasn’t until 1986 that Black and Latino populations were identified as disproportionately impacted by HIV/AIDS and therefore in need of targeted preventive care and testing. By 1990 Black people represented 28 percent of AIDS cases, despite making up only 12 percent of the total US population at that
time. These numbers continued to increase, with Black people representing 40 percent of AIDS cases in 1995 and 57 percent in 1998. In short, although the AIDS epidemic has been most firmly associated with white gay men in medicine, in the media, and among the general lay population, HIV/AIDS cases have never been exclusively among this population, and, in fact, by the 1990s the epidemic was increasingly impacting Black people and women.

The cultural association of HIV/AIDS with white gay men stems in part from the incredible activism that emerged in the wake of the epidemic. White gay men, many of whom had access to not only medicine and wealth but also media and arts outlets, organized quickly and loudly, demanding medical services, research, social services, and real concern for those sick and dying in their communities. As Nancy E. Stoller documents, many women, the majority of whom were white and/or lesbian, were also directly involved in the earliest stages of activism even though most were not HIV positive. In contrast, for numerous reasons, including the association of the disease with gay men and drug users, Black communities were slower to respond collectively to HIV/AIDS, but eventually this activism did emerge. The work of the NBWH on HIV/AIDS in the 1980s and 1990s therefore was on the cutting edge in many ways. It was one of the earliest Black organizations to mobilize around the disease and the first to focus on Black women’s experience with HIV/AIDS specifically. The NBWH’s activism in this area has not been discussed in other histories of the disease in part because the organization was not exclusively focused on HIV/AIDS activism but also because the NBWH was based in Atlanta and Washington, DC, whereas most major HIV/AIDS activist efforts in this period were based in either New York or San Francisco due to the size of these cities and their statistically larger population of gay men.

In terms of disability, as early as 1985 AIDS activists, such as those involved with the National Association of People with AIDS, were using rhetoric similar to that of disability activists, resisting their positioning as passive patients or dying victims and explicitly linking their fight to the civil rights, feminist, and disability rights movements. In the late 1980s, as disability rights activists worked to get the Americans with Disabilities Act (ADA) passed, the inclusion of people with HIV/AIDS was a sticking point for many conservative politicians, who associated the virus and disease with homosexuality and drug use and wanted HIV/AIDS to be removed from the legislation as a condition covered by the ADA. In fact, in her history of the ADA, Ruth Colker writes that “the primary source of controversy under the ADA was an exemption for restaurants so that they could fail to
employ individuals who were HIV-positive.” Despite this controversy and the unabashedly homophobic resistance to the protection of people with HIV/AIDS, disabled activists and Democratic politicians who were authoring the legislation refused to change their position, and HIV/AIDS remained a disability condition under the ADA.

Notwithstanding this political alliance and recourse to related activist discourses, as Robert McRuer writes, “people with other disabilities have at times, over the course of the epidemic, distanced themselves from the concerns of people with AIDS.” This distancing has occurred not only within disability activism and community work but also within disability studies. Despite the continued cultural impact of HIV on multiple marginalized communities, including queer men, Black people, Latinx people, sex workers, and people living with drug addictions, disability studies as a field has had limited engagement with HIV/AIDS. Generally this exclusion aligns with the lack of engagement with chronic illnesses and diseases in the field, especially those like HIV/AIDS and diabetes that are stigmatized via association with personal failure (to use a condom, to maintain a certain weight or diet, etc.). Further, as feminist disability scholars Alison Kafer and Julie Avril Minich have each noted, the disabling conditions most often left out of conversations and theorizations within disability studies are also primarily those associated with people in poverty and people of color. Disability studies scholars studying and analyzing HIV/AIDS as a medical, political, and social concern, however, make clear that “the cultural management of AIDS is of a piece with the cultural management of disability.” Disability studies theories and frameworks therefore strongly inform my interpretation of the NBWHP’s HIV/AIDS Black feminist health activism as Black disability politics. I draw more heavily in this chapter, however, on work in the fields of Black studies, queer studies, and gender studies, which each have longer and more robust histories of scholarly engagement with HIV/AIDS, even though this engagement has not tended to take a disability studies approach or even to conceptualize HIV/AIDS as disability.

Balancing Prevention and Support: A Black Feminist Health Activist Approach to the AIDS Crisis

In line with its overarching political, cultural, and holistic approach to health and wellness, the NBWHP understood the AIDS epidemic in the Black community, particularly among Black women, as a political and social concern rooted in health-care access, racism and sexism among medical and public
health practitioners, and patriarchal sexual norms. The NBWHP’s approach to HIV/AIDS was intersectional but centered on race and gender, not based in disability identity, contextualized and historicized, and holistic. As stated in a 1988 “AIDS Education Project Proposal,” the NBWHP aimed to “promote individual and collective behavioral changes that will lessen the risk and potential deaths of Black women and children from AIDS.”

Concretely, this promotion of individual and societal/collective change manifested through coverage in its organizational newsletter/magazine, Vital Signs (including special issues focused on HIV/AIDS in 1994 and 1995; the former of which is shown in figure 4.1); a chapter on HIV/AIDS in its health self-help book Body and Soul: The Black Women’s Guide to Physical Health and Emotional Well-Being; panels, speeches, and workshops at NBWHP annual conferences; a special conference focused entirely on HIV/AIDS and Black women; and the development of culturally specific HIV/AIDS programming. According to the organization’s AIDS program report in 1989, between July 1988 and January 1989, 2,410 people participated in NBWHP AIDS Program presentations, workshops, and self-help groups, and 73.8 percent of participants were Black women. These numbers underscore the significance and impact of the NBWHP’s work in this area. In addressing the AIDS epidemic, the NBWHP balanced attempts to prevent the spread of HIV/AIDS with work to socially and materially support Black women already living with HIV/AIDS. This combined approach represents an enactment of Black disability politics because the NBWHP approached the AIDS epidemic as a political concern inextricably tied to racial and gender identities, experiences, and norms and did so in a fashion that refused to stigmatize or abandon disabled Black people.

Generally, prevention of illness and disease is taken as an inherent, unquestionable good in American culture. And yet the medical research and public health practices that have undertaken the prevention of illness and disease have historically entailed abuses of power that subject marginalized populations, especially the disabled, people of color, and the poor, to isolation, incarceration, medical experimentation, and nonconsensual or nontherapeutic medical treatment in the name of the common good. Part of the challenge of contemporary work in disability studies, especially work at the intersections of disability and race, gender, sexuality, or class, is to offer historicized and contextualized analyses of specific medical and public health practices. This includes critical interrogation of prevention practices as political because the idea of prevention as an inherent good relies on larger cultural conceptions of cure.
Cure has long been the object of critique in disability studies as an ableist trope that assumes that all disabled people desire to be nondisabled and that nondisabled lives are inherently better, easier, more productive, or more valuable than disabled lives. Eli Clare argues that the ideology of cure in American culture includes not only cure strictly defined as the complete elimination of disability, disease, illness, or infirmity but also diagnosis, treatment, management, rehabilitation, and prevention. Clare writes that cure as ideology is “an inflexible set of values” that requires identifying and locating bodymind damage or harm and seeking an original, supposedly superior state of no harm, but cure as practice is “multifaceted and contradictory … [with] thousands of different technologies and processes. Each variation comes with its own cluster of risks and possibilities.”

In other words, engagement with the many practices that fall under the umbrella of cure, such as prevention, means dealing with the messy dangers and potentials of each individual practice. Further, I would add that we must perform this engagement with sustained attention to the sociohistorical context, power dynamics, and people involved in the use of these practices.
My engagement with prevention in this chapter therefore bears in mind prevention’s relationship to ableist discourses of cure while recognizing that, as scholars of chronic illness have explored, there cannot be a singular approach to cure and prevention practices when the bodymind effects of different disabilities vary so widely and can include pain and other effects that disabled individuals may seek to lessen or be rid of entirely.24

In this portion of the chapter, I first explore how the NBWHP took a Black feminist approach to the prevention of HIV through culturally based education initiatives that included work to destigmatize HIV. I then discuss how this destigmatization work served as the bridge to other work the NBWHP performed to materially and socially support Black women with HIV/AIDS. While many organizations undertook similar combined prevention-support approaches to the AIDS crisis during this period, the attention to race, gender, and disability as mutually constitutive categories within the NBWHP’s Black feminist health activism represents a little-discussed and intellectually instructive example of enacting Black disability politics.25

Prevention

The NBWHP recognized that to reduce the devastating mental, emotional, and financial toll the AIDS crisis was taking on Black communities, especially urban poor ones, efforts to prevent the spread of HIV had to take into account cultural norms within these communities in regard to sex/sexuality, gender, drug use, and engagement with medical professionals. The NBWHP critiqued existing prevention models formulated with or based on white communities, stating in a 1988 AIDS Education Project Proposal:

The messages designed to make a difference appear to be geared to the white population, are developed primarily among white professionals with little input from or representation by minority group members, and do not reflect the thinking or mores of the ethnic communities most at risk…. Further, these messages are inconsiderate of family planning beliefs, sexual behaviors, and religious attitudes of many of the people they profess to be interested in serving. Thus, there is a very real gap in the intent of the messages and their overall effectiveness in reaching and modifying or changing behaviors in order to save lives.26

The NBWHP aimed to fill this gap by creating educational publications and programming aimed at HIV prevention that took “into consideration many of the cultural and religious beliefs which form the norm for behaviors within
our community” with an “increased focus on the psychological/sociological issues that operate in the lives of the majority of Black women, whether adolescent or mature, which impact on their relationships, reproductive rights, and sexuality decisions.” These quotes demonstrate the overarching politics and ethics of the NBWHP’s HIV/AIDS work, which sought to understand and promote the particular needs of Black communities, especially Black women, to reduce the severity of the epidemic among Black people. Importantly, the NBWHP aimed to do this work in a way that understood HIV/AIDS not as an exclusively personal, medical concern but rather as a political issue inextricably tied to race and gender in its transmission and in its representation in medical literature and mainstream media.

The NBWHP’s prevention work operated primarily in the realm of education with an emphasis on educating Black women. The NBWHP created HIV/AIDS education materials and workshops that were attuned to the norms and needs of their primary audience. These materials first aimed to debunk myths about who is infected by the disease, how the disease is spread, and how the disease can be detected, making clear that Black people, straight people, and lesbians can all contract HIV. The debunking of myths was essential because of the widespread misinformation in Black communities about HIV/AIDS due to its association with white gay men. The NBWHP’s first goal in its HIV/AIDS prevention work was to make Black women aware that anyone could contract HIV. The organization then aimed to create safer-sex education materials that addressed specific concerns about and barriers to safer sex for Black women. This included non-HIV/AIDS-specific materials like the NBWHP’s Plain Talk program, which facilitated discussions between Black teenage girls and their mothers about sex, and the NBWHP’s fight to break “the conspiracy of silence” in Black communities regarding intercommunal sexual and domestic violence. These other programs and initiatives not focused exclusively on HIV/AIDS complemented and supported the NBWHP’s HIV/AIDS-specific programs and publications targeted at Black women because one cannot understand a social problem outside of its social context. The NBWHP made clear that understanding and addressing how sexuality is discussed and experienced in Black communities is essential to any public sexual health initiative that wants to reach Black people.

For example, in one of her multiple Vital Signs articles on HIV/AIDS, Dazon Dixon reflects on her experience hosting safer-sex parties for Black women, which taught her the complexities of sexual choice and freedom. She writes, “We facilitators learned quickly that there were many things on these women’s agendas that came way ahead of AIDS or condoms or even
sex. ‘What about my man who beats on me? I’d rather f__ him than fight him’ one stated. ‘How you expect me to deal with finding some condoms when I can’t even find a job or a man with a job?’ another queried.”

In a later article, Dixon elaborates for Vital Signs readers how simply telling Black women to make men use condoms is pointless if organizations do not address the general lack of sexual freedom for Black women, which may prevent them from safely advocating for their sexual health needs. She asks:

What about the women who fear getting beat if they change the dinner plans, much less their sex lives? What about the women who just don’t have the equal power in their heterosexual relationships to say what they want, when they want and how they want? Who supports and talks openly with the women who have had sexual violence or abuse in their histories and can’t even relate to their sexual selves yet, much less someone else’s hang-ups? Do we honestly expect that the messages around the connections between all sexually transmitted diseases including HIV/AIDS are going to suddenly galvanize struggling women into doing things differently than what we’ve been taught and socialized to do for generations?

In each of these articles, Dixon makes clear that educational materials and prevention programs that do not understand or address the reality of Black women’s sexual lives will be simply ignored or forgotten as the suggestions will seem impossible to implement. Further, the NBWHP argued that presenting strategies like “use a condom” and “get tested regularly” as simple, easy, and straightforward things one can and should do to protect against HIV infection creates distance, distrust, or lack of faith in public health officials and organizations because such things are not simple and straightforward for many Black women and other multiply marginalized people. Such ignorance of the realities of Black women’s lives on the part of public health researchers and practitioners results in Black communities being more severely impacted by sexual and other public health crises, increasing the likelihood of Black disablement, debilitation, or death. To counter the failures and ignorance of existing public health approaches to HIV/AIDS in Black communities, the NBWHP created educational prevention materials and programs that acknowledged and attended to the lived realities of their target audience.

To address the needs of Black women, the NBWHP disseminated and/or presented its own tailored prevention and education materials and workshops in spaces with the widest impact and reach in Black communities.
The NBWHP ran workshops and self-help groups in community centers and neighborhood churches, where Black women were more likely to show up and feel comfortable talking about intimate issues like sex. Also in line with bringing the work to the communities one intends to impact, the NBWHP also organized educational workshops for Black beauticians because of the central role and influence of the Black beauty shop in Black women’s lives and communities. All of these place-based initiatives allowed the NBWHP to do HIV/AIDS prevention and education work in Black-women-exclusive or Black-women-dominant groups where speaking and asking questions about sex and sexuality would likely feel safer. The choice of culturally specific locations in which to disseminate HIV/AIDS prevention education is also important because it moves public health education out of the space of clinics and schools and into places that feel more comfortable for many Black women, places they already frequent on a regular basis.

In addition to debunking myths, addressing barriers to safer sex for Black women, and disseminating information in key locations in Black communities, all of the NBWHP’s culturally specific prevention education also consistently politicized HIV/AIDS by connecting the disease to larger sociopolitical issues central to Black communities and Black empowerment. This broad, intersectional, contextualized approach to HIV/AIDS is a major reason I argue that the NBWHP’s HIV/AIDS prevention work enacts Black disability politics. In Vital Signs, Dixon writes, “If AIDS has done nothing else, it has magnified all the social, political, health and economic problems that have plagued people of color, especially African-Americans…. Many educators and activists in the Black community feel AIDS is a part of the bigger picture for survival, and not an isolated, number-one priority.” This quote demonstrates how the NBWHP’s HIV/AIDS work was disability inclusive rather than disability centered because HIV/AIDS was and is one of many health and wellness issues facing Black communities—issues that require Black disability political approaches. This perspective is further emphasized in the conference report “From Cries and Whispers to Action: African-American Women Respond to AIDS,” in which the NBWHP specifically names medical racism, health-care access, reproductive justice, and the prison industrial complex as political issues for Black people that intersect with the spread of HIV/AIDS in Black communities. By placing HIV/AIDS into a larger social and political context, the NBWHP emphasized that all Black people should be aware of and care about the spread of HIV/AIDS.
Part of the NBWH’s goal in this broader politicization of HIV/AIDS for HIV-negative Black people was to destigmatize the disease. Destigmatization for the NBWH involved reducing blame or moralizing around HIV/AIDS, including addressing the role of homophobia in the Black community and discussing the complexities of drug use and sex work among Black people.35 By moving away from the individualized, moralized approach to HIV/AIDS that blamed people for their own disease or disablement, the NBWH promoted a clearly politicized understanding of this disabling disease. By destigmatizing the disease and positioning it as a Black community political concern, the organization encouraged HIV-negative Black people to move into an ally role for people with HIV/AIDS. Destigmatization and politicization therefore serve as bridges between the NBWH’s prevention education work and its work to directly support Black women with HIV/AIDS. While debunking myths and destigmatizing the disease in its prevention work, the NBWH actively encouraged social support of people with HIV/AIDS on individual and collective, micro and macro, levels. For example, “From Cries and Whispers to Action” states: “Just as critical as individual support from family, sisters and lovers, is for that support to be multiplied into strong organizational advocacy for better care and treatment of African-American women with AIDS. In other words, sisterhood means not only the demonstration of individual kindness, but a willingness to speak openly within the organizations in our lives to call for a change in the health care system’s AIDS policies.”36 This statement is followed by a discussion of the role of the church and the ways Black women can help churches move forward in responding to the AIDS crisis. Here it becomes clear how the NBWH not only aimed to prevent the spread of HIV/AIDS in Black communities through culturally specific educational materials and workshops disseminated in culturally relevant locations in Black communities but also sought to destigmatize and politicize HIV/AIDS. In doing so, the NBWH laid the groundwork for increased social, political, and material support of Black women living with HIV/AIDS.

Support

What makes the NBWH’s Black feminist health activism on HIV/AIDS truly an enactment of Black disability politics is the way its prevention work bridged into work to support people already living with HIV/AIDS. As discussed in praxis interlude 1, prevention alone, no matter how politicized or culturally attuned, can easily veer into ableist tendencies to use disability...
as a scare tactic if that prevention work is not grounded in support of disabled people as well. The NBWHP’s support work occurred in part through its above-discussed work to destigmatize the disease. In addition, however, the NBWHP also advocated for and sometimes actively provided social and material support for Black women with HIV/AIDS.

One way the NBWHP provided support to Black women with HIV/AIDS was by publishing numerous stories in Vital Signs that aimed to build a community among Black women with HIV/AIDS where they could share knowledge and fight internalized oppression or shame. Articles were written by Black women living with HIV/AIDS as well as by HIV-negative Black women involved with HIV/AIDS activism in Black communities. As a whole, however, the NBWHP tried to center the voices and experiences of Black women with HIV/AIDS, including Black lesbians with HIV, who were almost nonexistent in most literature on the epidemic at the time. This centering of the voices of those most impacted by the epidemic and the need to provide broad forms of support for people with HIV/AIDS are most clearly articulated in the proceedings of and publications resulting from a conference on Black women and AIDS organized by the NBWHP in 1988—important archival material that I discuss at length here.

According to the conference report, “FROM CRIES AND WHISPERS TO ACTION: BLACK WOMEN TALKING ABOUT AIDS was a strategy development conference for Black women leaders sponsored by the National Black Women’s Health Project (NBWHP) on October 17–18, 1988 in Washington, D.C. This ‘think-tank’ conference was a first-time opportunity for Black women, who are most severely affected by the AIDS crisis, to meet on a national level. We were women living with HIV/AIDS (PWAs), advocates, caregivers, health and social service providers, educators, and government representatives.” As this description indicates, the conference aimed to bring together a variety of Black women leaders invested in addressing the AIDS epidemic. The conference was organized into three panels of speakers, one made up of women with AIDS speaking about their experiences and needs, a second made up of government representatives, and a third made up of service/advocacy representatives. Each panel was followed by a small-group discussion session in the model of the NBWHP’s self-help groups, with preassigned groups of Black women with and without HIV/AIDS. The conference report transcribes the panel discussions and features the stories of the individual women with HIV/AIDS who spoke about their experiences. The report also offers strategies collectively created by the conference attendees. These strategies highlight not only how the NBWHP framed HIV/AIDS as
a social and political issue for Black communities, as already addressed, but also how the organization explicitly centered and politicized the need to provide better social and material support for people with HIV/AIDS.

Before offering solutions and strategies, however, the conference report first acknowledges the way stigma impacts people with HIV/AIDS above and beyond any physical symptoms of the disease. The report asserts: “The AIDS stigma, combined with existing racist, sexist and homophobic prejudices, produces discrimination against PWAs, and others who are associated with AIDS in any way. People with AIDS often face abandonment by families and friends, loss of their jobs and health insurance, and eviction from their homes. Many are denied needed services such as ambulance transportation or emergency medical and emotional care. PWAs especially at risk of discrimination are those who have been stigmatized as a class—IV drug users, homosexuals, prostitutes, and (until recently) Haitians—who have been beaten up, bankrupted, evicted, and now disproportionately infected.”

Here the NBWHHP indicates that although people with HIV/AIDS unquestionably need quality medical care, a significant barrier to living well with HIV/AIDS is social stigma and discrimination. As a result, the conference report (and the subsequent HIV/AIDS programs and educational materials developed from the ideas generated at the conference) emphasized the need to support people with HIV/AIDS and their family members and caretakers physically, emotionally, socially, and financially. In doing so, the conference report also situates HIV/AIDS for Black women in political relationship to health-care reform, welfare reform, reproductive justice, and housing rights to build coalitions. These larger political arguments are an example of how the NBWHHP, while deeply focused on microlevel (individual) changes, also pushed for macrolevel (national) policy changes, viewing these arenas as interconnected and inextricable from one another in the effort to minimize or eliminate the AIDS epidemic.

Following the conference and its resulting publications, the NBWHHP used the knowledge and momentum gained there to create programming that would more immediately support individuals with HIV/AIDS. First, the NBWHHP created self-help groups for Black women with HIV/AIDS. As one informational publication explains, “Self-help is one mechanism for demonstrating what many African-American women with AIDS frequently ask for—a sense of sisterhood. They note that counselors and service providers who visit them in hospitals and shelters are often people who cannot empathize with and understand their concerns. Most of these people are white and demonstrate a limited appreciation of the impact of racism on African-American
AIDS sufferers’ lives.” By creating self-help groups specifically for Black women with HIV/AIDS, the NBWHHP created spaces for these women to form communities, share information, and provide hope to one another in ways that drew on their particular gendered and racialized experiences of the disease. These groups addressed a need for specific kinds of connection and support for Black disabled women, a need examined just a few years earlier in Audre Lorde’s *Cancer Journals*, published in 1980. In this text, one often discussed in feminist disability studies, Lorde reflects on how the white, straight woman who brought her a pink lambswool temporary prosthetic breast could not understand or talk with her about what a mastectomy or breast augmentation might mean for her as a Black lesbian. Instead, Lorde seeks advice and conversation from other lesbian breast cancer survivors and discusses the need for breast cancer survivors generally to be able to publicly identify and connect with one another. In a related fashion, the NBWHHP responded to the frustration of Black women with HIV/AIDS with white counselors and health-care providers who did not understand their experiences, concerns, and needs by creating self-help groups specifically for Black women with HIV/AIDS.

In addition to this more direct form of support for Black women with HIV/AIDS, the NBWHHP also created programming for people without HIV/AIDS that ultimately aimed to improve support for people with HIV/AIDS as well. For instance, the NBWHHP proposed creating “self-help/support groups for ‘first line’ health care workers: orderlies, nurses’ aides, licensed practical nurses who, due to their often-invalidated role within the system, may allow unexpressed fears, prejudices and attitudes to influence their interactions with potential AIDS/HIV-infected patients.” Although it is unclear based on archival records if funding was secured to create these groups, the idea itself is incredibly important. Using the information gathered from talking directly with Black women with HIV/AIDS about their primary needs and concerns, the NBWHHP sought to educate and support the first-line health-care workers who have the most contact with people with HIV/AIDS in medical settings. The NBWHHP also recognized that these first-line workers, unlike doctors, are often working-class people who, despite spending the most time with patients, are generally provided less professional development and support in addressing their own biases and areas of ignorance. As the education proposal explains, “Our support group development will provide a safe, trusting atmosphere *sic* in which these workers can consider and confront the myths and misinformation that may prevail among them, and be supported and appreciated for their pivotal role in the dispensing
of care and attention to AIDS patients and their families.” Similar to the conference report’s assertion that the family members of people with HIV/AIDS need financial, social, and emotional support, here the NBWHP sought to provide and improve support for people with HIV/AIDS by also addressing the educational and support needs of those who directly provide their health care.

Overall, the NBWHP took a holistic approach to providing support for Black women with HIV/AIDS, including publications prioritizing their voices and stories, self-help groups specifically for Black women with HIV/AIDS, and efforts to educate and support the individuals with the most direct contact with people with HIV/AIDS, such as family members, caretakers, and first-line health-care workers. The NBWHP’s efforts to create material and social support for Black women with HIV/AIDS, whom I consider Black disabled women, occurred alongside its prevention work within Black communities, demonstrating a careful, balanced enactment of Black disability politics.

Conclusion

The NBWHP’s balance of prevention and support in its HIV/AIDS Black feminist health activism reflected the organization’s political, cultural, and holistic understanding of health and wellness, discussed in the previous chapter, and also enacted Black disability politics. The organization unquestionably approached HIV/AIDS as a Black disability political concern that required an intersectional, contextual approach that attended to change on micro and macro levels in order to be effective. The way the NBWHP balanced prevention and education targeted at nondisabled people with education, support, and resources targeted at disabled people is also reflected in other disease/impairment-specific activism, such as the NBWHP’s work on mental health, depression, and suicide. This balance of prevention and support therefore reflects the Black disability politics of the organization overall, not just in regard to HIV/AIDS. Throughout its Black feminist health activism, the NBWHP never acted as if the mythical norm of total able-bodiedness or able-mindedness was achievable; rather, the organization sought a future in which people could make informed choices about their bodyminds and be supported, not shamed, in their health and disability statuses.

In this regard, the NBWHP’s Black feminist health activism explored here and in the previous chapter provides a potential model for bridging disability studies/disability justice and public health research and programming. There is limited engagement with disability studies in public health scholarship.
As Elena M. Andresen acknowledges, there are conflicts between public health and disability studies methodologies, particularly when it comes to perspectives on prevention work. Andresen writes, “For many people in disability studies, and certainly for disability advocates, talking about prevention of disability suggests prevention of people with disabilities,” whereas in public health it refers to “prevention of incidence and severity of injury, impairments, diagnoses, and conditions” via education and laws, such as seatbelt laws to reduce incidence of spinal cord and head injuries or prenatal nutrition education to reduce the likelihood and severity of certain congenital disabilities. Public health does not, Andresen notes, consider eugenic methods like abortion and euthanasia part of prevention work.46 However, as Katharine Hayward argues, “Past public health campaigns have played upon emotions of fear generated by possible disability to advocate desired health practices,” thus alienating and further marginalizing people with disabilities as “bad outcomes” to be avoided and even potentially blamed for their own disability status, such as in antismoking ads that depict sad, isolated individuals with oxygen tanks or drunk-driving-prevention commercials that depict sad, isolated people in wheelchairs. Hayward acknowledges that public health work uses both medical and social models of disability, with some campaigns, research, and programs leaning more heavily toward one model than the other. The variability of public health campaigns across time, space, and communities further necessitates close interrogation of specific initiatives and interventions, from their undergirding ideological assumptions to their potential impacts, materially and socially, on target populations.47 In other words, when bringing together public health and disability studies scholarship, we ought to ask, How does this specific public health program, campaign, or research help certain communities and ignore or even harm others? In the case of the NBWHFHP, the balance of prevention with destigmatization, education, and material and social support of Black women with HIV/AIDS made the organization’s work a useful model for better engaging disability studies and anti-ableism in public health work.

This chapter demonstrates how the NBWHFHP’s Black feminist health activism, although not exclusively about disability, clearly incorporated disability as a political concern. While the organization valued health and wellness, it did so in a way that was also anti-ableist and inclusive of Black disabled people. The Black disability politics of the NBWHFHP are therefore apparent not only in its general holistic, political, and cultural approaches to health and wellness, which shaped the organization’s mission and tactics, but also in the programming and publications the NBWHFHP produced in
regard to HIV/AIDS and other disabilities and health conditions like depression, hypertension, and diabetes. The NBWHP’s work simultaneously attempted to reduce instances of disability in Black communities and support Black disabled people in living well—whatever that meant for an individual’s bodymind. The NBWHP did not succumb to the common ableist move used in some public health work in which disability is represented as purely frightening, tragic, or pitiful. Disability is not used symbolically as a warning, but rather the severity and quantity of disablement in Black communities are understood in the NBWHP’s work as a consequence of racism, classism, and sexism that demands larger, intersectional approaches to health and politics, especially within the fields of public health and medicine. The NBWHP understood that only holistic, politicized, and culturally attuned prevention and care work would lead to improving health and wellness among all Black people, including disabled Black people. Importantly, the NBWHP didn’t just care about existing disabled people as part of prevention (i.e., take care of people with HIV so they don’t spread HIV further) but rather identified supporting Black people of all abilities and health statuses as integral to the organization’s Black feminist health activism. The organization did not, therefore, seek a disability-free world but a world in which people can make educated, supported choices about their health, well-being, and engagement with the medical industrial complex. From the Black disability political perspective of the NBWHP’s Black feminist health activism, life is not over or ruined once you become disabled or sick; the battle for health and wellness merely continues.

This chapter concludes the historical portion of this book with its focus on disability politics in Black activism in the late twentieth century. These four chapters have established, via analysis of the Black Panther Party and the NBWHP, that there is a history of Black activist engagement with disability as a social and political concern in the post–civil rights era that holds important lessons and information for us as scholars and activists in the twenty-first century. This historical portion of the book accomplishes two main tasks. First, it supports my claim that Black people have long engaged with disability politics but have done so in ways that diverge from the approaches in the white mainstream disability rights movement, resulting in this work often going unrecognized as disability activism. Second, these historical chapters also concretely demonstrate the four main aspects of Black disability political approaches that I have identified: that Black disability politics are intersectional but race centered, not (necessarily) based in disability identity, contextualized and historicized, and holistic.
Next, in praxis interlude 2, I provide a critique of how rarely the NBWHP engaged disability identity in order to then discuss how Black disability politics in the present might better critically engage with disability identity. This second praxis interlude engages more heavily with my interviews with contemporary Black disabled cultural workers, whose work and ideas are the focus of the final chapter.