Black Disability Politics

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PRAXIS INTERLUDE TWO

Approaches to Disability Identity in Black Disability Politics

In this book thus far, I have argued that a central quality of Black disability politics is that it is not necessarily based in disability identity. However, the lack of explicit engagement with disability as a social and political identity becomes more deserving of critique when we look at work closer to and within the twenty-first century. The National Black Women’s Health Project (NBWHP) did excellent work in including disabled people without stigma in their Black feminist health activism, but the lack of explicit engagement with disability rights warrants some critique. In this praxis interlude, I first discuss how the NBWHP failed to engage sufficiently with disability rights and disability identity. Second, I draw on my interviews with contemporary Black disabled cultural workers to discuss how to approach disability identity within Black disability politics. Finally, I envision how a Black disability political approach to disability identity could have been used by the NBWHP to benefit its Black disabled members.

The NBWHP’s work began in the 1980s and continued into the twenty-first century. Despite establishing the Public Education and Policy Office in Washington, DC, in 1990, the NBWHP does not appear to have had any active involvement with the passage of the Americans with Disabilities Act (ADA) that same year, nor did the organization cover it in Vital Signs. Vital Signs also does not contain any coverage in the following four years of ADA regulations going into effect. The ADA is a landmark piece of civil rights legislation that prohibits discrimination against people with disabilities in public sectors including employment, education, transportation, and government services.
This law is relevant to the NBWHP because many of their members had disabilities and could have received protections under the ADA. The NBWHP failed to inform all Black disabled members about the ADA and the ways it would impact them, even though the organization’s health book, *Body and Soul: The Black Women’s Guide to Physical Health and Emotional Well-Being*, explicitly mentions that “African-Americans have been much more likely than whites to be rejected for benefits under Social Security disability programs.”3 It is clear the organization understood in some regard that Black disabled people might need more education on what the ADA covers and how to advocate for one’s access needs under the new law. However, even in a *Vital Signs* article on how people with HIV/AIDS can apply for Social Security disability benefits, the author avoids referring to HIV/AIDS as a disability or to people with HIV/AIDS as disabled, even putting *disabled* in scare quotes once.4 In a similar, more detailed article a year later, the unnamed author also uses passive language when referring to people with HIV/AIDS and the Social Security disability benefits application process, such as “common HIV-related conditions that may result in a finding of a disability” and “he or she will be found disabled” by the evaluators.5 This avoidance of disability identity language in favor of disability medical language and passive voice is largely shaped by the authors’ focus on disability benefits rather than disability justice, community, or identity. This particular lack of engagement with the ADA and disability politics beyond medical and legal frameworks on the part of the NBWHP reflects a disconnect between the inclusion of Black disabled women in the organization’s work and the NBWHP’s understanding of the value of disability rights and identity for its membership beyond the receipt of Social Security disability benefits. Even as the NBWHP published articles detailing the social and emotional effects of chronic illness, HIV/AIDS, and other disabilities, the leap to a politicized disability identity beyond one’s specific disability or diagnosis remained absent.6 The NBWHP did not make connections between Black women with chronic illness, diabetes, and HIV/AIDS in ways that could have encouraged and built Black disability identity in the 1980s and 1990s.

I want to explicitly state here that being critical of the NBWHP’s lack of engagement with disability identity does not discount the value of its work with Black disabled women. When studying Black disability politics, we must hold the successes and the failures together in the light to understand what was useful and what was not, what we want to hold on to and what we want to change. I argue that contemporary Black disability politics must have a more explicit engagement with disability identity, but
our approaches cannot be the same as those of the predominantly white mainstream disability rights movements and organizations. To begin theorizing some Black disability political approaches to disability identity, I draw on the expertise of the contemporary Black disabled cultural workers I interviewed for this book.

One of the most significant differences between the Black disability politics of the Black Panthers or the NBWH and those of contemporary Black disabled activists and cultural workers is the place of disability identity. Every interview participant I spoke with identifies as D/disabled. As T. S. Banks puts it: “I am proud to say that I’m a disabled person within the Black community. I think that I deserve all the rights and protections and love and community like anyone else.”7 This widespread open identification with the words D/disabled and disability is different from what I have analyzed in the work of earlier Black activist engagement with disability even as Black people with disabilities were involved in the work. Contemporary Black disabled cultural workers understand the complexity and the value of Black disability identity to liberation work. They express clear historicized and contextualized understandings of why Black people may avoid identifying as disabled while simultaneously developing tactics that would bring more Black people with disabilities into a politicized Black disability identity. These tactics, which I discuss in more detail below, include (1) boldly claiming one’s own Black disability identity (including encouraging such claiming among Black public leaders); (2) offering new language and spaces for Black disabled people to develop their own distinct relationship to disability as an identity, experience, and community; and (3) not demanding that individuals claim the word disability in order to participate in or receive support from disability cultural work. But first I want to highlight how the Black disabled cultural workers I interviewed historicized and contextualized what TL Lewis refers to as the “Black disability consciousness gap” and the complex nature of Black disability identity.8

Multiple interview participants theorized why Black communities generally or Black activists specifically have “avoided” disability as a political concern and/or identity. I put avoided in quotes here because while almost every interviewee acknowledged that disability has been avoided in certain ways within Black communities, the majority also provided important historical and cultural reasons for that avoidance. Cultural and historical reasons for this gap identified by interview participants include historical events like enslavement, segregation, medical experimentation, standardized tests, and literacy tests as well as more generally the avoidance of further
stigmatization due to the historical association of Black people with inferiority or laziness—a concern Tinu Abayomi-Paul identifies as stemming from internalized racism. As Patrick Cokley further explains: “One of the reasons why, you know, the Black community has always been hesitant even to have discussions about disability is because disability has consistently been used as a bit of a hammer—the concepts of institutionalization or determining that a group of people is unfit to participate in society or even to procreate. Those aren’t new issues that were just brought up, you know, from the institutional period of disability, those were left over from our old slavery periods.” Dustin Gibson similarly states that for Black and other racialized people, “when disability comes to you in those [violent] ways and it’s responded to in those [violent] ways, whether it be through policy [or] individual treatment, all of those different things factor into how we think about it, how we view it, if we’re proud of it, if we’re ashamed of it.” Gibson continues, “The narrative is that people that are not white don’t discuss these things and haven’t discussed them. And I think that that is a false narrative. I think it is one that erases the ways in which, quite frankly, folks have survived, and it doesn’t acknowledge how disability lives in the bodyminds of different people.” TL Lewis agrees, explaining, “Our communities just don’t talk about disability in the same way as white-led organizations and [white] people do, and that doesn’t invalidate the fact that we do experience disability … literally at higher rates than non-Black peoples … with the exception possibly of non-Black indigenous peoples.” As these quotes make clear, these Black disabled cultural workers are aware and critical of the ableism and disability consciousness gap that exist in Black communities, but they refuse to address these issues as separate from the effects of racism and ableism generally and the white insularity, racism, and ableism of many disability and Deaf rights groups and organizations specifically.

TL Lewis discusses the role of white supremacy in creating and maintaining the Black disability consciousness gap in a way that demands extensive quoting. Lewis argues:

People shame Black disabled people for not identifying as disabled, and it is really important to push back on that. Somewhere I have written that often our survival depends on not identifying as disabled; and in the historical context, for example, identifying as disabled meant forced familial separation…. [W]hat white supremacy does is it removes the context for why things are happening and why people are behaving in particular ways… when you remove that context, you end up with these
shallow and incomplete narratives, but when you actually provide that context, we find that the source of the trauma, the pain, the violence, and the wrongdoing is usually the people who are accusing people of wrongdoing. In this case, white disabled people say, *Why aren’t the Black people doing this, that [and] the other?* It’s like, why didn’t you all make it safe for us to identify as disabled in the first instance? Why did you all maintain a monopoly on this narrative for all these years? Why when we say we’re disabled, do you say, *You need a piece of paper to prove that.* Those are the kinds of questions that should be asked in response . . . to offer analyses for and perspective around these so-called shortcomings or lack within Black Deaf/Disabled communities. . . . It must be said that white people are the culprit of this. The reason that Black folks are *arguably* not understanding [disability and disability politics] is because white people have had a monopoly on the manufacturing and distribution of what disability is, whose disabilities are valid, and what laws should be applied to remedy what they have determined are unacceptable disability-based injustices. . . . So it is important to put the onus on the people who are responsible.

Lewis makes immensely clear that white people, disabled and nondisabled alike, have socially, medically, and legally defined disability in a way that frequently leaves Black, racialized, poor, and other multiply marginalized experiences of disability unaccounted for and excluded from disability rights political work. This exclusion endangers Black disabled people and makes identification with disability more difficult. This exclusion is similarly reflected in the work of (white) disability studies, which has historically prioritized and theorized from white experiences of disability and lacked substantive engagement with the chronic illnesses and disabilities more common in racialized and poor communities, such as diabetes, HIV/AIDS, and asthma. For Black disabled cultural workers today, it is clear that historicizing and contextualizing Black experiences of and engagement with disability is a necessary practice for understanding how we got to where we are so that we may move forward toward collective liberation in ways that attend to existing failures and harms rather than ignore or exacerbate them. This historicizing and contextualizing of the Black disability consciousness gap also allows us to develop a more robust approach to disability identity in Black communities now and into the future.

Most interview participants for this project made clear that in an ideal world, Black and other marginalized people with disabilities would identify as
disabled. Participants named several benefits for individuals and for society that would result from more Black people with disabilities openly and publicly identifying as disabled. Vilissa Thompson, for instance, states that it is important “particularly [for] Black leaders and activists to understand disability, to self-identify [as] disabled, to create that visibility and . . . help erase that stigma and shame that can accompany certain disabilities.”

Thompson’s sentiments here echo the work of the NBWHP to reduce stigma and shame around HIV/AIDS for Black women even as the organization did this work without encouraging connections between Black women with HIV/AIDS and a larger disability identity or community. Candace Coleman elaborates on the value of disability identity, arguing that, politically speaking, if a person doesn’t identify as disabled, then it is harder for them to be counted and have their particular concerns incorporated into disability policies that impact them. Further, Coleman explains that embracing a disability identity can be “freeing” for people because they feel less alone, “have a sense of community to know some things that they were dealing with . . . [were not] just their own experience,” and consequently get less “stuck and tripped up on these various systems that oppress us the most.” Coleman asserts that “when you really are a powerful being who recognizes your disability identity and your cultural identity and [are] able to just be yourself . . . that’s very empowering to me, and I feel like you could take over any role, any anything you want to do.”

TL Lewis similarly embraces “being bold about the fact that we identify as disabled—and no, we might not have a formal diagnosis, but guess what, we out here . . . you can still identify as politically disabled [without a diagnosis], and you’ll be more powerful for it . . . So I feel like [disability identity,] it’s a way of just saying, I see you and being seen, having needs met, and then moving forward together . . . it’s literally in our marrow. It’s in our bones. It’s what has held and kept my ancestors. We couldn’t have gotten through all that we’ve gotten through without disability.” For Black disability political work today, there is clear value in disability identity for being “able to find our people” and “have some type of common language,” as Dustin Gibson puts it. At the same time, Gibson and others insist that claiming disability identity is not the most important thing in Black disability politics for two reasons: first, the way disability has typically been used and defined does not align with the experiences and needs of Black people; and, second, the goal is ultimately to provide bodymind liberation, safety, and care for everyone regardless of identity.

While all the interview participants identify as D/disabled themselves and the majority spoke to the political and social value of disability identity,
many were quick to contextualize their comments and explain why Black people with disabilities and chronic illnesses may be less likely to openly identify as disabled. These reasons often spoke deeply to my own experiences and helped me in my process of identifying as disabled, as discussed in the introduction. In short, Black disabled activists and cultural workers are critically aware of how white (disabled) people have homogenized our understanding of what counts as disability in ways that exclude and even deny the experiences of Black disabled people. I provide numerous and at times lengthy direct quotes here because this issue is incredibly important for contemporary Black disability politics.

First, Kayla Smith argues that white autistic people “dominate the conversation” about autism, often with no awareness of their privilege, thus violating or denying the experiences of nonwhite autistic people so that “Black autistics don’t feel safe” speaking about their particular racialized experiences of disability.14 Dustin Gibson similarly contends “that white supremacy has done a good job at allowing certain folks to be able to identify as disabled and helping to shape a disabled identity” that does not resonate with Black people. He elaborates by saying, “I think the process of disablement is so different for people that are marginalized that the language also has to be different … [because] disability lives differently in the bodies of Black folks.” Vilissa Thompson echoes this sentiment, stating:

I just really feel that [the] disabled community is not doing enough to address racism, is not doing enough to address race…. Your disability does not nullify your white privilege, you know, and, honestly, this is why, when it comes to certain disabilities, white folks get diagnosed more often than people of color. This is why, when it comes to treatment, white folks get things, get better quality of care…. We live in a very white supremacist society. Race plays a very big role in disability [with] who could get support and services, who doesn’t and why, who gets mistreated and why. And for the [disability rights] community to not be willing to just understand that on a basic level, it’s asinine … and it’s harmful because it helps to perpetuate the white supremacy that exists.

Finally, TL Lewis contends that “you don’t have to call it disability for it to be considered disability. And I think that is important because a lot of white disabled folks are out here demanding that everyone ‘Say the word disability!’15 Shouting at people. It’s like, yo, relax. Everybody doesn’t have to speak how you speak, identify how you identify, or invoke the things that you invoke. You still need to give us credence and respect and our just due
because we out here and we’ve been holding disability down since before a word existed for it.”

This issue of how Black people have lived and continue to live with disabilities despite erasure of our experiences was particularly evident in interview mentions of self-diagnosis in the face of financial exclusion and racism within the medical and psychiatric industrial complexes. T. S. Banks, for example, argues that the medical and legal systems that define disability and control who has access to accommodations and support were not made for—and in fact actively exclude and oppress—Black people so that “even with winning a class like disability . . . that is only a privilege” for those with racial and class privilege.16 Across the interviews these Black disabled activists and cultural workers were clear on how the racism of white disabled people and white-dominated disability rights organizations as well as the racism and classism of medical, psychiatric, and legal systems in the United States have made identifying with disability difficult to impossible for many Black people.

This awareness of the limiting, exclusionary, and white supremacist ways that disability has been socially, medically, legally, and politically defined was often paired with discussion of the need to have experience-informed strategies to combat this exclusion, particularly among participants who work within white-dominated disability rights and policy organizations, and who seek to create change from within. Patrick Cokley explains that “the disability community has done a poor job of moving the engagement into spaces . . . where there’s more majority people of color, and up until recently we have not done the best work at creating the language.” What he finds “disconcerting is that when you do things like that, when you leave out certain parts of your culture and certain aspects of your community, it then becomes harder and harder to bring them back into the fold. It takes a substantial effort to say we are going to address this differently . . . [but] we cannot afford to do this this way anymore. There has to be a change.” To provide an example of how he has attempted to do this sort of integration of disability political work in Black communities, Cokley shared the story of speaking about disability identity to a group of Black parents of students with disabilities as part of a White House initiative on historically Black colleges and universities. He states:

I was really trying to get them to understand some of these concepts with disability pride . . . and there was a lot of hesitancy…. So I said, “Okay. Tell me how you talk to your children about race,” and you know, all the
hands went up and they said, Look, it’s an aspect of who you are. It’s not a defining thing, but it is something important. You should be knowledgeable of it. You should know your history, should take pride in your personal identity and make sure that no one tells you that you’re less than because of it. You represent who you are, and you represent all of us. And I said, “Okay, fine. Now, what do you tell them about disability?” They said, Well, it’s nobody’s business. You know, you only say something if asked. You keep it to yourself… it’s not a big deal. You don’t have to think about it. I was like, “Okay, now let’s unpack what we’ve just learned there. We take pride in our cultural and racial heritage. We are told not to hide it but to use it as a sword and shield, and we gain strength from that…. You guys are in here talking about how you are having problems managing disability with your kids. It’s like you’re taking the power away from them. We can’t advocate for … self-realization on one hand and then at the same time turn around and say, Well, this one aspect, don’t talk about it all.” … Everything we’ve learned about the positive aspects of having strong Black identity in this country we have to use to apply to ourselves in the disability space, and it tends to make us a little stronger for it.

In this useful anecdote, Cokley’s own relationship to and knowledge of Black communities allowed him to present ideas about disability identity in ways that were more understandable and relatable to these Black parents. Candace Coleman similarly discussed her work with a campaign to address the “complexities of people within our [Black] culture in not being okay with the word disability and only looking at the stigma.” The campaign aimed “to center and have community conversations with folks who don’t identify with disability and folks who do” because, as Coleman explains, “you just have to meet people where they’re at. I think the more folks say it out loud and say it proud, the more we’re able to shatter myths and misconceptions and live life to the fullest. Some people are just not there, and that’s fine.” In each of these instances, Black disabled people have worked to shape and create disability identity within Black communities in ways that attend to issues of race and that center the experiences and needs of Black people.

What is apparent across the interviews is that Black disabled activists and cultural workers find value in disability identity yet fully recognize the reasons that Black people may be resistant to the word. Ultimately, interviewees did not want the word disability to be a barrier to participating in disability political work or to receiving protections and support for disability-related needs. These contemporary Black disability political approaches to disability
identity differ both from the Black disability politics of the Black Panther Party and the NBWHP, which mostly avoided engagement with disability as an identity, and from the bulk of mainstream, white-dominated disability rights work, which can be so focused on identification that other issues get lost. Dustin Gibson states that “it feels like [the] disability rights movement is largely concerned with people identifying as disabled in order to have the benefits that come along with that; to say, we’re the largest minority group, to say that we have this major voting bloc, to say that we represent this amount of people,” and that the movement is “less concerned with actually being able to respond to the needs of people like me. I don’t care if somebody says, I’m disabled, but if they have diabetes, I care that they have access to insulin…. Whether or not we call it disabled or disability doesn’t necessarily matter as much as creating systems that hold all of us.” T. S. Banks echoes this emphasis on ensuring people are supported, explaining that even if someone doesn’t identify as disabled or is self-diagnosed, they “still should have access to everything that folks who identify as disabled and have documented access to those things” receive as well. Ultimately, therefore, contemporary Black disability politics values disability identity but is not fixated on it as a requirement for entry into the work.

To recap, approaches to disability identity in Black disability politics include encouraging people to publicly claim Black disability identity, developing new language and spaces for Black disabled people to develop their relationship to disability identity, and not demanding that individuals claim disability in order to participate in disability cultural work or receive support. If we apply these approaches to the NBWHP, it is clear that the organization engaged in the third tactic of not limiting access to the work and the support if one did not identify as disabled, but the organization could have done more to encourage and develop Black disability identity among its membership. For example, the NBWHP could have included articles in its newsletter and other publications that more explicitly encouraged members, especially those with HIV/AIDS, chronic illnesses, and psychiatric disabilities, to understand themselves as disabled by featuring Black women discussing why they identify as disabled and how being part of a disability community benefits them. While the NBWHP’s health book, Body and Soul, did include sections on psychiatric disability and physical disability, each of which included a profile on one Black disabled woman, the lack of extended engagement with disability identity and the inclusion of charity-oriented organizations are notable. The most interesting aspect of these sections was the mention of a group called the Black Women with
Disabilities Alliance, but there were no further details on what the group did or who was involved. I retroactively long for the NBWH to have done a feature article in Vital Signs on the Black Women with Disabilities Alliance for our Black disability politics historical record.

Finally, the NBWH could have used the spaces of its self-help groups, conferences, and workshops to explore and develop members’ understanding of what a Black disabled woman identity entails. As chapters 3 and 4 indicate, the organization did have some disability-specific self-help groups for Black women with HIV/AIDS and diabetes and some condition-specific workshops at conferences. Since what happened within those groups remained confidential and as each group’s activities and discussions varied by the wants and needs of the group members, it is not impossible that this work did occur, but it remains mostly undocumented—like so much Black disability history. For instance, one woman with a psychiatric disability writes in the newsletter for the New York chapter of the NBWH that she did not feel accepted or welcomed in other spaces. She explains that she thought she was “losing [her] mind” due to “blackouts, intense fears, and hallucinations,” but “it felt like sensationalism” whenever she would speak in other spaces about her experiences. She writes that her NBWH self-help group “has been a Godsend” because it emphasizes, recognizes, and validates “the common stressors in black lives—racism, classism,” so she feels that she is “no longer an other with a special problem.” The feeling of no longer being Other as a Black disabled woman seems to suggest a level of disability consciousness and acceptance within the group, but that consciousness and acceptance do not appear explicitly in the national-level organization’s archive or publication.

Black cultural workers today can learn from the missteps and oversights of the NBWH and from the approaches to Black disability identity articulated by my interview participants in order to improve and increase engagement with disability justice at the personal and organizational levels. In the next chapter, I return to the present and take a deeper dive into Black disability politics now, as articulated and enacted by the Black disabled activists and cultural workers I interviewed for this project.