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## CHAPTER EIGHT



# Margins of the Margins of the Margins

## *On Being Black with Disabilities and/or Neurodivergence in Libraries and Archives*

Kai Alexis Smith

“I am sick and tired of being sick and tired!”

—Fannie Lou Hamer<sup>1</sup>

“Just like we cannot afford to forget the names of those victims,  
we also must not erase their disabilities.”

—Sarah Kim<sup>2</sup>

Sandra Bland. Eric Garner. Freddie Gray. What is overlooked with the tragic killings of so many Black lives is that they also experienced mental illness or developmental disabilities. A third to half of individuals killed by police officers experience disabilities.<sup>3</sup> According to the US Census, almost a quarter of the Black population has some form of disability.<sup>4</sup> Data supports that the Black population has an increased rate of mental health concerns, including anxiety and depression.<sup>5</sup> These conditions may go untreated as a result of a lack of access to appropriate and culturally responsive mental health care, historical trauma from unethical experimentation by the medical field, and everyday prejudice and racism. This also prompts Black people with invisible disabilities to hide their conditions to mitigate judgment and bias at the expense of equitable support.

Just as disability is left out of discussions about police brutality, it is also left out of the conversations on Black library professionals, library workers, or librarians. These conditions are compounded in the very white profession of librarianship, causing Black and disabled librarians to not receive the same access as their counterparts. These individuals experience further marginality or inequities and simply feel dually invisible.

The idea for this book chapter grew out of my own experiences with disabilities at the intersection of my Black womanhood. In 2020, just after we went into lockdown during two pandemics, I discovered that I had been living my life with a visual disability. With this new knowledge, I am learning to live my life in a whole new way while learning about disability communities and spaces where I might find myself welcomed and supported as a Black woman with disabilities.

## Terminology

Before exploring the concepts in this chapter, I will define key terminology. While researching this chapter, I discovered the vastness of terminology in the disability and Black communities. I learned that, while the dominant culture in the disability community prefers the term *disability*, many Black librarians that I informally interviewed for this chapter preferred to be called differently abled or neuroatypical. I wondered why that was and who determined what everyone should refer to themselves as. I am always interested in whether Black people were a part of the conversations when these decisions were being made. While in no way is this chapter comprehensive about this topic, some of this is uncovered in the section “A Look Back and Forward: Black Activists and Librarians with Disabilities and Neurodiversity” further along.

I am still new to exploring this part of my identity. I understand how the disability justice activists and community does not prefer the terminology of *differently abled*. For my own interest and the purpose of this chapter, I have immersed myself in the works of Black disability studies and Black disabled artists’ works. I found that Black women in particular (which I identify as) do not regularly use the term *disabled* in their work<sup>6</sup> and they describe and celebrate Black bodies in different ways. I struggle with the word/label of *disabled* as I explore the intersec-

tion of my own Blackness and disabilities in my art. According to the Harriet Tubman Collective, “The phrase ‘differently abled’ suggests that we are the locus of our disability when we are, in fact, disabled by social and institutional barriers. Not only is this term offensive, but it also reifies the marginalization that Black Disabled/Deaf people face on a regular basis by and within our own communities and oppressive state institutions.”<sup>7</sup> When I do use the term *disability*, I will use the Americans with Disabilities Act definition of disability, which is “A person with a disability is a person who has a physical or mental impairment that substantially limits one or more major life activity. This includes people who have a record of such an impairment, even if they do not currently have a disability. It also includes individuals who do not have a disability but are regarded as having a disability.”<sup>8</sup> I use this term in the context of disability justice activists community norms and when referring to the medical model used to define the term.

For the term *neurodiversity*, I will use the combined definitions by Australian sociologist Judy Singer,<sup>9</sup> who coined the term, along with the National Symposium on Neurodiversity’s definition:<sup>10</sup> “A concept where neurological differences are to be recognized and respected as any other human variation. These differences can include those labeled with Dyspraxia, Dyslexia, Attention Deficit Hyperactivity Disorder, Dyscalculia, Autistic Spectrum, Tourette Syndrome, and others.” While I have used the term *disabled* up until now, I will use the phrase “people with disabilities” or “people who are neurodiverse” instead of “disabled people” or “neurodiverse people” to front load the “personhood of people living with physical impairments, chronic illnesses, psychosocial disabilities, and cognitive/intellectual disabilities.”<sup>11</sup>

### **A Look Back and Forward: Black Activists and Librarians with Disabilities and Neurodiversity**

“Instead of inviting disabled people to inaccessible meetings and marches, pour into the activism and advocacy we’ve already started. Stop asking why we didn’t come to your twenty-mile march; let’s move forward using a diversity of tactics, holding each in equal respect.”

—Cyree Jarelle Johnson<sup>12</sup>

“We do not live single issue lives.”

—Audre Lorde<sup>13</sup>

In the past few years, there have been more open discussions and contributions to library literature around mental health in the library profession. Key thinkers and scholars on disabilities in libraries include J. J. Pionke, Karina Hagelin, and Alana Kumbier, all of whom are a part of the dominant culture. After the COVID-19 pandemic onset and protests in March 2020, it became crucial for Black Indigenous People of Color (BIPOC) librarians to have a space to discuss mental health and issues related to disabilities and seek support within the community. The Facebook group *We Here*<sup>14</sup> and conferences like BIPOC in LIS Mental Health Summit,<sup>15</sup> to name a few, created spaces for these necessary discussions and provided supportive environments. This chapter seeks to build on these efforts and centers works by Black disabled librarians, activists, and advocates that are not readily discussed in library literature or MLIS curricula. In addition to research, I informally interviewed Black librarians, library workers, and library professionals who identified as having a disability and/or are neurodiverse. These discussions helped me to better understand the unique and common struggles Black librarians with disabilities face every day in the profession and how these experiences may or may not correspond with the literature. Some of the questions that came up while doing research for this chapter included *Where are the Black librarian activists with disabilities? Are they choosing between their disability or their Blackness to advocate for or can they do both?*

Structural racism, heteropatriarchy, and ableism all shape the lenses of disability in the United States, making it particularly hard for Black people with disabilities to navigate the social structures that have very real effects on their everyday experiences and access to resources. Fobazi Ettarh (2014) explains in *Making a New Table: Intersectional Librarianship*:<sup>16</sup>

It can be more dangerous for POC [people of color] to speak up or “lean in” at the workplace. Compounded with other identities such as disability (disability justice) or gender, to visibly be their whole selves can seem impossible. Fear of job loss or not hiring; fear of not being allowed to use

appropriate restrooms; or even fear of physical violence are just a few of the very real issues that are swept under the rug when loud and explicit advocacy are offered as blanket advice. The “Lean In” advice is, in fact, about how to have it all, while offering precisely zero guidance on how to dismantle the structural barriers.

White supremacy is the backbone of the United States, and both the disability movement and librarianship have roots in this violent history. Disability activists reframed their approach to advocacy from the charity and medical model to the civil rights model,<sup>17</sup> repositioning disabled people from the poor or diseased minority citizens to that of a socially constructed state of oppression. This paradigm shift relied on the *Brown v. Board of Education* ruling to lay the groundwork for the rights of people with disabilities. The Black rights movement and the disability rights movement developed alongside each other; however, similar to the women’s rights movement, the disability rights movement initially centered on whiteness, with white activists and advocates at the forefront.

Shancia Jarrett writes in *Lost and Found: The Stories of Blacks with Disabilities Found in the Community*, “The predominant theories of disability which disregard the experiences of Blacks undermine the impact and existence of disability within minority communities. Disability is a non-discriminatory reality; anyone can acquire a disability. Thus, theories which deny the non-discriminatory reality of race fail to adequately represent disability.”<sup>18</sup> It is not possible to choose between being Black or a person with a disability as a single issue to address in the complex social systems we live in today. Despite the foundation of the disability movement on a single-issue base and centering white experiences,<sup>19</sup> Black disability rights activists and advocates did and do exist. They have to straddle a tightrope between the two movements and identities of being Black and being disabled.

Black disability rights activists like Johnnie Lacy and Donald Galloway had the unique perspective of seeing both sides at their best and worst. In a 1998 University of California Berkeley oral history archive interview, Lacy spoke of how the Black community promoted oppression without realizing that they were promoting the same behavior and attitudes toward the disabled that white people held toward the

Black community. “This belief in effect cancels out the Black identity they share with the disabled Black person, both socially and culturally, because the disabled experience is not viewed in the same context as if one were Black, and not disabled.”<sup>20</sup> She continued that this viewpoint makes it so that Black disabled people were either Black or disabled and not seen as being able to exist wholly as both. Black activists and advocates tried to unify the two movements. For example, the blind Black activist Galloway tried to integrate the Center for Independent Living in the 1970s by bringing Black people into positions at the center. He advocated to start a Black caucus to make sure their voices were heard. Sadly, he was dismissed from the board of directors. However, he was later successful in getting the Black Panther Party to ally with disability rights activists around political advocacy. Ultimately, he shared Lacy’s thoughts about the divide between the two movements. Scholar John Lukin captures it best in *Disability and Blackness*:

That “difference” is central to the conflict between the two movements—whenever one group said, “We are the same,” the other group said, with some insight “No. You are exploiting my group’s experience just so you can have a metaphor for your own.” And individuals who occupied both groups [Black and disabled] were caught in the crossfire. The tension created by one group feeling that its experience was being reduced to a metaphor still occurs in situations where people with disabilities seek representation alongside racial and ethnic minorities.<sup>21</sup>

In the 1990s, disability scholar-activist Mike Oliver created the phrase “social model of disability” noted by scholars Alana Kumbier and Julia Starkey in their article “Access Is Not Problem Solving: Disability Justice and Libraries.” They position his framework as “shift[ing] from individual persons’ medical diagnoses and impairments toward the material, physical, and social environments that impose limitations or create barriers for people with impairments. By reframing disability as an experience that is shaped by social, cultural, historic, political, and economic factors, disability scholars and activists are able to explore how these factors impact people’s lived experience of impairment.”<sup>22</sup> Disability as a social construct in relation to the effects of power is explored by scholar Garland-Thomson.<sup>23</sup> In the 2000s, the above-noted scholars and more contributed to the canon that lays a framework for

Black and Brown activists and scholars to address oppression and colonialism in disability.

With a new generation has come more intersectional activism for Black people with disabilities and neurodiversity. There are spaces now that cultivate Black advocates, activists, and artists to advance anti-ableist agendas in Black movement spaces like the incubator the Harriet Tubman Collective.<sup>24</sup> Black disability rights activists like Keri Gray are using social media to platform and organize around accessibility and rights for Black people with disabilities, most noticeably with the hashtag #Blackdisabledlivesmatter around the Black Lives Matter protests in 2020.

Organizations like National Black Disability Coalition and National Alliance of Multicultural Disabled Advocates were formed to advocate for Black people with disabilities and who are neurodivergent while scholars created and contributed to a new part of the literary canon around disability justice studies. This historical legacy of division between Black rights and the disability rights movements has permeated the policies of libraries and library literature canon through the lack of inclusion of Black people with disabilities as far as storytelling, recruitment, retention, hiring practices, and so much more. Black librarian activists like Ettarh, Jennifer Brown, Stacy Collins, and white collaborators are advancing anticolonial and anti-oppression work by remaining critical of the library profession and trying to evoke change within institutions. Black librarians with disabilities are subsumed within this work. Unfortunately, the area does not receive as much attention, at least in comparison to non-LIS circles, nor are budding young library activists being mentored or supported to do this work. Perhaps the attitude is that advocates should resist detracting from larger issues. There still seems to be that mind-set of “pick one or the other, but not both” in libraries, which must change if we are to realize progress.

### **Black Librarians for Disability Rights Activism**

Lacy and Galloway are pioneers among the Black disability rights activists community. They paved the way for today’s and future Black disability rights advocates including Fannie Lou Hamer, Sylvia Walker, Barbara Jones, Jazzie Collins, Audre Lorde, Dr. Nathaniel Marbury,



and LeRoy Moore, to name a few. A few Black librarians like Sadie Peterson Delaney and Effie Lee Morris have advanced disability rights in libraries.

Delaney is known as the Godmother of Bibliotherapy,<sup>25</sup> which promotes therapeutic healing through reading books. While serving as the head librarian at the Veterans Administration Hospital in Tuskegee, Alabama, Delaney worked with medical professionals to learn the interests of patients and paired them with books.<sup>26</sup> In addition, she developed outreach to bedridden patients, story hours, the Disabled Veteran's Literary Society, and more. Her work became well known by library school students and librarians in the United States, Europe, and Africa.

Children's librarian and activist Morris is most known for her service as the first Black person who served as president for the Public Library Association. However, she also spent a large part of her career working on advancing services for Black, low-income children and the visually impaired. During the 1950s, she was the first children's specialist for visually impaired patrons at the New York Public Library.<sup>27</sup> Morris accomplished a lot of firsts in her career, including being the first Black woman to work in an administrative position at the San Francisco Public Library as the first children's services coordinator, serving as the first woman chairperson of the Library of Congress as well as president of the National Braille Association for two terms.<sup>28</sup>

### **What We Can Learn: Exploring Principles, Pedagogy, and Praxis**

LIS professionals from all backgrounds can greatly benefit from a better understanding of the connection between libraries and Black disability issues, especially as they relate to broader social, cultural, and historical contexts. This section will introduce frameworks, principles, and praxis that can be used to understand and support Black, disabled, and neurodiverse colleagues and community members. This includes looking at Black disability studies pedagogy, disability justice, trauma-informed practices, Universal Design for Learning Guidelines (UDL), and more.

## Black Disability Studies

It is important for the LIS field to better understand Black disability studies as a scholarly field. Black disability studies scholarship developed when activists transitioned careers into the academy. This pedagogy addresses how structural racism and ableism affect the Black community; it recenters disability pedagogy to be more inclusive of Black disabled lives and intersectionalities. This is an ever-growing part of scholarship and education, and it is being incorporated into African American/Black diaspora studies courses across the United States, thus, promoting a more complex understanding of Black disabled people.<sup>29</sup>

## Disability Justice

More applicable to all types of institutions and library professionals and workers is the disability justice praxis. Developed and led by queer and gender-nonconforming disabled activists of color, this praxis was started by Mia Mingus<sup>30</sup> and Stacey Milbern, soon to be joined by Leroy Moore, Eli Clare, Patricia Berne, and Sebastian Margaret in 2005 to help normalize disability as a core component of identity. Disability justice comprises ten core principles: intersectionality, leadership of those most impacted, commitment to cross-movement organizing, recognizing wholeness, sustainability, commitment to cross-disability solidarity, interdependence, collective access, collective liberation, and anticapitalist politic. This framework can be used by library administrators to apply a lens to library policies and services across libraries.<sup>31</sup>

## Trauma-Informed Pedagogy

According to the Substance Abuse & Mental Health Services Administration (SAMHSA) trauma is “an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or threatening and that has lasting adverse effects on the individual’s functioning and physical, social, emotional, or spiritual well-being.”<sup>32</sup> The Ohio State University communications professor and open education leader Jasmine Roberts<sup>33</sup> reminds us that Black people “are experiencing collective trauma *on top of* collective

trauma (systemic racism, anti-Black violence paired with the COVID-19 pandemic)” and effects of pandemic (economic, health) are unevenly distributed.

Trauma-informed pedagogy, as practiced and discussed by higher education educator Karen Costa and grounded in science by Dr. Mays Imad, has been adopted by librarians and applied to library services and teaching in the recent past (most notably during the 2020 coronavirus pandemic). The Centers for Disease Control’s Office of Public Health Preparedness and Response, in collaboration with SAMHSA’s National Center for Trauma-Informed Care, describes six approaches: safety; trustworthiness and transparency; peer support; collaboration and mutuality; empowerment voice and choice; and cultural, historical, and gender issues. While this approach requires organizational-level implementation, this can be adopted in library service, reference interaction, and instruction—if not comprehensively incorporated by upper administrators within libraries of all types.<sup>34</sup>

## Universal Design for Learning Guidelines

Keeping in mind both invisible and visible disabilities and different ways of thinking and learning, this framework is aimed at postsecondary institutions and curriculum, but the guidelines mapped out can be applied to policies and services at any type of library to support a variety of neurodivergent thinkers and to meet accessibility needs. Based on scientific insight into how humans learn, these guidelines serve as a tool with which to critique and minimize barriers inherent in curriculum and provide support and increase opportunities for people who are neurodivergent. The three guidelines include Engagement, which is the “why” of learning that can materialize as expectation setting during the instruction session or reference consultation before getting started. There is Representation, which is the “what” of learning, or clarifying syntax, defining terms, and spelling out acronyms for library patrons and trying to be mindful of Westernized tones and slang in any of the service interactions and instruction sessions. Then there is Action and Expression, which is the “how” of learning and can look like considering multiple forms of communication for different types of learners and providing access to tools and assistive technologies, such as alt texting

your images in your slides and presentations for those who use screen readers.<sup>35</sup>

An understanding of these praxis, principles, and pedagogy can help library workers, librarians, professionals, and administrators shift power in libraries. It represents advancement toward reimagining collection development policies, acquiring donations and gifts that align with these frameworks, and redesign services to support inquiries from the community. These praxis and pedagogies can support change in library policies and administrative practices with a more inclusive and equitable lens including recentering those most impacted in leadership roles.

### **More than Just Access: A More Inclusive Future**

“Disability Justice is a vision and practice of a yet-to-be, a map that we create with our ancestors and our great grandchildren onward, in the width and depth of our multiplicities and histories, a movement towards a world in which every body and mind is known as beautiful.”

—Patricia Berne<sup>36</sup>

COVID-19 brought to the forefront the routine racism that Black people experience in all spaces in America and the correlative effects on our health. Examples of this in libraries include the open letter<sup>37</sup> by the Concerned Black Workers of The Free Library of Philadelphia, which highlighted that Black library workers routinely experience racism, microaggressions, and ableism, and Kaetrena Davis Kendrick’s research<sup>38</sup> on the low morale of library workers and library professionals in the conservative landscape of libraries. The shift happening in the activist community influencing legislation, laws, and policy changes has not reached the libraries across the United States yet. A sea change is needed to shift the medical approach in libraries that draws from the ADA’s definition of disability as invalid, defective, or deviant bodies, to the social model of disability with an intersectional approach. Kumbier and Starkey point to disability studies literature and activists when summarizing approaches to use like the “both/and” approach (a way of thinking indebted to Chicana theorizations of third-space consciousness): librarians and library workers need to recognize that

disability is experienced by individuals in specific ways, requiring particular (material) accommodations, and that disability is a “fluid, contextual social relation” that exceeds technological solutions, changes to a built environment, or better symbols of inclusion.<sup>39</sup>

As we think about what we want the future of libraries to look like beyond access, first, there must be a lot of unlearning and learning among library leaders and professionals. To address systemic change, I agree with Kumbier and Starkey that there needs to be a “mindshift from just problem-solving accessibility and reframing the approach to accessibility as a part of the larger project to dismantling ableism and white supremacy to transform libraries, organizations and the profession.” The praxis and pedagogies developed by activists and scholars can frame advocacy in libraries around Black and disabled library workers and the community. There is a great but unrealized potential for partnered training with community disability centers or campus disability offices that emphasize disability justice principles in training for library professionals. “Services to People with Disabilities: An Interpretation of the Library Bill of Rights”<sup>40</sup> already applies core principles of disability justice focused on services and facilities. Strategies can be developed around more inclusive policies that use the UDL for learning guidelines and scaffolding reference and instructional services with trauma-informed approaches. Redevelopment of services, strategic plans, visions, and policies is vital to engaging Black disabled library workers in decision-making and service design planning. We must also be mindful to recruit, educate, mentor, and cultivate Black disabled library workers and librarians into leadership positions. As South African disability rights activists Michael Masutha and William Rowland shouted, “Nothing about us without us.”<sup>41</sup>

## Notes

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## Resources

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