

Disability at Work: Libraries, Built to Exclude

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A middle-class Black woman who has a loving husband, a supportive church, and is a knowledgeable bibliographer... and who quietly copes with multiple sclerosis and complex PTSD.

A straight White man who has a great sense of humor, is a compassionate instructor... and who wages a public battle both with mental illness and with mental health stigma.

A non-binary Latinx person who battles generational poverty, is wicked good with computers... and whose chronic pain and limited mobility make going to work a daily challenge.¹

Disability as a Critical Perspective

My goal in writing this chapter is to use critical disability theory grounded in my lived experience to offer some possibilities for improving the working conditions of library employees with disabilities.² I begin by providing an overview of some mainstream and critical perspectives on disability. Next, I offer my own insights into being a disabled librarian by taking an intersectional approach to the construction of power. I conclude the chapter by suggesting some ways to bring theory and practice together to make the workplace more

¹ These descriptions describe an amalgamation of people I know. None of them are intended to be fully descriptive of any one person. I am providing these as a reminder that disabilities reach into every community; there is no one image that can represent a disabled person.

² The choice of whether to use people-first or identity-first language is contentious. I decided to alternate between saying disabled people and people with disabilities throughout this paper, as seemed most appropriate to me.

inclusive of people. Throughout the chapter, I share some of my experiences as a person with diabetes in an attempt to highlight how combining lived experience with social theories can improve the practice of library work.

There is no universally accepted definition of disabilities or single approach to disability theory. Legalistic definitions, including those presented in the Americans with Disabilities Act³ and the United Nations Conventions on the Rights of Persons with Disabilities⁴ tend to be exclusionary and restrictive in their ideations about humanity. By this, I mean that in their construction of disability and disabled people, they work from a deficit model in which disabled humans are treated as corporeal abnormalities.⁵ However, if one out of every seven human beings could be considered disabled, as research demonstrates,⁶ disability is a common part of human existence. For many of us, when we talk about in/accessibility in libraries, we're not just talking about things that others experience; we're talking about ourselves.

The definition of disability is contested. The model I will be using here is a fluid one in which “disability [is] a *dynamic* produced by interactions between that which is biological or physical with that which is sociocultural, historical, linguistic, etc.”⁷ Disabilities affect all classes of people, regardless of gender, race, age, socioeconomic status, sexual orientation, or nationality. Not everyone who has a legally recognized disability or disabilities identifies as disabled or acknowledges their condition(s) as a disability. Reasons for this range from fear of stigma to living in a place where their dis/ability is defined in other terms, for example, people who live in Deaf communities where deafness is treated as an unremarkable phenomenon.⁸ However, there are also social benefits of acknowledging your identity as a person with disabilities. Disabled people are similar to people who have

3 United States, “Introduction to the ADA,” *United States*, https://www.ada.gov/ada_intro.htm.

4 United Nations, “Conventions on the Rights of Persons with Disabilities,” *United Nations*, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>.

5 Nicola Martin, *Encouraging Disabled Leaders in Higher Education: Recognising Hidden Talents*. (London: Leadership Foundation for Higher Education, 2017): 3, <https://www.lfhe.ac.uk/en/components/publication.cfm/MartinST36>.

6 Jan Grue, “The Social Meaning of Disability: A Reflection on Categorisation, Stigma and Identity,” *Sociology of Health & Illness* 38, no. 6 (2016): 962.

7 Valeri M. Sousa, “Who’s Afraid of Chronic Illness as Disability? An Entire Field, Apparently,” *It’s Complicated* (blog), February 3, 2014, <https://valeriamsouza.wordpress.com/2014/02/03/whos-afraid-of-chronic-illness-as-disability-an-entire-field-apparently/comment-page-1/>.

8 Grue, “The Social Meaning of Disability, 957-964; Mairian Corker, “Deafness/Disability: Problematising Notions of Identity, Culture and Structure,” in *Disability, Culture and Identity*, eds. Sheila Ridell and Nick Watson (London: Pearson: 2003); Tracey Skelton and Gill Valentine, “It Feels like Being Deaf is Normal’: An Exploration into the Complexities of Defining D/deafness and Young D/deaf People’s Identities,” *Canadian Geographer / Le Géographe canadien* 47 (2003): 451–466, doi:10.1111/j.0008-3658.2003.00035.x.

LGBTQIA+ identities in that they are typically the only person among immediate family members with this social status.⁹ Acknowledging yourself as disabled admits you to a community of people who face similar challenges and “can contribute to understanding and interpreting your own experiences and to knowing you’re not alone.”¹⁰

Critical disability studies (CDS) is one approach that offers a way of including disabled people in academic discourse. In this approach, disabled people are participants and researchers who can engage in self-reflexive critiques—not just objects of study. While some theoretical models focus on binary categories that are presented in contrast to each other, such as contrasting social and medical models of disability or disability and impairment, CDS scholars focus on the entire lived experiences of disabled people. This allows for more complicated modes of analysis, such as acknowledging that disabilities may include both social and medical aspects.¹¹ CDS also questions the tendency of institutions and technologies to “classify, normalise, manage, and control” disabled people both overtly and by using rhetoric and policies that coerce humans into acting against their best interests. At the same time, CDS scholars acknowledge that those same institutions and technologies can literally provide life-saving supports.¹²

Throughout this article, I will be referencing my experiences as a person with diabetes. Diabetes is often discussed in medical terms only, by both medical professionals and diabetics. Many people with diabetes do not conceive of this aspect of their lives as a disability, because we often don’t have a community of peers to learn from. Instead, we are often socialized into our disabled lives by doctors. In my own experience, seeing how I fit into the social model of disability made me realize how often I experience ableism as a diabetic. Diabetics will often talk about experiencing stigma, or being marked as lesser-than because of their health condition. Stigma also seems to be the word that the medical community prefers. However, these discussions became more eye-opening to me when I realized that health stigma and ableism are rooted in the same prejudices. Ableism refers

9 Subini Ancy Annamma, David J. Connor, and Beth A. Ferri, “Dis/ability Critical Race Studies (DisCrit): Theorizing at the Intersections of Race and Dis/ability,” in *DisCrit: Disability Studies and Critical Race Theory in Education*, eds. David J. Connor, Beth A. Ferri, and Subina A. Annamma (New York: Teachers College Press, 2017), 16.

10 Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability*. (New York: Routledge, 1996), 12.

11 Helen Meekosha and Russell Shuttleworth, “What’s so ‘Critical’ about Critical Disability Studies?” *Australian Journal of Human Rights* 15, no. 1 (2009): 50, <http://www.austlii.edu.au/journals/AUJLHRights/2009/9.html>.

12 Meekosha, “Critical Disability Studies,” 57.

to acts of discrimination against people with disabilities based on stigmas about disabled people. I want to apply CDS to library work because we can't effectively criticize this form of discrimination unless we recognize the rhetorical devices used to maintain it. Again, speaking from my own experiences, doctors have saved my life, but that has also given doctors power over me in ways that aren't always healthy. It is hard to advocate for yourself when you are seen as lesser and when your worth is measured based on your compliance.

Disability, Intersectionality, and the Construction of Power

Intersectionality is a term coined by law professor Kimberlé Crenshaw to describe how power dynamics affect people who inhabit multiple realms of oppression. Her early use of this term offered critiques of feminist and anti-racist approaches that took a mutually exclusive standpoint rather than one that looks at how oppressive forces impact women of color in intersecting ways.¹³

My understanding of disability theory has been heavily influenced by critical, intersectional writings within the library profession. These writings have broadened my understanding of unspoken power dynamics that influence policy creation, cataloging decisions, and other aspects of professional work. They have incorporated several different theoretical lenses, including critical race theory,¹⁴ political philosophy,¹⁵ feminist theory,¹⁶ and queer theory.¹⁷ However, aside from a recent piece by Alana Kumbier and Julia Starkey, the little work done examining disability tends to have a narrow focus.¹⁸ In approaching the topic of disabled library workers, I have been particularly

13 Kimberle Crenshaw, "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color," *Stanford Law Review* 43, no. 6: 1242.

14 Angela Galvan, "Soliciting Performance, Hiding Bias: Whiteness and Librarianship," *In the Library with the Lead Pipe* (June 3, 2015), <http://www.inthelibrarywiththeleadpipe.org/2015/soliciting-performance-hiding-bias-whiteness-and-librarianship/>; April Hathcock, "White Librarianship in Blackface: Diversity Initiatives in LIS," *In the Library with the Lead Pipe* (October 7, 2015), <http://www.inthelibrarywiththeleadpipe.org/2015/lis-diversity/>.

15 nina de jesus, "Locating the Library in Institutional Oppression," *In the Library with the Lead Pipe* (September 24, 2014), <http://www.inthelibrarywiththeleadpipe.org/2014/locating-the-library-institutional-oppression/>.

16 Hope A. Olson, "How We Construct Subjects: A Feminist Analysis," *Library Trends* 56 no. 2 (1997): 509-541.

17 Emily Drabinski, "Queering the Catalog: Queer Theory and the Politics of Correction," *The Library Quarterly: Information, Community, Policy* 83, no. 2 (2013): 94-111.

18 Alana Kumbier and Julia Starkey, "Access is not Problem Solving: Disability Justice and Libraries," *Library Trends* 62, no. 3 (2016): 468-491, doi: 10.1353/lib.2016.0004; Heather Hill, "Disability and Accessibility in the Library and Information Science Literature: A Content Analysis," *Library & Information Science Research* 35, no. 2 (2013): 137, doi:10.1016/j.lisr.2012.11.002.

influenced by Gina Schlesselman-Tarango's call for library researchers to look at the intersections of race, gender, and class, to clarify the role these methods of oppression have had within the development of the field.¹⁹ That work was influential in my decision to write this reflective paper.

Through a series of ongoing personal conversations, nina de jesus has helped me take a historical approach to dis/ableism. Their insights into the racist underpinnings of eugenics and ableism led me to explore historical analyses of disabilities. As disability historian Douglas Baynton points out when talking about inequalities in U.S. history, “the concept of disability has been used to justify discrimination against [women, African-Americans, and immigrants] by attributing disability to them” and thus leading to conflicts between and within groups fighting separate battles for equality.²⁰ The intertwining of racism and ableism continues to cause harm.

The historical use of disability to justify discrimination against women, people of color, and immigrant groups (or all three, simultaneously!) makes taking an intersectional approach to disability necessary. Stigma, diagnosis, community building, and legal protections can differently affect people even with the same conditions.²¹ For example, African American, Latino, American Indian, and Native Alaskan students are disproportionately labeled emotionally disturbed or learning disabled compared to their White peers and are far more likely to be segregated in special education classrooms, subject to disciplinary action, or referred to the justice system, but are far less likely to enter college than White students with similar disabilities.²² In addition, poverty, racism, sexism and other social ills increase the types of trauma that can cause mental health problems and chronic illnesses.²³ Because of these interdependencies, it is not wise to examine ableism separately from other forms of oppression.

In the next section, I will talk about my experiences as a White, middle class person with disabilities that are not immediately apparent. I cannot speak to the experiences of people of color or others situated in realms of oppression that I do not inhabit, but I will point out that I am coming

19 Gina Schlesselman-Tarango, “The Legacy of Lady Bountiful: White Women in the Library,” *Library Trends* 64, no. 4 (2016): 681, doi:10.1353/lib.2016.0015.

20 Douglas C. Baynton, “Disability and the Justification of Inequality in American History,” in *The Disability Studies Reader, 4th edition* edited by Lennard J. Davis. New York: Routledge (2013): 33.

21 Alfredo J. Artiles, “Untangling the Racialization of Disabilities: An Intersectionality Critique across Disability Models,” *Du Bois Review* 10, no. 2 (2013): 329-347.

22 Annamma, “Dis/Ability,” 11-15.

23 Jay Watts, “Is Mental Illness Real? You Asked Google, Here’s the Answer,” *The Guardian* (April 12, 2017), <https://www.theguardian.com/commentisfree/2017/apr/12/is-mental-illness-real-google-answer>.

from a position of relative privilege and suspect that has allowed me more freedom in negotiating care.

Negotiating Care

Librarianship is a caring profession.²⁴ Library workers often take on the role of care-giver. However, library workers with disabilities sometimes need to receive care. I know from my own experience as a person with disabilities that library workers who are entrenched in their self-image as care-givers don't always ask about the boundaries of care-receivers. Using myself as an example again, it is not uncommon for co-workers to tell me what I can or cannot eat based on their assumptions about diabetes. I have also witnessed librarians go to great lengths to help library patrons while deliberately dismissing the care-receiving needs of peers. One example of this that I vividly remember is when a library worker publicly advocated for providing more staff training on how to meet the needs of disabled students, while privately saying to me that a co-worker needs to "get over" being autistic. I suspect this phenomenon happens for multiple reasons, both interpersonal and institutional.

On an interpersonal level, using a deficit model of understanding disability often leads us to conceptualize disabled people as lesser. Within Western cultures, being publicly disabled has historically led to censure, hostility, and "suspicion of malingering or an attempt to profit off the sympathy of others."²⁵ Fear of this reaction leads some disabled people to try to pass as abled by "concealing or minimising"²⁶ their identity or to perform approved forms of disability.²⁷ The need to perform socially approved forms of disability means that when I take a family member to the store and we park in an accessible parking space, I am very overt about taking out her walker to avoid complaints of "faking." Being perceived as faking can result in unpleasant interpersonal interactions as well as potentially losing access to social services.

However, we must also return to the idea of concealing or minimizing one's disabilities in order to perform normativity. For example, Susan Wendell presents the following response to expectations surrounding the feminist performances of care: "I feel as if my colleagues are ashamed of me because I am no longer the image of strength, competence, and independence that

24 Lisa Sloniowski, "Affective Labor, Resistance, and the Academic Librarian," *Library Trends* 64, no. 4 (2016): 645-666, doi:10.1353/lib.2016.0013.

25 Grue, "Social Meaning of Disability," 960.

26 Ibid., 961.

27 Wendell, *Rejected Body*, 55.

feminists, including myself, are so eager to project. There is clearly a conflict between feminism's rhetoric of inclusion and failure to include disability.”²⁸ I am arguing here that these expectations are also common to librarianship.

An example from my own life that I shared publicly on my blog a few years ago is when a former co-worker tried to have me fired for having diabetes.²⁹ Disabilities may not be immediately apparent, but they also can't be ignored just because they're inconvenient.

Legalistic approaches to disabilities such as the Americans with Disabilities Act requires that people with disabilities disclose their conditions in order to access legal protections. However, those disclosures are not always treated with respect or confidentiality. What seems like a reasonable accommodation to the person with a disability will not always be viewed similarly by a human resources or university finance officer. There are also expectations that disabled employees will justify their hiring by “overcoming” their disability or being otherwise inspirational.³⁰

Another challenge that comes from disclosing one's disability status is when co-workers believe that the person with disabilities is mismanaging or faking their condition. This is often the result of a lack of familiarity with the reality of disabled people as well as a misplaced locus of control. Those of us who grew up in Western cultures often believe we have direct control over our environments, but control “is an illusion.”³¹ Some disabilities are temporary, but many are permanent. Also, how those disabilities impact our lives can vary over time. Rather than allow ourselves to succumb to fear of becoming disabled and letting those fears have all the power, we should do a better job of intentionally incorporating people with disabilities as full members of public life. Creating a truly inclusive workplace includes normalizing body and performance differences, in our workplace policies and practices, as well as in the language we use to describe disability.

Reflection and Connection: Building Community

Critical disability studies attempts to reveal “the power relational dynamics within societies as manifested and reinforced via... seemingly innocuous means, at both the individual and the societal level.”³² In response to my call to reexamine the role of care in making workplaces inclusive of disabled

28 *Ibid.*, 96.

29 Jessica Schomberg, “My (Library) Life with Invisible Disabilities,” *Letters to a Young Librarian* (blog), October 8, 2015, <http://letterstoayounglibrarian.blogspot.com/2015/10/my-library-life-with-invisible.html>.

30 Martin, *Disabled Leaders*, 56-57.

31 Wendell, *Rejected Body*, 103.

32 Meekosha, “Critical Disability Studies,” 53.

people, one of the editors of the present volume asked, “How does that happen in a workplace that requires carework of its employees and has too much work?” My answer is that we all need to call out unreasonable work expectations and draw attention to the combination of interpersonal and institutional issues that cause us to be suspicious that our colleagues aren’t pulling their weight. Earlier, I mentioned how the rhetoric, or language, of ableism can perpetuate stigma. In this context, we can use critical disability theory to question the rhetorical patterns and institutional structures that emphasize individualism and self-sufficiency. We talk about library work as if productivity, efficiency, and countable things are the most important methods of evaluation.³³ We tell people to make good things happen and prevent bad things from happening through sheer force of will. This creates an environment of toxic individualism, to the point where these modes of thinking cause harm to others and ourselves.³⁴

Precarity—or burnout, if you prefer taking a psychological approach to this issue rather than a Marxist one—is a structural problem.³⁵ Whichever term you prefer, this condition can be based on unstable labor conditions brought on by irregular working hours, blurring of personal and private time, and contingent labor contracts. It can also be based on unstable life experiences in which one’s social and physical environments are too insecure to plan for the future.³⁶ These feelings of precarity are heightened when all of your life plans are determined based on your actual or potential work schedule.³⁷ They are heightened when library workers must respond to budget cuts that affect library staffing, the availability of childcare, the accessibility of health care, fears for personal safety when traveling to and from work, and similar destabilizing pressures.³⁸ This environment of precarity also relies on “the glorification of concrete outputs in performance measurements over emotional labor.”³⁹ These factors affect everyone, but can be especially burdensome to people who have “complex

33 Peter Heron and Ellen Altman, *Assessing Service Quality: Satisfying the Expectations of Library Customers*. 2nd edition. (Chicago: ALA Editions, an imprint of the American Library Association, 2010): 52.

34 Robin Tran, “3 Ways the US Uses Individualism to Blame Victims for their own Suffering,” *Everyday Feminism*, November 17, 2015, <http://everydayfeminism.com/2015/11/us-individualism-victim-blame/>.

35 Cynthia Harr, “Promoting Workplace Health by Diminishing the Negative Impact of Compassion Fatigue and Increasing Compassion Satisfaction,” *Social Work and Christianity* 40, no. 1 (2013): 71-88.

36 Barbara Biglia and Jordi Bonet Martí, “Precarity,” In *Encyclopedia of Critical Psychology*, ed. Thomas Teo. (New York, Springer, 2014): 1489.

37 Rosalind Gill and Andy Pratt, “Precarity and Cultural Work in the Social Factory? Immaterial Labour, Precariousness and Cultural Work,” *Theory, Culture & Society* 25, no. 7-8 (2008): 35, http://www.e-flux.com/wp-content/uploads/2013/05/Precarity_cultural.pdf.

38 Sloniowski, “Affective Labor,” 652.

39 Ibid., 658.

entanglements of class, nationality and ethnicity” or who are older, disabled, with less education or aren’t cis men.⁴⁰ In other words, rhetoric and incentives rewarding workaholic behavior mean that people who need care and are socially expected to provide care for others are more impacted by precarity than those who can live a highly individualistic lifestyle. Toxic individualism creates conditions in which precarity grows. Precarity depends on keeping people separated and focused on taking care of themselves above all else. It structurally privileges those labeled as white and abled. Precarity relies on a “relative lack of caring responsibilities... in which subjects can work unfettered by relationships or family”⁴¹ – and also unfettered by bodily constraints. It uses the rhetoric of individualism to make us think that being an adult means that “we *have* to take care of ourselves.”⁴²

I am arguing that the emotional work of exchanging care can provide some protection from the stress that precarity brings. While talking about the limits of self-care, Liz Kessler encourages us to broaden our focus to the communities we are part of, as a way to share the burden.⁴³ Similar to the process of creating theoretical frameworks to understand our lived experiences, by focusing on the bigger picture of our communities we can see that we are not alone and that we can help each other face similar problems. Intentional community care can create an environment that promotes satisfaction rather than burnout or precarity.⁴⁴ Social work researcher Cynthia Harr suggests several organizational approaches that can create a more supportive work environment. While her focus is on social workers, library workers can also make use of her recommendations. These recommendations include providing kitchen facilities and a break room so employees can engage in self-care while at work; discussing systemic issues that contribute to stress during staff meetings; making sure that all staff have continuing education and professional development opportunities; practicing conflict management at all levels of the organization; making sure all staff know what their role is in achieving organizational goals; protecting staff from excessive workloads and long hours; and providing team approaches to work problems in which more experienced staff members can mentor and collaborate with newer staff members.

40 Gill and Pratt, “Precarity,” 33.

41 Ibid., 33.

42 Kessler, “Why I Don’t Believe”.

43 Liz Kessler, “Why I Don’t Believe in ‘Self Care’ (And How to Make it Obsolete),” *Murky Green Waters* (blog), March 8, 2016, <https://murkygreenwaters.com/2016/03/08/why-i-dont-believe-in-self-care-and-how-to-make-it-obsolete/>.

44 Harr, “Promoting Workplace Health,” 76.

Harr's recommendations were developed with a normative body in mind, or at least the author does not discuss disabilities explicitly. However, many of the recommendations have specific benefits to disabled people in addition to benefiting abled people. Many people with disabilities experience fatigue, for example, that's related to existing a world not designed for us. Many disabled people also feel pressure to perform superlatively and "constantly have to prove their worth to their institution."⁴⁵ Because policies, buildings, work schedules, and everything else we encounter at work are designed with the assumption that only abled people will be present, disabled people have to work harder just to get in the door; Critical Disability Studies reminds us that disabled people use library services and also provide library services. CDS also reminds us to examine the power structures in place that determine for whom library policies are designed, how library values are operationalized, and who decides what care is necessary and appropriate.

Disability Theory from Critique to Action

Your community includes people with disabilities, whether or not they publicly disclose their conditions or identify as Disabled. Reconceptualizing work and the workplace using concepts of critical disability theory can help create a more inclusive environment. Expanding our conceptions of who belongs in the workplace and how we engage in work can improve organizational health for everyone. Ideals of community care can be used to create inclusive work environments and beat back against the tide of toxic individualism epitomized by ideologies of whiteness and capitalism. There is no one right way to incorporate community care within the workplace, but some ideas are suggested below.

Before implementing any initiative on behalf of others, first ask if it's welcome.

Recognize that more people have disabilities and more kinds of disabilities than you're aware of, and that dis/abilities may fluctuate over time and may not be apparent. If you need to know what's going on, ask. Don't criticize the answer, even if it doesn't make sense to you at the time. Take the opportunity to learn.

Possible community care ideas at the workplace include having regular potluck meals, welcoming infants and elders into the workplace, providing

45 Martin, *Disabled Leaders*, 57.

stimming devices in meetings,⁴⁶ engaging in group work to solve complicated problems instead of placing the burden on one person, allowing people to work at home as needed, and ensuring that employees receive clear guidance related to performance expectations and timelines.

Engage in collective action to ensure adequate access to sick days and adequate health care for all employees.

Government regulations and support services often take a restrictive approach to people with disabilities in a way that treats people as objects to be regulated and controlled; remember that people are not things.⁴⁷

Remember that medical care is often practiced on a commodities model, which means people who can't afford to pay for it often can't access it. This has implications for the biocertifications needed for the above-mentioned government services as well as for access to diagnosticians, medicine, assistive technology, and other resources.⁴⁸

I have had a successful career in librarianship as a disabled person, but meeting the performance expectations of academic librarianship has required me to risk my health and sacrifice opportunities to build community. Sadly, this is not unusual. My hope is that library workers will become vocally engaged in critically evaluating the policies and cultural norms that disadvantage disabled people—from stigma against people with noticeable disabilities to work expectations that require people to operate against their own interests. If we take an intersectional approach to the world, we quickly see that there are no true normative bodily experiences; instead, people come in a beautiful variety of shapes, sizes, colors, and movements. I would like for us to acknowledge and celebrate that by making sure that disabled people are fully incorporated into public life.

46 Stimming is short for self-stimulating, a repetitive self-soothing behavior used by neurodivergent people.

For example, I crochet in meetings and at conferences. Keeping my hands busy helps me stay calm so I can focus on what's going on without becoming agitated. Knitting can serve a similar function.

47 Meekosha, “Critical Disability Studies,” 51; Kate Rose Guest Pryal, “Can you tell the difference between Accommodation and Accessibility,” *Medium* (blog), April 12, 2016, <https://medium.com/disability-stories/can-you-tell-the-difference-between-accommodation-and-accessibility-7a7af9dacd7#.k1ya7a5wd>.

48 Ellen Samuels, *Fantasies of Identification: Disability, Race, Gender*. (New York: NYU Press, 2014): 122.

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