The Gendered, Racialized, & Dis/Abled Experiences of Neurodivergent Black Women Graduate Students Across Higher Education

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The Gendered, Racialized, & Dis/Abled Experiences of Neurodivergent Black Women Graduate Students Across Higher Education

A Dissertation Presented

by

KAT J. M. STEPHENS

Submitted to the Graduate School of the University of Massachusetts Amherst in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

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College of Education
The Gendered, Racialized, & Dis/Abled Experiences of Neurodivergent Black Women Graduate Students Across Higher Education

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DEDICATION

To my patient and loving Kai, thank you for your unconditional support and honest perspective. To baby Kat of the past, you were always capable and never broken. Lastly, I need to acknowledge myself today. I never quit. I fell down nine times and got up ten.
EPIGRAPH

“Part of the work of building disabled futures is to build more space for everyone to live their socially constructed and very real and truly at times disabling identities without fear. It is to resist every discourse that says such spaces do not matter.” (p. 146)

Milo W. Obourn, Disabled Futures, A Framework for Radical Inclusion (2020)
ACKNOWLEDGEMENTS

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happen in community. Thanks, Kanye, for my dissertation writing soundtrack. I could not thank everyone here – please mark it to my head and not my heart.
ABSTRACT

THE GENDERED, RACIALIZED, & DIS/ABLED EXPERIENCES OF NEURODIVERGENT BLACK WOMEN GRADUATE STUDENTS ACROSS HIGHER EDUCATION

SEPTEMBER 2022

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Black women graduate students with dis/abilities; those identifying as neurodivergent are scarce in contemporary research. Throughout widespread disability studies, research, and the research on neurodiversity, this lack is consistent regarding minoritized race and gender groupings (Matthews, 2019; Strong et al., 2020). Larger neurodivergent, ADHD, and Autism conversations tend to skew toward White boys and men (Travers, 2018). The convergence of disability (race, gender, and place/space) as another marginalized community and diverse student population, is an additional gap in the literature, despite the benefits of DisCrit (Annamma et al., 2013). Black women graduate students with disabilities, specifically those identifying as neurodivergent are barely visible in contemporary research. Throughout widespread disability studies, research, and the research on neurodivergence, this lack is consistent regarding
minoritized race and gender groupings (Matthews, 2019; Strong et al., 2020). This is a problem. Neurodivergent conditions and symptoms are often hard to detect.

When compounded with a community (Black women) who generally experiences high levels of institutional erasure, this is doubly concerning. This problem worsens without appropriate regard to cultural norms around diagnosis, treatment, and disclosure that are prevalent in the larger Black community (Artiles, 2013). The current interventions are tailored toward White (male) students (Loomes et al., 2017). These current interventions are ineffective at solving the problem because cultural norms do impact Black women, and their ability to receive appropriate campus support. Race and dis/ability need to be thought of alongside gender (Leake et al., 2014). Gender plays a role in the experiences of dis/abled Black women.

In acknowledgment of the dearth of literature on this, particularly, the attention paid to space and place - race, dis/ability, and Black women, this paper engages with those lenses. Black women’s ability to re-mix and remake harmful environments is remarkable and historical. Black women’s cultural production creates a means to transcend oppressively limiting situations (Schalk, 2018; Taylor, 2017) Cultural production’s link to Black feminism reflects the power of community. The cultural production is an adaptive response to the violence neurodivergent Black women graduate students experience in higher education environments (Hubain et al., 2012).
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CHAPTER 1
THE PROJECT OVERVIEW

Introduction

Students with minoritized identities experience challenges and struggles in higher education. Graduate and undergraduate students with minoritized identities experiencing microaggressions, and racialized oppression on campus, have been a topic of explored in research studies (Harper & Hurtado, 2007, Sethna, 2011, Quaye, 2015, Wagner, 2015, & Hubain, et al 2016). These challenging experiences that students have had are strengthened by the absolute pervasiveness of power, privilege, and oppression. Their time as students is made more challenging because institutions are not adequately prepared to support them. This institutional failure leads to “struggles” by individual students, which actually reflect institutional problems and a lack of effective solutions across the higher education landscape. To overcome these pressing equity issues, higher education institutions must change the ways they support minoritized students in recruitment, retention, and completion. Though universities are moving the needle toward success, (Gidley, et al, 2010, Bhopal, 2017, Smith, 2020), these increased efforts in diversity, equity, and inclusion work are still lacking equitable recognition of students with multiply marginalized identities. Among the many interventions vitally needed in contemporary higher education, those focused on support for disabled students—particularly disabled students with multiply minoritized identities—are urgently needed and also uniquely challenging to implement.
Part of the reason for this difficulty arises from dis/ability’s erasure in higher education. Nineteen percent of college undergraduates, (in 2015-2016 reports) have a disability (NCES, 2021), but dis/ability\textsuperscript{1} as an identity is routinely excluded from conversations about diversity, equity, and inclusion (Shallish, 2017, Scheef, et al 2020, & Smith et al, 2001). This erasure stems from a clash between higher education’s elevation of the life of the mind and the widespread societal belief that dis/ability represents a form of intellectual inferiority. Lower education, which exists opposite from higher education historically has housed people with dis/abilities. “Lower education” spaces, loosely labeled “schools” for the “feeble-minded” upheld exclusionary institutions (Dolmage, 2017 pg. 3) which further emboldened difference, upholding long-lasting norms of the academy. Such norms established the academy and “the ethic of higher education still encourages students and teachers alike to accentuate ability, valorize perfection, and stigmatize anything that hints at intellectual (or physical) weakness.” (Dolmage, 2017 pg. 3). As a result, many disabled faculty, staff, and students in higher education do not disclose their disability status and may indeed not even identify as disabled. Yet, the act of disconnecting oneself from parts of oneself is difficult. It serves as a distraction in one's educational and academic experience, complicating a student’s development.

Responding to the way that people experience dis/ability in tandem with their other social identities and the ways in which systems of oppression mutually reinforced one another, scholars have developed multiple theoretical constructs that tie disability

\textsuperscript{1} “dis/ability” is used by Annamma to “analyze the entire context in which a person functions” (Annamma et al., 2016, p. 1) and to acknowledge that “dis/ability is not a thing to find and fix, but a process” (Annamma, 2017, p. 7).
studies to other forms of critical inquiry. Race and Dis/ability Studies (DS) together meet at the intersection of Critical Race Theory (CRT), (Crenshaw, 2010) and DisCrit (Annamma, 2013). CRT and DisCrit recognize that race and ability are continually ‘othered’ – (minoritized races & dis/abled) and when placed together in a posture of power, they inform research and center the importance of diverse representation in research, practice, and policy. Likewise, the intertwining of gender, sexuality, and dis/ability—as well as related systems of oppression—can be observed via Crip Theory. As Kafer (2013) notes: “Imagining this kind of expansive dis/ability movement is to simultaneously engage in a critical reading of these very identities, locations, and bodies” (p. 12). Crip theory troubles the extent of inclusion and troubles the grouping of the “majority” / normative identities, whether race, gender, sexual orientation.

By focusing simultaneously on race, gender, and dis/ability, it is possible to further complexify thinking about dis/ability and in so doing add nuance to the way that colleges and universities work to support all salient identities of multiply minoritized students. Gender, race, and dis/ability remain non-linear regarding one’s positionality and movement in the world (Schalk, 2018 & Pickens, 2019). In response to this need, this study will examine the academic experiences and cultural production of self-identified Black women enrolled in graduate school. Looking closely, race and gender are categories with less representation in dis/ability research (Karpicz, 2020). Black women graduate students with dis/abilities, specifically those identifying as neurodivergent are barely visible in contemporary research and the larger dis/ability conversation. By focusing on neurodivergent Black women graduate students, my study will amplify the voices and experiences of people whose bodies and minds are regulated by three
overlapping systems of power, privilege, and oppression that center the experiences of able-bodied, able-minded cishet white men.

Assumptions of “neurotypical-ity” exist for all, and bodies and minds that behave outside of these bounds are actively subject to regulation. The idea of neurodivergence suggests that departure from neurodiversity is simply a function of human diversity that should be valued. Neurodiversity is a status of being *rather* than a judgment of value: bodies and minds do *not and should not* all operate similarly. The lens of neurodiversity identifies and normalizes widespread differences in the actions and inactions of all bodies and all minds (Legault, 2021). For further clarity, ‘neurodiversity,’ is “an umbrella term, originally coined in relation to Autism, for several conditions traditionally pathologized and associated with a deficit, including Dyspraxia, Dyslexia, Attention Deficit Hyperactivity Disorder, dyscalculia, autistic spectrum, and Tourette syndrome.” (Clouder, et. al, 2020, pg. 758). Connecting this work to race and gender— where Black women’s embodied experiences have also been subject to constant surveillance— will extend all three literature bases and result in actionable insight designed to make higher education spaces more just.

**Statement of Problem**

Dis/ability is a largely invisible experience on higher education campuses, in part due to able-washing. When dis/abled people are the focus of study, their other salient identities are typically rendered invisible. In this way, dis/ability becomes a monolith, but equality of representation and the utility of findings will continue to be out of reach if diversity among participants continues to be underrepresented in dis/ability research - by
gender and race (Karpicz, 2020). Notably, the reduction of disabled people to a single identity comes even as scholars have increasingly recognized the connectedness of multiple power systems, privilege, and oppression. The intersection of people’s multiple identities lends to a more robust understanding of people’s lived experiences within those identities. With this, scholars have often bifurcated the experiences of minoritized groups (race, class, gender & sexual identity, for example) from dis/ability (Ostiguy, 2018).

Although work on the intersectional experience of ableism and other systems of oppression is needed across a broad swath of identities and experiences, Black neurodiverse women represent a distinct dis/abled experience with a unique experience of ableism and related systems of oppression. Briefly, the racialized and gendered experience of disability means that the specific manifestations of ableism in the lives of Black neurodivergent women are likely to be acutely and uniquely felt. Moreover, their experiences are underrepresented in higher education literature, (Lovelace, 2021) and as a result, they are underserved with regards to environmental adjustments to dis/ability and appropriate support to manage a dis/ability.

Even amid this dearth of literature on their experiences, Black dis/abled women are attending and thriving within higher education. Since they have been rendered intersectionally invisible, however, their voices and stories have not been widely shared. A focus on Black neurodivergent women graduate students—people who have definitionally been successful in higher education but who have also likely encountered the sad, stark realities of the ways that oppressive ideologies of dis/ability, race, and gender manifest themselves in university settings—can help to address this gap in the literature. Since these students have also likely both struggled and thrived, they also
provide a unique window to understand the way that space and place have influenced their experiences in higher education. Notably, this statement entails a more precise understanding of space and place than is often encountered in everyday language. My framing of place and space are as follows: place - higher education institutions shape place. The entity of the institution becomes the “place” with rules, policies, norms, power structures, and adhering to various levels of order (Mitchell, 2017). Those aspects are not inherently negative, and they contribute positively to any institution. Here, place “becomes” negative when influenced by inequitable displays of power and oppression. Place is cultivated by the institution in charge, and whatever informs the institutions (Howard-Baptiste, 2014). Place is an indicator of tension because higher education is cultivated by the power structure that is the institution, which is informed by racism and other modes of oppression. Place is supported by a deep criticism of academic norms within the world of American literature (Morrison, 1992), whereas space is supported by a contextualized understanding of speculative fiction (Hinton, 2018), science fiction (Schalk, 2018) – the ability that Black dis/abled women have to shape their own environments absent of “othering.”

It is important to note that, while people hold positions of power in these institutions, the nature of power is such that they are (always) merely carrying out global norms of oppression. Place does not yield to the individual, nor is it driven by the individual, but rather the structures which people are hired to enact, in institutions with impenetrable firewalls of historical oppression. Place yields to the institution and is informed by the institution - not the students inhabiting it. Place, in the context of this paper yields a certain distance or remoteness from reality.
In contrast, as I use this term in this study, *space* is materialized as being led by, designed by, created by, and protected by minoritized people. In this study, the space is for and by neurodivergent Black women graduates (the people). *Space*, in the context of this paper creates closeness and community (Collins, 2000). Neurodivergent Black women alone shape their space(s). As space is constructed by neurodivergent Black women, for neurodivergent Black women, it is designed to center freedom and works to provide liberation from rules, policies, norms, and power structures, that support the institution. The spaces themselves are virtual, on Twitter, on Tumblr, on blogs, Zoom groups, and Discord. Additionally, the spaces can be imagined, for example, in literature such as science fiction novels, intergalactic created spaces popularized in Afrofuturism, speculative fiction, and even in academic literature (Hinton, 2018).

Almost no literature explores the experiences of Black neurodivergent women. Almost no literature explores place and space regarding dis/ability in higher education. Although it is difficult to prove a negative, it is plausible to conclude that literally, no literature explores the navigations of place and the creations of space that Black neurodivergent women graduate students utilize to succeed within academia. My study will certainly be among the first and likely the very first study to explore these experiences, navigations, and creations as Black neurodivergent women graduate students move through academia. Historically, Black women have risen to better circumstances despite the politics or policies of any situation they may be in. Black women’s ability to re-mix and reimagine environments that were set up to make their lives difficult is remarkable and repeats throughout history. Black women’s cultural production creates a means to transcend oppressively limiting situations (Schalk, 2018, &
Taylor, 2017) This cultural production connects to Black feminisms and the power of community within it. The cultural production is an adaptive response to the violence neurodiverse Black women graduate students experience in higher education environments (Hubain, et al., 2012).

**Research Questions**

Collectively, this study is comprised of distinct statements of the problems and the research questions that animate them. My entire dissertation is framed by an overarching question that structures my inquiry:

How do neurodiverse Black women graduate students navigate their race and dis/ability while enrolled in higher education?

In order to answer this overarching question, my inquiry must investigate the race, dis/ability, disability identity, and gendered experience my participants had and continue to have. The Black Feminist Disability framework (Bailey & Mobley, 2019) supports the complications of viewing people without nuance, and without intersectionality being central. These research questions frame an eventual existence where Black women do not have to hide parts of themselves, but rather they can show up whole, in the fullness of themselves.

To answer my research question, I also explore three supporting questions. First, how do Black neurodivergent women graduate students’ experience of and understanding of Blackness shape their experience in graduate school? Second, how does disability and diagnosis color the experiences of Black neurodivergent women as they navigate their
graduate studies? Third, how does neurodivergent Black women’s responsive cultural production allow them to create space in these (socio-political) times, despite being ensconced within the places (read environments) that are higher education institutions? To get to the end of my participants’ sense of their dis/abled self (not all of my participants identify as “disabled”), I must examine their experiences in the ableist higher education institutions they attend.

My questions will lead to me to findings that can help to support the realization of a more just, equitable higher education experience for Black neurodivergent women graduate students as well as for students whose experiences share any facet of these positionalities. My study addresses the problem that is self-identifying neurodivergent Black women graduate students do not receive a) adequate support from student affairs or academic affairs, b) recognition for being members of the dis/ability community, c) neurodivergent Black women graduate students’ right to exist just as they are; absent racist, gendered, and ableist gatekeeping around dis/ability and who “gets” to be dis/abled. It is important for this problem to be addressed so that I can, via this study, address the lack of institutional support for neurodivergent Black women graduate students by conducting a study on how they navigate higher education, (Moriña, 2020) and their identities regarding race, dis/ability, and gender.

I further identify gaps by examining the ways that Black women historically build community and thrive despite harsh conditions. This identification of a problem will signal to higher education that new representation is needed, and not enough is being done to support nor listen to this population of graduate students. If this issue is not addressed, higher education institutions will continue to cultivate campuses where
dis/ability is not adequately represented or represented, and neurodivergent Black women
graduate students will not receive the academic and socio-emotional support they need.
Lastly, there is less of an opportunity for real-world representation in educational
research, which has the potential for far-reaching impact.

Positionality Statement

I write this study as I enter the last and most arduous phase of my doctoral studies
during a seemingly never-ending global pandemic. At present, I am poised to complete
this advanced degree at the end of my 4th year of doctoral studies. Some would say that I
should not be here dancing with myself; with the words of my entire adult life behind me,
and the actions of ableist people, institutions, and learning environments littered about
my past, present, and future. I am sure you’re wondering how I got here, and what this
even means. In this body of work, I will attempt to unmask, and I will attempt to un-
mirror (un-mirroring refers to the act of mimicking actions and behaviors of others
deemed neurotypical) years and decades of learned and societally- acceptable behavior,
norms, and ways of thinking, being, and doing. In this revelation comes words, works,
and worlds from every which way. Creative and poetic inquiry take possession out of the
individual scholar-artists’ hands and bring forth communal experiences, from the mouth
of one, but of the mind of many. This work does not come to light without immense dark.
The work does not exist without a cry for representation. This work does not exist
without many a black ooman’ looking to find themselves within accolade-based ability,
and rather, losing themselves in confusion-based dis/ability. The work does not exist
without the emergence of neurodivergence in social media, and the emergence of many a
black ooman\textsuperscript{2} inna de schoolhouse. So, here I am readying a display of bravery, transparency, and keen self-awareness that only comes with the steep recognition that your brain works differently, very very differently. And not only was I not “supposed to be here” - it took me well into my doctoral studies to discover that my brain was not broken, but full of riches. In my second year of doctoral studies, I published an original creative scholarship, (a poem entitled) Just A Unicorn (Stephens, 2020) in a special issue (focused on Disability Justice, Race, and Education) of the JCSCORE journal. As a further embodiment of my positionality, excerpts are interwoven over the next few pages.

Please bear ah witness:

\textit{Just another Model Immigrant}

\textit{Dem: Yuh mek yuhself dotish or wah? Mi: But}

\textit{Dem: Yuh nuh ave’ no dis-ah-bil-uhTEE Mi: But}

\textit{Dem: *suck teeth*}

\textit{Dem: Yuh too smart for alluh dat}

My youth was steeped and defined in the plentiful West Indian enclaves of Brooklyn, New York, and Queens, New York. I did not know what I didn’t know, but I knew that I got in trouble a lot. I made silly mistakes, misplaced expensive eyeglasses every semester, and was blamed for forbidden inconsistencies and forgotten chores. In high school, I was kicked out and re-enrolled into the pre-law honors program at least twice a year. My guidance counselor knew when to call my mother at home, and we did

\textsuperscript{2} “Ooman” is a Jamaican patwah / patois word for woman (2022, April 14). \textit{Patois Definition on Jamaican Patwa}. \url{https://jamaicanpatwa.com/term/Ooman/1669#.YmH5oy-B1bU}
this song-and-dance like clockwork. It wasn’t my fault school was boring, or I spent most of class teaching my peers. I rarely did homework, aced random exams, and by junior year was skipping school entirely to attend TRL at MTV in Times Square. Surprisingly, I got into several unaffordable colleges, but attended a low-cost “public Ivy” where I skipped classes for weeks on end, then showed up for exams, submitted papers written on the subway ride, and bargained with my professors for the assignments I wanted to do, not the ones on the syllabus. This was partially because I could never find my syllabus, and partially because my attention was rarely captured, and I was rarely motivated. This landed me on academic probation for three semesters. I was never once referred to disability services. Eventually I was asked to not return and complied for another decade plus. This current-day educator before you H.A.T.E.D. school but L.O.V.E.D learning. I suppose that’s what one in that predicament does – they eventually get a Ph.D. My Guyanese immigrant experience in America was laced with expectations, familial pride, and the spirit of Sankofa. That sounds good until it’s time to do it, you know… be the perfect representation of generations of sacrifice, generations of parents working the jobs no one outside of our immigrant community wanted, and generations of the expectation of all-around excellence. During my first year of doctoral studies, I mentioned to a family member that I was in the midst of psychoeducational testing for a battery of neurodivergent conditions. That tiny conversation above was enough to let me know that in no circumstance could I be allowed to have any nuance of being, diversity in ability, or

---

3 Sankofa (2022, April 18) is an African word from the Akan tribe in Ghana. The literal translation of the word and symbol is “it is not too taboo to fetch what is at risk of being left behind.” The sankofa symbolizes the Akan people’s quest for knowledge among the Akan with the implication that the quest is based on critical examination, and intelligent and patient investigation. https://www.berea.edu/cgwc/the-power-of-sankofa/
high achievement while dis/abled. I never mentioned it publicly again. After all, I had a reputation as the smartest person in my already brilliant and accomplished nuclear family - who was I to let them down? A fraudulent PhD-in-training? Nope, I was just another model immigrant.

Just another Tuesday

Mistake number seventy-five
Deleted another final paper
Three minutes to eleven fifty-nine’s deadline
Obsessively reminding my mind to not forget

Only for anxiety and adrenaline to quarrel it out Sweat bridling down my left temple

Heart racing, making Timbaland-like beats

Yet another begging email being composed “Dear Dr.” insert [Whiteness] here
“Would you please grant” insert [Black] here “Me an extension” insert [Woman] here
“I do apologize” insert [First-Generation] here “For the inconvenience” insert [Immigrant] here

My graduate school experience was rife with near collisions over the work. I resonate with the “dog ate my homework” trope, but increasingly, it became - my reality because my brain led me astray. It is that consistent experience that led me to this dissertation. My positionality and worldview are informed by my educational background, childhood learning experiences, giftedness and special education experiences in childhood, and the inconsistencies in my trajectory. I do believe that
arriving at the end of my first year of doctoral studies with catastrophic challenges, I had to find out what was going on. My identity as a scholar was resting on my productivity, and it was “suddenly” challenged as a Ph.D. student. Part of my scholarly identity and orientation are built on truth and transparency - even if it goes against the hypervisibility of being a Black and dis/abled woman graduate student. The expectation that we all “have it together” and are entering with the same know-how is unrealistic and ableist.

*Just another Ableist University System*

*I’m working twice as hard*

*In neurotypical universities*

*That lack universal design*

*Pretending not to see us outside of disability office spaces*

*Where we need supportive accommodations*

*Oh! the anger, the loss, the relief*

*That came to me in doctoral studies*

*And finally, a doctor said*

*“I think it could be ADHD”*

*I cried tears that were thick and hot*

In my doctoral studies, in the space of learning, working with others, group projects and assignments - and one-size-fits-all syllabi, I was (am) working thrice as hard. There are words, sentiments, feelings, and emotions that I will be unable to express here in a traditional academic writing pattern. My positionality and desire here, (at the end of my doctoral studies), can simultaneously be the beginning. In this dissertation, there will be poetic inquiry, I will write in dialects, languages, and ideologies far and away from the
rigorous training of 7 years of graduate study. As a creative writer from birth, it will be embraced and included in this project. As a master linguist of several Anglophone Caribbean countries, languages from my country of origin will be woven in, as there are no American English words to convey what needs to be said. Furthermore, as a neurodivergent individual, sharing identities with my participants, I can say there will be point within my dissertation that grammar, word choice, and spelling may be “off.” Please charge this to my humanity, the neurodivergence of my brain, and additional related comorbidities. I can say that working thrice as hard will not cease, but I allow myself to be a human during this experience -- in opposition to rigid masking that has gotten me this far…the ravages and idiosyncrasies of ADHD, Autism, Dyslexia will appear, and for once I will let them.


It is not to suggest my work will be less than, but rather to honor myself and my participants. Perfection is indeed impossible, but it is also painful and an unhealthy goal. What I say or do not say matters. How I say things matters. I will not only write about neurodivergence and dis/ability, but I will allow myself to be both in and out of these pages,

*as a contemporary dis/abled academic, dis/abled scholar, and dis/abled researcher.*

As an omnivorous learner, as someone who prizes literature and scholarship whether in a Tweet thread, a series of TikToks, a Podcast, a chapbook…I will not delete other ways of knowing and saying.
Just another “Invisible” Disability

New vocabulary like
Executive functioning and
Comorbid and
Rejection Sensitivity and
Time-Blindness and
Motivation-less and
Adder*ll and
Cognitive Distortions and
Inattentive and
Emotional Dysregulation and
Working Memory and
Hyperactivity and
It’s so much more than
I lost my keys

Or

I forget a lot
It’s an invisible game
And I am the Jenga

Black Girl, Lost Keys (Brooks, 2022) is the space that first took me in. Struggling with a diagnosis and battery of additional testing, I went to Google. I stumbled upon the one space that single-handedly upgraded my sense of self, the mourning of pre-diagnosis Kat, medication, and brought comorbidities into focus. The blog, the space, the author-
advocate of it all, (Rene Brooks) is key to my navigation of life post-diagnosis. My initial feelings of confusion, anger, and many hours of deep reflection brings me to a space where no one would ever truly understand me, and I also found a community of Unicorns, many in graduate school also struggling to rediscover themselves at the nexus of race, gender, and dis/ability. It was an invisible game, one I was ill-prepared to play. Part of my positionality is community-oriented, meaning-making of “life now”, and doing so with thousands of Black women, virtually, every Monday evening for over three and a half years now.

*Just a Unicorn*

*Become Black girls in Ph.D. program*

*Finally learning how they learn*

*Even when it feels too hard*

*Even when the stigmas are real*

*Even when good island gyals don’t... Ask. For. Help.*

*Get. Diagnosed.*

*Take. Medication.*

*Use. Accommodations.*


*Look for the healing in the message.*

Being in weekly fellowship with thousands of community members from that space, not only did I learn to accept my reality, I learned to make peace with my
diagnosis. Seeing and hearing the nuances and experiences of others brought me here. It seemed a phenomenon that so many people were coming to this realization well into adulthood, and others were coming into a realization in their collegiate or graduate school experiences.

**Significance of Inquiry**

While the representation in research is important, so are culturally appropriate, accessible, and affirming research practices. Research shows intentional and specific production of qualitative methodology within the dis/abled community to be productive and impactful (Kozleski, 2017). Furthermore, centering student narrative is essential (Griffin, et al., 2009; Gillespie-Lynch et al., 2017) in outcomes and findings of said research. Regarding higher education research, there is a clear connection between student experiences and on-campus policies. In this manner, higher education research can impact practitioners working in a dis/ability or accommodations office, can impact all staff members or can impact a faculty member seeking to support a student with their accommodations (Dolmage, 2017). This is particularly important to consider because suspected neurodivergent Black women graduate students already experience life in an ableist, gendered, and racialized society. Living with multiply marginalized identities, such as gender and race, suspected neurodiverse Black women graduate students are triply at risk for being ignored, under/non-diagnosed, and experiencing educational challenges due to the Black community’s stigma of disability, diagnosis, accommodations, and medication as treatment (Travers, 2018).
My findings will help them to identify what they can put into practice in their day-to-day work, in support of students. The findings from this study will support staff and faculty in their engagement with Black women graduate students who are neurodivergent or display common symptoms of neurodivergent (sometimes recognized as neurodivergent) conditions such as ADHD, Autism, OCD, and Tourette’s Syndrome. The findings from this study will assist Black women graduate students in their dis/ability journey, wherever it may take them. Furthermore, the significance of this research is underscored by the interdisciplinary nature of it. By separating Black studies and Disability studies, and examining them together, “critical conversations will be revealed” (Pickens, 2019) in the realm of Black Madness and Mad Blackness. Here, Black women not only are allowed to be ‘mad’. They are allowed to be Black, they are allowed to be gendered as women, and they are allowed to be disabled. They are allowed to be mad at systems of power and oppression, ableist university structures, and mad at misguided interpretations of them as beyond the scope of belief as being part of the disabled community.

Dis/ability & neurodivergence are categorically presented as White & male. Black women, dis/ability, and neurodivergence are under-researched altogether. Black women are often urged to prioritize race over gender or other identities (dis/ability, class, nativity) in daily experiences. Communities are largely white; dis/ability is discussed in ways that suggest Black women are largely able-bodied. Black (USian) women’s historical roots of slavery lend to them being dehumanized (devoid of feeling pain) in Disability studies. Black Disability Studies (Hinton, 2021) posits that Black people are human & should be seen as such without erasing their race from Disability (studies).
Disability (studies) places Black women outside of being dis/abled, and Black Disability Studies invites them back in.

*Space* – as cultivated by neurodiverse Black women graduate students, is their own. The cultural production which results is empowering in sidestepping some higher education environments. Cultural production exists in many ways. Some spaces are online, Tumblr, Twitter, social media groups, and message boards. Some spaces exist in the literature, romance novels with dis/abled Black protagonists, science fiction, anime, television shows, and on YouTube. *Place* – as cultivated by power & oppression within Higher Education culture, is at times destabilizing to this community of students. Higher Education under supports dis/abled students, but especially neurodiverse Black women graduate students. This community effort by Black women graduate students is culturally relevant as it mirrors proven tenets of Black feminism, while it uses contemporary tools, such as technology, art, and media.

**Summary of Future Chapters**

The future chapters can be summarized by what they contain, explain, and ascertain. First, the next chapter lays a base of foundational information on the various contexts of dis/ability, race, gender, neurodivergence, and ableism. The literature review highlights what is currently known about the convergence of these aspects, but specifically narrows to focus on Black women graduate students. Next, chapter 2b lays out the theoretical frameworks that help to round out ideas beyond that of my conceptual framework. Further, chapter 2 lays out what is known about access to testing, and diagnosis of a variety of diverse students. Chapter 2 unpacks what literature pertinent to this study has shown, and Chapter 3 explores the conceptual framework, “Black Feminist
Disability Framework (Bailey & Mobley, 2019) at the center of this research study and dissertation. The Black Feminist Disability Framework in part, argues for better representation of Disability Studies and Black Studies in the lives of Black women living with dis/abilities.

The third chapter of this dissertation describes the overall organization of the study, and the practice that went into carrying it out. The methodology of my study will take center, and its components including the research design, participant sample, site details, data collection, and data analysis. Furthermore, prior to Chapter 4, (chapter 3a), I’ll center “brief profiles” of my 14 participants. The “profiles” will be executed via the use of poetic inquiry, (Leavy, P., 2020 & Faulkner, S.L., 2017). Chapter 4 of this dissertation will detail the findings of my study. In Chapter 5, the discussion will be highlighted in full detail. Chapter 5’s discussion will go further into detailing the intersection between the implications for future research and practice, and the intersection of discussing the findings.

**Glossary of Key Terms**

The terms I’m using in this dissertation may have different definitions in other communities that do disability or neurodivergence work. Terms like dis/ability, neurodivergence, neurotypical, DisCrit, and ableism are used throughout. For widespread and consistent understanding, the terminology in the way they’re being used in this study and dissertation follow.

- *Dis/ability*: Written with a forward slash is used by Annamma to “analyze the entire context in which a person functions” (Annamma et al., 2016, p. 1) and to
acknowledge that “dis/ability is not a thing to find and fix, but a process” (Annamma, 2017, p. 7). Moreover, Annamma (2017) states that disability without the forward-slash centers ability as the normative experience (dis = not, ability = able). (Lovelace et al., 2021)

- **Neurodivergence**: “an umbrella term, originally coined in relation to autism, for several conditions traditionally pathologized and associated with a deficit, including dyspraxia, dyslexia, attention deficit hyperactivity disorder, dyscalculia, autistic spectrum, and Tourette syndrome.” (Clouder, et. al, 2020, pg. 758)

- **Neurotypical**: a named category that classifies the ways brains operate and respond to “everyday” tasks related to executive functioning and more, (this is not entirely exhaustive).

- **DisCrit**: Disability Studies and Critical Race Theory in Education (a theoretical framework drawing upon DS & CRT. (Annamma, S.A., 2016)

- **Ableism**: “Ableism, we argue is the conscious and unconscious favoring of those perceived as ‘able’ over those perceived to be disabled, or indeed those assessed as disabled. Ableism positively values able-bodiedness (Dolmage, 2017). Anyone deviating from the norm is considered ‘tragic’, ‘dangerous’, ‘inferior’ or ‘less than human’ (Swain et al. 2003). As a society, being disabled has a specific stigma attached to it and ableism reinforces that stigma.” (Lynch, S., & Macklin, J., 2020)

- **Unicorn**: A term of endearment used by and toward neurodivergent (especially those with ADHD) Black women in online spaces created and curated by René Brooks. Black Girl, Lost Keys
Chapter 2

LITERATURE REVIEW

Introduction

Blackness relates to Black people, is understood by Black people, and enacted by Black people. Misunderstandings of Blackness and distortions of Blackness materialize by virtue of power and structurally unbalanced enactments of power. This occurs often through institutions and policies but also through people. Black neurodivergent women in graduate school can fully engage the spectrum of their Blackness. Additionally, through outside influences, Black neurodivergent women can have their Blackness poorly engaged with. It is through their experiences and navigations a beautifully broader picture can be framed, but that requires Black neurodivergent women in graduate school to be seen and listened to.

The experiences of neurodiversity and disability are distinct, and no one person’s experience of either is the same. Black women graduate students and disability via neurodiversity, are infrequently recognized as existing alongside one another. Dis/ability Studies literature is historically written and researched without a true intersectional application of race.

Environmental harm is real. It occurs on and off college campuses. Neurodivergent Black women in graduate school experience the complexity of it. Ableism, like racism, and sexism can permeate any environment. Black women graduate students live nuanced and complex lives. Negative experiences in academic institutions
can push a student to persevere or to leave. For neurodivergent Black women graduate students, they can redirect their energy to building community outside of higher education. Black women’s historical connection to cultural production helps them exit harmful environments, which as a communal strategy is consistent with the power of Black feminism.

**Black Feminism’s Historical Legacy**

The legacy of Black feminism strongly connects to a creation of one’s own. Black feminism’s roots highlight the need for community and the power of it. In the esteemed Cohambee River Collective (1974), a group of Black women thinkers, poets, writers, and feminists came together to fight for liberation and freedom specific to their needs. In their words, “we realize that the only people who care enough about us to work consistently for our liberation is us” (Collective, 1977, p. 212). A foundational hallmark of the Black feminist movement, the Collective’s legacy further concretized the importance of intersectionality and working together to avoid the silos that accompany single-issue arguments and movements. In a special issue commemorating the 40th anniversary of the Cohambee River Collective, we see a diverse community of Black women (alongside intentional non-Black women of color and white women) unite for a retrospective. Sociology scholar, Diane Harriford shares the impact (2017) of shared and collective Black women’s bravery in the 1970s to contribute to the zeitgeist of progression via their thinking, scholarship, and writings.

I am sure that Patricia Hill Collin’s groundbreaking *Black Feminist Thought* (1990), a text I teach in several of my women’s studies and sociology classes, was germinated by “Cohambee.” Other early works- Gloria Gaynor’s novels, Michele Wallace’s *Black
Macho and the Myth of the Superwoman (1978), and Ntozake Shange’s For Colored Girls Who Have Considered Suicide When the Rainbow Is Enuf (1974) - were also part of this period. The pressure and controversy that many Black women faced upon publication of their brave books speak to the courage it took to write during that time. Many Black women had to hold themselves together out of sheer will in the face of criticism aimed at them. Their work was dangerous and paradigm shifting. “Cohambee centered Black women within mainstream feminist spaces that were forced to expand.” (Bow, et al, 2017, p. 166).

Though this intentionally inclusive movement was able to do work that went far and wide on a variety of social justice issues and identity markers, they still were lacking in their mention and focus on dis/ability.

Their organizing efforts have not gone in vain. It is safe to say that it has laid a pathway for Black women and allies to follow. Their organized efforts of the seventies and eighties (Collective, 1977 & 1986) made it easier for women today to push the envelope, and work collectively for their own freedom and liberation. Today, it can be said the digital tools that are widely available are the pathways to an even more accessible collection of Black women living their best lives. The online, literature, science fiction, romance literature, Reddit, Twitter, and Facebook groups allow Black women to come together virtually and build community on their own issues, to their own advantage.

Blackness and Black Studies

The determining factor of beginning the orientation in this literature review with Blackness is that it serves as a grounding and directional. It does so for three reasons: 1) To understand the participants’ intersectionality we must highlight they’re connecting to race and their race, 2) in understanding the racialized aspect of disability and gender it's
important to have an understanding of Blackness. 3) Blackness is historically surveyed and surveilled - and that does not cease in discussing what these graduate students experience in contemporary higher education institutions. Understanding the functionality of one’s Blackness in their identity and lived experiences centralizes not only the importance of race but the operation of it as well.

Modern conditions and conceptions of Blackness continue to act as a snapshot of where the country is, what blackness as property can produce, and what blackness signifies. Frantz Fanon’s *Black Skin, White Masks* clearly captures the “facticity of surveillance in black life” (Browne, p. 7). Sylvia Wynter has been known to say that “Blackness as an objective fact” and the “Lived experience of the Black” speaks to an imposition of race in Black life, where one’s being experienced through others” (Wynter). Blackness on display (whether consented to or not) is fodder for curiosity, conversation, and others’ expectations. Much of what is known about Blackness “can help social theorists understand our contemporary conditions of surveillance” (Browne, p. 8). Blackness in any capacity but the possession of the singular Black person or collective Black group is dangerous. Higher education institutions and the academy materialize, monetize, and measure Blackness largely without centering Blackness. This is done via organizational leadership and operational structures and decisions not made with the protection of Blackness or Black people in mind. This may change with Black Studies as a discipline, which is the ultimate academic understanding and study of the phenomenon.

Education scholarship’s references of CRT (Critical Race Theory) serve to identify race in the contemporary world, and how it impacts all aspect of life. While CRT (Crenshaw, 2010) is a theory historically linked to legal studies and race, it also is
theorizes race, “a critique of White Supremacy” (Dumas & Ross, 2016), not necessarily designed to solely target ‘Blackness’. In reality and away from its inception, it highlights systemic anti-Blackness but is meant to be applied to any race of people in managing race. (Dumas & Ross, 2016). It successfully “relies on the Black experience of racism in the form of its tenets” to drive home the message of racial discrimination, racial interactions, and hierarchies. The true “theory of Blackness… a critical theorization of Blackness confronts the specificity of anti-Blackness” (p. 416), and that is BlackCrit (Black Critical Theory). BlackCrit (Dumas & Ross, 2016), provides an opportunity for Blackness to be in the center of its own retelling, storying, and history. It also creates an opportunity for a deeper understanding than a Black-White binary (Dumas & Ross, 2016). Furthermore, it “helps to explain precisely how Black bodies become marginalized, disregarded, and disdained, even in their highly visible place within celebratory discourses on race and diversity” (p. 418). Blackness in the gaze of others and in the grasp of technologies can be linked to surveillance.

A clear understanding of both Blackness and theories that reveal how social constructions of Blackness shape the lived experiences of Black people allows specificity to the understanding of, the discovery of, questioning of, and examination of Black people, Black experiences, and Blackness overall. This separation, especially in educational research which often surveys the person, demands a more thorough investigation of norms, behaviors, and understanding of self and the world - that directly and purposefully relates to Black people. This specificity is needed while conducting research, and opening avenues for acute accuracy.
Previous research has established that Black Studies as a discipline has origins and roots in liberatory actions and practices (Rojas, 2010). Black studies as an academic discipline. Blackness relates to Black people, is understood by Black people, and is enacted by Black people. Black Studies is understood to be used as a tool to disseminate information, approach new ways of storying, and explore the art and science of building blocks in research and citation practices (McKittrick, 2021).

Black Studies is also linked to knowledge production and “concerns itself with Black knowledge (Walcott, 2021). Whether the thinking or knowledge is due to work by non-black scholars or black scholars is important, but not the entirety of its basis. Black Studies (much like Blackness) without Black people, is empty and it is without direction. Walcott posits that “a Black Studies without Black people is an after-Black Studies moment, a textual figure gazed up on but not heard” (Walcott, 2021, pg. 102). Black Studies is an area of study with a clear focus – (a focus on Blackness, Black people, and cultural and social life linked to Blackness), yet that singularity in all things Blackness lacks in advancing the cause that is Blackness when Black Studies is siloed from other areas of everyday life. Such areas of everyday life are dis/ability and gender, that when siloed from Blackness create a missed opportunity to embrace the fullness of Black life as is.


It is a discipline where misunderstandings of Blackness and distortions of Blackness materialize by virtue of oppressive power and structurally unbalanced
enactments of others’ power. This occurs often through institutions and policies, but also people. Black Studies thrives under the positioning that supports patriarchy, and that supports a “race-first” ideology without respect for other salient identities people hold. Black studies would be greatly enhanced by more identity work, intersectional work, and overlap of intellectual work. Black neurodivergent women in graduate school can fully engage the spectrum of their Blackness. Additionally, through outside influences, Black neurodivergent women can have their Blackness poorly engaged with. It is through their experiences and navigations a beautifully broader picture can be framed, but that requires Black neurodiverse women in graduate school to be seen and listened to.

**Race And DisCrit**

One of the greatest challenges in linking dis/ability to other salient identities is that it is not done often enough in research. Of particular concern is the lack of intersectionality between dis/ability and race, for example. Some scholars successfully indicate the lack of connection many dis/ability scholars make regarding race (Bell 2006; Blanchett 2006; Connor 2008a). Scholarship about dis/ability often gets read as special education scholarship (Annamma, et al, 2016) further siloing the field of study due to an inaccurate thought process held by some researchers unwilling to embrace projects in Dis/ability Studies. This of course is incorrect, “we believe that issues of perceived dis/ability constitute issues of equity that involve all people. Like DuBois before them, many critical scholars outside the field of special education have recognized that the social construction of dis/ability depends heavily on race and can result in marginalization, particularly for people of color and those from non-dominant communities (Annamma, p. 13, 2016).
DisCrit, or Dis/ability Studies Critical Race Theory, address this challenge. It is a theoretical framing that is the result of combining “aspects of Critical Race Theory (CRT) and Dis/ability Studies (DS)” by successfully incorporating “a dual analysis of race and ability.” (Annamma, Connor, & Ferri, p. 1, 2013) This demonstrates intersectional thinking and attitudes about racializing ability and disabling race. Historically, race and ability were strung together in instances when Black people were believed to be of lesser intellectual ability, and the body attributed to negative assumptions about Black people. This system of racial classification was incredibly harmful and incorrect, an attempt to prove people of African descent possessed limited intelligence and were therefore not quite fully human (Annamma, Connor, & Ferri, p. 2, 2013). This new theorization continues with the blending of the two, but it strives to empower and develop new and applicable scholarship.

This does lend itself to ingrained ideas about people in minoritized communities, and academic ableism. It is not unusual to see the contemporary issues regarding accessibility and students of color when these histories can be traced back. Any problems arising for students and parents regarding testing, accessibility, and diagnosis have a genesis that is not a challenge to theoretically connect. Although this paper is grounded in postsecondary learning institutions, ideologies, and practices of secondary institutions and postsecondary institutions can shape (negatively or positively) the other (Gándara, 2001). Contemporarily, we see Black students and students of color largely categorized as “learning disabled, compared to their white peers” (Parish 2002).

DisCrit serves to point out the harms of ableism, and the structural nature that empowers its accompanying oppression. Ableism in effect is the enacted (though not
always) discrimination and bias towards individuals with, and the overall experience of dis/ability. Those experiences or ideologies, or policymaking with dis/ability in mind can and are under attack from ableism, and ableist norms and policies enacted in our everyday society. Essentially, “DisCrit seeks to understand ways that macro-level issues of racism and ableism, among other structural discriminatory processes, are enacted in the day-to-day lives of students of color with dis/abilities” (Annamma et al, p. 8, 2013) and this transcends level of education. Students in postsecondary education and secondary education alike will benefit from the intersectionality that DisCrit demands.

**Academic Ableism and Theories of Space / Place**

The academic environment is one that is structured and runs on deep-rooted rules, (spoken and unspoken), norms, and behaviors. Academia is a workforce, a workplace, an institution, an ideology, and a business. Academia is an environment where student and faculty stakeholders are measured by productivity and output, and valued by productivity and output (Dolmage, 2017). The environment even requires a satisfactory, solid, and consistent measurement of productivity for admission and employment. Academic ableism exists with varied ways of viewing disability, therefore meaning it can span a wide range of discriminatory policies, practices, and ideologies. Further, “depending on one’s ontological and epistemological view, dis/ability is either considered as the experience resulting from a biological or medical focus on the personal, or as the experience of social oppression and environmental barriers. Within the binary of the medical versus the social model of dis/ability, impairment or chronic illness focus on the biological and functional, whereas dis/ability reflects the social and environmental response to the biological and functional” (Brown, & Leigh, p. 986, 2018). The
complications in the ways ableism shows up are in that it can harm anyone, it can be directed toward an entire collegiate community, and impacts every part of the academic experience. As a construct, academic ableism is relatively silent on the subject of race but reading racialized (and gendered) experiences of disability into its overall ontological project can help to reveal the higher education experiences of Black neurodiverse women graduate students.

A Black (people and cultural) sense of the academic experience is made clearer by their environmental surroundings. Geography is the physical study of the earth and the land. Cartography is the study of drawing maps. Black geographies pertains to Black people’s (most often Black American - though not only) relationship to movement, new spatial territories (of their own making or by force), and the politics of place for a historically transient people (McKittrick & Woods, 2007; Bledsoe et al, 2017; Harris & Hyden, 2017; Eaves, 2019; & Hawthorne, 2019). The spatial relationship between space, place in the university system, and what my participants have experienced is centered in this study. Thinking about racialized experiences and the environment, it is important to understand some of the ways this occurs. Within higher education institutions serving as place, (or environment) where students make their experience to create their own safe space; the Whiteness of the institutions and Black space, also known as geographies meet. In McKittrick’s reading of geographies, she invites elements of Glissant’s thinking on geographies. Edouard Glissant “suggests that geographies produced in conjunction with, and often because of, white European practices of domination expose “various kinds of madness.” (McKittrick, p. 3, 2006) Furthermore, Black geographies, senses of
place and space are not conceived alone. The encapsulation of such concepts is rooted in relationality to various encounters to Blackness, as McKittrick posits:

A black sense of place is not a standpoint or a situated knowledge; it is a location of difficult encounter and relationality. A black sense of place is not individualized knowledge - it is collaborative praxis. It assumes that our collective assertions of life are always in tandem with other ways of being (including those ways of being we cannot bear). A black sense of place always calls into question, struggles against, critiques, undoes, prevailing racist scripts. A black sense of place is a diasporic-plantocratic-black geography that reframes what we know by reorienting and honoring where we know from.” (McKittrick, p. 106, 2020)

Higher education communities take on the shape of the norms and behaviors of the leadership, and the overall environment. The enclave that an institution exists in is of its own creation. Lastly, higher education institutions inherently are environments with power at play. The dynamics between faculty and students is an expected power dynamic where the professor is typically revered and respected. In the case of Black women professors, this is patently untrue for many of them. Teaching and the collegiate classroom are likened to the arctic for smart Black women, with the academy an especially damaging place. With daily and regular assaults on their intelligence, authority, and livelihood Black women professors are experiencing the harsh realities of the academy (Howard-Baptiste, 2014). This is of note since more Black women are becoming faculty members, they were also once graduate students. Though their rank and position may change, the graduate student is well trained over years to expect more of the same discrimination and hardships as they move up the ranks in higher education.

Considering McKittrick’s earlier points in the chapter, we see Blackness understanding place by virtue of said place’s hardships and barriers or actions against
Black people and Blackness. Furthermore, per “Sylvia Wynter’s analytical grounds make available, for geography, is a space to rethink the complex linkages between history, Blackness, race, and place. Wynter’s ideas [to] notice where Black human geographies might take us. Wynter opens up a new function for human geographies, one that takes ‘new forms of life” as seriously as it takes biocentric spatial organizations (or present forms of life). (McKittrick, p. 143, 2006)

Cartographies and geographies both shape the surroundings of its institution, the history of the land an institution rests on, the history of people in the neighborhood, and the story of relational and spatial interconnectedness. For this study, location and localities were important in several ways. Thinking back to Blackness, all my participants are (and identify as) Black, (racially and ethnically identify as African, African American, or Afro-Caribbean). Blackness can exist in any locale and my participants’ understanding of their own Blackness aside from their country of origin, their chosen graduate school home, and the school that they have enrolled in. Their spatial experiences and blackness travel with them wherever they are, and their graduate school’s spatial and environmental existence also contributes to their experience.

Reimagining Black Studies and Dis/ability Studies to include both Black life and Black bodies must include a reimagining of how they “operate” spatially, or in relation to. A template of Black life imagines the production of space, to counteract a “disturbing nowhere of black life.” (McKittrick, p. 98, 2017) The liberation operates through “the production of space not through patriarchal and colonial project trappings (e.g. we want our own space, on your (anti-black colonial) terms, give us a place in your system) but instead as a project that, to borrow from Glissant (1997), engenders relations of
uncertainty (e.g. space is relational to a praxis of Black human life, Black geographies are therefore not nouns but rather are verbs that are ongoing. Likewise, a full understanding of Academic Ableism must also include attention to both the environmental and socio-emotional lifeworlds of disabled Black women.

**Black (Feminisms) & Otherworlds**

Octavia Butler’s *Kindred (1979)*, her *Parable of the Sower (1993)*, Talia Hibbert’s romantic comedy novel, *Act Your Age, Eve Brown (2021)*, Toni Morrison’s *Audre Lorde’s Cancer Journals (1980)*, Harriet Jacobs’ *Incidents in the Life of a Slave Girl (1861)* - were all written featuring dis/ability, difference, neurodivergence, and autism for example. The juxtaposition between the harsh realities of being Black and a woman in the United States and being a rich contributor to culture is not to be ignored. The cultural production of these authors allowed them to speak to the horrors of slavery, of the bodily harm and desexing (Obourn, 2020) left over from brutal treatments. These experiences are often written about were not necessarily described as dis/ability, but remnants of chronic pain, dismemberment, and disconnection from memory, can be attested as such.

This earlier cultural production centered on dis/ability at the hands of tragic violence, connected to the physicality of slavery, and people being literal property. Jacobs’ recollection of her experience as an enslaved person spoke to stark realities toward liberation. Her body was severely harmed and impaired, but the bodily freedom was worth it despite the harm her physical body was subjected to (Bailey & Mobley, 2019). A century later, Lorde’s work in the revelatory and vulnerable *Cancer Journals,*
(1980) was one of the first works to highlight a Black lesbian woman’s struggle with cancer and blindness. The Caribbean poet, author, and activist chronicled her experiences in writing and by recording videos that would later become a documentary. She continued teaching at university as well, and her legacy will continue as a cultural producer.

To express the world in the ways they saw, lived, or imagined it, a plethora of Black women authors created new worlds. These new worlds came alive in their work as a refuge from the ravages of an unfair existence, and as a way to imagine possibilities not yet seen. Authors Octavia E. Butler, Tananarive Due, Nalo Hopkinson, N. K. Jemisin, Nnedi Okorafor, and Andrea Hairston are some of the brightest creatives to add much needed diversity to these overwhelmingly white genres of dystopian literature and science fiction. Toni Morrison and Alice Walker both wrote with magical realism themes and environments. They included “ghost stories, dream sequences, and other nonrealist literary devices” (Schalk, 2018, p. 21) in order to not only create new and better realities but to highlight the desire to have the realities of the anti-Blackness around them.

Other worlds were created at the hands, minds, and pens of these creative geniuses. Today, we have other authors writing no reflect a world more like the world they see and live in. These Black women authors, Talia Hibbert writes neurodivergent Black women characters in her romance novels (Get a Life, Chloe Brown), Theodora Taylor’s written (His Pretend Baby) with a main character and hero on the spectrum, and Alyssa Cole (Duke by Default) her novel has a neurodivergent heroine. These popular authors have taken their own experiences with disability and chronic illness and reflected the everyday nature of their characters' lives in their everyday lives, no dystopian or outer
space setting needed. This “normalcy” brings more attention to Black women and girls with conditions and dis/abilities that are considered neurodivergent.

The popularity of these authors today is linked to the cultural production of worlds other than what the average person is managing, and then on top of that, a Black dis/abled woman. In speculative fiction, the world of science fiction, and dystopian literature, it is a primarily White “world.” The creations of these Black women authors not only create new and imaginative worlds free of societal ills, but also create a world where their differences in ability, and portrayals of dis/ability is normalized. For other literature, creativity meets a future we do not yet exist in, and this cultural production comes as a continuation of Black women coming together to do new things. These new things have historically come about in Black feminist communities, and also have come about in literature across the range. Lastly, we see Black women creating their own cultural havens and large cultural productions online where technology is the biggest tool. The online spaces where these communities are being formed supplements the feeling of isolation many with these neurodivergent conditions and related comorbidities feel. This too, is history in the making and creates powerful community in a time where it is deeply needed.

*The world doesn’t deserve us*

*Creating the new, new*

*We are the new, new*

*We are not what’s old*

*But we are the past*

*And we are the future*
We are the mold

Standards, always gold

Black Studies

Studies in Black

Black in Studies

Studies Black

Who got next?

We are. We do. We will.


We all we got.
CHAPTER 2b
THEORETICAL FRAMEWORKS

The frameworks outlined here, serve as threads connecting the theoretical tapestry I arrived at this project with. The tapestry was already shaped by my lived experiences, and my curiosities surrounding Blackness and how it operates outside of the binary of Whiteness. Eschewing historical nods to this binary, my initial curiosities lead me to Black Studies as a field and general interdisciplinary thinking. In this way, it all comes back to Blackness, how Black people live with, make sense of, and how their Blackness materializes no matter the place. Firstly, Katherine McKittrick’s *Dear Science*, detoured greatly through Black Studies as it is typically known, as it appears via always changing Cultural Geographies or Black Cartographies, and the ways Gender Studies populates this broadening of Black Studies.

This project and my curiosities leading to its development begin with the grace of McKittrick’s words traversing works from essentialist Caribbean thinkers Edouard Glissant and Sylvia Wynter. Next central were works from thinkers and the intellectual worlds they’ve created. These ‘worlds’ have not been described as such by these scholars, but in my critical reading and imagining of their scholarship, the works help shape my ideas explored in this dissertation in a particular way. The works of Katherine McKittrick’s contribute to a universe where new ideas emerge regarding Black studies, place, space, and the power of Black things/thoughts/people. The works of Sami Schalk contribute to a universe where new ideas emerge regarding dis/ability studies, Black feminist studies, and science fiction studies. The works of Wilson Okello contribute to a
universe where new ideas emerge about the development of Black students, the identities of Black students using a Black feminist understanding, and using literature, such as work of Toni Morrison to explore the academic environment and Black students. These universes are not outright claimed by the aforementioned scholars, but they are my interpretive reading and meaning making of some of their works in the schema that developed over my time exploring this research topic and engaging with the study.

**Black Feminist Disability**

The framework that will be used to support this study is “Black Feminist Disability Framework” (BFDF) via Moya Bailey & Autumn Mobley (2019). This framework stems from their 2019 article entitled “Work in the Intersections: A Black Feminist Disability Framework.” The Black Feminist Disability Framework suggests that it serves as one because it centers race, gender, and dis/ability, challenging these generally siloed theories so that the realities and lives of the multiply marginalized are better understood. The Black Feminist Disability Framework succeeds at (and supports my research by) being emergent and intersectional. This framework allows various fields and disciplines to be used together.

This framework identifies that the widespread understanding that Black “resiliency” and Black “survival” inherently exists for *all* Black people is entirely ableist. This framework identifies that Black “hypervisibility” means Black subjects are “barred from weakness” while constantly being surveilled. This upholds a superhuman expectation for Black people in their day-to-day and erases their humanity altogether by this notion they are rarely unable to do, to perform, and be dis/abled all or some of the
time. This is additionally important when we consider the gendered response to Black women, a multiply marginalized group and one that frequently experiences erasure. Black Feminist Disability Framework strongly suggests that Black women’s identity categories (race, gender, class, disability) are consistently siloed from each other.

This separation causes two things: 1) Black women feel and choose different parts of their identity to center (but not at the same time), which contributes to a fractured way to live and view oneself, and 2) this continues in academic study and the fractured and incomplete nature of Feminist / Women studies, Black studies, and Dis/ability studies which mirror societal norms that view Black women as Black or Women, but not both - and certainly not dis/abled. This framework complicates the choices Black women must make, choices made for them, and historical rewrites of groundbreaking Black women. These rewrites miss an opportunity to tell the truth about Black women but also tell untruths about the impact of individuals living life with multiply marginalized identities (in this case, Dis/abled Black Women). The framework suggests that members of society, both academic and non, are being robbed of humanity and their own experiences.

I selected this framework because it urges both Disability Studies and Black Studies to be more inclusive and intersectional. By proxy, this framework “asks” higher education or academic institutions to do the same for neurodivergent Black women graduate students. Neurodiverse Black women graduates are whole as is, and the notion that they are expected to be “strong” and their disabilities are not taken as seriously, creates an environment where they are being told who they are by outside sources. Institutions do this with increasing matriculation from Black women but do not support them as whole people, with intersecting identities. These identities are all salient.
Neurodivergent and dis/abled Black women have made creative ventures into designing spaces that work for them and their dis/ability. These spaces are an adaptive response to the poor response by institutions in dealing with dis/abled students. This chronic mishandling of all their marginalized identities (focused on in this paper) race/gender/dis/ability, makes room for cultural production of newness, possibilities, and vital support against the isolation of invisibility.

**Blackness and Race**

The literature I’ve selected are consistent with supporting and shaping, my dissertation. With a focus on race, the first group of literature I’ve selected highlights race, Blackness, and dis/ability. Additional literature highlights how dominant ideologies and methodologies shape Blackness as identity, Blackness as self-conceptualization in the lives of Black students, and how Black students push back and center themselves. Lastly, additional literature supports recognition of and connection to autism, and *Black* autism, in the lives of dis/abled Black students.

My work in this study is centered on the Black Feminist Disability Framework (Bailey & Mobley, 2019) In my reading of the framework, race and Blackness plays a significant role in the lived experiences of dis/abled Black women. DisCrit (Anamma, Connor, & Ferri, 2016, serves as an additional framing for intersectionality between Critical Race Theory (Crenshaw, 2010) and Disability Studies. Both frameworks used together help me to think about race, Blackness, and dis/ability as they relate to Black women graduate students, their lived experiences, and understandings of (their)
Blackness. Perhaps most importantly, the frameworks support new and brilliant constructions of Blackness, not regularly seen.

The literature I’ve selected are consistent with supporting and shaping this, the theoretical framework chapter in my dissertation. With this chapter being focused on the theoretical frameworks that have informed my thinking, selected literature highlights Black feminism’s history, Blackness and race, Blackness, and dis/ability and ableism in the academy (Annamma, Connor, & Ferri, 2016; Ahmed, 2012, & Dolmage, 2017). The next literature grouping highlights how dominant ideologies and methodologies shape Blackness as identity (McKittrick, 2021), Blackness as self-conceptualization in the lives of Black students (Okello, 2020 & 2021), and how Black students push back and center themselves. Lastly, further literature supports recognition of and connection to intellectual worlds created by scholarship of Sami Schalk, Katherine McKittrick, Toni Morrison, and Wilson Okello. My reading, understanding, and compilation of some of these author’s works support larger ideas around disability in speculative fiction, geographies of Blackness, and John Henryism in the experiences of Black people in higher education (Schalk, 2018; Morrison, 1994; McKittrick, 2021 & 2011; & Okello, 2020).

**Disability & Ableism in the Academy**

The experiences of neurodivergence and dis/ability are distinct, and no one person’s experience of either is the same. Black women graduate students and dis/ability via neurodivergence, are infrequently recognized as existing alongside one another. Dis/ability Studies literature is historically written and researched without a true intersectional application of race. The neurodivergence of Black women (graduate
students) is often absent in recognition, but not absent from existence. Dis/ability’s over association with Whiteness obscures the reality of dis/ability’s association with Blackness. For Black women graduate students experiencing neurodivergence, the lack of visibility in the wider landscape of disability (culture and studies) is real. This unnecessary erasure furthers the ability to see the neurodivergence of Black women (graduate students), nor the dis/ability of Black women graduate students. Their dis/ability experiences must be made visible and understood and heard, whereas it typically is not.

In my reading of the Black Feminist Disability (Bailey & Mobley, 2019) framework, race and gender play significant roles in the experience of Black dis/abled women. This is also best supported by Black Disability Studies (Hinton, 2021) as a framework alongside the Black Feminist Disability Framework. Black Disability Studies serves as an additional framing for neurodivergence via dis/ability. Both frameworks used together help me to think about (Black) dis/ability via neurodivergence and dis/ability as it relates to Black women graduate students. Currently, neurodivergence is heavily racialized to reflect Whiteness and White people and is heavily gendered as male. Perhaps most importantly, Black Disability Studies helps the neurodivergence of both dis/abled and neurodivergent Black women graduate students to be recognized and to be seen.

Literature I’ve selected highlights Black women’s own neurodivergence, and the ways one can own themselves, their minds, and body (Pickens, 2019; Wynter, & McKittrick, 2015). The aspect of living in one’s humanity (Okello, 2020), adds to a simplicity often disconnected from dis/ability and dis/ability identity (Pickens, 2021).
Additional literature helps the reader to recognize a version of neurodiversity that is consistent with the lives and racial identity of my participants, Black women graduate students (Hinton, 2021; Gill, & Erevelles, 2017). Hinton’s Black Disability Studies, underscores this and rejects an understanding of one version of dis/ability and neurodivergence that is concretely White. This reclamation of dis/ability as Black recognizes that to know who is neurodivergent, we must first know who is not neurodivergent.

**Space & Place**

Environmental harm is real. It occurs on and off college campuses (Linder, et al 2019). Environmental harm is defined as the negative outcomes of power, oppression, and policies that add to an environment physically, culturally, or structurally. Neurodivergent Black women in graduate school experience the complexity of it. Ableism, like racism, and sexism can permeate any environment. Black women graduate students live nuanced and complex lives. Negative experiences in academic institutions can push a student to persevere or to leave. For neurodivergent Black women graduate students, they can redirect their energy to building community outside of higher education. Black women’s historical connection to cultural production helps them exit harmful environments, which as a communal strategy is consistent with the power of Black feminism.

Neurodivergent Black women graduate students are navigating burdens their classmates do not. These burdens result in a need to “step away” from institution-made places outside of their BodyMinds (Schalk, 2018), into self-created spaces. Higher
education’s steady admission of Black women graduate students is positive but can be quickly dissolved with the reality of ableism inside the academy.

This chapter’s focus on space and place is best articulated through the addition of Playing in the Dark: Whiteness and the Literary Imagination (Morrison, 1992) and Body Minds Reimagined: (Dis)Ability, Race, & Gender in Black Women’s Speculative Fiction (Schalk, 2018), as complementary frameworks.

Playing in the Dark (Morrison, 1994) reflects normative conditioning in higher education towards the “acceptable” (canon of literature and intellectuals) and seeks to hold up a mirror to the academy by interrogation. BodyMinds Reimagined reflects the will of dis/abled Black women to engage in spaces they create to their benefit. These frameworks tease out neurodiverse Black women’s will up against the collision of existing in academic places, and the power in cultural productions of welcoming spaces, whether they exist in social media platforms or in science fiction literature, and other forms of expression.

Both frameworks used together help me to think about my participants’ ability to navigate places like higher education institutions, and to create their own spaces that support them as they are. This cultural production can appear in a myriad of spaces outside of higher education physically. Morrison’s essay proves to be a great peek into her indictment of academic norms and the people they tend to leave out. Racialized dis/ability narratives/literature are sparse in higher education - Black women & dis/ability are less researched. Black women with dis/abilities are full members of all societies and place. Black women are whole and do not have to lean into a fractured existence,
especially at the design of power and oppression. the general challenges in academic
spaces that do not work to serve people with minoritized identities.

**Schalk’s Universe**

In Sami Schalk’s *BodyMinds Reimagined: (Dis)ability, Race, And Gender in Black Women’s Speculative Fiction*, literature takes center stage. In this work, speculative fiction (the types of creative literature that defies categorization and traditional techniques) is the site of a richer use of metaphor that Toni Morrison wrote about. The metaphors in the works that Schalk examines, are used in literature that defies norms, escapes realism, and depends on creativity to imagine new and different spaces for its reader, characters, and authors. This imagination of new spaces is used in part to advance the idea of “the representation of disability in Black women’s writing from slave narratives to contemporary texts.” (Schalk, p. VIII, 2018). Schalk’s *Bodyminds Reimagined* is the first monograph to focus on the representation of (dis)ability by black authors (p. 3).

Contemporary Black Women’s speculative fiction reimagines the possibilities and meanings of bodyminds, particularly in regard to (dis)ability, race, and gender. This reimagining changes the rules of interpretation, requiring modes of analysis that take into account both the relationships between (dis)ability, race, and gender and the contexts in which these categories exist. Contemporary black women’s speculative fiction changes the rules of reality to create worlds with new or different genders, races, disabilities, and other forms of life, and in doing so these texts also require a change in how we read and interpret these categories. (p. 3)

When Schalk uses the term speculative fiction, it is done so to encapsulate “creative writing in which the rules of reality do not fully apply, including magical realism, utopian
and dystopian literature, fantasy, science fiction, voodoo, ghost stories, and hybrid
genres” (p. 17). This umbrella for this broad base of literature encapsulates a variety of
activity within the creative works. This activity may reflect made-up dis/abilities, like the
hyperempathy that the protagonist, Lauren Olamina experiences in Octavia E. Butler’s
*Parable / Earthseed* (Parable of the Sower & Parable of the Talents) novels. This activity
may also reflect real dis/abilities like ADHD.

Further explanation of the exact speculative fiction Schalk included in the
umbrella,

the novels in this study do not collectively fit under any other single genre label, nor do
they all comfortably fit within other critical terms. For example, Mark Dery’s
*Afrofuturism* is primarily concerned with racialized uses of technology and the future,
while Marleen S. Barr’s *feminist fabulation* focuses on expressions of postmodern
feminist critique (Dery 8; Barr *Lost in Space* 11-12). Likewise, Ingrid Thaler’s term
*Black Atlantic Speculative fictions* is primarily concerned with race and nonnormative
notions of time, while *utopian literature* refers to ideal or (nearly) perfect imagined
societies and *dystopian literature* references its opposite; undesirable, nightmare fictional
worlds. (p. 18)

Further created a deeper understanding of the depth of worlds to examine. This
examination of modified, speculative fiction worlds essentially serves to center what
Black women’s *literature* and literary practices produce, but also a juxtaposition of the
need to produce, and the impact of the productions themselves. The decisions to focus on
(dis)ability sharply destigmatizes it, but also humanizes race, gender, ability; three
identity markers that have not been integrated nearly as much as it should.

In Schalk’s universe, there is power when Black women see and act upon what is
merely a dream, and not yet reality. The legacy of these creative Black women novelists
is far reaching. “Black women novelists have been central in the “effort to interrupt the
realist legacy” of African American literature.” (p. 21) The power that Black women possess is to create and reimagine their interactions with systems of oppression and people that subjugate. This power further arises when turned into artistic experiments, writing, creating new art, coming together in community to upend the stigmas of disability, Blackness, and womanhood. This is just done in *Bodyminds Reimagined* by celebrating the Black bodyminds to come, and those not yet in existence or dream.

**McKittrick’s Universe**

Katherine McKittrick has written extensively on Blackness, Black people, Black women, Black Studies, and Black people and geographies. Black women’s movement in the world as a result of displacement, slavery, and colonialism. In *Demonic Grounds*, McKittrick furthers the ideas that Black women have “geographies of domination” and “geographies”:

*Demonic Grounds* is, in its broadest sense, an interdisciplinary analysis of black women’s geographies in the black diaspora. It seeks to consider what kinds of possibilities emerge when black studies encounters human geography. Drawing on creative, conceptual, and material geographies from Canada, the United States, and the Caribbean, I explore the interplay between geographies of domination (such as transatlantic slavery and racial-sexual displacement) and black women’s geographies (such as their knowledges, negotiations, and experiences). The interplay interests me because it enables a way to think about the place of black subjects in a diasporic context that takes up spatial histories as they constitute our present geographic organization. The relationship between black populations and geography- and here I am referring to geography as space, place, and location in their physical materiality and imaginative configurations - allows us to engage with a narrative that locates and draws on black histories and black subjects in order to make visible social lives which are often displaced, rendered geographic. Black histories where, for example progress, voyaging, and rationality meet violence and enslavement are worked out in geography, in space and place, in the physical world. (p. x)

There is an acknowledgement of the various ways Black people and blackness has been impacted by movement, and by environments outside of their collective control.
Blackness (and its people) regular interplay with power and place does not indicate a shortcoming in the group, but rather - a creative, inventive, and imaginative people (and their response) to turmoil. This nod to geography and its ever presence connects to the geography of educational institutions my participants are experiencing. These fourteen institutions they are enrolled in all have their own geography in the way McKittrick refers to “geographies of domination.” The way Black women graduate students shift the narratives of the educational environments they’re in, speaks to the same “imaginative configurations” along with the “physical materiality” of their graduate schools, colleges, and programs.

The struggles that McKittrick speaks to is boundless. It can be experienced anywhere - with the consistent target of such struggles being Blackness. Regardless of potential for a more equitable experience, these anti-Black histories and stories move anywhere. Any environment, and any place can be made to be a site of harm.

McKittrick’s work in *Demonic Grounds* and *Dear Science and Other Stories*, both identify geographies as a rejection or response of poor post-slavery existence. In this, geographies for Black people it is an inconsistent solvent for this global harm (transatlantic) but the more consistent and profitable racism and oppression manage to be just as transient as the people it harms.

Geographies though, do not rob the black subject of their own autonomy (albeit sometimes limited), in taking matters into their own hands. The Black subject moved where they were told there was possibility, where they thought there would be a less harsh outcome. The “fugitive, underground, maroon” (McKittrick, p. 11, 2021) nature of Black geographies, as it’s been described was a reaction to specific historical experiences
but may also be expanded to the harsh anti-Black and ableist institutions that are higher education, but this time, that our Black subject willingly enters. Black geographies lead Black women to institutions of higher learning for betterment, and Black geographies lead Black women to create their own (literary, online, technology, art, Blerd⁴ life anime) spaces aside of those harmful places. McKittrick’s read of Sylvia Wynter’s take on geography is that otherness is always afoot “besides the dominant cultural logic.” (McKittrick, p. 123). Further, there are these important questions regarding Man and geography:

- So, how do Man’s geographies get formulated, cast as natural truths, and become overrepresented?
- How does this politics of mapping, and making space, shed light on the repetitive displacement of the planet’s nonwhite subjects?
- Can the naturalized but alterable geographies of black women, and subaltern subjects in general, be understood in ways that do not replicate our historically present spatial patterns?
- What kinds of new and possible spaces are made available through our past geographic epochs?
- What can Wynter’s discussions of “our fully realized autonomy of feeling, thoughts behavior,” her representation of the human subject, bring to bear on geography and geographic knowledge? (p. 123)

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Lastly, in McKittrick’s universe, it is asserted that “we,” Black people do not arrive at space without first experiencing place. Place and Blackness have exclusively come about together due to the aforementioned horrors of slavery and post-slavery life. In McKittrick’s Plantations, Prisons, and a Black Sense of Place, this extends throughout and is applicable to (American) history.

Part of the beauty in McKittrick’s universe is that it both acknowledges the outside influences and its impact. Here, the outside influence is power gone unchecked. This power and domination outside of Blackness has impacted Black people, Black existence, and the Black being. This Armageddon amidst structural and unobstructed power has triumphed during history. In its wake, this wake, racism is both built and blocked.

This is to say that the racial underpinnings of modernity, of which transatlantic slavery and colonialism are salient features, situate black people and places outside modernity, just as black people and places fully participate in the intellectual narrative of modernity. With this in mind, a black sense of place can be understood as the process of materially and imaginatively situating historical and contemporary struggles against practices of domination and the difficult entanglements of racial encounter. Racism and resistance to racism are therefore not the sole defining features of a black sense of place, but rather indicate how the relational violences of modernity produce a condition of being black in the Americas that is predicated on struggle. A black sense of place can also be understood alongside Massey’s (1994: 149) ‘sense of place’, which is ‘about what one might call the power geometry of it all; the power geometry of time - space compression… This point concerns not merely the issue of who moves and who doesn’t… it is also about a power in relation to the flows and movement. Different social groups have distinct relationships to this anyway differentiated movement: some people are more in charge of it than others; some initiate flows and movement, others don’t; some are more on the receiving-end of it than others; some are effectively imprisoned by it. With a black sense of place in mind, the plantation notably stands at the centre of modernity. It fostered complex Black and non-black geographies in the Americas and provided the blueprint for future sites of racial entanglement. Diverse spatial practices - wherein the structural workings of racism kept black cultures in place and tagged them as placeless, as those communities
innovatively worked within, across, and outside commonsense cartographic and topographical texts - help form a black sense of place. Thus, that which ‘structures’ a black sense of place are the knotted diasporic tenets of coloniality, dehumanization, and resistance; this is a sense of place wherein the violence of displacement and bondage, produced within a plantation economy, extends and is given a geographic future. (p. 949)

Again, power is built up for some, and power is blocked for others. The modernity McKittrick speaks of refers to where Black people can go, the directions Blackness can take when the journey is made with freedom and liberation in mind. The power of imagination and the Armageddon of imagination is so massive, that one can believe a Black future and Black geography fueled by Black people and Black ideas is possible. The violent geographical and spatial movements have been the norm, defining place and who is placeless. A new world is a possibility.

Diverse spatial practices have been used for harm. It is unexpected when used as a tool to free oneself. New and diverse spatial practices support Black people’s positive movement to new spaces unseen and unencumbered from history as McKittrick’s excerpt above indicates. These spatial practices are rooted in deep imagination, creative practices, and the beginning of a new Black story. When the world becomes too intense, the gift of literary imagination, speculative fiction, and artistic expression serves Black people well. Lastly, McKittrick’s notes on the use of metaphor in literature and language stems from her insertion of Toni Morrison’s statement on metaphor, into her argument on the black story mattering, and the intellectual task of getting in touch with our analytical worlds (McKittrick, p. 11, 2021).

In Toni Morrison’s Playing in the Dark: Whiteness and the Literary Imagination, there is a refrain on metaphor and the living of life. “It is worth repeating then, that this is
not a request to abandon metaphors. We need metaphors! Metaphors offer an (entwined material and imagined) future that has not arrived and the future we live and have already lived through.” (McKittrick, p. 11, 2021; Morrison, 1990) While Morrison’s *Playing in the Dark* stems from a speech given at an American university and is pointed in its reclamation that American literature is *not* without African Americans. It also pushes back against the Whiteness of the canon of literature and its effectual whitewashing of an American experience, while almost weaving Blackness and Black people in on the dirty, mangled periphery. The academic canon of acceptable and lauded American literature attempts to use race.

I am prepared to be corrected on this point insofar as it misrepresents the shelf life of racism in social and political behavior. But I remain convinced that the metaphorical and metaphysical uses of race occupy definitive places in American literature, in the “national character, and ought to be a major concern of the literary scholarship that tries to know it. (p. 52).

**Okello’s Universe**

Hallmarks of the scholarship from scholar Wilson Okello are authenticity in student development, truth, centering the black feminist epistemology, and the integration of literature and poetry. While this is not an exhaustive compilation of Okello’s full library of scholarship, it is a compilation of what has furthered my thinking, contributing to my dissertation topic. In “*Loving Flesh*”: *Self-Love, Student Development Theory, and the Coloniality of Being*, Okello highlights the power of black students finding their voice, “love [their] flesh,” and navigate higher education’s remnants of coloniality in their day-to-day lives (2020). His use of Toni Morrison’s (1987) *Beloved*, honed in on the
importance of self-love, and a desire for Black students to follow. “Baby Suggs, an elder, preached to a group of formerly enslaved Black folx about the necessity of self-love,” (Okello, p. 717) and it is followed by Morrison’s urgency and clarion call to be heeded (1987).

Here… in this here place, we flesh: flesh that weeps, laughs; flesh that dances on bare feet in the grass. Love it. Love it hard. Yonder, they do not love your flesh… Love your hands! Love them. Raise them up and kiss them… You got to love it, you!… More than the eyes or feet. More than the lungs that have yet to draw free air. More than your life-holding womb and your life-giving private parts, hear me now, love your heart. For this is the prize. (p. 88)

The call for those at the feet of Baby Suggs was for them to radically love themselves. The call for Black students is to love themselves, despite the extension of slavery’s harm to Black people and the harm of higher education institutions to Black students. “As extensions of White supremacy, higher education, contexts are rooted in colonization (Wilder, 2013). On this premise, Black students daily contend with the afterlife of coloniality (Maldonado-Torres, 2007) externally and internally” (p. 718). Okello posits that Black arts of letters and literature may shape development of the ways student development can be theorized in an anti-colonizing way (2020).

Further, his work intimates that meaning-making and self-authorship is an asset to Black students in higher education institutions. His use of literature and specifically, a Black feminist literary theory sets up a pathway for literature, and the voice, the strength of spoken words in facing the odds and traumas in their educational experiences (p. 722). This also creates a livable experience (2020). Okello also acknowledges that Black feminism contributes to self-authorship and self-definition.
Black feminism serves as a theoretical intervention that is duly unexplored. Black feminism has a deep intellectual tradition that has been used by educators like Gloria Ladson Billings and Venus Evans-Winters. Black feminism relies on the personal being political. Okello’s proposal of a new student development theory is the sociopolitical, which stems from a recognition that black feminist political thinking “demands a deliberate reckoning with the affective, physiological, social, historical, and political oppressions engendered by living in a minoritized body (Wingfield, 2015).” (p. 533) In another scholarly article, Okello brings forth the multiplicity of Black student experiences in an article entitled, Organized anxiety: Respectability Politics, John Henryism, and the Paradox of Black achievement (2020).

Taken from the folklore of John Henry, John Henryism is the outcome of exertion and exhaustion after outside pressures for perfectionism. John Henry faced intense pressures to be a dominant physical being, besting any man versus machine match. After one particularly challenging race, he collapsed and died. More specifically, “Henryism, thus is described as a ‘disorder, disposition, personality trait, or perfectionism’ (McGee and Stovall 2015, 498). John Henryism is a construct characterized by three major themes: efficacious mental and physical vigor, a strong commitment to hard work, and a single-minded determination to succeed. Furthermore, Henryism describes the ‘poor physical health outcomes among individuals who must respond to chronic strains that overwhelm their coping skills’ (McGee and Stovall 2015, 498). Henryism as a construct draws comparisons to what is commonly referred to as respectability politics, or the active adoption of standards rooted in whiteness (Kinchelo and Steinberg 1998; Mills 2014) as a regulatory instrument of ones' behavior and emotions. (p. 1). This construct of
Henryism and respectability politics within the Black educators and Black student affairs professionals’ communities can be extended to Black graduate students, though not originally written that way.

The history of Black women’s intellectual contributions cannot be erased, but there are always attempts at minimization (Harrison, 2022; Bay et al., 2015; & Harris, 2003). Meritocracy’s application with a new racialized twist appeared as subtext of Henryism - it almost now encouraged Black people to “present themselves as exceptional, which inherently stated that their existence carried an essence of inferiority, yet not irredeemably so. Black people could overcome their troubled nature by hard work and the achievement of notable successes.” (p. 3) This chase to excellence can be pathological if it is not rooted in something more self-led and self-motivated rather than reactivity to programming as a result of an oppressive history. Regardless, Black people, and Black women in particular want to be seen as “fully human and full citizens” (p. 6).

Achievement in this manuscript denoted the ways Black student affairs educators and professionals progressed through institutions of higher education. Black achievement in itself has functioned in the social imaginary as a paradox, or set of ideas, which are inconsistent (Dancy 2014). In spite of the ways these ideas do not fit together neatly in the public sphere (Pough 2003), Black people in many situations continue to maintain efficacious mental and physical vigor, a strong commitment to hard work, and a single-minded determination to succeed (James 1994), largely rooted in a historicized framing of inferiority. Much like the tale of John Henry, racial battle fatigue pits human versus machine. In this scenario, though Black folks demonstrate extraordinary persistence, one must ask, what is the mental, emotional, spiritual, and physical cost of their labor for and against a machine that will always require them to do more? Henryism prompts Black folks to overcompensate for their perceived deficiency with efforts that may, at worst, cost them their livelihood, and at best, earn the applause of those in power. (p. 16)

Labor that is un-edifying is poisonous. Racial battle fatigue is exhausting. Black folks are tired. And we want to claim the light. Black women graduate students are like teapots, special, to be handled with care, and they give until they’re tapped out.
CHAPTER 3

METHODS

Positionality Statement

My positionality concerning this research study is similar to those of the community (neurodivergent Black women graduate students) I sought to engage with. As a critical thinker, and a neurodivergent Black woman graduate student, I am deeply linked to this community since I am a member of it in a larger sense. This supports the research because it provides me with additional insight and cultural competency. Centering Black feminism (Bailey & Mobley, 2019, Collins, 2000) and intersectional identities (Collins, 2019, & Collins & Bilge, 2016) is important in the design of the study, particularly since my identities mirror the community of students I sought to engage with. Most importantly, my chosen methodology in data collection will honor the diversity and multiply marginalized identities of the neurodivergent Black women graduate students.

Considering the ways my identities and perspectives may share similarities to my participants, it may be an asset in easily identifying some things, while perhaps not being an asset due to those same similarities (or shared identities). I expect this similarity in identity (race, gender, ability, level of study) to be an asset while conducting my interviews as well as data analysis. I find this to be significant for these reasons, and for an intended understanding, portrait, and betterment of the Black women graduate students I will be in conversation with. I am conducting this research and writing this dissertation for them. Second, I am writing this dissertation for student affairs
practitioners and disability center staff across higher education institutions. Finally, this dissertation and accompanying research is written to support faculty members as they continue to navigate accommodations for their students.

This research study is critical and qualitative in nature. My choices and paradigm as a researcher are informed by my worldview which is a critical one. My methodological tool, Portraiture, was selected for this dissertation study and upholds my critical worldview and life experiences as a Black woman in higher education. This criticality lays the foundation for displays of power and oppression to be examined and questioned. I have used semi-structured interviews as a vehicle to collect data. Again, the methodology I have chosen for my dissertation is Portraiture, and a breakdown of my chosen methods follows below.

Methodology: Portraiture

My use of Portraiture as the methodology in my dissertation is not accidental. This method’s existence is largely credited to educator and social scientist, Sara Lawrence-Lightfoot. Lawrence-Lightfoot, a sociologist, designed Portraiture expressly for use in educational research (Lawrence-Lightfoot, 2005 & Hackmann, 2002). Portraiture as a methodology is a rigorous, intimate, and detailed methodology which prides itself on being a “cross between art and science, its blend of aesthetic sensibilities and empirical rigor, and its humanistic and literary metaphors.” (Lawrence-Lightfoot, 2005 p. 4) Portraiture is both analytical and community-minded in nature. In this methodology, the researcher or portraitist crafts their data and findings in a way as to shape the story. This storytelling centers on what participants share (O’Dea, 2021).
What sets portraiture apart is that the researcher’s “identity, character, and history are obviously critical to how he or she listens, selects, interprets, and composes the story” (Lawrence-Lightfoot, 1994). The researcher’s “self” has a “central and creative” role in the work and how it is disseminated. While all researchers display and engage in being reflective (to varying degrees), there is a level of objectivity that is standard good practice. Objectivity remains something to be pursued by the researcher or portraitist. I am the researcher, the portraitist, and the instrument behind this project. When referencing the “researcher / portraitist,” as Lawrence-Lightfoot intended, it is also meant to indicate the role and the person facilitating the duties of the role, in this case - myself. In addition to the researcher’s self, the researcher’s person becomes more entwined in the work and reporting of it. This is to say, the researcher as a portraitist:

Is seen not only in defining the focus and field of the inquiry but also in navigating the relationships with his or her subjects, in witnessing and interpreting the action, in tracing the emergent themes, and in creating the narrative. At each one of these stages, the self of the portraitist emerges as an instrument of inquiry, an eye on perspective taking, an ear that discerns nuances, and a voice that speaks and offers insight. (Lawrence-Lightfoot, 2005 p. 11)

This design and methodology are appropriate for my study because criticality are central elements of both. Furthermore, this methodology has allowed me to highlight the lived experiences of neurodivergent Black women graduate students via their own words and the subsequent storytelling that has arisen from the process of data collection.

The data that has been collected stems from the real-life experiences of members of this community (NDBW) who were willing participants in my study. Their participation renders me as a researcher/portraitist responsible for “capturing the
complexity and aesthetic of human experience” (Lawrence-Lightfoot, p. 4., 1997) and to “paint with words” (Lawrence-Lightfoot, p. 4, 1997). It is my intention with Portraiture as my chosen methodology, to move beyond the studying and holding up of participant experiences but be sure to humanize the neurodivergent Black women graduate students, who are central to my portrait of them. To that end, this methodology allows me to analyze their experiences, story them, and most importantly, implore others to hear and listen to them.

Portraiture as a method places the researcher as central to telling (Lawrence-Lightfoot & Hoffman Davis, 1997). Portraiture focuses on voice in “epistemology ideology, and method, reflecting the portraitist’s explicit interest in authorship, interpretation, relationship, aesthetics, and narrative. Six central ways the portraitist uses voice are voice as witness, second, voice as interpretation, third, voice as preoccupation; fourth, voice as autobiography; fifth, listening for voice; and finally, voice in conversation” (Lawrence-Lightfoot, p. 87., 1997). Portraiture as a method relies on deep reflection and re- reflection, memo-taking, and diving deeply to constantly revisit questions they ask and answers they receive. Portraiture is a derivative of ethnography (connected to ethnography), (a very specific type of ethnography), and is critical in nature.

Poetic Inquiry: Arts-Based Inquiry

Due to Portraiture’s focus on the researcher/portraitists’ ability to bring themselves to their research, to bring themselves to their participants’ stories, and to use their voice to interweave their experiences into their analysis, it was the obvious choice
for my study. Using arts-based research methods such as poetic inquiry as support to Portraiture, allowed me to express sentiments that could not otherwise be expressed as accurately. Seven main features of Arts-Based research (Barone & Eisner, 1997) are: “1) The creation of virtual reality, 2) The presence of Ambiguity, 3) The use of expressive language, 4) The use of contextualized and vernacular language, 5) The promotion of empathy, 6) Personal signature of the researcher/writer, & 7) The presence of aesthetic form.” (Esposito & Evans-Winters, p. 66, 2021) My acknowledgment of the power and reach of Arts-based research methodology is not to de-center Portraiture as the chosen methodology for my dissertation research. It is to further highlight the modality in which I have chosen to assemble some of my portraits.

The assembly of some of my findings, and other elements of my dissertation via poetic inquiry occur not because some things are best expressed poetically, but because my data can be presented in ways that highlight my participants “experiences in a direct and effective way (Prendergast, 2009, p. xxii)” (Esposito & Evans-Winters, p. 66, 2021). Using poetry to share data creates “cognitive and sensory” awareness, allows the “reader to experience the research findings in a visceral way” and lastly, “we are drawn to poetic inquiry because it allows research to be an embodied process informed by the lived experience and knowledge of the researcher.” (Esposito & Evans-Winters, p. 66, 2021) Poetry and poetic inquiry support the interpretation of what participants have shared with me.

Poetics as arts and poetics as data analysis are used in this dissertation as research-driven poetry. The three types of research-driven poetry are researcher-voiced, participant-voiced, and literature-voiced, and they are categorized by the voice most
engaged in the particular poetry (Leavy, p. 87, 2020) In this process of data collection, writing post-interview memo’s, and data analysis; as the researcher and instrument, I was keenly aware of the potential for this practice to support my evoking different meaning from the data and navigate deep thoughts and questions as a result of writing poetry. Lastly, it helps my audience and reader absorb the data in a variety of ways (due to the subjective nature of art and poetry). (Leavy, p. 86, 2020) Poetry is a powerful supplement to the honesty, authenticity, and strengths of Portraiture. Portraiture demands a truthful researcher and an observant one. According to Faulkner, “poetic inquiry” can be used “as both a method and product of research activity” (Faulkner, 2019, p. 14). I am using poetry and poetic inquiry to tell a more buoyant bit of the story of my participants, and to strengthen a more pedagogical tool in the hopes of expanding understanding of the many worlds inside of the academic ones my participants exist in using some of their own words and my own words.

**Design**

The design for this research project contained many elements en route to the start of data collection. In consideration of the hoped outcome (for my potential participants), I wrote and executed my design so my participants would be seen, heard, and respected. It was important to follow best practices and academic ethics for every part of this research project.

In my Institutional Review Board (IRB) documents, I reworked and wrote them to do several things. These were to 1) submit clear and concise documentation of my plans to conduct research on human subjects, 2) ensure that my documents were meeting the
institutional norms for conducting said research, 3) my interview protocol was supportive of open yet directed questions, and 4) my recruitment documents were easily accessible on various social media platforms and listservs, and 5) that my online screening and demographic surveys were legible, and simply written. After receiving IRB approval, I began to work on my marketing plan. Just prior to that, my demographics survey and screening questionnaires were uploaded online.

The two surveys were divided as such so as to not overwhelm an individual with a short attention span or focus and executive functioning issues. My demographic and screening questionnaires were made for use on Qualtrics software, and I created a unique shortened hyperlink for easy online sharing, and for less potential strain on readability for my potential neurodivergent participants. Throughout my design process and my data collection, I continued to tweak aspects of the experience based on commonalities in what was occurring in interviews, or similar questions my participants would ask. Designing and implementing a research project with a dis/abled or neurodivergent population in mind, required great attention to detail, a quick capture of tools or technologies (Gutsell, 2013) that may not work well for participants, and to keep accessibility at the forefront (Fitzwater, 2018, & Berger & Lorenz, 2016). Both questionnaires averaged 15 questions and would take approximately 15 to 30 minutes for someone to complete.

I utilized the settings for Qualtrics to allow for a “customized” experience for anyone interested in participating in the study. For example, such settings allowed for people to have their own links generated, to have a progress bar with a percentage indicating survey completion at the top of each webpage, and where applicable, Likert
scale question (Fowler, 2013) and answer, and fill-in (multiple choice) responses. I organized the settings so everyone would receive reminders in their email if they had not completed the survey. Capturing their university email near the start of each survey was important so that I could contact them.

My marketing plan consisted of a mix of social media (Twitter, Facebook Groups, Instagram), ADHD & Neurodivergence online advocates, online influencers, disability influencers, and listservs in and around higher education. Author and health advocate, Rene Brooks agreed to tweet about the study to her sixty-four thousand Twitter followers and allowed me to post about it in her Black women and ADHD Facebook groups. Emails were also sent directly within my network of graduate students, junior faculty, and graduate student organizations. The IRB-approved email template that was included in my documentation was used to connect with various people via email. My Instagram, Twitter, and Facebook group posts were sent with a brief & catchy caption to maximize the incredibly fast nature of social media. Furthermore, the e-flier that I designed was front and center in all posts. I designed e-fliers in Canva and made sure to use colors (black & white) for text & typography and sentence structure which kept attention and was easier to read, and more accessible (Williams, 2015). Rather than using age restrictions or official diagnosis as parameters for inclusion, I removed the age restrictions, and official diagnosis as an inclusion point.

Once respondents were found eligible to participate in the study, a series of email communication that I had pre-written and used Microsoft outlook technology for was disseminated. I programmed the email scripts to go out to each person ahead of time. This allowed me to send consistent messages, and have them “pre-programmed to send
out with one or two quick keystrokes was important for me as a researcher sharing the same identities as my participants. Furthermore, each was sent one document (and main direct ask) at a time, as needed not to overwhelm them. I also utilized Google forms (which is secure) to have each eligible and approved participant upload their signed informed consent forms. Technology was a constant tool in my design, data collection, and analysis. Next, I then used Calendly to have participants book their own interview times whenever was convenient for them, so they did not have to wait for me to respond to an email indicating when I could or could not meet. This was intentional so they could fill it out at 2 am if necessary, as many people with these conditions are up late at night working. I scheduled three reminder emails to be automatically sent to participants ahead of their interview, in the timeframe of 5, 2, and 1 day ahead of their scheduled interview. Bookings could not be made less than six days out.

**Data Collection**

Unlike quantitative inquiry, where the researcher comes with specific hypotheses to be tested, discrete propositions to be proved or disproved, detailed interview questions, predetermined observational schedules, and a well-defined research plan, the portraitist enters the field with a clear intellectual framework and guiding research questions, but fully expects (and welcomes) the adaptation of both her intellectual agenda and her methods to fit the context and the people she is studying (Lawrence-Lightfoot & Davis, 1997, p. 186).

After approval by IRB, recruitment tools consisting of e-fliers for social media and text of an email to be shared with listservs were disseminated. E-fliers were shared in
online spaces where graduate students frequent, such as graduate school-oriented Facebook groups and message boards and forums. Personal email invitations will be sent to affiliate identity groups like “Black Student Unions,” “Women in Business” or “Women in STEM,” for example. They will also include information about participants receiving an e-gift card, according to participation goals being met.

Data collection for this project will involve multiple steps beyond the dissemination of recruitment materials. First, interested participants will fill out an online demographics form on Qualtrics, followed by an online eligibility screener, also housed on Qualtrics. These serve to collect information and determine participant eligibility, but also so each minute in the interview can be used intentionally. Learning whether a participant has been diagnosed prior to our interview allows me to spend time learning “what diagnosis means” to them. That sort of response yields a more robust data set in this data collection process. Once three times the original (4), desired number of participants (equaling 10-12) have filled out the Qualtrics screener forms, recruiting became closed. After sorting through the screeners, fourteen eligible participants were contacted via email.

Their email contained informed consent forms (for them to sign & return via secure online site for upload), attached, and encourage them to contact me with any further questions. The body of the email contained thank you’s to them for their interest and informed them they’ve been found eligible to participate, and that those who’ve completed the interview process, will receive a small token of a $10 e-gift card to Amazon. There was a reminder of the 90-minute time commitment and that a stable internet connection is necessary to be interviewed online. Lastly, they were given a link
to an online scheduler (Calendly) to select their interview time of no more than 90 minutes, though some interviews went as long as 150 minutes.

Semi-structured interviews were conducted over the secure, university provided Zoom platform. Participants were given the opportunity to select their own pseudonyms prior to beginning their interviews. During interviews being conducted, participants were asked to confirm their university email so that it could be used again later. It was used to confirm the counseling center associated with the graduate institution they attended. Afterward, participants received an email to that address, thanking them for participating and asking them to share the e-flier with their network. It also included contact information for their individual university-affiliated mental health resource and campus counseling center. It also included an original and curated, eight-page, post interview resources guide that I made for participants with links to websites, support groups, podcasts, books, and more, that they could learn more about being neurodivergent, and more about specific conditions. I modified this once more to add resources for OCD as well. These were free resources I cultivated and wrote just for them, after my first two interviews. I felt that my participants needed more as a takeaway after the interviews. It was clear to me that they were fairly isolated, managing graduate school and their neurodivergence the best they could. Any opportunity to provide them with free additional resources was a welcome one. My interview protocol explored their experiences, regarding race, space/place, and dis/ability. I wrote post-interview memoing prior to doing my analysis, for each participant I interviewed.
Setting & Sample

Portraiture is comprised of these aspects: context, relationship, voice, the aesthetic whole, and emergent themes. Contextually, the research site is as important as the researcher. Portraiture allows for the “physical, geographical, temporal, historical, cultural, and aesthetic nature of the research site, participants, and their experiences” (Lawrence-Lightfoot, 1997, p. 41).

The study is based (I was granted permission to proceed) at the University of Massachusetts Amherst (UMass), a public, land grant, four-year, research and doctoral degree-granting institution in the New England region of the United States of America, as that is the university I attend. The study participants, however, are enrolled in various higher education institutions across the country. The site of the study is further complicated by the ongoing Covid-19 global pandemic, as a) all interviews were conducted virtually, and b) all interviews took place wherever participants had a strong internet connection, and a private space to engage in conversation. Preferably, their interviews took place at home, but some took place in their offices or their place of work. Furthermore, many interviewees had to consider their children studying from home, partners working from home, and the occasional mail delivery as interruptions.

In my role as researcher and portraitist of this study, I applied my knowledge of the neurodivergent graduate school population who made up my participants, to provide flexibility for them. Similarly to Dillard’s (2006) connection to her spiritually grounded qualitative research work on African American women in the academy, (as cited in Toliver, p. xiv, 2022) my connection to the research topic and my participants is partly
from shared lived experiences and the time spent in online communities with this population. Instituting flexibility in the experience for my participants, paid respect and acknowledgment to their experiences with neurodivergent conditions, and level of comfort via accommodations. This aided in building trust with my participants and is fully supportive of strong rapport and connection (Esposito & Evans-Winters, 2021) between myself as the researcher and my participants.

My study and its success were in part influenced by the specific eligibility qualifications. Due to the private, expensive, inaccessible, and deeply personal experiences related to diagnosis and dis/ability, it was not made mandatory that participants have a diagnosis. Without those qualifiers, any interested participant who was found eligible could participate in the study free of the necessity to have a diagnosis. This was done specifically to uphold that one could live with a dis/ability or a condition, and not be diagnosed and that while the pathway to diagnosis is more difficult for Black women, it would not be reified in this study, nor would it be used as a barrier. My participants range in age from 18 - 50. Eleven of my fourteen participants were enrolled in doctoral programs of study. 100% of my participants identified as Black and women.

Data Analysis

My data analysis was guided by the themes and the Black Feminist Disability Framework (Bailey & Mobley, 2019) which is the theoretical framework for this project. My data analysis included three coding cycles and one final phase of interpretation. My first coding cycle has included both inductive and deductive coding. I began by using deductive codes reflecting the concepts from my interview protocol and the Black
Feminist Disability framework (Bailey & Mobley, 2019). These are the twelve codes connected to my first order coding: race and being, race and stigma, race and support, disability and inclusion, disability and self-identification, dis/ability and disparities, higher education and accommodations, good online community, creativity, creating community, adaptive responses, and lastly, new futures. These are informed by my theoretical frameworks and by my literature review. In addition, I used open codes to identify recurrent patterns in participants’ experiences and meaning making. Where possible I have used participants’ own words for these codes through a process called NVivo coding using the NVivo qualitative data analysis software. It should be noted that the NVivo qualitative data analysis software was the technology used to facilitate and execute my analysis process.

After the initial coding, I then analyzed by examining the patterns in codes, looking for categories that bring together the most important ideas in my study. Examples of categories that could appear in my second round of coding include neurodiversity, disability identity, culture, participants higher education experiences, and categories related to my participant’s higher education experiences. In addition, I will compare my coding to prior literature on neurodiverse disabled Black woman graduate students to ensure that I’m thinking holistically about their experiences. This will also help me understand where my participants’ experiences might not be represented by existing literature.

My third-order coding process was a majority inductive process. My goal was to bring together multiple categories and therefore begin to explore the connections between them. A key step in this stage of coding is storying the data. To do that, I looked for verbs
that connect one category to another. In my third-order coding, I explored the relationship among all my categories.

After completing my formal data analysis (in three phases), I engaged in a portraiture process as a final interpretive step. In this step, I then selected representative participant excerpts which were then grouped together and written in a way where research questions are answered, pieced together, and display their overall and shared experiences. In portraiture, this can appear as “participant E” and “participant F” both having their own short (1-2 pages) storied vignette which spotlights them. I folded data from my participants into responses to the research questions. This allowed me to narrate the overall story from my participants and has served as a snapshot of participants’ narratives told in a way that highlights the story of them, sans analysis. These vignettes will be sectioned together in my retelling of their narrative, and altogether, it serves to repackage their story. It was important to show who my participants are in the context of each other, as they would never be in a room together.

Traditional qualitative analysis still occurred but was storied differently from the participant’s brief highlight. Portraiture as a method is open to a researcher’s interpretation, (how the portraitist observes, and reconciles what they are documenting) and is meant to be highly representative of one’s participants. My process in the analytic stage was further strengthened by the themes and coding process I have used. Both are central to portraiture, as again, this methodology relies on the researcher’s knowledge and lens to move in tandem with the dataset. What this allowed me to do, is to truly represent the sacred and important details that my participants entrust me with, while allowing
what they share to take center stage in their vignettes. This does not take away from analysis or shortchange the broader experience of data analysis.

Data Quality

To ensure reliability and credibility in my dataset, I will employ member checking during my interviews, by repeating and affirming what will be shared with me. The role of the researcher in qualitative research is instrumental to the work. In portraiture, the researcher (also referred to as the portraitist) is even more so. In portraiture, I as the researcher/portraitist embodies the work of being the instrument for both a retelling and restorying of participant experiences. As a result, in the methodology of portraiture, it is critical for the researcher/portraitist to engage in ongoing reflection. This is done using journals, memos, and a critical lens. This specific engagement during data analysis should result in a researcher/portraitist knowing themselves well enough to do two things. First, a researcher/portraitist who knows themselves very well will be able to incorporate their own story into the stories of their participants. Secondly, this primes readers to gauge the extent to which the researcher has become reactive to the stories being told in their study.

Lawrence-Lightfoot’s (1997) portraiture reflects an expectation for deep reflection, connecting to memory, and a consistent ability to reexamine yourself with what your participants share. This level of detail adds to already rigorous qualitative norms, while pushing authentication further by toggling back to the protocol questions, adjusting in real-time as needed and as your interviews dictate. In portraiture, there is an understanding that qualitative research changes and moves. There is no opportunity for
static reflection or stale mapping of the arc of this mode of qualitative research. This works to further secure integrity and trustworthiness in the process, one’s analysis, and ensuring portraiture’s built-in rigor. In this way, portraiture is a science and an art (Lawrence-Lightfoot, 1997).

To shift the criteria to which my research will be assessed, it is important to recognize that most qualitative researchers operate within normative social science paradigms. These norms in validity typology are drawn from quantitative work or are at least largely consistent with validity typology. Portraiture strives for something else entirely. It seeks authenticity, and judgments of authenticity. The reader is asked to place themselves in the place of both the researcher/portraitist and participants and ask themselves whether the presented stories being told are true.

For my participants, neurodivergent Black women graduate students; institutionalized power, privilege, and oppression have already positioned them out of many research retellings and restoryings examining race and dis/ability. Color-evasiveness in and anti-Blackness in higher education dis/ability research engages with a limited experience and point of view, centering whiteness (Stapleton, 2020) It would be similarly unfortunate to impose institutionalized scholarly norms to what a group of racialized, gendered, and dis/abled Black women graciously entrust any researcher/portraitist with when they agree to share their lived experiences. This research study implores for the voices of neurodivergent Black women to be heard, and them listened to.
Boundaries / Limitations

My intended sample is small, but impactful. With portraiture as my methodology, there is a great opportunity to tell, write, and narrate the stories my participants tell me. Portraiture is a fine, thorough, and nuanced methodology to support a sample size of 14 people. In my sample, I have included only cisgender Black women and it did not include participants who are transgender or non-binary. In this study, the experiences of cisgender Black women are centered. Like cis women, transgender women (and gender non-binary people) experience the negative effects of the cisheteropatriarchy. However, transgender and gender non-binary people are also differentially affected by heterogenderism in a way that might not be distinguishable from hegemonic masculinity in my study. Rather than risk misrepresenting the experiences of trans women, I have instead opted to be transparent that my study cannot accurately represent their experience. Systems of oppression extend beyond race and ableism, and I do not want to cause unintentional harm by widening the participant sample and criteria, thereby unintentionally reinforcing other systems of oppression. My recruitment of 14 participants makes the odds very low that I would have a sufficient number of transgender women to invite as participants in my study (specifically, I would want to include 5-6 transgender women in my sample to be able to talk about their experiences in a meaningful way). My desire is to do justice to all my participants, and that would be the same for transgender women participants, but if I am not going to be able to do that, I have opted to not include them here. I have no desire to do injustice to transgender women participants.
It is unlikely I will be able to interview across the full spectrum of neurodivergent conditions, and I did not. This study is not being written or researched from a medical model of dis/ability, but rather, taking on a social model of dis/ability, centering interpersonal relations between dis/ability, and conditions that are connected to dis/ability. The experiences my participants have that are not diagnosed, continue to allow me the room to engage with more people, and have a robust range of experiences to inform my research. Necessitating interviewing across the full spectrum of “neurodivergent conditions” is impossible, and shortsighted. Furthermore, people do exist in disabled, dis/ability spaces without having an official diagnosis which is often prohibitively expensive.

Dis/ability and diagnosis are stigmatized in the Black community, and I expected recruitment to provide challenges. These stigmas surrounding dis/ability in communities of color, and in Black communities more specifically is real. I expected these stigmas to complicate finding people to speak with in the community if people were already hesitant to identify as dis/abled. My sample size for a study on this topic is robust enough and would run the risk of oversaturation if I successfully interviewed 20 participants.

As the researcher, my positionality to this work is not only in existence to my sharing similarities in my identities as my participants, but also my three years plus of engagement with this population on Monday evenings during their weekly support calls, and numerous opportunities to support each other online in social media groups and pages. My paradigm predicates that I be a part of a community, and be invited in, rather than surveilling a group that is hyper surveilled (Browne, 2015). My paradigm as a critical qualitative researcher has been solidified by teachings of established researchers
centering the importance of bringing yourself to the work (Esposito & Evans-Winters, 2021; Bhattacharya, 2017).

**For Proposal, Procedures, & Timeline**

After my proposal (prospectus) was accepted, I continued on to data analysis. Prior to my proposal’s submission and completion, I submitted my IRB documents and was approved in November 2021. I started and completed data collection during November and December 2021, and the first week in January 2022. My prospectus was being written and revised in December 2021. I then, in February of 2022 presented and defended my dissertation proposal.

During the proposal phase, my strategy was to conduct and write a dissertation based on my study that was a three-article dissertation. This three-article plan was designed to include 3 articles; with each one based on the vectors of race, dis/ability, and space/place. Each article was set to be written in a traditional journal article format and style. That all changed once I met with my committee for the defense and we engaged in robust conversation.

During that conversation, I pivoted to a traditional 5-chapter style dissertation. My rationale was that format would give me more room to do a deeper dive into the interconnectedness of themes, and theoretical frameworks that support the intellectual pathway and journey I was headed toward. I then next introduced arts-based research and poetic inquiry during our next meeting a few weeks later. Starting in the month of February, I did light preliminary data analysis. In March and April of 2022, I continued
with my full analysis plan, and carried out the full procedural tasks outlined earlier in this methods chapter.

**Instrumentation Appendix**

All instruments, documents, and protocol associated with this research study and subsequent dissertation are in the appendix section as outlined in the table of contents.
CHAPTER 3a

PARTICIPANT VIGNETTES

This section presents participants’ narratives to familiarize my readers with participants’ stories beyond the pre-study questionnaires and my official findings chapter. All names used here are pseudonyms. At the 2017 annual meeting of the American Educational Research Association (AERA) conference, Sarah Lawrence-Lightfoot was being recognized, and had these things to say about Portraiture as a methodology and experience:

This is big work. This is intellectually discerning and, methodological, rigorous work, this is ethical and relational work. This is passionate, soulful work and this is work that we must do together with optimism, hope and respect with restraint and intentionality, with grit and grace. One must have grace to continue to go into these spaces…view, voice, visibility (American Educational Research Association, 2017).

As the researcher and portraitist, my point of view is also informed by deep reflection. The deep reflection benefitted my process of post-interview memo writing, and poetry writing. Each of my participants are uniquely special and I experienced a wide range of emotions after each conversation. These small vignettes are a peek into some demographic information about them. It is in no way a proxy for the buoyancy of these brilliant women but should be looked at to provide more about them than will be revealed in my findings. Below, you will find vignettes and some bits of memos or prose I was inspired to write after the interviews were conducted. As Lawrence-Lightfoot intimates, grace is a must, and I am deeply grateful to each of my participants for being open, brave, willing to talk about the hard things in their lives. Thank you all!
Hazel

Hazel is 27-years old, and African (Nigerian specifically). Hazel is in a Public Health master’s program, earning her MPH degree. She identifies as having a disability and did share she has ADHD. She identifies as being a first-generation student. Hazel is enrolled at a large northeast public university.

Memo excerpt

Hazel was remarkable in her energy, and positive outlook. She spoke to the hardships she experiences and spoke to solutions. Hazel relied on the internet often to make connections with other neurodivergent Black women.

Yasmine

Yasmine is a 28-year-old master’s student in a master’s program. She attends an Ivy League institution on the east coast. She is African American. Her degree is in education with a focus on education leadership. Yasmine does identify as dis/abled and was diagnosed with ADHD. She is not a first-generation student as her parents have attended college.

Memo excerpt

Yasmine shared a reflection several of my participants have shared. She said that she was relieved to talk to me and to share her story.
**Stevie**

Stevie is a 33-year-old master’s student. She is Caribbean, though she did not indicate which island. She is a first-generation student as her parents did not attend college. She attends a large public Southern institution and is earning her master’s degree in public administration. She does not identify as being disabled and has received a diagnosis of ADHD.

**Memo excerpt**

Stevie scheduled her interview with me after her workday, and needed a new time – I was happy to oblige. Our conversation was directed, and resulted in my shortest interview of all of my participants. Stevie was interested and uninterested in the questions at the same time, and did her best to address some of the challenges of suspecting being neurodivergent. This interview was so important to my experience, because it was a reminder to honor where my participants are, and understand that some things may be unresolved for them, are hard to talk about, and to make room for their humanity. I’m grateful for Stevie and her interview.

**Rhea**

Rhea is a 30-year-old Ph.D. student in her first year of her Education doctoral program. She is earning a Ph.D. in engineering education and is enrolled at a private institution. Rhea is not a first-generation student, as both of her parents have graduate degrees. She is African American and identifies as having a disability. She has been diagnosed with ADHD.
Memo excerpt

Rhea was diagnosed months before starting her program. She was the first to mention something besides ADHD. Though not diagnosed with OCD, it is something she is concerned about enough to do further research on. Rhea expressed thanks several times for the space to talk with me, and for the resource guide I promised to send. Rhea was one of the sweetest people in my experience on this project, and heartbreakingly real about it all. She spoke a bit about shame and not trusting herself as part of her ADHD experience. Rhea revealed there was pressure to succeed and stigma around her diagnosis. This interview hit me incredibly hard, as she was vulnerable. It was during and after this interview, that I was reminded of the gift I was given to hold their stories. It also reminded me… the world does NOT deserve Black women – at all!!

Sam

Sam is a 25-year master’s student. She is African-American. Sam is first-generation as her parents did not attend college. She attends a large public state institution in the Midwest in the United States. Her master’s degree is in human resources. She identifies as being dis/abled and has an ADHD diagnosis.

Memo excerpt

Sam happily reminded me of her desire to support my research, as a Black woman to another Black woman. She said she has a history of trying to support Black women researchers on their own projects. Sam was also completing her degree the time we spoke.
Pennie

Pennie is a 36-year-old PhD candidate in Education, Student Affairs specifically. She is a 5th-year student at a large public university in the northeast of the United States. Pennie is not a first-generation student, as one of her parents has a college degree. She is from the Caribbean, Jamaica specifically. Pennie identifies as being disabled. She has been diagnosed with both Autism and Obsessive-Compulsive Disorder.

Memo excerpt

Pennie was my pleasure to meet and chat with. Pennie is extremely thoughtful in her responses and spoke deeply about her experiences. She revealed things she’d never opened up about, in our interview. Her experiences with graduate school, the pandemic, and her classmates / program were incredibly sobering. This is another interview where I practiced intentional self-care afterwards. I added additional elements to the post-interview resource guide after our conversation.

Victoria

Victoria is a 33-year-old Anthropology student, (a Ph.D. candidate), and a 6th-year advanced student. She attends an Ivy League institution on the northeast coast of the United States. Victoria is not a first-generation student, one of her parents has a Ph.D. She is from Africa, Sierra Leone & South Africa specifically. Victoria identifies as being dis/abled and has been diagnosed with ADHD. She was diagnosed during graduate school.

Memo excerpt
Victoria was absolutely fascinating, and at the time of data collection was my longest interview at 2.5 hours. For the race focused questions, it was clear that race was not central for her. It seemed “un-nuanced” and “pedestrian” to occupy her mental space, and those were words she used. Those questions seemed to bore her and to uninspired her. I had to pivot a bit in the protocol that I’d prepared as I could not fit all the questions due to time restrictions. She came more alive when some of the gender questions arose. So many mic drops and early quotables. Overall, impression? Heady, heavily theoretical (stumped me a few times) but a great conversation overall. Additional post-interview reflections are to restructure some questions differently, perhaps I don’t need all the questions and can get thoughtful responses anyway. Depending on my participants dis/ability, some of the questions needed to be adjusted, and would benefit from simplifying some questions.

**Sabrina**

Sabrina is a 30-year-old Ph.D. student. She just passed her qualifying exams and is working on candidacy. She attends a private institution in the northeast of the United States. She is a 4th-year student in an Astronomy program, her degree is in planetary sciences. Sabrina is African American. She is first-generation as her parents did not complete / attend college. She identifies as being disabled and was tested and diagnosed during her doctoral studies. Sabrina was diagnosed with ADHD, Autism, and Auditory Processing Disorder.

Memo excerpt
Sabrina was truly remarkable, and hilarious. She did not mince words in her explanation of her journey through doctoral education. Sabrina is incredibly bright, and indicated she wanted to participate in this study so others coming behind her would not be as lost as she was once receiving her diagnoses. She was incredibly open and easy to talk with.

Viola

Viola is a 33-year-old Ph.D. candidate at a private institution on the West Coast of the United States. She is in Education and earning a degree in higher education and is in her 5th-year as a student. She is currently writing her dissertation. Viola is African American and does not consider herself first-generation in educational attainment. Both of her parents have professional graduate degrees. Viola identifies as being disabled and has not been diagnosed with ADHD, though she believes she has it. She started testing before but did not continue for cost prohibition.

Memo excerpt

Viola was a wonderful interview; she spoke about elements I had not considered yet. She informed my understanding by sharing her experiences as an advanced student. She was incredibly thoughtful and gracious in disclosing her own challenges in her doctoral program, her vision for a better experience for students and faculty alike did not leave the dis/abled out.

Rochelle

Rochelle is a fifth-year Ph.D. candidate at a large state, public university in the Southern region of the United States of America. She studies science education and is
currently writing her dissertation. Rochelle is 31-years old and African American. Rochelle is not a first-generation student as her parents went to professional graduate school for law and business, however, she is the first of her family to get a Ph.D. At the time of our interview, Rochelle was in the process of getting testing for ADHD. Rochelle later let me know that she did testing and has a diagnosis of ADHD.

Memo excerpt

Rochelle is incredibly smart and was happy to talk. This made things easier for me, as she was joyful in conversation, and she shared that she liked to talk. This aside, she was quite serious in her observations. I enjoyed our conversation, and gained “light” from this interview, I felt encouraged to do this work after our call ended.

**Kimberly**

Kimberly is a 29-year-old Ph.D. candidate at a large public southern institution. She is a 5th-year student, working on her dissertation. She transferred doctoral programs. She is African American. Kimberly is not a first-generation student as she has a parent with a graduate degree. Kimberly is earning her doctoral degree in education, with a specialization in Educational Psychology. She does not identify as dis/abled. ADHD diagnosis first came up when she was in high school, but her parents did not deem it a problem since she was a high achieving student. Kimberly tested for and was diagnosed with ADHD during the pandemic as a 4th year doctoral student. She uses Reddit to learn more about ADHD and joins Black women online groups for and social media pages for additional support.

Memo excerpt:
Kimberly is especially smart and spoke to the big issues plaguing education. She spoke with big terminology and it is clear that education is her expertise, she also had a few moments of revelations the more we talked. I wonder if some of her responses were based on her intellectualizing or speaking from her direct and personal life experience. She did not strongly identify with dis/ability identity at all. She was careful and considerate to not name others (classmates or faculty) in her responses. She was reticent about some of what was shared but talked freely about medication. As an interviewer, I tweaked my strategy after this conversation, so my questions and phrasing were simpler.

Nicole

Nicole is a 31-year-old Ph.D. student in her sixth year. Nicole is African American. She is enrolled at a large Southern public institution. She does not identify with being first-generation as her mother has a graduate degree. Her Ph.D. is in ecology. She did not identify as being dis/abled and did not select a neurodivergent condition as an option on her demographics form. She does not currently have a diagnosis but suspects she is living with the experience that is ADHD and discussed having considerable focus issues. Nicole does have an anxiety diagnosis and is managing that.

Memo excerpt

Nicole is also incredibly smart, and curious. She shared her problems with focusing and performing well and high productivity needed for a future potential faculty career. Nicole did end up obtaining her diagnosis in the time that passed after her interview. She sent me an email thanking me for the support and conversation that helped her take that step towards diagnosis. Her openness in discussing her anxiety, was refreshing.
Tangi

Tangi is a 32-year-old Ph.D. candidate, in the 3rd-year of her program. She is earning a degree in astrophysics and engineering. Her overall focus is STEM, but she is in astronomy as a discipline. Tangi also already has degrees in computer science, theater, physics, and mechanical engineering. She is not a first-generation, as her parents both have college degrees, and her mother has a graduate degree. Tangi is African American. She identifies as having a dis/ability, and has ADHD. She is also being treated and tested for other neurodivergent conditions and is managing depression and anxiety. She did not get a diagnosis until she sought support for her elementary school-aged child and their ADHD diagnosis. She believes her mother also has ADHD.

Memo excerpt

Tangi is a firecracker! She’s so full of energy, quite smart, and hilarious! So many thoughts came up, but how does she do it all was one of them. I’m wondering how to add an assistive technology aspect to my post-interview resource guide. I left this interview with the sentiment that Black women are not respected or heard. Tangi is also the first mom that I’ve interviewed. She is the quintessential adult with ADHD.

Louisa

Louisa is 50-years old and a master’s student. She is African American. She is earning her MPH degree in Public Health and is attending online due to the pandemic. Louisa’s adoptive parents did not attend college, so she identifies as being first-generation. Louisa’s birth mother did obtain her graduate degree. Louisa is a mother to several teenage children, and they all have ADHD, during their testing, she decided to get
testing of her own. She was diagnosed with ADHD two years before starting her graduate program. She identifies as being dis/abled. She is a returner to the academy after leaving her non-related job during the pandemic. Additionally, Louisa had a 22-year break between her undergraduate degree and returning for her graduate degree.
In order to have gotten to grad school...
YOU had to have
graduated from undergrad
YOU had to have had a series of
successful.
educational.
experiences.

There’s ALL these assumptions
built into
how
YOU’RE
trained.

That assume you don’t need support
you know

“you're a professional student” and so you can figure it out - Viola, PhD student

Viola’s sentiment highlighted the difficulties across many elements of the graduate school experience for the 14 Black women living with conditions labeled as neurodivergent. At the conclusion of data collection and robust data analysis, the dataset I was left with was rich and complex. As the researcher and portraitist, addressing the problem was paramount. Black women graduate students living with neurodivergent conditions have a range of experiences to account for in a) managing their education, b) navigating “invisible dis/abilities”, and c) doing it all in ableist academic institutions.
Dis/ability & race are complex identities and for this community, neurodivergent Black women - there are stigmas in education psych testing, diagnosis, medication, and disclosure. Testing norms and applied behavioral therapy approaches are not taught or practiced in ways with diversity or culture in mind. Neurodivergent and dis/ability experience gatekeeping in research participants, researchers, and funding. There is a representation problem that doesn’t match the current societal makeup in terms of diversity.

This is a problem because neurodivergence and its accompanying conditions (and their symptoms) are often invisible, and hard to detect. When compounded with a community (Black women) who generally experiences high levels of institutional erasure, this is doubly concerning. This problem worsens without appropriate regard to cultural norms around diagnosis, treatment, and disclosure that are prevalent in the larger Black community. The current interventions are tailored towards White (male) students. These current interventions are ineffective at solving the problem because cultural norms do impact Black women, and their ability to receive appropriate campus support. Race and dis/ability need to be thought of alongside gender. Gender plays a role in the experiences of dis/abled Black women in this context. This multiplicity of identities does not disengage from each other. They are all connected.

Expanding the literature base, while expanding the expectations of what a “dis/abled” student is, outside of the gendered and racialized lens which skews White and male. What may be the biggest purpose of this research study is to center Black women in dis/ability, center Black women as members of academic institutions, and center Black women in their own storying of their academic experiences, whether satisfactory or not.
The findings reflect the research questions more broadly. My entire dissertation is framed by one question that structures my inquiry, followed by three supporting questions. The main overarching research question is: How do neurodivergent Black women graduate students navigate their race and dis/ability while enrolled in higher education? The following three research questions complement the main and serve as an addition to the whole:

1. How do Black neurodivergent women graduate students’ experience of and understanding of Blackness shape their experience in graduate school?
2. How does dis/ability and diagnosis color the experiences of Black neurodivergent women as they navigate their graduate studies?
3. How does neurodivergent Black women’s responsive cultural production allow them to create space in these times, despite being ensconced within the places (read environments) that are higher education institutions?

Participants navigated their graduate school experience alongside their own experiences of Blackness. Participants reported their experiences must be made visible and understood. We know that dis/ability and diagnosis are not the same for everyone, and participants reported the especially different ways that they, as Black neurodivergent women navigate both. Participants reported that there should be a deep understanding of the intersections of Blackness, dis/ability, and gender. As a result of participant’s reporting, three themes are: 1) An understanding of Self, An understanding of Blackness, 2) The Road to Diagnosis is led by Disability, and finally, 3) Spaces that Heal & Places “that…” In the following sections, this breakdown of themes will be further discussed. This discussion will include participants’ exact responses to continue illustrating major
findings. Additional findings from the online screener can be found in the K appendix at the end of this dissertation.

Participants’ Reporting

Research Question 1: How do Black neurodivergent women graduate students’ experience of and understanding of Blackness shape their experience in graduate school?

I scheduled and facilitated semi-structured 90-minute interviews with each participant to discuss their graduate school and life experiences at the intersection of race, dis/ability, and gender. My participants reported an ethnic and racial sense of self in graduate school, diagnosis, and dis/ability (both) have played off of the other in their lives, and healing spaces are within their creativity, control, and community in order to survive places of higher education. I open theme one, a theme of understanding the self and an understanding of Blackness with this offering of prose:

Seen to Yourself

Do you really be seein’
All there is to see
Inside of yourself
The power you have
Gifts you possess
And I want to know
Are you seen to yourself?
Seen for yourself?
Not -
A regurgitation of their gaze
Throughout your school days
**Theme 1: An understanding of Self, An understanding of Blackness**

Higher education theoretical foundations and student development theories provide scholars and practitioners with a deeper understanding of the ways students make sense of themselves. Of incredible importance, this ceases to be nuanced for race and Blackness, leaving room for the social and political realities of contemporary Black (in this case, graduate) students (Okello, 2018). Pennie, a 5th-year doctoral student in education, stated:

There are epistemologies that come out of being black that aren’t welcome in the graduate school space. I have been socialized in graduate school to hide my blackness (not getting that from my advisor). My being black in graduate school has been like a tension, a constant rubbing against the “norm”. Being black in graduate school, I have to be somebody’s friend. I have to perform in respectable ways, it’s very much informed by respectability politics, which I don’t really ascribe to, and I’m not really interested in that. That has been a little difficult for me to engage in.

Pennie reported the complexity of Blackness for her, in relation to the expectations placed upon her for being Black. For Pennie, it was a sociopolitical reality that Blackness in graduate school was *almost* inconvenient, but she herself does not lean into those limitations. Similarly, Victoria, a 6th-year anthropology doctoral student reported about respectability politics and her understanding (of how others may also understand) her Blackness, and how gender and race “occupy” the academy:

Blackness distorts. Between how a black woman in academia is treated, received, read - versus a black man. There are many reasons, all are about anti-blackness, but one is the sort of way in which blackness is presumed to be male in the collective unconscious of the U.S. Regarding the Black male academic, there is a
cultural imagination operating, there’s Black men and there’s everybody else. So, I guess for me, everyone will think I have a bad attitude, most likely, and everyone will assume that I’m working on “Black things” or something. To me, unconsciously it’s actually a question of respectability. I don’t know if it’s respectability, so much as the exception. The exception to the rule, not exception as like exceptional.

This is consistent with the work on surveillance, and Black people (Browne, 2015). This ‘hyper sight” thrust upon her contributes to gendered exclusion (Browne, 2015). This exclusion is (to her) at the benefit of Black men and the expense of Black women. Stevie, a 2nd-year master’s student in public administration expresses her experience of Blackness in graduate school after considering how her expression of Blackness in a class assignment might “get her in trouble.” Stevie’s acute awareness shed light on the power of others to “identify, single out, and define” Blackness while she could suffer academic consequences for doing the same. According to Stevie:

I should have just went to [HBCU] for grad school. But seriously, it constantly makes me afraid honestly, and this past semester, my professor from [foreign country] - where I was honest in one of my essays about the black community, and in the back of my head I was like, “if I’m honest about my blackness, then are they going to grade me based on their perception of blackness as opposed to what I’m actually trying to say? Like, am I going to be Dave Chappelle, are they going to cancel me? Are they going to be able to see me as a whole person, you know, like is my work going to be seen as a whole body of work” and I hate to have to think and consider that.

When asked about how their Blackness shaped their experience in graduate school, participants were asked to reflect on both their experience and understanding of it. Pennie, Victoria, and Stevie shared reflections on their experiences second guessing themselves in the classroom, doubting the outcome of centering Blackness in their
assignments, and the weight of respectability politics. When asked how her understanding of Blackness shaped their experience in graduate school, Victoria stated:

The question of perfectionism is very much in the frame, I think I’d say. I guess if a [new] Black graduate student comes in, knowing that they will likely have to have a series of things to prove to their white colleagues, that’s been intensified, I guess. I mentioned [earlier] the black graduate student having to work harder in the field of anthropology, I think is further complicated by the fact that, if one is black and then one seeks to study black people in one’s work, one has to do a series of justification that aren’t required for the others to do to make it [scholarship].

Her assertion is that black graduate students in her field (anthropology), cannot simply study Black people in their work because of interest. To study Black people must be prefaced with justifications for their dedication direction and choice of study. This signifies that being in graduate school is a series of moments of proving oneself over and over, in response to invisible pressures and prejudices. Similarities in account do not continue with Pennie’s response. She spoke of Blackness in this way:

I think blackness is two things, there’s aspects of blackness that in some ways oppositional to whiteness, and then there’s that aspect of blackness that can be hard for me to necessarily say I ignore, BUT I think there’s another aspect of blackness that for me really feels like what has remained and stayed with us through generations of displacement, through forcible transport over the Atlantic [Ocean], and so I think a lot of what blackness is for me is the cultural practices relating to what we’ve brought with us, what’s stayed with us, how it’s [blackness] reinvented over time. I think there is a part of blackness to me that is about resistance and resistance to whiteness.

For Pennie, Whiteness is always in the way. But it is her reflection of Blackness that serves as a reminder that Blackness is not only revolutionary, but it shifts through historical displacement, regardless of what power is at play. Pennie’s understanding of
her Blackness while in graduate school is in part cultural practices and part holding on to what strengths her Blackness and ancestors bring her. Already, the understanding of and experience of Blackness means different things to different people. The vastness of Blackness and the diversity within its’ people create these rich understandings. Lastly, Stevie’s response highlights specific positive moments of being Black in higher education and negative moments in graduate school:

I think Blackness is a societal construct created - by others to exert a certain level of power, or perceived power over others and culture. Blackness sort of originated that way, blackness to me is a force, in the sense of what we’ve created and what we have. What we have taken from our so-called oppressors and made into what is ours is a thing of beauty. I started my grad program with a hopeful heart, and over time I became disillusioned. I was spoiled, I went to [HBCU] for undergrad where every and any class had a cultural underpinning of African American; every class was tied to cultural meaning making and how what we’re learning can help our community. I’ve tried to speak on it here [grad school] and it’s been shut down, it’s disgusting. Being a black graduate student at [university name] is a mixed bag.

Stevie’s response underscores the uncertainty in what Black students are faced with as they continue their studies. Institutional type has played a role in her ability to support her community, with the Historically Black College and University (HBCU) experience being a positive influence. For my participants, their reflections represent diversity in the way that Black people see themselves and the loud and quiet ways that blackness moves with their graduate school experience. In their lives as Black women and as currently enrolled graduate students, there are complexities thrust upon them at the time they matriculate and while they are enrolled, active students.
**Research Question 2:** How does dis/ability and diagnosis color the experiences of Black neurodivergent women as they navigate their graduate studies?

**Theme 2:** The Road to Diagnosis is led by Dis/ability

\[
\begin{align*}
This\text{-}ability\text{-}to \ (catastrophize) \\
This\text{-}ability\text{-}to \ (recognize) \\
This\text{-}ability\text{-}to \ (organize) \\
\text{Dis/ability\text{-}To} \ (follow. \ through) \\
\text{Dis/ability\text{-}To} \ (not. \ wanna. \ do) \\
\text{Dis/ability\text{-}To} \ (get \ diagnosed)
\end{align*}
\]

Dis/ability as related to what cognitive conditions my participants are managing have shared underpinnings of chaos, confusion, and lots of work. When asked about the regular practices of their life as graduate students, my participants shared about dis/ability’s impact on their graduate life. The challenges of living with symptoms of neurodivergent conditions like ADHD, Autism, and Dyslexia are many. Those executive functioning tasks linked to focus, memorization, and completing tasks are part of the recipe for the success of a well-performing and high-achieving graduate student. When asked about diagnosis, (or not), and their symptoms participants openly reported their challenges in graduate school. Hazel, a public health master’s student references her challenges with time, teaching a class, managing her assistantship workload, and studying less than she prefers to:

This is definitely not the time [9:45 am] that I want to be in that classroom, but luckily, it’s a little bit exciting. I think there are other times I work better. For me,
there are times having an assistantship where it’s not a cut and dry assistantship, - ‘you’re going to need to grade these papers by Friday. My deadlines are 20 hours a week they say. I wouldn’t say I’m overworking like a psycho, but like, I can just [barely] finish the initial steps and then, I found myself at 1,000 emails. This was just last week, working more than I study, that was hard for me.

Hazel’s experience with the demands on her time is not unusual for a graduate student. However, they can become amplified in intensity with a lessened ability to manage executive functioning. That feeling of overwhelm continues to be experiences beyond the classroom. For those of my participants who have identified with being dis/abled and having a disability, these aspects of their lives continue long beyond coursework.

The transition to being a doctoral student and scholar-in-training recalls other feelings for Viola, a 5th-year doctoral student. Viola’s standing as an advanced doctoral student requires a large ability to be self-motivated which is not something that comes naturally to her. In her position, there is a posture, and she speaks to the “assumption” of knowing “everything” and it is a sign of weakness for a doctoral student to need and ask for assistance. Viola shares:

The different pieces of writing a dissertation and involved cognitive processes that can be impacted by neurodivergence, but also mental health and so that whole phenomenon. Essentially, my program we we expect you to graduate in like four to five years. You know or it's we’re not going to really give you any support in terms of funding. What does that look like, so you're just going in with a time deadline like Okay, I have four years, so I want to graduate on time or five years if I want to graduate on time. And so, a year earlier for me, I was struggling, but the thing that was like the glaring red alarm in my brain was like you're hitting this time marks that you're not supposed to be hitting without having more done and nothing substantive.

It wasn't it was about the time it was like about the timing of it, and I think that that usually reflects that those assumptions around how long something is going to take for somebody and what's involved in things is a neurotypical fantasy. I think other types of like folks, those who have children, there are certain categories where it's okay if your time might be taken in ways.
Viola’s experience underscored the challenges of living with conditions or symptoms that impact executive functioning and the ability to complete tasks. She named difficulties with her program or the university’s lack of consistency among students who may need accommodations for time and assignment submission. She shared that parents receive leniency, but there is a lack of consideration for the needs of students with disabilities.

But what if it's not necessarily that the carving out of the time is the problem? It’s like when I sit down, my brain is in a million different places, you know. When people were like okay, you want to do your interview, and then you want to write notes after your interview and you're going to do, like a detailed journal, and analytic memos… and I’m like this is it [I’m tired]. I get out of an interview, and I’m so overwhelmed by the experience of having been in conversation, and [inside thoughts] like are you looking at the camera? And then also the THINKING, and the like. That, then, to sit down and be like and NOWWWWW, let me do it, I literally need to move my body, because I’m over. And then, by the time I moved my body my brain has gone to something else. It's just like these things don't work for me in the way that it works for you and I don't think you've ever thought [about that]. That thing, like the whole framework, is still, “this is the best way to do research”, and so there aren't... I would love a neurodivergent qualitative faculty member.

The assumption of neurotypical behavior leads a student like Viola to have trouble with their work, and then perhaps, also asking for help. As an advanced doctoral student, her ability to conduct research practices to the norms of academia is detrimental to her career. As an advanced student, she is learning essential skills as a researcher and simultaneously experiencing varying productivity levels depending on her needs to slow down and rest. Her desire to have publicly disabled faculty members is a real one. Similarly, Tangi speaks to the support she’s received from her faculty. Tangi, a 3rd-year doctoral student
talked about her faculty member suggesting she get support on campus. Tangi who has ADHD says:

Yeah, my disability has negatively impacted me in graduate school. People think that when I make a mistake, it’s because I can’t handle it. It took me six months to get my first appointment, I thought I was being proactive by calling [the university] ahead of time. The entire first semester, I’m teaching 50 students, taking four classes, and I want to see a therapist but no one’s available. I was on the waiting list for a year and a half, and my advisor is asking me ‘have you ever tried contacting… or contacting …” yes, I have and I’m on the waiting list for that too.

Diagnosis is a very personalized experience. It is also dependent on financial status, access to healthcare providers with the testing specialty, and people having information to even start thinking a diagnosis (testing experience) may be needed. Victoria, a doctoral student shares her costly “$750 student clinic evaluation” with an extensive wait time, “I was on a waitlist from July to October”. Victoria was confronted with a cost and wait time that is quite prohibitive, especially for a graduate student. Similarly, Louisa, a master’s student in Public Health also noted the financial barriers that came up for her while she was working on getting an evaluation and diagnosis.

An additional barrier to diagnosis outside of informational and financial is the lack of diverse providers. In addition to Louisa paying out of pocket due to providers not taking her insurance, and very limited (she lives in a small rural town) access to local providers, she worried about finding diverse practitioners. “I wanted to go to somebody that looks like me, and that was and is still somewhat of a barrier. I was constantly trying to find somebody that met the criteria, and preferably a black female. Then I got to the point where I figured I just need to get the diagnosis and find a therapist or whatever. It’s been hard to find someone in my area.”
Some participants had diagnoses come up in their childhood, rather than their adulthood. Astrophysics doctoral student Tangi ultimately had a pathway to diagnosis via getting her child diagnosed. Prior to that, Tangi was not diagnosed as a child because her mother was not in agreement, but she did find her way eventually. Tangi’s diagnosis story follows:

I was diagnosed recently, so the majority of my education has been undiagnosed. There are multiple reasons, but the main reason is that my mother didn’t believe. She kept saying ‘you’re gifted.’ I was a gifted kid, and there was this negative connotation with the special ed kids. Now, as an adult, my child is nine years old and diagnosed at seven. In my child’s process, I was like ‘Woah, it sounds like me.’

Diagnosis looks different for every one of my participants. For those of my participants who have been diagnosed with neurodivergent conditions like ADHD, Autism, or any other condition, their road to it all looks different and is incredibly personal. The pathways to obtaining an official diagnosis as referenced above, are different, and personal. My participants gender and race continue to add to any barriers they may face. Some additional barriers are “the church”, “feeling like I’m not disabled enough”, and “the pressure of always being perfect.” Several of my participants have discussed their concerns and were brushed off by suggestions to pray more or give it to Jesus. Some of my participants remarked that having a physically, visible, or medically disabled aunt, mom or grandmother made them feel like they didn’t need to look further into their own needs.

_Sis_  

_Is not a dirty word_
Rather

A freeing word

A freeing feeling

Free falling into

Supreme consciousness

Of (your) exactness

Is freedom. Is freeing.

They say (your) “excess” not welcomed

They say (your) “debts” unwanted

You ain’t got to be

Nobody else

Falling into the extraness of stigma

This was further amplified by them stating they knew people they deemed always in more need than them. Usually, this too was gendered. They rarely mentioned men in these mental equations. Lastly, they often mentioned that they were known for being successful in school as a child and teen, and for some, doing “well” in graduate school or well enough to be in a doctoral program meant that they would be taking up much-needed resources from other students in the school. This was often positioned as not wanting to be seen as a burden, or taking advantage of the accommodations, or things not being that bad because they knew how to pull it together and get decent grades consistently enough.
Unfortunately, racism and ableism both worked in tandem here. They were buying into the model minority myth and being a black woman on campus already comes with hypervisibility, and no one wants to be seen as less capable than their peers, another kind of visibility they obtain if dis/ability or neurodivergent experiences are added to the story. Many of my participants went online to create community and space in the challenging world that is a higher education place of learning.

**Research Question 3:** How does neurodivergent Black women’s responsive cultural production allow them to create space in these times, despite being ensconced within the places (read environments) that are higher education institutions?

**Theme 3:** Spaces that Heal & Places that "…"

*Space*… *is it something you take Somewhere*

*Perfectly* *Aligned with your Community of* *Exquisite, Excellence Chasers*

Community response to members needing help for themselves or their children were easier to come by, given the traditional ways that Black women support each other. These traditional ways are grounded in Black feminist behaviors and an embodiment of
‘Sankofa’ which is to bring folks with you and not leave anyone behind. This contemporary moment makes this more accessible than ever due to the technology and internet advancements that help perfect strangers get connected and stay connected. Viola shares her experience of connecting with others online, as it is a place of refuge aside from other everyday parts of her life. Viola says,

 Mostly social media, online, and there are other spaces that are meaningful in my life but they’re not organized around disability. Folks recommend writing groups, so it’s a way to body double or to have structure. I’m always just curious about what other people are doing. I’m not a very good writing group buddy cause I’m just waiting until we get breaks to find out what people are doing, I just want to know. I think the friendships that I have are one on one, and then the social media spaces are the spaces are restorative for me.

The online community Viola turned to were mostly on social media and other online spaces. The community worked well for her in finding people to work with, to experience the process of thinking and writing with. For Tangi, a doctoral student, the aspect of building community with Black people was especially important in her racially homogenous program:

 the internet for me is a virtual reality world where I get to be what I want to be. But on the other hand, as a black girl in STEM, I’ve always been the only one by myself so I’ve never really had black friends. My black friendship has been limited. The internet is like a cool virtual reality to find black people that I can be friends with. In college, I was president of my anime club, I also liked books a lot and read a lot of science fiction, but I didn’t see many black authors or stories about black people. I’m not just a one-dimensional Black girl, I’m more than that. Knowing a little bit about every interesting thing has brought social connection, they’ve helped me become who I am, a fuller person.

Like Tangi, doctoral student Sabrina values relationships that allow her to be herself.

Sabrina’s connections with the neurodivergent people in her academic life add something
meaningful to her graduate school experience and makes spaces that for her, are overwhelmingly positive. Consistent with the benefit of community and support in terms of neurodivergence or ADHD in my participant’s lives, Sabrina shares that the online groups of “unicorns” by Rene Brooks for Black women with ADHD have been a support in her life.

Furthermore, this supports her as a graduate student and creates supportive spaces outside of the classroom.

I’m noticing that I have this group of friends in my program and department, and I think we’re all neurodivergent. They’re my go-to people for life. I need to be around people who are like-minded and who understand it all. If I can’t stand someone, or I’m exhausted, or it’s getting hard, I just sometimes like to know that I can go to someone. We don’t meet up (or frequently) but the group itself, they make me feel safe to just take off my mask, not having to code switch even. Also, for the first time after my diagnosis, I felt lost. That’s where I found Rene Brooks’ group, and that was everything. It’s given me confidence and everything. Alongside that group, I like Blerd anime, and I like Blerd con. I like being around other black cosplayers, melanin is just awesome, and beautiful.

Sabrina, Viola, and Tangi’s experiences indicate successful ways they made space for themselves while in graduate school. The spaces they highlighted were spaces that edified them and supported a healthier sense of self. Whether they were in online spaces reading and writing groups, or they found themselves engrossed in anime or Reddit, or romance fiction - they all left positive impressions on my participants.

Place… Is it something they create

Priorities

Leaning Heavily

Away from people and

Careening Towards
Alternatively, the higher education landscape, the place that it is, has proven to be one that my participants have worked to navigate. The academic ableism of the higher education as place has a real tangible impact on my participants. Structural, institutional shortsightedness has a real impact on students. When asked about what made the place itself fall short for them, my participant Sabrina shared:

I recognize higher education wasn’t designed for ethnic minorities in mind, but you know - we belong. I’m very tired of higher education being like ‘we have initiatives’ - initiatives are great but it’s like what results do you have. Recruitment is great, but what is recruitment without retention.

The learning environment is long known to be impactful on educators and students alike. This environment has the ability to positively shape learning and shape norms for one’s field, and subsequent career. The place where this learning is taking place at times yields norms and behaviors that are harmful to students. Doctoral student socialization is no different. According to doctoral student Pennie:

Graduate school on a whole is super competitive, you have to protect yourself, you have to guard yourself. It’s like [they teach you] you can’t care about other persons, caring can come back to harm you, like there’s a lot of mistrust amongst everyone. I would naturally just like to be in community with folks, and in a caring environment but there’s so much mistrust, and protectiveness that people are holding. I think because I position my blackness a little bit as like being Trinidadian or being Caribbean and those educational experiences for me [historically] were a little bit more community oriented. Whereas here, [the U.S.] I feel like people kind of like hold you at arm’s length and that mistrust is just natural in this environment.
Pennie’s observation of the graduate environment she is in was echoed by three other participants (Stevie, Hazel, & Victoria) who are also from across the African Diaspora. Pennie’s classroom and advising experience with her dissertation chair, as well as classmates, have left her desiring more and feeling invisible. The invisibility she has spoken about is not merely a cultural clash, but also her experience of living with ADHD, Autism, and Obsessive Compulsive Disorder. This furthers her isolation, being misunderstood by her peers, and has dire consequences for her professional development.

Pennie has not presented at an academic conference in two years and is lacking people to collaborate with. She has shared doubts that she will be successful in networking in socially acceptable ways that consider her neurodivergence. Her neurodivergence has shaped her ability to connect with others, socialize to gain writing collaborations and author opportunities, and ability to mirror the high-touch nature (and expectation) of social science and education students. She “does not think” she will be successful in obtaining a tenure track position after she completes her doctoral studies.

Rhea, a doctoral student earlier in her graduate studies than Pennie has also indicated the challenges of “microaggressions from well-meaning white people” in her program. Her school is “pretty liberal” and while she does not identify with being at the receiving end of hardcore discrimination, the microaggressions were plentiful.

As the time drew near for me to attend, I started following these accounts online that speak to the black in academia experience. I read a lot of information about how difficult it can be to persist with the academy. Systems of Whiteness and White supremacy aside, I braced myself for impact in my grad school career. I had very low expectations for how I would be treated or validated by the institution. I haven’t reached a point where the racism I experience encourages me to leave the academy.
Black women graduate students navigate social systems within higher and postsecondary education that their White neurodiverse peers do not, in part due to race and gender and power and oppression. Their cultural production is an outcome of creating new ways of being within environments like higher education that have an overall problem with equity for all its stakeholders. Despite cultural barriers in the Black community surrounding dis/ability diagnosis and treatment, the spaces created by Black women represent agency, transformation, and power. Participants shared examples of this community and cultural reproduction, via online spaces. Some participants find online and virtual spaces to be affirming and in contrast to their day to day, and lives as graduate students. They spend time on Reddit, TikTok (like #cleanTok, #coffeeTok, #techTok), GoodReads for historical fiction, speculative fiction, or romcom novels (centering neurodivergent characters) communities. They also do BlerdCon, AnimeCon, and VideoCon. They explore their dis/ability online, create boards and online games as hobbies (Miller, 2017).
CHAPTER 5
DISCUSSION

As a reminder, the purpose of this study was to center the experiences of dis/abled Black women who are in graduate school, and their experiences of academic ableism. Furthermore, the study centered the historical community that arises from Black women and Black feminism when there is a need to come together for their betterment. Their cultural reproduction of creating inclusive and welcoming spaces using social media, literature, speculative fiction, anime, and more has supported them in thriving outside of the ableist academic spaces that are overrun with power. In this study, Black neurodivergent women graduate students bravely shared their graduate school experience with me. In this journey to self-understanding, I as a researcher created a space for them to further be themselves and discuss openly their graduate student lives at the nexus of race, gender, and dis/ability.

This research study links the ableist, racist, and patriarchal environments that are academic institutions (and policies) and the experiences of the Black women graduate students who are enrolled in them. These women use historical Black feminism tenets of community care and technology to broker new and affirming spaces for them to be themselves, and cope with, manage their dis/abilities. The neurodivergent conditions my participants have been experiencing or diagnosed with are Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Obsessive Compulsive Disorder (OCD), Dyslexia, Dyscalculia, Dyspraxia, Auditory Processing Disorder, and comorbidities like Generalized Anxiety Disorder (GAD), and Depression.
In this study, my participants share the challenges of being Black in graduate school, navigating executive functioning symptoms, obtaining a diagnosis, and managing the stigmas (model-minority, cultural and faith-based) barring access to testing and evaluation. My participants also have had difficulties with obtaining diagnoses for prohibitive costs, diverse representation in clinical practitioners, and lack of information. There we have the opportunity to face the problem of deeply gifted graduate students navigating doctoral and master’s programs of study without adequate support or accommodations, and the societal pressures and expectations placed on Black women to have it all together, leaving them to not ask for help as their peers are. Dis/ability is so gendered and racialized as Male and White, that my participants simply do not fit the bill of your average dis/abled student.

My findings are built upon my originally anticipated findings in this way:

- There is continued significance because neurodivergent Black women graduate students exist - because they exist, they are here, and higher education continues to enroll them, use multicultural admissions best practices; yet fails to adequately foster, support, and encourage the inherent cultural production that Black women students create anyway.

- This cultural production itself is linked to neurodivergent Black women (people with minoritized minds and bodies and the spaces they create for themselves), and at the same time flatly and patently inhibited.

- Higher education needs to listen more and pay attention to them. Simply put, higher education is a site and place of power, and as an ableist place, does not listen equitably; the spaces (real, imagined, literature based, online in social
media, science fiction, anime) created by neurodivergent Black women needs to be honored rather than contested.

- Black women’s cultural production is a gateway to healthy navigation of harmful higher education environments.
- This cultural production involves online communities, social media support groups, and alternative realities in science fiction literature.

Not only do my study findings invite empathy and understanding, but also place them and their blackness in the center of disability studies, and gender studies. Perhaps, the future will be more inclusive.

There are three research questions shaping this inquiry. The first research question is: how do neurodivergent Black women graduate students navigate their race and dis/ability while enrolled in higher education, and it is supported by three additional questions. Next, how do Black neurodivergent women graduate students’ experience of and understanding of Blackness shape their experience in graduate school? Second, how does dis/ability and diagnosis color the experiences of Black neurodivergent women as they navigate their graduate studies? Third, how does neurodivergent Black women’s responsive cultural production allow them to create space in these (socio-political) times, despite being ensconced within the places (read environments) that are higher education institutions?

**Overview of Themes**

To provide an overview of the themes explored in my findings, here I will explore the themes that directly respond to my research questions. As a result of participant’s
reporting, three themes are: 1) An understanding of Self, An understanding of Blackness, 2) The Road to Diagnosis is led by Disability, and finally, 3) Spaces that Heal & Places that “…” The main findings are that my participants understanding of themselves is deeply connected to their understanding of their Blackness and how it shapes their lives as graduate students. Another main finding is that a diagnosis is an option once my participants really embrace the symptoms of the neurodivergent condition or dis/ability that they’re managing. The acceptance and the curiosity are what play a role in their journey to diagnosis. While this is true, it is not exhaustive. Particular barriers to diagnosis exist regarding information, financial barriers, and diverse practitioners exist. These are connected to that finding, but lesser so. Lastly, another finding is that Black women graduate students are unafraid to find their own spaces for support and community. They do so in various types of spaces outside of their universities.

**Overview of the chapter**

From this discussion chapter, you can expect discussions that center the themes and research questions of this study. In addition, you can also expect the analysis to support particular theories from my theoretical frameworks or my main conceptual framework, the Black Feminist Disability Framework. Furthermore, this chapter will identify patterns in my data and participants, and this chapter will provide a space for discussion of surprise findings not centered as one of the main findings that led to the three themes coming to life. In this chapter, I will discuss the main points of the themes that were highlighted in the findings chapter. Lastly, it will serve as an interpretation of the findings, followed by an implications section, a boundaries section, a section to examine future research, and recommendations for the field and for policy.
My findings directly answer my main research question because they directly address how Black neurodivergent graduate student women navigate their race and dis/ability while enrolled in higher education. The findings will allow me to discuss all three points, 1) An understanding of Self, An understanding of Blackness, 2) The Road to Diagnosis is led by Disability, and finally, 3) Spaces that Heal & Places “that…”. This analysis of my discussion chapter supports the theories that intersectionality as modeled in Black Disability Studies (Hinton, 2021) and the Black Feminist Disability Framework (Bailey & Mobley, 2019) is key to the support and benefit of this student population. The intersectionality of their race, gender, dis/ability status; when paid attention to, when supported and understood is a powerful tool. As Mobley & Bailey’s BFDF and Hinton’s BDS both affirm that “a Black feminist dis/ability framework is emergent and intersectional, and these frameworks are rich and unexplored” (Bailey & Mobley, p. 21, 2019).

The real harm occurs when people and their identities are parsed separately. To be seen as fully human and whole acknowledges that all parts of Black women, their identities, and their bodies are best respected, seen, and liberated than other norms. The data suggest that my participants are complex individuals, bonded through the race, gender, and dis/ability. The data also suggests that my participants are woefully misunderstood and their experiences in both graduate school and within dis/ability and diagnosis communities are lacking.

They were experiencing academic ableism and weren’t even knowledgeable of it, and a Black feminist disability framework or black dis/ability studies would ground reality for many of them. The understanding of self and the understanding of Blackness is
significant because it relays an understanding that these Black women in graduate school have varying concepts of their Blackness in a graduate school context, and as their Blackness is a part of their being, as essential as other elemental parts of their salient identities. The explanations given by my participants showed they not only understood their own views, but also the views of classmates, faculty, their academic programs, and their institutions. In order for their fullest selves to be realized, it was important to have them start with their race and ethnicity. For my participants, their Blackness is not removed from their role as a graduate student trying to thrive in an inherently ableist academic environment, nor from their neurodivergent lives managing dis/ability stigma in the Black community and Black church.

The Black Feminist Disability Framework highlights the contradictions of both Disability Studies and Black Studies in their missed “opportunity” of being brought together (and used) together intentionally. As such, the problem of race and ability working in the opposite direction most occurs when the subject is racialized as Black and dis/abled. This leads to problems in both areas of study which are necessary for real research and inquiry to be done on a broader scale that represents many people. This truly representative framework considers that Black women are often placed in impossible positions (to choose which identity comes first) race or gender and ceases to recognize the fullness of their/our experiences. The data suggests that Black women in graduate school are fully aware of the ways Blackness impacts their experiences, opportunity, and future trajectories. They understand that they need to constantly advocate for themselves, and surveillance of the Black body, and the Black mind is ever present - whether at the point of inquiry regarding an institution or throughout their academic experiences. So
before getting to disability and the surveillance that comes along with that, where does Blackness fit in?

In my perspective, the next main point, (The Road to Diagnosis is led by Disability) is directly linked to the power of dis/ability. Dis/ability in its various forms, (invisible and not; medical and social) for example is powerful in its connection to funding, programs, legislation, policies, and the law. Dis/ability and the symptoms of some of the neurodivergent conditions my participants face is important. Current research (Lovelace et al, 2021) has revealed that over seven decades, the inclusion of Black autistic women and girls in autism (BAWG) medical and educational research has been beyond a deficit, with three identifiable research studies centering that population. In order for (BAWG) to receive diagnosis and treatment, a proportional percentage of research needs to be conducted. For these dis/abilities (Attention Deficit Hyperactivity Disorder, Autism Spectrum Disorder, Obsessive Compulsive Disorder, Dyslexia, Dyscalculia) the symptoms associated with them must not only be consistent but often disruptive enough for testing and diagnosis to be sought. Substantive educational research on graduate students at the nexus of disability and neurodiversity is small compared to undergraduates, but there is a change in a more inclusive direction (Carter et al, 2017; Gillespie-Lynch et al, 2017; Verdinelli & Kutner, 2016). For my graduate student participants, most of them enrolled in advanced doctoral studies, these executive functioning challenges are enough to sound the alarm. For students relying on focus, motivation, and other executive functions skills for their personal and professional day-to-day, the results can be debilitating.
Some hallmarks of symptoms related to the conditions grouped as neurodivergent are:

- problems with memory and forgetfulness
- Difficulty focusing
- Challenges processing numbers and time
- Chronic lateness despite numerous & varied efforts
- Labor-intensive reading and writing
- Enacting mental “rituals” such as frequent counting & memorization
- Frequent checking behind oneself for locked doors, off & unplugged appliances
- Missing appointments often
- Difficulty with social cues or processing facial expressions?
- Poor executive functioning
- Issues with motor planning
- Problems planning complex actions

These symptoms are particularly damaging to graduate students whose professional lives thrive the better they are at completing tasks related to these skills. For my graduate student participants, their ability to do these things well correlates to their academic value and career potential. Additionally, in order for my participants to make clear how the symptoms are impacting their lives, they have to acknowledge that they are worthy of receiving help and acknowledge that they are in the pathway of dis/ability and neurodivergence. This lack of acknowledgment does not appear out of the blue.
My participants’ resistance to dis/ability per se can be linked to the intense pressure placed on Black women to do well, and in this context, doing well is related to being highly productive. The productivity related to graduate school is at a level where the target is consistently moving and shifting. Furthermore, the triply minoritized student here (racialized, gendered, dis/ability) at the center of my dissertation has historically not been seen as people, but property to be owned and sold. Additionally, this population, (Black women) has been seen as superhuman, victims of respectability politics, Henryism, and being the strong Black woman (Okello, 2021; Alexander, 2019; Howard-Baptiste, 2014; Chrisman, 2011; Donaldson & Prendergast, 2011). For those not outwardly crumbling under the unfairness of respectability politics, we have folks nuancing their humanity and merely living, privately or publicly owning their dis/abilities or condition. Dis/ability studies terms the supercrip (Schalk, 2016; Grue, 2015; Gutsell & Hulgin, 2013; Hutcheon & Wolbring, 2013) a term used to mean, as Joseph Shapiro says, an “inspirational disabled person [...] glorified [... and] lavishly lauded in the press and on television” (16), (Schalk, 2016, p. 73). Additionally, Eli Claire (as highlighted in the Schalk’s text) says the supercrip is:

One of the dominant images of disabled people [...] A boy without hands bats .486 on his Little League team. A blind man hikes the Appalachian Trail from end to end. An adolescent girl with Down’s syndrome learns to drive and has a boyfriend. A guy with one leg runs across Canada. The nondisabled world is saturated with these stories. (p. 2), (Schalk, 2016, p. 73)

While dis/ability and the symptoms associated with them are different for every individual, those experiencing with neurodivergent conditions (often invisible to the untrained eye) do have their own struggles. In effort to perform as graduate students,
meeting high expectations of their programs, their university funding and scholarship structure, the Black women in my research study often suppress their own needs, rejecting formal accommodations, and other on-campus, or medical (prescription medicine) help as support. This sends a message that they cannot afford to be dis/abled, publicly, or privately so.

Several of my participants refused help, further boxing themselves into the trope of high-achieving (at all costs) graduate student. Unfortunately, this meant some of my participants had also internalized the outside influences of ableism quite well. The insidious nature of ableism is such that excels at subtlety and slinking into the everyday consciousness and everyday culture. This does not cease at the doorsteps of higher education institutions. My participants suffering in silence; navigating the challenges that accompany neurodivergence and the demands of graduate school. For some, this may mean difficulty seeing their own humanity, and not as productivity people. This corresponds well with Okello’s work on John Henryism and respectability politics (Okello, 2021). This drive to be the best or be perfect meant that they too were seeing themselves as beacons of diversity and perfection, or model minority (Linder et al, 2019). This is inherently unfair and sobering. It also prevented their student affairs and academic affairs professionals (and faculty) from supporting them adequately on campus.

**Implications**

My data fit together given the findings, and the prior research in this area, it is within the full scope of possibility that my data reveals and constructs a new model for understanding the experiences of Black neurodivergent graduate student women in
masters and doctoral programs. This will be done specifically with attention paid to centering space, place, dis/ability, and race. These vectors collide to create unique experiences for these graduate-level students, and my model helps to bring forward a new understanding of the world they both inhabit and create to survive postsecondary education. The spaces (both real and imagined) created by Black women who are neurodivergent must be brought into the fold of learning, pedagogy, and the academic climate across contemporary higher education.

My findings, 1) an understanding of self, and understanding of Blackness, 2) the road to diagnosis is led by dis/ability, and 3) the spaces that heal and spaces that “…” work together to relate with the existing research in the field of higher education. They do so in these ways - Black students’ sense of self is closely related to their Blackness. One way they make meaning of themselves in the higher education space is to find opportunities to celebrate, examine, learn about, engage with their Blackness. Institutions with support for student exploration and identity (diversity-focused spaces, racial affinity centers) help facilitate learning opportunities for all students, but also reflect the reality of what minoritized students in small percentages respond to. Diverse environments and interventions support a healthy institution. Similarly, when there is accurate and fair representation alongside institutional investment, students with dis/abilities find more support. The dearth of Black women graduate level students entering their programs with diagnoses further highlights the positive change and impact that diverse representation can have. Dis/ability centers staffed with diverse workers, counseling centers staffed with diverse clinicians, and lastly, faculty hiring practices being specific and intentional about increasing the number of dis/abled faculty members will support Black women students
in getting the help they need. This would help this student population because they suffer
greatly from the stigmas related to diagnosis, mental illness, and dis/ability within the
Black community, overall. Cultural competency in education and educational spaces
extends beyond issues of race and gender and sexuality. Though important, (and one does
mean trump the other) the addition and inclusion of dis/ability in on-campus initiatives,
operations planning, (universal) curriculum design, universal design, and cultural centers
make a more accessible environment for all institutional stakeholders.

Researchers and colleagues in our field (higher education) should care about my
contributions to the literature and conversation because the intersection between Black
studies and dis/ability studies has room to work together. The inclusion of a Black
feminist framework in this contribution diversifies the ways that an increasingly enrolled
student population gets support at the intersections of their social and cultural identity
markers. My contributions create a deeper understanding of the experiences of multiply
marginalized students and provide an entry point for increased (and diverse) dis/ability
scholarship in educational research. Lastly, this research and my findings support
Hinton’s (2021) work on Black disability studies – in that it needs to exist as an adjacent
area of research to dis/ability studies.

My findings, 1) an understanding of self, and understanding of blackness, 2) the
road to diagnosis is led by disability, and 3) the spaces that heal and spaces that “…”,
work together to agree with the existing research. The findings support existing research
in that we know that neurodivergent conditions are vastly underrepresented among those
who are marginalized. The research shows an overly pronounced representation of
students with dis/abilities and conditions linked to the wider neurodivergent umbrella.
ADHD, OCD, Autism Spectrum Disorder, and Dyslexia tend to skew white and male. This gendered and racialized account represents literature that already exists highlighting the small number of diagnosed Black women and Black students beyond secondary education (Lovelace et al, 2021; Gill & Erevelles, 2017). Literature exists showcasing the social culture of “invisible” dis/abilities like the neurodivergent ones that my participants are living with; and the norms surrounding popular culture being popularized as White and male (Matthews, 2019; Eilenberg et al, 2019; Travers & Krezmien, 2018; Travers et al, 2011; & Neighbors et al, 2003). We know that there is an active erasure of (and new hope for inclusion) Black people in disability research (Shaia, W.E., et al, 2020; Pellicano, L., et al 2018) and spaces (Gillespie, et al, 2017).

My findings are not consistent with all research, and there are differences within some existing research. There were unexpected considerations that do not fit neatly within the existing research, and they are, a specific attention being paid to the nuance of ethnic diversity and how that may shape a group’s (in this case, Black women) approach to and relationship with the medical, cultural, and social dis/ability. Furthermore, there are ways that neurodivergence and neurodiversity play out in and across the African diaspora, and the globally located people of the Africana diaspora. A recent report from the United Nations (2018) highlights the importance of addressing and creating a global dis/ability inclusion strategy.

The final conclusion I made from my research questions is that the student experience is complex. My participants, black women in graduate school, living with neurodivergent conditions, are interesting human beings with interesting lives outside of their status as advanced graduate students. They live beautiful lives, disrupted by poor
and impactful executive functioning which impacts their work and experience as graduate students, many writing their dissertation and about to go on the academic job market. My participants are navigating the traditional uncertainties that come along with being graduate students, the feelings of self-doubt and imposter syndrome. When respectability politics, model minority, perfectionism, and (academic) ableism come into frame, my participants are working to uphold expectations of them to never falter, and to be the strong Black women. When the

"Strong Black woman"

"Meets Supercrip"

"As Cream of the crop"

"their humanity is limited"

"others want a reason to clap"

My participants internalize the expectations placed on them to do well, refusing to seek appropriate care for the neurodivergent conditions they face. They advocate for the betterment of other racial and gender minorities on campus, but don’t see their own humanity enough to decide that they too are worthy of accommodations, that it’s not too late to ask for support since they’re (mostly) doctoral students and have made it through school thus far. They rank themselves among people with medical dis/abilities and outwardly visible dis/abilities as not that “bad” and they’re making do with the limited scope of support, inadvertently not providing their institutions with an opportunity to count them, provide documented culturally relevant support, and be better prepared for future enrolled black women with dis/abilities. My conclusion is that Black women are
being failed, and their internalizations of stigmatization then allow them to fail themselves by not seeking support neurodivergent documentation. This secondary failure is a deep internalization of where others and society places the dis/abled, and non-majority racialized and gendered people. This is why Black Disability Studies is so impactful and necessary - it is its own recognition of the way that race changes the dis/ability conversation and dis/ability changes the race conversation. While it is their right to not seek support, they do need to be heard and listened to.

The relevant theories and theoretical frameworks employed in this research study is the black feminist disability framework (2019). It provides a historical framework for Black feminist ideology and the values associated with it overall. The black feminist disability framework posits that the disconnect in dis/ability studies and Black studies have not only is a missed scholarly opportunity, but there are real ramifications when real people are involved and impacted aside from the pages of theories and scholarship. Black women are not super strong, and cannot do everything themselves. At the origin of this intellectual query, I believed that Black women graduate students are being misunderstood, their experiences with neurodivergence quite complex, and their workarounds - the social engineering of online and social media spaces for cultural production quite brilliant. Their usage of community to support them harkens back to traditional tenets of Black feminism, and black women supporting each other through various trials and tribulations of academic life and academic ableism. At the end of this intellectual inquiry, I still attest the same as what I started with. Black women are still uniquely creative in managing their lives and experiences, but where I am surprised is the strength of outside influences in creating stigmas around disability for this student
population. I did not expect the church and faith to play such a big role in how others suggested they care for themselves, situating faith and prayer as the solvent to their problems at the hand of ADHD, Autism, Dyslexia, other neurodivergent conditions, and the associated comorbidities like anxiety and depression.

These findings do not neatly fit with the theories from my framework automatically (as I thought) anymore, and for this initial reason: I assumed my participants were first-generation graduate students. As my data collection and interviews progressed, it became clear that a majority of my participants were not first-generation graduate students and had an understanding of academic life due to their parents or caretakers being in school. Secondly, I had not assumed what most of my participants were studying in graduate school. Upon data collection and the interview process, I learned that the majority of my participants were in education (STEM education, higher education, student affairs, teacher education and school leadership, educational psychology) or STEM (sciences, physics, astronomy, astrophysics).

When considering how to make sense of that, I consider that for all that the students were shortchanged in receiving full support in their academic lives, there is an aspect of them not being unfamiliar with the academy that might have given a surety (albeit small) in relying on themselves and own devices to navigate it. The data makes this much clearer and transparent for future readers and researchers. We know that prior higher education, dis/ability research has focused on this, but the results will be different when other multiply marginalized groups are centered.
Trustworthiness in Research Design

In the study, like others, credibility and trustworthiness is important. I am a credible research instrument because I employed methods with care, methodologically, and consistent efforts for follow through and checking on my own steps with the help of automated technologies. My work is reliable, not because I have striven for generalizability, but because my findings and the research do support each other. “In naturalistic studies, we don’t value being able to reproduce results. Though results should support and inform other work, and consistency means that analysis and collection can be shown to have been carefully and mindfully done.” (Galman, 2016, p. 89)

Furthermore, additional aspects taken into account to ensure trustworthiness and data collection in an ethical way were: participants will be provided with informed consent documents for their signature, prior to any interview being conducted, all treatment of human participants followed IRB rules and best practices; and confidentiality was a must. Pseudonyms will be given to all participants. They were allowed to select their own. I answered any questions about who is being recruited and who is not being recruited, should those questions have arisen.

Future Research

Based on the findings and boundaries of my research, I have ideas for future research. The first idea for future research is to investigate how the quantity and persistence of faith-filled messages and comments shape what Black students do in regards to neurodivergent testing and diagnosis. Based on my participants comments, a fair amount of them were told they should “be praying harder” to make symptoms
disappear. My second idea for future research is to conduct an inquiry on the relationship between black students whose parents have received an advanced degree (Masters or doctoral) and their experiences with self-advocacy on campus. Lastly, my next research inquiry would be an exploration of the self-taught academic practices that Black neurodivergent doctoral students use to thrive while in coursework and then in their post-coursework doctoral degree process. The methodological constraints and considerations to factor in would be similar to this study - the ability to write and conduct an accessible research study that benefits my participants and is to their learning style.

I would want to include aspects in data collection that would be neurodivergent friendly and be welcoming and safe for the nuances of people living with neurodivergent conditions. My participants would be the same as in this study, and I would like this to happen outside of a global pandemic. I would like to meet with my participants in person rather than zoom. The future research would take into account the ways to best communicate with graduate student participants managing a range of executive functioning. Further research is needed to establish the learning processes of graduate students from minoritized racial backgrounds as they are in the position of learner and then researcher. There are many aspects to doctoral research, training, and learning that is made especially challenging for those with executive functioning issues.

**Conclusion**

Black women graduate students navigate social systems within higher and postsecondary education that their White neurodiverse peers do not, in part due to race and gender and power and oppression. Their cultural production is an outcome of
creating new ways of being within environments like higher education that have an overall problem with equity for all its stakeholders. Despite cultural barriers in the Black community surrounding dis/ability diagnosis and treatment, the spaces created by Black women represent agency, transformation, and power.

Whether it is via social media, on Twitter, in the science fiction works of Octavia Butler, cancer diaries of Audre Lorde, or the Feminist thought of Patricia Hill Collins, Black women are staying true to themselves. Whether the trials of institutional failings or weak educational pedagogy, insurmountable hurdles of ableism and exist. Black women graduate students with executive functioning challenges, and conditions connected to neurodiversity are creating support and solutions out of nothing. And for that, institutions just need to listen to them.

*Just another Realization*

ADHD is the validation of my life
Before I was diagnosed
I owned w*ird, or brok*n, or *dd
But rather; I was invisible and ignored
Like many score before
Black girls in urban/poor/any/all schools
In the educational jungle
An educational ecosystem
With barely enough staff or resources
Become Black girls in liberal arts colleges
Referred to inaccessible private practice
For expensive testing
That didn’t take Medicaid
Become Black girls in the Ivy League
Willing themselves to perform excellence
Because the ancestors...

*Just a Unicorn*

Become Black girls in Ph.D. programs
The terms I’m using in this dissertation may have different definitions, in other communities that do disability or neurodivergence work. Terms like dis/ability, neurodivergence, neurotypical, DisCrit, and ableism are used throughout. For widespread and consistent understanding, the terminology in the way they’re being used in this study and dissertation follow.

- **Dis/ability**: Written with a forward slash is used by Annamma to “analyze the entire context in which a person functions” (Annamma et al., 2016, p. 1) and to acknowledge that “dis/ability is not a thing to find and fix, but a process” (Annamma, 2017, p. 7). Moreover, Annamma (2017) states that disability without the forward-slash centers ability as the normative experience (dis = not, ability = able). (Lovelace et al., 2021)

- **Neurodivergence**: “an umbrella term, originally coined in relation to autism, for several conditions traditionally pathologized and associated with a deficit, including dyspraxia, dyslexia, attention deficit hyperactivity disorder, dyscalculia, autistic spectrum, and Tourette syndrome.” (Clouder et al., 2020, p. 758)

- **Neurotypical**: a named category that classifies the ways brains operate and respond to “everyday” tasks related to executive functioning and more, (this is not entirely exhaustive).

- **DisCrit**: Disability Studies and Critical Race Theory in Education (a theoretical framework drawing upon DS & CRT. (Annamma, S.A., 2016)
• **Ableism**: “Ableism, we argue is the conscious and unconscious favoring of those perceived as ‘able’ over those perceived to be disabled, or indeed those assessed as disabled. Ableism positively values able-bodiedness (Dolmage, 2017). Anyone deviating from the norm is considered ‘tragic’, ‘dangerous’, ‘inferior’ or ‘less than human’ (Swain et al. 2003). As a society, being disabled has a specific stigma attached to it and ableism reinforces that stigma.” (Lynch, S., & Macklin, J., 2020)

• **Unicorn**: A term of endearment used by and toward neurodivergent (especially those with ADHD) Black women in online spaces created and curated by René Brooks. [Black Girl, Lost Keys](http://example.com)
APPENDIX B

Abbreviation Definitions

This study and its corresponding research use terminology that may not be familiar to all. To clearly express what is meant by the language around dis/ability and my word choice, I have included a glossary. This terminology may be more familiar to some and unfamiliar to others. They will be used throughout my study, and some words will be used in ways other than what they might typically appear in everyday language.

**ND** - Neurodiversity / Neurodiverse/ Neurodivergent

**BW** - Black Women

**Dis/Ability** - written with a forward slash is used by Annamma to “analyze the entire context in which a person functions” (Annamma et al., 2016, p. 1) and to acknowledge that “dis/ability is not a thing to find and fix, but a process” (Annamma, 2017, p. 7). Moreover, Annamma (2017) states that disability without the forward-slash centers ability as the normative experience (dis = not, ability = able). (Lovelace et al., 2021)

**DS** - Disability Studies

**DisCrit** - Disability Studies and Critical Race Theory in Education (a theoretical framework drawing upon DS & CRT). Annamma

**CRT** - Critical Race Studies

**NDBW** - Neurodiverse Black Women

**NDBWG** - Neurodiverse Black Women Graduate

**SNDBWG** – Suspected Neurodiverse Black Women Graduate

**BFDF** - Black Feminist Disability Framework (Bailey & Mobley, 2019)
Unicorn - a term of endearment used by and toward NDBW in online spaces (Brooks, 2018)
APPENDIX C

IRB APPROVAL LETTER

LETTER OF EXEMPT DETERMINATION

To: Professor Ezekiel Kimball and Kat Stephens, College of Education

Date: November 29, 2021

From: Professor Lynnette Leidy Sievert, Chair, University of Massachusetts Amherst

IRB

Protocol Title: Neurodiverse Black Women Negotiate Space: (Inner, Outer, Institutional, Online, Literary) Protocol ID: 2902

Review Type: EXEMPT -NEW

Category: 2 (ii)

Review Date: 11/29/2021

No Continuing Review Required

UM Award #:

The Human Research Protection Office (HRPO) has reviewed the above-named submission and has determined it to be EXEMPT from the federal regulations that govern human subject research (45 CFR 46.104)

Note: This determination applies only to the activities described in this submission. All changes to the submission (e.g., protocol, recruitment materials, consent form, additional personnel), must be reviewed by HRPO prior to implementation.

A project determined as EXEMPT, must still be conducted in accordance with the ethical principles outlined in the Belmont Report: respect for persons, beneficence, and justice. Researchers must also comply with all applicable federal, state, and local regulations as
well as UMass Amherst Policies and procedures which may include obtaining approval of your activities from other institutions or entities. All personnel must complete CITI training.

Consent forms and study materials (e.g., questionnaires, letters, advertisements, flyers, scripts, etc.) - Only use the consent form and study materials that were reviewed by the HRPO.

Final Reports - Notify the IRB when your study is complete by submitting a Close Request Form in the electronic protocol system.

Serious Adverse Events and Unanticipated problems involving risks to participants or others - All such events must be reported in the electronic system as soon as possible, but no later than five (5) working days.

Annual Check In - HRPO will conduct an annual check in to determine the study status.

Please contact the Human Research Protection Office if you have any further questions.

Best wishes for a successful project.
APPENDIX D

RECRUITMENT FLYER

Black Women Graduate Students!
Do you experience:
• Problems with forgetfulness?
• Difficulty Focusing?
• Challenges processing numbers, dates, and time?
• Chronic lateness despite various efforts?
• Labor-intensive reading or writing?
• Mental “rituals” such as frequent counting, memorization?
• Checking for locked doors, off & unplugged appliances?
• Missed appointments often?
• Missing assignment deadlines?
• Difficulty with social cues or processing facial expressions?
• Poor executive functioning?
• Issues with Motor Planning?
• Do you experience problems planning complex actions?

IF SO, YOU MAY BE ELIGIBLE TO PARTICIPATE IN MY STUDY on Black Women Graduate Students who have or SUSPECT they have ADHD, OCD, & AUTISM & other conditions. OR IDENTIFY AS NEURODIVERSE and/or DISABLED.

People who complete interviews for my study will receive a $10 e-gift card.

PI: KAT J. STEPHENS, ED.M. - PH.D. CANDIDATE
E: KISTEPHENS@UMASS.EDU
UNIVERSITY OF MASSACHUSETTS AMHERST
Dear Colleagues,

My name is Kat J. Stephens, and I am Ph.D. Candidate at UMass Amherst’s College of Education, in their Higher Education program. I am thrilled to share that I am currently recruiting participants for my dissertation study. For my study, I will be conducting a narrative inquiry about the academic experiences & lives of Black women graduate students living with (or suspected to have) conditions affecting a wide range of executive functioning needs, such as Autism, ADHD, OCD, Dyslexia, Dyscalculia, and Tourette Syndrome, and the community they build to offset their academic experiences. These conditions are often grouped together as neurodiverse conditions, and to some, may be a grouping of disabilities. My study is open to those who have an official diagnosis, and to those who do not have an official diagnosis. Participants in my study will receive a small token, a $10 e-gift card, (until goal number of participants is reached).

I would greatly appreciate if you would share this email with any faculty or student affairs professionals you know who work with Black women graduate students directly. Or feel free to share this with your graduate student community across the United States.
Individuals interested in participating can complete an eligibility screening form here: (INSERT Qualtrics link). Those who are eligible to participate and are selected will complete one 90-minute interview.

My IRB approval from the University of Massachusetts is attached, as is my recruitment e-flier, which you are welcome to share.

I look forward to beginning the data collection process and greatly appreciate your assistance in sharing this opportunity. If you have any questions or concerns, please let me know!

Thank you again for your assistance.

Sincerely,

Kat J. Stephens, Ed.M.
Ph.D. Candidate, UMass Amherst

E: kjstephens_
Hi,

Thank you for taking the time to participate in my research study. As promised, I am writing with my follow-up to your interview. Your time is valuable, and I appreciate your contributions to research. I want to provide you with resources, post-interview. Here is a link for the counseling center at your university, should you need it. Here is a link for the disability office at your university, should you need it.

Additionally, I have attached my resource list, which I have compiled of Mental Health, ADHD, and Executive functioning resources. The list contains videos, articles, social media, journal articles, book recommendations.

Again, thank you for your time. Please share my flier with anyone you think may benefit from sharing their story.

Have a great week!

Kat J. Stephens, Ed.M.
Ph.D. Candidate, UMass Amherst

E: kjstephens_
APPENDIX F

ELIGIBILITY SURVEY

1. What discipline or area of study is your degree in?

2. What is your current GPA?
   1. 1.5 – 1.90
   2. 2.0 - 2.49
   3. 2.5 – 2.90
   4. 3.0 - 3.49
   5. 3.5 - 4.0

3. Are you currently on any merit achievement such as honor society or dean’s list?

4. Have you ever been academically dismissed or on academic probation from school?
   1. What level of education did that happen? Undergrad, Grad School, High School?
   2. How many times have you experienced this?

5. Have you been diagnosed with ADHD?

6. Have you been diagnosed with Autism?

7. Have you been diagnosed with OCD?

8. Have you been diagnosed with Dyslexia?

9. Have you been diagnosed with Dyscalculia?

10. Have you been diagnosed with any condition which affects your executive functioning, ability to focus, remember information or details, makes reading challenging, numbers hard to work with, or highlight general processing issues?
11. Have you been diagnosed with any condition due to symptoms like hoarding, requiring order, frequent handwashing, checking appliances, touching objects, “mental rituals,” poor balance, clumsy gait and movement, poor hand-to-eye coordination, tendency to trip, fall, bump into things or people?

12. Have you been diagnosed with any condition due to symptoms like trouble doing mental math, being frequently late, missing appointments often, needing to write down a phone number immediately to remember it, having poor memory for number related information like dates and facts?

13. Have you been diagnosed with any condition due to symptoms like having slow and labor-intensive reading and writing, difficulty reading (aloud), mispronouncing words and names, or trouble keeping up in conversation, trouble interpreting body language, social cues, facial expressions, exhibiting strong special interests, outbursts when changes to daily routines occur?

14. Do you suspect you have ADHD?

15. Do you suspect you have Autism?

16. Do you suspect you have OCD?

17. Do you suspect you have Dyslexia?

18. Do you suspect you have Dyscalculia?

19. Do you suspect you are living with any condition that affects your executive functioning, ability to focus, remember information or details, makes reading challenging, numbers hard to work with, or general processing issues?

20. Do you identify as a neurodiverse person?

21. Do you believe you have executive functioning issues?
22. Do you struggle with making and maintaining a plan?

23. Do you struggle with keeping track of time?

24. Do you struggle with attending to personal care and needs like making meals, or often forget to eat?

25. Are aspects of hygiene routines like showering, brushing your teeth, combing your hair difficult to do or hard to remember to do?

26. As a child were you in gifted classes or gifted programs in school?

27. As a child were you constantly chastised for not using all your “potential,” or “underperforming” while being told how “smart,” “bright,” and “brilliant” you were?

Thank you for taking the time to answer my initial questions. If you are found to be eligible to participate in this study, you will be contacted via email with more details on what comes next.

If you feel that you have experienced any psychological distress or concern about the questions you were asked to reflect on or complex conditions like ADHD, Autism, OCD, and others, you can contact:

National Suicide Prevention Lifeline (24/7)
1-800-273-8255
https://suicidepreventionlifeline.org/

Crisis Text Line (24/7) Text HOME to 741741 from anywhere in the United States.
https://www.crisistextline.org

National Alliance on Mental Health (NAMI) Helpline
Call 1-800-950-6264 (Monday through Friday, 10 a.m. – 8 p.m., ET.) Text NAMI to 741741 (24/7)
https://www.nami.org/help
APPENDIX G

DEMOGRAPHICS SURVEY

1. What is your name?

2. What is your gender?
   1. Cisgender Woman
   2. Cisgender Man
   3. Transgender (Transwoman)
   4. Non-binary/non-conforming
   5. Prefer not to respond

3. How old are you?


5. Please specify your country of origin.

6. Do you identify as Black?

7. Do you have a disability?

8. Can you name your disability here? (there will be space for a short answer)

9. Are you currently enrolled as a graduate student?

10. What degree are you earning?
    1. Masters
    2. Doctorate
    3. J.D.
    4. M.D.
    5. MBA
    6. MPH
    7. Other graduate degree (please specify)
11. What university do you attend?

12. What is your university email? (Only your emailing ending in .edu)
This interview centers the experiences of Black women graduate students who live with (or suspect they live with) the conditions: attention deficit hyperactivity disorder (ADHD), Autism, Tourette Syndrome, obsessive compulsive disorder (OCD), dyslexia, dyscalculia, hyperlexia, dyspraxia, as examples. Some people with these conditions identify as being neurodivergent, and some people identify as being dis/abled, or living with a dis/ability. Some people do not identify as being neurodivergent, and some people do not identify as being dis/abled or living with a dis/ability. Participant’s diagnosis status (having one or not) status does not prevent participation in this study. Participant narratives shared will illuminate the experiences of Black women graduate students who may be disabled/ living with a dis/ability, or neurodivergent. This is not an exhaustive list of the conditions believed to be neurodivergent, but instead, many of the conditions with high visibility. I want to learn more about this community of students who experience various symptoms of poor executive function that is commonly found in conditions like ADHD, Autism, OCD, and more. They may be neurodivergent, and/or disabled, or they may not be – that is a personal choice as to how they identify. (more on neurodiversity here)

Introduction

The vectors through which this inquiry exists are race, space, place, and gender. Race and gender work alongside disability as identities which can be weaponized and marginalized. Space as the thing we create with others, highly inclusive. Space is
constructed by the person or by the people. Space is meaningfully designed to center freedom, liberation from rigid practices/norms of place. Place as I define it, is the result of constructions that come from institutions. Place center’s structure, order, and power which yield to the institutions themselves, their needs, and are informed by the institutions point of view.

Interview Guiding Questions Participant’s Racial/Ethnic & Disabled Identity

1. So, just to get started, tell me a little about yourself.
2. On your demographics form, you identify as being black. What does Blackness mean to you?
3. On your demographics form, you identify as being (African, Caribbean, or African American). What does your ethnicity (ethnic group) mean to you?
4. Tell me about your experience of being Black in graduate school. What is that like for you?
5. How would you describe your Blackness and disability together?
6. Now, add graduate school. How would you now describe it if you add graduate school?

Dis/ability Identity Section

1. How does your dis/ability status shape your day-to-day life?
2. How would you define dis/ability?
3. As you know, you’re participating in this study because you are diagnosed with a condition that’s neurodivergent, or you self-identify as being neurodivergent. How would you describe your disability?

4. What does that mean? How did you come to understand yourself in that way?

5. What does neurodivergence mean to you? (Provide a definition if needed)

6. How would you describe your disability identity?

7. How does disability identity influence your (academic) life?

8. We’ve been discussing this for about an hour or so. When I say disability what does it mean to you?

**Diagnosis and Dis/ability**

1. On the demographics form, you identified as having “---” what does that mean to you?

2. How did you first begin to understand yourself as disabled?

3. What are your experiences in and around the medical process of disability?

4. What are your experiences in and around the medical process of disability?

5. How do you feel about representation and disability together?

6. How do you feel about diversity and disability together?

**Race**

1. How (if at all) has your race impacted your graduate school experience?

2. How do your experiences with (----- name condition ---- ) and your race shape one another?

3. In what ways (if any) do you feel that your race impacted your diagnosis?
4. In what ways (if any) do you feel that your race impacted your ability to receive
treatment, or support?

5. In what ways (if any) do you feel that Black culture and society has impacted
disability culture?

Gender

1. How (if at all) has your gender impacted your graduate school experience?
2. How do your experiences with (----- name condition ---- ) and your gender shape
   one another?
3. In what ways (if any), do you feel that your gender has impacted your diagnosis?
4. In what ways (if any), do you feel that your gender has impacted your ability to
   receive treatment or
   support?

Perceptions of and Experiences within U.S. Higher Education as a

“Neurodivergent” Black Woman Graduate Student Section

(***Make sure to provide a transition into this section about “space” and “place”)

Space, Higher Education, & your experience as a Neurodivergent Black Woman

1. Does your race and (disability or condition if named) shape how you present
   yourself as a graduate student?
2. Can you share about the communities or spaces you feel connected to on campus
   or in academia more broadly?
   a. Probe for race and disability
3. What does community in graduate school look like as a neurodivergent Black woman?

4. What does community outside of graduate school look like as a neurodivergent Black woman? (Probe with these examples if useful) - Online spaces / social media? Reading groups? Science Fiction or literature? Anime?

Does the way you experience disability intersect with how you feel about your dis/ability? (*use the name of their dis/ability if they’ve shared)

**Place, Higher Education, & your experience as a Neurodivergent Black Woman**

1. Tell me about a time where your university or program has been welcoming toward you as a neurodivergent Black woman graduate student.

2. Tell me about a time where your university or program has handled your disability well as a neurodivergent Black woman graduate student.

3. Can you share a time that your institution was successful at empowering you as a neurodivergent Black woman graduate student?

4. How is your institution’s campus culture influenced by?
   a. Race
   b. Gender
   c. Dis/Ability

**Higher education and your experience as a neurodivergent Black woman Graduate Student**

1. Is there anything you would like me to know regarding higher education and your experience as a neurodivergent Black woman graduate student?
• In your classroom experience? *Probe if necessary
• With your professors?
• With your classmates?
• With accommodations?

Dis/ability and your experience as a neurodivergent Black woman Graduate Student

1. Is there anything you would like me to know regarding dis/ability and your experience as a neurodivergent Black woman graduate student?
   • In your classroom experience? *Probe if necessary
   • With your professors?
   • With your classmates?
   • With accommodations?

Closing:

Is there anything else that we haven’t discussed related to your college experience or your perspective on college regarding “neurodiverse” Black women graduate students that you would like to share? I may follow up with you one time within two months of the interview by phone or video for clarification of your interview responses. We are still recruiting for participation in this study and would appreciate your help in identifying others who you think may be open to participating. Here is a recruitment flyer that describes the study and has my contact information [insert link to electronic flyer in chat box]. I will also send you an electronic version of the flyer via email that you can email to other potential participants. Thank you again for participating in this interview. Are there any questions or concerns that you have for me? Thank you for participating.
APPENDIX I

POST-INTERVIEW RESOURCE GUIDE

The Nap Ministry

Description: “The Nap Ministry was founded in 2016 by Tricia Hersey and is an organization that examines the liberating power of naps. We engage with the power of performance art, site-specific installations, and community organizing to install sacred and safe spaces for the community to rest together. We facilitate immersive workshops and curate performance art that examines rest as a radical tool for community healing. We believe rest is a form of resistance and name sleep deprivation as a racial and social justice issue. We are very active on social media because we view our pages as one of our many tools to help deprogram the masses from grind culture. Please feel free to follow us to learn more about this justice movement.”

Web address: https://thenapministry.wordpress.com/about/

The Loveland Foundation

Description: “Loveland Foundation is committed to showing up for communities of color in unique and powerful ways, with a particular focus on Black women and girls. Our resources and initiatives are collaborative, and they prioritize opportunity, access, validation, and healing. We are becoming the ones we’ve been waiting for.”

Web address: https://thelovelandfoundation.org/
Free Mental Health Apps/Resources/Hotlines for Black, Indigenous and People of Color (BIPOC specific)

**The Liberate App**

web address: https://liberatemeditation.com/

Description: The app is designed to support Black folks on their path to healing by naming and offering resources for common cultural experiences, like internalized racism and microaggressions.

Age rating on App Store by Apple: 9+ years old (“Apps in this category may contain mild or infrequent occurrences of cartoon, fantasy, or realistic violence, and infrequent or mild mature, suggestive, or horror-themed content which may not be suitable for children under 9.)

**The Shine App**

Web address: https://www.theshineapp.com/

**Description:** “The Shine app is your support system for daily stress and anxiety. Prioritizing your mental health starts here. Learn a new self-care strategy every day, get support from a diverse community, and explore an audio library of over 800+ original meditations, bedtime stories, and calming sounds to help you shift your mindset or mood.”

Age rating on App Store by Apple: 4+ years old (“ Apps in this category contain no objectionable material.”)

Free Mental Health Apps/Resources/Hotlines (not BIPOC specific)
**Calm App**

**Action:** Free Mindful living calendars, free daily gratitude journals, free mental fitness training guide, and free calm intention cards.

**Description:** “Our mission is to make the world a happier and healthier place. We're devoted to helping you live mindfully, sleep better and breathe deeper.”

Web address: https://www.calm.com/blog/mindfulness-resources

Age rating on App Store by Apple: 4+ years old (“Apps in this category contain no objectionable material.”)

**MindShift App**

**Description:** Is anxiety getting in the way of your life? MindShiftTM CBT uses scientifically proven strategies based on Cognitive Behavioural Therapy (CBT) to help you learn to relax and be mindful, develop more effective ways of thinking, and use active steps to take charge of your anxiety.

Web address: https://www.anxietycanada.com/learn-about-anxiety/anxiety-in-youth/

Age rating on App Store by Apple: 4+ years old (“Apps in this category contain no objectionable material.”)

**SAMHSA’s National Helpline**

**Action:** If you, or someone you know, needs help with a mental or substance use disorder, call Substance Abuse and Mental Health Services Administration’s National Helpline at 1-800-662-HELP (4357)

**Description:** “a free, confidential, 24/7, 365-day-a-year treatment referral and information service (in English and Spanish) for individuals and families facing mental and/or substance use disorders.”
web address: https://www.samhsa.gov/find-help/national-helpline

**Trevor Lifeline**

Action: If you are thinking about suicide and in need of immediate support, please call the Trevor Lifeline at 1-866-488-7386 or select Trevor Chat below to connect with a counselor. (LGBTQ youth specific)

**Description:** “Our trained counselors are here to support you 24/7. If you are a young person in crisis, feeling suicidal, or in need of a safe and judgment-free place to talk.”

web address: https://www.thetrevorproject.org/get-help-now/

**National Suicide Prevention Lifeline**

Action: The Lifeline provides 24/7, free and confidential support for people in distress, prevention and crisis resources for you or your loved ones, and best practices for professionals. telephone:1-800-273- 8255

**Description:** “The National Suicide Prevention Lifeline is a national network of local crisis centers that provides free and confidential emotional support to people in suicidal crisis or emotional distress 24 hours a day, 7 days a week. We're committed to improving crisis services and advancing suicide prevention by empowering individuals, advancing professional best practices, and building awareness.”

Web address: https://suicidepreventionlifeline.org/

**Playlists, Podcasts, Individual Podcasts Episodes, YouTube Channels**

We Got Us Now Hip-Hop Saved My Life playlist
**Description:** “A collection of uplifting hip-hop music curated by the Actionists of We Got Us Now” web address: https://open.spotify.com/playlist/2ONxU3AlOeSwFyDRHHkUWZ?si=h9Nj3sS9SEKfjafYUyru3w

**Books & Online References. (Blogs, Newspaper articles, YouTube)**

**The Intersection of Race & Neurodivergence (Forbes, 2020)**

**Description:** “This week as part of my #ShareTheMic series I have invited the brilliant Tumi Sotire, known on Twitter and Instagram as The Black Dyspraxic, to talk about his experiences and thoughts on the intersection of race and disability. Tumi is a Research Assistant at The Newcastle University as well as a Neurodiversity advocate. His research interests are the economic consequences of health disparities.”


‘Autistic while black’: How autism amplifies stereotypes (Spectrum News)

**Description:** “As a black woman living in the United States, I am always mindful of what others think about me, and the assumptions they may make. As a black woman with autism, I am especially aware that colleagues often see me as an ‘angry black woman,’ even though my thoughts and behaviors are the opposite of this stereotype. (I prefer to label my ethnicity as black, not African American, because not all black people are African, and the majority are not American.) Such cultural stereotypes make it particularly dangerous to be ‘autistic while black.’ Part of the reason people are quick to stereotype me is that there is no research on middle-aged black women with autism.”
Where is the research into Black autism and ADHD? (Open Access Government)

Description: “In conversation with my counselling supervisor, I mentioned that my son was diagnosed with autism spectrum condition (ASD) aged almost nine. I prefer to use the word condition, instead of disorder, to discourage perpetuation of autism spectrum in the medical model. “What took you so long to get a diagnosis?” she enquired. “That’s a good question,” was my diplomatic response.

Web address: https://www.openaccessgovernment.org/black-autism/91621/

No Time to Confront Racism in Neurodiversity (Black Girl Lost Keys)

Description: What people don’t customarily talk about, is the dark side of what that means for people of color coming into spaces for the neurodiverse. I’m constantly telling people that we get attacked for the most benign reasons in these spaces. That the attacks are vicious and seemingly come out of nowhere.

Web address: https://blackgirllostkeys.com/adhd/no-time-to-confront-racism-in-neurodiversity/

‘No One’s Ever Talked to Me About This Before (New York Times)

Description: “When I was a kid, I had the sense things were more difficult for me,” Tiffany Bui recalled. It was hard for her to focus in school, and she was often forgetful. Throughout her life, she said, members of her family criticized these traits as faults. In
the fall of 2020, when she was a senior at the University of Minnesota, Ms. Bui, 21, was
struggling with anxiety and depression. She visited the school’s health clinic, where she
was prescribed an antidepressant, but her attention troubles persisted. When she later
returned to the clinic, the doctor asked if she had considered that she might have attention
deficit hyperactivity disorder, or A.D.H.D.

Web address: https://www.nytimes.com/2021/05/24/style/adhd-online-creators-
diagnosis.html

Black women with ADHD start healing, with a diagnosis at last (Washington Post)
Description: Miché Aaron has always been a high achiever. The 29-year-old is in her
third year of a planetary sciences doctoral program at Johns Hopkins University, where
she researches minerals found on Mars. She is a former NASA space grant scholar and
hopes to be an astronaut one day. But last year, Aaron was barely keeping it together –
missing classes, late on assignments and struggling to explain that she understood the
required material to pass her qualifying exams. Her academic adviser warned that if she
didn’t get professional help, she would flunk.

Web address: https://www.washingtonpost.com/health/black-women-bias-adhd-
diagnosis/2021/07/16/1784cda2-df22-11eb-9f54-7eee10b5fcd2_story.html

Double Trouble: Navigating Life as A Gifted Kid with ADHD (Black Girl, Lost
Keys)
Description: I make jokes all the time about how being an adult is a scam. It’s funny how we long for the day when we become the masters of our own destinies only to discover that being the master of your own destiny is NOT as fun as it looks from the outside. Being a grownup is the ultimate Ponzi scheme. But growing up a gifted kid with undiagnosed ADHD is a super close second. In the race for which is worse, it is a photo finish with being an adult leading by a hair.


**What It’s Like to Be ADHD and Black (How to ADHD, YouTube)**

Description: There are many factors that affect our lived experience of ADHD. This is the first in a series of videos that will explore what it’s like to be ADHD *and.* Given what’s going on in this country, I thought it was important to start with what it’s like to be ADHD and Black.

Web address: https://www.youtube.com/watch?v=oh-3ULQjiEY

**Divergent Mind by Jenara Nerenberg (Harper Collins)**

Description: “Divergent Mind: Thriving in a World That Wasn’t Designed for You” – “a paradigm-shifting study of neurodivergent women- those with ADHD, autism, synthesizea, high sensitivity, and sensory processing disorder-exploring why these traits are overlooked in women and how society benefits from allowing their unique strengths to flourish.

Website: https://www.divergentlit.com
APPENDIX J: Informed Consent

Protocol Study Name: Neurodivergent Black Graduate Women with ADHD & Autism

Negotiate Space: (Inner, Outer, Institutional, Online, Literary)

Purpose

Please briefly state the purpose of your study, including what you hope to learn.

The purpose of this study is to learn what measures (suspected neurodivergent) * Black graduate women take in their educational experiences. This study uses semi structured interviews to ascertain the educational experiences of diagnosed and undiagnosed Black women graduate students who are suspected to (or) have ADHD, Autism, other related conditions. Furthermore, the study focuses on how dis/ability, race, and space/place correspond to each other in the lives and experiences of Black women graduate students. This study’s purpose is to learn how these students navigate the complexities of dis/ability, diagnosis, disability identity. To understand how neurodiverse Black women graduate students navigate spaces like higher education. I will interview Black women graduate students who are currently enrolled in graduate school (graduate program).

*For this research study, what I mean by neurodiverse is: a range of differences in the ways that brains can function aside from the dominant perception of brain or neuro function. This diversity in the way brains operate is normal for the world, since no two brains are exactly alike. Neurodiversity and neurodivergence in this study are being used to describe a wide range of
neurological differences in the behaviour and biology of brains, and associated conditions that fall under the umbrella term of neurodiverse. Such conditions are ADHD, Autism, Dyspraxia, Dyslexia, Dyscalculia, OCD, Tourette Syndrome, and others. (for reference)

**Background** Please briefly describe past findings leading to the formulation of the study. Higher education research indicates a larger than expected (one-fifth) number of college students (De Brey et al., 2021) identifying as disabled or mentally ill. More concerning is a 2018 study highlighting the 39% of PhD candidates who have identified as experiencing “moderate-severe- depression” (Flaherty, 2018). This is a percentage anticipated to have grown during the global COVID-19 pandemic (Panchal et al., 2020). With that knowledge, additional postsecondary populations remain underrepresented in disability research - by gender and race (Karpicz, 2020). Black women graduate students with disabilities, specifically those identifying as neurodiverse are barely visible in contemporary research and the larger disability conversation. The convergence of disability (and race, gender, class for example) as other marginalized and diverse student populations is an additional gap in the literature, despite the benefits of DisCrit (Annamma et. al, 2013). Academia has the potential to produce disability scholars in various disciplines yet is less supported inquiry. With my research focus, I intend to elucidate the experiences of Black graduate women in higher education who identify as being neurodiverse (Stephens, 2020). It is known that student disclosure and receipt of accommodations is complicated, and unfortunately stigmatized (Kimball et al., 2016;
Miller et al., 2019); complicating that with race and gender will make for imperative research.

While the representation in research is important, so are culturally appropriate, accessible, and affirming research practices. Research shows intentional and specific production of qualitative methodology within the disabled community to be productive and impactful (Kozleski, 2017). Furthermore, centering student narrative is essential (Griffin et al., 2009; Gillespie-Lynch et al., 2017) in outcomes and findings. Lastly, for junior and novice researchers, conducting pilot research and pre-tests ensure a more successful dissertation from beginning to end (Malmqvist et al., 2019).

Considering the population I will research, there is marginal room for error, with accessibility norms to fold into my research design and data collection. I will conduct a range of 10-12 semi-structured interviews with Black women graduate students. This will inform my research study, and this number of participants will be robust given the topic and the lack of higher education literature on this participant community.

Please state how many participants (number or numerical range) you propose to enroll and the rationale for the proposed number or range. Be sure to account for attrition in your enrollment number.

*Please describe specific inclusion/exclusion criteria (age range, gender, ethnicity, physical and psychological health)*
Specific inclusion criteria are:

Race: Black

Ethnicity: Afro-Caribbean, African, African American

Gender: Cis Gender Women

Age Range: Adults, no children, or minors.

Psychological Health: Open to those with or without a formal diagnosis of ADHD, Autism, OCD, similarly, grouped conditions.

College degree status: Please be enrolled in a graduate level program of study and be in graduate school at the time of your participation in this study.

*Please describe your procedures for recruiting subjects, including how potential subjects will be identified and contacted for recruitment.*

I will recruit participants via online forums, social media groups on Twitter & Facebook, and list servs/e-mailing lists of professional higher education organizations that engage with graduate students. I will also contact graduate programs of study via email, to share with their student body. I will email and share digital recruitment documents (flier, informed consent, synopsis of study) to any list serv and in these communication efforts, there will be a link to an online demographics and screening survey via the online system, Qualtrics.
Please describe any screening procedures. Attach any scripts or questionnaires that would be used to screen potential participants.

All screening materials will be linked to a basic Qualtrics demographic and screening questionnaire. This demographics questionnaire will confirm potential participants’ demographic details (name, age, gender, race, ethnicity, current university matriculation status, do they identify as having ADHD or Autism, being disabled or not).

Screening questionnaire will also be on Qualtrics. The screening questionnaire will screen for eligibility to participate in this study. The screening questionnaire is attached to another document. The screening questionnaire will ask if they believe they have ADHD, Autism, or other similarly grouped conditions if they have an official diagnosis for any of those conditions or not, identify as having a disability or not.

All individuals participating in the pilot study will be included in the actual, full dissertation study, and its collected data set. They will be included in the full dissertation study, not just the initial pilot study. All individuals who fill out the demographic and screening eligibility form (even if not deemed eligible to participate) will be included in the pilot study and any additional dissertation study. This will be done to keep reporting information consistent.
Please describe the steps that will be taken to minimize any potential coercion or undue influence. Interactions, where coercion or undue influence may occur, include faculty/student, doctor/patient, supervisor/employee, etc.

I will not interview any classmates, or former students of mine.

**Study Procedures**

Attach copies of all questionnaires, surveys, etc. in the Attachments Section. Please describe in sequential order all activities participants will be asked to complete (e.g., completing a survey, answering questions in an interview, running on a treadmill, etc.).

1. Interested participants will complete Qualtrics demographic questionnaire.

2. PI will contact (via email) eligible participants to learn more about the study, provide them with the informed consent, and an online scheduler so they can select appointment times for an interview. They’ll also receive a copy of the e-flier. The participant will return their signed consent form as an upload to the secure cloud system the University uses/provides.

3. Participant will have to complete & sign the required informed consent before being interviewed. The signed informed consent must be uploaded to the University’s secure cloud service, which UMass uses/provides.

4. Once participants return the informed consent, and book an interview time, they will be confirmed via email.

5. Interviews will be conducted via zoom for a single session of 90 minutes total.
6. Participants will receive contact information for mental health/counseling resources that correspond with the university they are enrolled at via email.

7. I would like to conduct follow-up interviews, if necessary. I would like to gain permission to follow up later in the academic year. The main criteria for reaching out for follow up is if I as the researcher needs to clarify or confirm responses that my participants have shared. This would be equitable for all women that I have interviewed, but participants will not be contacted if there is no need for clarifying questions. If not, they will be thanked (via email) for their involvement and can expect no further contact.

*Please state the number of sessions and how much time each participant is expected to be involved in the study.*

Interviews will be conducted via zoom for one session of 90 minutes total. Follow-up interviews will be scheduled only if deemed necessary (for clarifying questions) and will be case-by-case. This will be for clarifying follow-up questions only.

*Will audio recording, video recording, photography, or digital recordings occur?*

Yes, the video / audio recording of interviews will be recorded on Zoom or another similarly secure platform that UMass provides us with.

The recording’s intended use is for interviews only, and the audio recording will be used for later transcription.

*Will deception or incomplete disclosure be used?*

No.
Will compensation (e.g., payment, experimental credit, gift card, etc.) be provided to subjects?

Yes, a small token of appreciation will be provided to participants. An Amazon e-gift card will be shared with participants via email. A nominal amount will be given, $10 USD.

Benefits

Please describe any direct benefit(s) to the participant.

The participant will know that they contributed to higher education research, which is necessary and currently under-researched. Their participation will shape contemporary research and may reach many people in positions to make change in higher education.

NOTE: Compensation is not considered a benefit, and in most cases, there may not be any direct benefits to the participant. If no direct benefits anticipated, please state so here and in the Consent document.

Please describe any anticipated benefits to society or a specific group of individuals.

All anticipated benefits to society will be added to knowledge in the field of higher education and disability studies. Furthermore, this will create greater visibility to Black graduate women in the academy with conditions like ADHD and autism.

Risk & Risk Management

For the categories below, please include a description of the risks associated with this study and how they will be minimized. If you do not anticipate any risk for a particular category, please indicate “No known risks”.

Physical Risks and how they will be minimized

No known physical risks are expected with participation in this study.
Psychological Risks and how they will be minimized

Any risks will be minute and might only develop from slight discomfort discussing their experiences as a student with one of the conditions (like ADHD or Autism). I will provide all participants with contact information for personalized mental health resources at the university they are currently enrolled at. If they are not affiliated with a university currently, I will provide them with free resources for an accessible, national counseling service. This information will be provided via email.

Economic Risks and how they will be minimized

Risk of embarrassment or reputational concern is the only economic risk, which is slight.

Social, Cultural, and Political Risks and how they will be minimized

Risks of embarrassment of reputational concern is the only risk, which is slight.

Breach of Confidentiality Risk and how it will be minimized

NOTE: Most research activities involve a risk of breach of confidentiality.

Pseudonyms will be given to all participants. The interviews will be conducted via Zoom and stored on the secure cloud server that UMass Amherst provides access to. Additionally, the data will not be made available to anyone aside from the PIs.

Please describe the process for handling a situation in which the researcher discovers that a participant is at imminent risk of harm to themselves or others.

No known risks. The process for handling such a situation will be to provide participants with contact information and direct online (website) information for each individual university that each participant attends. This information will be made available in email sent to participants after they participate in the study.
Confidentiality Procedures

Please describe procedures to protect the privacy of the participants and maintain the confidentiality of the data. Where will the data be kept and who will have access to it?

A secure cloud server system, that is provided by UMass Amherst will be used to store the data. Zoom (which is encrypted), is used to audio and video record my interviews. These are part of the tools used to protect the privacy & confidentiality of the participants and maintain the security of the data.

Will identifiable data be collected?

Yes. Audio / Voice recordings are identifiable data which needs to be stored securely. The audio recordings will be kept for 3 years, as transcription is a detailed process. The zoom recording will be maintained for one year. After transcription is complete, the identifiable data will remain in the secure cloud server system that is provided by UMass Amherst and will only be accessible by the researcher (for 5 years total).

Will you be collecting audio, video, or digital recordings?

Yes.

Will information derived from the study be provided to a government agency, or any other person or group?

Information derived from the study will not be provided to a government agency, or person. Information derived from the study will be used in conference presentations, or professional academic meetings where this data is presented, for academic purposes and audiences. All data will be used in my academic dissertation. All information will have pseudonyms used.

Please indicate if you are using or disclosing Protected Health Information (PHI)?
No, I will not be asking for personal, private health history (PHI) of my participants. I will not be asking for a medical history, but instead, we will be discussing disability (which I will not be asking if they’re (accurately) diagnosed). Discussing disability, and conditions like ADHD or autism has an entirely different (much lower) risk level than discussing Protected Health Information (PHI). I will be using information that participants willingly choose to share with me regarding disability, neurodiversity, and ADHD, Autism, and other similar conditions.

Potential Conflict of Interest

No conflict of interest.

I agree to the audio recording.

I do not agree to the audio recording.

I agree that segments of the recordings made of my participation in this research may be used for conference presentations, as well as education and training of future researchers/practitioners.

I agree to have my recordings archived for future research in the field of higher education.

I do not agree to allow segments of recordings of my participation in this research to be used for conference presentations or education and training purposes, or future research in the field of higher education.

Participant Signature: Print Name: Date:
By signing below, I indicate that the participant has read and, to the best of my knowledge, understands the details contained in this document and has been given a copy.

____________________  __________________   ____________

Signature of Person (PI):       Print Name:       Date:
APPENDIX J

DATA VISUALIZATION

What Is Your Current GPA?

- 23% 3.0 - 3.49
- 8% 3.5 - 4.0
- 69% No Response

Are You Currently on an Honor Society or Dean's List?

- 23% Yes
- 15% No
- 62% Unsure
Have You Ever Been Academically Dismissed or on Academic Probation?

- Yes: 46%
- No: 54%

At What Level of Education Did This Occur?

- Undergraduate: 46%
- Graduate: 39%
- No Response: 15%
Have You Been Diagnosed With Autism?

- Yes: 8%
- No: 92%

Have You Been Diagnosed With OCD?

- Yes: 8%
- No: 92%
Have You Been Diagnosed With Dyslexia?

- Yes: 8%
- No: 92%

Have you been diagnosed with Dyscalculia?

- Yes: 100%
- No: 0%

[Graphs showing the percentages of individuals diagnosed with Dyslexia and Dyscalculia]
Have You Been Diagnosed With Any Condition Affecting Your Executive Functioning, Ability to Focus, Retain Information, Makes Reading Challenging, or Highlights General Processing Issues?

- Yes: 23%
- No: 77%

Have You Been Diagnosed With Any Condition Due to Symptoms Like Hoarding, Requiring Order, Frequent Hand Washing, "Mental Rituals", Poor Balance, Clumsy Gait, Poor Hand-to-eye Coordination?

- Yes: 8%
- No: 92%
Have you been diagnosed with any condition due to symptoms like trouble doing mental math, being frequently late, missing appointments often, having poor memory for number-related information like dates and facts?

- Yes: 23%
- No: 77%

Have you been diagnosed with any condition due to symptoms like having slow and labor-intensive reading and writing, difficulty reading (aloud), mispronouncing words and names, trouble keeping up in conversation, trouble interpreting body language, social

- Yes: 27%
- No: 73%
Do You Self-identify as Neurodivergent?

- Yes: 73%
- No: 27%

Do You Struggle With Keeping Track of Time?

- Yes: 27%
- No: 73%
Do You Struggle With Making and Maintaining Plans?

- Yes: 86%
- No: 14%

Do You Struggle With Attending to Personal Care Needs Like Making Meals, Often Forgetting to Eat?

- Yes: 8%
- No: 92%
Do You Struggle With Aspects of Personal Hygiene Like Showering, Brushing Your Teeth, and Combing Your Hair? Are They Difficult to Do and Remember?

- Yes: 31%
- No: 69%

As a Child, Were You in Gifted Classes or Programs in School?

- Yes: 7%
- No: 93%
As a Child, Were You Chastised for Not Using Your "Full Potential" While Being Complimented for Being "Smart", "Bright", and "Brilliant"?

- Yes: 23%
- No: 77%


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https://www.nytimes.com/2021/05/24/style/adhd-online-creators-diagnosis.html


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