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## **Exploring the Experiences of Black College Women with Autism**

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### **Abstract**

This research paper explores the experiences of Black women with autism in college by adopting a framework of intersectionality. The paper specifically examines self-advocacy within these women and the impact that their intersecting identities may have on their ability to self-advocate. The development of self-advocacy skills in students with disabilities is crucial for their academic achievement in college, and students with autism face specific challenges in navigating the transition into post-secondary institutions. However, students with disabilities face challenges in developing self-advocacy skills due to the stigma surrounding disability and the need for self-realization and awareness. Black women with autism face additional challenges in self-advocacy due to the intersection of their marginalized identities, including racism, sexism, and ableism. The study will use a qualitative approach, collecting data through interviews and open-ended surveys with participants who are diagnosed with autism and pursuing an associate or bachelor's degree. The goal of this study is to determine the specific needs of Black women with autism as well as uncover the challenges and barriers they face at post-secondary institutions rooted in systemic oppression, such as racism, sexism, and ableism.

### **Keywords**

autism, black women, self-advocacy, intersectionality, post-secondary education,

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## Introduction

This research paper will take on an exploratory approach with the purpose of providing a better understanding of the experiences of Black women with autism in college. Black women with autism face unique challenges different than that of men and white women with autism due to the intersection of marginalized identities along race, gender, and disability. By adopting frameworks of intersectionality, this paper will specifically examine self-advocacy within these women and will illuminate the impact intersecting identities may have on their ability to self-advocate. The development of self-advocacy skills in students with disabilities serves a vital purpose in their academic achievement in college. Successful self-advocacy skills in students have been linked to higher graduation rates and grade point averages (Elias & White, 2018). However, students with disabilities face difficulties in developing their self-advocacy skills because of stigmatization around disability as well as the need to develop self-realization and awareness so they might be better equipped to handle problems that arise as a result of their disability (Downing et al., 2007). Students will be better prepared to handle such problems if they are provided with tools to fully understand their disabilities, strengths, needs, and limitations. Students with autism face specific challenges when it comes to navigating the transition into post-secondary institutions as the increased social, emotional, and academic demands of attending such institutions can be intensified due to their disability (White et al., 2011). Such results highlight the need for programs and interventions for students with autism as they transition into college and the importance of developing self-advocacy skills during this transition. Additionally, with the increase of students with autism entering college and university, there is a growing need for research surrounding these students' experiences in order to increase understanding of their needs (Cox et al., 2021). One's experience as a student with autism can vary based on their other social identities as well. The

implementation of intersectionality allows for the analysis of how different social identities such as race, gender, class, and disability are interconnected and produce further advantages or disadvantages for individuals. Black women with autism face unique challenges and barriers when entering college, particularly in their ability to self-advocate due to the intersectionality of marginalized identities. The goal of this study is to determine the specific needs of Black women with autism as well as illuminate the challenges and barriers they face at post-secondary institutions rooted in systemic oppression, such as racism, sexism, and ableism. By introducing the concept of self-advocacy and the skills and resources needed to develop self-advocacy, these college students may be better equipped to face the challenges presented to them and better positioned for success.

### **Literature Review**

This research paper is aimed at exploring the experiences of Black college women with autism and the influence that the intersection of their identities has on their ability to self-advocate. As the number of young adults entering college with autism is increasing, so does the need for research and a deeper understanding of autistic students' college experiences and outcomes (Cox et al., 2021). Additionally, the intersection of different social identities for students with autism can produce an entirely unique experience and present further challenges as marginalized identities such as race, class, or gender converge with that of disability. Very little research exists that specifically addresses the experiences of Black women and women of color with autism. Through the application of a theoretical framework of intersectionality, the ways in which various social identities come together and can create disadvantages based on systemic levels of oppression will be emphasized.

***Theoretical Framework: Intersectionality***

A theoretical framework focused on intersectionality has been implemented to better represent the experiences of Black women with autism within the collegiate environment. Intersectionality is a term coined by professor and researcher, Kimberlé Crenshaw, as a way to represent race intersecting with class and gender, particularly among women creating barriers and disadvantages for them (Littlejohn & Foss, 2009). Intersectionality has come to include numerous social categories or identities, viewing them in conjunction with one another rather than in isolation. Furthermore, social identities or categories are seen as being constructed socially and culturally, through communication, as well as demonstrative of the power differences that exist between different social categories (Littlejohn & Foss, 2009). For the purposes of this research study, an approach of intersectionality helps in understanding the distinctive experiences of college students as ability, race, and gender intersect. There are three approaches in which intersectionality can be understood and applied as suggested by Cho et al. (2013), they include using intersectionality as a frame of analysis, as a theoretical and methodological paradigm, and lastly as a means of political intervention, and reform. This recognition of the various fields in which intersectionality can be applied creates space to explore how these subcategories interact on their own and with one another (Cho et al., 2013). It is important to address that there is some debate about the limitations of using intersectionality theory within certain contexts. The historical implications that intersectionality has, particularly as its creation revolves around the experiences of Black women and their intersecting identities can call into question its appropriateness when examining other marginalized communities (Cho et al., 2013). However, for the purposes of this research study, intersectionality theory proves to be an appropriate tool of analysis. The application of intersectionality theory to research pertaining to autism allows individuals not to be viewed

solely based on their disability identity but rather calls for recognition of other aspects of their identity and experiences (Cascio et al., 2021). Intersectionality theory, therefore, serves to be particularly important when exploring disability alongside social categories that are marginalized or excluded within society.

### *Autism in Women*

Women in general face unique challenges when it comes to understanding the ways in which autism is presented, as their experiences with autism vary from those of men and therefore must be looked at through different lenses. Autism is diagnosed four times more in men than in women and as a result, has led to there being significantly less research exploring autism in women (Shmulsky & Gobbo, 2019). This lack of research produces numerous challenges for women as they seek to find resources and support to meet their needs. Due to the limited amount of research, women with autism often are presented with challenges in their mental health, as well as unmet social, educational, occupational, and health-related needs (Shmulsky & Gobbo, 2019). Women with autism are also more likely to be underdiagnosed or receive their diagnosis later in life (Milner, McIntosh, Colvert & Happé, 2019). Furthermore, the limited amount of research and understanding of women's experiences with autism also contributes to diagnosis rates and the adaption of strategies to cope with autism. An extremely common strategy that women embrace is that of masking or camouflaging their autistic behaviors (Milner, McIntosh, Colvert & Happé, 2019). In seeking to understand why these gender-related differences in autism diagnoses exist, some scholars turn toward notions of socialization for men and women and cultural perceptions related to gender. Gender-related differences are evident in the social behaviors of women and men with autism supporting the notion of masking or camouflaging autistic behaviors among women. Within a school environment, girls with autism compensate for their autistic behaviors by

staying engaged and within proximity of their peers, whereas boys typically play alone rather than in organized sports like their peers (Dean et al., 2017). These results suggest that gender differences impact the socialization of children with autism as well as their behaviors and demand consideration of gender biases when evaluating children with autism. Furthermore, the extreme male brain theory is one that aims at addressing gender and autism by viewing the female brain as more empathizing and the male brain as more systemizing (Baron-Cohen, 2002). Through this model, autism is viewed as the extreme characteristics of a male's systemizing brain, as autism exhibits traits that are viewed as traditionally male (Baron-Cohen, 2002). However, this theory perpetuates stereotypes about gender and sex and looks at autism through a male-centered lens, excluding everyone with autism that doesn't fit that description (Jack, 2011). As we seek to further understand autism, we must not limit our understanding of autism as it correlates with traditional understandings of sex and gender as it further marginalizes those with autism that don't fit these descriptions.

### ***Autism Among Black Youth***

For the purposes of this research study, it is just as important to review research centered around the experiences of Black youth with autism as it is to look at that of females with autism. Returning to the theoretical framework of intersectionality, it is consequential for this research study that the ways in which race, gender, and disability interact be acknowledged. Autism in Black students presents numerous challenges and barriers due to the intersecting of marginalized identities. Racism and discrimination within the United States, both historically speaking as well as its existence today, has significantly shaped the way disability and race have been viewed in conjunction with one another. Historically, unethical scientific research has been used as a tool to demonstrate inferiority and lower intelligence among Black individuals in order to support

segregation and slavery (Annamma et al., 2013). These beliefs in white superiority and inferiority among people of color are still evident in institutional practices and systems today and influence our understanding of disability specifically among people of color.

A great number of disparities exist in autism diagnoses among white children and Black children, particularly in regard to disability documentation, age of diagnosis, and the likelihood of co-occurring intellectual disabilities. Black children are less likely to have documentation of their disability when compared to white students (Mandell et al., 2009). Additionally, research supports that Black children are more likely to receive an autism diagnosis at a later age than white children (Baio et al., 2018). In a study that looked at autism diagnoses, Black children were less likely than white children to be diagnosed by the age of 36 months (Maenner et al., 2020). Later diagnoses among Black children with autism result in numerous challenges that can have social and educational impacts. Black children who received a diagnosis later in life displayed more autistic traits and lower cognitive functioning compared to white children diagnosed later in life (Habayeb et al., 2022). These findings also suggest that among older black children diagnosed with autism, those who report higher cognitive functioning as well as less intense autistic traits, are less recognized as having autism and have greater difficulty accessing resources (Habayeb et al., 2022). Regarding autism prevalence, research studies have historically shown a difference in autism prevalence between Black and white children. However, in the last few years, there has not been a statistically significant difference in the prevalence of autism between black and white students (Maenner et al., 2020; Maenner et al., 2021). Additionally, Black students with autism are also diagnosed with intellectual disabilities in a higher proportion than white and Hispanic students (Maenner et al., 2018). Ultimately, this research presents a need for further exploration into the specific intersection of race and disability for Black autistic college students.



Lastly, it is important that we turn our attention towards the experiences of Black women and girls with autism in previous literature as it relates to this research study. Black women and girls are further excluded from research pertaining to autism. In a study that reviewed existing literature on Black women and girls with autism, the researchers found only three peer-reviewed case studies focused on Black women and girls with autism and none of them included intersectionality (Lovelace, Comis, Tabb & Oshokoya, 2021). Additionally, in looking at Black girls' experiences within a school environment, racial disparities in punishment were found among Black and white girls. In a study that look at school discipline for Black girls, they were found to be overrepresented in disciplinary actions as well as in meeting the criteria for special education services however are underrepresented in research (Annamma et al., 2019). Black girls were also perceived as being more potentially threatening and defiant, received harsher punishments and more out-of-school suspensions than white girls, and are often positioned as being less feminine (Annamma et al., 2019). These results exhibit the intersection of both racism and sexism for Black girls within a school environment and the need for representation and research of their experiences at the intersection of both race and gender. These experiences are also subject to change at the intersection of disability as well, and with the limited amount of research on Black autistic women, more efforts must be taken to include them in research in order to address the systematic barriers in place that disadvantage and marginalize these women.

### ***Self-Advocacy***

A key component to the success of students with disabilities is that of self-advocacy, however, students with autism in particular, often face unique challenges when it comes to learning how to self-advocate. Self-advocacy is a term that falls under the wider scope of self-determination and can be defined as the ability of individuals to assertively communicate their wants, needs, and

rights, as well as pursue and obtain support all necessary in order to achieve goals (Santhanam & Bellon-Harn, 2022; Martin & Marshall, 1995). Self-advocacy is understood to be a contributing factor to success within the college environment for individuals with disabilities, specifically when it comes to academic success. Academic performance, completion of a college degree, and higher grade point averages are all influenced by self-advocacy skills and development (Fleming, Plotner & Oertle, 2017; Elias & White, 2018). However, students with autism often face unique challenges when it comes to learning and developing self-advocacy skills.

Young people with autism are presented with further struggles in their ability to successfully self-advocate, as they face challenges in everyday living and social skills, as well as in skills such as speaking up for oneself and emotional regulation (Elias & White, 2018). The development of skills such as problem-solving, understanding one's disability, and goal-setting are crucial components of self-determination in students with autism (Getzel & Thoma, 2008). Students who develop self-awareness, particularly in understanding their disability, directly related this skill to their success in college, as they understand their needs and strengths better than anyone else and therefore can better advocate for themselves (Getzel & Thoma, 2008). Additionally, the development of problem-solving and goal-setting skills required students to recognize limitations, set priorities, form relationships when assistance is necessary as well as persevere through opposition (Getzel & Thoma, 2008). As self-advocacy requires one to be self-determined, the development of these skills is important to the development of self-advocacy in college students.

Additionally, when considering self-advocacy for the purposes of this study it is important to bring into consideration intersectionality, analyzing how different identities such as race, gender, and class can influence self-advocacy in autistic students. Black students with autism and of lower socioeconomic status reported the lowest levels of self-determination (Shogren, Shaw,

Raley & Wehmeyer, 2018). As self-advocacy falls under the umbrella of self-determination it is important to consider how race and class can influence autistic students' communication and self-perceptions and therefore their ability to self-advocate (Martin & Marshall, 1995; Santhanam & Bellon-Harn, 2022). Additionally, in a study that looked at disability identification and self-efficacy, Black students scored the lowest in disability identification and in one of the measures assessing self-efficacy (Shattuck, Steinberg, Yu, Wei, Cooper, Newman & Roux, 2014). This is significant because understanding and recognition of one's disability is an important part of developing self-advocacy skills in students with autism.

### **Rationale**

A review of previous literature pertaining to Black women with autism's experiences on college campuses highlights the need for further research on the topic. Ultimately, the limited amount of knowledge pertaining to women with autism, specifically Black women is of concern and must be addressed. The overrepresentation of Black women and girls in special education programs and their underrepresentation in research demonstrates a troubling gap (Annamma et al., 2019). This study will be structured as a qualitative study, in which data will be collected through interviews and open-ended surveys, with the goal of providing a clearer understanding of the needs that Black women with autism have within a collegiate environment. Additionally, this paper will address the barriers that exist in preventing Black women with autism from being strong self-advocate. Previous research displays that Black students with autism in particular display lower levels of self-determination and Black students with a wide range of disabilities scored lower in disability identification compared to white students (Shogren, Shaw, Raley & Wehmeyer, 2018; Shattuck, Steinberg, Yu, Wei, Cooper, Newman & Roux, 2014). Understanding one's disability, the ability to make one's own life choices, and recognizing one's needs and strengths are key

components of self-advocacy (Santhanam & Bellon-Harn, 2022). It is therefore necessary to consider how race and gender can influence self-advocacy among students with disabilities. Through the acknowledgment of intersecting identities, a better understanding might be provided of the experiences of Black college women with autism and the systematic barriers in place that can further prevent them from becoming strong self-advocates. Building off previous literature the following research questions have been proposed for the purposes of this study.

RQ<sub>1</sub>: What challenges do Black women with autism face as students when it comes to self-advocacy?

RQ<sub>2</sub>: How does the stacking of marginalized identities influence the development of self-advocacy in Black autistic women?

RQ<sub>3</sub>: What implementations must be made in order to aid in developing self-advocacy in Black women with autism.

### **Methods**

This study draws on previous literature in order to explore the experiences of Black women with autism and their self-advocacy, ultimately proposing a new research study for future analysis in further exploring this topic. For this research study, a qualitative approach will be used, as the reasoning behind conducting a qualitative research study lies in the paradigm's nature to uncover experiences in a deep and meaningful way while accounting for the complexity of the topic. Qualitative research results in regard to studies about autism, aim to uncover the unique needs that these individuals have as well as seek to understand the experiences of marginalized communities (Cascio et al., 2021). Participants for this study will be women who have been formally diagnosed with autism or ASD as well as individuals who work with students with autism such as; caregivers, teachers, or service providers. Additionally, the participants who have been diagnosed with autism

must be enrolled as undergraduate or recent graduates of a college or university in pursuit of an associate or bachelor's degree.

### ***Data Collection***

Data will be collected for this study by conducting interviews and distributing open-ended surveys to students with autism as well as those individuals who work with autistic students. Ideally, these interviews will be done in person, however, if necessary, they may occur via video call. The interviews will be directed in a semi-structured model, in order to provide some guidance and direction in the interview process so that the research questions are being addressed, however, also allowing flexibility to explore participants' experiences and backgrounds in a deeper and more authentic way. Open-ended surveys will be distributed in order to measure self-advocacy more effectively. These surveys will be structured after the self-advocacy survey composed by Downing and others (2007) and will ask participants a number of questions regarding their knowledge of special education services, characteristics of their specific experience with autism, and how they would respond in different situations. It is important to address the limitations in administering a survey, as indicated in the literature review Black students hold lower scores in disability identification and therefore may produce misrepresentations in the results (Shattuck, Steinberg, Yu, Wei, Cooper, Newman & Roux, 2014). In order to provide a more comprehensive perspective the survey will all be administered to individuals who work closely with the students participating in the study. Furthermore, during the interview process, the participants will be asked a series of questions that aim to address the experiences of these women in college, looking at their social and academic lives, and encounters with stereotypes, stigma, and discrimination that impact self-advocacy.

### ***Data Analysis***

The results of this study will be analyzed by reviewing the interviews, surveys, and any additional notes and information and sectioning that data based on emerged themes or topics. Codes will then be created based on the key emerging themes and relevance to the study and research questions. Qualitative analysis software, NVivo, will be used in order to organize and interpret the data.

### **Conclusion**

With the increase of students with autism entering college and the limited literature that exists studying women and women of color with autism, it is crucial that more research be conducted exploring the experiences of individuals with autism at the intersection of race and gender. Current understandings and characterizations of autism perpetuate gender biases and stereotypes, reflecting a largely male population, therefore excluding individuals that do not fall into these descriptions (Jack, 2011). Gender-related understanding of autism only serves to exclude women from having a more comprehensive understanding of their diagnoses. Women are misdiagnosed, diagnosed less frequently, and diagnosed later in life compared to men, often adopting strategies that help conceal their autistic traits and behaviors (Milner, McIntosh, Colvert & Happé, 2019). More research is needed to further understand autism within women and how their experiences and the characterizations of autism in women. Additionally, turning attention to autism in Black girls and women, this population is not only overrepresented in special education programs in schools they are also underrepresented in research (Annamma et al., 2019). The presence of systemic racism and sexism within medical and educational fields must be explored and recognized as it impacts women of color with disabilities. This study aims at questioning existing notions that support traditional understandings of autism. The completion of this study

will provide a more extensive comprehension of the barriers that Black women with autism face within a colligate environment when it comes to self-advocacy. Ultimately, the hope of this study is to produce findings that are more inclusive and representative of Black women's experiences with autism, contributing to the existing literature surrounding the topic.

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