ONE SIZE DOES NOT FIT ALL: CREATING EDUCATIONAL EQUITY FOR LATER DIAGNOSED AUTISTIC WOMEN

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ONE SIZE DOES NOT FIT ALL: CREATING EDUCATIONAL EQUITY FOR LATER DIAGNOSED AUTISTIC WOMEN

by

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Submitted to Brigham Young University in partial fulfillment of graduation requirements for University Honors

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ABSTRACT

ONE SIZE DOES NOT FIT ALL: CREATING EDUCATIONAL EQUITY FOR LATER DIAGNOSED AUTISTIC WOMEN

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Autism research focuses on the externalized behaviors usually associated with the male phenotype of autism with little representation of the internalized behaviors associated with the female phenotype of autism. Even more so, there is little research involving later diagnosed autistic women — especially women of color. Beyond this, non-white individuals have been marginalized within the sphere of education, and their marginalization is exacerbated by an autism diagnosis.

In the realm of schooling, the relationship between race, gender, and disability lacks investigation. In this exploratory study, I draw upon qualitative data from interviews of 17 racially diverse autistic women ages ranging from 18-52. In these interviews, I investigate the questions (1) “What are the behaviors, attitudes during and towards schooling, and self-perceptions of late-diagnosed women with autism across different racial demographics?” and (2) “How do these attitudes and behaviors correlate to their GPAs?”

Since the current literature addresses the issues that autistic individuals have with camouflaging their autistic traits because of the toll it takes on their mental state, this can be
further analyzed in a school setting. This daily environment forces autistic individuals to exercise their camouflaging abilities while experiencing many changes and social interactions. I conducted a thematic analysis of the experiences of these women and compared their experiences to their past and/or current GPAs. These interviews have exposed a pattern that autistic women are consistently not believed and lack the resources they need to succeed in a formal classroom setting and school environment. In this study, women with disability and racial and ethnic minority status have had the opportunity to add their own voices to the research conversations they have historically been left out of.

Keywords: race, disability, disproportionality
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INTRODUCTION:

In this exploratory study, I address the intersection of gender, race, and autism and how it contributes to inequities within schooling institutions. I start by creating an understanding of what research has already been done regarding later diagnosed women with autism. There is a history of misdiagnosis, under diagnosis, and later diagnosis of autism in women (Belcher 2022). The way that autistic women present is different from the way that autistic men present, so their autism is often overlooked in childhood. For example, autistic women are able to mask, or camouflage, their autistic traits much better than men do because of societal norms concerning typical behavior of women. Moreover, women are subconsciously able to copy neurotypical behavior in order to hide their autistic traits (Bargiela 2016).

It is also important to note that in this study, “woman” as a gender identity refers to cisgender women, trans-femmes, demi-girls, and non-binary women at birth. Because the purpose of my study focuses on the intersection of race, gender, and disability, this is important to recognize as the scholarly literature recommended the exploration of different gender identities (Belcher, 2022). Though this particular intersection of different gender identities wasn’t a specific focus of my study, it is important to acknowledge. Because cisgender white men have been the focus of this scholarly literature, these underrepresented perspectives are significant when taking into consideration participants’ experiences with their later diagnosis of autism (Belcher, 2022).

Because this area of research is developing, there are several possible patterns or relationships that can be explored concerning later-diagnosed autistic women and other intersections. Additionally, autism research in general typically lacks the voices of those
being observed. Without the voices of autistic women, I would only have access to an outside perspective of those learning about autism rather than actually understanding humans with autism (Leeper 2021). The purpose of this research is to explore the experiences of autistic women who have historically been misunderstood, misdiagnosed, underdiagnosed, or later diagnosed.

After developing a deeper understanding of later-diagnosed autistic women, I will move towards what research has been done in regard to how autistic women present across different races. Addressing the relationships between race, gender, and disability is significant in the context of my research because it provides the opportunity for minority voices to be brought to light when their voices have historically been overlooked and ignored. Finally, ideas for future research will be outlined in order to connect the experiences of different racial demographics, autistic females, and inequities within schooling to not only look at each of these topics separately, but to further investigate relationships and correlations between each topic.

LITERATURE REVIEW:

In this study I explore how autism impacts an individual’s daily life—specifically in schooling. A review of the scholarly literature on the intersection of race and disability within the scope of education requires the definition of keywords race, disproportionality, and accessibility. In this context, racial classification does not only refer to the physiological features of a person’s identity, but also focuses on race as a structural concept. Past research indicates that the differences aren’t primarily biological, but the differences lie in social inequality (Tefera, 2020). Disproportionality refers to the lack of
equal representation between racially designated groups, such as white and non-white students, within the special education and other spheres (Tefera, 2020). “Non-white” in the US context refers to people of color, or any individual not visibly of European descent. Lastly, accessibility is the ability to receive the same quality of education (Elder, 2019).

One essential finding from the literature is the trouble of and history surrounding the misdiagnosis, under diagnosis, and later diagnosis of females with autism. Historically, autism features have been based on characteristics of white males. Because autism has been viewed as a male condition, more males have been studied than females (Belcher 2022). Since women have historically not been a huge part of autism research, people didn’t know that autism could vary in how it’s presented across different demographics. Not only does this bias towards white males affect research, but it contributed to a clinical bias as well. Diagnostic systems were based on how most males presented autism, and the female phenotype of autism was not included in this diagnostic system (Belcher 2022).

Most females with autism present with atypical autism which does not include the conventional condition that is most reported in research. As a whole, autism spectrum disorder (ASD) is characterized by issues with social interactions, social communication, processing different sensory stimuli, and schedule flexibility (Bargiela 2019). While this is experienced by all individuals with autism, autistic males are more likely to exhibit externalizing behaviors such as hyperactivity, impulsivity, and creating problems, while autistic females are more likely to experience internalized problems such as mood and eating disorders (Bargiela 2019). Though the definition of ASD remains the same, there
is confusion regarding ASD diagnosis when looking across different genders and specific examples of how it may be operationalized due to the male autistic stereotypes. Because of confusion with other conditions and lack of awareness of the female phenotype, there is a 10-year delay in women’s real diagnosis of autism (Belcher 2022).

While considering women as a gender minority in autism research, it’s also important to consider racial minorities in autism research since non-white individuals have historically been left out. One key finding from the literature is that teachers and schools often don’t have the comprehensive expertise and resources to work with non-white special education students as well as special education students generally. For example, in suburban settings, “cultural gaps and misunderstandings” led teachers to become “reluctant to discuss the role of race in disproportionality” (Tefera 2023). Not only do teachers lack the experience necessary to work with students with special needs, but they also often lack the sufficient training and contextual information to provide adequate assistance. Along with this, disabled non-white students at under-resourced schools typically have less qualified teachers compared to their white and abled counterparts (Cruz 2023). This hinders students’ opportunity for accessible learning, thus not allowing them to reach their full potential. The resulting attempts to provide general mainstream instruction to disabled students often leads to exclusionary experiences for these students.

In regard to the timing of diagnosis, there is a difference in the representation of Hispanic and Black individuals’ disability diagnoses as compared to their white counterparts. For example, a study documented that “Hispanic-children with foreign born parents had a substantially lower prevalence [of autism] than … all non-Hispanic white
children” (Jo et al. 2015). This study seems to indicate that children with foreign born parents are diagnosed at a lower rate, negatively impacting their access to healthcare services. Moreover, this is one example of a minoritized population that has been excluded from essential services due to under diagnosis or complete lack of a diagnosis due to the parents’ lack of awareness (Jo et al. 2015). Without an autism diagnosis, these children are left without resources that would provide the most help in their educational careers.

Across much of the literature, the call to individualize special education is loud and clear—however, it is impossible to fully individualize special education until each piece of the puzzle is put together. It is important to recognize the disproportionality across different racial groups in both the overrepresentation and underrepresentation in disability diagnosis. For example, while Black and Native American students were twice as likely to be identified with disabilities, Asian American students were “50% less likely to receive special education services compared to their peers” (Tefera 2021). Depending on an individual’s race, there are different disproportionalities evident.

It is important to note that these disproportionalities are not single-faceted. Not only are these students facing disproportionalities as racial minorities, but also due to their disability status. Here, it is important to realize that there are many factors of a student’s identity that could potentially be related to complex social and structural issues that they may face on a daily basis. Acknowledging different aspects of students’ identity allows researchers to understand the context of the unique burdens that multi-minority students may be facing.
Essentially, there is a lack of empathy and understanding about students’ struggles and lived experiences. Though autism is characterized by communication difficulties, slow-processing skills, and sometimes inability to read social interactions, most autistic females subconsciously develop skills of masking, or camouflaging their autistic traits to better fit in with their peers. They use strategies of mimicry to function well in classrooms and copy behaviors to be perceived as everyone else. However, this coping mechanism used to keep up with the world cannot always be sustained as everyone grows older. This act of masking becomes exhausting as autistic people are continually introduced to new people and new environments, making it harder to function. Because it takes so much energy to mask, autistic people then begin to lack the energy to carry out normal daily activities. Added to this is the pressure to mask and function well, which then increases suicidality because autistic people begin to feel that they are not good enough as they are. Moreover, because the female autistic experience is so complex and lacks understanding, there is much information missing as to what they go through on a daily basis (Bargiela 2019).

Overall, based on the literature on this topic, there seems to be patterns of exclusion among those with disabilities in general, and this marginalization is intensified when these students are non-white. Because of this, most individuals simply aren’t aware of the struggles of autistic people, which leads to prejudice and discrimination (Stagg 2019). Because most individuals aren’t aware of the struggles that accompany autism since it involves communication issues, there is little relevant information about diagnosis across different racial demographics. In other words, there is objective data, which doesn’t require learning about lived experiences, but very little research on how an
individual’s racial and disabled identity affects them in their adult years, especially as they are related to success within schooling (Stagg 2019). Ultimately, these topics are explored separately, but not together.

Looking at autism across different races and genders, the common themes in the literature include that female presentations are under-documented, and presentation varies across racial groups. Therefore, a clear gap can be found in recommendations of the literature—both gender and racial minorities’ presentations of autism still need to be further explored (Belcher 2022). Because so many of these individuals are under diagnosed or even misdiagnosed in their early years, most of these autistic narratives must be explored in later diagnosed women’s adulthood. It seems that in this intersecting population, there is a high rate of suicidality due to the high level of masking and lack of awareness of that masking (Belcher 2022). To move forward in autism research, I must incorporate these voices of non-white women of color that have historically been ignored in order to begin to address the prevalence of suicidality in this population.

METHODS:

1. **Participant Demographic**

This exploratory study involves in-depth interviews of 17 diverse individuals ranging from ages 18-52 to primarily assess the quality of classroom experiences. Included in this sample are 11 participants from three different non-white racial demographics—Black, Hispanic, and Asian—as well as six white participants. Four of these participants are also queer, self-identifying as either trans-femme, demi-girl, or non-binary (female at birth). Each participant is located in the United States or Canada.
I addressed two different research questions:

- What are the behaviors, attitudes, and self-perceptions of later diagnosed autistic women in schooling across different racial demographics?
- How do these attitudes and behaviors compare to their GPAs?

These questions are pertinent to this topic as the literature addresses the issues many students have with masking and adjusting because of the toll it takes on their mental state.
This can be further analyzed in a school setting where these individuals are challenged by many changes and social interactions, and they must exercise their masking abilities. Because there’s a relationship between how disability and race can impact one’s behavior and their own perception of themselves, limiting my scope to a formal school setting allowed us to thoroughly investigate these experiences.

2. Procedures

Before beginning this study, I received approval from the Institutional Review Board (IRB) to ensure that my methods used ethical processes. To begin this study, I first recruited participants through word of mouth, first, and then through social media. Because this study was motivated by my younger sister who received her later autism diagnosis at age fourteen, I was able to connect with participants due to the background knowledge that I had gained previously about later autism diagnosis. I was interested in this topic because of the struggles that my younger sister experienced at school because of a later diagnosis, and several individuals were willing to share their stories and similar experiences.

To then address the research questions, I conducted 45–60-minute in-depth interviews and completed a thematic analysis of these transcripts. Because autistic women of color have had a history of underrepresentation, I modeled this after previous qualitative studies to discover the personal stories and experiences that each individual has had in the classroom as a later diagnosed autistic woman. Because this research topic is focused on formal academic settings, I compared my observations from the interviews to GPAs that each individual received to look at any correlating patterns or themes. Prior to their interview, all participants completed a screening form to ensure that they were over 18
years old, received their diagnosis after eight years old, and to collect information about their racial and gender identity. All participants were also informed that the purpose of this study was to collect the perspectives of underrepresented later diagnosed autistic women and their experiences in schooling.

In the interviews, I focused primarily on 10 questions:

- When were you diagnosed with autism?
- How did you find out?
- What has your experience been in a formal classroom setting?
- What feelings do you associate with a formal classroom setting?
- How did your autism diagnosis impact the way you viewed yourself in academic settings?
- How did your autism diagnosis impact your performance in academic settings?
- How has your racial identity impacted your attitudes toward your diagnosis?
- How has your gender identity impacted your attitudes toward your diagnosis?
- What do you wish that people understood about you as a later diagnosed autistic woman?
- What do you wish was provided to you as a later diagnosed autistic woman?

Although participants were informed that the focus would be primarily on their academic experiences, they also were free to share other relevant experiences associated with being a later diagnosed autistic woman.

3. Plan for Analysis

Each participant’s interview was audio recorded and transcribed in order to complete the analysis portion of this study. I conducted a thematic analysis by developing codes
From my research questions, and sorting excerpts through using the program Dedoose. From my first research question, I generated codes focusing on attitudes, behaviors, and self-perceptions. From my second research question, I generated codes focusing on academic achievement. After generating these baseline codes, I went through the first few collected transcripts to develop codes more specific to participant experiences within the topic of attitudes, behaviors, self-perceptions, and achievement. From assessing the themes in these participants’ responses, I developed and followed a coding scheme to keep data analysis consistent across each interview. This is modeled after methods used in past qualitative studies (Charmaz, 2006).

After coding each interview according to the coding scheme that I created, I answered my second research question by comparing quotes from achievement-related codes to participants’ GPAs. Through this comparison, I analyzed their perceptions of academic achievements and experiences. I did this by creating a table that included participant GPA alongside their interview quotes about their perceived academic achievement.

RESULTS:

My research results are presented for each of the themes identified in my analysis. Major themes include attitudes, behaviors, and self-perceptions. Additional themes related to school achievement include participants’ perceptions of their achievement and their experiences with accommodations, burnout, diagnosis and masking.

1. Attitudes

Regarding attitudes towards schooling, nearly half of participants explicitly mentioned their negative feelings due to the bullying that they experienced at school. This was coded as, “hurt by bullying” which is defined as any experience where they
explicitly mentioned being bullied by others at school. Though this isn’t directly related to participants’ learning in a classroom, the majority of participants explicitly discussed their dislike towards social interactions in school, but there is a very social aspect related to school that can be negative.

- “I wasn’t bullied too bad—I was bullied somewhat indirectly. Most of it was an indirect kind of shunning. Like, you’re weird. And that’s hard in a classroom setting. It’s really hard.” (28 years old)

- “I think I went to school once a week my senior year because of severe paranoia. I had a student call me a **** in front of the entire class, and the teacher didn’t do anything. […] Everyone decided that I must be crazy and made fake Instagram accounts pretending to me just to make fun of me. And somebody slashed the tires on my car. And people would show up at my house all the time […] and I wouldn’t leave my house because I thought people were out to get me, and they kind of were.” (21 years old)

- “In 11th and 12th grade, I transferred to a private school. Up until the 10th grade, I was bullied and teased a lot for being good at school—back during that time, it wasn’t cool for a girl to be smart.” (52 years old)

Ultimately, several participants discussed resentment towards the idea of school not primarily because of the academic setting that they were in, but due to negative interpersonal interactions with their peers. This experience of bullying increased more when adding the intersection of race. After their autism diagnosis, several participants began reprocessing their school experiences and connected discrimination not only to
their racial identity, but to also to their autism diagnosis that they didn’t know about at the time.

▪ “I was bullied a lot in elementary school due to confusion with my racial identity. I’m a visible minority, and I do struggle with understanding now that the reason I was so disliked and bullied was because of my racial identity and my autism.” (18 years old)

▪ “Being one of the few black kids—and even being one of the few neurodivergent kids—led to being ignored or bullied by peers, even teachers. I was one of maybe two or three black individuals in a class of 30+. I was treated as an outsider, and people frequently brought up my race, asked ignorant questions, or made jokes about it.” (37 years old)

Considering this aspect of racial identity further complicates participants’ attitudes towards school. Not only were people struggling in social interactions because of the racial discrimination that they experienced, but they were also trying to navigate the social aspect of their school experience with an invisible disability that makes socializing more complex. These negative experiences of bullying have ties to both racist and ableist ideas. It is important to recognize that in these instances, participants were already having difficulty navigating social interactions, and their racial identity made this navigating much more complex. It seems that the participants’ racial identity played a significant role in socializing, which is an unavoidable part of school. The complex combination of these two identities in this social context created unique burdens.

2. Behaviors
While in school, students often exhibited internalized behaviors. These were represented by the codes, “socializing struggles,” “sensory overload,” and “not understanding social cues” that were coded for the majority of the interviews.

“Socializing struggles” referred to issues that participants had in interpersonal interactions at school, such as making friends. “Sensory overload” referred to sensitivities to external stimuli, such as noise, or touch. Lastly, “not understanding social cues” referred to specific experiences that participants shared about not understanding social interaction.

○ Socializing struggles

Demonstrated in this code are the issues that participants faced when interacting with others at school. This struggle with social interactions was a common theme across all participants—whether stated directly or indirectly. This often manifested as shyness or reluctance to engage with others.

- “I found that by the time I was comfortable joining in or interacting with the group, people had already made friends and felt I was standoffish. I sometimes stim [referring to repetitive motions or behaviors used to help cope with emotions], say awkward things, or am abnormally quiet, which usually leads to being bullied. All of the above made for a very alienating experience.” (37 years old)

- “I did have a hard time socially. Like, when there are some more social people talking to me, it was difficult having a conversation with them because I’d be exhausted.” (22 years old)
“Until I was about seven years old, the only people that I said words to were my parents, my siblings, and my friends—I did not talk to my teachers or my grandparents. I didn’t really have relationships with teachers.” (18 years old)

- Sensory overload

Frequently, autistic individuals experience sensitivity to external stimuli, and almost every participant either directly discussed their sensory issues or shared an experience where they experienced being overwhelmed due to their environment.

“To be honest, I really hated having to go to school […] it was not very sensory friendly. I dreaded walking down the halls which were really crowded, and I never wanted to see people I knew because I would constantly just be really overwhelmed.” (25 years old)

“There was oftentimes just the overwhelm of being in a classroom. And, you know, having a lot of people, and all of that was kind of exhausting to me because it was just so much happening, and so many people, and so many voices. I don’t filter out sensory information very well, so I hear all of it, and it can be very overwhelming.” (31 years old)

- Not understanding social cues

This code goes beyond what I discussed when struggling in social interactions but adds another layer of confusion experienced by participants. Participants often discussed times when they were not able to read verbal or non-verbal cues but was not aware of it at the time. This often resulted in miscommunication between the participant and those that they interacted with.
• “I tried a couple times to ask, then I realized the teacher would get upset and say there was no exception, so I would just try to hold it. And then I started having accidents. And the teacher got upset, and asked why I didn’t tell her I couldn’t hold it. And I said, because you said that I weren’t allowed to. That was the rule.” (21 years old)

• “I really struggled in a classroom with the social aspects of their rules. Sometimes, there’s extenuating circumstances and there’s gray areas.” (34 years old)

While not as prominent as the previous three themes, almost half of participants discussed liking the structure and repetition in a classroom setting, which I coded as “schedule repetition.” These participants liked the control that they felt with the repetition of a schedule and the predictability of the classroom, whereas in less structured interactions, that form of organization was absent.

▪ “Classrooms have structure that’s organized—you can use your own system. With hangouts and stuff like that, you can’t manage that because you’re not able to have control.” (20 years old)

▪ “I liked college a lot because the social aspects are much more optional. You can choose to go to class, take your notes, sit at a desk—I love that. I love the rigidity.” (21 years old)

▪ “What’s weird about me is the reason why I realized that college worked for me, and why I did so well and got such good grades, is because I could pick my schedule […] and I worked really hard to plan my schedule.” (37 years old)
Furthermore, as shown by the experiences of the participants, behaviors were often internalized. Though some behaviors can be recognized by an outside individual and could be considered externalized behaviors, there is much more that participants deal with inside their brains that they conceal from the outside world. For example, those interacting with participants may notice that they struggle in social interactions and are not able to read social cues. However, rather than understanding that socializing is difficult, participants’ behaviors are often perceived as rude.

Regarding sensory overload, others may notice that participants have adverse reactions to certain stimuli. Though several participants expressed discomfort in certain environments, some participants’ discomfort manifested as physical reactions, some even to the point of meltdowns. Though this external behavior may be perceived by outside observers, these persons may not realize the immensity of pain that results from this overstimulation—rather, participants choose between suffering in silence or being perceived as abnormal.

Lastly, though it is plausible that others notice that participants frequently repeat their schedule, outsiders may perceive this as being well organized and success. However, what outsiders may miss is the struggle participants have with change; they depend on a set schedule to function, which explains why the rigidity of a classroom setting may have worked well for some participants while in other situations change became overwhelming.

3. Self-perceptions

Reported self-perceptions while in a school environment were often negative prior to the participant’s diagnosis. Though experiences across participants were very individual
in nature, overall, there were often great amounts of pressure to succeed academically while also dealing with social pressure to behave and act like the other students. The amount of pressure that participants experienced was often associated with the way they viewed themselves.

- “I felt like there was something wrong with me for being the way that I was. I remember just having a lot of anxiety. Sometimes, I would go hide in the bathroom stalls because the lights were really overwhelming.” (25 years old)
- “Before my diagnosis, I felt stupid and slow. I often noticed others getting ahead much faster than I or simply getting by without them being bothered by their bad grades while I would beat myself up for getting an A-. As I grew older, I punished myself for getting less than perfect grades and felt like my achievements were still not good enough.” (36 years old)

It is important to note here that this participant grew up in the United States, but her parents had immigrated from a developing country. This participant also mentioned in her interview feeling that there was extra pressure for her to succeed due to the sacrifices that her parents made to live in a new country. This status as a first generation college student and child of immigrants adds more layers to her identity, and more of a burden for her to carry as she navigated school. Not only does this add multiple minority statuses that systemically made school difficult—especially with autism—but there was also an increased pressure for her to succeed.

On the other hand, after receiving their diagnosis, there was an uplift in the way that participants viewed themselves.
• “I feel a lot more compassion toward myself. There was a moment when I was like, oh I wasn’t dumb, I wasn’t lazy; I just didn’t have the resources to thrive and show up well in these environments.” (28 years old)

It’s important to note that in her interview, this participant specifically discussed being a minority student at school. She brought up discrimination that she experienced while in the school environment and attributed her struggles in school to systemic reasons. However, it was later that she realized her multiple minority identities, and how the combination prevented her from getting the resources that she needed. Not only was she experiencing oppression as a woman of color, but being autistic, it was even more difficult to socially interact and communicate with others to self-advocate for the resources that she needed.

4. Comparing Schooling Experiences to Reported GPA

While I focused on comparing participants’ attitudes, behaviors, and self-perceptions in schooling to their GPAs, I also looked at participants’ evaluation of their schooling experience. In this discussion, this was represented by the codes “accommodations,” “achievement,” and “burnout.” Accommodations can be defined as alterations of school environment or curriculum format to help those with disabilities complete assignments, projects, or exams. This code specifically referred to the experiences participants reported related to using or attempting to use their accommodations. The vast majority of participants had some sort of interaction with accommodations. Common examples of these accommodations are distraction-reduced testing rooms, extensions on assignments, written and detailed instruction for class, and permission to audio-record lectures. “Achievement” referred to how participants
perceived their own success in education. This referred to how a participant may interpret their own quantitative scores, or also how they evaluated their overall performance in the classroom. Lastly, “burnout” referred to exhaustion they most associated with their school efforts. This was coded when participants used this specific language of burnout.

○ Accommodations

Participants in college who were able to receive accommodations only had positive experiences when they were supported by their instructors when asking for accommodations. Those who didn’t receive that support had a more difficult time in school.

▪ “I think the hard part about accommodations is that people don’t understand because they don’t see it. It’s not like a physical disability. They’re confused why you could possibly need these things. They don’t believe you.” (31 years old)

▪ “[The teacher] brought it up in front of the whole class, being like, will you do fine on tests? Like, you don’t need [accommodations], right? And I’m like, yeah, I guess I’m fine. I just felt stupid because the other students didn’t know what she was talking about. And like, I had good grades, so she thought it was weird that I was asking for accommodations.” (18 years old)

▪ “After I got my diagnosis, I got accommodations. I was able to do test taking in a place where it was sometimes just myself […] and it was very quiet with no disruptions. Although my grades were basically the same when taking tests with accommodations, the anxiety was definitely not the same. I felt more confident and more comfortable taking tests with accommodations.” (36 years old)
“I didn’t even know I could get accommodations in college until a professor told me I should apply so she could give me the help I needed. […] I went from a 3.5 to a 4.0 just because I could focus on my test and not every single sound in the room.” (21 years old)

On the other hand, students who attempted to get accommodations in high school had more negative experiences. Many students described experiences where they attempted to get accommodations, but the school prevented them from receiving it. This resulted in receiving low GPAs and negative attitudes, behaviors, and self-perceptions towards school.

“It was very much like, we need a diagnosis for this, and we’re not going to help you get the diagnosis. You have to pay for that out of pocket from a different doctor. And that doctor required a different note from a different doctor who needed a note from your therapist. Essentially, it’s a bureaucratic mess and you’re like, no wonder it takes years to get any form of accommodations.” (20 years old)

This inaccessibility indicates barriers to school resources due to class status, even within a public school system. This participant specifically discussed the different socioeconomic barriers that her family faced which prevented her from receiving a diagnosis, and consequently prevented her from receiving accommodations. Again, this shows a combination of statuses—class and disability—creating a complex burden, making necessary resources inaccessible.

In other instances, participants knew that they needed help, but were unable to receive help upon reaching out. For example, one participant wanted a distraction reduced testing room and asked her teachers. Her teachers told her she needed an IEP in order to receive
that accommodation but wasn’t offered the opportunity to begin the process to receive an IEP.

- “There was this sureness that the adults in my life had that I didn’t actually need resources, I just needed to not be depressed, get back together, and start doing the things that I was good at.” (28 years old)

Though this study concentrated mainly on the experiences of participants living in the United States, a few participants discussed their experiences with accommodations outside of the United States. Those attempting to receive high school accommodations outside of the United States seemed to be much more successful than their United States counterparts.

One participant discussed their experiences going to school in Uganda compared to their experience in the United States. In the United States, she mentioned how it took years to get any form of accommodations due to the lack of diagnosis and the lack of resources to get that diagnosis. However, when this participant lived in Uganda, within two months, teachers wrote their family referrals for free diagnoses and voluntarily provided accommodations to the participant to better help them and individualize their education experience—a stark difference to their experience in the United States. Reflecting on this, the participant had very positive attitudes toward this support. Now, this participant continues to use their paperwork collected from different diagnoses in Uganda to qualify for accommodations at college in the United States. Because formal diagnoses are too expensive, they rely on this paperwork to get the resources they need to get through school.
“I just kind of feel like I was cheated by the system. There’s an analogy I heard where it’s like, you don’t realize you’re driving a bad car until you look at other people’s cars, and then you realize you’re driving a bad car. And like, that kind of explains my life. I never realized that these aren’t normal issues. These are issues that I was suffering with, and there’s a solution for them. It was behind a paywall. And no one wanted to pay. And I couldn’t pay because I was 12.” (20 years old)

Ultimately, though experiences with accommodations varied between participants, each interview echoed a similar theme that accommodations were only helpful when also supported by their instructor and school administration. This support from administration was often tied to a formal diagnosis, which was dependent on the participant’s socioeconomic and class status, as well as racial identity. Again, this combination of disability, socioeconomic status, and racial identity create a multifaceted issue that students face when attempting to get the resources that they needed.

- Achievement

The majority of participants discussed their high levels of academic achievement and acknowledged that they did do well in a classroom setting. However, several participants did note that this level of achievement came at a high price. I coded “achievement” as any instance of participants discussing their success in a classroom setting. With these high levels of achievement often also came burnout, which I coded separately. Beyond this, it was very common that while students continued to succeed academically, the way that they perceived themselves and their success was very negative.
Because not all participants were able to provide their transcripts due to cost or inaccessibility, I also assessed their self-reports of academic achievement. I found that although participants’ reports of their attitudes, behaviors, and self-perceptions at school had common themes of emotional dysregulation, they still often achieved high GPAs. Though this is not represented by each participant that reported their GPA, this was a very common theme across interviews. The following table provides both the GPAs for participants and interview quotes indicating assessments of their academic performance or achievement. Though this table shows a very strong theme of high GPAs, many of the participants with these high GPAs experienced issues with negative self-perceptions and suicidal ideation.

Table 1: Table of participant age, GPA, and quote regarding school

<table>
<thead>
<tr>
<th>Participant Age</th>
<th>GPA</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>22</td>
<td>2.49</td>
<td>&quot;I didn't use my accommodations because I just wanted to be normal and not feel different than the other students because they didn't have those accommodations. [...] I definitely did have a lot of stress around some assignments and using the accommodations I had probably would have made things a lot easier for me emotionally, which was also a very stressful part of it.&quot;</td>
</tr>
<tr>
<td>36</td>
<td>3.7</td>
<td>&quot;It was very stressful to juggle everything because for some reason in my head, everything that I do has to be done almost perfect [...] so sometimes, I felt like that I wasn't being the best parent that I could or I didn't want to get grades under an A because then I thought that was failing myself.”</td>
</tr>
<tr>
<td>31</td>
<td>3.93</td>
<td>&quot;You know, having a lot of people, all of that was kind of exhausting to me because it was just so much happening, and so many people and so many voices, and I don't filter sensory information very well. I hear all of it and that can be very overwhelming.”</td>
</tr>
<tr>
<td>18</td>
<td>3.92</td>
<td>&quot;I'd rather not be paying attention than be paying attention not being able to keep up. But then my teacher got mad at me because I was talking to someone else [...] and he's like, what's the answer then? [...] If I was in a room alone, I would've had it in like 20 seconds. But everybody was looking at me [...] and I knew there was more pressure. People saw that I was struggling, but they thought I was just being funny and they try to get my attention and distract me even more, and I started crying. I couldn't talk after that and then I was just quiet but still in distress.”</td>
</tr>
</tbody>
</table>
| 21              | 3.82 | "Therapists and I started picking up on the fact that I was not neurotypical because I couldn't transition back properly [after the pandemic]. Like the way that things
changed from being in person to online, it just threw me off so much and I still have not been able to go back to normal."

"The extra nice [professors] will say they got my email and they put all my extensions in for me, and I'm like thank you, that's so nice! Those ones, I feel really comfortable around. Other professors will ignore it, and it's like, well, I'm too scared to ask for an extension or for help here because I feel like it won't be well received [...] and it sounds like it takes a lot of energy. Usually, I try to do the best I can, but you know, it's definitely bringing my grade down."

"No one wanted to help me or work with me because I was too smart. [...] My junior year, I had a meltdown, and because no one knew what autism was, everyone decided I must be crazy [...] so my junior year, I tried to kill myself."

"People look at me and they're like, she has a master's degree, she's gotten straight A's, there's no way she can't work. She's faking, she's lazy. But I think that all the mental gymnastics I was doing to function and the breakdowns that I would have, and like trying to commit suicide four times is not normal. When it gets to that level, it's really unbearable."

"I actually first graduated [high school] with honors, and I had scholarships to college. But I've always fallen asleep in class because I was bored and I still ended up in chronic burnout because I wasn't well and my evaluation showed that I did do a lot of masking."

"I had all A pluses but [I] decided to check [myself] into the counselor's room like once a week. [...] [I'm] having meltdowns during class [...] but it's not disruptive enough because I've learned to internalize everything because the boys that act out are the ones who get the attention, but also the help. As a girl, the last thing I want to do is be more of a burden."

"I really hated having to go to school, especially high school and middle school. It was one of the most depressed points of my life and I would physically hide in the bathroom when I got overwhelmed. I knew I was considered really smart, but I just crashed when I reached the end of high school and beginning of college."

"I didn't struggle with education itself, but the socializing around it. I don't think I had friends basically the whole time in middle school. I was singled out with another person for being more weird than everybody else, and people in middle school weren't particularly kind."

"I was like this close to crying or getting up and running out of the classroom just because people don't understand that it hurts. People don't understand [...] I get sensory overload and sensory overload can lead to burnout or shut down, which can lead to suicidal episodes. And that's just how it is."

As reflected in the table, participants with these negative self-perceptions experienced issues with depression and suicidal ideation.

- “It was a lot of pressure to only focus on learning and my grades. I was just very perfectionistic, even in high school, and I think I just felt that academics were everything and very prized, so I just struggled a lot with my mental health.” (25 years old)
“Because I wanted to feel loved, my outlet was school, so I just excelled in school. That’s how I thought that I would be loved.” (20 years old)

These reports of academic achievement were reflected not only by high GPAs—participants also acknowledged their achievement in their interviews. However, there was a strong theme of struggles with mental health. Again, this achievement came at a high cost.

○ Burnout

Though these participants were scoring high academically, they still had internal struggles and emotional dysregulation that they had to manage while completing school. This feeling of being overwhelmed by school was also exacerbated by social exhaustion, which led to burnout. Participants frequently used the specific language of “burnout” to explain their struggles.

- “Group projects are a personal hell for me. I don’t work with people very well because I don’t communicate very well. […] I often don’t communicate what I need, so I end up overworking myself and burning myself out.” (20 years old)
- “When I moved to high school, I was put in all honors classes. I got burned out because I couldn’t force myself to do all the English, Chemistry, and everything else all at once plus the socializing.” (18 years old)
- “That’s a good example [of burnout] with how I’ve needed to take more breaks from school. […] It’s really frustrating because I just want to do school and finish, but my brain isn’t okay with that […] dealing with expectations, and roommates, and classmates, and things where you have to work together, and trying to explain
the way that I do things and need to do things without crying or having a shutdown or meltdown.” (20 years old)

Furthermore, the codes, “accommodations,” “achievement,” and “burnout” help contextualize a student’s school experience and success by providing more information than a quantitative score.

While the focus of this study was the schooling experiences of later diagnosed autistic women, there were several common themes related to experiences outside of school brought up by everyone—one of these themes involved participants’ diagnosis. While a diagnosis is not directly related to school, a diagnosis is a significant part of an autistic individual’s experience. Because school is such a social environment and autism affects the way students may interact with others, participants’ diagnosis experiences were important to investigate.

- Diagnosis

Upon receiving their diagnosis, participants frequently experienced issues with cost. Several participants discussed how expensive it was for them to receive a formal diagnosis, and those who have been able to receive a formal diagnosis acknowledge it as a privilege.

- “I got very lucky because not everyone is in my position—especially people who are low income. I got very lucky with my parents not being low income, having very good insurance, and just any kind of resources. My mom works at the hospital, so I got kind of an advantage with that, and I know it’s not the same for everyone.” (18 years old)
Earlier, I discussed how participants’ socioeconomic and class status prevented them from receiving a formal diagnosis and school resources. This participant explicitly talked about how her class status gave her the opportunity to receive a formal diagnosis, which provides another example of status playing a key role in receiving resources.

Beyond economic barriers experienced by participants, each participant either directly or indirectly expressed the personal relief that they experienced as a result of their diagnosis.

- “I knew it, but I’m glad to finally have it officially so I can really know what I need to do and want to do it.” (24 years old)
- “I realized I’m not a horrible person. I’m just sick and misunderstood, and I believed I was a demon child for so many years.” (20 years old)
- “It was like a weight lifted off my chest because I was finally figuring out not necessarily what was wrong with me, but what has been this concern my entire life.” (18 years old)
- “It felt nice to have that as an answer. It’s made me a lot more patient with myself because I would get frustrated.” (21 years old)
- “It definitely helped me feel like things made more sense.” (31 years old)

Each individual interviewed expressed an overwhelming sense of relief that came with an autism diagnosis and autistic identity. A few participants provided insights on how they’d like their identity to be handled. For example, one participant spoke about their opinions on high-functioning and low-functioning autistic labels.
“People need to understand that autism is a spectrum and everyone’s different. I think that saying someone’s high functioning or low functioning is very dehumanizing. I feel like it makes us sound like machines.” (18 years old)

This participant’s commentary supports recent autism literature concerning practices labeling individuals as a high-functioning or low-functioning. The developing literature shows that autistic people prefer that those labels not be used (Buijsman, 2022).

Another aspect of language addressing their autistic identity had to do with the debate between person-first and identity-first language. It is common both in clinical practices and teacher trainings to refer to an autistic individual as a person with autism (person-first) rather than an autistic person (identity-first). One participant explained why this may be harmful.

“Autism isn’t a list of behaviors—it’s how my brain works, and it’s not able to be separated from me. […] I prefer to say autistic person than person with autism because person-first language softens the blow for people with internalized ableism. They say, they’re a person first, not their disability, and you’re like, but you can’t separate the two. It’s a part of me.” (18 years old)

This comment also supports the developing literature concerning language regarding autistic identities. Though it has been more common in the past to use person-first language, the developing literature is recognizing several autistic individuals’ preferences for identity-first language (Buijsman, 2022). Insights from these participants are significant as clinical practices and teacher training continue to evolve. These insights can also help the public understand the language that autistic people would like to be used.
Regarding racial intersections with an autism diagnosis, non-white participants often experienced unique forms of discrimination. Due to multiple identities that a participant may have beyond disability status, such as race, gender, and socioeconomic status, the combination brings a complex weight in the discrimination that they faced.

- “I went to a Black therapist because a lot of what I experienced was direct racial trauma. But any time I would display any autistic behaviors, she would question me. But when I’ve gone to therapists that specialize in autism, they are very much in denial of the racial aspect and say, maybe that person wasn’t racist. It becomes a thing as a Black autistic woman where I feel like I don’t fit anywhere.” (37 years old)

- “There’s a whole list of ways that autism presents differently. My own brain chalked it up to like, I’m a woman of color in this space. I need to be extra careful about what I say and who I interact with. […] I come from a low socioeconomic family, and a primary caretaker for my parents. I just thought that I was tired because of systemic reasons. I didn’t realize that my autistic burnout added more layers to that.” (28 years old)

Here, both participants spoke about alienating experiences. The first participant suggests a very alienating experience with lack of resources in whichever community they turn to, and the second participant suggests confusion between autism and oppression. These unique forms of discrimination add to the literature more barriers that autistic women of color face outside of the disability itself.

- Masking
Because school is a highly social environment, the concept of masking was frequently brought up. Not only is masking a behavior exhibited at school, but it was subconsciously a part of participants’ daily lives. Masking was often brought up as a survival skill in order to endure the social aspect of school. This created a very exhausting experience for the majority of participants.

- “I still mask every now and then because I want to try to make friends. I want to be social, I want to be, you know, loved, and appreciated like any other human being. (20 years old)
- “While I’m in my apartment, luckily, I can unmask a whole lot more […] and I can be open with how I’m feeling and what my needs are. But when I’m in the general public, I don’t do that out of fear and not wanting to be seen as strange, and messed-up, and weird.” (20 years old)
- “I wouldn’t use my accommodations as a form of masking to try to blend in with everyone else. I also didn’t want to bring attention to myself by being wrong because […] they would notice and make a negative judgment about me.” (22 years old)
- “There are people who don’t have to count how many seconds of eye contact they have to make […] or having all this inner monologue to get through socializing to come off normal enough to navigate your own educational experience. Because the social aspect does impact how you learn.” (34 years old)

Experiences with masking did not only point to general social behavior, but also affected their relationship with gender. Participants who do not identify with the binary gender identities discussed how masking their autism related to masking their gender.
They discussed mimicking what they perceived to be correct, in the sense of learned gender roles.

- “I don’t fully connect and identify with being a woman. When I would interact with people and mask the way that I understood I was supposed to, it was very feminine, very girl, very woman presentation […] and unmasking is quite the process, and I’m not done learning that one.” (25 years old)

Moreover, the experiences that participants described in regard to masking suggests that this is something they would not like to do, but simultaneously feel that it’s necessary to do so in order to function. Forcing themselves to mimic neurotypical behavior created several alienating experiences, and even more so when multiple identities intersected.

DISCUSSION AND CONCLUSIONS:

In this section, I summarize the main findings and their relevance in relation to each of my research questions. This is followed by some concluding statements, limitations of the study, and recommendations related to policies and future research.

1. What are the behaviors, attitudes, and self-perceptions of later diagnosed autistic women in schooling across different racial demographics?

   - **Study Results**

   - Findings of this study indicate that participants frequently displayed negative attitudes towards their idea of school, behaviors demonstrating issues with socializing with other peers, and negative self-perceptions in relation to their academic success.
Though my questions were geared to assess each student’s classroom learning environment, it’s important to note that several students struggled with the social aspect of school that is a very big part of their classroom experience.

- **Relevance of Findings**

The findings of this study relate to other findings regarding classroom environments as students touched on difficulties with interpersonal communication.

- This supports prior research concerning the student-instructor relationship in regard to accommodations—students continue to need the support of their instructors for their accommodations to be helpful. However, these interviews also address the difficulty that their peers add to their learning environment as well.

2. How do these attitudes, behaviors, and self-perceptions compare to their GPAs?

- **Study Results**

It is unlikely that an outsider would guess that students would be struggling due to the pattern of high GPAs across the vast majority of participants. While findings suggest themes of negative attitudes and internalized behaviors towards school, this was often directed at the social and emotional aspect of school rather than the actual academic elements of the school environment.

- A student’s perceived academic achievement (through attitudes, behaviors, and self-perceptions) and GPA do not always match.

- **Relevance of Findings**
This study supports other research findings that concentrate on how later diagnosed autistic women present in the classroom—high achieving with similarly high levels of emotional dysregulation.

- These findings also add that although these participants appear to be successful on paper, they have other needs which are consistently not being met.

Below is a visual showing the connections between my research questions and findings. It is important to note that participants’ lived experience with their race, socioeconomic status, and gender had several intersections with their autism. Each theme listed was not just connected to autism itself, but one or more minority statuses as well, creating unique burdens to navigate in education with their disability. This acknowledges that participants were not limited to a singular identity, but rather, several individuals lived a combination of different identities. These different identities created a complex experience in school in regard to receiving the resources they needed and in social interactions with others at school, which they have to do daily.


Conclusions

While school achievement does have a lot to do with the academic part of learning and processing information about the classroom, all participants discussed the difficulty of the social aspect of school. It seems that school isn’t just about the classes, but it does include interpersonal relationships with other students and instructors, which makes it such an overwhelming environment for the autistic individuals involved in this study.

Study limitations

Being a vulnerable population, it was difficult to recruit participants to complete an interview. As a result, I recruited a wide age range of participants to have as large a
sample as possible. Several of these participants who had already finished school or were not attending school reflected on their past school experiences in their interview. I was not able to collect transcripts from every participant due to cost or accessibility issues, but I was able to collect transcripts from over 75% of my participants. Individuals who were not able to provide a transcript either self-reported their GPA or spoke about their personal academic achievement in their interview.

In this study, I prioritized diversity, as this is what the developing autism literature lacks. Because past studies have not investigated in depth the intersection of race and later diagnosed autism, I wanted to make sure that racial diversity was reflected in this study. Past studies have reflected the necessity to investigate the presentations of later diagnosed women across different racial demographics as well as presentations of people beyond the cisgender gender identities. Though this wasn’t my focus, I was able to interview four people whose identity lies beyond a cisgender woman and see how this may affect the way they perceive their multiple minority identities.

I also included in this study individuals that are formally diagnosed, recommended to be diagnosed, and self-diagnosed. Formally diagnosed individuals underwent a full clinical evaluation. Those recommended to be diagnosed have discussed the potential of autism with their therapist, identified with the criteria of autism. Some participants who were recommended to be diagnosed are currently in the process to receive their diagnosis but are on a waitlist. Lastly, those who are self-diagnosed and those recommended to be diagnosed who are not currently on a waitlist are not pursuing a formal diagnosis due to struggles with cost. For adults, diagnoses are not covered by insurance and schools, and often cost up to at least $900 as an out-of-pocket expense,
making a formal diagnosis extremely inaccessible, especially for college students. The vast majority of participants did have a formal diagnosis, while three participants are either self-diagnosed or recommended to be diagnosed. It is also interesting to note that two participants received their diagnosis outside of the United States to gain access to lower costs and lower wait times to see a clinician.

Because this is an exploratory study, I also recognize that my sample is not representative of the general later diagnosed autistic population. However, this begins to look at unique perspectives not previously investigated in-depth in the scholarly autism literature.

**Recommendations**

- **Perceptions of autistic people**

  Participants frequently discussed how they wished that others viewed them differently than they already do. For example, they often wished that others understood that although their autism may not look like outsiders’ perception of autism, that it’s still a disability and it’s still difficult. Others mentioned that they cannot “turn off” their autism and that it’s innately a part of them. Ultimately, the vast majority of participants discussed how they wish that people can understand what it means to be an autistic person in order to lessen exhaustion attempting to function and socialize in a neurotypical world.

- **School resources**

  Participants also provided suggestions for what schools can do to better serve autistic students. This involves access to different trainings to educate both students and instructors about autism. Some participants recommended disability assemblies to increase autism awareness in schools to establish a greater culture of inclusivity. Others
recommended that teachers would be trained to work with autistic students in regard to their accommodations. Because autistic students already find it difficult to communicate needs due to struggles with socialization, having instructors that understand this struggle and support their needs would greatly improve their academic experience.

- Research

Future research involving later diagnosed autistic individuals can focus primarily on people of color or different gender identities. Though this exploratory study has taken a step in this direction, studies can focus on either population to analyze presentations in much more depth. When focusing on either population, it would be important to continue to look at the impact of intersectional identities. Because people are not limited to a singular identity, learning about the complexity of autistic individuals’ experience is significant to this developing research.
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