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“I was always on the outside, watching quietly”: Autistic women reflect on school experiences

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Voices of autistic women and girls have historically been absent from research. Even now, there is limited knowledge about the experiences of autistic girls and women, particularly in the school setting. To address this gap, this phenomenological study explored a broad range of school experiences for autistic women, from kindergarten through college. Interviews of 6 participants were conducted through a pilot study to inform the development of the interview protocol and process. A total of 14 autistic women participated in the full study, which also included the initial 6 from the pilot. Interviews were audio recorded and transcribed. Two researchers independently analyzed the data to identify themes using thematic analysis. Six themes were identified: (1) Accuracy of diagnosis matters; (2) Details matter; (3) Meaning of sensory and emotional experiences; (4) Invisibility/Not belonging; (5) Relationship and friendship challenges; (6) Layers of vulnerability. We identify recommendations for educators, administrators, counselors, and school social workers.

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Study purpose

There has historically been little research focusing on girls and women with autism (Attwood, 2006; Gould, 2017), though this topic has gained increasing attention in recent years. In particular, there is increased attention to the underdiagnosis and misdiagnosis of autism in girls and women, and how this contributes to the overall lack of support in schools and other settings (Leedham et al., 2020). Missed diagnosis and misdiagnosis occur in the autism community in general with one study finding approximately 1/4th of participants reporting at least one misdiagnosis in their lifetime, if not many (Kentrou et al., 2024). This is particularly true for girls and women, where misdiagnosis of borderline personality disorder, mood disorders, or OCD frequently occurs, though there is also recognition that sometimes a person with autism may have these co-occurring conditions (Iversen and Kildahl, 2022).

Part of the issue around misdiagnosis pertains to stereotypes but also overlap in conditions and presentation of symptoms in addition to limitations in assessments and assessment tools in addition to preparing practitioners for assessment of autism (Gould, 2017; Halladay et al., 2015; Marshall, 2014). Specifically, while there are some new assessment tools for the identification of autism in females, many clinicians are not educated about, nor do they report the use of these tools (Gould, 2017; Halladay et al., 2015; Marshall, 2014). Further, school psychologists are not readily accessible to all schools, and this shortage could contribute to the use of older, more prevalent assessment tools designed for and tested on boys (Attwood, 2015). Many family doctors, mental health therapists, and other healthcare providers are not confident or trained in the identification of autism in adults, let alone in girls and women (Bargiela et al., 2016; Gould, 2017). Beyond a general understanding of the challenge of identifying and reaching women with autism, few approaches have been developed regarding how to best support them (Gould, 2017; Henry, 2017; Lawson, 2017). Many autism experts acknowledge limitations in research regarding women and few studies focus on the unique needs of this group, particularly from a qualitative perspective. A qualitative perspective is important, though, as it provides the direct experience of persons in their words and as they understand it (Creswell and Creswell, 2018). This seems particularly important for marginalized groups, whose perspective has largely been absent.

Foundational to this study, a thorough literature review revealed a handful of qualitative studies focusing on the experiences of girls and women on the autism spectrum (Bargiela et al., 2016; Essex and Melham, 2019; Kanfiszer et al., 2017; Mademtzi et al., 2018; Milner et al., 2019; Tint et al., 2018; Webster and Garvis, 2017). Few focused on school experiences—transition to college (Essex and Melham, 2019)—while a second focused on parent perspectives on interfacing with schools (Mademtzi et al., 2018). Additionally, two focused on mainstream school experiences for a small sample of adolescent females in Britain (Moyse and Porter, 2015; Miles et al., 2019). Broader experiences in all levels of school and in the United States remain to be explored. The voices of women with autism are already suppressed due to communication and social challenges. Equally concerning is that their perspective has been largely missing from research that would serve as foundational to the development of supports and interventions.

A better understanding of the experience of females with autism is important. Current research in this area suggests that females with autism are uniquely vulnerable in that they are less likely to have their autism identified, more likely to be misdiagnosed, and therefore possibly not receive the best or most appropriate support options, while also being likely targets of abuse or exploitation (Sevlever et al., 2013). It is known that persons with autism in general may struggle with identifying boundaries, communicating needs, thoughts, and feelings, and reporting what they have experienced (Gould, 2017; Marshall, 2014). Additionally, victimization rates of women with autism may be much higher than we know, with already half of those with autism surveyed (both men and women) reporting histories of being abused (Brown et al., 2017; Sevlever et al., 2013). They are also much more likely to be bullied or ostracized in the school setting or be victims of dating violence (Trundle et al., 2022). This group is vulnerable therefore to increased risk of social challenges, abuse, co-occurring mental health conditions, and lack of support due to missed opportunities in diagnosis, support, and services (Trundle et al., 2022).

For all of these reasons, it is critical to understand the experiences of females with autism as they are best positioned to identify why their autism was missed and what would have helped in general and at school. Because school is a tremendous part of a child's life and plays a pivotal role in how and where autism may be identified, it seems also critical to learn about the school experiences of autistic persons (Grandin, 2013). To illuminate the schooling experiences of girls and women with autism, this phenomenological study centers on the voices of women who have been diagnosed with autism.

Theoretical framework

The primary theories framing this study are Critical Autism Theory and Intersectionality Theory. Critical Autism Theory stems from Critical Disability Theory and aims to center and ground policy, research, teaching, and clinical work in the voices of autistic persons (Gillespie-Lynch et al., 2017). It assumes that persons with autism are the best experts on their own lives and are critically important contributors to all aspects of intervention and advocacy (Gillespie-Lynch et al., 2017). It calls out unequal societal powers and a history of marginalization of autistic voices suggesting the inclusion of diverse experiences of all with Autism Spectrum Condition (O'Dell et al., 2016). Diversity within the autism community presents Significant challenges for diagnosis and contributes to uneven access to services and supports (Niles and Harkins-Monaco, 2019). This means that some with autism are more excluded and vulnerable, particularly autistics who are Black, otherwise racially or culturally diverse, are living in poverty, have mental illness, identify as LGBTQIA+, have comorbid conditions, and those who are female on the spectrum (Niles and Harkins-Monaco, 2019). Thus, we also take up intersectionality theory, recognizing layers of vulnerability and oppression. Intersectionality speaks not only to multiple aspects of societal injury but the importance of understanding the unique perspectives of those who lie at the center of those experiences. Understanding the experiences of autistic women, for example, is crucial and provides insight into the overlap of those experiencing pervasive sexism and ableism in their everyday lives and in their schooling experiences in particular (Crenshaw, 2017).

In using these theories and intentionally rooting this study in participant experiences, this paper chooses the term "autistic" as opposed to "persons with autism" for the remainder of this paper due to the participant's request that "autistic" is the "most accurate" label they identify with. Specifically, 11 of 14 participants expressed a preference for the term "autistic" while all participants shared that, even if preferring "person with autism," identifying as "autistic" was also acceptable and something they do on occasion. Participants preferred the term "autistic" due to "it's what I hear nowadays" and due to autism being deemed central to identity. One participant shared that the autism cannot be removed from her and "I wouldn't be me without it." Similarly, participants preferred the use of the term "autism spectrum

Table 1 Participant demographics.

	N	%
Age		
18–25	4	29
25–35	5	36
35–50	3	21
50–70	2	14
70+	0	0
Race/ethnicity		
Asian	1	7
Black	0	0
Latinex	1	7
White	8	57
Other	4	29
Sexual orientation		
Asexual	1	7
Bisexual	2	14
Heterosexual	7	50
Lesbian/Gay	1	7
Pansexual	1	7
Other/Did not identify	2	14
Diagnosed before age 18	3	22
Diagnosed after age 18	11	79
Type of school		
Public	10	71
Private	1	7
Other/various types of schooling	3	22

Table 2 Themes.

Accuracy of diagnosis matters
Details matter
Meaning of sensory and emotional experiences
Invisibility/not belonging
Relationship and friendship challenges
Layers of vulnerability

condition" instead of "Autism Spectrum Disorder." The authors of this paper believe it important to elevate the voices of autistic women and honor the language they wish to use to describe themselves, their condition, and their experience (Tables 1 and 2).

The aim of this study, therefore, was to explore the experiences of autistic females and elevate their voices through sharing their experiences, needs, challenges, and suggestions for change. This study aimed to address the gap in the literature pertaining to not only the qualitative experience of females with autism but also regarding their school experiences, which comprise a substantial portion of childhood and even adult lives.

Literature review

Understanding Autism. Autism spectrum condition is a social and communication "disorder" classified in the Diagnostic and Statistical Manual (DSM)-V as a developmental disability (American Psychiatric Association, 2013). Autism spectrum condition is broad and encompasses a vast range of challenges and needs. Several diagnoses were collapsed into the broader autism spectrum diagnosis (such as developmental delay, pervasive developmental disorder, and Asperger's Syndrome). This decision was informed by research that demonstrated significant overlap in symptomatology and experience across all of these conditions (Faroy et al., 2016). Perhaps due to this collapse, along with increased awareness of some with autism who may have fewer support needs, the number of autism diagnoses has been on the rise, with currently one in 48 children being diagnosed with autism (CDC, 2022). Males are still much more likely to be diagnosed with autism, with most recent numbers indicating a 4:1 male-to-female diagnostic ratio (CDC, 2022). Research estimates indicate this number may be significantly skewed and that the true ratio could be 3:1 or even 2:1 (Loomes et al., 2017). One study estimates that females could be as likely or more likely to have autism than males, and rather just remain undiagnosed (McCrossin, 2022). This study also suggests that as many as 80% of females remain undiagnosed at age 18 with potentially serious consequences to the health, mental health, well-being, education, and functioning of autistic women (McCrossin, 2022). Burrows et al. (2022) most recently found genetic support for autism being as likely to occur in infant girls and boys. The progression of studies therefore indicates increased support for girls being as likely to have autism, despite significantly lower rates of diagnosis.

To better understand the missed diagnosis and misdiagnosis of autistic women, and how missing this diagnosis might impact therapeutic supports, modification, and accommodations at school, it is important to examine, foundationally, how we currently understand autism and what comprises our assumptions and current knowledge. Our current understanding of autism is historically based on the male experience (Gould, 2017). Early studies used to develop testing instruments as well as interventions were based on male participants. Autism was even believed to be, with few exceptions, a male condition (Attwood, 2006; Henry, 2017). Early autism literature explored not only the male experience but also more severe expressions of autism, with the autism diagnosis being given to those with higher support needs (Bargiela et al., 2016; Grandin, 2013). The development of a "higher functioning" type of autism did not occur until the early 1990s, with the official diagnosis of Asperger's emerging in the DSM-IV in 1994 (Attwood, 2015). Therefore, studies based on more verbal individuals with autism who perhaps live independently or function with fewer supports are relatively recent in the research realm. Studies exploring the experience of women and girls are even more recent, with most of these emerging in the 2000s. There are still substantial gaps in the literature pertaining to the female autistic experience.

Autism research overall is vast and primarily stems from the fields of education, medical sciences, and psychology, to name a few. Fewer contributions in the social work literature appear until very recently (Presnell and Keesler, 2022). To date, research has explored employment, functionality, sensory challenges and experiences, health and wellness, personality, family, parenting, educational and life transitions, and college experiences of autistic persons (Latta et al., 2014; Ward and Webster, 2018; Harn et al., 2019). However, again, most of these studies have been primarily based on the male experience with predominantly male participants, or have focused on both male and female experiences, therefore revealing a wide gap in understanding the strengths, support needs, and life experience of autistic females. This is particularly true regarding educational experiences. However, late diagnosis of autism can lead to poorer academic outcomes and increased vulnerability socially (Lupindo et al., 2023) and children with autism already have a high level of vulnerability to bullying and abuse even with supports in place (Sreckovic et al., 2014).

Autism in girls and women. Research pertaining to autistic girls and women has primarily focused on diagnostic differences and missed diagnosis or misdiagnosis of autism in females, as well as parent experiences of the diagnostic process for autistic females (Bargiela et al., 2016; Gould, 2017; Halladay et al., 2015; Kanfiszer et al., 2017; Leedham et al., 2020; Lawson, 2017). However, the extant literature is expanding examining other dimensions of the experiences of autistic girls and women. For example, some research has explored gender differences, autistic girl experiences in adolescence, female masking, as well as sexual orientation, gender identity, gender roles, and expression differences for autistic persons (Dewinter et al., 2017; Halladay et al., 2015; Lai et al., 2014; Sandland, 2018). In one study, Mademtzi et al. (2018) explored the experience of parents of autistic females. A few studies have explored trauma, specifically sexual abuse as well as sexual or stalking offenses or bullying of autistic persons (Brown et al., 2017; Sevlever et al., 2013; Sullivan and Knutson, 2000; Wiley, 2012). Recent research highlights the rate of victimization of persons with disabilities, specifically persons with intersections of vulnerability, such as autism in girls and women. However, this is a very new area of research with much yet unknown (Reuban et al., 2021).

Finally, there have been very few qualitative studies exploring the experiences of autistic women, specifically. School experiences of autistic females have only recently been researched, such as Hannah and Stagg's (2016) study pertaining to sex education experiences of young adults on the autism spectrum. In one article, the author, who is a speech and language pathologist and also has autism, describes the school experiences of 67 autistic women and makes professional recommendations based on the author's expertise, though it does not appear that this was a formal qualitative study (Honeybourne, 2015). Moyse and Porter (2015) explored the experiences of three autistic girls in ethnographic case studies that included observation of these three autistic students as well as conducting interviews with their mothers and class teachers. Findings revealed that these girls and their needs tended to go unnoticed, and they masked social issues and also tended to underachieve academically (Mosye and Porter, 2015). It also identified a gap in teacher education and preparation for identifying and supporting autism in girls. Similarly, Miles et al. (2019) conducted a qualitative study with a relatively small sample exploring the experiences of autistic girls specifically in British "mainstream" schools, with this focusing on adolescent-age students in particular. This is a very specific subset of participants and a very small sample but this study indicated that students with autism wanted to build friendships and are motivated for social contact just as non-autistic counterparts would be (Miles et al., 2019).

In addition to these few qualitative studies, there is also a formal textbook concerning the school experiences of autistic girls, which raises issues to various intersectional challenges, such as for Black autistic girls or autistic girls with mental health conditions (Carpenter et al., 2019). This textbook also provides professional insight into leadership issues, teaching and curriculum strategies, and raising awareness of the problem of missed diagnosis or misdiagnosis of autism in females. Tomlinson et al. (2020) also conducted a systematic review pertaining to the school experiences of autistic girls and adolescents and found eight studies that met the inclusion criteria. However, these studies also explored parent and boy experiences and were not specifically qualitative studies exploring the school experiences of autistic girls and women directly. Tomlinson et al. (2022) followed up with a qualitative study with 3 autistic girls to better understand their school experiences, which is the only study to date these authors have found seeking the voice of autistic girls or women. Therefore, continuing to center the voices and experiences of autistic females in our research efforts is critically important as this population is largely absent from research, clinical, and social discourse, yet has high rates of trauma, and misdiagnosis, and for whom our systems of support continue to fail (Reuben et al., 2021).

Qualitative exploration of the Autistic female experience. Understanding the experiences of autistic persons and elevating their voices is very important (Gillespie-Lynch et al., 2017; O'Dell et al., 2016). A qualitative approach, particularly phenomenology, lends itself to exploring significant experiences identified by the autistic person and centers the meanings that they have made of their experiences. The approach demands that participants lead as experts on their life experiences. It counters mainstream treatment of those with disabilities who often endured ableism and are told what their symptoms and experiences are and have these predefined for them (Creswell and Poth, 2018). Our use of the phenomenological approach seeks to shift the power and place participants in the role of expert and a critical part of framing and defining their own experiences (Seidman, 2013). Further, it seeks to provide a safe and intentional space for sharing an inner world, and amplifying voices that are quietest (Seidman, 2013; Munhall, 2012).

Until recently, the voices of autistic persons have been largely absent from research. The few qualitative studies exploring female autistic experience, so far, have focused on trauma, masking, misdiagnosis, or missed diagnosis (Bargiela et al., 2016; Gould, 2017; Halladay et al., 2015; Kanfiszer et al., 2017; Leedham et al., 2020; Lawson, 2017). Almost no qualitative research has currently explored school experiences for autistic girls and women, specifically, though we know school is a formative space where children spend the majority of their waking hours (KavithaKiran, 2015). We know that school is the primary place for building friendships and developing a range of peer-to-peer and youth-to-adult relationships, as well as the road to future academic achievement and functioning (KavithaKiran, 2015).

Research has also demonstrated that autistic persons, regardless of gender, experience much higher levels of trauma, bullying, and abusive relationships as well as academic, school transition, and functional life challenges (Brown et al., 2017; Ohlsson Gotby et al., 2018). We know this is particularly true for girls and women who have been diagnosed. It is difficult to fathom what the experiences may be like for females who are not diagnosed and who are without appropriate support and accommodations in the school setting where many primary friendships and relationships and academic foundations are built (KavithaKiran, 2015). Therefore, understanding the school experiences of autistic girls and women is crucial to better exploring systemic cracks and failures, better understanding how females are being missed, what their school experience was like, what they needed, and what they recommend for school administrators, helping professionals, and educators. This study, therefore, aimed to give voice to autistic female school experiences, learn from these voices and experiences, and make recommendations for change.

Methods

The research questions guiding this study were as follows: What is the lived experience of autistic women? What is the lived experience of autistic women in educational settings, from kindergarten through twelfth grade and even in college? Also, what are the lived experiences of autistic women as they interface with educational institutions, whether from their experience as a student or parent of a student or another perspective?

We started with these broad questions as we wanted to better understand educational experiences in general, from how autistic women experience the school environment to how these experiences may have impacted other areas in their lives. As we started this study, we recognized that people with autism might be difficult to find for recruitment and that there might be some need for guidance from them regarding what questions to ask and how to best proceed with understanding their educational experiences, which is another reason the study had a broad focus.

Study pilot. Identified as a "difficult to reach population," it was important that we began with a pilot phase to test and refine our methods and protocols for interviewing autistic women. We began with six participants and a set of open-ended interview questions. These six participants were recruited through two local organizations in Indiana that serve autistic individuals on a statewide level. These organizations did not select participants but just shared the opportunity with those they serve. Potential participants then reached out to the primary researcher independently via e-mail. These organizations did not advertise publicly but only to those they serve directly, and participants also provided verification of how they were referred to the study and affiliated with the referral organization. Participants received no compensation for participation and engaged based on their own interest and volition and desire to share their story. Participants shared deeply and thoroughly and sometimes participants needed more than one session to engage. This was true for both the pilot and follow-up round of interviews.

After the pilot, and as a result of it, we learned that participants strongly preferred receiving questions in advance of the interviews. In addition, they preferred very specific questions, as opposed to more open-ended types of questions. Consistent with autism spectrum difference (Grandin, 2013), and through conversation with participants and transcript review, we found that participants appeared to benefit from both preparation and concrete direct questions. Participants also reported feeling comfortable responding to and sharing suggestions for study improvement. Two of the six pilot participants are researchers themselves and offered their expertise in question development. We used photos and artifacts provided by participants to prompt discussion of school memories. These photographs were any pictures they provided that connected to their school experience (some used yearbooks, some looked at images of their schools online, and some viewed family photographs taken in a school setting).

Interview design. In general, photo-elicitation has been deemed useful and helpful in tapping into memories, particularly for groups who may have an increased likelihood of visual-based memory understanding, such as some autistic persons (Coussens et al., 2020; Danker et al., 2016). However, there were mixed reviews on this approach to evoking memories and conversation with some participants expressing that it was very helpful, particularly in tapping into sensory and emotional experiences, while others shared that viewing photographs was a negative experience for them or did not seem to help in the reflection process. Specifically, some experienced negative memories when viewing the photographs (and expressed wishing they had not viewed them), and some expressed the request to look at photographs was vague and unhelpful. Due to this feedback, we also adapted interview questions to include some questions specifically pertaining to the photographs and asking what the photographs meant to them and what memories or feelings were evoked as a result of viewing the photos. We also made sure to inform participants up front they were not obligated to look at any photographs during their interview if this would not be helpful to them.

Following the pilot, interview questions were revised, and the format shifted to Semi-structured interviews. All six participants from the pilot engaged in a second round of interviews and another nine joined the study. Participants were purposefully selected through their affiliations with local organizations in Indiana specializing in autism services. Participants were recruited through these organizations, social media, and also by a prominent psychologist in Indiana who specializes in autistic women. The target for participation was 8–15 participants as most phenomenological designs recommend 6–12 participants depending on saturation (Creswell and Poth, 2018; Marshall and Rossman, 2016) and availability.

Sample. Participants were recruited via e-mail. A formal e-mail describing the study and requesting volunteer participants was sent to the identified organizations specializing in autism services in Indiana. Participants reached out to the first author to express interest. The sample of participants was diverse, with various races and generations represented, along with sexual identity diversity. Ages ranged from 25–70. Only three study participants were diagnosed with autism in their childhood or teenage years, the rest being diagnosed after age 18.

Inclusion criteria for participation were that individuals: (a) have a formal Autism diagnosis, though Asperger's was also acceptable (if they were diagnosed prior to the development of DSM-V); (b) diagnosis did not have to happen in childhood; (c) were older than 18 years of age; (d) are residents of Indiana or a surrounding rural state or at least attended k-12 in Indiana (for simplification, ease of access to participants, and because school conditions vary by state); and (e) attended a public or private school for k-12. Inclusion criteria of a formal diagnosis did not require participants to show proof of diagnosis and, as with any other information presented by the participant, their self-report of formal diagnosis was accepted in good faith.

Though verification of diagnosis was not required, the researchers attempted to obtain integrity of the data through no compensation for participation in the research. The primary interviewer is also a trained social work clinician who has worked clinically with the autistic community and has clinical and research experience serving this group. These measures hopefully provided sufficient protection against scamming or any other dishonest engagement in the study. The inclusion criterion of diagnosis was intended to set parameters to ensure participants are sharing from the autistic experience (as opposed to someone who may believe they have traits of autism, without meeting full diagnostic criteria). However, it became apparent from the interviews and participants' feedback that obtaining a diagnosis can be expensive, time-consuming, and may not be covered by insurance. In addition, there may be too few experts specializing in the diagnosis of women specifically, per participant report. Participants recommended if a future study emerges from this one, self-identifying autistics, without formal diagnosis, should also be included.

Data collection. Most interviews were conducted via distance technologies, both due to safety precautions during the COVID-19 pandemic and to honor participant preferences. Interviews had both audio and video components as means to connect and communicate. Prior to all interviews, the first author prepared by reflecting on her own knowledge and experience with autism spectrum condition in order to treat the information as novel and to more fully attend to the voices and experiences of participants. She examined the situated relationship between researcher and researched in the space together, from physical, social, cultural, generational, and other capacities (Cannella et al., 2016; Creswell and Poth, 2018). This was done by reflecting on and journaling about her own knowledge, educational journey, and personal experience pertaining to autism and to reflect on how this experience might impact the perception of participants. This author sought to keep this bias in check and enter each interview with an open mind and placing the participant in the spot of expert on themselves and their experience.

This attention to and respect for participant needs was also at the forefront during interviews, with the first author prioritizing participant comfort and engagement through the balanced level of eye contact with the camera, leaning in, and expressing interest through body language. Though many participants had or expressed some difficulty with eye contact and some may have communicated less nonverbally, all participants engaged and shared rich details about their life experiences. Interestingly, the few interviews that took place in person wrought less interaction and more need for prompting. Participants consistently expressed increased comfort and preference for the virtual format.

Regardless of medium, all interviews were lengthy, some requiring 2-3 sessions to allow time to respond to all questions. It is possible that multiple factors contribute to the length of interviews and the depth and variety of information shared by participants. First, the interview schedule was fairly intensive, with many questions pertaining to various levels of their autism as well as educational experience across the lifespan. Additionally, participants shared in very detailed ways, many of them sometimes delving into several different topics in one paragraph. There is a large amount of overlap of attention deficit hyperactivity disorder (ADHD) co-occurring with Autism and also Autism in general can bring about attentional, focus, and conversational differences that must be acknowledged and honored (Pinto et al., 2016). With the primary researcher's own neurodivergence, there was conversational synergy, with occasional difficulty on the researcher's part with bringing the focus back to the discussion at hand at times, both in an attempt to be respectful of and empowering to participant voice as well as appreciating the depth and breadth of information shared.

Regardless of the length of the interview or topic covered, all were audio recorded with informed consent. Once transcribed, the transcriptions were de-identified (codes replaced names) and saved in an encrypted file on a password-protected computer, with the encryption key backed up as well. In addition, participants were fully informed of all efforts to maintain confidentiality. They were also reassured that the first author would not disclose what they had shared with mutual acquaintances or those who may know of their diagnosis.

Data analysis. First, it is important to share that while study questions focused on school experiences and autism, participants also shared about relationships and even abuse their experiences. While analyzing data, the primary research employed a broad approach, analyzing everything that participants shared regardless of how closely it tied to the original research questions. This led to the development of broader themes about the experience of growing up as autistic females rather than only about school experiences.

Additionally, the primary researcher spent time in contemplation following each interview to hopefully absorb and understand all that was shared. This time, known as "dwelling" (Munhall, 2012), was to reflect on the interview experience, review and finalize field notes, jot down thoughts and questions, and allow reactions and feelings to settle. This process also included intentional reflection on the researcher's experiences as a neurodivergent person and as a parent of autistic children. It included an analysis of how this might impinge on interpretations of participant stories, and reflexive journaling exercises to confront this and stay as grounded in participant experiences as possible. Second, the first author transcribed the interviews as well as typed handwritten field notes allowing for repetition of the information to capture additional details. Each interview transcript was situated by context (location, time period, medium of interview, etc.). Data segments from the transcripts were organized into rows in a Microsoft Excel file for coding and thematic analysis. The primary author followed the steps for thematic analysis as outlined by Braun and Clark (2006) including becoming familiar with the data (which also happened as a result of dwelling and transcription), generating initial codes, identifying themes, and then confirming themes and defining them. Both authors then engaged in iterative analysis of the data and compared findings to develop themes.

Credibility analysis. To enhance the trustworthiness of the findings, we used triangulation to cross-check and analyze data and themes. Triangulation across participant interviews supported the reliability of data interpretation (Munhall, 2012; Priest et al., 2002). Additionally, participant member checking was used at multiple levels of data collection and analysis. Participants not only provided feedback on interview style and questions but also engaged in discussion about study findings. The first author shared a list of preliminary themes and de-identified findings with participants to further verify data and to engage in discussions about accuracy, the need for additional clarification, and increased understanding (Creswell and Creswell, 2018; Seidman, 2013). The first author completed all data collection and transcription while the second author provided research design and analysis support.

Researcher positionality. The first author has personal experience working in the mental health field and supporting autistic women. In addition, she has children and family members with this diagnosis. This primary researcher is also neurodivergent but prefers to not divulge particulars. Neurodivergence can include conditions such as ADHD, Autism, giftedness, OCD, PTSD, to name a few) (Turner and Smith, 2023). The intimate knowledge the primary author brings to the study and her professional background shape the overall approach to the study and her relationships with the research participants. While the second author does not have direct experience with autistic females, her research centers on the ways minorities and marginalized communities navigate schooling.

Findings and discussion

Participants were representative of multiple generations, sexual orientations and levels of ability. There was a broad range of school experiences, with some sharing very positive memories, such as about mentors who were helpful to them. However, many also shared barriers and ways they felt schools had not identified their needs and therefore not offered solutions to support them. Consistent themes emerged from the rich data collected. These six themes were: (1) Accuracy of diagnosis matters; (2) Details matter; (3) Meaning of sensory and emotional experiences; (4) Invisibility/not belonging; (5) Relationship and friendship challenges; (6) Layers of vulnerability.

Accuracy of diagnosis matters. Almost all participants, 11 out of 14, were diagnosed with autism in adulthood, many in their mid-thirties and beyond. All shared difficulty with obtaining accurate diagnosis. Three who were diagnosed in childhood were diagnosed later—one in middle school and two at age 17. The late diagnoses of participants in our sample were even later than national statistics, which indicate boys, on average, are being diagnosed by around 4.1 years of age and girls being diagnosed by 4.7 years (CDC, 2022). However, national statistics also reveal that boys are significantly more likely to be diagnosed with autism, with approximately one in 42 boys receiving an autism diagnosis vs. one in 189 for girls (CDC, 2022). echo larger challenges with the diagnosis of autism for girls and women, as highlighted in prior research (Bargiela et al., 2016). It is possible that missed diagnosis and misdiagnosis could also be more likely to occur in smaller, rural areas with fewer resources, such as the location of schools attended by most of our study participants. Some of our study participants also represent various generations, and diagnosis of autism in girls may have improved some, even if it remains a significant challenge. Finally, many participants also indicated co-occurring diagnoses such as ADHD, depression, and/or anxiety. At the same time, participants reported being misdiagnosed with bipolar or were simply missed altogether.

> When, in elementary school? No, I think *I flew under the radar* then. I think *I was just quiet and not what you would really think of when you think of a kid with autism*. I mean I'm not a genius. I was never one of those smart ones…they didn't figure out that I had anything. No.

This feeling of not being the "stereotype" of autism was expressed often. This seems to have impacted the likelihood of diagnosis. This includes self-diagnosis where even participants may have only been familiar with autism stereotypes, not initially considering they might have it. Obtaining the diagnosis often occurs through recognition of symptoms by someone else, such as a family member or a friend. Often, recognition was by someone who also has autism. In some instances, the participant having an autistic child raised their own awareness of and familiarity with symptoms and diagnostic criteria. For instance, one participant shared,

> My son was diagnosed with a spark of autism when he was eight. He's sixteen now. He told me he thought I had it. I wasn't going to go get the diagnosis, but I kept getting in trouble at work for stupid shit. Or crap. Sorry. But anyway, he said that I should check into it.

Another participant recalled,

> My son was diagnosed when he was in high school. I also have a good friend who is a woman and she had been diagnosed and I actually believe I am more like her. I really started to think maybe I had it after talking with her and she suggesting that I have autism. I wasn't going to get a diagnosis because it would just cost money, but she actually helped me pay for it to get the testing because I also have had some other disabilities and had never looked into getting disability, you know, payments.

Participants reflected on not only the struggle and process of obtaining the diagnosis and finding a clinician who specializes in autism for females but also that it is an expensive process as well.

> And so, for me, what closed the gap was getting my diagnosis, and having language to attach to the things I experienced. So that from that position of self-awareness and knowledge, I could choose between disclosing, getting an accommodation…I think I just flew under the radar before because I was quiet and got along and they didn't know what to call my challenges.

Lack of awareness of symptoms of autism in females, in clinicians, educators, and the general public, as well as potential lack of available resources or affordable options, make diagnosis a privilege that is not available to many. Participants expressed that the diagnosis has been very valuable to them and reflected the sentiment "now my life makes sense." They also shared that diagnosis has helped with access to accommodations, connections to others with autism, self-understanding, coping, and even parenting their own children, especially if their children also have autism. There are many reasons diagnosis has helped and participants seem to view autism as both a disability and as something that brings strength, beauty, and benefit to their lives.

For most participants, their autism was not recognized until after k-12, though some received accommodations in high school and some in college. Even in college, even though diagnosis and accommodations have been helpful, there is still a need for ongoing advocacy and education.

> I had one time where they just wouldn't even work with me even when I had accommodations set up and they had record of my diagnosis. For my qualifying exam, I was supposed to have my headphones and extra time and it was really hard for me to focus and finish this exam. It was terrible. It helps me realize how much we need to advocate for the accommodations we need. The diagnosis is just the first step. But it is a critical step.

When reflecting on what might have helped improve the diagnostic process, participants shared that they felt counselors, educators, and parents should also receive better education about how autism presents in females. They also shared that autism in females should be more visible in everyday culture.

> I feel there are all these examples of men with autism on TV and that is just like the stereotype but I feel like we need to have more acceptance of autism traits in girls and women and we need to be showing it on shows. And people need to know what to look for.

Participants shared how limited understanding of how autism may present differently in each individual and in women specifically additionally isolated them in ways as autism in women was not visible, not normalized, and not historically acknowledged.

Details matter. Participants shared in rich detail about the academic, social, relational, sensory, and emotional aspects of their school experiences. Memory descriptions were vivid and encompassed all aspects of an event, including thoughts, insights, and details leading up to and surrounding events. Details were not trivial or extraneous but rather were central to meaning-making and understanding, and the thoughtfulness and analytical nature brought to interviews allowed for deep exploration. Participants shared how some details, however small, were actually central to their understanding of an experience, particularly given that many expressed feelings of and preference for being "in my world."

Participants often shared in detailed ways during interviews. A few reflected on the need for things to be "accurate" and they made sure to inform the interviewer if there had been a misunderstanding or if they wanted to further clarify or explain. Some also shared how there was sometimes conflict or miscommunication with others related to their need for something to be accurate and right and fair. Though participants also reflected on a desire to get along with others, the need for accuracy often won out as being most important.

> I had one teacher who was very unfair with grading. I felt like she just didn't like me. I couldn't figure out why she was so harsh. I saw the essays, the writing of friends, and we would compare, and she always scored me lower than most in the class. I also wasn't used to not doing well academically. It was so hard to know how to handle it. I would talk to friends and my parents, and I would think on it over and over and I finally told the teacher I didn't think my grade was accurate. She disagreed and shared her points and I felt too overwhelmed and shocked, I guess, to say anything else. I remember just being shocked and thinking she was wrong but didn't know what to do to convince her. I finally just said I disagreed and thought her grading was

> unfair. It didn't improve and I didn't do well in that class. I did fine in other classes, though. My grades were good. I don't know why Mrs. Jones didn't like me but I believe that's what it was.

Details sometimes became a point of contention, therefore, as they would focus on some details and then experience frustration on the part of parents or teachers who would inform them "those things don't matter." One participant shared about how details are important to her and how they impact whether or not she would eat on a given day.

> I think I shared the main points. The rest of it would just be random details that maybe matter to me but likely wouldn't matter to others. Well, details are important to me. They are important to autistic people. Some of the strange details I remember are like the weird bags of milk. The milk literally came in bags. I also remember I almost never liked the hot lunches. I thought they smelled terrible and they didn't look appealing either. I usually took a packed lunch, but even that was never appealing. I like warm food but I mainly liked my food at home, like my macaroni and cheese and spaghetti and pizza rolls. There is only so much you can do with packed lunch and my parents didn't have much money. But all these details made a difference because I couldn't eat. I couldn't even if my sandwich had been prepared that morning. It needed to be fresh. I couldn't eat if I wasn't at the right seat. I couldn't eat if they changed something about lunch. All the details somehow mattered to me.

Details sometimes therefore provided a sense of routine and normalcy and perhaps even safety. Details mattered not just for accuracy but for a sense of predictability, which sometimes was misunderstood by others. They reflected on the details of surroundings, clothing, but also of words and understanding, and how all of this impacts their well-being and sense of safety and that all details do indeed, individually and collectively, matter.

Meaning of sensory and emotional experiences. Participants also reflected on how sensory experiences were also very emotional for them, and emotional experiences were often entrenched in sensory experiences. Several participants shared that sensory experiences in the school setting were overwhelming or even painful.

> I remember hating the experience of sitting in the rows of desks under the fluorescent lights looking at big glossy-paged textbooks. I liked the band room though. I don't remember any other positive sensory experiences. The gym was too loud. I preferred study hall. I wasn't comfortable in most spaces in high school. I would spend time reading, hiding out, or skipping class or school altogether. I started blowing off my schoolwork and skipping class. My parents got a letter from the school threatening legal action if my attendance didn't improve. I just didn't want to be there. It was terrible. I didn't fit in, and it was loud and overwhelming. I don't have much positive I can say about school, I guess. I think it was a big and overwhelming place and I just remember feeling scared a lot of the time.

Participants also shared how the school environment was even sometimes scary to them. One participant reflected on how the very structure of the school building evoked some anxiety for her.

> I remember how the hallways were really long and really most of the classrooms were along this one long hallway. Or maybe it just seemed long to me back then because I was little. I'm not sure. I just remember certain aspects of that building really creeped me out. I remember being afraid of the black toilet seats. That may sound weird to say but they just scared me, and I didn't like going to the bathroom there. And I just remember the whole building was so big, or it seemed like it.

Participants also shared how sensory experiences were intertwined with one another, as well as with thoughts and emotions. These sometimes seemed to jumble together in a way that was particularly intense and left participants feeling confused or unsure of how to proceed. One shared how parenting was particularly challenging due to sensory and emotional overwhelm.

> But there again I got pretty stressed with the boy sometimes. I would yell at him. Sometimes he wouldn't quit crying and I would just put him in his bed. I didn't know what else to do. So, I guess I needed the help, really. I wanted to do things with him but taking care of him all the time was just too much.

This overwhelm impacted not only parenting in later life but also academic functioning and achievement at school. The noise combined with social challenges was just too much for some to be able to concentrate on their work. One shared:

> I had a teacher who was very bad at class management and so I don't know where I was going um…it was like election time I think and the students were being just really boisterous and loud and I was trying to study and just remember having a panic attack. Like it was so overwhelming like hearing everybody and I had to leave and and I burst into my mom's office. She was working at the school at the time and that was like one of the first times that it became apparent that it was a surrounding and sensory type of thing um but even as a little kid I guess I was terrified of things like fireworks like any type of thing like loud. I was terrified but also overwhelmed and couldn't focus. I wore headphones like all the time. I would always be having like a Walkman and listen to music as a kid a lot like and that was looking back that was probably like sensory like kind of closing people off. But keeping up with everything was hard then because I would miss instructions. It was just all so overwhelming.

Though sensory experiences could be positive also, with one participant sharing "I get excited about my pearls, and I've always had a hobby, like glitter and glow-in-the-dark stuff," most sensory experiences in the school setting seemed to be unpleasant or even upsetting. This did not seem to improve with time, and instead, puberty brought additional relational and social nuances.

> I didn't like boys yet. I hadn't entered puberty yet. I felt lost and overwhelmed. I was struggling with keeping up with a more complicated schedule and more homework. So much noise. It was just harder all the way around.

There was mention of multiple other sensory challenges, including smells and crowded halls. Some participants also described how viewing photographs of themselves or their schools evoked some memories they had disconnected from. They shared that the visual prompt of photographs helped connect them to other sensory and emotional experiences associated with school.

Invisibility/not belonging. Every participant reflected on feeling some form of disconnection from others. Some viewed this as working or playing "parallel" to peers instead of with them as reflected in one participant sharing "like I feel like I'm in a parallel universe or alongside them." Several experienced "invisibility" and a sense that "I just didn't belong." Some participants connected not being seen to a reason for professionals and supportive persons having missed the autism diagnosis. Additionally, many developed "masking" skills that allowed them to "fly under the radar" to the point of being able to develop some friendships, or at least avoid conflict with peers.

> So, I just kind-of felt with my regular peers a little bit invisible…but as I said, they saw me as—they saw me as this echolalic way that I use language to communicate makes me sound smarter than I am. You know what I'm saying? So, they just always heard the way I presented myself and thought, god, she's smart—it was just weird.

This masking and social echolalia also allowed most participants to blend into the background in a classroom environment, with most reporting a stronger relationship with adults than peers not only due to good behavior but also adults are more predictable and easier to understand.

> I think the adults liked me and thought I was a good student…but I also think I seemed invisible to them. They were busy trying to mess with the problem students. They didn't have time to pay much attention to me. I did well academically but I was not the star student in their class.

Another participant shared:

> Yeah, so I never really felt like I belonged at school. It was like we spoke different languages. I couldn't figure people out or what they wanted from me. I felt like teachers didn't really know who I was. I was just on the outside and quiet and trying to figure out the rules but never able to figure it out. Everybody else could figure out everything quickly but I would need time and it just, I don't know, it just took me longer…I was always on the outside, watching quietly.

Another shared the harm caused in functionality and wellbeing, as well as academically, because the autism diagnosis was missed.

> There were lots of issues like this in college also. Being unidentified as an autistic and gifted student with ADHD, SPD and learning disabilities along with generalized anxiety and panic attacks…this has helped my schooling. Massively impacted my schooling. I have not achieved what I wanted in life. I always thought I lacked intelligence but aspired to higher learning. I always felt alive when learning about things that interested me…and if my learning would have been based around my interests, I believe I would have excelled…but instead I floundered for years and struggled to keep my head above the surface with my self-esteem taking continuous beatings…socially and academically

Though k-12 had been difficult, and participants expressed a lack of belonging, many participants attended college and expressed that these school experiences were, overall, more positive. Still, many experienced executive function challenges, such as difficulty finding classes and tracking homework, among other transitional challenges, they overall expressed believing that college was a better fit and was more accommodating to their needs.

> So, in terms of school and moving beyond that, I don't really feel like I belonged in there. I got to college, and then it was just so much better. Because there was more break time. When you can schedule classes was a little bit more flexible…college is my jam.

Participants shared that they appreciated the deeper level of analysis and processing in college, the availability to go home after classes (meaning less socialization was required), and they appreciated their instructors, many of whom participants expressed feeling "I was like them. I connected to them." They also shared a deeper sense of belonging and connection to college in terms of connection to professors and enjoyment of learning, even while "I was still different from my peers." They overall identified feeling invisible in the school setting in multiple ways, including socially, academically, with disability missed and support missing as well.

Relationship and friendship challenges. In addition to diagnostic, academic, and sensory challenges, participants also reflected on how it was often difficult for them to build friendships. Many of them attributed this to general difficulty in "reading others" as well as difficulty with relating to peers, or with peers relating to them as well. Though some participants shared they were able to make some friends through efforts of withholding autistic traits, when possible, many shared difficulty developing friendships and feeling that they didn't fit in with other students. Some participants reflected on how this lack of belonging impacted self-esteem and mood. They reflected on the pain of feeling separate and "different."

> I was just different. I was—as a friend put it—I was tortured. Especially later on. I would be made fun of for knowing things, or I just wouldn't… I didn't understand… Nobody really wanted to understand that it was ok for everybody to have different interests and not everybody to just want to do sports or something.

Another participant reflected on how it was difficult to make friends in earlier school years, they developed more friendships as they better understood themselves in adulthood.

> I just didn't understand how to go about making friends. Everyone else seemed to be able to do it and I was just clueless on it. I believe it would have helped if I really got myself better but I didn't. I couldn't figure out which parts of me they liked or didn't or why…so it was just a guessing game of what upset them or what helped them get along with one another. It always seemed really arbitrary and confusing, especially in middle school and high school. Later, I understood a little better but it was way too much trial and error.

Though many reflected on difficulty knowing how to build friendships, it should be noted that some participants spoke about having one very close friend who understood them, and that close friendships helped them feel safe and accepted.

> I finally had Ashley and it made all the difference. I had gone all that time not fitting in and feeling alone and once I had her, I had someone that got me and all I really needed was that one person.

Participants also reflected on their teenage and adult years and friendships and relationships. One shared about how it was difficult for her to understand or develop friendships with other girls and women.

> Men are much more straightforward and easier to understand. Women, oh my god, I need a margarita to talk about women.

Relationships were also challenging for many participants, with some having difficulty finding dating partners or maintaining relationships, while others shared, they often landed in unhealthy or abusive relationships.

Layers of vulnerability. Participants reflected on abuse experienced at the hands of friends, relatives, and partners, as well as abuse endured when systems failed them. Systemic abuse includes times when bullying was not addressed when no one intervened when they experienced childhood sexual abuse when no one recognized their autism or additional communication or social challenges.

Importantly, the majority of participants ($N = 9$) reported they had been bullied by peers. Not only did they indicate that the bullying was often unaddressed by teachers, but some shared that they in fact had been blamed for any self-defense or retaliation. It should be noted that participants come from various generations and teacher involvement and interventions have likely changed some over the years.

> I remember having instances of me trying to defend myself against bullies. And I distinctly remember pulling my arms into my coat and flapping it up, telling them to get them out of my face, and I got in trouble for hitting. And I spent like an hour sobbing. When I just wanted a bully to leave me alone.

Another participant also shared bullying experiences, with a focus on teachers not intervening, even blaming her for the abuse.

> It shouldn't have been allowed but it is how things were then. It wasn't right but it is what they did. I remember this one little boy picking on me a lot. I don't know why he did it. I remember trying to tell my teachers I didn't understand something but after a while I was afraid to. And he would make fun of me and call me stupid, that boy did. I have ADHD also, so I really struggled in school. I don't think the teachers knew what to do with me. It was terrible. I was the problem.

While some participants shared direct and blatant examples of bullying, others shared about more covert, insidious methods.

> I had a few that were mean to me. I don't really know why. Like some just straight up stopped being my friend because I guess I wasn't popular enough or I didn't fix my hair much or whatever. I didn't look bad, but I didn't care much about clothes and hair and make-up. I felt like some of the girls just excluded me. They would flirt with the boys, and I was never sure what was appropriate flirting or joking. Sometimes I would try to joke or flirt, and it would just sink. They would just all look at me like I had just slapped someone in the face, and I would try to figure out what I had said that was wrong. It seemed like something any of them would have said. I didn't understand it. So, it wasn't like direct bullying. Like I didn't notice that…but it was like all that kind of stuff. Leaving me out of the circle. I couldn't do anything right…I thought if I could figure it out, I could make it better. But it was just beyond my grasp, I guess.

This participant and others reflected on how sometimes being themselves, dressing as they wanted, dressing comfortably, did not feel accepted or even safe. They would be excluded or potentially even bullied due to differences; differences innate to who they are. Some participants reflected a similar level of difficulty, anxiety, and uncertainty around dating and difficulty knowing how to seek support for abuse endured.

> High school was much of the same. I didn't really date boys. I tried once and he ended up being controlling and abusive and my dad helped me with setting boundaries with him and getting him to leave me alone. I was shy and struggled with that.

One participant reflected on abuse endured by the father of her children.

> Their father and I divorced when they were children and he is not very involved. I'm not sure if this is helpful to the study or not but he's a narcissist. I think women with autism are particularly vulnerable to those kinds of men. He was very verbally and emotionally abusive. At the very end, it also became physical in a few ways. I didn't get a protective order and I just tried to avoid conflict. I absolutely hate conflict and it scares me. Anyway, he obtained new supply, and he married her, and they moved several hours away. I was able to raise my boys mostly by myself, which was kind of hard at first but ended up being the best thing.

Participants sometimes looked inwardly to see ways they may be particularly vulnerable to abuse, but they also looked at ways additional factors may have increased vulnerability as well. One participant reflected on now knowing how to respond or what to do when confronted with sexual abuse. It should, however, be recognized that a freeze response is also common in situations of trauma regardless of whether a person has autism (Scaer, 2014). When reflecting on sexual abuse in childhood, this participant noted how understanding what she is feeling at a given time and how to communicate that is a challenge for her, particularly when it is a traumatic circumstance.

> Well, I think I know that now, but it took me years of studying it. I just couldn't piece it together. I wasn't even really sure how it made me feel. I think I felt afraid maybe, but I have realized I have a hard time knowing what I'm feeling sometimes. I felt like I should have been angry or something. I just went on with my day and life like it hadn't phased me. It was kind of strange.

Similarly, another shared how difficult and frustrating it is for her to try to identify her own thoughts and feelings, as well as the intentions of others. This sense of the unknown in social situations leaves her wary and confused.

> I have problems like fantasizing about things um I have problems seeing or sensing or feeling like superficial emotions um I struggle to identify emotions in myself and in other people and um, so you know a lot of that sensory processing. I get frustrated and overwhelmed because sometimes I don't know what they want to intend. I don't know how to read them. Especially the superficial stuff where they say one thing and want another.

Compounding the challenges of noticing, recognizing, and reading their own inner emotional terrain, is the challenge of noticing, recognizing, and reading the terrain of intent of others. One participant indicated that she had read that autistic people, on average, tend to be more trusting. The instance she describes points to the way such readiness of trust may contribute to difficulty in recognizing and reading manipulation.

> Yeah, like one time, one of the older kids, said "Oh, I'm going to teach you this word, and if you put this word all over your paper, the teacher is going to be so impressed." And it was like a foul language word. And so, I did. I put it all over my paper of my spelling test or something. And the teacher was horrified and called in my parents. And I just remember from that… that kind of thing happened several times, where people would talk me into things, and then I'd get in trouble for it. And then I just started to feel like

> maybe I was a bad person. Since I seemed to keep getting in trouble.

Sadly, as this participant demonstrates, the manipulation for her is translated into further self-doubt and vulnerability. What remains unchallenged are relations and dynamics nurtured by a system that too often looks past bad behavior. Where collective responsibility may have helped to address what clearly is a relational problem in the classroom, instead, the individual participant and her parents are held to account.

The women in this study reflected on their beliefs that the lack of diagnosis and support, lack of intervention for bullying and abuse, coupled with ableism experienced once the diagnosis was known, also contributed greatly to increased vulnerability. The ableism referenced can be seen in what one participant shared,

> When they thought I had autism, they thought I couldn't do anything. And before they thought I had autism, I could do everything.

Another stated that she was appalled by how long it took to get her diagnosis. She reflected on layers of vulnerability surrounding the difficulty of being accurately diagnosed. Without adequate resources, access (whether material or as a result of implicit and explicit biases), insurance, and funding, she highlights how diagnosis in itself is a privilege.

> We're taking something that's sexist and making it even more sexist. One of the things that I think that I bring up more than previous generations is that this is an inherently sexist diagnosis. It's sexist. It's racist. It's problematic for minority communities especially. Because a lot of the behaviors that are recognized are the adaptive behaviors of white kids who probably have more access to space and stuff. And not the kid who's in a 2-bedroom apartment with 3 other kids. So, her teacher—her preschool teacher. I was actually talking to her because it was her best friend's birthday party, and she was actually delighted to learn—she's one of the most open people, most open educators that I've met. She was delighted to learn some of the ins and outs of red flags for autism in girls that age, that wouldn't have come up otherwise.

These layers of vulnerability, therefore, impact access to assessment and diagnoses, access to services and supports, and ultimately the empowerment needed to make decisions and confront injustices. When asked how educators and administrators could make a difference on this and other matters, participants recommended professionals become well versed in symptoms of autism in girls and women, and to believe and support them.

> We need the world to stop what they are doing and also make changes for people with autism. In the same way, we need people with autism to realize they may have to adapt some…I would tell educators to think about ways they have been different and treated differently and to believe us. We do need support and accommodations. We know they are busy. We know they are overwhelmed. We know the answer is also beyond them, but we all have to work together to fight this… We are out there. Girls and women with autism are not the stereotype. There is so much beneath the surface. We need your support. We need you to help us.

This help is needed in multiple areas to improve safety. It is noteworthy to point out that participants feeling safe and comfortable to share this information is important and critical, particularly since the aim of this study was to better understand school experiences. While trauma-based questions were not a part of the interview schedule for this study, it seems there is a strong need for continued research in this area if this study is any indication. A few other participants also shared about sexual abuse and sexual assault and domestic violence and it seems unfortunately the rates of trauma of all types are very high for persons with autism and other disability, potentially especially for females.

Implications

A review of the overall findings reveals that participants speak to multiple layers and intersections of vulnerability. This supports "Intersectionality Theory" as proposed by Dr. Kimberle Crenshaw (2017) in understanding the overlap in identity and the complexities and even vulnerabilities that can come from multiple forms of marginalization. Additionally, participants speak to systemic issues that impact and even foster this marginalization including (a) lack of accommodations; (b) lack of identification/diagnosis; (c) exclusion by educators; (d) unaddressed bullying; (e) lack of social and educational supports; and (f) being silenced on the sidelines (Gould, 2017). Many shared suggestions for school counselors and administrators including (a) using empathy; (b) believing autistic girls and women; (c) owning and becoming educated on autism in girls and women and how it presents differently; and (d) promoting strengths (as opposed to focusing on deficits and trying to get autistics to fit a mold). Some spoke of school as a means to learn how to navigate effectively in the world. However, they too voiced a need for schools to be safe spaces where others can learn to adapt and include those with differences.

Participants also reflected on ways to bridge gaps in the identification of autism in girls and women, hopefully contributing to earlier diagnosis in the future. Specifically, participants shared that social workers, school counselors, teachers, and other educators should receive training, in college or also on the job, on how autism presents in females. This includes understanding that girls may be less disruptive, may have more socially normative special interests, and may show higher levels of empathy/social awareness. Participants also shared how recognizing key signs, such as reticence, difficulty navigating social relationships, the vulnerability of being taken advantage of, difficulty reading others, social withdrawal, special interests, deep focus, and intense interests should all be indicative of signs of potential autism. Participants shared that sometimes co-occurring conditions could impact diagnosis as well, with one saying "They saw my ADHD so they didn't see my autism." Participants recommended education on the high level of overlap in both conditions. Also, at least based preliminarily on the findings of this study, autistic girls also have high rates of trauma.

In addition to education for educators and counselors, participants recommend increased education to pediatricians, family doctors, OBGYN specialists, and parents on autism symptoms. This would concern not just stereotypical early autism symptoms, such as delayed speech or regression in speech (APA, 2013), but also an understanding of how autism might present in females, specifically. Participants also suggest more normative social and cultural examples of females with autism in media of all forms to hopefully dispel myths and increase awareness.

Overall, the experiences of these study participants, and the suggestions that come from them, strongly point to the need for earlier and accurate diagnosis of autism. This suggests the need for intentional education of school counselors, mental health counselors, and school psychologists in the best evidence-based screening tools for detecting autism in girls. It is also important that educators, school social workers and counselors, and teaching assistants become educated and aware of the signs and symptoms of autism in girls and how and where they might refer for further evaluation. Autistic girls and women should be central to the development of this education. As noted by a number of the participants, it was difficult if not impossible for these women during their primary and secondary school years to identify and communicate what they were experiencing. Further complicating this were the challenges of interpreting the actions and interactions of others in ways that would facilitate "expected" responses or norms of behavior. This suggests the need not only for greater awareness but also intentional attentiveness to what is occurring within and beyond the classroom walls.

Considering additional support such as support groups, accommodations, and policies that enhance and nurture the social support and academic learning of autistic girls in schools is clearly needed. At the same time, a re-examination of existing policies and practices that may currently serve to punish behaviors that potentially are sensory seeking, sensory avoiding, or seeking emotional and cognitive respite from over-/underwhelming school environments may help to reveal ways that school systems might create more flex to serve not only this population of students but students more broadly who find themselves vulnerable in similar but distinct ways.

Though much can be drawn from the findings of this study, it is important to point to limitations as well, with a significant one being the sample size. There were fourteen participants in this study, with most of them attending primary school in the state of Indiana or surrounding states. Another potential limitation includes that the study scope itself was very broad, inviting participants to share about multiple aspects of school experience, both from a student as well as parent perspective (interacting with schools as a parent with autism). Also, not all participants are parents so not all were able to share about that aspect of school interaction. As previously mentioned, another limitation could include the choice to include only participants with a formal autism diagnosis and some may meet the criteria but may have financial or other barriers to receiving a diagnosis. Finally, but also critically important, participants in this study seemed to have high verbal language and cognitive abilities. Therefore, it is important to consider, explore, and include the experiences of autistic women with less advanced language skills or higher support needs to more fully understand autistic women's school experiences as well as diagnostic issues.

Even though there were limitations, much was gleaned from this study. Study participants shared deeply and openly about school experiences. Participants also represented a wealth of school experience (from k-12 with many also attending college) in a variety of school settings, including Montessori schools, intermittent periods of homeschooling, and public, and private schools. There is also great diversity in the sample for a predominantly white state such as Indiana, with 6 out of 14 participants identifying as other than white, and additionally a great amount of diversity in sexual orientation and age. Perhaps both a limitation and benefit include that participants shared about various generations of school experience, though despite generational gaps, participants shared similar challenges and gaps in support.

With findings and limitations in mind, there is much room for additional research in this focus area. Firstly, it seems important to consider and explore how we might broaden inclusion criteria to those who identify as autistic, whether or not they have been formally diagnosed. This study could be replicated with broader inclusion criteria and include a broader geographical area. It would also be interesting to know more deeply about specific school experiences for autistic girls and women currently still in school to see if additional changes have been or are being made. It would also be interesting to know what advocacy might be taking place by autistic persons or others in local schools to bring about change, though this study did not specifically explore this. Additionally, future research could further explore interpersonal and systemic trauma experienced by autistic girls and women. Exploration to identify cracks in the system and resource gaps is needed to better reach those who have been underserved. Future research could also delve into school personnel's understanding of and attitudes toward autism, particularly in girls and women. There are many avenues for future study to build on the knowledge and insight gained here from these participants.

Significance

This study illuminates the voices of those who are marginalized in multiple ways and have historically been a difficult-to-reach population of study. The latter results in poor representation in autism research. Thus, this study seeks to build from the knowledge, insight, and experience of autistic women and provide recommendations for educators, administrators, counselors, and school social workers in improving conditions of education for an often ignored group. It seeks to call attention to the need for action, based on the oppression and trauma shared by the autistic women of this study, and it seeks to not only highlight the need for change but insist upon it. Autistic girls and women have struggled, sometimes lifelong, to obtain a diagnosis and get the necessary support. Many do so while enduring unhealthy and abusive friendships and relationships, being sandwiched into a school system where they didn't feel they belonged, and living with autism without guidance on how to cope. They also have many individual strengths—many referencing the "superpower" aspect of autism, this term being directly used by multiple participants, though it is not to minimize challenges. Individual strengths and what they bring to the table cannot be ignored. Autistic girls and women should have the chance and capacity to operate at their best level, with strengths nurtured, while also being safe and respected. It is the call of this paper to elevate these critical issues and to suggest ways, as informed and as rooted in the words and experiences of autistic women, how change may indeed occur.

Interview schedule

You were selected to participate in this interview because there is a very limited understanding of women diagnosed with autism. In particular, we don't know much about their experiences with schools and schooling. Your experiences, memories, and reflections on your schooling will help us to better understand and, hopefully, improve schooling for young girls.

Please bring something with you that has special significance from your school days (object, picture, etc.). Please share with me about your chosen object/picture and why this has significance to you.

What other memories stand out to you when looking at your object? What feelings?

Elementary school experiences. Elementary school

I would like for you to think back to elementary school. Please share some about your elementary school. Think back to your sensory experiences (feel free to look at your chosen photographs to help stimulate memory). What sounds, sights, smells, and textures stood out to you? Think about academic spaces (classroom, library, etc.) and non-academic spaces (cafeteria, gym, playground, etc.), what did these different spaces feel like for you? Were there spaces at school where you felt more comfortable/less comfortable? Could you tell me about this?

How would you describe yourself as a student?

What were your relationships like with classmates? Tell me about your closest peer relationships. Tell me about any especially difficult relationships with your peers.

What were your relationships like with the adults at school? Tell me about adults who you felt especially close to, if any. Tell me about any especially difficult relationships with adults in the schools.

Did you receive any academic or social support during elementary school? If so, please describe and explain.

Did you engage in extracurricular activities associated with your elementary school (sports, etc.) and, if so, could you tell me a little about this?

Middle school experiences. Let's reflect a little on middle school. Could you share some about your middle school experience?

Think back to your sensory experiences. (Again, feel free to look at your chosen pictures you brought with you to help stimulate memory). What sounds, sights, smells, and textures stood out to you? What about the cafeteria or gym? What was free time/study hall like for you? Were there spaces at school where you felt more comfortable/less comfortable? Could you tell me about this?

How would you describe yourself as a student in middle school?

What were your relationships like with peers? Can you tell me about your closest peer relationships during this time? Tell me about any especially difficult relationships with your peers.

What were your relationships like with the adults at school? Can you tell me about adults who you felt especially close to, if any? Tell me about any especially difficult relationships with adults in the school.

The transition between schools is often described as challenging, how did the transition from elementary to middle school go for you?

Did you receive any academic or social support during middle school? If so, please describe and explain.

Did you engage in extracurricular activities associated with your middle school (sports, etc.) and, if so, could you tell me a little about this?

High-school experiences. Let's reflect a little now on high school. Could you share some about your high school experience?

What sounds, sights, smells, and textures stood out to you? What about the cafeteria or gym? What was free time/study hall like for you? Were there spaces at school where you felt more comfortable/less comfortable? Could you tell me about this?

How would you describe yourself as a student in high school?

What were your relationships like with peers? Can you tell me about your closest peer relationships during high school? Tell me about any especially difficult relationships with peers during this time.

What were your relationships like with the adults at school? Tell me about adults who you felt especially close to. Tell me about any especially difficult relationships with adults in the school.

Looking back, do you think there are other ways autism may have impacted your school experience?

As with elementary to middle school, middle-to-high school transitions can be challenging. How did the transition from middle to high school go for you?

Did you receive any academic or social support during high school? If so, please describe and explain.

Did you engage in extracurricular activities associated with your high school (sports, etc.) and, if so, could you tell me a little about this?

Overall schooling experiences. Tell me about a time that you really loved school. Tell me about a time when you really hated school.

Tell me about a time when you felt you really belonged in school. Tell me about a time when you felt really out of place in school.

As you reflect on your overall schooling experiences, do particular individuals (within or outside of the school), programs, events, or anything else stand out as having been key in your ability to navigate schools? If so, please tell me about them.

Looking back, do you think there are ways autism may have impacted your school experiences? Please describe.

Autism diagnosis and college. At what age did you receive your autism diagnosis? Can you tell me about that, please? What lead to the diagnosis? How, if at all, has the diagnosis changed things for you?

Have you been in school since your diagnosis? If so, in what ways has the diagnosis been a part of your schooling experiences?

Have you attended college? If so, please share with me the positives and challenges of your college experience. Did you stay in a dorm or commute to campus? How would you describe peer relationships in college? Did you have stable housing and finances? Tell me about how you managed your course schedule and assignments. Can you tell me a little bit about the transition to college?

Parenting and school experiences from a parent perspective. Do you have children? If so, tell me about your interactions with schools from a parent's perspective. Please describe.

Has/Have your child/ren been diagnosed with autism?

Given your own experiences, what kind of parental advice do you give to your child/ren as they navigate school? Relationships with peers and teachers?

Based on your experiences in schools, what advice would you give to teachers, administrators, counselors, and other faculty about how to provide better schooling for kids like you?

Demographic survey. Where they grew up; family background (education, siblings, others in the family diagnosed with autism, participant education level); types of schools attended (public, parochial, private, etc.); race/ethnicity; age; gender identity.

Data availability

Due to this being a small sample in a rural area and also a potentially vulnerable population, we prefer to not share data directly unless required. This protects the confidentiality and safety of participants, particularly since some shared about traumatic life circumstances.

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Author contributions

The primary author created the initial draft of qualitative interview questions as well as additional interview questions (beyond the pilot). The primary author also completed qualitative interviews and completed transcription as well as reflexive journaling and data analysis and composed the first draft of this paper. The second author assisted with the theoretical development of the paper, assistance and guidance in qualitative research design and interview question development, and consultation as needed. The second author also assisted with data analysis for data triangulation and assisted in contributing to and editing drafts of the paper.

Competing interests

The authors declare no competing interests.

Ethical approval

This exempt study was approved and ethical approval was obtained by the Indiana University Institutional Review Board. This study was performed in line with the principles of the Declaration of Helsinki.

Informed consent

Informed consent was obtained from all participants. Participants received copies of the informed consent document and study information sheet for their review and had the option of phone or video discussions with the primary researcher to answer questions and determine if they would like to engage in the study. All participants were fully consenting and competent adults.

Additional information

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