

Comparing the Severe Mental Health Experiences of Adults with Autism Spectrum Disorder

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Abstract:

The purpose of this mixed-methods study was to explore risk and protective factors for severe mental illness (SMI) among clinically and self-diagnosed autistic adults ($n = 11$), comparing those diagnosed in childhood with those diagnosed in adulthood. It also explored participants' perceptions of existing mental health care (MHC). Quantitative data were collected using the PHQ-9 and GAD-7 and analyzed through descriptive statistics, correlation analysis, ANOVA, and t-tests; qualitative interview data were thematically analyzed. No significant relationship was found between age of autism diagnosis and severity of depressive or anxiety symptoms. However, participants with support systems reported higher anxiety levels, suggesting these supports may not fully meet their needs. Key protective factors included community support and access to MHC. Barriers to MHC included obtaining a clinical diagnosis, early termination of care, and provider knowledge gaps. Limitations included small sample size and lack of control group. Suggestions include increasing social worker knowledge about ASD and policy advocacy. Further research should prioritize effective mental health interventions for autistic adults.

Introduction:

Autistic adults* have a fivefold increased risk for suicidal ideation (Brown et al., 2024). However, current studies on the population do not explore co-occurring disorders that manifest as SMI, i.e., any mental illness that seriously impacts functionality and interferes with one or more major domain of life (National Institute of Mental Health [NIMH], 2024). This poses a concern as approximately 2.21% of adults, or 5,437,988 individuals, in the United States have ASD (Centers for Disease Control and Prevention [CDC], 2024a). Moreover, children are being diagnosed with ASD at an increasingly exponential rate. In 2000, approximately 1 in 150 eight-year-old children were diagnosed with ASD; by 2020, however, 1 in 36 eight-year-old children were diagnosed with ASD (Centers for Disease Control and Prevention [CDC], 2024b). The implication, then, is that the rate of adults with ASD will also exponentially increase in due time, as will adults with ASD experiencing co-occurring mental health challenges.

*This thesis uses identity-first language to minimize stigma (Gernsbacher, 2017).

Methods:

This study used mixed methods to address the following research questions:

1. Is there an association between age at time of ASD diagnosis and severity of presenting mental health concerns?
2. What, if any, association is there between age at time of ASD diagnosis and gender?
3. Is there a relationship between identified support systems and the severity of mental presenting health concerns?
4. What protective factors exist for severe mental illness among adults diagnosed with ASD?
5. How do autistic adults perceive existing mental health care?

The study was approved by the CSULB IRB. 11 individuals participated in the current study. Participants were 18 years of age or older, clinically or self-diagnosed with autism, resided in the United States, did not exhibit current symptoms of psychosis, and spoke English. The researcher's personal social network, i.e., Instagram, was used to recruit participants. The Bob Murphy Access Center (BMAC) at CSULB also advertised the study via mailing list to recruit additional participants.

Potential participants were screened via phone call. Eligible participants were sent the informed consent form and quantitative survey, to be reviewed and completed at their own pace. Participants provided verbal consent and were interviewed via Zoom or phone call. Interviews consisted of 13 questions, lasted 30-90 minutes, and were transcribed using Otter.ai; survey data were downloaded securely to IBM SPSS Statistics software. Participants were compensated with a \$15 gift card to a retailer of their choice, contingent on answering at least 11 interview questions.

Results:

- No significant relationship between age at time of diagnosis and severity of mental health concerns (Table 2 & 3)
- No significant difference in age at diagnosis among genders (Tables 4 & 5)
- Positive relationship between support systems and GAD-7 score (Tables 6 & 7).
 - Implication: personal support systems do not meet autistic adults' needs.

TABLE 1. Sociodemographic Characteristics of Participants ($n = 11$)

Demographics	<i>f</i>	%
Gender		
Cisgender female (assigned female at birth, identifies as female)	7	64%
Cisgender male (assigned male at birth, identifies as male)	2	18%
Nonbinary/gender non-conforming (does not identify as male or female)	2	18%
Race/Ethnicity		
White	3	27%
Hispanic or Latino	6	55%
Asian	2	18%
Sexual orientation		
Heterosexual	4	36%
Bisexual/Pansexual	6	55%
Asexual	1	9%
Primary source of income		
Work	8	80%
SSI	1	10%
Familial support	1	10%
Missing/Unknown	1	10%
Relationship status		
Single	5	46%
In a relationship	4	36%
Married	2	18%
Housing arrangement		
Rent	2	18%
Own	3	27%
Stay with friends/family	4	36%
Other	2	18%

TABLE 2. Information on Diagnosis ($n = 11$)

Demographics	<i>f</i>	%	Mean	SD
Age of Diagnosis			22.36	12.52
Clinically Diagnosed	7	64%		
Self-Diagnosed	4	36%		

TABLE 3. Correlations ($n = 11$)

	Age of Diagnosis	PHQ-9 score	GAD-7 score
Age of Diagnosis			
Pearson Correlation	1	-.255	.187
Sig. (2-tailed)		.449	.582
PHQ-9 score			
Pearson Correlation	.11	1	.537
Sig. (2-tailed)	.449		.089
GAD-7 score			
Pearson Correlation	.187	.537	1
Sig. (2-tailed)	.582	.089	
N	11	11	11

TABLE 4. Descriptive Statistics ($n = 11$)

Age of Diagnosis	<i>M</i>	<i>SD</i>
Cisgender female (assigned female at birth, identifies as female)	27.71	12.13
Cisgender male (assigned male at birth, identifies as male)	11.0	9.89
Nonbinary/gender non-conforming (does not identify as male or female)	15.0	4.24
Total	22.36	12.51

TABLE 5. ANOVA

	Sum of Squares	<i>df</i>	Mean Square	<i>F</i>	<i>p</i>
Between Groups	567.117	2	283.558	2.27	.166
Within Groups	999.429	8	124.929		
Total	1566.545	10			

TABLE 6. Group Statistics ($n = 11$)

Support system	<i>n</i>	Mean	Std. Deviation	Std. Error Mean
PHQ-9 score				
Yes	7	12.14	5.11301	1.93
No	4	10.00	5.77	2.88
GAD-7 score				
Yes	7	12.14	4.61	1.72
No	4	6.00	3.16	1.58

TABLE 7. Independent Samples Test

			Support System			95% Confidence Interval of the Difference
		Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
PHQ-9 score	Equal variances assumed	.538	2.14	3.34	5.43183	9.71754
GAD-7 score	Equal variances assumed	.042*	6.14	2.59	.26141	12.02431

*Significant at $p < .05$ level.

- 73% of participants reported previous mental health crises; 36% reported previous suicide attempt(s).
 - 55% of participants engaged in maladaptive coping skills during mental health crises.
- 82% of participants reported struggling with emotional regulation due to ASD. *"It's like constant PMS."* – Chelsea, 26
- Reported protective factors against SMI:
 - History of supportive community
 - Current mental health care
 - Personal resilience
 - Structured social environments*"I did my masters. Loved it. It gave me purpose again. It gave me focus. It gave me something to do."* – Fatima, 34
- 82% of participants reported a history of positive mental health care experiences. Reported barriers to care included:
 - Difficulty obtaining clinical diagnosis
 - Premature termination of services
 - Knowledge gaps among practitioners
 - Internalized stigma*"It should be made easier to get diagnosed."* – Jessie, 35
- 27% of participants emphasized diversity within the autism spectrum; 55% called for a wider understanding of ASD. *"We're people just like everybody else...I just kind of wish that at this point in time, people would just view me as just another person, just with, you know, that's a little bit different."* – Rhea, 23

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Implications:

Implications for Social Work Practice

Based on the current study, autistic adults reported generally positive mental health care experiences. However, most participants in the study had experienced mental health crises and over a third had attempted suicide. Moreover, over half of the sample engaged in maladaptive coping skills during mental health crises. This implies that current mental health care is not adequately tailored to autistic adults' needs.

With autism diagnoses among children increasing yearly, it is likely that a clinician will eventually work with an adult client either clinically or self-diagnosed with ASD. Like so, it is crucial for clinicians to inform themselves of mental health struggles and risks unique to autistic adults to best inform their practice going forward with these clients.

Implications for Policy

This research identified higher education as a support system for some autistic adults. In the first month of his presidency, President Donald Trump has remarked that he plans to dismantle the U.S. Department of Education. This action would result in, among other consequences, the abolition of federal student aid and an increase in the costs of higher education (Walker, 2025). In turn, autistic adults who depend on financial aid would be deprived of a support system.

If autistic adults enrolled at a higher education institution are unable to finish their schooling due to increased costs, the sudden change in routine may be distressing and result in increased mental health symptoms. Social workers should therefore advocate to protect the Department of Education by writing to their elected legislators and working with NASW to achieve advocacy for autistic adults, who already face significant challenges.

Implications for Research

Suggestions for future research include exploring effective interventions for this population and ways to establish psychoeducation among clinicians and the public on adult autism.

Conclusions:

Findings of the current study indicated that autistic adults have elevated rates of mental health concerns. Having established support systems was identified as a protective factor against severe mental illness but can lead to increased rates of anxiety symptoms. Mental health care experiences overall are generally positive for autistic adults, but existing mental health care can be improved by educating clinicians on ASD, especially among the adult population, and modifying existing mental health interventions for the autistic population.

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