

# Access and Utilization of Mental Health Services Among Autistic People

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## INTRODUCTION

- Autism Spectrum Disorder is often associated with co-occurring psychiatric conditions (e.g., anxiety, depression, PTSD), this could be as high as 70% in autistic youth vs. 25% of non-autistic youth [22, 23, 28, 35, 50]. Consequently, many people remain undiagnosed or misdiagnosed [3, 5, 17, 33, 34, 48].
- Although autistic people have a higher risk of mental health (MH) problems, affordable and appropriate healthcare is often inaccessible [16].
- This literature review was conducted to identify knowledge gaps and summarize recent research findings.

## METHODS

- Searched for relevant articles using Google Scholar, PubMed, & PsycINFO databases.
- Our search strategy included (1) terms for autism spectrum disorder, (2) terms for MH, and (3) terms for psychological interventions. On Feb. 6, 2023, the researchers conducted an initial search, followed by a second search on Mar. 16, 2023.
- Inclusion criteria included: (1) mental health focus (e.g., anxiety, depression, ADHD); (2) sample size greater than 10. Exclusion criteria included (1) targeting non-mental health conditions or symptoms (e.g., social skills, sensory sensitivities, core symptoms of ASD) as the primary target; (2) if the article was older than 15 years.

## RESULTS

- Autistic MH research has made remarkable strides in recent years. Many autistic individuals feel the mental health system has fallen short; many however receive high-quality neuro-affirming care regularly.
- The availability and utilization of these services are hindered by a number of barriers and roadblocks. It is also important to note that providers face numerous obstacles when providing services to autistic clients. Changes on a systemic level take time, but some steps can be taken immediately.

**Table 3.** Types of support received and would ideally have liked, stratified by sex.

Support	Currently receive support			Would ideally like support		
	Male (n = 60)	Female (n = 99)	Total (n = 159)	Male (n = 61)	Female (n = 101)	Total (n = 162)
Mental health care	13 (21.7%)	22 (22.2%)	35 (22.0%)	33 (54.1%)	66 (65.3%)	99 (61.1%)
Mentoring	9 (15.0%)	10 (10.1%)	19 (11.9%)	33 (54.1%)	101 (67.3%)	101 (62.3%)
Social activities	5 (8.3%)	7 (7.1%)	12 (7.5%)	29 (47.5%)	53 (52.5%)	82 (50.6%)
In the home	7 (11.7%)	10 (10.1%)	17 (10.7%)	15 (24.6%)	31 (30.7%)	46 (28.4%)
Employment	5 (8.3%)	6 (6.1%)	11 (6.9%)	33 (54.1%)	40 (39.6%)	73 (45.1%)
Health care	6 (10.0%)	8 (8.1%)	14 (8.8%)	16 (26.2%)	30 (29.7%)	46 (28.4%)
Finance	5 (8.3%)	6 (6.1%)	11 (6.9%)	20 (32.8%)	40 (39.6%)	60 (37.0%)
In the community	4 (6.7%)	8 (8.1%)	12 (7.5%)	15 (24.6%)	25 (24.8%)	40 (24.7%)
Organization	1 (1.7%)	4 (4.0%)	5 (3.1%)	16 (26.2%)	50 (49.5%)	66 (40.7%)
Education	5 (8.3%)	13 (13.1%)	18 (11.3%)	19 (31.1%)	39 (38.6%)	58 (35.8%)
Other	5 (8.3%)	14 (14.1%)	19 (11.9%)	17 (27.9%)	13 (12.9%)	30 (18.5%)

Camn-Crosbie et al., 2019

**Table 2.** Comparison of treatments participants received or were currently receiving to treatments participants needed but had not received, stratified by sex.

Treatments	Treatments previously received/currently receiving			Treatments previously/currently needed but not received		
	Male (n = 65)	Female (n = 99)	Total (n = 164)	Male (n = 8)	Female (n = 21)	Total (n = 29)
Mental health	56 (87.5%)	91 (93.8%)	147 (91.3%)	6 (75.0%)	17 (81.0%)	23 (79.3%)
Self-injury	7 (10.9%)	20 (20.6%)	27 (16.8%)	0 (0.0%)	7 (33.3%)	7 (24.1%)
Thoughts of ending life	17 (26.6%)	38 (39.2%)	55 (34.2%)	5 (62.5%)	8 (38.1%)	13 (44.8%)
Other	13 (20.3%)	18 (18.6%)	31 (19.3%)	3 (37.5%)	3 (14.3%)	6 (20.7%)

Camn-Crosbie et al., 2019

## BARRIERS & ROADBLOCKS

- “Punting” between different “Silos of Care”
- Reluctance to work with Autistic Individuals
- Financial Constraints
- Exclusion in Research



“Should I concentrate on something else?”  
 “How do we affect change when we only see this individual one hour a week?”  
 “Should I just give up on this...”  
 “a lot of what seems to work with other children doesn't work with autistic children”  
 “Am I going down the wrong path here...”

## AUTISTIC INDIVIDUALS EXPERIENCES WITH MENTAL HEALTH SERVICES

- Symptoms dismissed
- Negative experiences with clinicians
- Needs not met
- Not all experiences were negative

“I felt like I was having a breakdown inside but I didn't know how to make the inside feelings show to other people.”  
 “I haven't requested any, because people like me don't get support. Any time I have enquired about such things that has been made very clear.”  
 “I tried to kill myself and I was really f\*\*\*ed up and need counseling. The wait list was nine months. I could not wait nine months... I only got through that period by abusing drugs.”  
 “I often don't realize just how bad things have become. In the last year I have started thinking about suicide, even though I don't want to die, and that has been the thing that made me realize how bad things might be.”  
 “... Some people don't think you can really be struggling if you are in university/working but dropping my routine would be even worse.”  
 “If I had not been able to borrow money to see a therapist privately, I would still be living a nightmare full of untreated anxiety and self-hatred because I thought it was my fault I was different.”  
 “CBT was more effective than I had thought it would be. It explained my thought processes and why I behaved the way I did.”

## POSITIVE ADVANCES & FUTURE OUTLOOK

- Considerable increase in MH and Implementation Research for Autism across the lifespan
- Growing Evidence for MH Interventions
- Need focus on translation of research to community based practices.

## PRACTICAL CHANGES

- Advocate for change in the workplace
- Thoughtful Language Choices
- Individualized Approach
- Leverage Strengths
- Actionable Steps

## DISCUSSION

- Based on the articles reviewed the results indicated that addressing the co-occurrence of Autism and MH problems is important.
- It is encouraging to see the recent advancements in MH services and implementation research for Autistic individuals. However, significant gaps remain in the accessibility and quality of MH for autistic individuals, particularly those from racial/ethnic minorities and low-socioeconomic families.
- It is important to note that many have positive experiences with their MH providers.

## FUTURE DIRECTIONS

- Design evidence based interventions for community based implementation.
- Strengthen the MH workforce.
- Promote for restructuring policies.
- Advocate for systemic changes.

## ADDITIONAL CONTENT

- This poster utilizes identity-first language throughout, as this is the most widely endorsed preference among autistic individuals [32].
- Cervantes and colleagues (2022) reported that clinician participants received the most miniature training for identifying suicide risks among individuals with Autism Spectrum Disorder and co-occurring mental health disorders.

**Table 1** ASD training history

	N = 16	M (SD)
<b>Training areas</b>		4.06 (0.68)
Recognizing and diagnosing ASD		4.00 (0.63)
Recognizing and diagnosing comorbid mental health disorders in youth with ASD		3.63 (0.81)
Screening for and identifying suicide risk in youth with ASD		3.94 (0.57)
Delivering intervention for the treatment of ASD symptoms		3.81 (0.75)
Delivering intervention for the treatment of comorbid mental health disorders in youth with ASD		3.63 (0.81)
Managing and intervening on suicide risk in youth with ASD		3.69 (0.70)
Coordinating care for patients with ASD across providers and service systems		26.75 (4.29)
<b>Total ASD training score</b>		

Cervantes et al., 2022

