

# Barriers to Mental Health Services for Autistic People

## What We Found

*Autistic peoples' mental healthcare needs are not well met, due to a range of logistical barriers, absence of specialist knowledge, and lack of individualised treatment pathways.*

### 1. Logistical Barriers

*Nobody's Problem:* there is a disconnect between mental health services and other branches of healthcare, preventing direct referrals for autistic people. Sometimes this comes down to practical issues, like who is allowed to access parts of an electronic health record.

*Referral and Availability:* Self-referral can be difficult for autistic people and / or their families to prioritise. Stigma also prevents autistic people from proactively seeking support. Some services require dual referral from two sources, or eligibility based on long-lasting mental illness. Even when referral is achieved, services can be far away, expensive or have long waiting lists.

### 2. Lack of Knowledge

*Diagnostic Uncertainty:* clinicians and autistic people were frequently confused between symptoms of mental illness and features of autism, and unsure about what mental health care was needed. Autistic expressions of emotion were often misinterpreted by clinicians, meaning serious mental health problems were missed. This reduced patient-doctor trust.

*Treatment Issues:* clinicians felt it was unlikely that autistic patients' mental health could improve and so they did not challenge them. Clinicians also reported feeling unconfident when making treatment recommendations for autistic patients, and everyone agreed more training would help. Autistic people needed more time for interpersonal interventions to build a therapeutic rapport. Finally, clinical settings often caused sensory overload.

### 3. Individualised Care

Autistic people wanted more attention paid to their preferences, and often withdrew from care if these were ignored. Individualised care is linked to empowerment, autonomy and inclusion. Services for children were perceived as more joined-up and individualised.

## What We Suggest

Autism care should be centralised, or inter-agency communication improved, to make care more accessible.

Physicians lack autism knowledge and so training should be available to improve knowledge and combat stigmatising and outdated beliefs.

Autistic people should be provided with more information to encourage them to recognise the signs of mental ill-health and advocate for their care.

Guidelines exist on how to tailor care to autistic patients, but these are under-utilised. The reasons why need to be better understood, so they can be overcome.

*Some solutions require structural changes, but there's also potential for improvements based on clinical training, patient information and better use of existing resources*

## What We Did

*Our analysis of barriers to mental health care for autistic people drew exclusively on qualitative data, from interviews, focus groups and surveys.*

This policy briefing is based on an undergraduate student project completed in 2022.

The student searched for papers with qualitative data, in which barriers for autistic people seeking and getting treatment for mental health problems were discussed. Initially 1473 results were found and screened, and 14 papers were identified as having relevant information for this review.

Of these papers:

- two reported on information collected from clinicians
- one reported on data from prison workers (the focus was on mental health care for incarcerated autistic adults)
- three reported on information provided by parents of autistic young people
- the remaining eight all reported on information collected from autistic people.

While autistic people are the authorities on their healthcare experiences, the diversity of perspectives included in this review strengthens the conclusions and increases relevance to a range of readers.

The papers were read through and the student used a thematic analysis process to identify common themes across multiple papers. The themes were initially descriptive, and largely dictated by what information was present in the original papers. They were then refined to generate theme labels which were pertinent to our research question – namely, what are the barriers to accessing mental health care for autistic people?

## Why We Did It

*Autistic people experience very high rates of mental health problems and there is also strong evidence that they find healthcare inaccessible*

There are high rates of mental health issues in autistic populations, with estimates as high as 72.5% having one or more psychiatric diagnoses as well as autism [1]. Consequences of this can be severe, including high rates of suicide amongst autistic people [2] and large numbers of autistic people stuck in inappropriate long-term hospital placements [3].

There's also substantial evidence that autistic people find healthcare inaccessible [4].

## Thank you

1. Abdallah, M. W., Greaves-Lord, K., Grove, J., Nørgaard-Pedersen, B., Hougaard, D. M., & Mortensen, E. L. (2011). Psychiatric comorbidities in autism spectrum disorders: findings from a Danish Historic Birth Cohort. *European child & adolescent psychiatry*, 20, 599-601
2. Hedley, D., & Uljarević, M. (2018). Systematic review of suicide in autism spectrum disorder: current trends and implications. *Current Developmental Disorders Reports*, 5, 65-76
3. Read, M. (2024). Transforming Care: supporting people with learning disabilities, autism and mental health issues to move out of long-stay hospitals. *Learning Disability Practice*, 27(2)
4. Calleja, S., Islam, F. M. A., Kingsley, J., & McDonald, R. (2020). Healthcare access for autistic adults: A systematic review. *Medicine*, 99(29), e20899

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