

# POLICY BRIEF

## IMPROVING ACCESSIBILITY OF MENTAL HEALTH SUPPORT FOR ADULT AUTISTIC INDIVIDUALS WITHIN PRIVATE PSYCHOTHERAPEUTIC SERVICES

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### Executive Summary:

- The private psychotherapy field does not currently have sufficient policy to facilitate the ethical and meaningful therapeutic support of autistic clients.
- Policy, research and training must be led by autistic voices and suitably responsive and meaningful.
- Feedback highlighted the need for policy to include an understanding of acceptable terminology, the right of individual autonomy, the importance of adequate training, making the environment accessible, improving communication, building effective therapeutic relationships, and making complaint and safeguarding processes meaningful.

### Introduction

Around 1% of the population in the United Kingdom meet the criteria for Autism Spectrum Condition (ASC) [1,2,3] although recent trends show an increase in autism diagnosis, possibly due to equalisation of diagnosis within female, adult, and minority community demographics [4,5]. Autism is clinically characterised by persistent social deficits, repetitive behaviour or interests, and sensory difficulties [6,7]. Autistic individuals also experience significant mental health comorbidities, especially anxiety and depression [8] and misdiagnosis of mental health conditions such as personality disorders are frequent, especially in autistic women [9, 10]. Following their survey, the All Party Parliamentary Group on Autism [11] reported that 76% of autistic adults reached out for mental health support in the preceding five years with 82% saying that getting support from services took too long. Only 14% of participants said that there was sufficient support available in their area and many reported that the support offered was inappropriate to their needs. The inadequate and inappropriate support options within the National Health Service (NHS) is a common point of feedback [1,12,13,14,15]. In 2018 the Counselling Directory noted a 22% increase in enquiries for private counselling<sup>16</sup>, which aligns with the general increased demand for mental health support in the UK [17].

## Key Points:

- The autistic community understand the barriers they experience to accessing mental health support and can clearly express their needs.
- There is a significant expression of distrust towards mental health services from the autistic community
- The most common concerns expressed are lack of support options, absence of knowledgeable staff and therapists, and a failure to understand autistic traits and difficulties such as shut-down and meltdown responses
- Many participants requested an investment in offering autistic therapists and support staff.
- Some participants reported being turned away from NHS services specifically due to their autism diagnosis and having to access private support instead.
- Sensory, cognitive and mobility issues are frequently experienced as unsupported.
- Communication needs are often unsupported and few alternatives offered in services.
- Participants expressed a fear of speaking up or complaining due to risk of punitive discharge or withdrawal of service.

Well In Mind Therapy (WIM) is an autistic owned private counselling service offering psychodynamic, person-centred, and integrative therapists, as well as Cognitive Behavioural Therapy (CBT) and Eye Movement Desensitisation and Reprocessing (EMDR) support. While online services are available, requests for support are primarily for in-person sessions. Since 2020 we have seen a marked increase in demand for autistic affirmative support and currently 20% of our client base is autistic. Service in-session feedback from clients however highlighted some inadequacies in accommodating autistic needs. We realised that the service had to make changes and that an autism support policy was urgently required to standardise our quality of care. As a service whose members are all registered with the British Association for Counselling and Psychotherapy (BACP), the largest registration body for therapists [18], we were surprised to realise that they offered no policy or guidance for working in private practice with autistic people. In fact, none of the professional registration bodies did. It is clear that an autism led policy is urgently required within the field of private psychotherapy. As a service WIM has drafted the Policy for Affirmative Psychotherapeutic Autism Support (PAPAS) for implementation within our own service. This policy brief aims to highlight the importance of policy guidelines within private psychotherapy services and encourage professional registration bodies such as the BACP and other private therapists to utilise it as a starting point for drafting a shared industry policy, thereby holding itself to the same expectations as the NHS [19] for outcome based, service-user informed policies and guidance.

## Survey Parameters and Limitations

Aligning with the ethos of “nothing about us without us” [20], a core tenet of the disabled community and held closely by the autistic community [21], we approached the autistic community directly for feedback. A survey was drafted considering various barriers to therapy and offering feedback opportunity.

The questionnaire consisted of 38 questions and was made available online using a free to access Google form. No identifying data was requested. The link to the survey was offered to 4 online autism support groups and 1 online forum. 2 groups declined participation, citing member exhaustion with research and demands to 'educate professionals', while 2 groups and the forum participated. In total there were 38 participants that completed the survey. There are definite limitations to the process. Feedback was limited to online participation only, which would exclude anyone without internet connection or computer literacy. One group was limited to members who identified as women and consequently this would affect the participant demographic.

**Table 1**

*Respondent feedback summary*

Co-morbidity/Cognitive difficulty	% of respondents	n = 38
Autistic	100%	
ADHD	58%	
Sensory Processing Disorder	18%	
Learning Difficulties	3%	
Non-verbal expression (intermittent)	24%	
Dyslexia	8%	
Deafness	3%	
Executive Function Disorder (EFD)	79%	
Time Blindness	29%	
Prosopagnosia (face blindness)	37%	
Eye Contact Aversion	61%	
Memory Problems	58%	
Alexithymia	61%	
Dyspraxia	3%	

## Survey Outcomes:

### Participant Demographics & Support Needs

Participants were primarily between the ages of 25 to 45, with 26% being in the age group 41-45. 71% of respondents were female, a possible reflection of the listing limitations. 92% of respondents were white and 8% identified as British Asian, possibly correlating to the underdiagnoses of autism within ethnic minority communities [22,23,24].

Reported co-morbidities and cognitive impairments can be seen in Table 1. Estimates of comorbid ADHD in ASC vary from 30% to 70% [25,26,37]. ADHD often presents with impairment in executive functioning (EFD), time perception, and inhibition control [27,28]. These cognitive difficulties not only impact an autistic person's ability to access therapeutic environments, but also affect the process of building therapeutic relationships.

21% of respondents have difficulty being seated for extended periods and 16% needed support with mobility. There appears to be a significant co-morbidity between autism and hypermobility spectrum disorders such as Ehlers-Danlos Syndrome (EDS) [29,30,31] which might affect comfort and cause chronic pain.

All participants reported having sensory difficulties as can be seen in Table 2. Sensory hyper- and hyposensitivity are key features of ASC clinical descriptions [32,33] and studies suggest that sensory hypersensitivity might underly the autistic demand for sameness [34]. These can make it very hard to access new environments or build relationships with new people.

**Table 2***Respondent feedback summary*

Sensory Difficulties	% of respondents	n = 38
Sound	97%	
Visual	66%	
Touch	55%	
Smell	50%	
Vestibular	5%	

There was also significant feedback regarding the lack of appropriate services available to support autistic patients, the need for less manualised approaches and the importance of valuing the autistic lived experience. Some respondents reported being turned away from mental health services upon disclosing their autism diagnosis and expressed their sense of abandonment after diagnosis. 53% of respondents attended therapy through the NHS while 37% attended private therapy. Only 8% of respondents did not attend any therapy to date. Some reported having attended NHS therapy, but then pursuing private sessions subsequently.

### Accommodation & Responsiveness

What is clear from the survey feedback is that the autistic community perfectly understand both the barriers to accessing meaningful support and the adaptations that will overcome these obstacles (see Table 4).

Additionally, they are very well able to express their experience and their needs, but often felt that their lived experiences were discarded in favour of untrained professionals' opinions or disbelief. While the most significant request made was for the adequate training of professionals, it is evocative to note that the appeal for empathy and patience was made 31 times.

### Barriers to Accessing Support

Feedback consistently expressed the experience of autistic people feeling unsupported and misunderstood (see Table 3), with most frustration relating to lack of trained providers and the limited understanding of autistic traits.

**Table 3***Summary of barriers to accessing support*

Barriers	Number of mentions	n=38
Lack of Family Support	2	
Lack of Professional Knowledge	21	
Inappropriate Communication Methods	8	
Overstimulating Environments	4	
Lack of Adjustments	1	
Communication Barriers	6	
Inappropriate Therapy Options/No Therapy Options Available	20	
Failure to value autistic lived experience	7	
Failure to understand autistic traits / Lack of training	33	
Not client led	3	
Limited / short sessions offered	3	
Manualised / CBT approaches unsuitable to autism	9	
Failure to offer options / choice	1	
Failure of continuity / consistency	1	
Lack of consistent empathy / Failure to build positive therapeutic relationship	8	
Lack of lived experience / Insufficient autistic led providers	3	
Resistance to autism diagnosis	2	

## Complaints & Safeguarding

Responsive complaints processes ensure that services remain customer focussed [35]. It is the service user's opportunity to influence change and voice their needs.

Table 4

Summary of accommodation/access requests

Accommodations/Suggestions	Number of mentions	n=38
Invest in appropriate services		1
Empathy & Patience		31
Alternative therapies to CBT		18
Alternative communication support / adaptations		19
Sensory friendly & de-medicalised environments		25
Staff & providers adequately trained / experienced in working with autism		50
Relationship continuity		3
Openness to lived experience		14
Employing autistic providers		15
Accommodate mobility & pain needs (comfort / pacing / etc)		2
Accommodate sensory needs (fidget toys/sensory stimulation)		3
Offer visual resources / written summaries / homework		??
Understand & accommodate autistic traits		7
Reduce eye contact		3
Empower with choices		3
Show active listening & check understanding		7
Text reminders of appointments		4
Build strong therapeutic relationship / Relationship continuity		3
Trauma informed Approach		3

Table 5

Summary of barriers to complaints & safeguarding

Barriers to safeguarding	% of respondents	n = 38
Seeming overwhelmed by disclosure		5%
Unresponsive until crisis		5%
Inappropriate support/remedy offered		5%
Feeling judged		3%
Disregarding distress		3%
Fear of repercussion		8%
<b>Barriers to complaints</b>		
Lack of independent processor		5%
Unresponsive to complaint		3%
Offering no meaningful solution		3%
Process too difficult		5%
Unable to self-advocate		8%
Fear of repercussion		5%

## Summary

Autistic people have significant need for mental health support, but face unique challenges in accessing physical environments, being understood by adequately trained therapists, and having their lived experiences valued with empathy. They have expressed the need for services and approaches that are adaptable, knowledgeable, autistic led and meaningful. They also know how this might be achieved and simply need services to be willing to listen and be responsive. We have drawn up the PAPAS holding on to this ethos: autistic led and responsive to their concerns and requests. This policy focusses on clarifying acceptable terminology, the entitlement to autonomy, the importance of adequate training, accommodations to making the environment accessible, improving communication, building effective therapeutic relationships, and making complaints and safeguarding processes accessible. We encourage professional registration bodies and all other private service providers to commit to meeting the increasing need of support of a community currently under-represented and under-served by adopting these guidelines towards a shared industry policy for working with autistic clients.

Equally safeguarding processes protect the wellbeing of service users and are at their core patient focussed [36]. These processes can however only be meaningful if they are accessible and responsive. Respondents expressed difficulty accessing them, fear of repercussion and a lack of meaningful outcomes (see Table 5).

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