

POLICY FOR AFFIRMATIVE PSYCHOTHERAPEUTIC AUTISM SUPPORT



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August 2023



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1. INTRODUCTION

The Policy for Affirmative Psychotherapeutic Autism Support sets out the expectation for standards of practice, training, and ethical principles in working therapeutically with the autistic community. It holds to the disabled community's ethos of "nothing about us without us" and has been drafted with the direct input of autistic service users. It is worth remembering that our understanding of autism is incomplete and that the field of research is continuously expanding. Additionally, the autistic community is increasingly stepping into the forefront of self-advocacy and members are rightfully speaking up for themselves - accordingly it is important that policies are frequently reviewed and updated to incorporate any changes in terminology, research and community needs.

This policy was guided by the input of online autistic groups and forums who kindly participated in a survey on the barriers experienced accessing mental health support, offering both feedback and suggestions to clarify how services might meaningfully offer accessible support. They commented on previous experiences of therapy, preferred terminology, and required accommodations. This policy prioritises feedback from the community over existing practices suitable to a neurotypical client demographic.

2. KEY TERMS

The autistic community expressed a clear preference for using appropriate language and the importance of using preferred and appropriate terminology and language is frequently highlighted (Monk et al., 2022). It is important to keep updated on the current preferred language of use, but to always be led by the self-identified preferences of each client in session.

Identity first language:	The autistic community expressed a clear preference for identity first language due to autism being seen by the community as being inseparable from the person and therefore an integral part of their identity. Where previously used person first language referred to "person with autism" or "has autism", it is now the preferred convention to use "autistic person" or "is autistic" (Taboas et al., 2022).
Neurodiverse:	This is a collective term acknowledging all variations of human neurology, recognising that neurological differences such as dyslexia, ADHD or autism are results of normal gene variations (Autism Education Trust, n.d.)

<p>Neurotypical:</p>	<p>This refers to an individual or group who are not characterised by autistic or other neurologically atypical patterns of behaviour or thought (Autism Education Trust, n.d.).</p>
<p>Functioning labels:</p>	<p>Previously labels such as “low functioning” or “high functioning” were used to categorise an individual’s ability to fit into ‘normal’ society. These labels are largely rejected by the autistic community and are considered harmful and limiting (Aylward, 2017).</p>
<p>Support needs:</p>	<p>Instead of using harmful functioning labels, referring to support needs is a way of acknowledging ways someone might be meaningfully supported without typecasting or stereotyping (Bottema-Beutel et al., 2020). Support needs might vary from person to person over various aspects such as executive functioning, sensory processing, repetitive behaviours, motor skills, perseverating thinking, social awareness, verbal and non verbal communication, and information processing.</p>



<p>Asperger's:</p>	<p>Asperger's Syndrome was a diagnosis previously given to individuals with an autistic profile that did not include learning disabilities (sometimes referred to as "high functioning autism"). While it is now the standard to diagnosis people as having Autistic Spectrum Condition, some people might still use the label of Asperger's. There is some contention within the autistic community around the use of this diagnosis, due to the problematic history of Hans Asperger during the Second World War. It is important to follow a client's precedent and preference in utilising this label or not (National Autistic Society, 2020).</p>
<p>Disorder:</p>	<p>Many participants giving feedback expressed their preference to not be called disordered, or to be referred to as having a disorder. They instead preferred the use of Autism Spectrum Condition or simply autism</p>
<p>Invalidating language:</p>	<p>Participants expressed their frustration at commonly used turns of phrase that resulted in a sense of invalidation and dismissal. These included "everybody is a little autistic", "you don't look autistic", being called "eccentric", references to "suffering" from autism, and references to autism as a "superpower". Following a client's preferred vocabulary and terminology is once again the best way to proceed.</p>



<p>Challenging/maladaptive behaviour:</p>	<p>What might seem like “challenging” behaviour is often a meaningful and accurate expression of distress for an autistic person.</p>
<p>Autistic traits:</p>	<p>Autistic traits are the individual characteristics of autism each person might experience or express. Remember, when you have met one autistic person you have met one autistic person - all autistic people are unique and individual (NHS Inform, 2023).</p>
<p>Puzzle piece:</p>	<p>The puzzle piece was originally used by the National Autism Society in 1963 in the United Kingdom but was subsequently adopted by Autism Speaks in the United States. Many autistic people find the puzzle piece offensive, partly due to some controversy surrounding Autism Speaks’ representation of autism as a tragic disease and the interpretation of a puzzle referencing autistic people having a ‘missing piece’ or being ‘incomplete’ in some way (Altogether Autism, 2021).</p>



<p>Non-verbal:</p>	<p>While non-verbal often refers to an autistic person unable to express themselves through language, possibly instead utilising adaptive communication tools such as Alternative and Augmentative Communication (AAC) devices, it is also colloquially used by autistic people for experiences of selective mutism during moments of overwhelm, change or shutdown. Despite the term selective, these are periods where an autistic person does not choose to lose their ability to speak and that they often find distressing and embarrassing (Embrace Autism, 2023). The autistic community often prefers the use of situational mutism to indicate this experience.</p>
<p>Meltdown:</p>	<p>Meltdowns are externalised expressions of high distress due to dysregulation caused by overwhelm. Meltdowns can often seem scary and as if the person is having a 'tantrum' or a panic attack. While some people might lash out, others might hurt themselves and might show very heightened emotion and upset. Autistic people do not choose when to have a meltdown (National Autistic Society, 2020a).</p>



<p>Shutdown:</p>	<p>Shutdowns are internalised expressions of high distress due to dysregulation caused by overwhelm. Shutdowns can often result in withdrawal, selective mutism, and avoidance. When in shutdown an autistic person might be perceived as rude or disrespectful and might find eye contact unbearable. Autistic people do not choose when to have a shutdown (Aylward, 2017b).</p>
<p>Slang terms:</p>	<p>While some autistic people might use slang terms such as "Aspie", "autie", "neurospicy", etc., others indicated in their feedback that they found these terms offensive. Following a client's preferred vocabulary and terminology is once again the best way to proceed.</p>



3. ETHICAL PRACTICE



3.1. IMPROVING EQUALITY

Minority ethnic groups, women and socioeconomically underprivileged communities are historically significantly underrepresented in autism research, consequently resulting in disparities in equality in healthcare and mental health support (West et al., 2016; Robertson et al., 2017). Autistic traits are often interpreted as antisocial behaviour in people of colour (Burkett, 2020) and support services and workers might respond with judgment and fear instead of understanding and accommodation. Women are more likely to be diagnosed in adulthood and are frequently misdiagnosed with personality or anxiety disorders (Fusar-Poli et al., 2020; Gesi et al., 2021).

It is important that psychotherapeutic services are aware of inequalities experienced within these communities, of difficulties in getting diagnosis and of experiences of distrust these clients might have towards mental health professionals.

3.2. AUTONOMY & CONSENT

Autistic research rarely focusses on the experience of being autistic and tends to spotlight autistic behaviour and approaches to bring such behaviour within expected social norms (Späth & Jongsma, 2019). Multiple theories of autism abound, some of the most pervasive being that autistic people universally lack theory of mind (the ability to understand the mental states of other people and make sense of their actions, behaviours, and thoughts (Olson et al., 2023), lack empathy, and lack the ability to socially interact (Gernsbacher & Yergeau, 2019). In their review Gernsbacher & Yergeau (2019) found that this was a harmful and empirically doubtful assertion. This can lead to the assumption that autistic people are unable to make meaningful and informed choices for themselves, resulting in a pedagogical approach to care that infantilises and disempowers the autistic community. The entitlement to self-autonomy and choice can be undermined by the unjustified interference of professionals who base assumptions on outdated theories, are untrained and unknowledgeable about current autism facts and make paternalistic choices on behalf of autistic patients (Späth & Jongsma, 2019).



While feedback from the autistic community showed their ability to make good use of support systems such as online forums, family, partners and spouses, as well as friends and services, they were also able to clearly express how they would like their information to be managed and shared. They had an informed understanding of the barriers they have experienced in accessing mental health support and were able to suggest meaningful and reasonable accommodations that would improve not only access to support but also improve outcomes.

The individual's rights to make their own decisions, including medical decisions, in England is guaranteed by the Mental Capacity Act 2005.

This policy confirms an ethical commitment to upholding the autistic community's right to autonomy and choice through:



- i. Investing in keeping up to date with current autism research and therapeutic practice.
- ii. Committing to listening to autistic voices through forums, autistic authored books, podcasts, blogs, etc.



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- iii. Committing to valuing autistic lived experience over assumptions.
 - i.v. Offering information and choices to allow autistic individuals to make informed decisions of care.
 - v. Taking feedback and adapting approaches and methodologies to incorporate autistic traits and needs.
 - v.i. Committing to viewing autism as a neurological variation with a focus on improving quality of life through accommodation and support, rather than a disease or maladaptive behaviour to be cured or corrected.
 - v.i.i. Committing to improving equality and the highlighting of autistic voices within research, theory, and practice.
 - v.i.i.i. Encouraging professional bodies to engage with policy regarding the ethical commitment to ensure the autonomy and choice of autistic clients.

3.3. ADEQUATE TRAINING & SKILL DEVELOPMENT

The most significant request received from the autistic community was the request for adequately trained and knowledgeable therapists and support staff. This is supported in research as the most significantly reported barrier to accessing mental health support (Lipinski et al., 2021). Lipinski et al. (2021) found in their study that 53% of participating psychotherapists reported having very little knowledge or training of autism. Only 2% self-reported as being highly educated in the subject. 70% of psychotherapists reported their lack of training being a deterrent in their willingness to work with autistic clients. It is clear that a refocus on pursuing training and education in understanding autism, autistic traits and successful adaptations to therapeutic methodologies is a high priority in offering meaningful psychotherapeutic services to an underserved community.




While there seems to be some increase in autism related training, there is a criticism that much of these trainings are being offered by neurotypical trainers to an implied cohort of neurotypical service providers instead of being led by autistic voices (Bartlett & Carrington, 2021; Lawrence, 2022). When seeking out training it would be meaningful to demand autistic led trainings to balance other trainings available and to create an expectation within the psychotherapeutic field of raising the voices of those with lived experience.

This policy confirms an ethical commitment to pursue adequate and ongoing training and education through:

- i. Committing to ongoing professional development through a minimum of 10 hours autism specific training, conferences or presentations per year.
- ii. Committing to ongoing development by engaging with autistic voices through autistic authors, forums, journals, etc.



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- iii. Committing to supervision with an autism affirmative professional engaged with this policy.
 - iv. Joining professional special interest or speciality groups if available.
 - v. Encouraging professional bodies to commit to policy regarding training and professional development to further enhance autism affirmative training.



4. ENVIRONMENT

Due to sensory hypersensitivity, intolerance to change, and high anxiety (Hodgson et al., 2016) accessing new environments can pose a lot of challenges to autistic people. In their feedback participants expressed sensory overwhelm as well as the need for detailed information to alleviate the intolerance to uncertainty and suggested accommodations to facilitate accessing services.

BARRIER	ACCOMMODATION
Sensory overstimulation: Sound	Check for aversive sounds. Low noise waiting areas and consultation space. Option to use noise reduction/noise cancelling headphones or earplugs. Option to wait outside prior to session. Option to leave premises and return to mitigate overstimulation. Using noise free clocks, fans, etc.

BARRIER	ACCOMMODATION
Sensory overstimulation: Lights	<p>Check for aversive experiences.</p> <p>Avoiding florescent bulbs and spotlights.</p> <p>Offering lighting that can be dimmed or low-level lighting.</p> <p>Use warm bulbs instead of bright bulbs.</p> <p>Not having flashing or intermittent lights.</p> <p>Having blinds or curtains to block sun glare.</p> <p>Option to use coloured, tinted or sunglasses.</p>
Sensory overstimulation: Smell	<p>Check for aversive odours.</p> <p>Not using air fresheners or diffusers.</p> <p>Not wearing perfume.</p> <p>Ventilate with open windows or using a fan.</p>



BARRIER	ACCOMMODATION
Sensory overstimulation: Tactile	<p>Check for aversive textures.</p> <p>Option to bring corrective textures along, example a blanket, stuffed toy, etc.</p> <p>Avoid touching, shaking hands, etc.</p>
Medicalised environments	<p>De-medicalise waiting rooms and session rooms by adding soft furnishings, soothing pictures on the walls or some plants.</p> <p>Avoid clutter that might cause overwhelm.</p> <p>Avoid excessive signage, memos, and notes.</p> <p>Avoid using medicalised language or terminology.</p>
Sensory stimulation seeking	<p>Offer fidget toys.</p> <p>Offer a sensory stimulating corner.</p> <p>Offer engaging activity, example adult colouring books, etc.</p> <p>Option to pace and move around.</p> <p>Option to sit on pillow or stand.</p>





BARRIER	ACCOMMODATION
Communication difficulties	<p>Options to communicate in text, by writing or using AAC devices.</p> <p>Reception and staff understanding need for communicating with reduced eye contact.</p> <p>Offering written summaries and instructions for all directions and instructions</p>
Seating: physical pain and discomfort	<p>Offering seats that accommodate all bodies.</p> <p>Offering seats with armrests sufficient to facilitate using them to sit down or stand up.</p> <p>Offering a selection of soft and hard seating options.</p> <p>Offering pillows to support safe sitting.</p> <p>Offering footrests to elevate feet.</p> <p>Offering step-free access.</p> <p>Option to pace or stand during sessions</p>





BARRIER	ACCOMMODATION
<p>Intolerance to change/unknown environment</p>	<p>Offer photos of building, waiting room and session rooms prior to attendance or on website.</p> <p>Offering clear instructions and explanations of processes and procedures.</p> <p>Offering photos of therapists and staff prior to attendance or on website.</p> <p>Offering copies of all registration documents, outcome measures and/or questionnaires prior to attendance.</p> <p>Staff continuity - allowing clients to build relationships and offering good warning of change.</p> <p>Environment continuity - not changing layouts and/or decorations without good warning</p>
<p>Lack of support</p>	<p>Option to be accompanied by support worker or family member during assessment session.</p> <p>Option for support worker or family member to be able to wait nearby and be available if needed</p>



5. EFFECTIVE COMMUNICATION


The autistic community highlighted significant barriers to accessing support due to unaccommodated communication needs. Autistic adults express complex understanding of communication difficulties and report both internal and external factors as having an influence on moment-by-moment communication needs (Cummins et al., 2020). Feedback suggested that these could include becoming non-verbal, sensory overload, changing environments, overwhelm, shutdown, meltdown, or eye contact aversion. Other difficulties with effective communication can include difficulty with unstructured dialogue, interpreting non-verbal communication such as body language or facial expressions, interpreting implicit meaning and subtext, and having to infer requests for information or action (Müller et al., 2008). Research surveys have identified that the predominant factors in communication difficulties were the experience of anxiety, an overwhelming environment, and the communication partner (Cummins et al., 2020).



In our survey autistic participants expressed the barriers to communication they experienced as:



- i. Lack of professional knowledge of communication difficulties and needs.
- ii. Lack of empathy and patience during communication difficulties.
- iii. Lack of alternative options for communication.
- iv. Unwillingness to offer adaptations or flexibility.
- v. Sensory overwhelm.
- vi. Executive functioning overwhelm.





This policy commits to offering meaningful accommodations and support to facilitate communication by:



- i. Therapists and support staff showing empathy and understanding.
- ii. Allowing patience and time - following the client's pace and lead.
- iii. Being knowledgeable of autistic traits and communication difficulties.
- iv. Being flexible and understanding that communication needs can shift and change depending on context.
- v. Offering written instructions, information, summaries and/or requests in advance to allow information processing.
- vi. Understanding alexithymia, interoception and neuroception difficulties and how these might affect responses and communication.
- vii. Offering visual communication resources and allowing alternative communication methods.

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- viii. Reducing eye contact and sensory overstimulation.
 - ix. Utilising direct communication and avoiding subtext, the need to infer meaning, vague metaphor or passive communication.
 - x. Facilitating executive functioning difficulties with text reminders, written summaries of sessions, reminders of homework, etc.
 - xi. Allowing personal vocabulary and following personal preferences.
 - xii. Allow for non-verbal and shutdown presentations.
 - xiii. Asking for feedback, suggestions and offering choices.
 - xiv. Check mutual understanding and reframe if necessary.



6. BUILDING RELATIONSHIPS


The therapeutic relationship is generally accepted as a predictor of positive therapeutic outcomes (Fiedler, 1950; Cuijpers et al., 2019). Research has shown that to build a meaningful therapeutic relationship with autistic clients therapists need to invest in a deeply authentic relationship, show accurate empathy through correct interpretation, adjust pacing to avoid cognitive overload, utilise direct and unambiguous language, and reduce overstimulation or overwhelm (Hume, 2022). The social model of disability posits that autism is a different neurological way of being that results in a person being excluded from society due to their difference instead of a medical model that views it as a medical disorder to be corrected (Anderson-Chavarria, 2021). This removes the demand from the autistic community to adapt to neurotypical expectations and instead asks how they might be supported to participate in society instead (Jellett & Flower, 2023). Bulluss (2021) argues that the autistic experience creates an autistic culture and that it is the responsibility of the therapist to learn about autistic culture to be able to accurately interpret communication cues with their client and build a congruent relationship. This means setting aside neurotypical socio-cultural norms which underlie the core assumptions society holds around ways of interpreting non-verbal and verbal language.



The following aspects were highlighted as important in building a meaningful and successful therapeutic relationship:

- i. Creating a sense of 'bonding' and relationship.
- ii. Following the client's lead and championing autonomy and client consent.
- iii. Avoiding manualised approaches and tick box exercises.
- iv. Being adequately knowledgeable and competent in understanding autistic traits and communication needs.
- v. Being able to be flexible and adaptable - offering multiple choices of therapeutic approach.
- vi. To be consistent and reliable, and to avoid change and cancellations without good notice.
- vii. To value the lived autistic experience and not criticise responses through a neurotypical lens.



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- viii. To value client autonomy and avoid infantilisation or pathologizing autistic traits and experiences.
 - ix. To avoid a medicalised, paternal, or hierarchical approach.
 - x. To prioritise empathy and patience.
 - xi. To be flexible, respectful and responsive.



7. ACCESSIBLE COMPLAINTS AND SAFEGUARDING PROCESSES

The importance of the autistic community having an active voice and participation in identifying priorities of research and processes of practice is being increasingly recognised (Danker et al., 2019; Benevides et al., 2020). One of the important ways of directly influencing services by speaking up is the complaints process. This allows service users to express their needs, voice what is not working and actively influence change. In the same manner the safeguarding processes are not only in place to keep service users safe, but also to give them an avenue to express need and influence the support they receive (Montgomery et al., 2021). The feedback we received however showed a significant distrust of both these processes and an inability to meaningfully access them.

Participants expressed reasonable concerns and offered adaptation suggestions to make meaningful participation in these processes possible.

BARRIER	ACCOMMODATION
Processes that were too difficult to understand.	<p>Simplifying process descriptions and using layman language.</p> <p>Making processes and policies easily accessible and transparent.</p> <p>Offering neutral support in understanding processes and engaging with them.</p> <p>Offering information and advocacy support</p>
Support staff and therapists who seemed overwhelmed.	<p>Ensuring all staff are adequately trained and have the support systems to bear and manage service user needs and distress.</p> <p>Ensuring appropriate, adequate, and consistent clinical and professional supervision.</p> <p>Holding appropriate boundaries regarding self-disclosure.</p>
Inappropriate or no meaningful support and/or solutions being offered.	<p>Taking feedback from autistic people and communities regarding supportive and unsupportive processes.</p> <p>Commitment to having sufficient training and knowledge to understand autistic culture and traits, and meaningful adaptations.</p> <p>Focus on meaningful outcomes instead of a tick-box process of self-protection.</p>





BARRIER	ACCOMMODATION
Feeling as if their distress was disregarded or misunderstood.	Show authentic empathy and care. Show active listening. Giving feedback and updates to reflect engagement in the process.
Feeling judged.	Showing authentic empathy and care. Showing understanding and acceptance of autistic traits.
Fearing repercussions or loss of service support.	Offering advocacy support. Offering option of anonymity. Ensuring processes are not insular and embrace multiple points of participation to ensure transparency and neutrality.
Communication difficulties.	Having sufficient training and knowledge to understand common communication difficulties. Offering alternative methods of communication. Offering written updates, summaries and/or feedback.





BARRIER	ACCOMMODATION
A failure to appoint an independent processor to allow for neutrality and transparency.	Offering transparency and advocacy by offering a neutral independent point of contact for complaint processes.
Staff and services did not show sufficient training and knowledge of autism, instead working from a neurotypical point of view.	Commitment to having sufficient training and knowledge of autism and autistic traits to understand autistic culture. Acknowledging that existing processes are developed from a neurotypical viewpoint. Commitment to valuing autistic lived experience.
Limitations in self-advocacy ability.	Encourage the participation of support services or systems e.g. advocacy groups, spouses/partners, support workers, family, friends, etc.



8. CONTINUING DEVELOPMENT

Despite the significant advances in our understanding of autism it seems that services are still lagging behind (Howlin, 2021). Therapists still do not feel adequately trained and this affects service willingness to support autistic clients (Lipinski et al., 2021). As society shifts from a medicalised model to a social model of autism, the requirement for an understanding of autistic culture, communication and traits increases (Anderson-Chavarria, 2021). This policy demands a commitment to ongoing professional development, to spotlighting autistic voices and a willingness to adapt and grow clinical practice in line with the autistic community's guidance.

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Drafted: August 2023
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