National Autistic Society

NHS Talking Therapies for anxiety and depression

Guide to support reasonable adjustments and adaptations when working with autistic adults

Contents

1 Background and introduction

The current evidence suggests that some forms of evidence-based psychological therapy for depression or anxiety such as those offered by NHS Talking Therapies services may be effective for autistic adults, but more high-quality evidence is needed to better understand the effects of different interventions. However, in the absence of such high-quality evidence, the recommendation is clear that autistic people should be given access to mental health interventions available to non-autistic people, following principles of person-centred care.[1]

With this in mind, there is little guidance on how NHS Talking Therapies treatments should be adapted and adjusted to best support autistic people. This guide looks to address this gap in order to reduce barriers in access and support good outcomes for autistic people who access NHS Talking Therapies. This is particularly important because we know autistic people are under-represented in NHS Talking Therapies services, and outcomes are not as good as outcomes for non-autistic adults.[2]

Whilst evidence on the effectiveness of adaptation strategies is not currently strong, the adaptations and adjustments highlighted in this guide are ones that are found in research to be 'simple', 'helpful', 'acceptable' and 'feasible' by autistic people who use mental health services. However, it is important to keep in mind, when reading this guide, that individual preferences about which adaptations and adjustments to use and are helpful will differ, and it will be important to discuss preferences with individuals from the outset.

Furthermore, whilst this guide makes suggestions for adjustments and adaptations to best support autistic adults, these considerations may also be useful for those without an autism diagnosis and/or who are waiting to be assessed for autism. This is particularly important because research shows that adults and older adults have high levels of underdiagnosis.[3] Again, it will be important to discuss preferences with individuals from the outset.

There is further work underway on an 'Enhancing accessibility and acceptability of NHS psychological therapies for autistic adults - National guidance' (title subject to change), to consider how NHS psychological therapies might go further. The aim is to consider how services may be better able to achieve good outcomes for autistic people and reduce the current inequality being experienced compared to those outcomes achieved by non-autistic people. For more information on this work, please email **england.autismteam@nhs.net**

Until this research is made available, the hope, in publishing this guide, is to shine a light on some of the simple and common-sense considerations that services can take on board that should support and benefit autistic adults.

The scope of this reasonable adjustments and adaptations guide is to:

a. inform NHS Talking Therapies for anxiety and depression therapists about common features of autism

b. support reasonable adjustments, adaptations and individual sensory needs

c. identify barriers to psychological interventions faced by autistic adults with common mental health conditions

d. provide recommendations to reduce barriers to access and improve clinical outcomes through adjustments and adaptations.

This guide should not be considered a standalone resource. It is complementary to completion of training such as **The National Autism Training Programme**, **The Oliver McGowan Mandatory Training on Learning Disability and Autism** and others compiled by **NHS England's autism team**.

The guide has been developed by the National Autistic Society and is informed by their analysis of the 2020 Mental Health Survey for autistic adults, alongside knowledge gained from over 50 years of working together with autistic people. Some of the research used to develop this guide does have certain limitations. Focus group participants and survey respondents were young people, parents of autistic children and professionals working with autistic children. The findings from the focus group were included in the analysis for this guide and because it is aimed at NHS Talking Therapies professionals working with adults, it is important to bear these limitations in mind.

About NHS Talking Therapies for anxiety and depression

NHS Talking Therapies for anxiety and depression (formerly, Improving Access to Psychological Therapies (IAPT)) provide evidence-based psychological therapy for people with common mental health problems such as depression and anxiety disorders. The programme also provides evidence-based therapy for people experiencing anxiety or depression in the context of long-term physical health conditions or medically unexplained symptoms. People can refer themselves to NHS Talking Therapies services or they can be referred by professionals such as their GP. This reasonable adjustments and adaptations guide is aimed specifically at professionals working within adult NHS Talking Therapies services.[4]

About the National Autistic Society

The National Autistic Society is the UK's leading charity for people on the autism spectrum and their families. Since 1962, the charity has been providing support, guidance and advice, as well as campaigning for improved rights, services and opportunities to help create a society that works for autistic people.

What is autism?

Autism is a lifelong developmental disability which affects how people communicate and interact with the world. At least one in 100 people are on the autism spectrum and there are more than 700,000 autistic adults and children in the UK.

Autism affects people in different ways but autistic people can share difficulties in:

Social communication - Interpreting both verbal and non-verbal language like gestures or tone of voice; eg sarcasm, taking things literally.

Social interaction - Difficulty recognising or understanding others' feelings and intentions and expressing their own emotions, finding it hard to form friendships, seeming 'socially inappropriate'.

Repetitive and restrictive behaviour - The world can seem a very unpredictable and confusing place to autistic people, making routines comforting.

Sensory sensitivity - Over- or under-sensitivity to sounds, touch, tastes, smells, light, colours, temperatures or pain. For example, background sounds might be unbearably loud or distracting.

Highly-focused hobbies and interests - These can change over time or be lifelong. Autistic people can become experts in their interests and often like to share their knowledge.

Anxiety - Particularly in social situations or when facing change. It can affect a person psychologically and physically and impact quality of life for autistic people and their families.

Meltdowns and shutdowns - A meltdown happens when someone becomes completely overwhelmed by their current situation and temporarily loses behavioural control. Shutdowns are also a response to being overwhelmed; they can be equally debilitating but may appear more passive – eg an autistic person going quiet or 'switching off'.

Get more information about what it means to be autistic **here**.

Some autistic people do not discover that they are autistic until later in life. If you suspect that someone is autistic, it may be helpful to find out more information about traits, the diagnosis process and how you might be able to support them. **This page** might help you to start a conversation about it.

Above all, it is important to understand that the experience of being autistic is unique to the individual. Many autistic people have co-occurring conditions (eg ADHD, learning disabilities), which may influence their experiences of NHS Talking Therapies. It's important to ask questions to identify where this may be the case.

How autism can present

Whilst all autistic people will have social and communication differences and patterns of repetitive and restrictive behaviour, presentations can vary widely. For example, for some, social and communication differences might manifest as difficulty with initiating and maintaining conversations. Others may appear to be at ease in social situations but feel fatigued and require time alone afterwards. Repetitive behaviour for some autistic people may present as intense interests in specific topics whilst others may find that a need for routine has a bigger influence on their day-to-day life. There is a vast spectrum of associated traits, needs and preferences, making a one-size-fits-all approach inappropriate for autistic individuals.

Mental health support and autistic people

Research suggests that cognitive behavioural therapy (CBT) interventions, including behavioural, cognitive and mindfulness-based techniques, are 'moderately effective treatments for autistic people with co-morbid anxiety and depression symptoms'.[5] Further, studies have shown that mental health support and treatments such as those offered in NHS Talking Therapies services can improve anxiety and depressive symptoms for autistic people.[6,7,8]

This finding is corroborated by a 2022 meta-analysis of interventions to improve anxiety, depression and other mental health outcomes for autistic people.[9] The analysis suggests that "some forms of cognitive behavioural therapy may decrease anxiety and depression scores in autistic children and adults; mindfulness therapy may decrease anxiety and depression scores in autistic adults with previous mental health conditions".[10] The study concludes by recommending "that autistic people are given access to mental health interventions available to non-autistic people, following principles of person-centred care".[11]

Furthermore, a 2023 study using linked electronic healthcare records, including national data from over two million individuals who accessed psychological therapy in primary care in NHS Talking Therapies services across England, arrived at similar conclusions.[12] The authors of the study found that evidence-based psychological therapy for depression or anxiety may be effective for autistic adults; however, outcomes were less favourable compared to non-autistic adults.[13]

In the study, outcomes were compared in people with a diagnosis of autism and a propensity matched control group of people without a diagnosis of autism. Over half of the autistic group showed reliable improvement (56%) and a third (33%) recovered compared to the matched control group which showed reliable improvement of 62% and recovery of 39%.[14]

Although research is limited and more is needed, evidence would suggest that autistic adults should be offered interventions provided by NHS Talking Therapies services for common mental health conditions, but adaptions and adjustments set out throughout this guide should be considered. However, it is also critical to remember that the adaptations and reasonable adjustments required by one autistic person will not necessarily be helpful to another. It is important to understand the sensory, communication and support needs of an autistic person on an individual basis and as soon as possible to make sure that any changes implemented work for them.

Some autistic people report concerns that CBT "doesn't work" or can "make things worse". It is important to explore this concern early on in an individual's NHS Talking Therapies journey in order to share the evidence that CBT can be effective. It is also important to clarify that, should the individual not find it helpful, they can opt out of treatment at any time or consider alternative options.

For more information on the relationship between autism and specific mental health conditions, please refer to the **further reading list** at the end of this guide.

Policy context

In 2015, the Department of Health and Social Care published the latest binding *Autism Act* statutory guidance, which states that autistic people should have support adapted to their needs if they have a mental health difficulty.[15] The NHS Long-Term Plan (2019) also aims to improve mental health support for autistic people in the community.[16] In the recent publication of the revised National Autism Strategy for children and adults (2021), the Government reiterates the need for autistic people to have reasonable adjustments in their care, and they highlight that currently, professionals cannot always identify the adjustments they require.[17] Reasonable adjustments are a legal requirement under the *Equality Act 2010* to make sure health services are accessible to all disabled people. This includes autistic people.

Use of terminology

Adaptation – In many cases, autistic people are able to engage with, and benefit from, the therapeutic interventions offered within NHS Talking Therapies settings, when adaptations are made. This could include allocating more time or increasing the number of sessions, as well as adaptations like changing the content of a session to include the interests of the autistic person. These adaptations would apply to any of the modalities offered within NHS Talking Therapies services at both high and low intensity.

Reasonable adjustment – Autistic people are entitled to reasonable adjustments under the *Equality Act 2010*. When possible and reasonable to do so, it is a service's duty to make changes to the delivery of a service to suit an individual's needs. Examples of reasonable adjustments are providing clear information about sessions in easy read letters or allowing the autistic person to be accompanied by somebody else for sessions.

Barriers – Access to therapeutic interventions can be more difficult for autistic people as a direct result of being autistic. Barriers can be attributed to a lack of autism awareness and understanding as well as insufficient services and resources to accommodate the specific needs of autistic people. Examples include a lack of services with the training needed to support autistic people who do not communicate through speech.

2 National Autistic Society engagement with stakeholders and limitations

Survey background

In November 2020, the National Autistic Society conducted a mental health survey to find out more about the mental health experiences of autistic people. Questions were based on the GAD-7 and PHQ-9 questionnaires for anxiety and depression and also included loneliness and life satisfaction questions taken from the Office for National Statistics. Participants were invited to complete the survey online via the National Autistic Society website. 1,580 surveys were completed by autistic adults and 900 by family members of autistic individuals.

This guide is also based on in-depth discussions with 17 autistic people, eight family members and 15 mental health professionals.

Survey participants and those invited to focus groups included autistic people of varying ages, LGBTQIA+ autistic adults and young people, autistic parents of autistic children, autistic people from ethnic minority backgrounds and autistic people who become non-verbal when anxious.

We spoke to professionals working with autistic people who are non-verbal, and therapists working in NHS Talking Therapies services, the community, inpatient settings, diagnostics and private practice. Therapists' experience varied from over 20 years to trainee psychologists which is reflective of the variety of professionals that work with autistic adults and children.

They were approached via pre-existing National Autistic Society networks including through the NHS Autism Workstream and via mental health charities.

Autistic focus group participants were either formally or self-diagnosed with autism and had experience of mental health problems (specifically anxiety and depression). Participants had either received talking therapy or had requested therapy and been unable to access it. Some participants with specific communication preferences engaged with the project via email.

The principles of thematic analysis were used to examine the data and identify common themes which were subsequently used to form the basis of the checklists and recommendations presented in this guide.

There are limitations to the data that has been analysed which may not make it entirely representative of all autistic people. Those that participated in the mental health survey, interview and focus groups are likely to have previously been aware of the National Autistic Society and its aims. Further biases may have been introduced through the analysis of qualitative data by National Autistic Society staff. For example, there may be an element of confirmation bias to consider due to National Autistic Society staff expecting to see particular results due to prior knowledge and research. Due to demographic limitations within the data, it may not be entirely representative of those from marginalised communities.

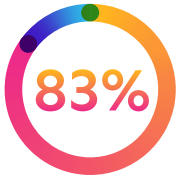
Findings from our engagement

Recent research estimates that around **40% of autistic people** will develop anxiety and/or depression in their lifetime.[18, 19]

Many of the autistic people who completed the National Autistic Society survey had or were experiencing mental health problems, including anxiety and depression.

Of those surveyed:

94% of autistic adults experienced anxiety; almost six in ten said this affected their ability to get on with life. 40% had a current diagnosis of an anxiety disorder and almost half fell into the severe category based on the GAD-7.



83% experienced depression, half said this affected their ability to get on with life and almost 30% fell into the severe category based on the PHQ-9.

The autistic people surveyed also reported experiencing risk factors that can contribute to anxiety and depression including:

having a much lower life satisfaction than the general population.[20]

being eight times more likely than the general population to feel lonely often or always.[21]

The National Autistic Society's inquiry with the All-Party Parliamentary Group on Autism (APPGA) into the Autism Act: 10 years, illustrated that despite a clear need for mental health interventions, autistic people struggle to get the support needed.

The inquiry found that most autistic adults and their families felt that getting support from mental health services took too long and there were not enough mental health services in their area to meet their needs.[22]

Autism is not a mental health condition, but many autistic adults and children develop mental health problems and too many reach crisis point avoidably. The 2020 mental health survey results reinforce existing evidence that autistic people suffer disproportionately with poor mental health when compared to the general population.[23]

3 Reducing barriers to access for autistic adults

Preventing escalation and crisis

Despite a clear clinical need, the National Autistic Society's recent engagement and understanding of autistic people shines a light on how, too often, autistic people report being transferred between different settings. Autistic people often spend years being shifted from service to service and being labelled as 'too complex' for existing services, leaving them without support. Not only has this had serious impacts on their self-esteem, but it has also led to some people developing a distrust of mental health professionals and anxiety around interacting with services. This is backed up by the literature, which has demonstrated that mainstream mental health services are often not confident in their understanding of autism and refer autistic patients to disability services that are not well-equipped to provide mental health care.[24, 25, 26, 27]

This is a particular issue for autistic adults without a learning disability. Although there may be some similarities between the needs of autistic people and people with a learning disability, for example, a need for communication adjustments and for appointments to be at a set time, the two are fundamentally different and may require a very different approach.

The differences between approaches are not in the scope of this guide but more information on reasonable adjustments and adaptations for people with learning disabilities within NHS Talking Therapies services can be found in: **Improving Access to Psychological Therapies (IAPT) for people with learning disabilities | Foundation for People with Learning Disabilities**.

Too often, being unable to get the right kind of treatment can result in problems escalating until emergency or inpatient care is required.[28]

Being clear on adaptations to encourage referrals and self-referrals

A recent UK study found that, despite a clear need for adjustments, autistic people have limited access to them across healthcare settings.[29] Our engagement suggests that the lack of primary and community mental health services that are adjusted and adapted to support autistic people's needs contributes to autistic people disproportionately facing mental health crisis. The next section sets out adaptations to consider in NHS Talking Therapies services. It is good practice to be clear on any public facing channels, eg websites, leaflets, what adaptations can be made within the service to support improved access for autistic people.

Scoping and delivering training for the workforce

i. Training to improve knowledge and understanding of autism was seen as key to improving access and the therapy experience for both autistic people and health professionals during the National Autistic Society engagement.
ii. Providing all staff with some level of autism training can give health professionals the knowledge and confidence to make decisions about adaptations and adjustments that might be needed and to then follow through with these.
iii. Training should focus on person-centred practice and take a holistic view of people's experience and identities. There may be multiple components of identity to consider including a person's ethnicity, gender identity and sexual orientation and the relationship between these things and the person's autistic identity.
iv. Training should incorporate people with lived experience.
v. Where possible, it may be helpful to give therapists access to training in different formats; for example, online resources in addition to face-to-face training. Therapists can then access and reflect on this as and when needed, including discussion within clinical supervision.
vi. Therapists who worked within NHS Talking Therapies highlighted that training around how to adapt specific therapy techniques was particularly important to them.

A list of useful resources and training available nationally can be found **here**.

Ongoing review of service performance

Continuous quality improvement is a key feature of better performing NHS Talking Therapies services. Data-informed, service-level, reflective practice is encouraged and will build intelligence around reducing barriers and improving access and clinical outcomes for patients including autistic people. NHS England is due to update the national dataset to include ASD as a code in future revisions. This will help drive continued improvements for this community in a data-driven way.

4 Considerations and adaptations to therapy sessions

The National Institute for Health and Care Excellence (NICE) recommends adapting therapy to suit the needs of autistic people.[30] A recent UK study identified what reasonable adjustments autistic people benefit from in healthcare and mental health settings, which included three factors: 1) sensory environment, 2) clinical and service context, and 3) clinician knowledge and communications.[31]

The National Autistic Society's engagement with mental health professionals and autistic individuals suggests that adaptations are not being applied consistently in mental health services, including NHS Talking Therapies. Adaptations and adjustments need to be made at every point of a person's journey: from the first time an autistic person seeks a health professional and/or service, to how they are assessed, to setting therapy goals and measuring outcomes.[32] This is important as tools used throughout therapy have not yet been validated for autistic people.

These findings are consistent with recent NHS reasonable adjustments guidance as well as a growing body of evidence showing that adapting therapies such as cognitive behavioural therapy (CBT) increases its effectiveness for autistic people.[33, 34, 35]

This guide aims to outline ways to establish a more consistent approach for autistic patients across all NHS Talking Therapies services.

Making initial contact

The initial stages of communication between an autistic person and a health professional/service are incredibly important for increasing future participation. For many autistic people, previous negative experiences and uncertainty about new situations will cause additional anxiety. Providing as much clear and accessible information as you can before starting treatment can alleviate this and build rapport. Allowing someone to visit the site if they wish and offering as much flexibility as possible will be hugely helpful.

If an autistic person has been referred to NHS Talking Therapies by their GP, does he/she/they know and understand why they have been referred to your service and what they can achieve? Some autistic people have said they find it very hard to visualise abstract concepts such as 'starting to feel better' and without clear direction can feel de-motivated. Bringing in real-life examples of what they can achieve, based on what they have told you, can boost engagement and support the best possible outcomes.

Examples of things that are useful to include in a pre-appointment letter:

- Say who you are: Make sure the letter is from and signed by the actual therapist seeing the person, not just a generic letter from the admin team as this has been found to be confusing and add to a person's anxiety.

- State what therapy will look like/how it will work; this could include a rough agenda for the first session.
- State what is expected of the person and what might be useful to prepare.
- Manage expectations from the beginning by suggesting some key benefits that therapy may achieve. Provide real-life examples such as: 'Therapy can help you understand what makes you feel stressed about a certain situation and what steps you can take to reduce that.'
- Add a picture of what the waiting room and therapy room will look like (or the online platform if delivering therapy online). Use photos of the specific rooms wherever possible, as walking into a different room from the one they had prepared for could make an autistic person more anxious.
- Say how long the session will be.

Autistic people have communication differences that may make some forms of communication more difficult. Allow for flexible ways of contacting the service. Could appointments be offered and managed via email, text or online booking systems instead of a phone call? Also consider what these communication preferences might mean for how therapy is delivered eg face-to-face vs online vs text.

Many autistic people and families told us they didn't know that adjustments and adaptations can be made for them. When you first contact a new patient, have an active and equal conversation about adjustments by providing examples of possible changes that could make the environment work better for them. This should not be a one-time conversation but something you work on with the patient across sessions.

Being aware of the sensory environment

Many autistic people experience sensory differences, meaning that processing everyday sensory information can be difficult. Any of their senses may be over- or under-sensitive, or both, at different times. An over-sensitivity to everyday sensory information is referred to as hypersensitivity and an under-sensitivity to everyday sensory information is referred to as hyposensitivity. Individuals experiencing hypersensitivity may become stressed and anxious and even experience pain from certain kinds of sensory input such as sound, light or touch. Those experiencing hyposensitivity may instead seek out sensory stimulation like spinning in a chair or chewing objects to help them to feel regulated. An autistic person's sensory profile will be unique to them but it is important to think about this before someone even enters the therapy room.

Changes to the sensory environment to suit the needs of an autistic person can make it easier for them to engage with therapy and may therefore improve therapy outcomes. Working actively to reduce any potential anxiety not only reduces the chance of a person feeling overwhelmed, it helps build trust and rapport with both the service and their therapist.

Consider:

- allowing the person to wait where it is best for them or making adaptations to the waiting room to minimise unnecessary stress a person may experience before starting therapy. If possible, provide access to somewhere quiet.

- minimising unnecessary clutter.
- reducing any loud or distracting noises, such as the radio playing or a ticking clock. If the person experiences sound sensitivity, try to remove as much sound from the room as possible.
- using dimmer lights or natural lighting can be a positive alternative to artificial and fluorescent lighting for somebody with light sensitivity.
- the impact of smells can be distressing or uncomfortable for somebody with hypersensitivity to smell. Avoid wearing perfume or aftershave and remove anything from the room with a strong smell; for example, food and drink.
- clearly signposting toilets, water fountains etc. so that the person does not need to rely on anybody else to point these out.

The therapy room

Similar to the waiting room, is your therapy room set up with an autistic person's sensory needs in mind or could it potentially be an overwhelming space? Ask your patient about the adaptations and adjustments they need.

Examples of adaptations:

The room:

- One therapist spoke about being able to request using the quietest room on the corridor when she knew she was working with autistic patients.
- If you are using pens to draw or create visual support or you are giving the person the pens to use, do they have a smell? Could you find ones that are more neutral?
- Think about the seating – could the texture of the chair potentially be distracting?
- What is the temperature of the room like? If it is warm, can you open a window, turn off the heat or otherwise cool it down before the appointment?

For phone calls:

- Minimise all background noise.
- Provide plenty of time for the individual to respond to questions and cues.
- Ensure questions and prompts are clear without relying on tone of voice to convey meaning.
- Be aware that autistic people may find it difficult to know when it is their turn to speak and aim to make this clear.

For video calls:

- Use a neutral background, such as a plain colour background.
- If possible, give them the option to take part on or off camera.
- Minimise all background noise and use headphones wherever possible.
- Be aware of how to use the whiteboard function if meeting remotely, making sure that you can both collaborate to write/map/draw things out, if needed.
- Be aware that autistic people may find it difficult to know when it is their turn to speak and aim to make this clear.
- If switching between video calls and in-person sessions, ask which reasonable adjustments are needed for both, without presuming they will be the same.

Conducting an NHS Talking Therapies assessment

When completing an NHS Talking Therapies assessment, consider adaptations to help obtain a full and accurate picture of an autistic person's needs, which can reduce barriers to accessing therapy.

- Before you assess someone, you should give them clear information about the service, the therapist's role and the purpose of the assessment. Break down questions and ask them one by one to make them less abstract. For example, instead of 'How are you?' or 'How do you feel about next week', an autistic person may find it easier to answer specific questions like 'Have you felt worried today?' and 'Do you feel anxious about your plans for Monday?'
- Support further understanding by providing real-life examples. For example, when asking 'What effect does this have on your ability to get on with life', you can clarify the question by asking questions such as 'Have you been able to cook regular meals?', 'Have you been able to keep your home tidy?', which may be easier for an autistic person to answer whilst still providing an insight into the level of interference a mental health problem is having on everyday life.
- Do not assume that your patient can identify, understand or talk about their emotions. Think of ways you can help with this; for example, some autistic people will find it useful to communicate their feelings through writing or drawing.
- Have you given the person time to process the question?
- Can you provide written and visual support?
- Have you adapted the environment to meet sensory needs?
- Have a pen and paper available so that you can write or draw things if necessary.
- Are you delivering the assessment in a way that suits their communication needs? Would it suit them better to ask them questions face-to-face?
- Can they respond in a way that suits their needs? Do they need to write things down? Is it possible to record the session so that they can listen again?
- At the end of the assessment, summarise the key points. Provide a written list if needed.

What happens if patients are assessed with having more than one problem descriptor?

If an autistic person is identified as having more than one problem descriptor during the assessment, NHS Talking Therapies services can support this complexity. As with any other person accessing NHS Talking Therapies, the treatment plan should be based on an order that works from the problem/s causing the person the greatest to the least distress.

What happens if the patient scores low on the GAD-7 or PHQ-9 but clearly is symptomatic?

Treatment is not dependent on assessment scores alone. At assessment, therapists should glean information on what difficulties the person is experiencing, how these are impacting on their life and how talking therapies can best treat these difficulties. People with social anxiety for instance can often present with low GAD and PHQ scores as they are avoiding what makes them anxious.

This would be explored during the assessment and ADSMs should be used to guide appropriate treatment options.

Delivering therapy sessions and content

Structuring sessions

Being able to adapt and change the structure of your therapy offer to suit an autistic person's needs is key. Providing a session structure can support a person's ability to process information and help them manage uncertainty about what is expected of them. Some professionals shared that following an agenda also made it easier to set boundaries and communicate when a session is coming to an end. Making sessions as predictable as possible can really help increase a person's participation and enjoyment.

- It is important not to rule out offering a certain type of session until preferences have been explored. For example, some therapists emphasised that being able to meet with a person one-to-one initially can be important for deciding with them whether group sessions could be beneficial. This can also ensure that the person feels prepared and supported to join group therapy sessions if appropriate.
- For some autistic people, change can cause a lot of anxiety or distress. You may need to accommodate a need for consistency; for example, by making sure the person sees the same therapist at the same time every week.
- Consider sharing an agenda with rough timings before the first session. After this, you can work collaboratively with the autistic person to set agendas together at the end of each session.
- Be flexible about the number of sessions offered. Some autistic people may need additional sessions in order to process information and therefore, respond better to treatment.
- There are multiple reasons that attendance can be more difficult for autistic people. For example, experiencing sensory overwhelm or unexpected changes before an appointment could lead to the autistic person having a meltdown or shutdown and missing their appointment. It is best practice to be flexible around missed appointments wherever possible. This also includes flexibility around the way an autistic person may contact the service to cancel or rearrange an appointment.
- Adjust the length of sessions accordingly; some people may benefit from longer sessions to slow the pace of the therapy and provide extra time to process information and feel comfortable with communicating. Others may need shorter appointment times or breaks in sessions to maintain focus and prevent feeling overwhelmed.
- The initial session(s) may be anxiety-provoking for an autistic person. If your patient is very anxious and this is impacting communication and engagement, take time to talk about topics that are of interest to them before finding out more about problems and distress.

Delivering interventions

- Develop clear objectives (with examples) of what you want to achieve from each session. For interventions, use the SMART framework to develop individualised goals that are specific, measurable, achievable, realistic and fit within the timeframe of any intervention being offered.

Encourage the autistic person to identify goals that are meaningful and important to them.

- Consider the foundation skills needed for an intervention. Take time to make sure that the autistic person you are treating can identify and notice changes in emotion before continuing with the symptom-focused change aspects of a treatment protocol.
- Consider emphasising changes in behaviour rather than thoughts and beliefs as the main vehicles for change in the intervention. It can be unproductive and off-putting for the person you're treating if they struggle with flexibility in thinking.
- When working at a behavioural level, try to begin with a gentle, graded approach to help build confidence in the intervention model.
- Make sure that any tasks to be done between sessions are clear and specific. Support the autistic person to make concrete plans about when and how they will manage these tasks. Identify if they need any support with these. It may be appropriate to offer prompts outside of sessions if possible.

Communication adaptations

Make sure that sessions are carried out in the best possible way for that person to engage. For some, this might involve being able to paint at the same time. For others, it could be going on a walk outside. It depends on the person.

Previous Coronavirus restrictions meant that services had to offer sessions online via video chat or over the telephone instead of in-person. For some autistic people, remote delivery has worked really well and it may be useful to consider whether telephone, video chat, SMS or other digital therapy sessions could be more useful and accessible than in-person appointments.

Consider their communication needs. Do they require:

- you to write things down? Or you to draw things and provide additional visual support?
- to write things down themselves? To draw things themselves?
- for you to write down key notes from the session or for the session to be recorded? Would it be helpful for somebody else to be in the session to help with note-taking or recording?

Being able to provide a recording or brief notes on what was covered and what is expected of them in between sessions can really help to support achieving therapy goals.

Interpreting both verbal and non-verbal language like gestures or tone of voice can be difficult for some autistic people, as well as understanding abstract concepts and sarcasm.

Ways you can help:

- Avoid open-ended questions. Keep questions short and to the point. For example, by replacing questions like 'How have you been?' with 'Do you feel sad/angry?'
- Bear in mind that some autistic people may find it very difficult to identify and talk about the way they feel. Writing or drawing may be easier for some.
- Some autistic people may find it easier to identify how they feel physically first and then explore how this is related to their emotions; for example, feeling shaky due to anxiety.

- Offer options or choices where possible; for example, by explaining the way an exercise or technique works to the autistic person before beginning and making sure that they are happy and confident to proceed.
- Avoid asking more than one question at a time.
- Provide clear examples and use unambiguous language. Try and notice the metaphors and 'jargon' you use as part of your practice and minimise this.
- Establish the types of speech and phrasing the person is comfortable with and uses themselves. Depending on the individual, it may be important to avoid using irony and sarcasm, figurative language and/or rhetorical questions.

Processing large amounts of new information, coupled with negative previous experiences, can feel overwhelming for some autistic people. Some autistic people can find it difficult to filter out information if there is too much going on. This can lead to 'overload' where a person can feel completely overwhelmed and no further information can be processed, making a person appear unresponsive. The language you use in sessions is important. Help someone to understand what you have said by breaking concepts down.

Consider:

- saying less and saying it slowly
- using and repeating specific key words. Work with the individual early on to see what terminology they prefer to use; for example, 'depression' or 'low mood' as well as talking about what these words mean to them.
- pausing between points
- leaving time for the person to answer. Don't always just rephrase the question.
- checking that what you have said has been understood correctly.

Please note: Record all required adaptations in the person's health record to ensure they are communicated with everyone they may have contact with in the service. If the person carrying out the assessment isn't the same as the therapist delivering the therapy, any adaptations made during the assessment stage should be shared with the therapist before therapy sessions start.

Involve others

Give autistic people the opportunity to choose someone close to them to advocate on their behalf in sessions. Some people say they benefited from having a close family member or friend with them in the first session, while some only wanted someone present just at the end of sessions and others always wanted someone there. This won't be a suitable adjustment for every autistic person but it can change the experience entirely for some and enable them to engage.

Naming feelings and emotions

Often it is assumed that everyone understands what a specific feeling or emotion is. Many autistic people have alexithymia. This means that naming feelings and emotions can be particularly difficult. Therefore, before referring to a feeling or emotion, you should make sure the person you're treating understands the emotion you are referring to and can relate to it. For some, being able to talk about specific physical sensations can be particularly useful.[36] Consider using a body map as a visual aid to get a good description of the person's experience of the emotion.

Incorporate interests

Many autistic people have intense and highly focused interests. Some therapists spoke about using these to build on their therapeutic relationship and in therapy goals. Some autistic people shared it can be motivating for them when a therapist takes a genuine and respectful interest in what they care about.

The principles set out in this section, from providing structure to incorporating interests, should be considered when delivering the actual therapeutic intervention; eg, during goal setting, setting up homework, considering relapse prevention techniques etc.

Monitoring outcomes

The PHQ-9 questionnaire has been "validated and found to have acceptable psychometric properties in cohorts of autistic people with heterogeneity in their autistic characteristics and co-occurring intellectual disabilities".[37]

The GAD-7 has been used in autistic populations, but their psychometric properties have not been fully validated in this population, and the extent of their validity in representative autistic cohorts is not known.[38]

On both measures, it may be necessary to make adaptations. Some autistic people will interpret language very literally and may struggle with filling in forms. Many autistic people may also find it difficult to identify or understand their emotional responses. It may therefore be helpful to discuss the meaning of each question in the surveys being used and check understanding prior to completion.

Some questions may be less useful for monitoring autistic patients unless they are explained. For example, many autistic people have limited but highly focused interests and so questions like 'Over the last two weeks, how often have you been bothered by little interest or pleasure in doing things?' may not be a useful indicator of mood. Instead, you can first ask the autistic individual what their interests and hobbies are and whether their engagement with these things tends to change or stay the same regardless of the way they are feeling. Similarly, autistic people may approach food in a routine way or struggle with interoception, making questions about appetite less informative.

It may be helpful to spend some time explaining the aim of each question as well as the autistic person's specific indicators of low mood or anxiety. These will be unique to the individual and you may wish to use this information to further probe some of the questions asked in the standardised surveys.

Providing opportunities for feedback

Provide feedback opportunities to evaluate how the autistic people you are working with are benefiting from the adjustments and adaptations your service may already have in place.

Consider how accessible your current feedback process is:

- Are questions in feedback forms accessible? Have you avoided open-ended questions for example?
- Are views given anonymously?
- Is there the ability to submit feedback in different ways?
- Is there a process of reviewing this feedback and using this to inform changes in practice?

Ensuring good clinical supervision

Regular specialist supervision is a core expectation of service delivery. During our research, many professionals described additional benefits when able to access specialist autism support within their service or from a service nearby (eg via service autism champions). Running special interest groups was also strongly encouraged to allow professionals to explore potential adaptations and adjustments.

Sophie, an autistic adult, has had both positive and negative experiences with NHS Talking Therapies services. Below she reflects on how this could have been improved.

If a professional doesn't understand autism, they may make assumptions about you and what you need. We need professionals that understand autism in the first place, and then you as an individual service user secondly. If they don't understand one or both of these things, this can lead to a breakdown in the service user-professional relationship, which isn't helpful for any party involved.

When thinking about what specific changes I would recommend to NHS Talking Therapies professionals to make therapy better for autistic people, I would say first, be clear with the service user how they can get in contact with you. My preferred way of contacting professionals is emailing them. Then, always have a structure to each planned session with your service user, even if you're having a quick check-in call with someone. Verbally state this structure when you start the session. I used to like having this structure in front of me and I was encouraged to write down the structure of the session at the start. This really helped. Be open to involving others where appropriate, sometimes my mum acts as an advocate for me. She has sat in on some sessions and is able to speak on my behalf, which I find helpful.

Additionally, it is important to know that our PHQ-9 and GAD-7 scores may not always be wholly representative of how we are feeling. For example, I have scored fairly highly on the PHQ-9 in the past (which I believe assesses an individual's mood), but I scored highly on the question around concentration because of my heightened level of anxiety, not because of a low mood. I answer questionnaires literally. This needs to be considered.

Overall, professionals who understand autism, are flexible to working with the service user, not against them, and support that has a clear focus and trajectory has been most useful for me.

A lead therapist we spoke to in the North-West shared their thoughts on what has made the biggest difference to their practice, alongside some of the barriers.

By the time some autistic people get to us, it can be really difficult for them to trust/think we can help because of their previous experiences. Taking time to build up that therapeutic relationship and understanding can really make a difference; don't dive straight into the work but instead listen to that person's narrative.

By taking time at the beginning, it can help you to understand their difficulty in context. Being flexible about session times is also really important. For example, changing session times and not necessarily taking the full 50 minutes is something that has worked really well for me. I negotiate this individually with the patient and see what works for them.

Also, if they express a real interest in something, integrate it into sessions. For example, one person I worked with really enjoyed dressing up in re-enactments, so I used to bring that into the session. Not only did it develop our relationship but it also made it easier to embed some skills. We would talk about how you are when you are re-enacting and really tolerating that tension just before you start and we transferred that experience and skill into discussing tolerating uncertainty. This made it much more relatable and easier to understand.

Our practice could be improved with access to in-depth training based on people's lived experiences as well as regular follow-up training. Most people I work with really want to give the best support to autistic people but do not always feel confident they know exactly what to do and can worry about doing something wrong. In the past, I have had the opportunity to attend a full day of training but it was many months until I actually got to apply that knowledge. Being able to access something to support my practice, such as online materials for when I see someone, would be great.

5 Checklist to improve support for autistic adults

Understanding autism:

- ❑ Does every member of your team have access to autism training?
- ❑ Are autistic people involved in the design and delivery of the training?
- ❑ Is the autism training accessible to all and available directly, face-to-face and indirectly using online materials?

Does the training cover key topics such as:

- ❑ what is autism – explaining the core characteristics of autism
- ❑ intersectionality (people's overlapping identities – including their gender, race and class)
- ❑ common co-occurring conditions such as ADHD and mental health conditions
- ❑ therapy adaptations and adjustments for autistic people
- ❑ suicide awareness.

Therapy/clinical environment:

- ❑ Do your waiting rooms and therapy rooms consider different sensory needs? Do you have an alternative waiting room for autistic people which is quieter and has fewer people?
- ❑ Have you had an active and equal conversation about adjustments and provided examples about possible changes that could make the environment work better for the individual?
- ❑ Have you minimised background noise and got headphones for video calls?
- ❑ Have you discussed preferences re. video calls, phone calls and in-person sessions?
- ❑ Do you understand the sensory needs of the autistic person and have you made all necessary adjustments?

Processes and systems:

- ❑ Do you have a flexible attendance policy? Can autistic people contact the service in multiple ways as opposed to only by phone?
- ❑ Have you provided as much information as possible about the service and what to expect?
- ❑ Are autistic patients able to access shorter or longer sessions if needed?
- ❑ Can autistic patients access more or fewer appointments than standard if needed?
- ❑ Can breaks within sessions be accommodated?

- Can patients see the same therapist consistently if needed?
- Can appointments be rearranged via text, email and/or online booking?
- Are your appointment letters clear and do they include:
    - name of the practitioner?
    - an outline of the session?
    - what will be expected from the autistic person?
    - examples of what the session aims to achieve?
    - photographs of the therapy environment?
    - a sign off from the therapy practitioner?

Practitioners:

- Does every member of your team have:
    - access to specialist autism practitioners/champions who can support treatment plans to ensure that these are tailored to the autistic adult's needs?
    - access to clinical supervision with a supervisor who specialises in working with autistic people?
    - opportunities for peer support (from other practitioners or champions) on supporting autistic people?
    - opportunities for reflective practice specific to treating autistic people?
- Is there an opportunity for your service to develop a special interest group which focuses on good practice and/or to communicate with other practitioners and services nationally to share best practice on working with autistic adults?
- Is joint training between NHS Talking Therapies clinicians and clinicians working within pathways/services specific to autism (these pathways include statutory, voluntary or charity sector organisations) in place to encourage shared learning and best practice?

Feedback and improvements:

- Do you have an anonymous feedback process?
- Is the feedback process accessible to autistic people?
- Have autistic people co-produced this feedback process?
- Is there a process of reviewing feedback and using this to inform changes in practice?

Considerations and adaptations to therapy sessions

Suggestions for adapting your therapy sessions to support autistic people:

- Start your session by asking your patient if they need any adjustments and if so, what they may be. Always have some examples of adjustments available to help structure this discussion.
- Do you understand their communication needs and can they communicate in a way that meets these needs?
- Make sure you introduce yourself and explain what your job role is.
- Ask your patient if they know why they have been referred for therapy.
- Explain why you believe they have been referred for therapy.
- Develop some clear objectives (with examples) of what you both want to achieve.
- If you are going to complete an assessment, explain why you are doing it and what it will involve.
- Explain how your session will be structured; use a timetable or schedule if required.
- Speak clearly, using unambiguous language and avoid words with multiple meanings.
- Always allow processing time after you speak.
- Have a pen and paper available so that you can write or draw things if necessary.
- At the end of your session, summarise the key points. Provide a written list for them to take home if needed. Some patients may welcome a recording of their session that they can listen back to, to help them to process all the information.
- Offer your patient the opportunity for someone to attend their session with them.
- Do not assume that your patient can identify, understand or talk about their own emotions and think of ways you can help with this.
- Work with your patient to identify what their interests are and how you could incorporate these into your sessions.
- Work with your patient to complete outcome monitoring whilst being careful not to invalidate the outcome tool. This means, for example, explaining each question in a way that is understood by the person.

Delivering interventions

- Have you developed clear objectives (with examples) of what you want to achieve from each session?
- Have you used the SMART framework to develop goals for interventions with the autistic person?
- Have you supported the autistic person to make concrete plans about when and how they will manage tasks in between sessions?

6 Further reading

Anxiety

An evidence-based guide to anxiety in autism: **https://www.city.ac.uk/__data/assets/pdf_file/0020/557201/Anxiety-in-Autism-Guide-021219.pdf**

Parr, J. et al (2020). Treating anxiety in autistic adults: study protocol for the Personalised Anxiety Treatment-Autism (PAT-A©) pilot randomised controlled feasibility trial. *Trials* vol. 21,1 265. doi:10.1186/s13063-020-4161-2

Russell, A., Jassi, A., and Johnston, K. (2019). *OCD and autism: A clinician's guide to adapting CBT*. Jessica Kingsley Publishers.

Depression

Author: Lida, H. et al (2019)
Title: ***Disability, functioning, and quality of life among treatment-seeking young autistic adults and its relation to depression, anxiety, and stress***
Source: *Autism*. Vol. 23(7), pp. 1675-1686

Author: Cassidy, S. et al (2018)
Title: ***Measurement properties of tools used to assess depression in adults with and without autism spectrum conditions: a systematic review***
Source: *Autism Research*. Vol. 11(5), pp. 738-754

Alexithymia

Alexithymia | Autistica

Self-harm

Author: Camm-Crosbie, L. et al (2019)
Title: ***'People like me don't get support': autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality***
Source: *Autism*. Vol. 23(6), pp. 1431-1441

Author: Licence, L. et al (2020)
Title: ***Prevalence and risk-markers of self-harm in autistic children and adults***
Source: *Journal of Autism and Developmental Disorders*. Oct 26 [Epub ahead of print]

OCD

Russell, A., Jassi, A., and Johnston, K. (2019). *OCD and autism: A clinician's guide to adapting CBT.* Jessica Kingsley Publishers.

PTSD

Author: Rumball, F. et al (2020)

Title: ***Experience of trauma and PTSD symptoms in autistic adults: Risk of PTSD development following DSM-5 and Non-DSM-5 traumatic life events (2020)***

Author: Rumball, F. (2019)

Title: ***A systematic review of the assessment and treatment of posttraumatic stress disorder in individuals with autism spectrum disorders***

Adapting therapy

Brice, S. et al (2021). The importance and availability of adjustments to improve access for autistic adults who need mental and physical healthcare. *BMJ Open* ;11:e043336. doi:10.1136/ bmjopen-2020-043336

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Hayes, S. (2019). *A liberated mind - the essential guide to ACT.* Vermillion.

Linehan, M. (2014). *DBT skills training manual.* 2nd Ed. Guildford Press.

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Russell, A. et al (2020). The feasibility of low-intensity psychological therapy for depression co-occurring with autism in adults: The Autism Depression Trial (ADEPT) - a pilot randomised controlled trial. *Autism*. (6):1360-1372. doi: 10.1177/1362361319889272

Training resources

Autism, stress and anxiety

Mental health (autism.org.uk)

Professionals (autism.org.uk)

7 Endnotes

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