

Good practice guide

For professionals delivering
talking therapies for **autistic**
adults and **children**





Contents

4 Executive summary

- 4 Background
- 4 Our project
- 5 Important things you can do

10 Methodology

13 Across your service

- 14 Improve autism understanding
 - 14 Training
 - 18 Masking
 - 19 Suicide and self-harm
- 20 Change the physical environment
- 22 Change the structure of your therapy offer
 - 22 Number and length of sessions offered
 - 24 Deciding on therapy delivery
- 25 Provide information before therapy starts
- 27 Possible extra support
 - 27 Supervision
 - 27 Support for parents and carers
- 28 Ask for feedback
- 29 Previous negative experiences
- 31 Checklist

51 Acknowledgements

53 Further reading

6 Background

- 6 What is autism?
- 6 Autism and mental health
- 8 Getting services
- 9 Growing evidence of adapting therapy
- 9 Our project

33 In therapy sessions

- 34 Manage expectations
- 36 Discuss what adaptations and adjustments can be made
- 37 The therapy room
- 38 Use of assessment tools
- 40 Adapt your communication
 - 42 Use direct language
 - 43 Break things down
- 44 Structure the sessions
- 45 Involve others
- 46 Support with labelling feelings and emotions
- 48 Incorporate their interests
- 49 Note down what you have covered
- 50 Adapting therapy checklist

52 Glossary

54 Endnotes



Executive summary



Background

Autism is not a mental health condition, but many autistic adults and children develop mental health problems and too many reach crisis point avoidably. Our research suggests that this situation is driven by a lack of community mental health services that are adjusted and adapted to support autistic people's needs.

Our project

Our Mental Health Project, in collaboration with Mind, aims to establish how to make mental health talking therapies better for autistic people.

This guide incorporates the views of over 1,500 autistic people and almost 1,000 family members who responded to our mental health survey in October and November 2020. It is also based on our in-depth discussions with 17 autistic people, eight family members and 15 mental health professionals.

Talking about autism

Research shows that many autistic adults prefer to use 'identity-first' language to describe themselves.¹ Being described as an autistic person is generally favoured by those who view autism as a central and defining element of identity, similar to gender or race. 'Person with autism' is favoured by those who see autism forming just one element of their identity. As these terms can be emotive for individuals, it is best to follow the lead of the person you are speaking to – using terminology that they prefer and giving them control over how they are spoken about.² For our resource, we have chosen to use identity-first language throughout.





The most important things you can do

Across your service:



- ✓ improve autism understanding for all staff through training
- ✓ make the physical environment in both waiting and therapy rooms less overwhelming
- ✓ think about ways you can all change the way therapy is delivered in your service to make it more autism-friendly
- ✓ provide additional support to autistic clients
- ✓ ask for and use feedback from your autistic clients
- ✓ make sure the information about your service is autism-friendly, clear, concise and specific
- ✓ explain the different therapy delivery types you can offer and give your client a choice about what works best for them.

In therapy sessions:



- ✓ make sure the therapy room isn't overwhelming
- ✓ use simple, plain language
- ✓ give time for autistic people to process information and answer questions
- ✓ ask them if they would like someone close to them to be involved in sessions
- ✓ support them to be able to label their own feelings and emotions
- ✓ try to integrate autistic people's interests if that will help them
- ✓ note down what you have covered and share this with the autistic person.

Although these are some of the most important changes you can make, there are many other useful tips in this guide.

Background



What is autism?

Autism is a lifelong disability which affects how people communicate and interact with the world. There are approximately 700,000 autistic adults and children in the UK.³ It is a spectrum condition, meaning some people may require more help and support than others. Despite some autistic people sharing certain characteristics, every autistic person is different and individual in their needs and preferences.

Autism and mental health

Autism is not a mental health condition. However, incredibly high numbers of autistic people experience poor mental health: a 2019 survey found 76% of autistic adults report reaching out for mental health support in the last five years.⁴ Anxiety and depression are the most common mental health problems among autistic people.

Higher rates of anxiety and depression in autistic people have been associated with lower life satisfaction, greater social difficulties, loneliness and insomnia.⁵ This

can have devastating consequences. Research shows that autistic people are significantly more likely to think about, attempt, and die by suicide than the general population.^{6 7 8 9} This includes the National Institute for Health and Care Excellence (NICE) 2018 guidance on suicide prevention which recognises autistic people as being among those at the highest risk.¹⁰

Unfortunately, the situation is not much different for autistic children. 70% of autistic children have a mental health problem (such as anxiety or depression), and 40% have more than one.¹¹ In addition to this, between 7% and 41.7% have self-harmed and/or attempted suicide.^{12 13}

The coronavirus pandemic has only exacerbated the mental health crisis for autistic people. The rapid withdrawal of mental health and social care services has left many without the support they need. This means that over the coming months and years, autistic people may reach out to mental health services for help in even greater numbers. It's vital that the support they get works for them.

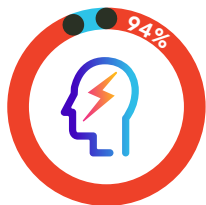
Our *Left stranded* report found that during the first lockdown:

- **nine in ten** autistic people worried about their mental health
- autistic people were **seven times more likely** to be chronically lonely than the general population; and **six times more likely** to have low life satisfaction.



Mental health survey results

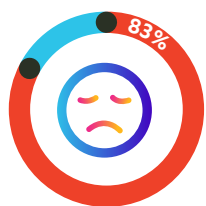
Nearly all autistic adults have experienced anxiety and around two in three have had this diagnosed by a health professional.



94% of autistic adults reported experiencing anxiety.



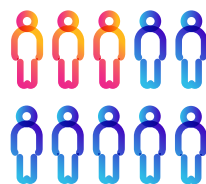
Almost 6 in 10 said this affected their ability to get on with life.



83% reported experiencing depression.



Half said this had a high impact on their ability to get on with life.



Almost 3 in 10 fall into the severe depression category based on the PHQ-9.



Almost half fall into the 'severe anxiety' category of the GAD-7, showing if an autistic person did report experiencing anxiety, it was more likely to be severe.



2 in 5 are currently diagnosed with anxiety and **1/4** have had a diagnosis in the past.



Autistic people reported **much lower life satisfaction** levels than the general population.¹⁵



Eight times as many autistic people report feeling often or always lonely when compared to the general population.¹⁴



As anxiety levels increase, life satisfaction decreases.



The more lonely a person reported they were, the more likely they were to experience greater anxiety and more severe depression.

Getting services

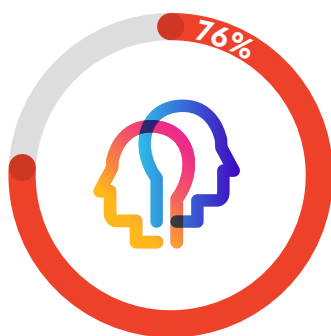
Autistic people report being pushed between different settings. Often, mental health services are not confident in 'dealing with autism' and refer autistic patients to disability services that are not well-equipped to provide mental health care.^{16 17 18 19} This is a particular issue for autistic adults without a learning disability, and too often results in problems escalating until emergency or inpatient care is required.²⁰

Our inquiry with the All-Party Parliamentary Group on Autism (APPGA) into the Autism Act: 10 years on showed that only 14% of autistic adults and 11% of families said there were enough services in their area to meet

their needs.²¹ Furthermore, 82% and 86% of families told us that the process for getting mental health support took too long.

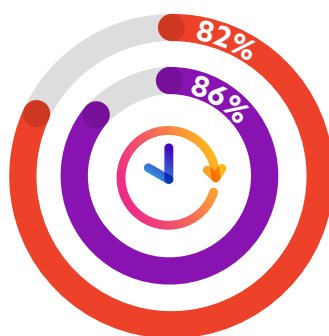
Autistic people who managed to get mental health support often told us they ended up receiving care that was not appropriate for their needs as an autistic person. The counselling they received was not adapted and their behaviour was misinterpreted. Other research has found healthcare professionals can lack experience in supporting autistic people's mental health and can lack confidence with autistic clients.^{22 23 24}

Key:  Autistic adults  Families



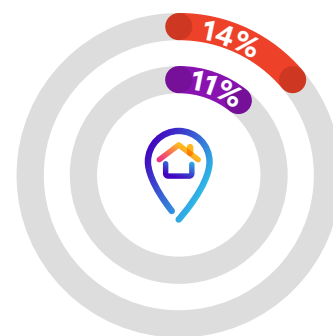
76% of
autistic adults

had reached out for
mental health support in
the last five years.



82% of autistic
adults and **86%**
of families

said getting support from
mental health services
took too long.



Only 14% of
autistic adults and
11% of families

said there were enough
mental health services in
their area to meet their
needs.

Growing evidence of adapting therapy

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.²⁵ The NHS Long Term Plan (2019) also aims to improve mental health support for autistic people in the community.²⁶ The National Institute for Health and Care Excellence (NICE) recommends adapting therapy to suit the needs of autistic people.²⁷ A growing body of evidence shows adapting therapies such as Cognitive Behavioural Therapy (CBT) increases the effectiveness for autistic people.^{28 29 30}

Key adaptations from these studies include:

- providing clear examples and using unambiguous language
- slowing down the pace of the session
- using a more concrete and structured approach.

These are not surprising findings. These adaptations are used to support autistic people in lots of situations. But our research suggests they are not being applied consistently in mental health services.

Adaptations and adjustments need to be made at every point of a person's journey through mental health services: from their first contact, to therapy goals to measuring outcomes. This is important as tools used throughout therapy have been developed for the non-autistic population. The Royal College of Psychiatrists advises that this can make them unhelpful or misleading if not adapted.³¹

Our project

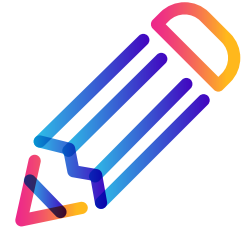
Few studies have directly sought the views of autistic people to discuss what works for them. There is also currently little published evidence on how best to adapt practice for autistic adults nor is there guidance for therapists.

We want to change this. Learning from autistic people and family members, we identified the biggest barriers to accessing talking therapy in the past, as well as what support has worked best. We then worked with mental health professionals to understand what is practical and achievable. We also discovered a lot of good practice examples that therapists are already using to deliver positive outcomes.

Our research is also supported by the findings of our mental health survey which was conducted in October and November 2020.

The results of this research are set out in the following guidance. Many of the changes are simple to do and the benefits will be felt by autistic clients and therapists alike.

Training on how to make adaptations and adjustments for autistic adults and children is key. Previous studies have shown that a therapist's confidence to make useful adaptations for autistic people was not associated with their years of practice or how many adaptations they made but was dependent on how much training they received.³²



Methodology

Advisory board

We recruited an advisory board to govern and oversee the project. The board was made up of experts by experience including parents of autistic children, autistic adults and young autistic adults as well as clinicians, researchers and Mind. We consulted with the board on the project's aims, the different stages of the research - including reviewing the overall findings - and on the production of this resource.

Research

580 autistic adults and 500 family members completed both our coronavirus survey in July 2020 and our follow-up mental health survey. We then used a website pop-up to capture the views of 1,000 more autistic adults and 400 more family members for the mental health survey. Overall, we got responses from 1,580 autistic adults and 900 family members.

We also ran focus groups with autistic people, family members and mental health professionals. We spoke to eight autistic young people (aged 16 to 24), 17 autistic adults and 15 mental health professionals.

Remember

Person-centred practice is key.



Overall demographics

We include perspectives from:

- autistic adults and young people, including people
 - with a variety of communication support needs
 - from ethnic minority backgrounds
 - who are LGBTQ+
 - across different age ranges
- parents of autistic children, including parents who are autistic themselves
- professionals with experience of working with autistic people with different support needs and some who are autistic themselves.

The therapists we interviewed worked in:

- IAPT – Improving Access to Psychological Therapy services
- community mental health services
- inpatient settings
- diagnostics
- private practice.

The experience of clinicians varied from over 20 years to trainee psychologists. This gave a broad picture of the types of therapists working with autistic adults and children.

To find professionals with experience of delivering talking therapy to autistic people, we used our pre-existing networks and worked with the NHS England Autism Team, Mind and the Centre for Mental Health.

Many of the findings would in fact help the general population. But for autistic children and adults, it could be the difference between being able to benefit from therapy at all.



Not every autistic person will have an autism diagnosis and others may not feel comfortable to disclose that they have one. Knowing the high rates of mental health conditions amongst autistic people, you may decide that it would be appropriate to use some of this guidance even when someone does not have a confirmed diagnosis.

There are boxes throughout this resource that describe some of the characteristics autistic people may have as well as our top tips and recommendations. For further information, visit www.autism.org.uk.

Every autistic person is different and there are many factors other than a person's autism that need to be considered when adapting their therapy. As a therapist, you should also consider, for example, a person's ethnicity, gender identity and sexual orientation to ensure you are using person-centred practice to inform how you treat and work with the person in front of you.

The adaptations and adjustments described in this guide are a combination of the experiences of autistic people, parents of autistic children and mental health professionals. We have provided some background information on each suggestion, quotes from the participants and a checklist which we hope you will find useful for your everyday practice.

We have divided this guidance into two sections:

Section one:



Recommendations across your service

Section two:



Recommendations for therapy sessions

Although we have divided it into sections, they overlap. We recommend reading and considering the guide as a whole to think about how you might need to make changes across several areas of your service.

Remember

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.



Section one: Recommendations across your service



Many services are working hard to adjust their practice and policies to suit the needs of autistic adults and children. In this section, we highlight useful advice on what services can do as a whole to improve the experiences of autistic clients.

Our top recommendations include:

- ✓ improve autism understanding for all staff via training
- ✓ make the physical environment in both waiting and therapy rooms less overwhelming
- ✓ be flexible about the way therapy is delivered
- ✓ provide additional support to autistic clients
- ✓ ask for and use feedback from your autistic clients
- ✓ make sure the information about your service is autism-friendly, clear, concise and specific
- ✓ explain the different therapy delivery types you can offer, including online and face-to-face, and give your client a choice about what works best for them.



Improve autism understanding



Training

Everyone we spoke to highlighted better autism understanding as key to supporting better therapy experiences and therefore better outcomes.

Mental health survey results

When ranking what was most important in mental health therapies for autistic people, people ranked:

1

First, the therapist's understanding of autism.

2

Second, having information about what therapy will be like before it starts.

3

Third, the process for accessing therapy.

Across our conversations, there were clear inconsistencies in therapists' training on working with autistic adults and children. While some therapists had received several days of face-to-face training, some had received nothing at all. The stress and impact on the individual therapist expected to work with someone they have had no support or teaching about is considerable. Training is needed for autistic children and adults to benefit from therapy but is also key to support the wellbeing and confidence of therapists.



“Not knowing enough about how autism and OCD overlap made me feel really stuck in knowing what to do. I felt so helpless as a clinician in not being able to help. I worked with that young man ten years ago and it still really sticks in my mind.”

Department lead clinician

“I don’t feel like I’ve had much training in terms of what I am doing now and in terms of making adjustments. It’s a lot on me to try to find out what is going on. There is nothing in training to specifically tailor therapy to different groups.”

CBT therapist

Services should provide training in line with the Autism Act statutory guidance and the Core Capabilities framework for supporting autistic people.^{33 34} Giving all staff some level of autism training can make a massive difference, as you can make adaptations and adjustments from the moment the person first interacts with a service. Training should include people with lived experience. Giving clinicians access to online resources **in addition** to face-to-face training has been found to be useful. Therapists can then reflect on and access this as and when it is needed.

“All staff are expected to be trained. Our training has been developed by colleagues who have autistic children and is very experiential. First, they run a half-day workshop for all staff and then run a second one just for clinicians as a whole day workshop specifically about working with autistic people in therapy.”

Assistant clinical lead

Previous research has shown it is not their years of experience or the number of adaptations therapists have made which gives them confidence in adjusting their practice for autistic people, it is the level of training they receive.³⁵

Training should focus on person-centred practice, taking a holistic view of people's experience and identities. This includes considerations of factors such as a person's ethnicity, gender identity and sexual orientation to inform how therapists treat and work with the person in front of them. Furthermore, it is common for autistic people to have co-occurring conditions such as Attention Deficit Hyperactivity Disorder (ADHD), dyslexia, dyspraxia or a learning

disability. An awareness of what these conditions are and how they can intersect with someone's needs as an autistic person is important.

The impact of poor understanding from therapists was highlighted again and again throughout our conversations. Some therapists were open about their lack of knowledge and wanted to learn more from their clients - autistic adults sometimes found this a positive and rapport building experience. However, others felt exhausted having to educate their clinicians on what autism is. All health staff should have an underlying understanding of autism, to build on with each autistic client.

"Most therapists' understanding is based on the white male brain. They need to understand cultural and gender differences."

Lauren-Rochelle, autistic adult

"Many autistic people identify as LGBTQ+, you need to be clued up on this. It makes a massive difference."

Billie, autistic young person

"Most professionals don't understand autism. What makes it difficult is the myths about autism, that autistic people lack empathy and can be cold-hearted. People in that profession should understand myths aren't true and at least learn the basics."

Parent of an autistic child



For more in-depth information about co-occurring conditions, please see the National Autistic Society's page on related conditions <https://www.autism.org.uk/advice-and-guidance/topics/related-conditions/related-conditions/all-audiences> as well as our advice and guidance for professionals around common mental health conditions <https://www.autism.org.uk/advice-and-guidance/topics/mental-health>

“I had a really good counsellor who I thought got it. Then they just dropped in a myth about autism and I just remember thinking you’re doing a really good job of getting it but you’re just not getting it. It undermines that trust.”

Sara, autistic adult

“13 years in and out of mental health services, diagnosed with everything but autism. 13 years in the system. All the medications, nobody was looking for it.”

Suzanne, autistic adult

When developing your understanding about how best to work with each autistic client, listen to their views. If the client is happy for you to do so, it can be very valuable to speak to their close network. Parents and caregivers we spoke to emphasised how much of a resource they are, in knowing and understanding both autism and their child in depth. However, too often, they said their views are dismissed and they are not properly listened to. Taking the time to seek these views can save time in the long run and help inform person-centred practice.

Almost every autistic person and parent in our focus groups had been back and forth between services for many years.

For many, there had been several interactions with mental health services prior to any autism diagnosis. Many felt frustrated and sad that no therapist had considered or mentioned that they might be autistic. Having the awareness and skills to be able to recognise autistic characteristics and - where appropriate - start these conversations can be life-changing and save ‘years of pain’. This does not mean all staff need to be able to diagnose autism. This requires specialist skills and training. However, being open to these discussions could make a big difference to many people, alongside referring or signposting people to diagnosis services if appropriate.

“Being open to having things explained and not brushing things aside [is important]. The counsellor I had admitted he didn’t know anything about autism. Instead we work together, he tells me how a neurotypical person would process something then asks how I process it and how I am different. That to me is really helpful because I’ve learnt a lot about the way I think and the way I am different to neurotypical people. So I’ve learnt a lot and I’ve taught him a lot.”

Suzanne, autistic adult

Masking

What is masking?

Masking is when an autistic person has learned to consciously or subconsciously hide or suppress some of their behaviours to 'fit in' with non-autistic people's expectations.³⁶ Although all autistic people might mask, masking is common particularly in women and girls.³⁷ It can be exhausting for autistic people and may be associated with:



- low self-esteem
- anxiety
- increased emotional overload
- meltdowns.³⁸

Many autistic people told us that they want therapists to be aware of masking. Many feel their therapists might judge them for being autistic.

This can lead someone to:

- answer questions with what they think a therapist expects of them
- suppress stimming/self-stimulating behaviour such as rocking and hand-flapping so they appear more 'normal'.

Masking can be exhausting and can give an unrealistic picture of how significant someone's mental health difficulties are, as well as make their needs less clear.

Be aware that the person you are working with may be masking. After building a rapport with them, discuss masking and ask whether they feel they are doing this in sessions. This will give you a clearer picture of their needs and the work you will do together. Displaying a good understanding of autism and offering reassurance will help your autistic client.

Key considerations:



- Do you know what masking is and why an autistic person might mask?
- Have you discussed masking with the person you are working with?
- Have you considered how autistic characteristics might be masked both inside and outside of the therapy room and the impact this can have on the person's life?

"Lots of people are undiagnosed, everyone who is autistic is different. If you want to, you can hide that you are autistic. For some people, it is very hidden or very subtle so therapists need to take time to understand us."

Autistic adult

Suicide and self-harm

Tragically, autistic adults and children are at a higher risk of taking their own lives than the general population. Most suicide awareness training is based on the non-autistic population. The differences some autistic people may have in communicating and interacting means they may present differently to how you would expect. For example, an autistic person may be able to follow their usual routine to get ready for an appointment and still have suicidal intent. Alternatively, they may discuss plans in what appears to be a 'matter of fact' way.

The Royal College of Psychiatrists recommends using well-defined and specific questions when assessing intent. Doing this will give a more accurate reflection of an autistic person's thoughts and help avoid unexpected and logical answers.

For example, instead of:

- How often do you think of suicide?
- How likely are you to harm yourself in the future? (which could for example lead to calculating self-harm over the next 40 years)

Use:

- How many times have you thought of harming yourself today?
- How long did you think about this when you had these thoughts?
- Do you think these thoughts will be less or more over the next week?
- What do you do when you have these thoughts?³⁹

Key considerations:



- Does every member of your team have access to autism training?
- Were autistic people involved in the design/delivery of the training?
- Is the autism training available face-to-face and using online materials?

Does the training cover:

- key autistic characteristics
- intersectionality (people's overlapping identities - including their gender, race and class)
- common co-occurring conditions such as ADHD
- specific ways of adapting therapy
- suicide awareness
- speaking to family, partners or close friends?

Language around suicide:

The Samaritans recommend using terms such as 'die by suicide' and 'taking their own life'. This is why we use this language throughout our resource.⁴⁰

"When you cannot see any other solution it can seem like the only logical step. Just because I've got make-up on and I am smiling doesn't mean I won't, we are routine-based. When someone tells you they are on the edge, please listen."

Michelle, autistic adult

Change the physical environment

This is also covered in the later chapter *[The therapy room](#)*



Making adaptations to the waiting room can minimise unnecessary stress a person may experience before starting therapy. This will allow for better engagement and therefore better outcomes.

Many autistic people experience sensory differences. It is important to think about this before someone even enters the therapy

room. Could the waiting room and process be causing someone unnecessary distress if it's busy and loud, for example?

Some practices told us they are able to operate two waiting rooms. One is a low sensory environment with dimmer lights, fewer notices on the board, less visual clutter, minimal noise and it is purposefully less busy.

Sensory differences

Processing everyday sensory information can be difficult for autistic people. Any of their senses may be over-sensitive or under-sensitive or both, at different times. These sensory differences can affect how they feel and act, and they can have a profound effect on a person's life.



Sometimes an autistic person may behave in a way that you wouldn't immediately link to sensory differences. A person who finds it difficult to process everyday sensory information can experience sensory overload or information overload. Too much information can cause stress, anxiety, and possibly physical pain. So, overload may look like withdrawal, distressed behaviour or meltdown.⁴¹

Adaptations to waiting rooms:

- minimise unnecessary clutter
- be aware of loud and distracting noises, such as the radio playing or a ticking clock
- consider using dimmer lights or natural lighting
- consider the impact of smells
- allow the person to wait where is best for them.

One person told us they could wait in their car before sessions (a comfortable environment). They were then sent a text when their therapist was ready to see them. This helped minimise unnecessary anxiety before a session so they were ready to engage right away.

Minimising 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.

Remember

Unexpected changes can be really anxiety-provoking. This can include appointments not running to time. We know that sometimes delays are unavoidable.

Try to give accurate information about the length of the delay and reassurance that their appointment won't be affected. Be aware that this might mean that an autistic person is already experiencing a high level of stress at the start of the appointment.



Change the structure of your therapy offer



Number and length of sessions offered

Some services offer autistic children and adults additional sessions from the outset. This applies to people with and without a diagnosis. The therapists that have been able to do this highlighted how important it is in developing trust and understanding their clients' needs.

Autistic people also told us this gives them enough time to process therapy as well as to build a rapport and trust with a therapist. Similarly, **having the same therapist**, for longer sessions and meeting with them over a longer period, were mentioned as some of the best adaptations a service can make.

Some people need longer sessions to help process all the information, while for some a full session of communicating in a new situation could be overwhelming; it is all down to the individual. Making person-specific changes can really help boost engagement and improve therapy outcomes as a person can process it in the time and way they need. Being flexible and adapting to someone's needs from the beginning gives the best opportunity to meet therapy outcomes and avoid someone ending up being unnecessarily re-referred or moved up to a higher need service.

Without being offered more sessions in the first place, autistic people may end up being re-referred to services and having to start the whole process again.

"If you are lucky enough to access a service, six sessions won't get you anywhere. The first six sessions, you are developing an element of trust."

Autistic adult

“Being able to offer sessions virtually is actually better for one of my clients as he doesn’t have to leave his bedroom, he much prefers not having to come to hospital and is much more comfortable.”

CBT therapist

“I have permission from my service to use an initial four to six sessions to develop an understanding of the person’s unique experience of autism and understanding of what can be done on that basis. Then I use another set of sessions to embark on treatment.”

CBT therapist in IAPT

“Changing session times, so not necessarily taking the full 50 minutes, is something that works really well. I negotiate that with the client I am working with.”

Department lead clinician

Keep a flexible attendance policy

Time management can be difficult for some autistic people. Keeping appointments at the same time every week not only improves consistency and predictability but can support attendance. Make sure you are being flexible in the ways a person can contact a service if they are unable to make an appointment. Remember that some autistic people find talking on the phone difficult which can create an unnecessary barrier.

- Can making initial appointments, as well as arranging ongoing appointments, be done via text or email?
- Do not strike autistic people off for missing an appointment, work with them to understand why this happened and what adaptations need to be made.



Deciding on therapy delivery

Don't let stereotypes or assumptions cloud clinical judgement: treat the person in front of you as an individual. Therapists told us they changed their behaviour and approach in fixed ways when they knew the person they were working with was autistic and sometimes this made things worse. It can hinder person-centred therapy techniques as decisions are based on stereotypes, not individuals. For example, one therapist we spoke to automatically chose to give an autistic client one-to-one therapy. Speaking to them in sessions, they learnt that the client would have much preferred group therapy and it was clear this would have been beneficial. She reflected she had unintentionally restricted what was offered to the client's detriment.

Furthermore, coronavirus restrictions have meant that some therapists and autistic people are having sessions online. For some, this has been working really well, and it is worth highlighting this as a future therapy choice. However, others would prefer to see people face-to-face. Mind's *Trying to connect* research report also highlights the importance of people being able to choose how they receive mental health support.⁴²

Every person is different: this applies to the therapy techniques you use throughout your sessions.

“Helpful for them to have a basic understanding of what autistic traits might be and ask you how that impacts your life, rather than taking it from a manual.”

Autistic young person

Use a person-centred approach by involving your client in the decision.

- Explain different therapy options to help decide what would suit them best.
- What do they think they would benefit from?

“This guy I am working with at the minute, he's not got a diagnosis and I carried out interventions with him that I wouldn't usually do if I knew the client had ASD and he's absolutely smashing it. Then when I think about clients in the past, I've maybe not tried certain things I could have.”

High intensity trainee therapist



Provide information before therapy starts



For many autistic people, new and uncertain situations cause anxiety. Previous negative experiences only add to this. How you set up appointments can be incredibly important for increasing future participation. You should try to provide as much information as you can – in a clear and accessible way – before starting treatment. Just like making environmental adaptations, reducing unnecessary stress before a person begins therapy is key to building a good relationship.

“We need information before the session about what will be expected of you and what will happen, it is so stressful walking in and not knowing what is going to happen.”

Billie, autistic young person

Examples of things that are useful to include:

- Say who you are. Make sure the letter is signed and from 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 stress.
- State what therapy will look like/how it will work, this could include a rough agenda of the plan for the first session.
- State what is expected of the person, 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. 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.

“How one sets up an appointment/ where one sits makes a difference, the most important thing is to write an appointment letter that is as clear and straightforward as possible. This should be signed by the therapist, not an administrator, and have information about what is going to happen and who they are going to see. Being thoughtful from the beginning means people are more likely to feel confident.”

CBT therapist and researcher

Key considerations:

- Have you sent the person a letter beforehand?



Make it clear:

- where they are going
- who they are going to see
- why they are there
- what to expect.

Provide a picture of the waiting room and therapy room and if the therapy is taking place online, the online equivalent.

Possible extra support



Supervision

Regular supervision is a core expectation of working in mental health services, and it is central to delivering good practice. Being able to share experiences with peers and ask opinions helps clinicians to gain new perspectives on their practice. Many therapists said they benefit from being able to access specialist support within their service or a service nearby. Many described benefiting from special interest groups run in their service. For example, a group of clinicians with a specific interest and experience in a topic run a session describing key adaptations and adjustments they have made in the past and the most important things to try.

Does every member of your team have:



- access to a specialist autism practitioner who can support them in their therapy planning?
- opportunities for peer support?
- Is there an opportunity for your service to develop a 'special interest group' which focuses on good autism practice?

Support for parents and carers

Introducing services to support parents and carers can make a difference. One service we spoke to had introduced a counselling service for parents alongside their child's therapy. This was not originally introduced for parents of autistic children, but all parents who went through that scheme had autistic children, showing a clear need. This helped to support their mental health and educate them on how to support their child's mental health at home. The service found far better therapy outcomes approaching support in this way.

Other examples of services that were offered include:

- free counselling for couples
- direct input from a link worker
- courses and advice about autism.

The IAMHealth programme has found group-based interventions for families can help them to develop management strategies and reduce distressed behaviour.

<https://iamhealthkcl.net/research-studies/treatment/>

“Providing that additional support for parents made a massive difference in resilience.”

Lead diagnostic psychiatrist



Ask for feedback

Many services are already making really positive changes. To assess how much the autistic people you are working with are benefiting, provide opportunities for anonymous feedback on what is working well and what can be improved. Asking for feedback in this way can pinpoint key areas for improvement.

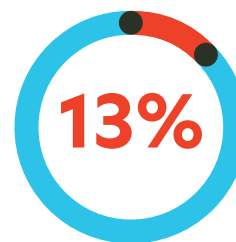
Key considerations:



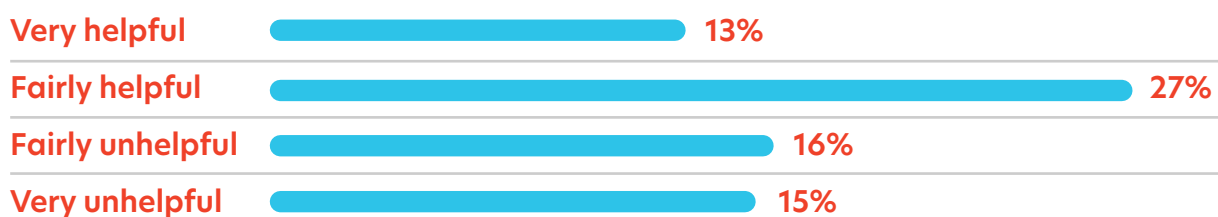
- Do you give opportunities for service users to provide feedback about the service?
- Are questions in feedback forms direct and to the point?
- Are their views given anonymously?
- Have you avoided open-ended questions?
- What do you do with this feedback?
- Is there a process of reviewing feedback and using this to inform changes in practice?

Mental health survey results

When asked how helpful is your GP concerning your mental health?



Only 13%
found their GP
very helpful



Previous negative experiences



“I have a complex about being too complex.”

Billie, autistic young person

Many autistic people have spent years being pushed from service to service and being labelled as ‘too complex’ – leaving them with nothing. Not only has this had serious impacts on their self-esteem, but it has also led to some developing a distrust of mental health professionals and anxiety around interacting with services.

For example, some autistic people we spoke to said they could become involuntarily non-verbal in the initial screening assessment and the initial sessions. This will require reasonable adjustments and adaptations – such as being able to offer a face-to-face screening assessment and allowing a client to write things down – in order to achieve a fully reflective picture of an autistic person’s needs. Ask the autistic person what might help.

In addition, many parents and autistic people shared with us that they were only ‘taken seriously’ and received help when things were ‘really bad’ and they were at crisis point.

“People’s previous experiences of therapy can create a barrier as this really deters them from seeking out therapy again or feeling able to talk to a therapist. Many people have just had a below par experience and it is harder for them to imagine that it could be different in the future. This makes them feel even less comfortable about being open about thoughts and feelings, you should consider it might take people longer to warm up.”

CBT therapist and researcher

“You need a sensitive approach right from the beginning if someone’s had a late diagnosis in their life, like me. We’ve already experienced self-isolation and not being understood; all that stuff needs to be worked through first before you go to something much deeper than that.”

Simon, autistic adult

“By the time people get to us, it can be really difficult for them to trust/think we can make a difference because of their previous experiences. Taking a lot of time to build up that therapeutic relationship and understanding really makes a difference.”

Department lead clinician

Letting someone know that they have control and power within the session can be a really useful way of making them feel more confident and gaining their trust. One therapist recommends asking clients where they want to sit and where they want you to sit as this empowers them in sessions right from the start.

“I say you choose your seating space and you tell me where to sit. By asking this, it starts off sharing the power straight away.”

Autistic private practitioner





Checklist

In your service:



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 available face-to-face and using online materials?

Does the training cover key topics such as:



key autistic characteristics

intersectionality (people's overlapping identities
- including their gender, race and class)

common co-occurring conditions such as ADHD

specific ways of adapting therapy

suicide awareness?

Do your waiting rooms and therapy rooms consider different
sensory needs?



Are there options of where to wait?

Do you have a flexible attendance policy?

Can appointments be made and rearranged via text and email?

Do your appointments letters:



say who you are?

state what therapy will look like, including a rough agenda and how long the session will be?

state what is expected of the autistic person?

offer some examples of what they may achieve?

include photographs of the therapy room and waiting room? and the equivalent for online sessions?

include the signature of the therapy practitioner?

Does every member of your team have:



access to a specialist autism practitioner who can support them in their therapy planning?

opportunities for peer support (from other practitioners)?

Is there an opportunity for your service to develop a 'special interest group' which focuses on good autism practice?

Feedback



Do you have an anonymous feedback process?

Is the feedback process accessible to autistic people?

Is there a process of reviewing feedback and using this to inform changes in practice?

Section two: Recommendations in therapy sessions



In the first session with a new client, have an active and equal conversation about what changes could be made to make the environment work better for them. This should not be a one-time conversation but something you are aware of and work on with the client across sessions to make sure the environment and the way you are delivering therapy is the best it can be.

"You can work collaboratively, we will come at you as equals in that and work with you. The right person wants to work with you and understand you."

Autistic adult

Our top recommendations include:

- ✓ change the therapy room to make sure it isn't overwhelming
- ✓ use simple, plain language
- ✓ give time for autistic people to process information and answer questions
- ✓ ask them if they would like someone close to them to be involved in sessions
- ✓ support them to be able to label their own feelings and emotions
- ✓ try to incorporate autistic people's interests if that will help them
- ✓ note down what you have covered and share this with the autistic person.



Manage expectations/ explain what they can achieve



Start off the first session by reinforcing why they are there and what they can achieve. Some people said they can find it very hard to visualise abstract concepts such as 'starting to feel better' which can make therapy demotivating as they don't understand how it will actually benefit their life. Others said, without proper direction from their therapist, they had unrealistic expectations about what they could achieve and felt demotivated. Giving autistic people clear expectations of what they could achieve can significantly improve motivation and engagement.

For example, if they are depressed and finding it hard to be motivated to go for walks which they usually enjoy, explain that by working together they can have more energy to do things they like such as going for walks. Or if they are feeling overwhelmed, describe how therapy can help break down those feelings and develop strategies that won't make them feel so stressed. Bring in real examples of the things they have told you motivate them to help achieve the best possible outcomes. To build trust and rapport, reassure them they are not alone and that many people can feel the way they do.

"Start off with what makes the person tick, what are their drives, what are the states that they really enjoy. Have a deeper dive with that person."

Autistic practitioner

“You need to tell me why I am there and what am I actually going to achieve?”

Autistic adult

“It helps you when someone explains the risks and the benefits.”

Simon, autistic adult

With any tool or assessment you do, take the time to explain the purpose. What is the assessment? What is the goal? Also examine how do you know that they have understood?

“Making sure whoever you are with, you are really clear what you are here for. I often ask ‘what did you hear me say’ so they can articulate what they think they heard to really make sure I know they have understood.”

Autistic private practitioner

Key considerations:

- Does your client know why they have been referred to therapy?
- Have you discussed what they want to achieve?
- Have you given real-life examples of what they could achieve?
- Do they know what the assessment is and why they are doing it?
- Have you developed some clear objectives (with examples) of what you both want to achieve?



Discuss what adjustments and adaptations can be made



Many autistic people and families told us they are not aware that adjustments and adaptations can be made for them. Therefore, they don't know how to ask for the adjustments that best suit them. We also heard that many do not know what exactly they need initially. By keeping the conversation active, equal and ongoing across sessions, together you can figure out what works best.

Examples of adaptations and adjustments

The following pages include suggestions for adaptations and adjustments that therapists, autistic people and parents of autistic children have shared with us.

Giving examples of the types of adjustments and adaptations that can be made can be a really useful way for someone to understand what they can ask for.

- Start conversations about adaptations and adjustments.
- Provide examples of what these could be.

“[If adjustments haven't been made] I've gone away from that therapy even more heightened than when I walked in. It hasn't felt like therapy. Then the chances I am gonna go back the following week are very limited.”

Simon, autistic adult

The therapy room

For more information, see the previous chapter
[Change the physical environment](#)

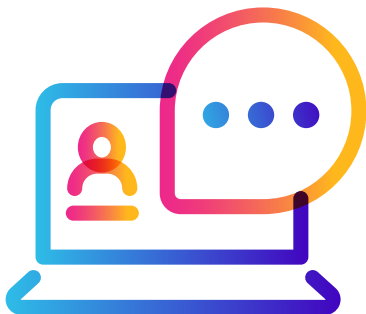


As with the waiting room, you should ask yourself if the therapy room is a suitable environment for someone with sensory differences? Are there small changes that can be made to make it more suitable? Is it a distraction-free, calm and comfortable space? This can form part of the conversations around possible adaptations and adjustments.

One person we spoke to described how the therapist wearing perfume could feel completely overwhelming. Another described how they were able to bring their own cushion with them to sessions which made them feel really calm.

“I can’t focus on anything; my focus is on that perfume.”

Autistic adult



Examples of adaptations

The therapy room:

- Make lighting dimmer where you can.
- Minimise clutter such as lots of books and papers around the room.
- Minimise background and outside noise as much as possible. One therapist said she could ask to use the quietest room on the corridor when she knew she was working with autistic clients.
- Avoid wearing strong perfumes or aftershaves.
- 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?

For video calls:

- Use a neutral background.
- Use headphones where possible to minimise background noise.
- Give them the option to take part on or off camera.
- Minimise all background noise.

You can make some of these adaptations before someone comes into the room. With others, you can work with your client to find out together what works best.

Use of assessment tools



Many autistic people and parents had been unable to access any therapy in the first place. Often, they are pushed from service to service. Too many said their needs had been described as 'too complex' to receive any support.

One reason is that mental health screening tools have been developed for a non-autistic population. Without adaptation, they might not give a full and accurate picture of an autistic person's needs.

"The ranges are difficult for me to interpret. I can't filter that out. When they ask me to score 0 to 10, I don't know what 10 is like."

Georgina, autistic young person



"One of the hardest things has been the Minimum Dataset Questionnaires, because we are asking people to consider how they felt in the last two weeks. That is impossible for him. At the beginning he was getting quite stressed as he knows how he feels right now and doesn't know how he was feeling last week. Now I send them out before the session so he can look at it for longer, he doesn't need to worry about it, then he can just fill it in for that day."

Clinician



Key considerations for assessments:

- Before you assess someone, you should give them clear information about the service, the clinician's role and the purpose of assessment.
- Break down questions to make them less abstract.
- Support further understanding by providing real-life examples. For example, 'Were you able to get your daily tasks done today? /yesterday?', 'Have you been able to cook regular meals?', 'Have you been able to keep your home tidy?'
- Do not assume that your client can identify, understand or talk about their emotions. Think of ways you can help with this.
- Have you given the person time to process each 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?
- At the end of the assessment, summarise the key points. Provide a written list if needed.

Adapt your communication



This includes being flexible about how therapy is delivered. Some people shared with us that it was useful to be able to 'do something' while in a therapy session, whether that be drawing, painting, walking with their therapist outside etc. For some, not having the main focus on the therapist asking them questions and them answering felt much more comfortable. This does not mean that they are not paying attention.

"Don't make assumptions that the person is going to be able to fit in to your communication, you have to adapt your communication with theirs."

Autistic adult

"Having someone say that eye contact isn't required is really important. I will always try and make eye contact but it often means I have less energy to engage with the session, knowing that the therapist understands that eye contact is difficult [helps me]."

Rosie, autistic young person

Key points to consider:

- Is the way you are conducting a session the best possible way for that person to engage?
- Do they need:
 - you to write things down?
 - to write things down themselves?
 - visual support?
- Could they benefit from being able to engage in an activity of their choice at the same time (drawing, painting, walking)?
- Could they benefit from recording the session?

"Often I am not allowed to communicate in a method that suits me. Verbal communication is not always my preference but the mental health services are set up for verbal therapy. For example, in sessions I have been told I cannot write my feelings down on paper and I must speak them."

Lauren-Rochelle, autistic adult

"We all learn differently and listen differently, verbal information isn't great for me, best way of understanding is to be practical."

Autistic adult

"Maybe have other activities (like arts or walking about) to do at the same time as talk therapies to lessen the intensity of the situation and make it less like an interrogation."

Autistic young person

Social communication difficulties

Autistic people have difficulties with interpreting both verbal and non-verbal language like gestures or tone of voice. Some autistic people are unable to speak or have limited speech while other autistic people have very good language skills but struggle to understand sarcasm or tone of voice.

Other challenges include:

- taking things literally and not understanding abstract concepts
- needing extra time to process information or answer questions
- repeating what others say to them (this is called echolalia).

Autistic people often have difficulty 'reading' other people - recognising or understanding others' feelings and intentions - and expressing their own emotions.⁴³



Use direct language

Therapists can sometimes misunderstand a person's communication needs. For example, therapists may assume because someone appears to be answering questions that they are fully understanding everything they are being asked. This can lead them to forget to break questions down and allow time for processing.

Easy ways to make your communication more direct include:

- Keep questions short and to the point.
- Leave time for the person to answer. Don't just re-ask the question straight away.
- Instead of focusing on open-ended questions relating to emotions, such as 'how are you feeling today', ask more specific and direct questions such as 'what do you notice in your body right now?' and 'what did you do today before you came to our session?'
- Offer options or choices where possible.

Every autistic person is different. Some people may take what you have said literally, therefore, avoid using:

- irony and sarcasm
- figurative language (this includes similes, metaphors, idioms, puns etc) such as saying 'It's raining cats and dogs'
- rhetorical questions (asking a question to make a point rather than to get an answer such as saying 'What time do you call this?' if a person is late).

If you say something and your client has not understood, explain what you have said and be really clear about what you mean to say.

"My biggest disability is my ability."

Billie, autistic young person

"Professionals should be cautious not to overlook someone like myself who is regarded as 'high functioning'. As I am confident and outgoing I am often not taken seriously, even when I am asking for support."

Lauren-Rochelle, autistic adult

"We usually start with the what went well and what didn't, quite bad at forgetting things unless specifically asked about something and work about my feelings around that."

Autistic adult



Break things down

Becoming overloaded

Some autistic people can find it difficult to filter out less important 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. This can make someone seem unresponsive and disinterested and, for some, can even lead to them being unable to speak. Others may become overwhelmed and experience meltdown.

The language you use in sessions is important. There is lots of information to cover and lots for a person to absorb when they start therapy. Help someone to understand what you have said by **breaking concepts down**.

Tips to help clients process information:

- Say less and say it clearly.
- Use specific key words, repeating and stressing them.
- Pause between points to give the person time to process what you have said, and give them a chance to think of a response.⁴⁴
- Use visual supports if appropriate such as writing things down or drawing things and allow the person to do the same.

It is up to you to assess how much you should modify your language to suit the individual's needs. You can check with them what would be best for them at the start and then check-in regularly to make sure it is still appropriate and if it needs adapting. It is important when you do this that you remain respectful and not patronising as this can be detrimental to the therapeutic relationship.

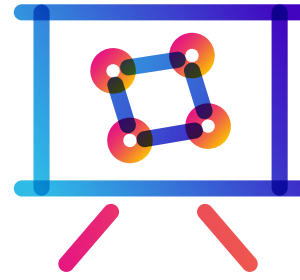
"If I am talking about it, I also need to process it. If I am talking to a therapist then they go straight on to say you could try this or do this, I won't process that information as I need time to understand and talk through the information I have shared."

Lauren-Rochelle, autistic adult

"Being encouraging and have an appreciation that I'm doing my best to communicate rather [than] assuming that I am being difficult or that I have nothing to say."

Autistic adult

Structure the sessions



Structure each session to support a person's ability to process information and help them manage any uncertainty about what is expected of them. Send the structure of the first session in a letter to them before, including approximate timings. After this, work collaboratively to set agendas.

Therapists we spoke to said that by setting an agenda with their client each week and sticking to it, they noticed a real difference in the person's participation and enjoyment of the sessions.

Following an agenda can make it easier to follow a structure throughout sessions, help set boundaries and make it clear when a session is coming to an end.

"One of the things that has made the biggest difference is making sure there is a clear set plan for how things are gonna go. This makes it as predictable as possible."

High-intensity therapist

"Make it the least anxiety-provoking it can be by sending stuff in advance so they know what I am planning, send recaps afterwards, bit of a summary and this is what I am asking you to read, making it as easy as possible."

Clinician

Key considerations:



- Set an agenda and send to the client before sessions – you can even add timings.
- Set an agenda together at the end of each session for the next session.
- Use and stick to the agenda throughout sessions.
- Manage when you are coming to an end by giving clues. For example, you could say 'There are five minutes left and so we are now going to talk about next week's agenda' and stick to this structure each week.

Involve others



Having therapy can be daunting for both autistic children and adults. Giving people the opportunity to involve a chosen person, close to them, can be a great way of easing someone into the process.

Their chosen advocate can support communication during initial sessions, helping to alleviate additional anxiety. They can be there to provide support as well as help to embed strategies learnt in therapy. Involving them in the screening assessment can help build a clear picture of the autistic person's needs. The advocate can help

to make them feel more comfortable and work with you to support the person's communication.

Both therapists and autistic people say there is some resistance in some services to involve others in the therapy process. There can be rigid beliefs that the time is only for the person receiving therapy or that parents should not be involved in their teenager's therapy. This won't be a suitable adjustment for every autistic person but for some, it can change their experience of therapy entirely and enable them to actually engage.

Triangle of Care

When recognising the essential role carergivers play, professionals should be guided by the Triangle of Care model. This is the therapeutic alliance between carers, service users and professionals. Its six principles aim to promote safety and recovery and to sustain wellbeing in mental health by including and supporting carers.⁴⁵



“Involving a close family member is a good way to make sure what is learnt in the sessions moves into the real world, translating things from one situation to another. This could be by sticking something on their fridge for example.

“You could try it as a hybrid by starting with family involved [if the young person is] anxious about meeting new people, until they feel comfortable. You could also split the session; we have our time and then family come in for the second half and we agree what we want to tell them beforehand.”

Consultant clinical psychologist

Support with labelling feelings and emotions



Naming feelings and emotions

Around half of autistic people have difficulties understanding and describing their own emotions. This is known as alexithymia.⁴⁶ They may also struggle to show or feel emotions which are viewed as socially appropriate.⁴⁷



Having alexithymia can contribute to anxiety because:

- it can mean the person struggles to sense physical symptoms of anxiety such as an increase in heart rate. This can make symptoms seem confusing and unpredictable, making their anxiety feel much worse.

Some autistic people may have alexithymia, meaning that they have specific difficulties recognising their feelings and emotions. However, many autistic people with or without alexithymia can struggle to label their feelings and emotions. Often it is assumed that everyone understands what a specific feeling or emotion is. This is not the case. This is key when considering what you are including in therapy goals and subsequently sessions; does your client have a concrete understanding of the feeling or emotion you are talking about?

Using tools such as a feelings wheel can help autistic clients better recognise and name their emotions by providing visual support.⁴⁸ One person talked about how useful an emotions to sensations feeling wheel is. Not only does it list the particular emotions someone could feel, it also links those to commonly felt sensations, making the concepts easier to understand and relate to.

“They need to understand you don’t always understand how you feel, all through mental health services the focus is on talking. There is not enough understanding that autistic people can’t talk about their own feelings. You could try drawing or art other than just talking.”

Autistic adult

Key considerations:



- Does the person understand the feeling or emotion you are talking about?
- How can you support their understanding? Can you use a feelings wheel?
- Can you ask them to think about how they physically feel?
- Can they draw it for you or write it down?
- Can they keep a feelings diary to build awareness?

“[I] move away from a label of anxiety and get them to show me in the body where they’re feeling it and what it is they’re noticing and where.”

High-intensity therapist

Mental health survey results

Some autistic people’s difficulties with and desire to improve the naming of feelings and emotions is highlighted by our mental health survey. When asked ‘What would you have liked to have known about mental health when you were younger?’ almost 80% ranked ‘How to communicate how I was feeling’ as the highest priority. Next was ‘help understanding my mental health needs’.

Almost **eight in ten** would have liked to have been able to communicate how they were feeling when they were younger.

How to communicate how I was feeling		78%
Help understanding my mental health needs		70%
How sensory needs affect mental health		66%
About my own strengths and weaknesses		65%
Who to go to for support		64%
How to access services		52%
How to reach and speak with other autistic people		48%

Incorporate their interests



Highly-focused interests

Many autistic people have intense and highly-focused interests, often from a young age. These can be on any topic and can change over time. Engaging with these interests is fundamental to autistic people's wellbeing and happiness and can be key to building a good therapeutic relationship.⁴⁹



If a person has a particular passion or special interest, work with them to integrate this into sessions. This can help build the relationship and support a person's engagement.

Autistic people said this can't be done superficially or forced, a person has to integrate it meaningfully and respectfully.

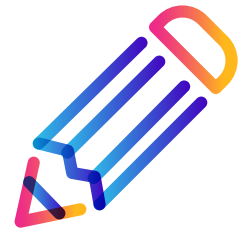
Does the person have something they are particularly interested in? Could you incorporate it meaningfully into sessions? Could you use this to embed key skills?



"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-enactment, so I used to bring that into the session because 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."

Department lead clinician

Note down what you have covered



A particular adjustment that many found useful, therapists and autistic people alike, is the therapist providing a few bullet points about what was covered in the session.

For some autistic people, being given lots of information can lead to 'overload'. Previous negative experiences can also contribute to overload as many autistic people can feel so anxious about the way they have been treated and prior experiences, this can also make it difficult to process initial sessions.

It can also be difficult to use the strategies discussed in therapy in everyday life. Being able to visually see in clear easy language what has been covered can act as a reminder for using strategies too. Allowing autistic people (if this is something they would like) to bring in a family member to support them in therapy might help them implement strategies after the session.

Could you write down four to eight bullet points of what has been covered? This can help build on strategies and support a person's understanding of the session. Alternatively, some clients may welcome a recording of their session that they can listen back to.




"Often the responsibility would be for the person to make notes. This is asking people to divide their attention between talking about something difficult and also make notes. This is a lot so the responsibility should be on the therapists to do that. What really helps is I will send four to eight bullet points of the main things we have talked about and summarise any homework I would need them to do."

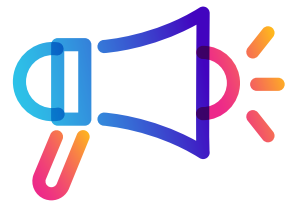
CBT therapist and researcher

Adapting therapy checklist



- 
- Does the person know why they are there?
 - Have you discussed what they want to achieve?
 - Have you given real-life examples of what they could achieve?
 - Do they know what the assessment is and why they are doing it?
 - Have you given the person time to process each question?
 - Are you using direct language?
 - If you use humour or indirect language, are you explaining what you mean?
 - Have you asked them what adjustments they might need?
 - Have you given examples of adjustments they could ask for?
 - Are you conducting the session in the best way for someone to engage?
 - Do they need to write things down or draw?
 - Do you need to write things down or draw?
 - Have you structured sessions? By providing an agenda?
 - Have you asked if they want someone to attend the sessions with them?
 - Do they need support understanding the feelings and emotions you are talking about?
 - Have you incorporated their interests meaningfully?
 - Have you supported them by providing bullet points on what you have covered?

Acknowledgements



Pears Foundation

This project was funded by the Pears Foundation. We would like to thank them for their continuing support and for making this guide possible.

We are grateful to every member of the advisory board for so generously sharing their time and expertise.

Thank you to all the professionals, autistic people and family members who shared their thoughts, experiences and suggestions for improvement. Your input into our survey and discussions was invaluable and we are incredibly grateful.

A big thank you to all the volunteers who supported the analysis of the project. This includes James Randall, Jon Wilkes, Liz Bushby, Janet Jenkins-Johnston and Hayley Swain.



Glossary

ADHD (Attention Deficit Hyperactivity Disorder): people with ADHD experience inattentiveness and hyperactivity-impulsivity. For some people with ADHD, their difficulties mainly lie in just one of these two areas.⁵⁰

AMHS (NHS Adult Mental Health Services): mental health services that take referrals for adults.

Autism: a lifelong developmental disability that affects one in 100 people in the UK. While autistic people share certain characteristics, they are all very different individuals.

CAMHS (Child and Adolescent NHS Mental Health Services): mental health services that take referrals for children and young people.

CBT (Cognitive Behavioural Therapy): a type of talking treatment which focuses on how your thoughts, beliefs and attitudes affect your feelings and behaviour. It teaches you coping skills for dealing with different problems.⁵¹

GAD-7 (Generalised Anxiety Disorder 7): a standardised assessment tool used to look at how anxious someone is.

IAPT (Improving Access to Psychological Therapies): an NHS-provided service that offers talking therapies for treating people with depression and/or anxiety and other common mental health conditions.

MDS: Minimum Dataset Questionnaire (this refers to both the PHQ-9 and the GAD-7).

PHQ-9 (Patient Health Questionnaire 9): a standardised assessment tool used to look at how depressed someone is.



Further reading

Our resource provides an overview for professionals delivering talking therapies with autistic adults and children.

For further reading on the topic please see:

- An Evidence-Based Guide to Anxiety in Autism: https://www.city.ac.uk/data/assets/pdf_file/0010/466039/Anxiety-in-Autism-A5-guide.pdf
- 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.
- Gaus, V. (2018). *Cognitive-Behavioural Therapy for Adults with Autism Spectrum Disorder*. Guildford Press.
- Gilbert, P. and Choden (2013). *Mindful Compassion - Using the Power of Mindfulness and Compassion to Transform Our Lives*. Robinson.
- Hayes, S. (2019). *A Liberated Mind - The Essential Guide to ACT*. Vermillion.
- Linehan, M. (2014). *DBT Skills Training Manual*. Guildford Press.
- Psychological Therapy for Autistic Adults: A Curious Approach to Making Adaptations. <https://www.authenticistic.uk/>
- 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.
- 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.

Endnotes



- 1 Kenny, L. et al (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20, pp442-462.
- 2 Autistica (2020). Supporting autistic children and young people through crisis. <https://www.autistica.org.uk/downloads/files/Crisis-resource-2020.pdf>
- 3 Brugha, T. et al Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of general psychiatry* (2011). 68(5):459-65.
- 4 All-Party Parliamentary Group on Autism. (2019). *Autism Act: 10 years on*.
- 5 Stark et al (2021). Psychological therapy for autistic adults (1st digital ed.) Authentic Research Collective. Retrieved February 24, 2021 from <https://eliosestark.org/authentic.html> (no longer available online).
- 6 Kølves, K. et al (2021). Assessment of suicidal behaviors among individuals with autism spectrum disorder in Denmark. *JAMA Network Open*, 4(1).
- 7 Conner, C. et al (2020). A comparative study of suicidality and its association with emotion regulation impairment in large ASD and US census-matched samples. *Journal of autism and developmental disorders*, 50(10), pp3545-3560.
- 8 Hand, B., Benevides, T., and Carretta, H. (2020). Suicidal ideation and self-inflicted injury in medicare enrolled autistic adults with and without co-occurring intellectual disability. *Journal of autism and developmental disorders*, 50(10), pp3489-3495.
- 9 Hedley, D., and Uljarević, M. (2018). Systematic review of suicide in autism spectrum disorder: current trends and implications. *Current developmental disorders reports*, 5(1), pp65-76.
- 10 NICE (2018). *NICE guidance on preventing suicide in community and custodial settings* [NG105]. National Institute for Health and Care Excellence. <https://www.nice.org.uk/guidance/ng105>
- 11 Simonoff, E. et al (2008). Psychiatric disorders in children with ASD: prevalence, comorbidity and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry* 47(8), pp921.
- 12 Mayes, S. D. et al (2013). Suicide ideation and attempts in children with autism. *Research in autism spectrum disorders*, 7, pp109- 119. <https://doi.org/10.1016/j.rasd.2012.07.009>
- 13 Mikami, K. et al (2009). Frequency and clinical features of pervasive developmental disorder in adolescent suicide attempts. *General hospital psychiatry*, 31, 163-166. <https://doi.org/10.1016/j.genhosppsy.2008.12.003>
- 14 <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/datasets/coronavirusandthesocialimpactsongreatbritaindata>
- 15 When compared to ONS data <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/datasets/measuringnationalwellbeinglifesatisfaction>
- 16 Autistica (Unpublished). What would a more inclusive and supportive society look like? Online consultation of autistic people and supporters, conducted in October 2018.
- 17 Camm-Crosbie, L. et al (2018). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*.

- 18 Hallet, S. and Crompton, C. (2018). Too complicated to treat? Autistic people seeking mental health support in Scotland. Autistic Mutual Aid Society Edinburgh (AMASE) www.amase.org.uk/mhreport
- 19 Maddox, B. and Gaus, V. (2018). Community mental health services for autistic adults: Good news and bad news. *Autism in adulthood*. Mar 2019:15-19. <http://doi.org/10.1089/aut.2018.0006>
- 20 Vohra, R. et al (2016). Emergency Department Use Among Adults with Autism Spectrum Disorders (ASD). *J Autism Dev Disord* 46(4), pp1441-1454.
- 21 All-Party Parliamentary Group on Autism. (2019). *Autism Act: 10 years on*.
- 22 Camm-Crosbie, L. et al (2018). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*.
- 23 Cooper, K. et al (2018). Adapting psychological therapies for autism. *Research in autism spectrum disorders* 45, pp43-50.
- 24 Au-Yeung, SK. et al (2019). Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults. *Autism*.
- 25 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf
- 26 <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>
- 27 <https://www.nice.org.uk/guidance/cg170/chapter/Key-priorities-for-implementation>
- 28 Cassidy, S. et al (2018). Measurement properties of tools used to assess depression in adults with and without autism spectrum conditions: A systematic review. *Autism Res*. 11(5):pp738-754.
- 29 Spain, D. et al (2015) Cognitive behaviour therapy for adults with autism spectrum disorders and psychiatric co-morbidity: A review. *Res Autism Spectr Disord* 9, pp151-162.
- 30 Cooper, K. et al (2018). Adapting psychological therapies for autism. *Research in autism spectrum disorders* 45, pp43-50.
- 31 Royal College of Psychiatrists. The psychiatric management of autism in adults (CR228). https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr228.pdf?sfvrsn=c64e10e3_2
- 32 Cooper, K., Loades, ME., Russell, AJ. Adapting psychological therapies for autism - Therapist experience, skills and confidence. *Res Autism Spectr Disord*. 2018 Jan 1;45:43-50. doi: 10.1016/j.rasd.2017.11.002. PMID: 30245739; PMCID: PMC6150418.
- 33 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf
- 34 <https://skillsforhealth.org.uk/info-hub/learning-disability-and-autism-frameworks-2019/>
- 35 Cooper, K. et al (2018). Adapting psychological therapies for autism. *Research in autism spectrum disorders* 45, pp43-50.
- 36 <https://www.autism.org.uk/advice-and-guidance/professional-practice/mental-health>
- 37 <https://www.autism.org.uk/advice-and-guidance/stories/stories-from-the-spectrum-carly-jones>
- 38 <https://www.autism.org.uk/advice-and-guidance/professional-practice/mental-health>
- 39 Royal College of Psychiatrists. The psychiatric management of autism in adults (CR228). https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr228.pdf?sfvrsn=c64e10e3_2

- 40 https://media.samaritans.org/documents/Media_Guidelines_FINAL.pdf
- 41 <https://www.autism.org.uk/advice-and-guidance/topics/sensory-differences/sensory-differences/all-audiences>
- 42 <https://www.mind.org.uk/about-us/our-policy-work/remote-mental-health-services/>
- 43 <https://www.autism.org.uk/advice-and-guidance/what-is-autism>
- 44 <https://www.autism.org.uk/advice-and-guidance/topics/communication/tips>
- 45 <https://carers.org/resources/all-resources/53-the-triangle-of-care-carers-included-a-guide-to-best-practice-in-mental-health-care-in-england>
- 46 <https://www.autistica.org.uk/what-is-autism/anxiety-and-autism-hub/alexithymia>
- 47 Ibid.
- 48 <https://blog.calm.com/blog/the-feelings-wheel>
- 49 Autistica (2020). Supporting autistic children and young people through crisis
<https://www.autistica.org.uk/downloads/files/Crisis-resource-2020.pdf>
- 50 <https://www.autism.org.uk/advice-and-guidance/topics/related-conditions/related-conditions/all-audiences>
- 51 <https://www.mind.org.uk/information-support/drugs-and-treatments/cognitive-behavioural-therapy-cbt/about-cbt/>



About the National Autistic Society

The National Autistic Society is here to transform lives, change attitudes and create a society that works for autistic people.

We transform lives by providing support, guidance and practical advice for the 700,000 autistic adults and children in the UK, as well as their three million family members and carers. Since 1962, autistic people have turned to us at key moments or challenging times in their lives, be it getting a diagnosis, going to school or finding work.

We change attitudes by improving public understanding of autism and the difficulties many autistic people face. We also work closely with businesses, local authorities and government to help them provide more autism-friendly spaces, deliver better services and improve laws.

We have come a long way but it is not good enough. There is still so much to do to increase opportunities, reduce social isolation and build a brighter future for people on the spectrum. With your help, we can make it happen.

