

# Autism Practice Guidance

## Using this guidance

This guidance has been written by tri.x to support practitioners to understand autism and think about some of the ways that they may need to adapt their practice to maximise the involvement of a person with autism in care and support processes.

It should be used as supplementary guidance to available procedures, and all statutory requirements of the Care Act 2014 apply.

## What is Autism?

Autism spectrum disorder is a neurological and developmental condition that affects how people interact with others, communicate, learn and behave.

Autism or autism spectrum disorder (ASD) refers to a broad range of conditions however, the precise nature of those difficulties will be unique to the individual.

Autism can co-exist alongside conditions that can exacerbate difficulties and affect how well a person with Autism is able to develop and implement strategies and approaches that may be helpful to them. Common conditions include:

- a) A learning disability;
- b) Dyslexia;
- c) Dyspraxia;
- d) Attention Deficit Hyperactivity Disorder (ADHD);
- e) Mental health issues.

### **The core difficulties**

**Everyone** with autism may share the following difficulties:

- a) Social communication and social interaction; and
- b) Restricted and repetitive patterns of behaviour.

Restricted and repetitive patterns of behaviour are defined as:

- a) Repetitive behaviour and routines;
- b) Highly focused interests; and
- c) Sensory sensitivity.

### ***Social communication***

Social communication is the ability to interpret meaning behind:

- a) The spoken word; and/or
- b) Tone of voice; and/or
- c) Facial expressions; and/or

- d) Jokes, sarcasm and hidden meanings.

Because of their difficulties with social communication, a person with autism may:

- a) Not speak, or have limited speech;
- b) Use alternative means of communication (e.g. Makaton or behaviour);
- c) Find it hard to understand or use abstract concepts;
- d) Only talk about the same topics;
- e) Repeat what other people say (known as echolalia).

### ***Social interaction***

Social interaction is the ability to 'read' other people and respond accordingly. People with autism have difficulties:

- a) Predicting how other people may act, or want *them* to act;
- b) Understanding the feelings and emotions of others;
- c) Understanding concepts such as personal space, privacy, and consent; and
- d) Expressing their own feelings and emotions.

A person with autism may:

- a) Withdraw from or avoid social interaction;
- b) Behave in ways that are thought to be socially inappropriate (e.g. touching someone without consent);
- c) Appear insensitive to the needs of others (e.g. laughing if someone is upset);
- d) Find it hard to form friendships, or be at risk of forming inappropriate relationships;
- e) Express their own emotions through repetitive behaviours (e.g. through aggression, pacing, hand flapping or self-harm).

How a person interacts socially can also be influenced by any sensory sensitivities they may have (see overleaf).

### ***Repetitive behaviour and routines***

People with autism often rely on routines. This provides stability and assurance as to what is going to happen but can lead to heightened anxiety when things change or do not go as planned.

### ***Highly focused interests***

Many people with autism develop specific interests that they focus a lot of time and attention on. These interests can be very important to the person's wellbeing, even if they do not make sense to anyone else. These can change over time or be lifelong, and they often like to share their knowledge.

### ***Sensory sensitivity***

Many people with autism are hypersensitive and/or hyposensitive to a range of things:  
Certain sounds and volume:

- a) Light;
- b) Touch;
- c) Temperature;
- d) Colours and patterns;
- e) Taste;
- f) Smell;
- g) Pain;
- h) Body awareness; and
- i) Vestibular senses (balance).

If a person is hypersensitive to something they require much less exposure to it and sometimes need to avoid it altogether. Too much exposure is normally very distracting and can cause significant anxiety, feelings of nausea and even physical pain.

If a person is hyposensitive to something they may seek it out or be desensitised to it altogether.

(See examples on the following page of hypo or hyper sensitivities that may be experienced).

### **Helpful strategies and approaches**

There are a range of strategies that, depending on their particular difficulties, may help a person with autism to:

- a) Communicate with others;
- b) Understand the communication of others;
- c) Identify emotions in themselves and in others;
- d) Learn about appropriate social interaction in specific circumstances;
- e) Develop and manage routines;
- f) Adapt to change;

- g) Cope with feelings of anxiety and being overwhelmed;
- h) Identify risky situations; and
- i) Learn to carry out everyday tasks independently.

These strategies are normally agreed with a Speech and Language specialist or a Clinical Psychologist. It is important that anyone supporting a person with autism is able to apply the approaches effectively as what may help one person may not be effective for another. Examples include the use of social stories, visual aids, and systems such as TEACCH.

## Preventing, Delaying and Reducing Needs

Prevention services such as Reablement and Assistive Technology or Telecare can be extremely beneficial for a person with autism, particularly if they have low level care and support needs.

### **Reablement**

A short term Reablement service can support a person to learn daily living skills, or to effectively implement a strategy or approach recommended by another professional that will then enable them to better manage some of their difficulties independently.

### **Assistive Technology or Telecare**

The virtual support provided by Assistive technology devices can promote independence and reduce the risk of a dependency upon particular carers developing.

Examples include:

- Aiding communication
- Setting up daily activities and routines
- Help with motivating

They can also reduce any anxiety associated with:

- a) Social interaction;
- b) Carers arriving late or early;
- c) Changes to attending carers.

## Maximising Involvement in Care and Support Processes

The precise ways to maximise each Autistic person's involvement in care and support processes will be determined by their unique needs. Practitioners should avoid making assumptions or generalisations about this and always take steps to find out the best way to maximise their involvement *before* proceeding including talking to the individual or seeking advice from their carer

The following table sets out some of the steps that practitioners should consider taking in most circumstances.

Step	Further information
<b>Limit disruption to normal routines</b>	<p>Try to plan meetings outside of times when key routines take place, or if this cannot be avoided take breaks to allow a person to carry out a particular activity or task.</p> <p>The person may be reliant on their routines to provide stability to their day, without which they could become overwhelmed or anxious.</p>
<b>Provide as much information, as early as possible and in as much detail as the person needs</b>	<p>Provide information about the purpose of the meeting, the planned duration, the venue, the agenda, any planned breaks, who will be there, what will be discussed etc.</p> <p>Liaise with any other person who may be able to support the person to understand the information and prepare for any meeting.</p>
<b>Stick to the plan above</b>	<p>If you set expectations make every effort to meet them.</p> <p>Any last-minute changes could damage rapport with the person and cause significant anxiety to the person. This includes lateness.</p>

<p><b>Consider any support the person may need</b></p>	<p>The person may benefit from the support of an advocate, friend or carer.</p> <p>This support may not only be needed during the meeting, but also beforehand to help the person prepare, or afterwards to help them talk through the meeting and next steps.</p>
<p><b>Consider using alternative methods of assessment</b></p>	<p>Self-assessment or communication via email or text can work well for a person with autism, as it allows for them to provide information at a time that works best for them and avoids the need for face-to-face social interaction.</p>
<p><b>Create the optimum environment</b></p>	<p>Find out what is likely to cause a distraction, anxiety or distress. Aim to create as calm an environment as possible.</p> <p>This could be literally anything and may not be obvious so don't make assumptions. For example, a bright light, a ticking clock, a busy road outside, the clothes that you wear, the colour of the room, a perfume, the smell of food cooking etc.</p>
<p><b>Talk about the person's specific interests</b></p>	<p>Talking about the person's specific interests can be reassuring and calming for them. It can also help build rapport and support the person to move on to talk with you about other things.</p>
<p><b>Use the person's name if you are speaking to them (e.g. Tom, can I ask you about....?)</b></p>	<p>The person may also have difficulty filtering out background noise to focus on one particular voice. Using their name at the start of a sentence or question will help them focus.</p>
<p><b>Break information down</b></p>	<p>Too much information can quickly become overwhelming, so try to break things into manageable chunks.</p>
<p><b>Communicate effectively</b></p>	<p>Find out how the person is normally provided with information and try to replicate this. This could be through a storybook approach, or through the use of visual aids.</p>
<p><b>Be literal</b></p>	<p>Speak literally at all times, to the person and to others present. Do not make jokes or use hidden meanings. Keep it simple.</p>

	Avoid making jokes with other people who may be present when the person is there, as they may not understand why people are laughing and could become confused or upset.
<b>Don't ask too many questions</b>	Answering questions can be difficult, because this involves social communication and interaction. Try to keep this to questions that are needed and useful.
<b>Allow time to digest information</b>	The person may need time to process information, and support to make sense of it and consider a response.
<b>Wellbeing checks</b>	The person may become overwhelmed, but because of difficulties with social communication and interaction this may not be obvious from their facial expressions or what they say. Offer opportunities to take a break, particularly if the meeting is long or the person is being provided with lots of information.

## Specialist Information and Advice

Most autism diagnoses happen in childhood, meaning the person and their family may already have received a lot of information and advice. However, autism in adulthood can present with a whole new set of challenges and steps should be taken to ensure that people have access to the information and advice they need, or that would be of benefit to them.

The National Autistic Society provides a range of information and advice to people with autism, their families, carers and friends. The number to call is 0207 833 2299 or email [nas@nas.org.uk](mailto:nas@nas.org.uk)

If the adult does not have a diagnosis and feel they would benefit from an assessment, further information can be found on the NHS website, see: [How to get an autism assessment.](#)

Practitioners should also consider the benefit in making a referral to a Clinical Psychologist or Speech and Language Therapist if there are no strategies in place to support them or their carers.

## Supporting Carers

The impact of caring for a person with autism should not be underestimated and every carer is likely to need support at some point over the course of their caring role.

The risk to the wellbeing of carers is increased when;

- a) They have limited informal networks of support;
- b) The person's difficulties require intensive support; or
- c) Strategies or approaches to support the person with autism to manage their difficulties are not in place or are not effective.

[AutismAwareness.com](https://www.autismawareness.com) was founded by a parent and is described as a community for people facing similar challenges.

All carers should be offered a carer's assessment in line with the statutory requirements of the Care Act.

## Further Reading

[NHS - Autism](#)

[NHS - Useful information and resources](#)

[National Autistic Society](#)

[Ambitious about Autism](#)

[Autism Central](#)