

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.

The information about Autism contained in this guidance is not comprehensive, and further information can be found on the National Autistic Society website <http://www.autism.org.uk/>

What is Autism?

Autism is caused by unusual brain development and is a lifelong condition.

There are core difficulties experienced by every person with Autism; however the precise nature of those difficulties will be unique to the individual.

Autism can affect people across all levels of intelligence, and not all people with Autism have a learning disability or difficulty. For example, Aspergers Syndrome is a form of Autism that affects people who are average, or above average intelligence.

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) A mental health issue.

The core difficulties

Everyone with Autism shares core difficulties with;

- 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 focussed 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.

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 not appropriate (e.g. touching 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 develop inappropriate relationships;
- e) Express their own emotions inappropriately (e.g. through aggression or self harm).

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

Repetitive behaviour and routines

People with Autism often become dependent on repetitive behaviour and routines. This provides stability and assurance, 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.

Sensory sensitivity

Many people with Autism are hypersensitive and/or hypo sensitive to a range of things;

- a) Certain sounds and volume;
- b) Light;
- c) Touch;
- d) Temperature;
- e) Colours and patterns;
- f) Taste;
- g) Smell;
- h) Pain;
- i) Body awareness; and
- j) 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, and it is important that anyone supporting a person with Autism is able to apply the approaches effectively. Examples include the use of social stories, visual aids and systems such as TEACCH.

Examples of hyper and hypo sensitivity

Peter is hypersensitive to bright light. At home he keeps his curtains drawn and when he goes out he always wears sunglasses.

Susan is hyposensitive to pain and touch. She regularly bangs her head onto things if she is anxious as she finds this calming.

John has a hyposensitive vestibular system. He spends several hours a day rocking backwards and forwards and spinning around.

Moe is hyposensitive to sounds. He always has the TV on very loud, bangs doors and likes being in noisy places.

Sandy is hypersensitive to sound. She can hear conversations from a long way away and finds them very distracting as she cannot block them out. Loud noises become distorted and overwhelming.

Carol is hypersensitive to the texture of food in her mouth. She will only eat smooth food like mashed potato or ice cream.

Sandeep is hypersensitive to touch on her scalp. She finds it difficult to wash or brush her hair and experiences this as pain.

David has hyposensitive body awareness. He finds it hard to navigate a room and regularly bumps into objects and people.

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 gadgets can promote independence and reduce the risk of a dependency upon particular carers developing.

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 difficulties. 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.

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

| Step | Further information |
|--|---|
| Limit disruption to normal routines | <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> |
| Provide as much information, as early as possible and in as much detail as the person needs | <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> |

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| <p>Stick to the plan above</p> | <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>Consider any support the person may need</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>Consider using alternative methods of assessment</p> | <p>Self assessment or communication via email 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>Create the optimum environment</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>Talk about the person's specific interests</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>Use the person's name if you are speaking to them (e.g. Tom, can I ask you about....?)</p> | <p>The person may also have difficulty filtering out background noise so as to focus on one particular voice. Using their name at the start of a sentence or question will help them focus.</p> |
| <p>Break information down</p> | <p>Too much information can quickly become overwhelming, so try to break things into manageable chunks.</p> |
| <p>Communicate effectively</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> |

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| <p>Be literal</p> | <p>Speak literally at all times, to the person and to others present. Do not make jokes, use hidden meanings or ‘beat around the bush’.</p> <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.</p> |
| <p>Don’t ask too many questions</p> | <p>Answering questions can be difficult, because this involves social communication and interaction. Try to keep this to questions that are pertinent to the situation in hand.</p> |
| <p>Allow time to digest information</p> | <p>The person may need time to process information, and support to make sense of it and consider a response.</p> |
| <p>Wellbeing checks</p> | <p>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.</p> |

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 has a dedicated national helpline, providing a range of information and advice to people with Autism, their families, carers and friends. The number is 0808 800 4104.

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 to manage their difficulties.

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.

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