

Understanding and Supporting People with Autistic Spectrum Conditions

A guide for the public and professionals on supporting and communicating with Autistic people
Derbyshire



**Derbyshire Autism
Partnership Board**

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What is an Autistic Spectrum Condition?

Autism can be referred to as many different names including, Asperger's (primarily differentiated from Autism by the person's language skills), Autism, Autism Spectrum Disorder (ASD), Classical Autism, High Functioning Autism. This document will refer to this as Autism Spectrum Condition (ASC).

Autism Spectrum Condition – is a term used to describe a complex neurodevelopment condition that affects how a person experience and understands the world around them. It is a lifelong condition and affects how people make sense of the world around them.

There are around 700,000 adults and children living with autism in the UK.

The many challenges that a person with ASC may face and the common traits of ASC are often broken down into three specific categories:

1. An impairment of social understanding and relationships
2. An impairment of communication and interaction
3. An impairment of imaginative thought and inflexibility in thoughts and behaviours

A person with ASC may also find the following challenging:

- Sensory integration – including touch, noise, smell and light and colours
- Processing and understanding their experiences

It is important to recognise that all people with Autism experience their Autism differently. Each person will have their own strengths and difficulties. Everyone's Autism is different – this is why it is called a spectrum condition.

When thinking about Autism, it's helpful to remember:

“If you've met one individual with autism, you've met one individual with autism”

Autism is a spectrum condition, which means that people with autism have a wide range of ways in which they may communicate and interact with people. People with Autism also have differing abilities, interests and difficulties, which can vary dependent upon the environment and stressors they are currently dealing with. Autism is often called a “hidden” disability because not every person with autism

presents with the same or with obvious characteristics. For example, some people with autism can have good eye contact, be sociable and share normal interests. People can often mask their difficulties by copying the behaviour of others. Problems may only become apparent when individuals are expected to be highly flexible and tolerate a lot of environmental demands.

How ASC May Affect People

As ASC is a condition that affects how a person perceives the world around them, many aspects of everyday life can therefore be much more challenging for a person with ASC. Activities that *Neurotypical* (the word used to describe people who do not have ASC) individuals often take for granted, can be overwhelming for a person with ASC, for example, shopping at the supermarket, going to the cinema. All these activities include navigating a series of unpredictable situations, interacting and communicating with lots of different people, and coping with a variety of competing sensory experiences. People with ASC often describe the social world as overwhelming and significantly anxiety inducing.

Because of the unique way a person with ASC's mind works, they may also exhibit the following characteristics, which other people may find difficult to understand:

- An unusually strong interest in a specific topic or subject
- Repetitive actions or behaviors
- Non-typical emotional responses or expressions
- Under or over reaction to specific sensory stimuli or an extreme dislike of something
- Restrictive eating habits
- A need for strict routine or the development of habitual behaviour.

This often leads to a person with ASC feeling 'different' to others and finding the social world and building relationships with others frustrating.

You can find out more about Autistic spectrum conditions at www.nhs.uk/autism

What Causes Autism Spectrum Conditions?

It is not currently understood what causes ASC. One thing that is known is that it is not caused by a person's upbringing or their social circumstances and is not any fault of their own that they have ASC. In some families there is thought to be a genetic component. There is no 'cure' for ASC, instead, people with ASC develop coping strategies to better manage the social world around them.

General Advice on Supporting people with Autistic Spectrum Conditions

This leaflet has been put together for health, social care, voluntary sector staff, as well as anyone else who works with or supports people in their job or daily life.

General information for those who work with people who may have Autism

There are some general things you can do to communicate with people with Autism and help to make them comfortable:

- Ask questions or give instructions one at a time, as simply as you can.
- Use plain, concrete language and avoid anything metaphorical.
- Allow the person time to process what you have said. If you don't receive a response, try rephrasing it or writing it down.
- Explain each stage of what you are about to do and what will happen next.
- Be consistent with what you say.
- At the end of your call/appointment ensure that what has been discussed or advised is confirmed in writing, either by email or letter. The pressure of the appointment/call may make it difficult for the person to remember what you have said. The confirmation should state clearly what they need to do and what you have offered to do for them.
- Consider the person's behaviour in terms of their Autism – this may manifest as frustration, speaking loudly/quietly or repetitive behaviours (like asking the same questions) – stay calm and consistent and try not to judge, as this may be their coping mechanism.
- The person may be experiencing extreme anxiety, which may make speaking with you overwhelming. This may result in a 'meltdown' or 'shutdown.' Pause the advice you are giving and focus on their wellbeing instead. Ask if they are OK and

give them time and space to recover. This may result in arranging another call or appointment.

Making Reasonable Adjustments for People with ASC

Be prepared to support someone, have our communication poster in your office and re-read, have a 'meltdown' plan – how could a person leave quickly if they needed to? Have guides to your service or environment available before a person arrives so they can familiarise themselves.

Being person-centred

Follow the individual's lead, ask them what they require – room, sensory issues, do they have an autism passport or documents to help you? Assure them they decide the pace of your work and allow them to break whenever they need to.

Minimising sensory disturbances and Creating a safe environment

1) Visual aspects:

- a) Lighting – natural or artificial? The more natural lighting you are able to incorporate, often the better. Fluorescent lights flicker and some individuals with ASC report that they can actively see this flickering. This sort of lighting should be completely avoided if possible.
- b) Wall colours – light, pastel colours in shades of green and blue are often considered the most soothing, restful and least stimulating (owing to the wave patterns they create in the brain), whereas harsher brighter colours like yellows and reds can be very stimulating.
- c) Patterns – do the walls, curtains or any furnishings have patterns on them? Again, this can be over stimulating and can in fact cause a person living with ASC a lot of distress
- d) How many things are on display in the space (like posters, TV screens, clocks)? All of these require visual awareness or recognition so can again be over stimulating and thus overwhelming. Try to reduce the number of items on display to the bare minimum.
- e) How 'busy' is the space? As well as things on the walls, are there lots of objects around. Think about how many objects are around that may cause unwanted distraction and thus distress.
- f) Could you provide tinted or coloured glasses in an Autism box for use by clients living with ASC? Remember to provide cleaning wipes if you store equipment.

2) Auditory aspects:

- a) How much sound can be heard in the space? Is there a clock, a TV screen, a radio, noisy plumbing?
- b) How much sound can be heard from other rooms?
- c) How much noise can be heard from outside?
- e) What noise do your alarm systems make? Could you put up a warning about the noise or inform all clients that if an emergency happens there will be a loud noise so they can be prepared? Have you considered a visual alarm system instead?
- f) Could you provide headphones or ear muffs to prevent noise? Again, in an Autism box. Don't forget cleansing wipes/a sterilising process if you choose to provide them.

3) Touch/pressure aspects:

- a) Do the soft furnishings have textures or patterns on them that can be felt? What material are the chairs or sofas made from? For someone living with Autism, touch can be one of the only ways they can control their environment and regulate their sense of self, therefore unpleasant or unexpected sensations of touch can be very distressing and cause huge discomfort
- b) Could you provide positive touch items to reduce distress, such as stress balls, fidget spinners or a weighted blanket? These can be accessed when a person requires them.

4) Olfactory aspects:

- a) What smells are around? Is there is a kitchen or bathroom nearby? Can you smell food or cleaning products? Are there any scent plug-ins? Are there any plants or flowers that smell? Smell can be quite nauseating for someone living with ASC, it is therefore essential to try and maintain a neutral smelling.

5) Vestibular and proprioceptive aspects (movement and space):

- a) Is there space for someone to move around? Would someone be free to get up and pace, rock on their chair, tap their foot, flap their arms? Can a person sit with their back to a wall? Stimming (making movements to express or control anxiety or to self regulate) is a really important means of expression for someone living with ASC, it is important that space is made for this activity.
- b) Are there quick exit routes? Are these clearly marked so a person does not feel trapped? If a

person starts to feel anxious or overwhelmed, can they remove themselves easily and without harm or drawing attention to themselves? Is the outdoor space safe? If a person fled the building, which is the safest way to flee? For example, is there a busy road outside that someone could flee into when distressed and thus harm themselves?

- c) Where they are sitting, can they see the whole room? This can help a person feel more at ease and in control of what is happening as nothing appears to be hidden.
- d) Can you see where noises are coming from or can you have signs to explain noises? For example, hearing people talking and not knowing where that noise is coming from can be very distressing. Could signs be used to explain where noise is coming from and what is being discussed (however vaguely – “Advisors supporting people”) or could you explain to clients as they arrive what noises are coming from where and why?
- e) Can a person go outside when they need to? Can they go to the toilet when they need to? Maps would help with this
- g) If spaces are being used for large numbers of people, are there smaller spaces available too? Could you offer a smaller ‘quiet room’?



General Communication Tips for Those Supporting People with ASC

- Ask questions or give instructions one at a time, as simply as you can.
- Use plain, concrete language and avoid anything metaphorical.
- Allow the person time to process what you have said. If you don't receive a response, try rephrasing it or writing it down.
- Explain each stage of what you are about to do and what will happen next.
- Be consistent with what you say.
- At the end of your call/appointment ensure that what has been discussed or advised is confirmed in writing, either by email or letter. The pressure of the appointment/call may make it difficult for the person to remember what you have said. The confirmation should state clearly what they need to do and what you have offered to do for them
- Consider the person's behaviour in terms of their Autism – this may manifest as frustration, speaking loudly/quietly or repetitive behaviours (like asking the same questions) – stay calm and consistent and try not to judge, as this may be their coping mechanism.

The person may be experiencing extreme anxiety, which may make speaking with you overwhelming. This may result in a 'meltdown' or 'shutdown.' Pause the advice you are giving and focus on their wellbeing instead. Ask if they are OK and give them time and space to recover. This may result in arranging to see them another time.

Information for Teachers and Those Working with Children and Young People

If you are a teacher or work with young people, it's likely that you have access to a special needs professional who can provide information, advice and support if you suspect a child in your care may have an Autistic Spectrum Condition.

However there are some general tips you can use to help understand the difference between Autism and bad behaviour:

Many of the behaviours that are typical of children on the autism spectrum might be deemed discipline problems in other children,

for example:

- Kids with autism may screech or yell when overwhelmed or frustrated.
- Some autistic children bolt from the room, hit others, or even injure themselves when upset
- Children on the spectrum may not look directly at a person when speaking.
- Autistic kids may rock, flick, or pace when they are expected to sit still
- Children with autism may be self-absorbed and inattentive to events or emotions around them.

In school, children with autism may over or under-react to others' requests or needs (for example, pushing other children in line or ignoring requests to move or hurry). Autistic behaviours are usually the result of a few very specific challenges. Because every person with autism is unique, the challenges will look different for each child, but they exist, at some level, in anyone who is correctly diagnosed with an autism spectrum disorder. Sensory challenges may also be the reasons behind "misbehaviour" when in a crowded or loud room, or even in online environments. How can you tell when sensory issues are causing a problem?

Ask. The child may be able to explain their behaviours if asked.

Watch. If the child is covering their ears, it's reasonable to assume that something about the sound in the room is causing a problem.

Keep tabs on behaviours. If the child is usually able to handle a situation, but on one occasion becomes loud or runs out of the room, it's fairly apparent that something specific has occurred to cause the behaviour. But if the behaviour is consistent, there may be an ongoing sensory challenge in the environment.

Things you can do

Provide Direct Instruction - if the child is able to respond to and act on direct instruction, provide it. In some cases repetition can be beneficial

Remediate challenges – if you know a particular smell or sound is likely to trigger the child then try to mitigate and remove these

Time out, stimming opportunities – duties to hand out books to help manage stimming

Involving family – two way communication between teacher and fam. Understand child more than clinical understanding of Autism.

Work to put in place a contract between you, the family and the child—for example using

time out passes.

Get support from your SEN coordinator.

What you can get from MAT support teams – joined up multi-disciplinary working. Working with other pros involved with the child.

Access any training that is available to you / speak to your manager about suitable courses to enhance your knowledge.

Quotes from coproduction workshops with autistic people and their family members and with autistic children and young people

“There will be a logic to what I do, it just might not be your logic”

“Some autistic people are really good at doing some things very well or quickly - believe and value this”

“I can hide my autism, but I can't switch it off “

“You understand autism not just in your head but in your gut and in your heart”

“If someone at school makes a plan with me for something to happen, they need to stick to it as if they don't, I can get really upset”

“I like being different - I'd rather be weird than have a bear”

“Tell me what it is you are going to do”

“I need things explained to me clearly, be given space and time”

“Give me time and don't get annoyed when I do stuff with my body and tics. Believe me when I say I can't help it”

“Choices are hard for me - the word 'or' is a horror”

Information for Health and Social Care Staff

Health and social care staff need the capabilities to support and encourage people with Autistic Spectrum Conditions (ASC) to optimise their physical and mental health.

They need to promote and implement reasonable adjustments, remove barriers to access and enable the health needs of people to be met.

Staff should:

- a) ensure they know basic facts about autism including:
 - how common it is
 - that autism is neurodevelopmental and life long
 - that every autistic person has a different combination of traits and sensitivities and is unique.
- b) Be able to use respectful terminology.
- c) Understand what common autistic characteristics may look like in real life situations e.g. at home, in the classroom, in care settings, in the community.
- d) Take responsibility for meeting an autistic person's unique communication and information needs:
 - understand that communication includes both giving and receiving information and the importance of actively including autistic people, regardless of their ability to communicate verbally.
 - be aware how autistic people may become overwhelmed and need time and quiet space to process and understand information. For example, when overwhelmed some people may 'shutdown' or simply acquiesce to anything said in order to bring the experience to a close; therefore, you will not get accurate information and they will not retain what you have said.
 - be aware of (e.g. through reading their communication passport) and respect the different methods of communication that an autistic person may use.
 - actively listen to what a person is 'saying' and be prepared to use patience and perseverance in communication – including being silent to allow thinking time.
 - be aware that processing and understanding spoken language is a challenge for many autistic people,



especially when anxious or in difficult sensory environments.

- be aware that autistic people often take language literally so it is important to use clear, unambiguous language, responding positively when autistic people use direct language and give direct feedback.
- be aware of difficulties and differences in non-verbal communication e.g. facial expression; eye contact; and personal distance.

e) Be aware that behaviour seen as challenging may be a form of communication or an indication of distress.

f) Recognise some key differences in social interaction e.g. processing time, difficulties with small talk, social rules, understanding and interpreting emotions.

g) Be aware that autistic people may live with other physical or mental health conditions or impairments that will also impact on their lives.

h) Understand the role of trauma in the lives of autistic people leading to a wide range of mental health problems in later life and the importance of building trust and making choices for recovery.

i) Understand how sensory issues can impact on autistic people e.g. over- sensitivity or under-sensitivity to lighting, sound, temperature, touch, smell and how anxiety and stress can contribute to sensory tolerance.

j) Be able to make simple changes to ensure an environment is accessible to autistic people, including opportunities to avoid sensory overload (e.g. turning off unnecessary lights, TV / radio, offering quiet space, enabling the use of sensory protection such as noise-cancelling headphones), and consider the use of an alternative location.

k) Plan changes in advance whenever possible. Provide preparation and information about upcoming events using a variety of communication methods.

l) Recognise the importance of passionate interests and hobbies.

m) Be able to consistently put key adaptations into practice, for example:

- Don't spring surprises!
- Don't touch without consent
- Slow down and pause
- Create or find a calm, quiet environment
- Explain first, then do.

o) know where to access resources and further information.

Health and social care staff should be aware of the Equality Act 2010, Human Rights Act 1998 and Mental Capacity Act 2005.

Autistic people (children, young people and adults) have a right to access good quality healthcare. Autistic people generally have more health problems than other people and a higher risk of premature death. There are many reasons including: above average rates of co-occurring conditions; lack of understanding and awareness among health and other professionals; difficulties faced by some autistic people and those who support them in recognising symptoms and expressing their needs; poor information systems; and the fact that many autistic people are economically and socially disadvantaged.

Core training to raise staff awareness and improve communication also helps to improve access to services for people who have autism, so speak to your manager about training opportunities.

Co-occurring conditions for healthcare staff in practice

Autism rarely presents with core symptoms alone. There are a huge range of co-occurring conditions which can accompany autism. The associated condition (or co-occurring condition) can significantly change the physical health needs of an autistic person. But health practitioners may not always understand these conditions.

Healthcare professionals may not know and understand the core symptoms of autism and the interplay with co-occurring conditions. Those professionals who have some awareness of autism may be more likely to look out for co-occurring conditions.

There have been limited studies into the interplay between physical co-occurring conditions such as epilepsy, for example, and autism. This is a concern and should be a priority for research. Epilepsy has a prevalence of 0.97% in the general population but has an incidence of more than 20% in the autistic population.

It is becoming increasingly clear that the combination of epilepsy and autism needs to be understood. A large, quality Swedish study shows that autistic people who also have a learning disability die an average of 30 years prematurely

The leading cause of death is epilepsy. Yet we do not have a good understanding of the

relationship between these two conditions nor do we have specialists or specialised treatment to tackle this.

But it is not just epilepsy that autistic people are more susceptible to

The same Swedish study found that autistic people die prematurely in almost all cause-of death categories. Cancer, cardiovascular disease, congenital malformations and almost all other diseases are causes of premature death in this autistic group. But reducing the obstacles to accessing healthcare can improve the detection and treatment of these diseases and improve life expectancy.

Other studies have found that autistic patients appear to be more susceptible to stroke, Parkinson's disease, gastrointestinal and sleep disorders, diabetes and immune conditions

Without a holistic understanding of the autistic person's physical health needs and without a person-centred approach to this, the health needs of autistic people may go unmet.



Quotes from health lead co-production workshops with people with ASC and their families

“You might not be able to tell when I’m in pain or distress”

“Don’t tell me something won’t hurt if it will”

“I make reasonable adjustments all the time for neurotypical people and it exhausts me”

“Don’t get stuck aiming for 100% right, we don’t get everything right for everyone!”

“Doctors need to talk to me as well as my Mum and Dad”

Further Resources and Information - National websites

National Autistic Society: www.autism.org.uk

NHS: www.nhs.uk/autism

Ambitious about Autism:

www.ambitiousaboutautism.org.uk

Support Services in Derbyshire and Derby

Autism Information and Advice Service

The service provides accessible information about the support and services available to any person in Derbyshire living with Autism, as well as their friends, families and carers. The service is provided by Citizen's Advice Mid-Mercia and also provides support and training for Derbyshire based professionals and businesses seeking to become more autism aware or to support employees with autism.

tel: 01332 228 790

visit: www.autisiminformationservice.org.uk

Relate Living Well with Autism service

The service provides training about living a good life with autism. The free one day course is open to Derbyshire residents, including anyone on the autism spectrum and their family members or carers. The service also offers free coaching and counselling sessions. Relate Derby also offer a Living Well with Autism telephone helpline which is a free service where you can speak to a specially trained counsellor without having to book an appointment.

Tel: 01332 301350 (counselling)

tel: 0808 178 9368 (Autism telephone helpline)

visit: www.livingwellwithautism.org.uk

Disability Employment Service

The service can help people with an Autistic Spectrum Condition to find training, work experience, voluntary work and paid employment. They can support with applications, mock interviews as well as support once in employment.

tel: 01629 532440

visit: www.derbyshire.gov.uk/des

Derbyshire Autism Services

The service's website has information about services for adults, children, families and carers, siblings as well as a dedicated page for professionals. They also offer support groups, one to one support and social activities.

tel: 01773 7411221

visit: www.derbyshireautismservices.org

Autism East Midlands

The service's website has lots of information about autism as well as support services for adults and children with autism. The website also includes details of specialist local events and training.

tel: 01909 506 678

visit: autismeastmidlands.org.uk

Mental Health Helpline

The mental health helpline is available to Derbyshire and Derby residents of all ages. The support line is open 24 hours a day, seven days a week and is available for carers and families supporting someone with mental ill health.

tel: 0800 028 0077 - this is a freephone number and calls from landlines and mobiles should be free.

Autism Outreach

Schools and maintained early years settings can refer to Autism Outreach for advice around individual pupils and training.

visit: www.schoolsnet.derbyshire.gov.uk and search for autism outreach

Umbrella

Umbrella are a local organisation who can support children with additional needs and their families.

tel: 01332 785658

visit: <https://umbrellall.uk.net>

Carers in Derbyshire

The Carers in Derbyshire website is a one stop shop for unpaid/ family carers and provides information and advice on how carers can get support to maintain their own wellbeing.

visit: www.carersinderbyshire.org.uk

Council websites

Derbyshire County Council and Derby City Council both have information about support for both adults and children with ASC on their websites.

visit: www.derbyshire.gov.uk or www.derby.gov.uk and search 'autism'

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