



Include Autism



**Top tips and practical resources
for parents and carers**

Do you think your
youth group could
be more accessible?



Would you like
to learn how to
make small changes
that make a big
difference?



Do you want
to hear from
young autistic
people about
what works?



**We are the Ambitious
about Autism Youth Patrons**
and we have the answers
to your questions.



Introduction to Include Autism

Who are we?

We are the Ambitious about Autism Youth Patrons; a group of autistic 16-25 year olds from across England. Some of us sit on the Youth Council, some on advisory boards for external projects and others are on the Ambitious Youth Network and help us create content, run campaigns and lobby for change. We volunteer our time and expertise to help make the ordinary possible for other autistic young people through the projects we run.

Why did we start Include Autism?

We think extra-curricular activities and youth groups are an extremely important part of young people's lives. They allow young people to make new friends, be part of a community, develop skills.... and have a positive impact on mental health and wellbeing. And it's every young person's right to go

Unfortunately, we know that many young autistic people are unable to access these opportunities due to inaccessibility and misunderstanding of autism.

Whilst discussing our experiences, we realised that lots of us had been excluded from youth groups and extra-curricular activities. Our parents were told that the groups couldn't 'deal with us', our peers wouldn't engage with us and the environment was never welcoming or accessible.

It isn't fair that young autistic people are missing out on youth groups just because people don't understand.

With the help of our guide you will realise just how easy it is to Include Autism.



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How to use the Include Autism toolkit

We wanted the Include Autism toolkit to be as useful to as many people as possible. It opens with information about autism and then splits into resources for youth group leaders, parents and autistic young people.

You can download one specific section or all of the sections. The toolkit is editable so that you can fill in section with your own information.



For parents and carers of autistic young people

Parents and carers of autistic young people may wish to highlight this toolkit and resources to leaders of their local youth groups to help them develop groups and spaces which appeal to and include autistic children and young people.

The Include Autism toolkit can also be used to start conversations about what autism is and help your young person feel comfortable in youth group environments.



Section 1

Information about autism



What is autism?

Autism is a processing difference that can have an impact on many areas of a person's life. Autistic people can often experience differences in how they process information, their sensory environment and how they interact with other people. It is estimated that one in 100 children, teenagers and adults in the UK are autistic.

While autistic people share some similar characteristics, they are also all different from each other. This is because autism is considered a spectrum. The autism spectrum is not linear from high to low but varies in every way that one person might vary from another.

Autism is lifelong condition; autistic people are born autistic and autism can be identified at any point in a person's life. You can't see if someone is autistic just by looking at them and some people might not have been diagnosed as autistic when you meet them.

Many autistic people also have co-occurring conditions which can make their needs more complex. Autistic people may also have ADHD, anxiety disorders, depression, mental health issues, learning disabilities, physical health conditions and communication difficulties. Officially, autism is considered a disability, but some people do not identify in this way. Autism can be viewed as a disability or disabling due to the impact autism and co-occurring conditions can have on daily life.

One in 100

**children, teenagers
and adults in the
UK are autistic.**

Being autistic is not a bad thing and does not make you less than other people; autistic people have a lot of strengths that balance the challenges and difficulties they may face. Some of these strengths may include: having exceptional attention to detail, having an increased interest in a topic that brings them joy and the ability to offer different perspectives to questions.

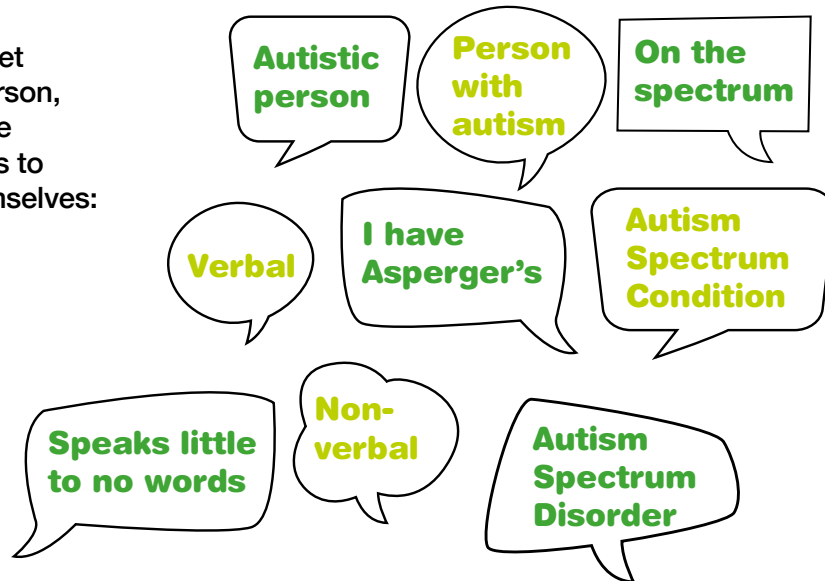
Young autistic people already face exclusion from school, activities with friends and the opportunities offered to their peers because they have been misunderstood and don't receive the support they need. A youth group can change this by offering the space to develop independence, friendships and new skills.

Most importantly, while there are similarities amongst autistic people, when supporting an autistic individual, the best approach is to ask the person what they like and don't like for support.

How do we talk about autism?

There have been a lot of changes and differences to how people talk about and understand autism. There have also been many terms used, some of which are still in use today as they still hold meaning and understanding.

When you meet an autistic person, they might use different terms to describe themselves:



People have different preferences of what they like used when describing them and autism, so it is always best to ask the individual themselves what their preference is.

There are also different labels used when talking about an autism diagnosis; some are no longer used, and some are new. Some autistic people may have been diagnosed with: Asperger's Syndrome, Autism Spectrum Condition or Disorder, Pathological Demand Avoidance, Atypical Autism, Pervasive Developmental Disorder or High Functioning Autism. These are all autism but have different labels and have been used to mean slightly different profiles of autism.

Talking positively about autism:

- + When talking about autism don't use terms like 'suffer' or 'disease'. Autism is not a mental health condition or a disease, it is a different way of experiencing and processing the world around you. You could describe what someone struggles with, what challenges they may face and the strengths they have.
- + Try not to use 'high functioning' or 'low functioning'. Instead you could describe a person's support needs. Some autistic people might need higher levels of support in a situation that they find difficult and others may have low support needs as they can put in place strategies to manage a situation by themselves or with less outside support.



- + Try not to assume what someone might be like because they are autistic but instead ask them or someone who knows them well what their strengths and difficulties and likes and dislikes are. It is better not to make a presumption about what someone is like or their abilities before you meet them as the idea of what someone is like can often shape how we treat them.

What are meltdowns and shutdowns?

Meltdowns are often the result of situations which are highly stimulating or create high levels of anxiety which feel like they can't be escaped. When in extreme distress like this the reaction is either to flight, fight or freeze. If the person cannot escape that leaves two options: either fight or freeze. Meltdowns are similar to the fight response and shutdowns are similar to freeze.

Meltdowns

When an autistic person is having a meltdown they often have increased levels of anxiety and distress which are often interpreted as frustration, a 'tantrum' or an aggressive panic attack. It's important to understand that a meltdown is not a tantrum but is a reaction to a highly distressing situation or environment.

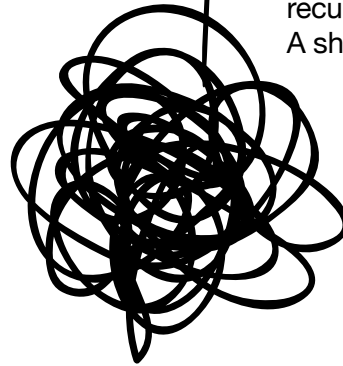
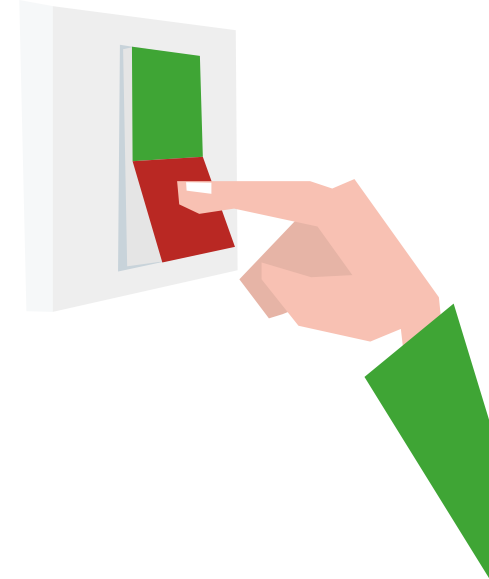
While in a meltdown the person can be injurious to others or themselves because of the extreme state of anxiety their body is in. To try and avoid a meltdown, put in place pre-emptive planning that mitigates triggers. For example, reducing anxiety related to uncertainty by providing information and agendas before events and sticking to them. Another way to reduce the likelihood of a meltdown is to create enabling environments which don't overwhelm the senses. There are some [top tips](#) later on in the Include Autism toolkit to help achieve this.

Shutdowns

Shutdowns are often the result of situations with high demand in one or a several of the following areas: social situations, situations that require a lot of thinking, lack of sleep, very emotional situations and those that are very active or physical.

An analogy for a shutdown is like a computer trying to turn on but it can't because there isn't enough power to do so. In a shutdown an autistic person might not seem themselves because they're so overwhelmed that their focus has shifted to the basic functions. As they are at a reduced ability to process what is going on they may struggle to communicate as they normally do which can mean they are mute or have a lot of difficulty forming coherent sentences.

The best remedy for a shutdown is giving the person the space to rest, recuperate and recover without placing additional demands on them. A shutdown can be like a reset for an autistic person.



Masking and camouflaging

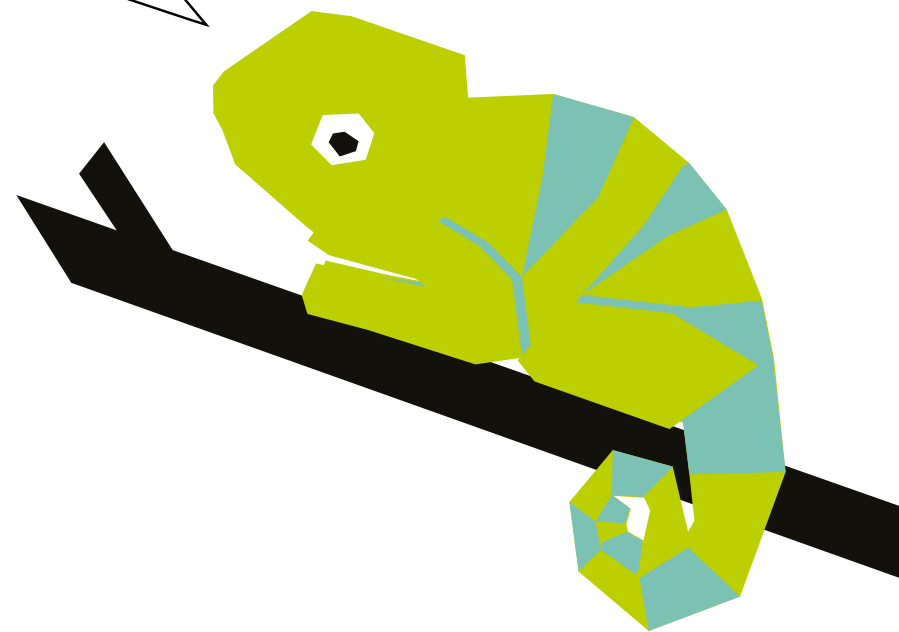
Some autistic people can appear very able in social situations, so much so that it might be difficult to 'see' that they are autistic. While people tend to socially perform in a given situation to appear their 'best self' an autistic person may mask being autistic or some behaviours deemed visibly autistic.

This means that an autistic person can appear to be fine and coping or excelling in a social situation but often the repercussions and effects of performing can become evident afterwards. In the school context, young people can mask during the day but once they get home they may have a meltdown or be fatigued.

To support an autistic person you can encourage them to be themselves as much as they are comfortable. They may not realise they are masking or camouflaging or the detrimental effects masking can have on them. By creating a welcoming environment where **self-stimulatory (stimming)** behaviour, different communication styles and sensory needs are accepted, you can reduce someone's 'need' to mask. Through reducing the perceived consequences of being visibly autistic and allowing for difference an autistic person may not mask or mask less which is beneficial for all involved.



Some autistic people feel like they need to camouflage themselves to fit in.





Section 2

Top top tips and practical resources
for the environment

Top tips for youth group spaces!



We know that youth groups, clubs and extra-curricular activities can take place in all sorts of environments. We also know that lots of groups do not have access to funding in order to improve these environments in the way that they would like, or they are using a rented space that they're not allowed to change.

To combat these issues, we have pulled together our ideas on how to make the environment better for young autistic people. Some of these ideas cost money and others don't but all are valid. And you'll soon realise that making these adjustments can make a difference to all young people.

Our biggest tip would be to ask the young people what works for them before you put anything into place. You don't want to invest in an adjustment that isn't useful!



Sometimes the sound would echo so much the levels of noise would be unbearable.

Noise and sounds

Youth groups can be very noisy. Here are our tips to tackle noise:

- ✓ Allow young people to wear their ear-defenders or headphones inside – even better, provide some! They can still hear what you're saying but it blocks out background noises.
- ✓ If possible, let the young person know how many other young people will be there. Sometimes knowing in advance how crowded and noisy it might be can be useful in making plans.
- ✓ If the main room is too overwhelming, provide a break-out space or quiet room and allow frequent breaks. If you have the budget to buy some stim-toys, these can be great additions to the room. The room doesn't have to be anything special, just ensure that it is a designated space and it is respected as a quiet room.

Top tips for youth group spaces!

continued...

Lights

We know that lighting is expensive and might be hard to change. Here are our tips for creating a nicer ambience without a big budget:

- ✓ If you can change lightbulbs then buy softer or warm colours. Neon and fluorescent lighting can cause some serious headaches!
- ✓ If you can't change your lighting, allow the young person to wear dark glasses inside and don't allow peers to mock them. If you need help explaining autism to the rest of the group, [head to this section](#).
- ✓ If the club is running during the summer, keep the lights off for as long as possible. Daylight can be much softer.
- ✓ Allow the young person breaks from the rooms with bright lights – the designated quiet room or breakout space should have soft lighting where possible, or even darkness!



Access

Sometimes it can be hard to gear ourselves up to go into a club or group and sometimes there are physical barriers stopping us. Here are our tips to ensure everyone can access your group:

- ✓ Have a person in the group who is available to meet young people who may want to be escorted in. This can really help getting over the anxiety of walking in alone. Or have a buddy system where young people can support others throughout the meeting or session.
- ✓ Make sure your building is accessible for all disabilities – both physical and hidden.
- ✓ Have visual timetables of what is happening in the club or group that day. Having a schedule can reduce the anxiety of 'free socialising' and what is happening next.
- ✓ Allow the young person to leave the room if they want to; they know themselves best and leaving the room for a breather can be a coping mechanism.
- ✓ Lots of youth clubs offer cooking clubs – please let people know if these are on at similar times to another group or if the group is held in a shared or multi-use space. Different odours affect people differently and can stop them being able to enjoy their group.

Top tips for youth group spaces!

continued...

Including those who speak few or no words

Some autistic young people don't express themselves with verbal language as they communicate differently. This means that to include all autistic people we also have to think about how to include those who don't communicate verbally at all or only some of the time.

When supporting a young person to communicate, do:

- ✓ Recognise and value the young person's communication strategies.
- ✓ Engage specialist support when necessary e.g Speech and Language Therapists.
- ✓ Create and use visual materials to support understanding.
- ✓ Use concrete, literal and precise language.
- ✓ Say the young person's name before any directions or instructions.
- ✓ Be consistent in your language and communication.
- ✓ Allow time for processing. They may have heard you but need to work out what you said and the meaning.



When supporting a young person to communicate, don't:

- ✗ Make assumptions based on the young person's use of language. They may understand more than they speak.
- ✗ Talk too much or ask multiple questions at once.
- ✗ Use a metaphor or idiom without explaining it - some metaphors don't make sense unless you know the meaning.
- ✗ Rely on body language and facial expression as messages can be misinterpreted or missed.
- ✗ Assume the young person has understood your instruction or request.



Section 3

Top tips and practical resources
for parents and carers

Tools for parents and carers

Top tips for parents and carers about youth groups



Youth groups and extra-curricular activities can be a really positive experience for both parents and young people. Sometimes young people need support to join a youth group as they are unsure of what is on offer and whether the environment will be inclusive. Here are our tips for parents and carers on supporting their young person to access new opportunities:

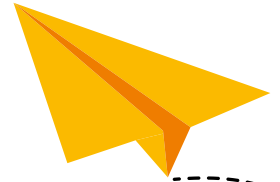
- ✓ Your young person may not be willing to be left at the youth group at the start. Talk to youth group leaders about whether you are able to stay in the building and work with your young person on phasing out your presence.
- ✓ When talking about going to a youth group to your child the best approach is to showcase the positives they will gain from their experiences and discuss what negatives there might be. Many of the negatives are often things that can be mitigated against such as uncertainty of what will happen or change in routine, people won't talk to them or they won't know what to do.
- ✓ To reduce uncertainty, you can do a test drive of the route to the youth group, look at the building it will be in and discuss what happens with a youth group volunteer or leader.
- ✓ If there is a young person who already attends the group who is willing to talk to your young person about their experiences, this can alleviate some anxiety.
- ✓ Talk to the youth group about if they can have a buddy system so there is someone your young person can go to who is a familiar face. This buddy can help facilitate socialising or accessing activities.
- ✓ Youth groups and activities are a great place for your young person to learn new skills. There will be some skills that your child can do, some they are learning and some things they wouldn't have done before. You can use our [goal planner](#) to help your young person develop skills in a structured way.

How to build positive relationships with youth groups

- 1 Identify the key staff members at the youth group and contact them early.** Work out which staff members are the best to contact regarding your young person and get in touch before they join the group. Sharing information with key staff members helps you, your young person and the youth group to build effective support.
- 2 Agree a way to keep in contact that works for you and the staff.** Agree with the key staff the best method for contacting one another and how often. It can be helpful to work out a way to distinguish emergencies, positive comments and things that need to change.
- 3 If necessary, arrange a parent-staff discussion about supporting your young person.** These arrangements and action plans can be subject to review as the young person develops and feels more comfortable in the group. Think about what works at home or school in terms of support if you are struggling to think of things to put in place.
- 4 If you feel your young person is not being properly supported, follow-up with the staff.** You and your young person are the experts. You can help advocate for their needs or empower them to become their own advocate. Do however allow the staff to explain the circumstances and any issues and work together to resolve them making sure the young person is at the centre of all discussions.

Most importantly, remember you are all working to best include the young person and achieve the same goal.

Letter or email to a youth group



Dear _____,

My _____ would like to join your youth group that runs on _____ at _____. My _____ has a diagnosis of autism which means they need support to take part in the activities that your youth group runs. My _____ is really interested in what you do at _____ and is keen to join their classmates / friends in taking part.

This letter/ email is to tell you a little bit more about how to include and support _____ to attend your youth group.

My _____ needs some extra support in these areas to take part:

- ✓ Social interaction
- ✓ Social communication
- ✓ Routines and repetition (social imagination)
- ✓ Sensory issues

My _____ has a lot to offer your youth group and I know they can flourish with some structured support. I am happy to talk further about what needs to be done so that *Son/Daughter/Young person* can attend.

Together we can create a support plan and put in place the tools available in the Include Autism toolkit.

I look forward to hearing from you in the near future about having _____ join your youth group.



Understanding autism - Talking to other members

Many autistic young people can be anxious about talking to their peers about being autistic or viewed as different. As a part of supporting an autistic young person this could include helping them talk about autism and how it affects them with their peers by making a strategy for talking about autism and the young person during a session.

This is a resource for you to talk about autism with the young people who go to your group and the youth group workers. You can also use the opening section [Information about autism](#) and the [Glossary of Terms](#). You can give the members of the group this information to read or make it into an activity.

However, always ask the young autistic person if they are willing to disclose their diagnosis before you do this.

Information sheet on Understanding Autism

Autistic people are similar to those around them, they just have a couple of differences that you might not be able to see. Autism has four main areas of difference where an autistic person is a little bit different to someone who isn't autistic.

The four areas of difference are:

- 1 Social interaction
- 2 Social communication
- 3 Routines and repetition (social imagination)
- 4 Sensory issues

1 Social interaction

Autistic people may find social interactions difficult because they socialise differently to non-autistic people. They don't lack the skills to interact with other people, some of these rules might be difficult to remember or confusing to them. Instead they need more information and support to socialise with people.

Social interactions can often be tiring for autistic people because they have to think about all the parts of socialising other people might not have to focus on. There are lots of rules that we use when talking to someone else, but these rules aren't always the same, this is difficult for autistic people who generally like rules.

2 Social communication

When you talk to another person you listen to what they are saying, look at the actions they make with their face and body and think of what to say in response. Autistic people may struggle to do all of these things at the same time so might communicate differently using words, sounds or gestures.

3 Routines and repetition

Autistic people really like to know what is going to happen and when. They normally have set routines for the activities they do, and everything may have to be in the right order. They can also have routines and repetition around the things they like such as clothes, food, hobbies and conversations.

4 Sensory issues

Some autistic people can have sensory issues in a range of different areas. This can impact how they interact with the environment and how their ability to interact with other people.

Sounds, lights, touch and smells can be painful or very uncomfortable for an autistic person. By changing the environment or allowing someone to change the environment for themselves you can better include autistic people. People might wear sunglasses indoors, prefer a certain temperature, wear ear defenders, not like to be touched or only eat specific foods.





Section 4

Further resources
and signposting

Further resources



The Include Autism workshop

If you're interested in learning how to put the Toolkit into practice or to learn more about how to include autism in a youth group you can request a workshop led by autistic young people involved with the Include Autism project.

In the workshop you can learn more about the skills, resources and scenarios where you can make small changes that have a big impact.

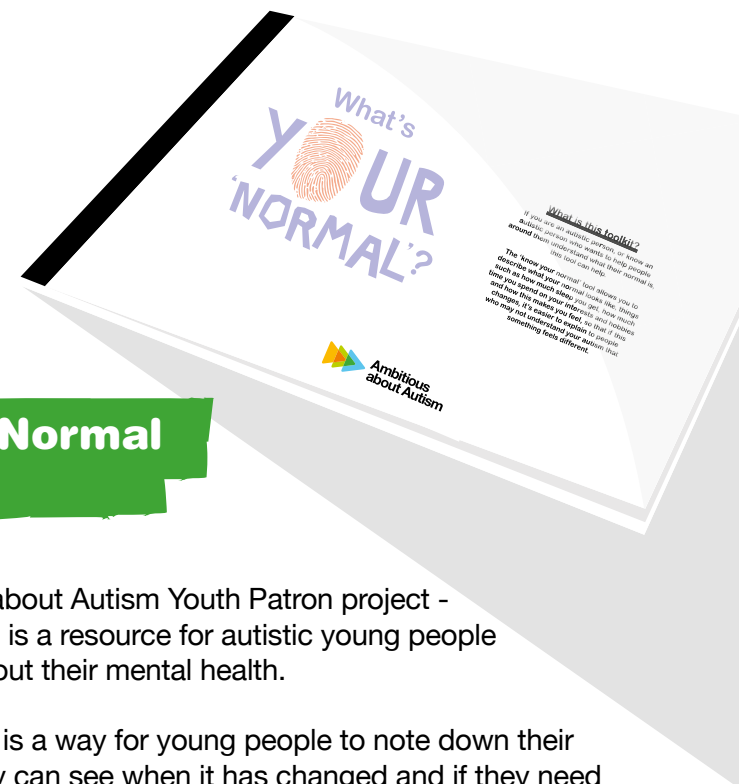
[Request more information about the Include Autism workshop](#)

Know Your Normal toolkit

Another Ambitious about Autism Youth Patron project - **Know Your Normal** is a resource for autistic young people to communicate about their mental health.

The practical toolkit is a way for young people to note down their 'normal' so that they can see when it has changed and if they need to seek advice and help.

The Know Your Normal Toolkit can be downloaded at ambitiousaboutautism.org.uk/our-toolkit



Training and Consultancy at Ambitious about Autism

Further resources and support for understanding autism can be accessed via the Ambitious about Autism Training and Consultancy team. For more information, email training@ambitiousaboutautism.org.uk

Glossary

A

ADHD or ADD - Attention Deficit Hyperactivity Disorder and Attention Deficit Disorder are conditions that someone can have alongside autism. People who have ADHD might be more hyperactive or struggle with attention than people who don't have ADHD.

Alternative and augmented communication (AAC) - This is an umbrella term which covers the different communication methods that may be used by people to communicate or aid communication. These can range from picture cards, symbols and gestures to computer software.

Anxiety - Anxiety is a condition which means you worry more than normal about things. Anxiety can be mild or very difficult to live with and can change dependent on the situation and support available. There are many causes for anxiety and different ways it can present and it doesn't always make sense to the non-anxious person.

Ask, Listen and Do - This is a strategy you can use to ask for feedback, listen to what the person is saying and do what they say. For autistic people and those with learning disabilities this structure can help them to voice their opinions.

Auditory Processing Disorder - This is a condition where the person has difficulty processing sound as you would expect. They might understand speech more slowly, struggle to distinguish similar spoken words, be unable to concentrate when there is lots of noise and might hear music differently.

Autism and Asperger's - Autistic people process the world around them differently to non-autistic people.

Someone who is autistic or has a diagnosis of autism/ Asperger's is different in four areas. These are social interaction, social communication, routines and repetition (social imagination) and sensory issues.

B

Behaviour that challenges - When an autistic person is distressed their behaviour indicates their distress. The behaviour of those around them can be challenging for the autistic person and the autistic person's behaviour can be challenging for those around them.

Burnout - When an autistic person over-stretches themselves by doing too many tasks, too much socialising or making their brain work too hard they can burnout. Burnout is similar to when you are ill, tired and need a rest but are unable to do so.

The autistic person might not act like themselves because they aren't able to think as clearly as they did before a burnout started.

D

Disclosure - Autistic people can choose whether to tell other people that they are autistic and what that means for them. Some people choose not to disclose and others choose whether to disclose depending on the situation they are in.

Dyslexia - This condition means the individual has a difficulty with reading and processing written information.

E

Echolalia - This is repetition of another person's spoken words or repeating of the same word over and over. It can help someone to process the information that they have been given.

Empathy - Empathy is our feeling and our understanding of other people's feelings.

- **Cognitive Empathy** - This is understanding another person's perspective. Autistic people may struggle to empathise with non-autistic people in this way. Non-

autistic people may struggle to understand an autistic person's perspective in a similar way.

- **Emotional Empathy** - This is where we understand another person's perspective and respond in an emotional way. Some people become sympathetic and show compassion when another person is distressed, other people show empathy by becoming distressed themselves.

Executive function - This is our ability to manage multiple tasks and responsibilities at once. Autistic people might struggle with one or more of the areas of executive function.

- **Working memory** - This is the thinking skill of holding information in your mind and being able to apply it to the situation you are in.
- **Cognitive flexibility** - This is the ability to think flexibly or have multiple approaches to the same problem. Autistic people may struggle with this due to liking routine and plans that do not change.
- **Self-control** - This aspect of executive function means controlling your actions and keeping track of what you are doing and how they relate to your goals.

Glossary

L

Learning difficulty - Unlike a learning disability, a learning difficulty does not affect intellect. Examples of learning difficulties are: dyscalculia, dysgraphia, dyslexia, dyspraxia and language and social communication disorders.

Learning disability - A learning disability is a reduced intellectual ability which may result in difficulty with everyday activities or taking longer to develop new skills. Learning disabilities are lifelong and can be mild, moderate or severe. With the right support people with learning disabilities can lead independent lives. Some people can be autistic, have a learning disability or both.

M

Masking - Masking or camouflaging is when an autistic person acts to appear less autistic or not autistic at all. They may change how they look, how they talk and their behaviours. Too much masking can lead to a burnout.

Meltdown - A meltdown is a response to an overwhelming situation. The response can be very loud and sometimes physical. The person needs time to recover and should not be laughed at for having a meltdown.

N

Neurodiversity - Neurodiversity is the idea that the way we think is not always the same. Instead, this recognizes that all variations of human neurology should be respected as just another way of being, and that neurological differences like autism and ADHD are the result of natural variations in our genes.

Neurotypical - This is someone who is not autistic.

R

Routine - Some autistic people might have very strict routines that they like to stick to. Their routine is predictable and helps them to manage anxiety.

S

Sensory processing and sensitivity - Sensory processing is how we take in and perceive sensory information. This may include hyper (high) or hypo (low) sensitivity to the 5 senses, as well as balance and body awareness.

Shutdown - Shutdowns are similar to meltdowns but are not as visible or loud. A person may withdraw instead of being their usual self.

Special interest - This is an intense and passionate level of focus on things of interest on a specific subject. For some people this can be a game or TV show, a type of animal, a type of machine or a country. Special interests are varied and bring the person joy.

Social Communication - This is the way we communicate, understand and use language with others. Autistic people might show differences in understanding and expressing communication and language.

Social Interaction - This is how we interact with other people, develop relationships and socialise with other people. Autistic people may differ in the ability to understand social behaviour and the feelings of others, which informs the development of friendships and relationships.

Social Stories™ by Carol Gray - A Social Story™ describes a situation, skill, or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format. The goal of a Social Story™ is to share accurate social information in a patient and reassuring manner that is easily understood by its audience.

Stimming - Stimming is short for 'self-stimulatory' behaviour. Stimming can be a repetitive movement, repeating words, hand movements and making noises. Some stims are barely noticeable and some are very visible. Stimming behaviours are a way of self-regulating and shouldn't be stopped or reduced as they are an autistic person's way of managing a situation.

Stim toy - An object used for stimming or fiddling with when a person might be feeling anxious. Stim toys come in a range of different types and can include fidget spinners, playdoh, tangles, pens, soft toys and balls. Each person's preference is unique and personal, using their preferred stim toy can help them to feel comfortable and engage in the situation they are in.

Getting in touch

Ambitious about Autism

Ambitious about Autism is the national charity for autistic children and young people.

We provide services, raise awareness and understanding, and campaign for social and policy change. Through TreeHouse School, The Rise School and Ambitious College we offer specialist education and support.

Our ambition is to make the ordinary possible for autistic children and young people.

About our Youth Patrons

Ambitious about Autism works with a wide network of autistic young people aged 16-25 to shape everything that we do. Some of these young people sit on our Youth Council, on advisory boards for the work we do with external partners and create content for our website and other channels. They volunteer their time and expertise to help make the ordinary possible for other autistic young people through the projects we run.

If you're interested in the work of the Youth Patrons or would like to know how to get involved email participation@ambitiousaboutautism.org.uk

We also run an online service called the Ambitious Youth Network for young autistic people aged 14-25. The Youth Network is a place to talk to other autistic young people, find out about employment opportunities through our Autism Exchange programme and get involved with our consultations and campaigns.

If you would like to become a member of our online Ambitious Youth Network please [click here](#) and fill in the short consent form.



Contact us

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Comic Relief

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🌐 www.comicrelief.com

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