

Information booklet for volunteers

# WHAT IS AUTISM & NEURODIVERGENCE

### What is autism?

Autism is a lifelong developmental disability that fundamentally affects how the person experiences the world due to differences in the way environmental, sensory, and social information is processed. Autism is often only seen through its negatives, but autism has benefits due to the different

thinking style. This can include more direct communications not led by social scripts, 'rabbit hole' conversations that examine issues in detail, and neurodivergent thinkers can have excellent problem-solving skills. Depending on an individuals' interests, they may well have expert knowledge in specialist areas or be skilled at explaining complex ideas in simple terms.

Autism exists on a spectrum, meaning that all autistic people will have different strengths and support needs, and this spectrum is explained more later in the booklet.

### What is Neurodivergence?

Neurodivergence is a way at looking at some developmental disabilities, such as autism and ADHD, for example, and some mental health conditions such as OCD and Schizophrenia, as they are often only seen in a medicalised way. A very good way of thinking of neurodivergence is that neurodivergent people have a different flavour of brain and think in a different way. Neurodivergence means neuro=brain, diverse=different, while neurotypical, (typical=same) is the opposite and is the term for most people.

Neurodivergence is about the differences in the way we think, learn, and connect with others.



The term 'Can't see the forest for the trees' is often said about neurodivergent people, as they often find it difficult to see the bigger picture (forest) and focus on smaller details (the trees). Fundamentally it's about how people process information. This difference in natural thinking is one of the many ways neurodivergence is highlighted in autism and other disabilities.

Below is the symbol for neurodivergence...







### **Social** Communications

### Linear autism spectrum

Many people hear "autism spectrum" and think of a line, where a person is going to be somewhere between neurotypical and having high support needs. This way of thinking about autism' does not consider context such as environmental, mental or physical factors.



### Circular autism spectrum

By thinking of autism as a circular spectrum it illustrates aspects of autism that change from person to person. It also shows that different parts of the autistic person's abilities and actions can be affected in different situations.

This could mean in times of stress an autistic person, who is normally verbal, could become non-verbal and possibly have a hard time with their sensory processing, finding everything around them too much. This is called a sensory overload and is explained more later on.

This type of response can also happen from positive feelings such as when doing things to do with their special interest or by having a little break to regulate themselves.



### **Autism and communication**

Autism causes social and communication difficulties. This sometimes comes in the form of misunderstanding sarcasm, idioms, facial expressions, tone of voice and social cues.

Difficulty may also come from how the young person expresses themselves. They might not be fully aware of the tone or volume of their voice. The same may be true of body language or facial expressions, and sometimes questions and phrases they use may be seen as odd in timing or subject.

### **Communication Aids**

Autistic people may communicate in different ways and can respond better to a different style of communication. It can help to think through your approach before speaking or slightly adjusting the way you speak.

One of the easier things to do is to speak more directly. The use of direct language can really help as being clear and concise makes the information easier to process. For example, this can be done by changing "This table is messy and needs clearing up" to "Clean your table, thank you". There are fewer words to process and what is being asked is much clearer.

Some autistic people respond well to having visual cards showing what they need to do such as not talking when the leader is talking. Visual communication cards are often used within educational settings to help two-way communication. No one communication aid will work for every young person as each person is an individual. It may help to talk with parents, perhaps when they share the diagnosis, and you can speak to the Kent Scouts Inclusion Team - the contact information is available at the end of this booklet.







### What is stimming?

Stimming means self-stimulatory behaviour. This is when the person repetitively does a physical movement, makes a sound, repeats words or fiddles with an object. It can be done, either consciously or unconsciously, to help regulate emotions such as anxiety or to express an emotion that is being felt strongly. Everyone stims in different ways from the more obvious, such as spinning and flapping, to some less obvious ways such as rubbing of fingers and tapping.

When you are anxious do you fiddle with your hair or bite your nails? Or perhaps you jig your leg? Well that's stimming; everybody does it. However autistic people do it more than most and it's harder for them to supress. Often it's done as a way to self soothe or to gain sensory input to maintain focus, or it may be a way to deal with stress and anxiety. Being able to focus on something that can be controlled may feel soothing to the person. Many people use fidget toys such as fidget cubes, spinners or tangles and neurodivergent young people should be encouraged to use these if it helps them.

### Why do people stim?

Most, but not all, autistic people stim. The reasons for this vary from person to person, but they commonly include;

- It's enjoyable
- It provides sensory input
- Rocking stimulates the balance system
- Hand flapping may give both visual and kinetic stimulation
- It reduces anxiety and stress
- Using a stim or fidget toy enables the person to focus on one controllable thing and drown out other stimuli.

### What should I do?

You don't need to intervene as it is usually a positive way of regulation for the young person. If you can it might be useful to have some fidget toys such as fidget cubes or tangles. However, you should step in if they inflict injury by biting or scratching themselves or others. Because this is self-harm, as leaders, you are duty bound to report it. It is a hard line to draw as some parents may be very well aware that their child might do this and may have spoken to the leader in charge. Even then however, it is worth noting down any discussion and include details of the conversation that took place and then take advice directly from your line manager in the first instance.

More information about safeguarding and self-harm is available from the National Scout website.



### Mental Health



### **Eating Disorders**

Some studies suggest that autistic traits are common for people who have eating disorders. It is unclear why some autistic people develop them; most people's motivations are around weight or body image. This is the same for autistic people, but also there could be a sensory issue such as ARFID (Avoidant Restrictive Food Intake Disorder), adherence to rules and routine or not being able to sense the feeling of hunger.

If you are concerned about a young person you are duty bound under POR to report it to your line manager. For more information about eating disorders and scouts safeguarding around them head to scouts.org.uk

### What is masking?

Many autistic people can struggle in social situations, often resulting in difficulty making friends or being more susceptible to bullying. Because of this, many autistic people mask their autistic traits by suppressing behaviours that are deemed socially undesirable, for example, stimming and 'info dumping' which is when someone has gathered up so much information on a special interest that they can give an incredibly deep and detailed summary, often during a conversation related to it. Masking is done consciously to fit in and appear 'normal'. Autistic people of all genders deploy masking as a social survival technique; however autistic women and girls are more likely to do it and start at a younger age. The facade of being normal does not come out of thin air but from years of trial and error, learning from other people. Masking can often be damaging to the autistic person's mental health as they have to devote a lot of energy and thought to suppressing their natural behaviour.

### **Anxiety**

Anxiety is described by the NHS as "a feeling of unease such as worry or fear, this can be mild or severe." Autism often goes hand-in-hand with anxiety and research shows disorders including phobias and social or general anxiety are very common. One cause of anxiety is sensory processing; this is when a person is under or over sensitive and may find it hard to predict and cope with some sensory situations. Anxiety can also be triggered by change and transition, from the fear of the unknown, and that may be why many autistic people like routines and to know exactly what's going to happen.



### **Sensory**Differences



### **Sensory sensitivities**

Sensory sensitivity, meaning someone perceives more (hyper) or less (hypo) sensory information, is very common with autism. When someone is experiencing hypo sensitivity they become sensory seeking and are likely to be stimming. If they have a fidget toy let them use it as using it often decreases anxiety and helps them keep more focused. People who are hyposensitive may not be aware of their body and have challenges recognising pain or hunger and thirst, for example. Hyper sensitivity can also be very distressing and sensory inputs can come from sight, sound, smell, taste, touch, balance or body awareness resulting in a sensory overload.

### **Sensory overload**

Sensory overload is not exclusive to autistic people but it is common to neurodivergent people and those with anxiety. Sensory overload is where a person receives too much sensory information and becomes overwhelmed. Different people have different sensitivities and may be more sensitive to certain sensory input than others. Factors such as stress and tiredness can also play a part.

On the next page is a link to The National Autistic Society's campaign, TMI (Too Much Information) running from 2015-2018 about sensory overloads. There are 4 videos each depicting sensory overloads in different environments. You could watch them to get a better understanding of what sensory overloads are like and how distressing they can be for a person, young or old. While the scenarios cannot really be applied to scouting, they should hopefully highlight the everyday things that most pass without noticing, which can cause a lot of distress to others. After watching the videos, please take a moment to list all the sensory input you can feel at the moment, then really focus on everything around you. Is it a lot of different things? Try imagining all of these being felt at the same 'volume' in your head. Is your list a lot bigger now than when you first did it? Remember that not everyone feels things at the same 'volume'.



'Can you make it to the end?' 'Could you stand the rejection?' 'Make it stop.' and, 'Diverted' are all videos made by the National Autistic Society showing how it feels to have a sensory overload.

https://www.autism.org.uk/what-we-do/campaign/public-understanding/too-much-information







### What is a meltdown?

Meltdowns are an intense reaction to an overwhelming situation. A meltdown is a fight, flight or freeze response; as everything is getting too much and the person can't leave (flight) they meltdown (fight), or shutdown (freeze). This results in the autistic person temporarily being unable to control their behaviour.

Meltdowns are often expressed verbally by shouting and screaming, or physically by lashing out at others or themselves. While a shutdown happens the person is unable to interact, so they withdraw from the overwhelming situation.

### They are not tantrums

Meltdowns are often misunderstood as tantrums; this is not the case. Tantrums are intentional and have an aim so stop quickly when the aim has been met. A meltdown is very distressing for the autistic person and is not intentional. It is an extreme form of communication when overwhelmed, as when shutting out as much information as it can, the brain often becomes rigid and less able to communicate.

### What can be done to help?

Meltdowns are often scary to witness but are far scarier for the autistic person experiencing it. Here are some tips on how to support someone during a meltdown.

- Keep in mind it's a very traumatic experience for the person having the meltdown.
- Remain quiet and observe to ensure person having the meltdown and others are safe.
- Make space for the person.
- Try to reduce sensory impact during and after the meltdown.
- Restraining a person young person is not allowed in scouting and could make the situation worse.
- After the meltdown stay quiet.
- Encourage the person to talk about their special interest or something they like and give them more time to answer as audio processing will be slower than normal.
- After the meltdown it may be helpful to talk with other leaders to try to identify the cause or any triggers to see if any can be minimised in the future.
- The person may be emotionally vulnerable and need reassurance or comforting but ensure safeguarding and safety for everyone involved.



### Language



### Talking about autism

When talking about autism terminology is very important. Many people prefer identity first language (autistic person) as autism is a part of them and how their brain works, they feel 'with' suggests it's something that could be removed from them, which it cannot. However, some people prefer person first language (person with autism) as it holds the meaning that the person should be seen before their disability.

The important thing to remember is that how someone likes to be referred to is really down to them and should be respected.

### Talking to autistic people

Autism affects communication and there can be misunderstandings especially with instructions. To reduce this, try breaking down instructions into small steps using clear and literal language and avoid metaphors or sarcasm, as not all will understand it. At the beginning of any instruction, use the persons name to get their attention so that they know you're talking to them, as they may not realise this.

An autistic person may be aware of more information going on than most people so need more processing time before they answer a question. It is helpful to say less, speak more slowly and use specific keywords. The National Autistic Society suggest using the six second rule - count to 6 in your head before repeating the instruction to allow extra processing time. It can also be useful to write instructions down, such as what you want the person to do and by when, as this can help to keep them focused and they can refer back to the instructions.

Some autistic people find verbal communication difficult, others are non-verbal or become non-verbal when stressed or overwhelmed. Augmentative and Alternative communication known as AAC can help communication. This can be in the form of picture exchange communication system, known as PECS, in which a person hands over a picture as a way to communicate. Other forms of non-verbal communication include British Sign Language (BSL), Makaton or Sign Supported English and voice output communication aids that generate digitised speech.

As every autistic person is an individual and will respond to aids differently, talk with them and their parents or guardians to see what will work best.





## Gender & Sexuality



### **Sexuality**

One part of autistic people's lives that is often overlooked is their romantic and sexual relationships, as autism is often infantised. They may be heterosexual and heteroromantic (straight), however, many autistic people are LGBTQ+ and should be included and involved in discussions about sexual orientation and relationships within scouting.

### Gender

There are many autistic people who are 'trans' or transgender, meaning they do not identify with their assigned gender at birth, and there is evidence to show a link between autism and gender dysphoria. This means it is possible that an autistic young person might begin exploring their gender identity and choose to use different pronouns within Scouting. It's important we support all young people to be the best versions of themselves and this includes those who are trans. For more information about gender and how best to support trans young people in scouting, please email inclusion@kentscouts.org.uk



### Reasonable adjustments

For some people with autism the meeting place, badge requirements and completing activities can be very challenging compared to the rest of Colony, Pack, Troop or Unit. To remove as many barriers as possible within all areas of scouting POR allows for flexibility through reasonable adjustments. Reasonable adjustments are applied in three ways;

- 1. Physical features (e.g. the meeting place)
- 2. The way things are done (e.g. age ranges, the programme, routines)
- Support provided (e.g. equipment, adapting communication, level of support)

# Scouting & Reasonable Adjustments

Reasonable adjustments can be made in many ways such as allowing a young person to take off their necker due to sensory issues, training a leader to communicate using BSL or Makaton, or adapting badge requirements to remove barriers making it more accessible. What is reasonable will vary from group to group and will depend on the effectiveness of the adjustment, whether practically it can be done, the cost involved and the resources available.

### **Equal Opportunities Policy**

Autism is a disability and as such is a protected characteristic in the Equal Opportunities Policy which we, as volunteers, have to follow. The Equal Opportunity Policy within scout POR is;

No young person should receive less favourable treatment on the basis of, nor suffer disadvantage harassment or discrimination by reason of:

- Class or socio-economic status
- ethnic or national origin, nationality (or statelessness) or race
- gender (including gender reassignment)
- marital or civil partnership status
- sexual orientation
- disability
- political belief
- pregnancy and maternity
- religion, belief or faith (including the absence of religion, belief or faith)
- se
- age





### **Sharing a diagnosis**

It's often when a young person joins scouting that parents or guardians may disclose that they are autistic. This is a good time to arrange an informal meeting with them, that includes the young person, to discuss the support you can give. It can be helpful to create a plan of action for what to do if the young person is overwhelmed or has a meltdown, and any other useful things leaders could do. All of these are good ways of better understanding the needs of the young person to better support them. The Parent or Carer Framework can be a useful tool when preparing for this meeting. It's important to note that some autistic people are happy for their autism to be talked about openly whereas others are not, so ensure you involve them in discussions that affect



### Support available

Supporting young people with disabilities and additional needs within your group can be difficult and sometimes leaders may need a bit of support. Fortunately there is plenty available whether you want more detailed information or sources for funding.

If you have questions, need more information about a disability, or have a question regarding inclusion you can always contact us at <a href="mailto:inclusion@kentscouts.org.uk">inclusion@kentscouts.org.uk</a>





### **Autistic people's experiences**

Hearing autistic people's experiences is another way to learn about autism as it shows the diversity of needs, personality and accomplishments of autistic people.

If this sounds interesting, check out some of theses Instagram pages:

- @ the.autisticats (Twitter @autisticats)
- @ theautisticlife
- @ cosmo.aut
- @ myautisticsoul

### **Booklet information and charities**

The information in this booklet came from the knowledge and experience of autism of Max Clinch, a member of the Kent Scouts Inclusion team who themself is autistic and one of the National Autistic Society's Young Ambassadors.

The booklet is supported by information found via the resources listed below.

National Autistic Society - Autism.org.uk Kent Autistic Trust - kentautistictrust.org

Autism Alliance - autism-alliance.org.uk

Scouts - Scouts.org.uk





### **Get in Touch**

Have a question about this booklet? Autism in scouting? Or just about autism in general? Please contact us at inclusion@kentscouts.org.uk