

The guide to autism

Information pack

Bucks CAMHS statement on neurodiversity

All CAMHS clinicians aim to offer a neuro affirmative service to young people, families and other professionals. This means that we will support the young person and the people around them to better understand their neurodivergent needs in a strengths based and compassionate way so that the diagnosis becomes a positive and helpful part of a young person's identity. By doing this we hope to empower young people and families to communicate with others about their strengths and differences in a way that others can be supportive through difficult situations. CAMHS aims to offer interventions that are flexible and adapted based on the young person's neurodivergent needs.

Introduction to the document

This document was made by Becca, an assistant psychologist in the Bucks CAMHS neurodevelopmental assessment team. Becca has personal experience with ADHD and autism in herself and her family. She made this pack to try to combine her experiences with her psychological training and provide a “big sister” style guide to help young people and families navigate the world of neurodiversity and all the resources out there.

This document is designed to help you, your child, and your child's family better understand your child and their brain. You do not have to read it all at once, and you can skip to the sections which are most useful for you.

Note on terminology:

Words such as ‘family’ are used throughout this leaflet. This is to make the information as simple as possible to understand. However, there are many forms of family, which can include genetically-related and genetically-unrelated members, and gender-diverse members. When we speak of ‘family’, we mean the network around the child, which may be parents, grandparents, other relatives, carers, guardians, adoptive/foster families, and ‘chosen family’ (the family that the child or young person chooses for themselves such as close friends).

We also use identity-first language (see glossary) as that is usually preferred by autistic people.

Autism is usually called autism spectrum disorder/condition by medical professionals. We have chosen to avoid this medical name for autism as we do not believe that autism is a medical condition, but instead is a natural difference in brain development.

Some words are underlined. The underlined words are words that you can find definitions of in the glossary section.

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Glossary of useful terms

ADHD

ADHD is a neurodevelopmental difference which is very common in autistic people. It involves unusually high hyperactivity, impulsivity, and/or attention problems. People with ADHD will often find that they cannot control their thoughts and behaviour as easily as neurotypical people, so will either spend a long time doing one thing exclusively (hyperfocusing) or will struggle to focus on one thing.

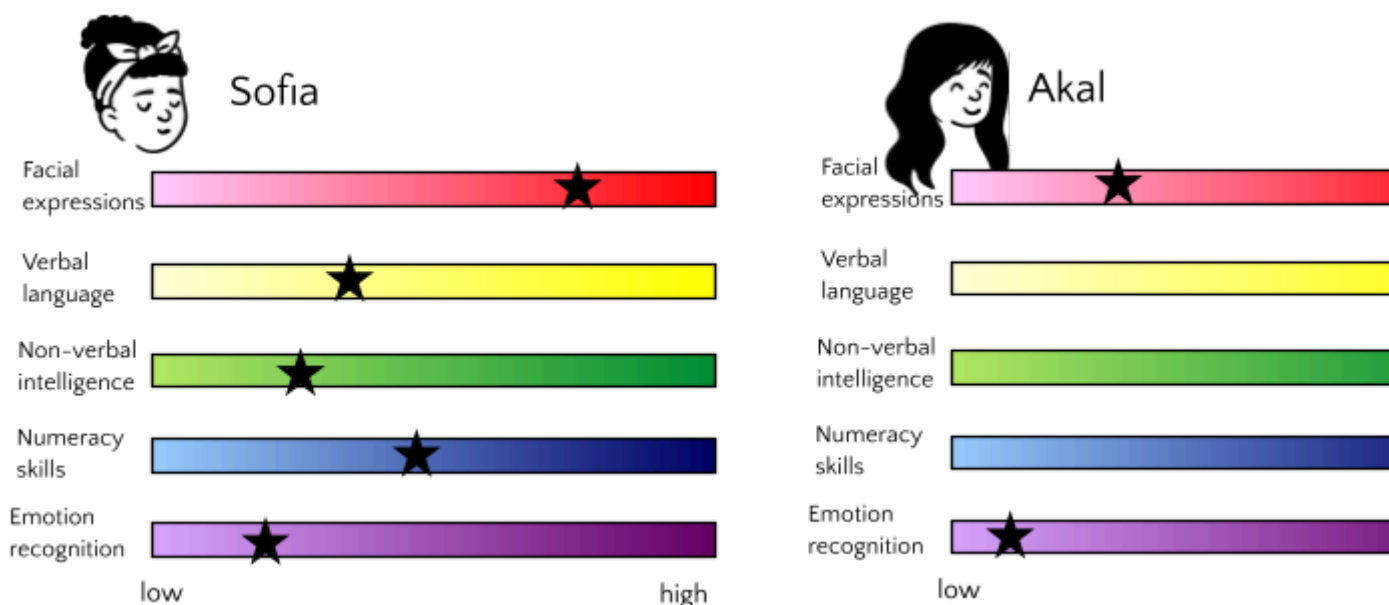
ARFID

Avoidant Restrictive Feeding Intake Disorder. ARFID is a type of eating disorder where people have a very small range of 'safe foods' and can't eat anything else. ARFID often appears when children are young and is much more common in autistic people. Unlike the stereotype of eating disorders, ARFID isn't about weight or appearance but is instead usually about sensory elements of food. Many people with ARFID will have safe foods which are bland and predictable because they find unpredictable, strong-tasting, or strange-textured food impossible to eat.

AuDHD

Given that a lot of people with ADHD also are diagnosed with autism, AuDHD is a term for people who both have ADHD and autism. This may involve wider challenges, such as the conflict between wanting routine (typical of autism) but not being able to keep to a routine (ADHD).

Autism Spectrum

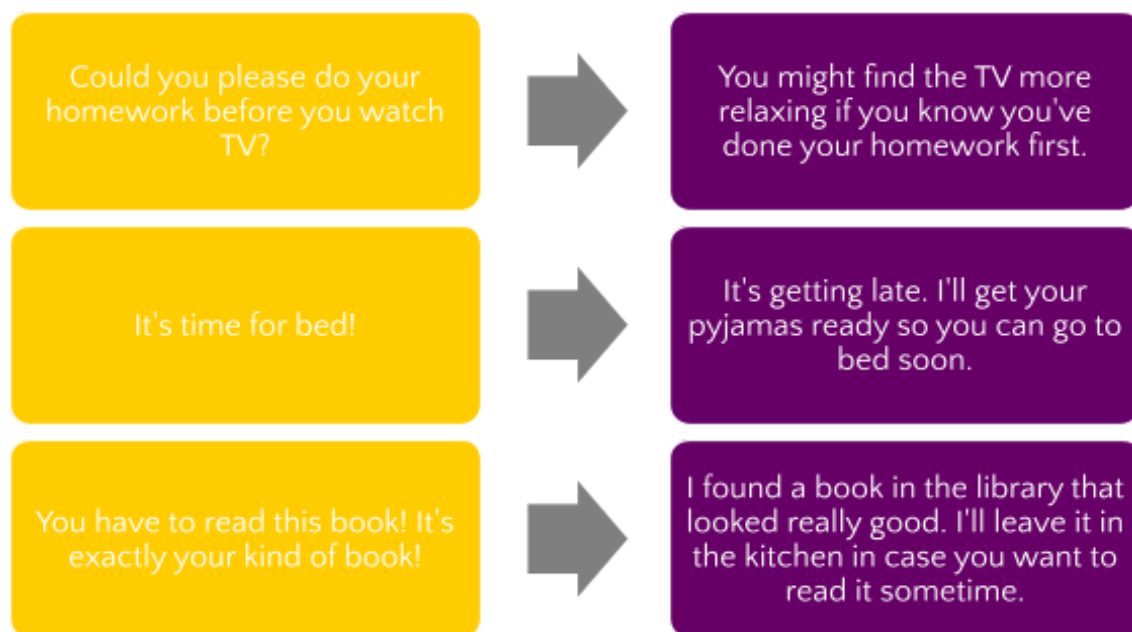


A lot of people talk about 'the autism spectrum' and it can be hard to work out what they mean. Some people think that it means that everyone is on a spectrum of autism, and so everyone is 'a little bit autistic'. This isn't true and it can make autistic people feel like their struggles and needs are being ignored. Autism is best seen as made up of many spectra. For example,

sensory sensitivity is one spectrum, and social-communicative abilities are another. See the image which shows how two autistic people could be completely different but still both be autistic.

Demand avoidance

Some autistic people find that they struggle to follow direct instructions. For example, an autistic young person might find that when their carer says, "Please go and brush your teeth," that they suddenly can't do the task. It could even affect times that a young person is told "You must watch this TV show – you'd love it!" or times when they're told to "keep up" an activity they're already doing. This could be due to perfectionism where the young person is too anxious about the task to do it. It could also be a need for some control. Outwardly, demand avoidance may look like a 'tantrum', but it is not bad behaviour. It is hard to deal with demand avoidance because every young person is different. You could try phrasing instructions in a different way (see below). Your young person may be able to help you to rephrase things in a way that doesn't feel threatening for them.



Double empathy

The double empathy problem is the idea that whilst autistic people struggle to communicate with and understand neurotypical people, neurotypical people also struggle to communicate with and understand autistic people. There is lots of research evidence for this¹ and it is important to remember that autism isn't a disorder of communication but a difference in communication. In a neurotypical world, these differences cause problems because neurotypical people follow a set of unspoken communication rules that autistic people often have to figure out. The communication problem that autistic people have is not because autistic people can't communicate, but because they communicate differently.

¹ Mitchell, P., Sheppard, E., & Cassidy, S. (2021). Autism and the double empathy problem: Implications for development and Mental Health. *British Journal of Developmental Psychology*, 39(1), 1–18.
<https://doi.org/10.1111/bjdp.12350>

Executive (dys)function

Executive functions are the skills that help us to do tasks. These generally include attention, working memory (how much information we can hold in our heads at one time), planning, and other skills. For example, to go to the shops, we need to *plan* our route, pay *attention* to navigating to the right shop, and *resist impulses* to buy unneeded items. Someone with executive dysfunction (like someone with ADHD or autism) would struggle with these skills, which will have a knock-on effect for the rest of their daily life.



Fragile X syndrome

A genetic disorder which is very common amongst autistic people. People with Fragile X can have a range of difficulties, such as learning disabilities, language delays, and mental health problems. Many people with Fragile X are also very sensitive to others' emotions, which can be a strength and a challenge (information from <https://www.fragilex.org.uk/syndrome>).

Identity-first language

Lots of autistic people prefer to be described as 'autistic person' rather than 'person with autism'. This is identity-first language. Autistic people usually prefer that because they often see their autism as a big part of who they are, and calling them a 'person with autism' suggests that the autism can be separated from them. However, some people will prefer 'person with autism' so it is most important to call people what they would prefer.

Masking

When a neurodiverse person hides their traits to appear neurotypical. This is often proposed as a reason for under-diagnosis of autism and ADHD in girls – they are often believed to mask more than boys and therefore their symptoms may be missed. However, masking often has a high cost as it requires a lot of energy. This means that people who mask may find they crash when they get into a safe place, and may develop mental health conditions because of the stress.



Meltdown

Meltdowns are the results of being overwhelmed for a long time, or extreme overwhelm. They often look like tantrums, with person sometimes crying and shouting. They can also be dangerous to the person or those around them, because some people will lash out physically and may hit themselves against walls or floors. Meltdowns are not intentional and can be experienced by autistic people of any age. However, they are likely to reduce in frequency when an autistic person is able to control their own environment and therefore make their environment less overwhelming. Some autistic children (possibly particularly girls) will display shutdown instead of meltdown, where they become less responsive and less able to do normal tasks. An autistic person in shutdown may seem to not hear you, or may not take care of themselves very well, such as not eating or not brushing their teeth.



Neurodevelopmental

Something related to the way that the brain naturally develops throughout life. For example, concentration problems that develop through life may be neurodevelopmental, whereas concentration problems due to a stroke would not be neurodevelopmental (it would be acquired).

Neurodiverse/neurodivergent



Neurodiversity is a term that covers a range of neurodevelopmental and neurological acquired differences, including ADHD, autism, Tourette's syndrome, and Down syndrome. An individual person would be called a neurodivergent person. The precise conditions included are not agreed, but neurodivergent people are usually defined as people whose brains work differently to most other people. The opposite of neurodiverse/neurodivergence is neurotypical – a person without any neurodevelopmental or neurological differences.

SEN

Special educational need; the things that a young person needs to access education, usually as a result of a condition such as ADHD, dyslexia, Down syndrome, or autism.

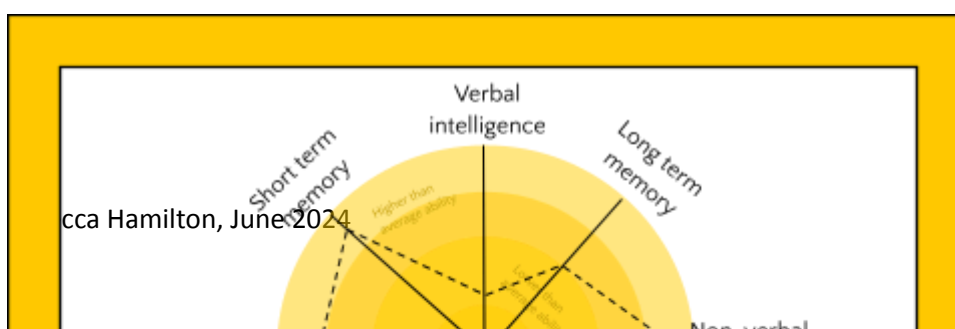
Social model of disability

The social model of disability is the theory that disability is based on environment rather than condition. For example, being shortsighted is not a very big disability (and most people who wear glasses would not describe themselves as disabled) because the world is good at dealing with it – we have large print books and leaflets, good access to glasses and opticians, and people are accepting of others wearing glasses. In contrast, someone who uses a wheelchair because they cannot walk far will often find that the world isn't made for them. They may struggle to get places because there's no lift, or their chair may not fit through doorways. If the world was designed for them, this wouldn't be a problem so their disability would be much less. Similarly, lots of people say that autism is only a disability because the world is designed for neurotypical people, with bright lights and lots of non-literal communication.

Special interest

An interest which is more intense than most people's interests. This is one of the defining features of autism, and is stereotypically something like trains, but could also be anything from fashion to birds to the periodic table. An autistic person will know a lot of detailed information about their special interest, to a much higher level than the rest of their knowledge, or they will spend a large proportion of their time pursuing the interest. You can use someone's special interest to engage them in other areas. For example, a child who rarely exercises could be supported to exercise by using their special interest (e.g. "Why don't we go on a walk and see how many insects we can find?"). A child who isn't interested in school could use their special interest to motivate themselves, such writing stories about their special interest to develop grammar, or doing maths problems involving their special interest.

Spiky profile



Many autistic people (and other neurodiverse people) will have big differences in their abilities between different skills. For example, they may find social communication very hard, but be very good at memory tests. See the diagram for more explanation.

Stim

Stimming is a repetitive movement or action which brings someone joy or helps them deal with difficult emotions. This could include fidgeting (twirling hair around your finger or clicking a pen), hand movements (e.g. flapping your hands), and many other movements. It can also be sounds, such as singing a line of a song, making a clicking noise with your tongue, or humming. Autistic people will often stim but their stims may be different when they're stressed or upset. For example, a happy stim may be hand flapping, whereas a stressed stim may be humming. Stims aren't always obvious unless you're looking out for them.

Support needs

Support needs refer to the amount of help someone needs to be able to live their life as they want. An autistic person may have high support needs in some areas (e.g. budgeting) and low support needs in others (e.g. navigation). Support needs will depend on context, so an autistic person who chooses to do things that are hard for them (e.g. an autistic person who goes to university and has to cope with all the changes in routine) will have higher support needs than an autistic person who chooses to keep doing things they find easier.



Overview

Background

Autism is a lifelong neurodevelopmental difference that affects how a person communicates and interacts with other people, as well as other areas such as how people move (Forster et al., 2016).

Autistic people often need sameness. That leads to them having, for example, unusually strong interests (special interests) and/or

less flexible behaviour. For example, an autistic child may have a very intense interest in a band and be able to tell you the band members' full names, dates of birth, parents' names. That same child may find reading a lot harder than others their age (demonstrating a spiky profile), which might seem confusing to people around them.

The need for sameness may also be a coping mechanism; autistic people often find the world quite overwhelming because they often have more sensitive senses, and routine can be soothing.

Autism is also referred to as Autism Spectrum Disorder (ASD) or Autistic Spectrum Condition (ASC). Sometimes, you might see people use different names for autism, such as Asperger's syndrome, which used to be used to describe an autistic person with normal or high intelligence. We don't use terms like this

anymore because Asperger's suggests that the autistic person doesn't need as much help as an autistic person with lower intelligence. Someone with high intelligence may need the same amount of help (or more) as someone with low intelligence, just in different areas. We usually describe autism in terms of support needs now, with some people having low support needs (needing less help to live the life that they want to live) whilst other people have higher support needs.

Autism is *not* an illness or disease, and it cannot be 'cured'. However, it is generally seen as a disability because autistic people experience a variety of difficulties that can have a significant impact on what they are able to do and their quality of life. This is usually because autistic people's brains work differently to neurotypical (see neurodiverse) people, but the world is designed around neurotypical people. For example, the bright lights in a shopping centre might be fine for a neurotypical person, but not for an autistic person because of their sensitive senses. This doesn't mean that autism is a bad thing – it comes with strengths and weaknesses. One big strength is the way that special interests lead to young autistic people having extremely detailed knowledge or ability in specific areas.

There are lots of approaches and strategies that can help young autistic people and their families manage any difficulties associated with autism. The first step is making sure that an autistic child has the right support in educational settings and that their social, emotional, and behavioural needs are well understood both in school and in other areas, such as afterschool clubs or when with wider family.



Everyone's experience of autism is different. For some personal stories of autism, you can look at the resources section at the end, which links to stories by autistic people. If you find anything particularly useful (whether we recommended it or not), then let us know so we can help other people! You can also talk to your child to ask about how it feels to be them, what they find hard, and what they like about themselves. After all, your child is the expert on how autism feels for them.

How many people are autistic?

The World Health Organisation estimates that 1 in every 100 children is autistic. However, this may be an underestimate because more girls and women are being diagnosed with autism nowadays, so it may be more.

Genetics



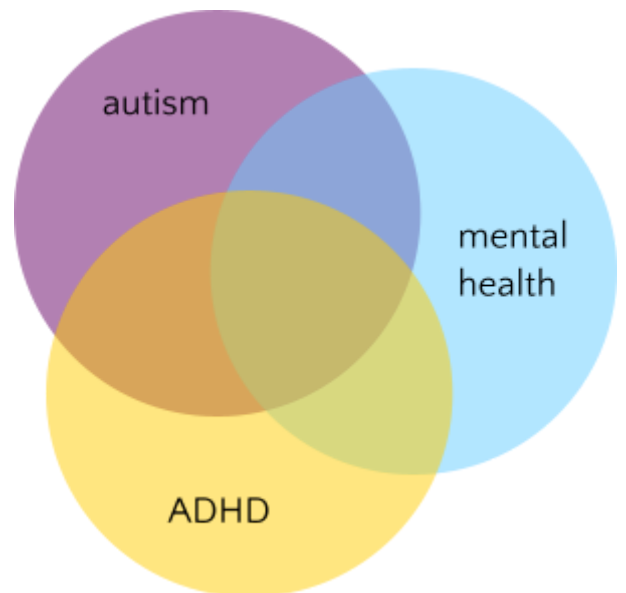
Genetic factors probably play a key role in autism. Autistic people are more likely to have autistic children than neurotypical people. However, there is no one autistic gene – it is likely that there is a combination of genetic differences and environmental differences that affect your chance of autism. You cannot cause your child's autism, and we do not know enough about how autism develops to be able to tell what caused autism in any one child.

Conditions associated with autism

A lot of conditions are more common in autistic people (see the diagram on the right). These include mental health problems (such as eating disorders), other neurodevelopmental differences (such as ADHD), physical conditions (such as muscular dystrophy), neurological conditions (such as epilepsy), and genetic conditions (such as Fragile X syndrome). The reasons for this aren't always clear. Mental health problems may be more common because living in a neurotypical world as a neurodivergent person is often stressful. The reason that physical and genetic conditions are more common in autistic people is less easy to work out.

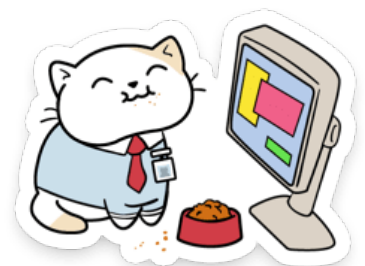
If an extra condition was suspected by the clinician assessing for autism, then a referral will be made for more investigations and treatment if needed. For example, a child may be referred for speech and language therapy or occupational therapy.

The more we learn about autism, the more we learn about co-occurring conditions. For example, there is increasing discussion about whether periods are more likely to be unusually heavy or painful in autistic people. It's likely that more associations will appear with time.

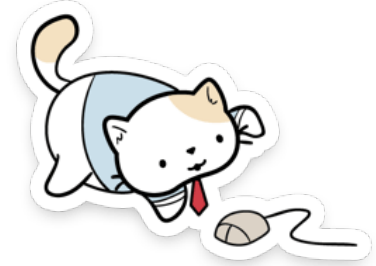


AuDHD

AuDHD is the common name for the combination of ADHD and autism that a lot of people have. This is usually not as simple as having both



ADHD and autism traits because a lot of the time, the traits seem to contradict each other. For example, lots of people with ADHD struggle with routines, whereas a lot of autistic people find routines very important. In someone with AuDHD, this may look like someone who loves routine but struggles to follow a routine, or has rigid routines for some things but absolutely no structure for others. People with AuDHD may also have a need for consistency but also a need for novelty to prevent boredom, so oscillate between following a strict routine and seeking new experiences. AuDHD is quite common, and it might lead to extra challenges compared to just being autistic, but it is not an illness and most people with AuDHD see it as part of who they are. The resources section will support you more with AuDHD.



Main features of autism

The ways that autism shows in people varies a lot. Some people will have lots of difficulties associated with autism, whereas other people will have lots of strengths and fewer difficulties. This depends partly on the person's context (see [social model of disability](#)). Autism is therefore referred to as a 'spectrum' disorder or condition. However, every autistic person experiences significant differences in social communication and social interaction, and has repetitive patterns of specific behaviours, or special interests. Many autistic people will also have problems with [executive functioning](#). Strong sensory preferences and/or sensitivities are also very common in autistic people. For example, some autistic children will refuse to wear many types of clothing because they say they are itchy or too tight, which is because they are more aware of their senses than [neurotypical](#) children.

Social communication and interaction

Autistic people often:

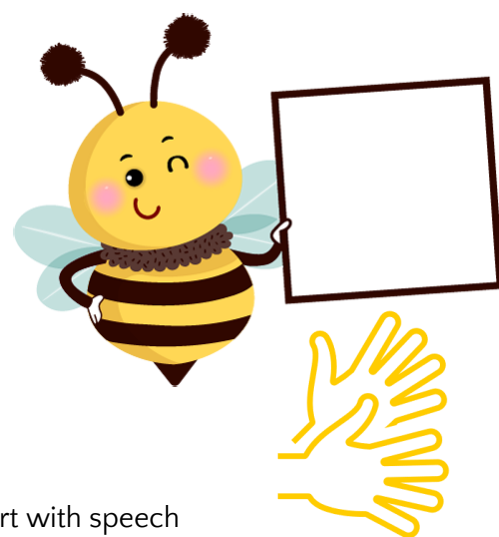
- Have difficulties communicating what they need or want because of their differences with verbal and non-verbal communication. For example, a lot of autistic people use very literal language. This means that they may struggle to understand figurative or non-literal language (or must think more about the language so the conversation is delayed, see the picture on the right). This isn't necessarily a weakness – from an autistic person's perspective, [neurotypical](#) people tend to say things in strange roundabout ways!
- Find informal conversations more difficult. They may struggle to work out what someone is thinking in a conversation, so they might say things that are seen as a social 'no-no' or not respond as expected (e.g. giving a lot of detail when someone asks, "How was your weekend?"). They may also be more likely to talk about their interests without asking about others' thoughts. Again, this is a different style of communication rather than a simple weakness, and many autistic people will learn to [mask](#) this by using rules such as "only talk about my interest for sixty seconds and then ask a question".
- Struggle to understand other people's non-verbal communication (facial expressions, gestures) and tone of voice. This may affect emotion-reading and also working out what people are thinking. However, many autistic people are extremely empathic, and if they know someone is upset, will feel their emotions an unusually high amount. This can mean that autistic people find emotions overwhelming or exhausting.
- Don't know and/or understand the unwritten social rules around what is ok and what is not ok to say (so may make insensitive or insulting comments) and how to behave in social situations (and may, therefore, for example, stand too close to another person). Autistic people may [mask](#) this by learning specific rules (see the imagined conversation on the right).



All of this means that social situations are often very unpredictable and stressful for autistic people. If an autistic person breaks a social rule that they do not know they're breaking, they will be surprised and confused by the negative reaction. This may lead some autistic people to avoiding social situations because they are so stressful. Other autistic people will mask by memorising rules to avoid these situations, which will make social situations very tiring (see the table below for an example).

What a <u>neurotypical</u> person is thinking	What an autistic person is thinking
"Oh, that's an interesting idea!"	"Ok, need to remember three points from what they just said so I can ask about it later."
"I like chatting to this person."	"I'm not doing enough eye contact – I'll look at their eyebrows for three seconds and then away for two seconds and then repeat. Then I'll nod three times, so it shows I care. Oh no – I got distracted by eye contact and haven't listened!"
"She seems happy to be spending time with me."	"She asked how I am, so I must give a vague positive response and then no more than two sentences about the last week. And remember to ask her back!"

Because autistic people often struggle with communication, they may use alternative forms of communication. Some autistic people use electronic tablets to communicate, and others use signs. Some autistic people may also communicate through behaviour, such as running away or hurting themselves. This is usually when an autistic person is upset or overwhelmed and cannot communicate it in any other way – it is not naughtiness and shouldn't be punished. Even though it may be hard to cope with, it is a form of communication and needs to be replaced with other communication rather than trying to stop it alone. For example, you could introduce a sign that the autistic young person can use when they feel overwhelmed so that you can help them before things spiral.



Bucks speech and language therapy has a series of webinars to support with speech and language:

<https://www.buckshealthcare.nhs.uk/cyp/speech-and-language-therapy/training-for-parents-early-years-and-school-staff/>

Special interests and repetitive behaviours

Autistic people often experience the world as unpredictable and confusing. As a result, they often seek certainty and predictability by focusing on things that interest them and that they know about, or by creating routines or set ways of doing things. Autistic people also tend to stim, which can be a way to deal with or express strong emotions, or can be something which brings joy in itself.



Many autistic people may benefit from having a visual planner to help provide them with predictability, which can reduce their experience of anxiety. It is also important to prepare autistic children and young people for changes in advance. For example, if a child is changing teachers at school, it may help to ask the school whether the child can meet the teacher in advance, or sit in their new classroom in advance.

Special interests can be used to help motivate autistic children at school and other areas, such as doing exercise or doing chores. If a task can be related to a special interest, it may be easier for the child to do it. This is especially useful for younger children, and older children may learn how to use this tip for themselves.



Sensory preference and sensitivities

Many autistic people are under-sensitive (hypo-sensitive) or over-sensitive (hyper-sensitive) to sensory input. Sensory input includes tastes, smells, sounds, visual input, touch, bodily movements (proprioception), balance and spatial orientation (vestibular sense), and internal physical body states such as feeling hungry or knowing when to use the toilet (interoception).

If someone is over-sensitive to sensory information, they might feel it very intensely. For example, a background noise that most of us can block out can be experienced as something very intrusive, distressing or even painful to the young person. If they are under-sensitive to sensory information, they might have a high pain threshold or not be able to feel extreme temperatures or hunger. However, it is important to bear in mind that autistic people may communicate discomfort differently. An autistic child may appear unbothered by a sensory experience, but this doesn't mean that they aren't uncomfortable.



Sensory sensitivities may particularly affect eating. Lots of autistic people will have very specific food that they will eat, and often this is 'unhealthy' food because a processed food like a chicken nugget is more predictable in taste and texture than a fresh food like a tomato, so is easier to eat (see graphic below). The most important thing is that your child is eating, and it is not anyone's fault if the child has a specific or restricted diet. If your child is eating from all the food groups (carbohydrates, fruit/vegetables, protein, dairy/dairy-substitutes, and fats) and seems healthy (i.e. has energy, is happy, is gaining weight similarly to other children) then there's not usually a problem. You may just need to make sure that your child always has safe foods available when you go out, and keep encouraging them to try new foods (but it is ok if they don't want to). If you're concerned, speak to your GP, who can advise you and get you further help if needed.



Sensory sensitivity can be a good thing. Someone with sensory sensitivities will experience the world in a much more intense way, which may bring happiness as well as anxiety. Many autistic people have particular sensations that they seek, such as soft fabric or particular colours. Sensory experiences can be another source of joy for autistic people.

Sensory sensitivities will look different in different children, and how it's best to deal with it will vary a lot. The most important thing is to listen to your child, in whatever way they communicate. Believe your child if they communicate sensory distress; just because you don't notice the things your child notices, it doesn't mean they're not there. If you think your child may have unmet sensory needs, you can access webinars on <https://www.buckshealthcare.nhs.uk/cyp/occupational-therapy/webinars/>. Your child may also have strategies that they put in place, whether they realise it or not. For example, some children may seek out particular textures or play loud music to block out negative sensory experiences. Helping your child to recognise these strategies and use them in different environments may help them to self-regulate better.

Mental health

As this booklet has mentioned, autistic people are more likely to have mental health problems such as anxiety disorders or eating disorders. There are likely to be many reasons for this, and autism may affect how people recover from mental health problems. For example, autistic people may need different recovery plans for eating disorders because of sensory sensitivities. An autistic person may need a much more restricted meal plan because they may have fewer foods that they can bear to eat.



Even in autistic people without mental health diagnoses, autistic people are usually under more stress than neurotypical people. The results of the overwhelm and stress of being autistic in daily life can appear in a number of ways. Some autistic people may have a meltdown, whereas others may appear to go backwards in their abilities or communication for a while (shutdown). Whatever the response, the autistic person is not doing it on purpose or for attention. This may be an area where occupational therapy may be useful; an occupational therapist may be able to help a child to find new strategies for dealing with overwhelm so that it doesn't reach the point of meltdown/shutdown.

Emotional difficulties

Autistic people often struggle to identify their own feelings and/or understand why they are feeling a particular way (this is called alexithymia and is also seen in conditions like depression). This will mean that autistic people may find emotions overwhelming or not know what to do to help themselves. You may need to support your child with identifying their own emotions and self-soothing behaviours.

Sleep difficulties

Many autistic people will experience difficulties with sleep at some point; they may struggle to get to sleep or to stay asleep or wake early. Increased anxiety, processing what happened during the day, sensory



sensitivities, unhelpful routines or a lack of daytime routines and structure can all impact on sleep.

Establishing a healthy sleep routine can help improve sleep. This can include creating a visual bedtime routine with your child, reducing stimulating activities and increasing relaxing activities at least one hour before bedtime; making the bedroom as comfortable as possible and explaining to your child why sleep is so important. There isn't much evidence for normal exposure to blue light from screens affecting sleep much (one good study reported 5 minute difference in time to fall asleep between using a high-blue light phone and a no-blue light phone; Mortazavi et al., 2018), but the stimulation from screens might make it harder to sleep. Helping young people to relax their bodies such as doing deep body relaxation before they go to bed may also help prepare them for sleep.

However, all children are different. For some children, screens may be an important part of a routine, such as watching an episode of their favourite programme. For some children, physical activity may help them sleep by helping them to connect with their senses better, or let out some anxious energy. If your child is best helped by unusual sleep routines, that is ok.

Strategies and support

What support can Child and Adolescent Mental Health Service (CAMHS) offer you?

Autism Early Support offers groups for families around diagnosis.

There are also several different services that CAMHS can offer should your child need further mental health support. More information can be found on our website <https://www.oxfordhealth.nhs.uk/camhs/bucks/>. We operate a self-referral process for young people and parents or carers, and therefore, you can do this a number of ways:

- call the CAMHS Single Point of Access on 01865 901 951 or
- make an online referral <https://secureforms.oxfordhealth.nhs.uk/camhs/> or
- request your child's GP does this for you.

When they become an adult, they can self-refer to Talking Therapies (<https://www.oxfordhealth.nhs.uk/bucks-talking-therapies/>).

Education

There are lots of strategies that may help your child in school. For exams, they may be able to get a separate room so that they have a quiet calm environment. Some schools can give students passes to get out of lessons when they feel overwhelmed, or regular meetings with a mentor. If your child's teacher knows that your child is autistic, they may also be more understanding of your child, such as allowing stimming or ear defenders.

All children have the legal right to an education which meets their needs. This means that if they struggle in school, your child may have SEN and be entitled to extra help. Most teachers have some experience of teaching autistic children, but some teachers will be more comfortable than others. There are services that can support you to get the right support in education for your child. Speak to your child's school Special Educational Needs Coordinator

and sharing any diagnostic reports can also be helpful. Navigating the educational system can be very daunting but there are some useful links in other support and resources section below. You can also remind schools of their obligations under the SEND Code of Practice:

- 6.2 Every school is required to identify and address the SEN of the pupils that they support. Mainstream schools must
- use their best endeavours to make sure that a child with SEN gets the support they need – this means doing everything they can to meet children and young people’s SEN
 - ensure that children and young people with SEN engage in the activities of the school alongside pupils who do not have SEN
- (<https://www.ipsea.org.uk/how-your-nursery-school-or-college-should-help>)

If your child’s needs are causing them difficulty in accessing education or reaching their academic, social or emotional potential, then you may be able to request a formal Education and Health Care Plan (EHCP) assessment to explore what the council needs to do to meet their needs. The EHCP is legally binding and lists all of a child’s additional needs, and specifically how these can be met. More information about these can be found at

<https://familyinfo.buckinghamshire.gov.uk/send/education-and-send/education-health-and-care-plans/>

The National Autistic Society offer an Education Advice Line that can advise you on your child’s rights and entitlements and on what you can do if your child isn’t getting the support they need. Call 0808 800 4102 or email educationrights@nas.org.uk

After school

From the age of 16, lots of people do further education like A-levels. Some of those young people will go to university. If you go to university, you can access the Disabled Student Allowance (<https://www.gov.uk/disabled-students-allowance-dsa>) – funding for adjustments such as extra software or mentors.

Lots of young people go into job-based education instead of more academic qualifications. This might be an apprenticeship or a T-level. The government Access to Work scheme (<https://www.gov.uk/access-to-work>) can help young people with disabilities (including ADHD or autism) moving into work, such as by funding mental health support or workplace adjustments.

Strategies that can help with communication, anxiety, and challenging behaviour

Autistic children and young people can be helped by others making changes to the social and physical environment around them and through others supporting them to learn new ways of coping. Making even small changes might initially increase your child’s level of anxiety so you

might see an increase in challenging behaviour. It will usually be best to only introduce one change at a time and wait for the initial level of anxiety to reduce before adding a new change. You can try the following strategies:

1. Try to provide structure and routine for your child (e.g. by introducing a visual timetable). This should make day-to-day life more predictable for them and reduce anxiety.

2. Prepare your child for changes and transitions. Some autistic people need a lot of advanced warning about (major or minor) changes and transitions, others benefit more when they are told about changes or transitions only a short time in advance. You will need to work out what suits your child best.

3. Provide 'bridging activities' (activities that distract or motivate the young person before during and immediately after a transition) at times of transition (e.g. on the journey to or from school).



4. Make sure that your child has regular breaks built into their day. They might need time on their own or to spend time engaging in a special interest to recharge their batteries and reduce anxiety.

5. Support the young person to understand instructions or rules by providing pictures or photographs (e.g. on a mobile phone or iPad). Examples might include using:

- A timer to help the young person wait – remember some young people will prefer one that ticks whilst others will find the ticking unbearable.
- 'Now and next' cards (e.g. a picture of the current activity and a picture of the next activity). If the young person struggles when plans are changed last minute, try to help them anticipate a possible alternative activity or a plan b, e.g. in advance tell them if it's raining, we will go to a café instead of the park.
- Visual timetable or calendar.



6. Talk about positives rather than focusing on negatives. For example, tell them what to DO rather than what *not* to do; for example, rather than saying "Don't stand so close to me.", try "Can you show me good personal space? Well done!". This way, the focus is on how to improve, and the child gets positive reinforcement.



7. Use short simple sentences, repeat if needed, and allow time for them to process what you have said. You can also use a 'talking stick' for this so that the young person can hold the stick whilst processing and put it down to signal that they have processed and are ready to continue. It's important to remember that this isn't the same as babytalk. Many autistic people have excellent vocabularies but struggle with processing what they hear, so it is best to use a normal tone, but just a little simpler sentences.

8. Break steps down – ask them to do one thing at a time (when they are more able/comfortable with a task, then the number of steps could be increased).



9. If a young person struggles with executive function, it may be best not to give the young person too many options and instead use a limited choice, e.g. "Would you like an apple or a pear?" (ideally ensuring they like both options). This helps to give them some choice and a sense of control but reduces the demand and is less overwhelming. If the young person has demand avoidance, it may be easier to avoid asking a direct question, and instead say something like "I know you like apples and pears. I thought you may be hungry, so I'll leave an apple and a pear out here for you in case you need a snack. I'm happy to cut it up if you want me to."

10. If your child struggles with special occasions and holidays, you can use your child's interests to mark the occasion. You may need to compromise on what you think of as required of the holiday e.g. maybe your child does not want turkey at Christmas because that's out of the normal routine, or maybe they don't want to dress up for Halloween. Two autistic children may be very different in that respect; one child may find holiday routines very important (e.g. "We always open presents at Nanny's house.") whereas another may need an everyday routine (e.g. "I don't want to go to Nanny's. We never go to Nanny's before breakfast.")



You can also try to:

- Buy gifts that are related to the young person's interest
- Go on days out that are linked to the young person's special interests (e.g. a farm or a train station)
- Go to familiar places
- Limit the number of places that you visit in a single holiday
- Try to replicate some home structure, e.g. take your own duvet cover, same foods that you have at home.

11. A communication passport (see examples here: <https://mycompass.com/downloads/>) which describes how a person communicates (e.g. gesture, sign, verbal, written, letter/word board) and some important things to know about them (e.g. what they like/dislike, how to help them if they're upset, any allergies or adverse reactions).

12. Be curious and listen to your child (however they communicate). Asking why and thinking about the possible underlying triggers for their behaviour helps build your relationship and your child's ability to trust you. Strategies are more likely to be effective if they agree with them.

There are many online resources that provide visual tools that you can download for free, and some autism websites listed in the next section also offer advice on strategies.

Mental health

Mental health is often an important thing to consider for neurodivergent young people. There are lots of different services available, and that can be hard to navigate sometimes.

In Buckinghamshire, the charity Mind offers counselling for young people aged 13–21. You can access this via their online form on their website (<https://www.bucksmind.org.uk/counselling-for-young-people/>).

As a young person moves into adulthood, they can access support from Buckinghamshire Talking Therapies (<https://www.oxfordhealth.nhs.uk/bucks-talking-therapies/help/>), to which they can also self-refer.

Some of the resources in the resource section will also help with mental health.

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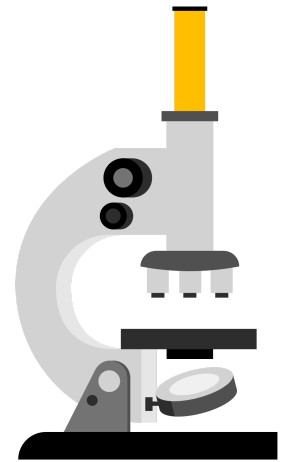
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How to tell a child they are autistic.

Deciding how to tell your child they are autistic is often a sensitive issue. Being autistic can be linked to a mixture of difficulties, and at the same time we need to remember that autistic people have wonderful qualities.

You know your child best, and you are the best-placed to work out the best way to talk to your child. However, the template below may be useful.

Some children (especially older children) will want to know about autism in scientific terms, such as the fact that it's genetic but we can't identify which genes are involved because there are so many.



The most important thing is to show your child how autism comes with strengths and doesn't mean that they cannot be successful or happy. It might help to show them that many celebrities are autistic, including activists (e.g. Greta Thunberg), writers (e.g. Holly Smale, author of the Geek Girl books which has recently been turned into a Netflix series), comedians (e.g. Hannah Gadsby), and many others. These celebrities often have succeeded because of autism not despite it; Greta Thunberg has said that her autism is a big part of her activism.



Older children might have complicated feelings. Older children will have had autism traits for years and may have suffered for it, such as believing that they were naughty or 'stupid'. Learning that they have a difference in their brain might make them grieve the life that they might have had if they had known earlier. Older children are also more able to access communities such as watching autistic influencers (see the resource list below for some ideas), so you might find that their autism becomes something they take as part of their identity. One child may also respond in different ways over time.



Template for talking about autism

Choose a time when the child is feeling fairly calm and is able to listen. Given that many autistic people struggle with executive functions, this conversation may need to happen in parts. The following bullet points may help to guide the conversation, but it is up to you how you tell your child. The conversation will differ based on factors like the age of the child, how involved they have been in the process of diagnosis (e.g. whether they had suspicions themselves or whether it was just school/parents), and the child's understanding of autism.

- Tell them that the tests they did recently were for autism
- Explain that the tests showed that they are autistic
- Autism isn't an illness; you can't catch it from anyone else – it just means that their brain works in a different way

- Autism means that you find some things (like interpreting facial expressions) harder than most people, but you might also have strengths like having really deep interests (special interests)
- Talk about what can be done to help – adaptations at home and school
- Talk about what autism means to them – what they think about the diagnosis and what they think they need to help them

Resources

Benefits

You may be entitled to claim some benefits for you or your child; some of which are available regardless of your income or employment status. These include:

- Disability Living Allowance
- Carer's Allowance
- Extra Child Tax Credit
- Income Support or Universal Credit
- Housing Benefit or Council Tax reductions

Please look here for more information – <https://www.gov.uk/browse/benefits>.

Alternately you can visit your local advice centre (e.g. Citizens Advice Bureau) who will also be able to help with filling in claim forms.

The Autism Early Support service

You can get access to courses from the specialist local organisation **Autism Early Support (AES)** which is delivered online for 10 weeks.



Autism Early Support®

<https://autismearlysupport.org.uk/programme-of-support-for-parents-carers/>. Despite the name, its workshops and consultations are targeted to cover both ADHD and autism. They are covered by CAMHS separately to the paid support they also offer.

It includes a series of interactive workshops and webinars that are designed to help you:

- Gain a broader understanding of the ways you can support your child and advocate for their needs.
- Develop a profile of your child's needs to share with their teachers and other professionals who work with them.
- Learn practical solutions to adopt with your child at home.
- Better understand and respond to their behaviours.
- Gain access to a peer support network with other parents.
- Better understand neurodiversity and how it can impact your family.

AES also runs family support groups for you to get support from other parents.

Finally, AES also offers targeted 1:1 sessions with experts if you feel you would benefit from that after attending the webinars.

You can contact us to be referred, or you can refer yourself through the parent portal on their website.

Support groups for parents

The Autism Directory – <https://www.theautismdirectory.com/>

A directory of groups across the country for autism support.



Autism Bucks – <https://autism-bucks.charity/>

A charity which informs on autism and holds meetings – not for children but open to parents of autistic children. This may also be a good option for your child to access as they move into adulthood.



SPACE – <https://spacesupport.co.uk/>
<https://www.facebook.com/groups/594309283994002>

A group which holds support groups for parents of autistic/ADHD children in Buckinghamshire; also has a library of resources.



Activities/support for kids

Thomley Hall Activity Centre – www.thomleyhall.org

A centre specifically for people with additional needs and their families (including siblings), which has resources including a soft play centre, sensory rooms, outside play. Has specialist play staff and costs around £13 per child but has some allowances for low-income families. They also run a life skills programme for 16–25 year olds with an EHCP and programmes for families in receipt of free school meals in Oxfordshire and Bucks.



The Parasol Project – <http://www.parasolproject.org/>
<https://www.facebook.com/people/The-Parasol-Project/100064441641318/>

Organises regular activities such as laser tag or cooking for children and teenagers with disabilities. Note: is in Oxford but may still accept children from Buckinghamshire.



Chiltern Music Therapy – <https://www.chilternmusictherapy.co.uk/>

CMT is a service which provides music therapy for a range of people, including children and young people with ADHD or autism. They charge for their services (usually £600 for a set of assessment sessions and then £95 sessions if desired to follow up but costs vary), with this

cost sometimes covered by Bucks County Council (usually via EHCP). They provide discounts or bursaries on a case-by-case basis. They also do group therapies in some areas.

Government websites and support

SEND local offer – <https://familyinfo.buckinghamshire.gov.uk/send/>

The Buckinghamshire council information on SEN, which includes ADHD and autism, and what can be done in schools.

SENDIAS Bucks –

<https://www.buckinghamshire.gov.uk/schools-and-learning/bucks-sendias-service/>

A free confidential advice service offered by the council for impartial advice on all areas of SEN and disabilities for both young people (from birth to 25) and their families.

Information/activism

National Autistic Society – <https://www.autism.org.uk/>

Nationwide charity which provides education, resources, and access to a community; has local chapters which may be able to offer support and meetings – i.e. Milton Keynes, South Bucks, Aylesbury.



Autism Education Trust – <https://www.autismeducationtrust.org.uk/>

Run by the National Autistic Society and Ambitious about Autism, it's a nationwide group which educates on autism and provides training.

Ambitious about Autism –

<https://www.ambitiousaboutautism.org.uk/>

Charity which works towards helping autistic young people's rights and access to opportunities. Also provides information and resources.



Cerebra – <https://cerebra.org.uk/>

A charity which funds research into brain conditions/differences (including autism) and gives advice and resources.



IPSEA – <https://www.ipsea.org.uk/>

Education and support on legal matters in SEN.

Clearly Speaking – <https://clearlyspeaking.org.uk/services-we-provide/>

Clearly Speaking is a charity which works with children and young people with hidden support needs, especially children with mental health problems or neurodevelopmental differences. They provide services such as support with educational entitlements or attending meetings with a child's school or local authority. They also work with young people to develop their independence. These services are not free, but a comprehensive price guide is on their website. They also run groups for children, such as a Dungeons and Dragons group and a group for girls.

Birmingham Food Refusal Service – <http://www.foodrefusal.co.uk/>

Information on ARFID; also gives training for professionals and parents currently priced at £200 per hour.

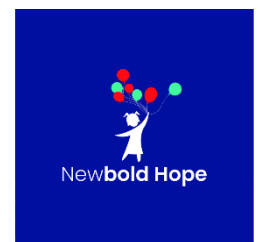
ARFID Awareness UK –
<https://www.arfidawarenessuk.org/>

Information on ARFID; also runs support groups.



Newbold Hope – <https://www.newboldhope.com/>

A website with resources (free and paid for; webinars cost £8.50 each) about violent behaviour in neurodiverse children and how to cope as a parent



Autism Understood – <https://autismunderstood.co.uk/>

Autism advocacy by autistic young people.



Spectrum Gaming – <https://www.spectrumgaming.net/>

Autism advocacy and social meetings; also gives webinars and hosts gaming in person (not in Bucks)

Resources on social media

Lou

Becca Hamilton, June 2024



neurodivergent_lou (Instagram), @neurodivergent_lou (TikTok)

Young autistic British woman who educates on autism – recent posts include a response to the idea that autism is a trend, how to cultivate autistic joy, and discussing sensory rooms



(un)masked

weareunmasked (Instagram), also has a blog (www.weareunmasked.com)

Founded by Ellie Middleton, runs national events for autistic people and people with ADHD, publicises talks on autism/ADHD/AuDHD and her book.

Myk

autisticayla (Instagram), @autisticayla (TikTok)

A young Canadian person who talks about AuDHD, referencing research papers, and discussing their experience.



Kaelynn Partlow

Kaelynnvp (Instagram), Kaelynn Partlow @Kaelynnism (Youtube), @kaelynn_vp (TikTok)

A young American woman who went on Love on the Spectrum and discusses areas such as neurotypical empathy, support needs, and the experience of intense autistic emotions.



Toren Wolf

toren.wolf (Instagram)

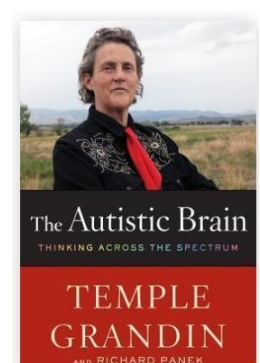
A young American man who talks about his autism/ADHD, how it presents in him vs his mum, his experiences of ARFID.



Books

(also see list on

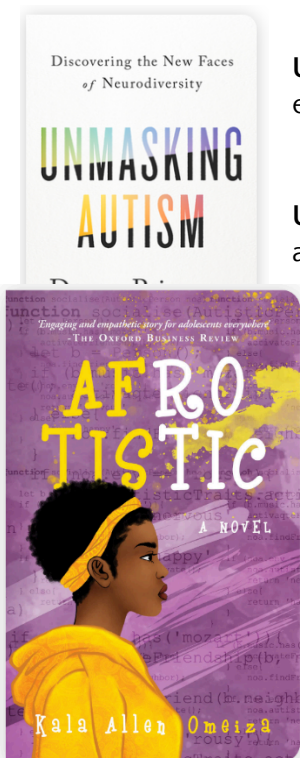
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<https://notanautismmom.com/2021/08/25/inclusive-childrens-books-on-autism-and-neurodiversity/>)

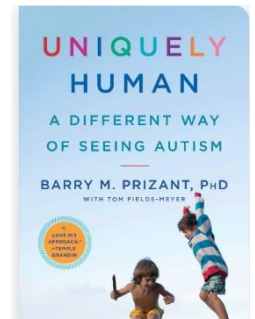
Books for parents/carers (and older children)

The Autistic Brain (Temple Grandin) – A book by autistic scientist Temple Grandin, who talks about autism across different groups of people and the benefits that autistic people bring to the world.



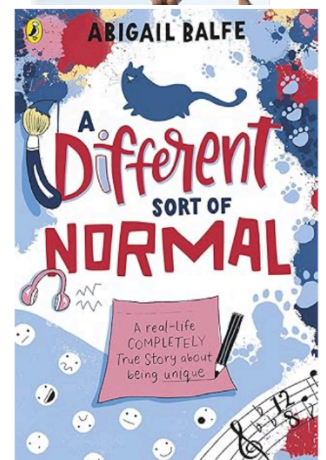
Unmasking Autism (Devon Price) – A book on masking – what it feels like, its effects, and how to unmask so that you can be yourself as an autistic person.

Uniquely Human (Barry Prizant) – A book discussing the idea that autistic traits are responses or coping mechanisms for a world that is not designed for autistic people. It discusses how autistic traits can be positives.

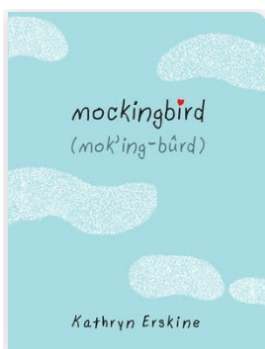


Afrotistic (Kala Allen Omeiza) – a young adult fiction book about an autistic Black girl navigating her identity and trying to win an academic award by creating a social group of autistic people

A Different Sort of Normal (Abigail Balfe) – a self-illustrated memoir by an late-diagnosed autistic woman about her childhood/adolescence before she knew she was autistic

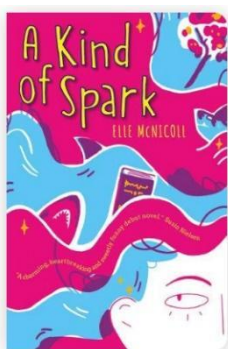
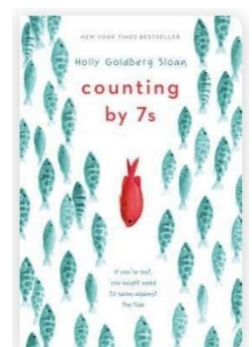


Books for young people (including siblings)



Mockingbird (Kathryn Erskine) – A fiction book for older children about an 11-year-old girl called Caitlin who is autistic (in the book, she was diagnosed as having Asperger's) and how she copes in a world where her older brother has died.

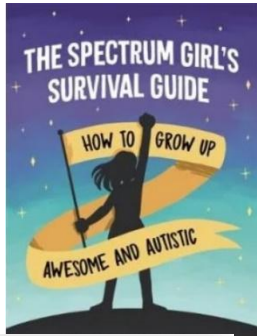
Counting by 7s (Holly Goldberg Sloan) – A fiction book about a girl called Willow whose parents die in a car crash, and she is taken in by her friends' mum. Whilst she is not explicitly autistic, she has a lot of traits and is believed by many reviewers to be autistic.



A Kind of Spark (Elle McNicoll) – A fiction book about a girl who has a special interest in the local witch trials in her area. She believes that the witches

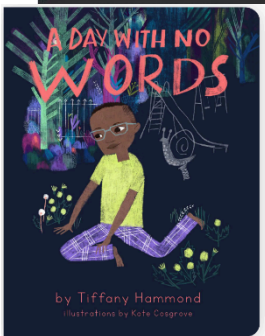
weren't magic but instead people who were different, which she relates to. The book was also made into a BBC series of the same name recently.

All Cats are on The Autistic Spectrum (Kathy Hoopman) – An introduction to autism, using cats as a comparison to autistic people's traits.



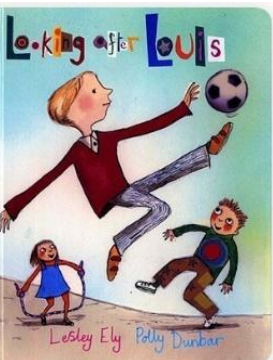
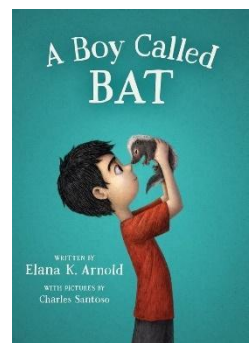
The Spectrum Girl's Survival Guide (Siena Castellon) – A 'guidebook' on how to deal with living in a neurotypical world as an autistic person.

Picture books for (younger) siblings



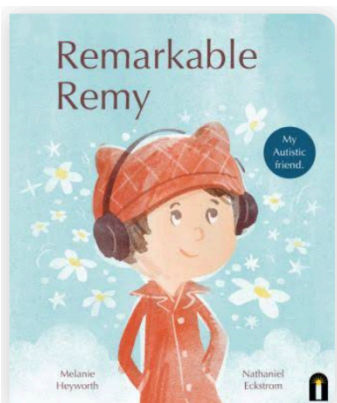
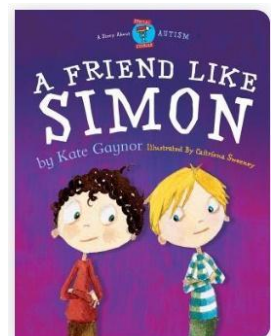
A Day with No Words (Tiffany Hammond) – a picture book about a non-verbal autistic boy and his mum who spend a day using a tablet to communicate with everyone instead of speaking

A Boy Called Bat (Elana K Arnold) – A chapter book about an autistic boy called Bat who adopts a baby skunk.



Looking after Louis (Lesley Ely) – A picture book about a boy at school who is different – explicitly about an autistic boy but he is not identified as autistic in the story so may need additional explanation.

A Friend Like Simon (Kate Gaynor) – A picture book about an autistic boy at school from the perspective of his neurotypical classmates



Remarkable Remy (Melanie Heyworth) – a picture book about the ways that autism makes Remy (who has they/them pronouns used so that every child can identify with them) the person that they are.

Poster 1: Advertising the Buckinghamshire local offer for SEND



Poster 2: autism positivity mind map



Poster 3: advertising Aylesbury Youth Hub (running July/August 2024), which is a programme of group activities and mentorship to help young people with an EHCP/SEND with the next steps of their career. Email info@buildingfuturesbucks.org.uk for more information.



**Funded by
UK Government**

Aylesbury Youth Hub

For ages 15 - 25 years old



**Starting
15th
July**

Meet new friends, learn new skills and have fun

- Based in Central Aylesbury throughout July and August 24.
- Group activities every Tuesday and Wednesday.
- 1-1 sessions to provide guidance and support for young people with SEND / EHCP's in exploring and preparing for their next steps and future career plans.
- Up to 6 months additional skills and employability mentoring available.

To find out more email: info@buildingfuturesbucks.org.uk

Comments, compliments and complaints. We value your feedback because it will help us to improve our service. If you would like to comment, compliment or let us know about any problems you've had with the service please get in touch.





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