A GUIDE FOR PARENTS AND CARERS, WITH A PART WRITTEN FOR YOUNG PEOPLE

Understanding Autism in the Teenage Years

A guide for parents, carers and young people aged 12 to 17

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The latest version is always at umid.co.uk/resources

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BEFORE YOU START

About this guide

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- Who this guide is for and how to use it
- Where to find the most recent version
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This guide is for parents and carers of young people aged 12 to 17 who have recently been diagnosed as autistic by UMID. Part 10 is written for the young person to read for themselves, and you may want to show it to them when the time feels right.

The guide is the same for every family who receives a diagnosis of autism in this age group. It is not a summary of your young person's assessment and it does not describe any individual. Your young person's report sets out what was found in their own assessment and what was recommended for them. Not every section here will apply to your family, and it is fine to read only the parts that matter to you now and come back to the rest later.

The information describes services and law in England. Some arrangements differ in Scotland, Wales and Northern Ireland.

KEEPING THIS GUIDE UP TO DATE

This guide is updated regularly. The most recent version is always available at umid.co.uk/resources. If you received this guide some time ago, please check there for the current edition.

IF YOU NEED HELP URGENTLY

UMID is not an emergency or crisis service and cannot respond to urgent concerns. If you are worried about your young person's safety, or they are worried about their own, please use one of these services straight away.

- **Call 999 or go to A&E** if someone is in immediate danger, has seriously harmed themselves, or may act on thoughts of ending their life.
- **NHS 111**: call 111 and choose the mental health option, or use 111 online, for urgent mental health help in England at any time of day or night.
- **Samaritans**: call 116 123, free, 24 hours a day, for anyone who needs to talk.
- **Shout**: text SHOUT to 85258, free, 24 hours a day, for support by text message.
- **Childline**: call 0800 1111, free, for anyone under 19. Young people can also chat online at childline.org.uk.
- **The Mix**: for people under 25, text THEMIX to 85258 for free support by text at any time.

Your young person's GP can also arrange an urgent appointment, and if your young person is already under a mental health team, that team's crisis contact is usually the best first call.

PART 1

First steps after diagnosis

IN THIS PART

- The essentials in brief
- What is worth doing in the first few weeks
- Support from UMID after the diagnosis
- What can wait

The essentials in brief

If you read nothing else for now, these are the points that matter most.

- **Autism is a lifelong difference in how a person experiences and makes sense of the world.** It is not an illness, and nothing you did caused it. It is not caused by vaccines or medicines.
- **Your young person has not changed because of the diagnosis.** What has changed is that you now have a clearer way of understanding them, and a basis for asking others to understand them too.
- **Many teenagers are diagnosed after years of working hard to cope.** Relief, grief, anger and indifference are all common reactions, in young people and parents alike.
- **Mental health matters.** Anxiety and low mood are more common in autistic young people. Know the warning signs described in Part 5 and keep the urgent help numbers above somewhere easy to find.
- **School is legally required to consider your young person's needs.** You can share the diagnosis with the school's special educational needs coordinator (SENCo) and ask what support will be put in place.
- **Big legal changes happen at 16**, including consent to treatment and benefits. Part 8 explains them.
- **No treatment removes autism, and nothing should try to.** Good support aims to reduce distress and help your young person live well as themselves. Be cautious of anything that claims otherwise.
- **If you are unsure what further help would suit your young person**, you can book a free 30-minute appointment with UMID's Clinical Director to talk it through. The section "Support from UMID after the diagnosis" below explains how.

In the first few weeks

Read the report, and ask about anything that is unclear. The report sets out what was found and what was recommended. The section "Support from UMID after the diagnosis" below explains how to contact UMID with a question about the assessment.

Talk with your young person about what the diagnosis means to them. Part 3 offers some ways to begin. Follow their lead on how much they want to discuss and when.

Share the report with your young person's GP, if this has not already been done with your agreement. The GP holds the medical record and is the route to most NHS services.

Decide, with your young person, what to share with school. A meeting with the SENCo to agree practical adjustments is usually the most useful first step. Part 6 explains what schools are expected to do.

If exams are approaching, raise access arrangements with the SENCo early. Arrangements have to be planned and evidenced in advance and cannot be put in place at the last minute.

Look after yourself. Part 5 includes support for parents and carers.

Support from UMID after the diagnosis

The feedback meeting will have covered the support options that may help your young person. Some families find that the diagnosis and the information in this guide are what they need. Others want further help, either now or later on. Both are fine.

UMID offers a range of services after diagnosis: psychiatric care for any mental health needs that come alongside autism, occupational therapy and psychological therapies. These are arranged separately from the assessment, and current fees are set out on the UMID website at umid.co.uk/our-fees.

If you are unsure what would help, you can book a free 30-minute appointment with UMID's Clinical Director to talk through your young person's support needs after the diagnosis and which options would best meet them. To arrange this, or if you have any question about the assessment, please email umid@umid.co.uk.

What can wait

It is easy to feel that everything must be done at once. Most things can be taken at your own pace. Applications for benefits, decisions about post-16 education, reading every book on autism and joining every group can all wait until you and your young person are ready. The exceptions are anything about safety, and any deadline set by school, the council or the benefits system.

PART 2

Understanding autism in the teenage years

IN THIS PART

- What autism is, and the words people use
- Why some young people are diagnosed in their teens
- Masking, camouflaging and exhaustion
- Autistic burnout
- Conditions that often come alongside autism

What autism is

Autism describes a difference in how a person's brain develops, which shapes how they communicate and relate to other people, how they process information from their senses, and how they experience change, routine and their own interests. It is present from birth and continues throughout life, although how it shows itself changes as a young person grows and as the demands on them change.

Every autistic person is different. Some autistic young people speak fluently and do well academically; others have a learning disability or use little or no speech. Many have areas of real strength alongside areas of real difficulty, and the same young person may manage very well in one setting and find another overwhelming.

Some features are common. Autistic young people often find the unwritten rules of social interaction hard to read, and may find conversation, eye contact or group settings tiring. Many prefer predictability and find unexpected change stressful. Many have deep, focused interests that bring them knowledge, pleasure and calm. Most experience sensory information differently, which can mean being more sensitive to sounds, lights, smells, textures or touch, less sensitive to some sensations such as pain or temperature, or a mixture of both.

It can help to know that social difficulty is not only a matter of what the autistic person finds hard. Researchers have described a "double empathy problem", in which autistic and non-autistic people find it hard to understand each other because they communicate in different ways. In one experiment, information passed from one autistic person to another was shared as accurately as information passed between non-autistic people, and less accurately when autistic and non-autistic people were mixed. This way of thinking puts some of the responsibility for understanding on everyone, not only on your young person.

The words people use

The medical name for the diagnosis is autism spectrum disorder. You may also have heard of Asperger syndrome; this term is no longer given as a diagnosis, and is now included within autism spectrum disorder in both of the main diagnostic manuals. Some people who were diagnosed with it keep the term because it is part of how they understand themselves.

In the United Kingdom, many autistic people prefer to be called "autistic" rather than "a person with autism", because they see autism as part of who they are. Others prefer different words. This guide uses "autistic", but the words that matter most are the ones your young person chooses for themselves.

Why some young people are diagnosed in their teens

Many autistic young people are not identified in early childhood. Some manage the demands of primary school, where there is usually one class, one teacher and a predictable day, and begin to find things much harder at secondary school, where the social world becomes more complex, the day involves many changes, and expectations of independence rise. The international diagnostic guidance recognises that autistic differences may only become clearly apparent when demands exceed a person's ability to manage them, which is often in adolescence. Girls are more likely to be identified later, and so are young people of any gender whose difficulties are hidden because they work hard to fit in.

For parents, this can bring mixed feelings. You may feel relieved that there is an explanation, sad that it took so long, or worried that you should have noticed sooner. These are understandable reactions. Autism in young people who cope outwardly is often hard for anyone to see, including experienced professionals.

Masking, camouflaging and exhaustion

Many autistic young people work hard, often without realising they are doing it, to hide or compensate for their differences so that they fit in. This is often called masking or camouflaging. It can include copying other people's expressions and phrases, rehearsing conversations, forcing eye contact, hiding a strong interest, or holding in distress until they are somewhere safe.

Masking can help a young person get through the school day and avoid being singled out. It also takes a great deal of effort. A common pattern is the young person who seems settled at school and then collapses, withdraws or becomes very distressed as soon as they get home. This is not a sign that they are behaving well for others and badly for you. It is often a sign that home is where they feel safe enough to stop holding it together.

> **WHAT THE RESEARCH SAYS ABOUT MASKING**
>
> Research on masking is relatively new. Most studies so far have involved adults and have relied on people describing their own experience. They consistently find that people who report more masking also report more anxiety, low mood and exhaustion, but it is not yet clear how much masking causes these difficulties and how much the two simply occur together. There is less research in teenagers. The pattern described above is widely reported by autistic people and families, and is a reasonable guide to practice, but it should be understood as an area where knowledge is still developing.

Autistic burnout

Autistic people have described a state they call autistic burnout. It involves deep and lasting exhaustion, a loss of skills or abilities the person previously had, such as managing conversations, self-care or schoolwork, and much lower tolerance of sensory input and change. It is usually described as building up over time when demands, including the effort of masking, are greater than the person's resources, and when there is not enough opportunity to rest and recover.

Autistic burnout is not a formal diagnosis, and it can look similar to depression, although autistic people often describe it as different. Most research has been with autistic adults, particularly women diagnosed later in life, so we know less about how it affects teenagers. What autistic people describe as helping recovery is consistent: rest, time alone, relief from sensory overload, fewer demands, and understanding from the people around them. If your young person seems to be losing skills, withdrawing or becoming exhausted over weeks, speak to their GP so that depression and physical causes can be considered as well.

Conditions that often come alongside autism

Several conditions are more common in autistic young people than in others. These include attention deficit hyperactivity disorder (ADHD), anxiety, depression, obsessive-compulsive disorder, sleep difficulties, eating difficulties, and epilepsy. Having one of these is not a part of autism, and each can be assessed and helped in its own right. If you notice something that seems new or different, it is worth raising with your young person's GP.

> **DEMAND AVOIDANCE AND PDA**
>
> Some families come across the term pathological demand avoidance, often called PDA. It is used to describe a pattern of avoiding everyday requests and expectations, often driven by anxiety. It is not a recognised diagnosis in the current diagnostic manuals, and there is continuing debate among clinicians, researchers and autistic people about whether it describes a distinct profile. Demand avoidance itself is a real and often exhausting experience for families, and the practical strategies used to help, such as reducing pressure, offering choice and lowering anxiety, can be useful whatever label is used.

PART 3

Talking about the diagnosis

IN THIS PART

- Talking with your young person
- Your young person's own voice
- Telling other people
- Brothers and sisters

Talking with your young person

Teenagers who took part in their assessment will already know something of why it happened. What they make of the diagnosis varies a great deal. Some feel relieved that there is a reason for experiences they had assumed were their own fault. Some are curious and want to read everything. Some are upset, worry about being seen as different, or simply do not want to talk about it. All of these are understandable, and a first reaction is rarely the last.

In a large survey of parents, most had told their autistic child about the diagnosis and were satisfied with how it had gone, and parents stressed the value of openness and of explaining autism in a way that suits the individual child. Some approaches families find helpful:

- Keep the tone matter-of-fact. Autism is a description of how their mind works, not a verdict on their future.
- Connect the diagnosis to things they recognise in themselves, including their strengths, rather than to a list of difficulties.
- Let them ask questions and admit when you do not know the answer.
- Offer resources rather than insisting on them. Part 10 is written for them, and some of the books in Part 11 are by autistic young people and adults.
- Expect to return to the subject many times, often at unexpected moments such as car journeys or late in the evening.

Your young person's own voice

As young people move through their teens, their own views should carry increasing weight in decisions about their support, their education and their care. This is good practice and, from 16, it is also a legal expectation in many areas (Part 8). Wherever possible, involve your young person in meetings about them, or ask what they would like said on their behalf. Some find it easier to write their views down or send them by message rather than speak in a meeting.

Many autistic adults describe how much it mattered to them as teenagers to be believed about their own experience, particularly about sensory discomfort, tiredness and anxiety, which may not be visible to others.

Telling other people

Whether and how to share the diagnosis is a personal decision, and as your young person gets older it increasingly becomes theirs. Some want everyone to know; others want only a few trusted people told. There is no right answer.

It is usually helpful for school staff who work closely with your young person to know, so that they can understand and adjust. It is worth agreeing with your young person, before you contact school, what will be shared and with whom. Friends and wider family can be told when and if your young person is comfortable. Some young people choose to explain it themselves; others prefer a parent to do so.

Brothers and sisters

Siblings may have questions, worries or feelings of their own, including feeling that their brother or sister receives more attention. Age-appropriate explanations help. The short animated film “Amazing Things Happen” by Alexander Amelines, free to watch on the Amazing Things Project website (amazingthingshappen.tv), was made for young non-autistic audiences and can be a gentle starting point for younger siblings and wider family. Sibs, a UK charity for brothers and sisters of disabled children, offers information and support for siblings of all ages (see Part 11).

PART 4

Everyday life at home

IN THIS PART

- Sensory needs
- Predictability, change and planning ahead
- Energy, recovery and rest
- Meltdowns and shutdowns
- Sleep, food and eating

Sensory needs

Sensory differences can make ordinary environments uncomfortable or painful: a noisy canteen, a crowded bus, clothing labels, strong smells, flickering lights or unexpected touch. For some young people the difficulty is the reverse, and they seek out strong sensations such as movement, pressure or particular textures. Sensory needs often explain behaviour that otherwise seems puzzling, such as refusing certain clothes, leaving busy places abruptly or needing to move constantly.

Practical steps that many families find helpful include:

- asking your young person which sensations they find difficult and which they find calming, and taking their answer seriously;
- noise-reducing headphones or earplugs for noisy places;
- choice over clothing, including soft fabrics and labels removed;
- a quiet, low-light space at home they can retreat to without needing to explain;
- small, discreet items to hold or fiddle with, which can help with concentration and calm in class and elsewhere;
- planning journeys and outings to avoid the busiest times where possible.

Some of these can also be requested at school as reasonable adjustments (Part 6). An occupational therapist can assess sensory needs in more detail if they are having a significant effect on daily life; your young person's GP or school can advise on local routes.

Predictability, change and planning ahead

Many autistic young people find uncertainty and unexpected change stressful, often because they cannot predict what will happen or whether they will know how to cope with it. Giving warning of changes, explaining what will happen and why, and making plans visible can all reduce anxiety.

For teenagers, this usually works best in forms they already use: a shared calendar or reminders on their phone, a written plan for a new situation, photographs or maps of a new place, or a visit in advance. Some young people like to know the plan for the whole week. Over time, the aim is for your young person to become confident planning for themselves, with less support from you.

Energy, recovery and rest

Social contact, sensory demands and the effort of masking all use energy. Many autistic young people need genuine downtime after school and at weekends: time alone, time on an interest, time gaming or watching videos, or simply quiet. This is not laziness or avoidance. For many it is how they recover enough to manage the next day.

It can help to think of energy as a budget. If a day includes something especially demanding, such as a school trip, an exam or a family gathering, plan for a quieter time before and after. Your young person is the best judge of what drains them and what restores them, and learning to notice this is a valuable skill for adult life.

Meltdowns and shutdowns

A meltdown is an intense response to overwhelming stress, sensory overload or emotion, in which a young person temporarily loses control of what they say or do. It can involve shouting, crying, lashing out or running away. A shutdown is a quieter response to the same kind of overload, in which the young person may withdraw, stop speaking or seem unable to respond. Neither is deliberate, and neither is a tantrum.

During a meltdown or shutdown, the priority is safety and reducing demands. Speak less, lower sensory input where you can, give space while staying nearby, and avoid questions or discussion until they have recovered. Afterwards, when things are calm, it can help to think together about what built up beforehand and what might help next time. Many young people show signs of rising stress before a meltdown, such as pacing, repetitive movements, irritability or going quiet, and learning to spot these can help everyone step in earlier.

If meltdowns are frequent, very distressing or involve risk of harm, please discuss them with your young person's GP. It is important to check for things that make distress worse, such as pain, poor sleep, anxiety, low mood or a difficult situation at school.

Sleep

Sleep difficulties are common in autistic young people, and adolescence brings its own natural shift towards later sleep. Poor sleep affects mood, concentration and the ability to cope with everything else.

Helpful steps include a regular bedtime and waking time, including at weekends where possible; a wind-down routine; a bedroom that suits your young person's sensory needs in terms of light, noise, temperature and bedding; and screens away for a period before sleep, agreed with your young person rather than imposed where you can. National guidance recommends that sleep difficulties in autistic young people are first assessed and addressed with a sleep plan. Medication to help sleep, usually melatonin, is considered only if a sleep plan has not helped and the problem is having a significant effect, and only following advice from a specialist. If your young person snores loudly, seems to stop breathing or chokes in their sleep, tell their GP, as this should be checked.

Food and eating

Many autistic young people have strong preferences about food, related to taste, texture, smell, appearance or the need for sameness. A restricted diet is often manageable and does not need to become a battle. It does need attention if your young person is losing weight, not growing as expected, very distressed at mealtimes, or eating so few foods that their health may be affected. Some autistic young people have a condition called avoidant/restrictive food intake disorder (ARFID), in which food is avoided because of sensory discomfort, fear of choking or being sick, or low interest in eating, rather than concern about weight or shape. Eating disorders such as anorexia nervosa are also more common in autistic young people. If you are concerned, speak to your young person's GP.

PART 5

Emotional wellbeing and mental health

IN THIS PART

- Anxiety
- Low mood, self-harm and thoughts of suicide
- Getting help
- Looking after yourself

Anxiety

Anxiety is one of the most common mental health difficulties in autistic young people. Estimates vary between studies, but a large review found that around four in ten autistic young people met criteria for at least one anxiety disorder, a much higher rate than in other young people. Anxiety may focus on social situations, change, uncertainty, school, particular fears or intrusive worries, and in autistic young people it can show itself as irritability, increased need for routine, avoidance, physical complaints such as stomach aches, or meltdowns rather than as obvious worry.

Reducing unnecessary pressure, sensory overload and uncertainty helps many young people. When anxiety is persistent or is stopping your young person from doing things that matter to them, professional help is worthwhile. National guidance advises that cognitive behavioural therapy (CBT), a talking therapy, should be considered for autistic young people with anxiety who are able to take part in it, with the therapy adapted to their needs, for example through more visual and written material, a more concrete and structured approach, regular breaks, involvement of a parent, and use of the young person's interests. It is reasonable to ask any therapist how they adapt their approach for autistic young people.

Low mood, self-harm and thoughts of suicide

Depression is also more common in autistic young people, and so are thoughts of suicide. A large review of studies of autistic children and young people up to the age of 25 found that around one in four had experienced suicidal thoughts. Young people in these studies reported more than their parents did, which is a reminder that a young person may be struggling with thoughts that others do not know about. We tell you this not to alarm you, but because knowing it helps you notice and respond early.

Signs that a young person may be having thoughts of suicide include:

- expressing strong feelings of hopelessness, worthlessness, guilt or shame;
- saying things such as "I wish I was not here" or "people would be better off without me";
- withdrawing from friends and family, or losing interest in things they usually enjoy;
- talking, writing or drawing a lot about death;
- giving away their belongings;
- seeming very agitated, or behaving in ways that are out of character;
- using alcohol or drugs to cope;
- self-harm, such as unexplained injuries or covering up their arms or legs in warm weather.

Autistic young people may express distress differently, or find it hard to put feelings into words. A change from their usual pattern is often the most important sign.

IF YOU ARE WORRIED ABOUT SUICIDE OR SELF-HARM

Asking your young person directly whether they are having thoughts of suicide does not put the idea in their head, and it can be a relief to be asked. Use clear, plain words. Listen without rushing to solve things. If they have harmed themselves seriously or you think they are in immediate danger, call 999 or go to A&E. Otherwise, contact NHS 111 (mental health option) or their GP the same day. The urgent help box at the start of this guide lists services that are available day and night.

Getting help

The GP is usually the first step for any mental health concern. They can offer advice, arrange physical checks where needed and refer to children and young people's mental health services (often called CAMHS) or other local support. Some schools also have mental health staff or teams who can offer support. Waiting times vary, and it is worth keeping a note of your concerns and any changes over time to share at appointments.

It is reasonable to tell any professional that your young person is autistic, share the relevant parts of the diagnostic report, and ask how support will be adapted. Autistic people have described barriers to getting psychological help, including therapy that does not take account of how they communicate and process information.

For young people aged 16 and over, Autistica, the UK autism research charity, and King's College London offer a free app called Molehill Mountain, developed with autistic people using adapted CBT approaches to help understand and manage anxiety. In a first study of 100 autistic people aged 16 and over, most of them adults, most participants found it easy to use and their anxiety reduced on average, but there was no comparison group and it has not yet been tested in a full clinical trial. It is not a substitute for professional help when anxiety is severe.

Looking after yourself

Parenting an autistic teenager can be rewarding, and it can also be tiring and worrying, particularly while you are learning about a new diagnosis and dealing with schools and services. Your own wellbeing matters for its own sake, and it also affects your ability to support your young person.

- **Talk to others who understand.** The National Autistic Society runs a Parent to Parent emotional support service with trained parent volunteers, an online community and local branches. Contact, the charity for families with disabled children, runs a free helpline on 0808 808 3555.
- **Ask your council for a parent carer's needs assessment.** Local councils in England must assess the needs of parent carers of disabled children when asked and when the legal conditions are met. This can lead to support such as short breaks.
- **Check whether you can claim Carer's Allowance.** This may be available if you care for your young person for at least 35 hours a week and they receive the middle or highest care rate of Disability Living Allowance or the daily living part of Personal Independence Payment (Part 8), and you meet the other conditions, which include an earnings limit and not being in full-time education yourself.
- **Look after your own health.** If you are struggling with your own mood or sleep, speak to your own GP. The YoungMinds Parents Helpline (0808 802 5544, weekdays) offers advice to parents worried about a young person's mental health.

PART 6

Secondary school, college and exams

IN THIS PART

- Working with the school
- Education, Health and Care plans, and the reforms announced in 2026
- Exams and access arrangements
- When school becomes very hard to attend
- Bullying

Working with the school

Every school has a special educational needs coordinator (SENCo), who is usually the best first contact. Schools must use their best endeavours to meet the needs of pupils with special educational needs, and under the Equality Act 2010 they must make reasonable adjustments so that disabled pupils are not put at a substantial disadvantage. Autistic young people will often meet the Equality Act's definition of disability, which depends on the effect of a condition on everyday life rather than on any particular level of special educational needs support.

Most autistic young people are taught in mainstream schools. Some are best supported in a specialist setting, and a place at a special school usually requires an EHC plan (see below).

Support in school without a formal plan is called SEN support. It should follow a cycle of assessing needs, planning support, putting it in place and reviewing whether it has worked, with you and your young person involved. Adjustments that are often helpful for autistic secondary pupils include:

- a named member of staff your young person can go to;
- a quiet space to use at break and lunchtime, and a way to leave a lesson briefly if overwhelmed;
- advance notice of changes to the timetable, staff or rooms;
- permission to use headphones, fiddle items or sunglasses where sensory needs require it;
- leaving lessons slightly early to avoid crowded corridors;
- homework instructions given in writing, with clear deadlines;
- flexibility in uniform where sensory needs make it difficult;
- careful planning for school trips, supply teachers and other changes.

A written plan, sometimes called a support plan or pupil passport, agreed with your young person and shared with the staff who teach them, can help make sure adjustments are applied consistently.

If you feel your young person's needs are not being met, free and impartial advice is available from your local Special Educational Needs and Disabilities Information, Advice and Support Service (SENDIASS), which every council area has, and from IPSEA, a national charity that offers free legal information and template letters.

Education, Health and Care plans

An Education, Health and Care plan (EHC plan) is a legal document, issued by the local council, for children and young people up to the age of 25 who need more support than a school or college can normally provide through SEN support. It describes the young person's needs, the outcomes they are working towards, and the support that must be provided.

Parents can ask the council for an EHC needs assessment, and from the end of Year 11 a young person can ask for one themselves. The council must decide whether to carry out an assessment within 6 weeks of the request, and the whole process, from request to final plan, should take no more than 20 weeks. If the council refuses to assess or to issue a plan, or you disagree with what the plan says, there are rights of appeal to a tribunal. IPSEA and your local SENDIASS can advise.

From Year 9, when most young people are 13 or 14, every annual review of an EHC plan must include a focus on preparing for adulthood. This covers four areas: education, training and employment; living as independently as possible; friendships, relationships and being part of the community; and being as healthy as possible.

> **CHANGES TO THE SEND SYSTEM ANNOUNCED IN 2026**
> In February 2026 the government published a white paper setting out major changes to support for children and young people with special educational needs and disabilities in England, including a new Individual Support Plan for every child with special educational needs and changes to how EHC plans work. The government has said it intends to change the law to bring these in. At the time of writing, these are proposals and the law has not yet changed. The Department for Education has said that no changes to the support given by EHC plans will begin before September 2030, and that young people in mainstream school who already have an EHC plan and are older than seven will keep it until at least 16. The current system described above therefore still applies. The online version of this guide will be updated as the changes take effect.

Exams and access arrangements

Access arrangements are adjustments to how a young person takes public exams such as GCSEs and A levels, so that they can show what they know without the exam itself being made easier. For autistic young people they may include supervised rest breaks, extra time, taking exams in a smaller room or separately from other candidates, a prompter to help them stay on task, or use of a word processor. Where a young person's needs arise from something other than a learning difficulty, as they usually do in autism, the current rules ask the school to consider supervised rest breaks before applying for 25% extra time.

The rules are set by the Joint Council for Qualifications (JCQ), and a few points are worth knowing:

- **The school or college decides, not the diagnosing clinician.** A diagnosis is important background, but a diagnosis alone does not entitle a young person to access arrangements. Arrangements depend on evidence that the young person's difficulty affects their access to exams.
- **Arrangements should reflect how your young person normally works.** Schools gather evidence from lessons, internal tests and mock exams, so support used in class throughout the course is the strongest basis for arrangements in the real exam.
- **Start early.** Tell the SENCo as soon as possible, ideally at the start of a GCSE or A level course. In further education, students should record their needs on the college's enrolment form.

When school becomes very hard to attend

Some autistic young people reach a point where getting into school becomes extremely difficult or impossible, often because of anxiety, sensory overload, social pressures, unmet needs or exhaustion. This is sometimes described as emotionally based school avoidance or emotionally based school non-attendance. Research suggests that autistic pupils are more likely than other pupils to miss school for these reasons. It is not truancy, and it is not a sign of poor parenting. Most young people in this situation very much want to be able to go.

What tends to help is early, calm, joint work between home, the young person and school to understand what is making school so hard, followed by practical changes to reduce those barriers. The Department for Education's guidance for schools says that:

- absence must be recorded as authorised when a pupil cannot attend because of illness, including mental health illness;
- schools should work with parents and the young person to agree a plan of support to reduce specific barriers to attendance, with regular reviews;
- a part-time timetable can be used as a temporary measure, agreed by everyone and aimed at building back up, but it must not be used to manage behaviour;
- schools should tell the council when a pupil is likely to miss more than 15 days because of health needs, and councils then have a duty to consider whether alternative education should be provided. Councils must not have a fixed policy of requiring medical evidence before making that decision, and must look at each young person's circumstances.

Please speak to your young person's GP if anxiety, low mood or exhaustion is affecting attendance, and consider asking the school or council about an EHC needs assessment if your young person's needs cannot be met with the support currently available. Your local SENDIASS can help you understand your options.

Bullying

Research shows that autistic young people are more likely than their classmates to be bullied at school, and bullying can also continue online. Signs can include reluctance to go to school, lost or damaged belongings, changes in mood, or withdrawal. If you suspect bullying, listen calmly, keep a record of what has happened, and raise it with the school, which is required to have a behaviour policy that includes measures to prevent bullying. If your young person is being harassed online, keep evidence such as screenshots and use the reporting tools on the platform concerned.

PART 7

Friendships, relationships and life online

IN THIS PART

- Friendships
- Relationships, sexuality and gender identity
- Consent and personal safety
- Life online

Friendships

Many autistic young people want friendships very much, even if they find the unwritten rules of teenage friendship confusing or tiring. One small UK study of teenagers in special schools found that autistic girls were as motivated to have friends as other girls and described friendships of similar quality, but also described a lot of conflict within their friendships and difficulty dealing with it. Some autistic young people are content with one or two close friends, or with friendships that centre on a shared activity, and that is a perfectly good way to have friends.

Things that often help include:

- shared-interest activities and clubs, in person or online, where conversation has a natural focus;
- meeting other autistic young people, for example through National Autistic Society branches or Ambitious about Autism's youth network, where many young people feel they can relax and be understood;
- talking through confusing social situations afterwards, in a way that respects your young person's perspective rather than assuming they were at fault;
- accepting that your young person may need time alone after socialising.

Relationships, sexuality and gender identity

Autistic teenagers have the same range of feelings, curiosity and hopes about relationships as other teenagers. They may benefit from information that is more explicit and concrete than is usual, because the unspoken signals of flirting, attraction and consent can be hard to read. Clear, factual information about puberty, bodies, relationships, sexual health and consent, given in good time and in a way your young person can take in, is protective. Schools must teach relationships, sex and health education, and it is reasonable to ask how this is adapted for your young person. Brook, a national charity, offers free, confidential sexual health information online and clinics in some areas for young people.

Research, mostly with adults, suggests that autistic people are more likely than others to identify as lesbian, gay, bisexual or asexual, and that autistic traits and diagnoses are more common among people who are transgender or gender diverse. If your young person talks to you about their sexuality or gender, listening calmly and without judgement is the most important thing you can do. If they are distressed about their gender, their GP can discuss the options available.

Consent and personal safety

Autistic young people can be more vulnerable to being taken advantage of, because they may trust what people say, find it hard to spot manipulation, or want very much to be accepted. It helps to talk clearly and specifically about what a healthy relationship looks like, what consent means and how to say no, the

kinds of requests that should raise concern (such as being asked for images, money, or to keep secrets from parents), and who to tell if something feels wrong. These conversations are most useful when they are calm, factual and repeated over time, rather than a single warning.

If you are concerned that your young person is being sexually exploited or groomed, online or offline, contact the police. Concerns about online sexual contact with a child can also be reported to the Child Exploitation and Online Protection command (CEOP).

Life online

The online world can be especially important to autistic young people. It offers communication at their own pace, communities built around shared interests, and friendships that may be easier than those in person. For many, time online is a genuine source of connection, learning and calm, and simply cutting it back can remove something valuable.

It also brings risks, including bullying, contact from people with harmful intentions, pressure to share images, exposure to harmful content, and difficulty stopping. Approaches that work well are usually agreed with your young person rather than imposed:

- talk about what they do online and take a genuine interest;
- agree together on sensible limits and on keeping devices out of the bedroom overnight, if sleep is a problem;
- use privacy settings and parental controls appropriate to their age and maturity;
- make sure they know they can tell you about anything that worries them online without fear of losing their device.

Internet Matters has a section of practical online safety advice for parents of children and young people with special educational needs and disabilities.

PART 8

Growing towards independence and adulthood

IN THIS PART

- Building independence skills
- Decisions, consent and confidentiality at 16
- Moving from children's to adult services
- College, work and university
- Learning to drive
- Money and benefits

Building independence skills

Adolescence is when many of the skills needed for adult life are learned: managing money, cooking, travelling independently, organising time, looking after health, making appointments and speaking up for oneself. Autistic young people often learn these skills best when they are taught explicitly, broken into small steps, practised in real situations and supported with written instructions or phone reminders until they become routine.

It helps to start well before the skill is needed, to build on what your young person is already motivated to do, and to gradually hand over responsibility. Practising a bus journey together several times before your young person does it alone, or supporting them to book their own GP appointment, are examples. Speaking up for themselves, sometimes called self-advocacy, is one of the most valuable skills of all: being able to explain their needs and ask for adjustments will help them at college, at work and in health care.

Decisions, consent and confidentiality at 16

Several important legal changes happen around 16, and it helps to be ready for them.

Consent to treatment. Young people aged 16 and 17 are presumed to be able to consent to their own medical treatment, in the same way as adults, unless there is significant evidence that they cannot. Young people under 16 can also consent to their own treatment if they are judged to have enough understanding and maturity to fully appreciate what is involved; this is often called being Gillick competent.

Mental capacity. The Mental Capacity Act 2005 applies from age 16. It says a person must be assumed to be able to make their own decisions unless it is shown that they cannot, and that they must be given all practicable help to make a decision before anyone concludes they cannot. If your young person has a learning disability or other needs that affect their ability to make particular decisions, the Act sets out how decisions are made in their best interests.

Confidentiality. As young people get older, health professionals will usually offer to see them on their own for part of an appointment, and will respect their wishes about what is shared with parents, except where there is a risk of serious harm. This can feel difficult for parents who have been closely involved. It is a normal part of growing up, and most young people continue to want their parents involved in important decisions.

Education rights. From the end of the school year in which they turn 16, young people have the right to make their own decisions about their EHC plan, including requesting an assessment, choosing a school or college and appealing. Parents usually stay closely involved, with the young person's agreement.

Moving from children's to adult services

Many autistic young people are not under any specialist service, and their GP remains their main point of contact through adolescence and into adulthood. Young people who are under children's services, such as CAMHS or a paediatrician, will move to adult services or back to their GP, usually around their 18th birthday. National guidance says planning for this move should start by Year 9 (age 13 or 14) at the latest, should involve the young person, and should include a named worker to help coordinate it. Autistic young people under CAMHS or children's health services should be reviewed at around 14 to decide whether they will need continuing care as adults.

If your young person is likely to need care and support as an adult, for example help with daily living, you can ask the council's adult social care team for an assessment before they turn 18, so that support can be planned in advance rather than starting from scratch.

College, work and university

Autistic young people go on to a wide range of education, training and work. Things to know include:

- **Sixth forms and further education colleges** have duties to support students with special educational needs, and an EHC plan can continue up to age 25 while a young person remains in education or training. Visit early, meet the learning support team and tell them about your young person's needs.
- **Supported internships** are structured study programmes based mainly with an employer, for young people with an EHC plan who want to move into paid work.
- **Apprenticeships** combine paid work with training, and employers must make reasonable adjustments.
- **Access to Work** is a government scheme that can pay for practical support at work, including support with managing mental health, for people aged 16 or over who live and work in England, Scotland or Wales and are in or about to start paid work. Northern Ireland has its own scheme.
- **University students** from England can apply for Disabled Students' Allowance to cover study-related costs arising from a disability or long-term condition (students from Scotland, Wales and Northern Ireland apply through their own funding body), and universities have disability services that can arrange adjustments.

Ambitious about Autism offers employment opportunities, supported internships and resources for autistic young people.

Learning to drive

Many autistic young people learn to drive. The Driver and Vehicle Licensing Agency (DVLA) says that a driver must tell it if they are autistic and this affects their ability to drive safely; if it does not affect their driving, there is no need to tell the DVLA. A driver can be fined up to £1,000 for not reporting a condition that affects their ability to drive safely. If your young person is unsure, they should ask their doctor. Learners do not usually need to tell the DVLA, because the driving test assesses whether they can drive safely, but they should tell it before their test if a doctor has said that autism affects their driving. Learning with an instructor who explains things clearly and at a steady pace often helps, and some instructors have experience of teaching autistic learners.

Money and benefits

This section describes the rules at the time of writing. Benefit rules change, and at the time of writing the government is reviewing Personal Independence Payment (PIP) through the Timms Review, which is due to make its final report in autumn 2026. Always check the current position on GOV.UK or with an advice service such as Contact.

- **Disability Living Allowance (DLA) for children** can help with the extra costs of looking after a child under 16 who needs much more looking after than other children of the same age, or who has difficulty walking.
- **At 16, your young person will be invited to apply for PIP in place of DLA.** The Department for Work and Pensions writes shortly after their 16th birthday. DLA stops unless they apply by the date in the letter; if they do, DLA continues until the PIP claim has been decided. PIP is assessed differently from DLA, so it is worth reading the guidance carefully and describing the help your young person needs on a typical day, including on their worst days. If your young person cannot manage their own benefits, a parent can apply to become their appointee, which means managing the claim on their behalf.
- **Carer's Allowance** is described in Part 5.
- **Other help** may include support from your council's Local Offer, short breaks, and help with transport to school or college. Your council's website publishes its Local Offer, which lists local services for children and young people with special educational needs and disabilities.

PART 9

What the evidence says about support and interventions

IN THIS PART

- What national guidance recommends
- What national guidance says should not be used
- A note on approaches that aim to change autistic behaviour
- How to judge claims you come across
- Medication

What national guidance recommends

In England, the National Institute for Health and Care Excellence (NICE) publishes guidance on support for autistic children and young people up to the age of 19. It is the main reference for NHS services, and it was last reviewed in 2026. NICE has said it plans to update its recommendations on psychosocial interventions, so some details may change.

In summary, NICE recommends, or advises professionals to consider:

- a personalised plan developed with the young person and their family;
- support that takes account of the young person's communication, sensory needs and environment;
- a social communication intervention, delivered by a trained professional and adjusted to the young person's stage of development, which aims both to help the people around the young person understand and respond to their way of communicating and to widen the young person's own communication;
- assessment of anything that may be causing distress, such as pain, sleep problems, anxiety or depression, before assuming behaviour is simply part of autism;
- treatment of co-occurring conditions such as anxiety, depression and ADHD, adapted for autistic young people, including CBT adapted for anxiety;
- careful planning of the move to adult services.

Much of what helps autistic teenagers is not a therapy at all. It is an environment that understands them: adjustments at school, predictability, respect for sensory needs, time to recover, and people who listen to their experience.

What national guidance says should not be used

NICE is clear that some interventions should not be used, because they do not work, can cause harm, or both.

- **No medication treats autism itself.** NICE says medicines such as antipsychotics, antidepressants and anticonvulsants should not be used to manage the core features of autism. Medication may still be appropriate for a co-occurring condition such as ADHD, depression, anxiety or epilepsy.
- **Exclusion diets**, such as gluten-free or casein-free diets, should not be used to manage the core features of autism.
- **Secretin, chelation and hyperbaric oxygen therapy** should not be used in any context to manage autism.

- **Neurofeedback** should not be used for speech and language problems, **auditory integration training** should not be used for speech and language problems, and **omega-3 fatty acids** should not be used for sleep problems in autistic young people.

A note on approaches that aim to change autistic behaviour

You may come across applied behaviour analysis (ABA) and related programmes, sometimes offered privately and at considerable cost. ABA is a broad term for approaches based on observing behaviour and changing the circumstances around it. NICE does not recommend ABA by name. Views about it are strongly divided. Some families report benefits from particular programmes, while many autistic people, including some who received it as children, describe intensive programmes as harmful, particularly where the aim was to make them appear less autistic. The National Autistic Society has said that it does not support interventions that use punishment or try to make people "less autistic", and that some ABA interventions used today are not sufficiently person-centred and are too intensive.

UMID does not recommend any programme whose aim is to make a child or young person appear less autistic, to stop harmless behaviours such as stimming, or to achieve compliance for its own sake. Stimming means repetitive movements or sounds that help with regulation. Good support is led by the young person's own goals and wellbeing, reduces distress, and respects who they are.

How to judge claims you come across

Families of newly diagnosed young people are often offered products, programmes and therapies, sometimes with confident claims. Some questions to ask:

- Does it claim to cure autism, or to make autism go away? If so, it is not credible.
- Is it recommended in NICE guidance, or supported by good-quality research that is publicly available?
- What is it trying to achieve, and would your young person agree that it matters?
- Does it respect your young person's wellbeing, consent and dignity?
- What does it cost, what are the risks, and what would you be giving up to do it?
- Who is recommending it, and do they gain financially?

If you are unsure about something you have been offered, it is reasonable to ask your young person's GP or another clinician involved in their care.

Medication

There is no medication for autism itself. Medication may be recommended for a co-occurring condition, such as ADHD, depression, anxiety, epilepsy or sleep problems, by a doctor who has assessed that condition. Any such decision should be made with your young person and you, with clear information about expected benefits and possible side effects, and with regular review.

PART 10

For you, the young person

IN THIS PART

- What your diagnosis means
- Knowing yourself
- Your say in decisions
- When things feel like too much
- Places and people that can help

This part is written for you. You can read it on your own, with someone you trust, or not at all.

What your diagnosis means

Being diagnosed as autistic means that your brain works in a particular way, one shared by many other people. It affects how you experience the world around you, how you communicate, what you find easy and what you find hard, and what you enjoy. It is not an illness, and it is not something you did. You were autistic before the diagnosis; the diagnosis gives it a name.

Some young people feel relieved when they are diagnosed, because it explains things they had been blaming themselves for. Some feel worried, angry or unsure, or do not want to think about it much. All of these feelings are fine, and they may change over time.

You get to decide how you describe yourself. Many people say “I am autistic”. Some prefer other words. Some talk about it openly; others keep it private or tell only a few people. That is your choice.

Knowing yourself

Autistic people are all different, but many find it helps to notice a few things about themselves.

Your senses. Which sounds, lights, smells, textures or crowds are hard for you? What helps you feel calm, such as headphones, quiet, movement or something to hold? Knowing this helps you plan and ask for what you need.

Your energy. Some things drain you, like busy places, lots of talking or trying to fit in. Other things recharge you, like your interests, time alone, music or games. Needing time to recover is not lazy. It is how you look after yourself.

Masking. Lots of autistic people hide how they really feel, or copy others, to fit in. This can get you through the day, but it can also be exhausting. It is worth having places and people where you can be yourself without having to try so hard.

Your strengths. Many autistic people have deep knowledge about the things they care about, notice details others miss, think honestly and logically, and are very loyal. Your interests are a real part of who you are.

Your say in decisions

You have a right to be involved in decisions about you, at school and in your health care. As you get older, your views matter more and more.

- At school, you can ask for changes that help you, like a quiet space, notice of changes, or time out of a lesson when things get too much.

- If you have an Education, Health and Care plan, your views should be written into it. From the end of the school year when you turn 16, you can make decisions about it yourself.
- At 16, you can usually agree to your own medical treatment. Health professionals may offer to see you on your own for part of an appointment, and what you tell them is usually kept private unless they are worried you or someone else could be seriously harmed.
- You can ask for things to be explained in a way that suits you, such as in writing, with pictures, more slowly, or by message.

When things feel like too much

Everyone has hard times. Autistic young people are more likely than others to feel very anxious or low. If you are finding things hard, please tell someone you trust: a parent or carer, a teacher, your GP, or another adult. You do not have to have the right words.

> **IF YOU ARE NOT SAFE, OR THINKING ABOUT ENDING YOUR LIFE**
>
> Please get help now. You deserve support.
>
> - Call 999 or go to A&E if you are in danger or have seriously hurt yourself.
> - Call Childline on 0800 1111 (free, for anyone under 19), or chat online at childline.org.uk.
> - Call Samaritans on 116 123 (free, any time).
> - Text SHOUT to 85258 (free, any time). If you are under 25, you can also text THEMIX to 85258.
> - Call NHS 111 and choose the mental health option.

Places and people that can help

- **Ambitious about Autism** runs an online youth network and opportunities for autistic young people aged 13 to 25. www.ambitiousaboutautism.org.uk
- **Autistica** has information written with autistic people, and the free Molehill Mountain app for managing anxiety, for people aged 16 and over. www.autistica.org.uk
- **Childline** has information and advice about feelings, friendships, relationships and school, as well as counsellors to talk to. www.childline.org.uk
- **Brook** has information about relationships, sex and sexual health for young people. www.brook.org.uk

Books written by autistic young people and adults, for young people like you, are listed in Part 11 under "Books for young people".

PART 11

Where to find more help

IN THIS PART

The organisations below were checked in September 2026. They are listed as examples of reliable sources of information and support, and inclusion does not mean that UMID has any connection with them.

National organisations

- **National Autistic Society**. The UK's largest autism charity, offering advice and guidance on every aspect of autism, an Autism Services Directory for finding local and national services, local branches, an online community, and a Parent to Parent emotional support service with trained parent volunteers for parents and carers of autistic children and adults. www.autism.org.uk
- **Ambitious about Autism**. A national charity for autistic children and young people, with an online youth network, employment programmes and resources for parents. www.ambitiousaboutautism.org.uk
- **Autistica**. The UK's autism research charity, with evidence-based information about autism, mental health and everyday life, written with autistic people. www.autistica.org.uk
- **Contact**. The charity for families with disabled children, offering a free helpline (0808 808 3555) and information on benefits, education and family life for parents of children aged 0 to 25. contact.org.uk
- **Autistic Girls Network**. An organisation supporting autistic girls and young women and their families, with information and peer support. autisticgirlsnetwork.org
- **Sibs**. The UK charity for brothers and sisters of disabled children and adults, with information for young siblings and for parents. www.sibs.org.uk
- **NHS**. Clear information about autism, including support after diagnosis. www.nhs.uk/conditions/autism/

Education and legal advice

- **IPSEA (Independent Provider of Special Education Advice)**. Free and independent legal information about special educational needs, including guides and template letters for asking a school or council for support. www.ipsea.org.uk
- **Your local SENDIASS**. Free, impartial and confidential information, advice and support about special educational needs and disabilities for parents and young people aged 0 to 25, available in every council area. Search online for the name of your council and "SENDIASS", or look on your council's Local Offer page.
- **Special Needs Jungle**. A parent-led website with information and commentary about special educational needs and disability law and policy for families. www.specialneedsjungle.com

- **Joint Council for Qualifications (JCQ)**. Publishes the rules on exam access arrangements, including a short guide for parents, carers and students. www.jcq.org.uk
- **GOV.UK**. Official information on special educational needs support, benefits, Access to Work, Disabled Students' Allowance and driving. www.gov.uk

Mental health and wellbeing

- **YoungMinds**. Information for parents about young people's mental health, and a Parents Helpline (0808 802 5544, weekdays). www.youngminds.org.uk
- **Royal College of Psychiatrists**. Information for parents and young people about autism and mental health, written by psychiatrists. www.rcpsych.ac.uk
- **Samaritans**. Free, confidential support for anyone, at any time, on 116 123. www.samaritans.org
- **Shout**. Free, confidential support by text, at any time. Text SHOUT to 85258. giveusashout.org

Relationships, safety and online life

- **Brook**. Free, confidential information and services about sexual health and wellbeing for young people. www.brook.org.uk
- **Internet Matters**. Practical online safety advice for parents, including a section for families of children with special educational needs and disabilities. www.internetmatters.org
- **CEOP (Child Exploitation and Online Protection)**. For reporting concerns about online sexual abuse or grooming of a young person. www.ceop.police.uk

Finding local support

Every council in England publishes a Local Offer describing the services available locally for children and young people with special educational needs and disabilities, including short breaks, youth groups, leisure activities and transport. You can find your council through GOV.UK (www.gov.uk/find-local-council) and then search its website for "Local Offer". The National Autistic Society's Autism Services Directory and local branches are another good starting point, and your young person's GP and school may know of groups and services nearby.

Books for parents and carers

- **Autism: How to Raise a Happy Autistic Child** by Jessie Hewitson (2018). A warm, practical guide by a journalist and parent, drawing on the views of autistic adults.
- **Uniquely Human: A Different Way of Seeing Autism** by Barry M. Prizant (revised edition 2022). Helps parents understand autistic behaviour as meaningful rather than as something to eliminate.
- **The Real Experts: Readings for Parents of Autistic Children** edited by Michelle Sutton (2015). Short essays by autistic adults, written for parents.
- **Autism and Masking: How and Why People Do It, and the Impact It Can Have** by Felicity Sedgewick, Laura Hull and Helen Ellis (2021). An accessible account of masking by researchers and an autistic author.
- **Can't Not Won't: A Story About a Child Who Couldn't Go to School** by Eliza Fricker (2023). An illustrated account, based on a family's experience, for parents whose child is finding school impossible to attend.
- **Unmasking Autism** by Devon Price (2022). Written by an autistic social psychologist, mainly for adults; parents and older teenagers may find it helpful in understanding masking.

Books for young people

- **The Spectrum Girl's Survival Guide: How to Grow Up Awesome and Autistic** by Siena Castellon (2020). Written by an autistic young woman for autistic girls, covering school, friendships, bullying and self-care.
- **The Awesome Autistic Go-To Guide: A Practical Handbook for Autistic Teens and Tweens** by Yenn Purkis and Tanya Masterman (2020). A positive, practical guide for autistic young people in their early teens.
- **Different, Not Less** by Chloé Hayden (2022). A memoir and guide by an autistic writer and actor, suited to older teenagers.
- **M is for Autism** by the students of Limpsfield Grange School with Vicky Martin (2015). A short novel written by autistic teenage girls about a girl's experience of being autistic.
- **Autism, Anxiety and Me: A Diary in Even Numbers** by Emma Louise Bridge and Penelope Bridge (2016). A teenage girl's diary of living with autism and anxiety, written with her mother.
- **The Autism-Friendly Guide to Periods** by Robyn Steward (2019). A clear, detailed guide for autistic young people who menstruate, and their parents.
- **The Autism Spectrum Guide to Sexuality and Relationships** by Emma Goodall (2016). An explicit, practical guide suited to older teenagers.

AT THE BACK

Words used in this guide

IN THIS PART

- Plain explanations of terms that appear in this guide

Access arrangements: adjustments to how a student takes public exams, such as extra time or a separate room, agreed by the school or college under rules set by the Joint Council for Qualifications.

ADHD (attention deficit hyperactivity disorder): a condition affecting attention, activity levels and impulsiveness, which is more common in autistic people.

Appointee: a person, often a parent, who is authorised to manage someone's benefits on their behalf when they cannot do so themselves.

ARFID (avoidant/restrictive food intake disorder): an eating condition in which a person eats a very limited range or amount of food because of sensory discomfort, fear of consequences such as choking, or low interest in eating, rather than concern about weight or shape.

Autistic burnout: a state of deep exhaustion and reduced ability to cope, described by autistic people, usually after a long period of demands exceeding their resources.

CAMHS (children and young people's mental health services): NHS services that assess and treat mental health difficulties in young people.

CBT (cognitive behavioural therapy): a talking therapy that helps people understand links between thoughts, feelings and behaviour and develop practical ways of coping. For autistic young people it should be adapted to their needs.

Double empathy problem: the idea that misunderstandings between autistic and non-autistic people arise from differences on both sides, rather than only from the autistic person.

EHC plan (Education, Health and Care plan): a legal document from the local council describing a child or young person's special educational needs and the support that must be provided, available up to age 25.

Emotionally based school avoidance: difficulty attending school because of anxiety or other emotional distress, sometimes called emotionally based school non-attendance.

Gillick competence: the legal term for a young person under 16 who has enough understanding and maturity to consent to their own medical treatment.

Local Offer: information published by every council in England about services available for children and young people with special educational needs and disabilities.

Masking or camouflaging: hiding or compensating for autistic characteristics, consciously or not, in order to fit in.

Meltdown and shutdown: involuntary responses to overwhelming stress or sensory overload, involving either an outward loss of control (meltdown) or withdrawal and reduced responsiveness (shutdown).

Mental Capacity Act 2005: the law in England and Wales about making decisions for people aged 16 and over who may lack the ability to make a particular decision themselves.

NICE (National Institute for Health and Care Excellence): the organisation that publishes national guidance on health and social care in England.

PIP (Personal Independence Payment): a benefit for people aged 16 and over to help with extra costs caused by a long-term health condition or disability.

Reasonable adjustments: changes that schools, colleges, employers and services must make under the Equality Act 2010 so that disabled people are not at a substantial disadvantage.

SENCo (special educational needs coordinator): the member of school staff responsible for coordinating support for pupils with special educational needs.

SEN support: help for a pupil with special educational needs provided by a school or college without an EHC plan.

SENDIASS: the free, impartial Special Educational Needs and Disabilities Information, Advice and Support Service available in every council area.

Stimming: repetitive movements, sounds or actions, such as rocking, hand movements or humming, that many autistic people use to regulate their feelings and senses.

AT THE BACK

Where this information comes from

IN THIS PART

- The guidance and research this guide relies on

This guide is based on current national guidance, government and regulatory information, and published research. Where the research is limited or still developing, we have said so in the text. The sources below were checked in September 2026.

National guidance and law

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3. National Institute for Health and Care Excellence (NICE). Transition from children's to adults' services for young people using health or social care services (NG43). 2016. Guidance on planning the move to adult services. www.nice.org.uk/guidance/ng43
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