

A-Z glossary of autism and related conditions

Able Autism

See high-functioning autism.

AD(H)D – Attention Deficit (Hyperactivity) Disorder

AD(H)D can present with or without related hyperactivity. If no hyperactivity is included in the diagnosis then it is known as ADD (Attention Deficit Disorder). AD(H)D causes a range of problems including difficulty concentrating, hyperactivity and poor impulse control. It is far more common in males than in females. There is no cure for ADHD but there are various mechanisms that can help people to cope with the symptoms and many people see a decrease in their symptoms with age. AD(H)D can cause people to have low self-esteem and low confidence which can affect their relationships and work life.

People with AD(H)D can appear inattentive to others and may struggle to take turns as well as talking excessively and interrupting others. AD(H)D can also make it extremely difficult for people to follow instructions that they are given and to act on them. The effects of AD(H)D can cause people to find it more difficult to get along with their peers and this can cause anxiety and mental health issues as well as defiant and deviant behaviour (such as alcohol and substance abuse).

Anxiety

May be specific phobias or general anxiety because of changes in routine, communication difficulties or not understanding a situation. May be shown in behaviour or emotional responses (anger, distress, self-injury), disturbed sleep or eating patterns or difficulties in education or employment. Anxiety is common for people with autism due to the nature of the condition. However, when this becomes sustained and distressing it needs to be addressed as more than just part of the person's autism. There are various relaxation techniques available and exercise and medication can help with more acute symptoms. The best course of treatment is entirely dependent upon the cause of the anxiety and the individual in question.

Asperger syndrome

An autism spectrum disorder that affects the way a person communicates and relates to others. A number of traits of autism are common to Asperger syndrome including:

- Difficulty in communicating
- Difficulty in social relationships
- A lack of imagination and creative play.

However, people with Asperger syndrome usually have fewer problems with language than those with autism, often speaking fluently though their words can sometimes sound formal or stilted. People with Asperger syndrome also do not have the accompanying learning disabilities often associated with autism; in fact, people with Asperger syndrome are often of average or above average intelligence.

Attachment disorder

Difficulties in relating to other people, forming and maintaining relationships. Usually caused by interruption to a person's emotional development in early childhood as a result of trauma, separation, constant change of routine, neglect or abuse.

Additional learning difficulties

A sizeable proportion of people on the autism spectrum (estimates vary) will have additional learning difficulties which can be moderate, severe or profound.

Atypical autism

Used to describe people with many of the features of autism but do not fulfil all of the diagnostic criteria.

Autistic continuum

Means the same as 'autistic spectrum' or 'autism spectrum'.

Autistic features

This is a vague description of autism. If you or your child is described as having these, seek clarification from an autism specialist.

Autistic savant

Someone with autism whose ability is generally low to average, but who has one skill which is much more developed, for example a significant talent for music, maths or art.

Autism Spectrum Condition or ASC

The same as autism.

Autism Spectrum Disorder or ASD

The same as autism.

Autistic tendencies

See 'autistic features'.

Autistic traits

See 'autistic features'.

Bipolar disorder

Bipolar disorder is an illness which involves cycling between elevated and depressive moods. The time that each episode lasts varies significantly between different people. Bipolar disorder often occurs in late adolescence or early adulthood but childhood-onset bipolar disorder has become more widely recognised in recent years. Bipolar disorder may be underdiagnosed in people with autism because some of the symptoms are similar to some of the features of autism. Many people with autism exhibit symptoms of bipolar disorder, even where no strict mood disorder diagnosis can be made. Treatment is usually a combination of counselling, or Cognitive Behavioural Therapy, and medication.

Bowel/immune

There is very little research into or evidence of specific links between bowel problems and autism, however these issues do seem to be quite common amongst individuals with autism. Bowel problems affect a number of people with autism and can mean either loose stools and difficulty getting to the toilet in time, or anxiety around toileting which may result in severe constipation and pain when passing stools.

Immune problems are less common but still prevalent amongst people with autism. There is also very little research into or evidence of a link between immune problems and autism. Most of the research is focused on immune changes during development in the womb. There is some evidence that suggests that autism may be associated with an immune response during pregnancy.

Childhood Disintegrative Disorder (CDD)

CDD is a rare condition in which children develop normally until around the age of two and then have a sudden and dramatic loss of skills. It presents similarly to autism but often occurs later than autism does and presents far more severe regression. Children lose their skills in various areas; these include social skills, motor skills and language and speech skills. The cause of this disorder is unknown as there simply isn't enough research to discover patterns.

Classic/Classical autism

Describes those with severe difficulties in all key areas of autism and sometimes additional learning difficulties.

Core autism

See 'classic autism'.

DAMP – Disorder of Attention, Motor Co-ordination and Perception

Significant difficulty in all attention, motor co-ordination and perception.

Depression

Can occur in people with autism at all ages and levels of ability. A family history of depression is a risk factor. Warning signs may be changes in behaviour, apathy, tearfulness, sleep problems, aggression or self-injury.

Dyslexia

A specific learning disability causing ongoing problems with reading, writing and spelling (and often maths) because of perceptual difficulties (interpreting what we see) in identifying letters and numbers, which may appear blurred or distorted, and listening difficulties in identifying sounds which make up words and matching the spoken word with its printed symbol.

Dyspraxia and motor clumsiness

Dyspraxia appears in childhood and causes significant difficulties in motor skills and development. The condition is lifelong and often results in severe deficits in spatial awareness and communication skills. People with dyspraxia often find it difficult to relate to others and to participate in imaginative play. They also frequently struggle with understanding and following instructions and may appear very slow to respond to given information or requests. Some people with dyspraxia may not want to take part in activities that require motor skills. They may also have very poor handwriting and poor fine motor skills and concentration.

Epilepsy

Epilepsy is a seizure disorder and these seizures may be easily noticeable if they involve fitting (tonic-clonic seizures). However, seizures may also mean unexplained staring and loss of response (absence seizures) as well as loss of muscle tone and sudden limpness (atonic seizures). Seizures are often followed by periods of confusion. It is believed that some of the differences in brain structure found in people with autism cause seizures to occur. Epilepsy can be treated with anti-epileptic medication to reduce the frequency and severity of seizures or eliminate their occurrence altogether. However, they do not cure the condition and seizures will return if the medication is stopped.

Fragile X Syndrome

Fragile X Syndrome is the most common identifiable cause of inherited learning disability. It is caused by an overly long DNA sequence on the X chromosome which interferes with brain development. Fragile X is caused by a mutation in the FMR1 gene, which supports intellectual development. Some people have a mutation which increases the length of this gene but not to the extent that they develop Fragile X. This lengthening in the gene is likely to expand through generations and therefore children of people with a lengthened gene are at a higher risk of having the gene lengthened to the point where Fragile X will manifest. Girls are often less affected by Fragile X because they tend to have one clear X chromosome that compensates to some degree.

Fragile X almost always causes language and speech delays and echolalia is common (repeating the words of others). Speech tends to be affected by poor rhythm awareness and disjointed conversation which can make speech difficult to understand. Individuals may also talk extensively about a single topic and struggle to move away from this. Feeding and sleeping can also be affected in Fragile X, as well as understanding of abstract concepts and problem solving. Many people struggle to focus on a specific task and cannot "shut out" other stimuli and this can be confusing and cause great anxiety.

A minority of people with Fragile X also have autism but many more share traits with those on the autism spectrum. An avoidance of eye-contact, sensory issues and distress in social situations are all common for people with Fragile X.

Global developmental delay

Significant delay in every area of the person's development.

Hearing impairment

Hearing difficulties are quite common for those with autism but often overlooked.

High functioning autism

Used to describe people with at least average cognitive ability. Their earlier language difficulties may have improved but they will still have significant difficulties with social interaction.

Kanner Syndrome or Kanner's autism

Same as 'classic autism'. Leo Kanner was the first to describe and name this condition.

Learning difficulties/disability

Delay in overall development and ability to learn. May be described as mild or moderate (MLD), severe/profound (SLD) or general (GLD).

See also 'Additional learning difficulties'.

Literacy

Some people with autism have difficulties learning to read and spell. Others are fluent readers but do not understand the meaning of what they are reading. This is known as hyperlexia.

Mental health

Mental health issues are common amongst people on the autism spectrum. These include anxiety, depression, bipolar disorder and obsessive compulsive disorder. Many people with autism struggle to identify and communicate their emotions and concerns and this can cause distress and also make that distress hard to recognise and diagnose. It is thought that, since depression in particular is most common amongst children and adolescents, many negative thoughts are caused by a growing awareness of their disability. It is also around this time that many young people report frustration at their inability to understand the social rules that would enable them to form a peer group or be part of one.

A significant change in patterns and behaviour must be taken seriously. People with autism may lose communication skills due to stress and anxiety and this can make it difficult to rely on verbal discussions to establish their mood. It is often more telling when the person's sleep habits and stress levels change and there is an increase in stereotyped behaviour. Many people will benefit from social skills classes or social groups in which they can meet like-minded people and learn to build their self-esteem.

Mild autism

This is not a helpful term, see high functioning autism.

OCD – Obsessive Compulsive Disorder

Obsessive Compulsive Disorder occurs when a person has recurring, obsessive thoughts that they cannot control. This may lead to repetitive actions and frequently recurring ideas that cause the person anxiety and distress. This differs from stereotyped behaviour as although this behaviour may also be compulsive it may be therapeutic in some way and therefore welcomed by the person with autism.

PDA – Pathological Demand Avoidance disorder

Actively resistant to ordinary demands, a person with PDA does everything on his/her own terms.

PDD (Pervasive Developmental Disorder)

Describes autism and similar conditions.

PDD-NOS (not otherwise specified)

See PDD.

Pica

Pica is defined as an abnormal craving for non-food substances such as dirt, grass, paint, or clay.

Rett Syndrome

Rett Syndrome is a condition caused by a mutation that affects the body's production of the protein MeCP2, which is vital for brain development. The mutation in the MECP2 gene occurs on the X chromosome. This means that cases amongst males are incredibly rare. Whereas girls have two X chromosomes and therefore have two of the genes and thus enough healthy production of the MeCP2 protein to allow them to survive, boys only have one X chromosome and therefore usually do not live beyond 2 years with the condition.

Rett Syndrome is present at birth but may be undetected until the child is around one year old as this is when severe developmental regression tends to occur. This regression usually presents as a loss of acquired skills, the development of clumsy posture and gait and the appearance of repetitive hand movements. The condition is genetic but it is not hereditary and the mutation usually appears to occur spontaneously. The condition causes multiple physical and learning disabilities and leaves people entirely dependent throughout their lives.

Sensory issues

Many people with autism suffer from sensory processing difficulties. This can mean that sounds, smells and sights can be overwhelming and distressing. Hypersensitivity means that the person is over-sensitive to sensory input so they may see images as fragmented and distorted; hear sounds more loudly and struggle to isolate particular sounds such as conversation; feel textures and touches more acutely causing discomfort and pain.

Sometimes a person with autism will experience the opposite and be under-sensitive to sensory input. This may mean that they see images as blurred and dark and depth perception may be poor; they hear sounds as muffled and dull and may have trouble listening to particular sounds; they feel textures and touch less than others and may therefore enjoy weighted items and deep pressure contact. They may also have a high tolerance for pain and potentially self harm.

Other senses that are not as commonly thought of are balance and proprioception (body awareness). Sensory issues with balance may result in a need to rock or spin for sensory input or, on the other hand, difficulties stopping quickly, being in any position where the head is not upright and with sports. Issues with proprioception may cause a person to be unaware of their proximity to others and struggle to avoid obstacles. They may struggle with hand-eye co-ordination and fine motor skills.

There are lots of things that help a person with sensory difficulties. The key is to tailor the approach to the individual's specific needs in each environment.

Self-injurious behaviour

Self-directed violence including hitting the head with a clenched fist, banging the head against hard objects, skin picking and eye gouging.

Self-stimulation or 'stimming'

Behaviours which are thought to be used to provide stimulation to the individual. These occur more commonly in people who have severe learning disabilities, especially if they have autistic traits or are under-stimulated. Stimming is a word commonly used by parents and professionals for the self-stimulatory behaviour shown by some people with autism.

Such behaviour is also sometimes referred to as stereotypic behaviour or stereotypy. It can take different forms and involve the stimulation of different senses, for example staring at an object in motion or a light, rocking back and forth, vocalising or making repetitive noises, hand flapping or spinning round.

Sleep problems

Sleep problems are common amongst people with autism and this can have serious long-term health effects. It is believed that sleep helps to cement our learning and memories and to build a strong immune system. Some studies suggest that there may be an altered sleep/wake cycle for some people with autism and irregularities in melatonin production - this is the key hormone in sleep/wake cycle regulation.

Some other causes of poor sleep are anxiety issues which are common in people with autism. It is also more difficult to get to sleep if your bedroom is also a place where you engage in stimulating activities during the day as this can affect your brain's ability to "shut down" enough for sleep. It is also possible that an attachment to routine, which is associated with autism, may mean that people with autism struggle to fall asleep; even the most seemingly minor changes to a person's night time routine may cause enough anxiety to reduce the chance of effective sleep.

Social Communication Disorder

A way of describing those with autism. Not all people with social communication difficulties have autism.

SPD – Semantic Pragmatic Disorder

A term to describe people who have difficulties with language and communication. Today, most would meet the criteria for autism.

Special interest

Something a person with autism is particularly interested in that brings them joy/pleasure. Common special interests include transport/trains, Doctor Who, Harry Potter, statistics, chess and music. Special interests are different to obsessions, which are distressing/unpleasant.

Specific learning difficulties

Overall development may be appropriate for the person's age, but there may be specific areas of difficulty for example reading, writing or maths.

Speech/language difficulties

Extremely common as communication is one of the three main areas of difficulty for those with autism.

Tourette syndrome

Tourette syndrome consists of involuntary tics that are uncontrollable, rapid and frequent. These tics can affect social interactions and may potentially cause embarrassment which can be unpleasant and distressing for the person exhibiting them. Tics may also worsen in certain situations, usually those of heightened stress. It is possible that medication can be prescribed if tics are particularly severe but often stress reduction, physical activity and adequate sleep are the main treatments.

Tuberous Sclerosis

Tuberous Sclerosis is a rare condition that causes benign (non-cancerous) lesions to grow throughout the body. These can grow in any organ and so the effects vary widely between people. The signs of the condition can be a lot of things, from light patches on the skin to behavioural problems and seizures. Other common complications arise from lesions in the kidneys, heart or lungs, which can cause these organs to malfunction or underperform.

There is no cure for tuberous sclerosis but the cause is thought to be a mutation on the TSC1 or TSC2 gene. These are believed to prevent cells from growing too fast and the mutation means that excess growth occurs, resulting in lesions and tumours. There is some evidence of parents passing on the damaged genes to their children but around 2 in 3 cases appear to be spontaneous and not hereditary.

Visual impairment

Difficulties with vision are quite common but often overlooked for those with autism.

Williams syndrome

A genetic disorder which is associated with distinctive facial features and learning difficulties. People with this diagnosis often display some of the behaviour seen in people with autism (for example, talking repetitively about certain topics; social isolation from peers; attention difficulties), but unlike many with autism, a characteristic feature of Williams syndrome is their over-friendliness with others, including strangers.

XXYY Syndrome

Many of those diagnosed with this rare genetic condition are also on the autism spectrum.

Other terminology

The terminology used by professionals can be confusing, especially to someone who has just received a diagnosis of autism. In this section, we've outlined some of the common terminology an individual with autism or their family members may come across.

ABA - Applied Behavioural Analysis

An approach for changing behaviour that involves the systematic application of a set of principles derived from psychological theories of learning.

Advocacy

Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocates and advocacy schemes work in partnership with the people they support and take their side.

ALDT

Adult Learning Disability Team

Assessment/Assessment of needs

A systematic and thorough evaluation of the needs, goals and aspirations of a person.

Aspie

A person with Asperger syndrome may refer to themselves as an “aspie”.

BESD

Behaviour, Emotional, and Social Difficulties

BSS

Behaviour Support Service

CAF - Common Assessment Framework

The CAF is a four-step process whereby practitioners can identify a child’s or young person’s needs early, deliver coordinated services and review progress. The CAF is designed to be used when:

- A practitioner is worried about how well a child or young person is progressing (e.g. concerns about their health, development, welfare, behaviour, progress in learning or any other aspect of their wellbeing)
- A child or young person, or their parent/carer, raises a concern with a practitioner
- A child’s or young person’s needs are unclear, or broader than the practitioner’s service can address.

The process is entirely voluntary and informed consent is mandatory, so families do not have to engage and if they do they can choose what information they want to share. The CAF should be offered to children who have additional needs to those being met by universal services.

CAMHS

Children and Adolescent Mental Health Service

Carers

Family members, professionals or paraprofessionals who provide care.

CAT Team - Communication and Autism Team

Specialist support for children and young people with autism.

Casein

Protein found in milk and milk products.

Central coherence

A theory on the way the brain processes the world. People with strong central coherence find meaning in the whole context of a situation but may miss the details. People with weak central coherence, concentrate on the details but may miss the meaning in the whole situation because they cannot see the ‘the big picture’.

CDC

Child Development Centre

CDT

Children's Disability Team

Challenging behaviour

Behaviour of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to or use of ordinary community facilities, or impair a person's personal growth, development and family life.

CLASP

Complex Learning and Social Problems

Communication

Sharing experience/ideas/information and relating to others by letting people know what you want/need and how you feel. Understanding the information people convey to you in speech, gesture and body language.

Compulsions

Stereotyped behaviours that are repeated again and again. They are not inherently enjoyable, nor do they result in the completion of inherently useful tasks.

CPN

Community Psychiatric Nurse

DDA

Disability Discrimination Act

Developmental disabilities

Generic terms relating to all children and adults with a substantial continuing disability originating in childhood.

DfE

Department for Education

DoH

Department of Health

DLA

Disability Living Allowance

Domiciliary care

Care provided in the home.

Early intervention

Action taken utilising medical, family, school, social or mental health resources and aimed at infants or children at risk of, or in the early stages of mental, physical, learning or other disorders.

Early Years Setting

Pre-school; nursery

EBD/ESBD

Emotional Behavioural Difficulty/Emotional Social Behavioural Difficulty

Echolalia

Repeating speech (or signs/gestures), rather than replying, usually when the person cannot understand what is said. Can be immediate or delayed.

Ed Psych/EP

Educational Psychologist

EHCP - Education, Health and Care Plans

EHCPs are a replacement for statements and aim to simplify and streamline the statementing process. They will provide an outline of care for young people from birth to the age of 25.

Elective mutism

Condition in which people talk in one situation, for example, at home, but remain silent elsewhere, for example at school or at college.

Executive function

Ability to plan, organise, switch attention and respond appropriately to situations. Poor executive function can result in repetitive, rigid behaviour, inflexible responses to changing situations and a lack of planning skills.

Facial recognition

Disturbances in gaze and patterns of facial interaction are prominent aspects of social dysfunction in autism; facial recognition is an aspect of visual data processing. It simply relates to the ability to recognise faces for what and who they are.

Facilitated Communication

Approach to assist people with no speech or with dysfunctional speech to find alternative means of communication. The facilitator normally supports a client's hand, wrist or arm while that person uses a communicator to spell out words, phrases or sentences. This approach is controversial as there have been a number of cases where it was claimed a person with autism was communicating when it was in fact the facilitator.

Fine motor skills

Ability to handle small objects with dexterity: use scissors, hold a pencil appropriately and exercise control in writing, drawing etc.

Genetics

Branch of biology concerned with heredity and individual characteristics.

Gluten

Protein found in wheat.

GP

General Practitioner

Gross motor skills

Control over where your body is in space and time. This includes the ability to walk, run, jump, climbing with agility. It also includes throwing, catching and kicking a ball, a sense of balance, for example riding a bike, and spatial awareness.

Inclusion

Placement and education of students with disabilities in general education classrooms with students of the same age who do not have disabilities.

Interventions

Any action designed to help a person with autism.

IEP - Individual Education Plan

A plan which describes targets set for an individual child and the plans made by the school to ensure that these targets are achieved.

IMCA - Independent Mental Capacity Advocacy

Advocacy for people who do not have the capacity to make their own decisions. IMCAs support these people through issues around medical treatment or residential care.

IQ - Intelligence Quotient

A score which is used to measure intelligence.

JSNA - Joint Strategic Needs Assessment

Joint strategic needs assessments analyse the health needs of populations to inform and guide commissioning of health, well-being and social care services within local authority areas. The main goal of a JSNA is to accurately assess the health needs of a local population in order to improve the physical and mental health and well-being of individuals and communities.

LA

Local Authority

LSA/LSP

Learning Support Assistant/Practitioner

LSS

Learning Support Service

MAA

Multi Agency Assessment

MD

Medical Doctor

NAS

National Autistic Society

Neurobiology

Study of the biological processes in the nervous system.

Neurotypical/NT

A person who does not have autism.

Non-verbal communication

Communication through use of facial expression, posture, gesture and body movement.

Obsessions

Ideas, images or impulses which enter a person's mind again and again in stereotyped form. They are almost invariably distressing.

Optician

Person qualified to make and sell spectacles and contact lenses.

Optometrist

Person trained in detecting and correcting poor eyesight.

Orthoptist

Person trained in the study or treatment of irregularities of the eye, especially eye muscles.

OT - Occupational Therapist

Method of treatment by means of purposeful occupation. The goals are to arouse interest and confidence and exercise mind and body.

PCP

Person Centred Planning or Person Centred Plan

PCT

Primary Care Trust

PECS

Picture Exchange Communication System

PPS

Parent Partnership Service

Prevalence

One of the main ways to measure the frequency of a disease in a particular population - it is the total number of cases that are present at any one time - covering both old and new cases.

Pronoun reversal

Difficulty knowing when to use 'I', 'me', 'you' and may call self 'you', 'he' or 'she' because these are the words used about, or to, the person.

Provision mapping

A document identifying all additional input and interventions used to meet children's special educational needs in school.

PSP

Pastoral Support Programme

Regression

To go backwards. This usually refers to the loss of skills previously acquired, especially those basic skills related to early childhood.

Repetitive behaviour

Abnormally intense preoccupation with one subject or activity; distress over change; insistence on routines or rituals with no purpose; repetitive movements, such as hand flapping.

Residential care

Residential care is long-term care given to adults or children who stay in a residential setting rather than in their own home or family home.

Respite care

Respite care is the provision of short-term, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home. Respite programs provide planned short-term and time-limited breaks for families and other unpaid care givers of individuals with autism in order to support and maintain the primary care giving relationship. Respite also provides a positive experience for the person receiving care. The term "short break" is sometimes used to describe respite care.

Ritualistic behaviour

Ranges from simple stereotyped movements such as spinning objects, picking threads from carpets, flicking pieces of string, opening and shutting doors, spinning the wheels of toys through motor mannerisms - such as rocking, hand flapping or flicking - to more sophisticated and complex behaviours as IQ levels rise.

S(A)LT

Speech and Language Therapy/Therapist

School Action

Support for a child from a school's own resources.

School Action Plus

Additional support for a child from outside agencies, eg: Educational Psychologist, Specialist Teacher for autism.

Self-advocacy

When someone speaks and acts for their self to present their case. Many self-advocates have come together to form a collective voice on issues that impact on their lives. This is also sometimes called group advocacy.

SEN

Special Educational Needs

SENCO

Special Educational Needs Co-Ordinator

SPELL

An educational approach that stands for Structure, Positive, Empathy, Low Arousal, Links.

Statementing

The name often used to describe the Statutory Assessment process. A statement of special educational needs is a legally binding document which sets out the person's strengths and needs and how they will be met. These are being replaced by Education, Health and Care Plans (see EHCP).

Statutory Assessment

The formal process of finding out about a child's Special Educational Needs and how to meet those needs appropriately.

Supported living

Supported living is where people with autism (and others) live in their own home and receive care and/or support in order to promote their independence. The support that people receive is tailored to their individual needs. It aims to enable the person to be as independent as possible, and usually involves social support rather than medical care.

TA

Teaching Assistant

Theory of Mind

A theory on a person's ability to understand things/situations from the point of view of someone else.