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Autism and Asperger syndrome resources in Ireland

Information for people from adolescence to adulthood who are living with autism and Asperger syndrome in Ireland



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A GLOSSARY OF AUTISM TERMINOLOGY

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A glossary of autism terminology

This is a glossary of terminology and abbreviations related to autism spectrum disorder. Although we have tried to avoid using abbreviations and unnecessarily medical or technical language within this book, there are times when it is hard to avoid jargon, and times when the abbreviation is simply more commonly used than the fully-written phrase.

ABA — Applied Behaviour Analysis is a well-documented and well-validated process of intensive behaviour modification for children with autism.

ADD — See *attention-deficit disorder*

ADHD — See *attention-deficit hyperactivity disorder*

AQ — The Autism Spectrum Quotient (or AQ) test is a screening questionnaire in which a higher score indicates a greater probability of “clinically significant levels of autistic traits”. Online versions have appeared in a number of places, including Wired magazine www.wired.com/wired/archive/9.12/aqtest.html

AS — See *Asperger syndrome*

ASD — See *autism spectrum disorder*

Asperger syndrome (AS) — A specific diagnosis within the group *autism spectrum disorder* that has evolved a distinct identity from *high-functioning autism* (HFA). There is debate about whether Asperger syndrome is biologically distinct from other forms of autism.

attention-deficit disorder (ADD) — A subtype of *ADHD* in which inattentiveness predominates and in which hyperactivity and impulsiveness are not pronounced.

attention-deficit hyperactivity disorder (ADHD) — A neurobehavioural disorder involving inattentiveness, hyperactivity and impulsiveness.

autism spectrum disorder (ASD) — a group of neurodevelopmental conditions classed as a pervasive developmental disorders (PDD). Autism spectrum disorders are characterised by the “triad of impairments”: social deficits, communication difficulties and stereotyped or repetitive behaviours and interests.

CAMHS — The Child and Adolescent Mental Health Service is a referral-based service for children and adolescents that is a body responsible for children with autism who have needs separate from education, before and throughout school age. There is some overlap with both education and disability services. The charity Reach Out describes the services available at ie.reachout.com/getting-help/face-to-face-help/services-explained/child-and-adolescent-mental-health-services/



CAO — The Central Applications Office is the centralised system for processing applications to the first year of undergraduate courses at higher education institutes in Ireland, www.cao.ie/. The CAO does not make decisions about accepting or rejecting students, which is still done by each institution independently. DARE, the Disability Access Route to Education, provides reduced-points access for students with disabilities — see *DARE*.

CBT — Cognitive Behavioural Therapy is a talking therapy that encourages people to challenge difficult thoughts and behaviours, with proven effectiveness in treating anxiety, depression, eating disorders (anorexia and bulimia) and OCD. CBT is both the first line (before medication) and preferred therapy for most of these mood-related conditions.

Concerta — See *methylphenidate*

DARE — The Disability Access Route to Education (DARE) is a college and university admissions scheme which offers places on a reduced points basis to school leavers under 23 years old with disabilities. www.accesscollege.ie/dare/index.php

DBT — Dialectical Behaviour Therapy combines CBT and Mindfulness therapies and may be a particular counsellor's approach to talking therapy.

DNA — Deoxyribose nucleic acid, the molecular content of our genes.

DSM — The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, one of the primary reference guides for diagnosis. Autism was first included as "infantile autism" 1980 (revised to "autistic disorder" in 1987) in DSM-III, then within the pervasive developmental disorders in DSM-IV in 1994. The DSM-5 (May 2013) combines autism, Asperger syndrome and pervasive developmental disorder, not otherwise specified (PDD-NOS) within a single diagnostic category of Autism Spectrum Disorder.

dyscalculia — A learning disability involving difficulty understanding or learning mathematics. Dyscalculia affects people across the entire intelligence range. www.sess.ie/categories/specific-learning-disabilities/dyscalculia

dyslexia — A learning disability involving difficulty understanding, reading or writing text. Dyslexia affects people across the entire intelligence range. www.sess.ie/categories/specific-learning-disabilities/dyslexia

EBT — Employer-based training combining further education with on-the-job training, often associated with enhanced welfare allowances.

empathy — The ability to recognise, identify and respond to emotions — of other people and yourself. Cognitive empathy (theory of mind) describes the ability to identify mental states, whereas affective empathy describes the ability to respond appropriately. People with autism have impaired cognitive empathy (fail to recognize emotion, in themselves or others) but unimpaired affective empathy (will feel the appropriate emotion once it is understood).

EPSEN — The Education for Persons with Special Educational Needs Act 2004, which defines the rights to an educational assessment, a statement of special needs and an action plan. www.irishstatutebook.ie/2004/en/act/pub/0030/print.html



Education and Training Boards — the 16 regional ETBs within the ETBI provide state-funded further education and training, absorbing the former VECs and some functions of FÁS. <http://www.etbi.ie/>

executive function — A collection of processes involving problem-solving, task management and responding to unexpected change (or interruption) that are impaired in autism. Executive function can be supplemented with good planning and effective note-taking.

FÁS — the Employment and Training Authority or Foras Áiseanna Saothair (www.fas.ie/en/), which means 'growth' in Irish. FÁS was dissolved in 2013 and its functions absorbed by Solas <http://www.solas.ie/> and the *Enterprise and Training Boards* (ETBI) <http://www.etbi.ie/>.

GFCF — A gluten-free, casein-free diet eliminates all gluten (occurring naturally in wheat, rye and barley, and by contamination in oats) and all casein (dairy protein). The diet is widely used with children with autism, although many bodies (including the The American Academy of Pediatrics, the Cochrane Collaboration and NICE) have concluded that there is no compelling evidence for the diet — except in children with confirmed coeliac disease. Some people also exclude soya and soya-contaminated produce, the GFCFSF diet.

GP — The General Practitioner is the first point of contact for many services, including non-medical services (such as welfare-related benefits). Access to psychiatric and educational assessment is by referral from a GP or other front-line professional.

gravitational insecurity — Fear or nervousness associated with balance and underactive vestibular processing, which can lead to caution with heights, swinging motions or climbing. It is notable that some people with vestibular dysfunction react positively to vestibular stimulation and enjoying swinging, spinning and other motion. Gravitational insecurity is associated with *Sensory Processing Disorder*.

HEA — The Higher Education Authority (www.hea.ie/) is the statutory body responsible for planning and policy for third-level education in Irish universities, institutes of technology and some other third-level institutes.

HFA — See *high-functioning autism*

high-functioning autism (HFA) — A diagnosis that is frequently made for people with autism who have no cognitive deficits. HFA is usually diagnosed earlier than Asperger syndrome, and some clinicians argue that the two conditions are otherwise indistinguishable.

HR — Human Resources is the department of an organisation responsible for recruitment, training and discipline of employees — also called a Personnel Department.

HSE — The Health Service Executive of Ireland, hse.ie/eng/

hyper- — A prefix meaning elevated, raised or excessive.

hyperacusis — Excessively sensitive hearing in which noise can be unpleasant or painful, with defensive responses such as wearing ear-muffs (in any weather), covering the ears or



moving away.

hypersensitive — Excessively sensitive in one of the principal five senses (sight, hearing, touch, smell or taste) or the lesser known three senses (vestibular, proprioceptive and interoceptive).

hypervigilance — A state of heightened sensory arousal accompanied by anxiety and behaviours associated with detecting threats, such as monitoring the environment for changes, movement or fearful stimuli. Hypervigilance is tiring.

hypo- — A prefix meaning lowered, reduced or inadequate.

hyposensitive — Under-responsive in one of the principal five senses (sight, hearing, touch, smell or taste) or the lesser known three senses (vestibular, proprioceptive and interoceptive).

IBS — Irritable bowel syndrome is a symptomatic diagnosis based on function gastrointestinal disorder, usually diarrhoea or constipation (which may alternate) and pain or discomfort. Despite affecting perhaps 10% of the population and causing great distress, there is no identifiable organic cause. Soluble fibre, dietary changes and symptomatic relief of spasm and pain may help some people.

ICD — The World Health Organisation's International Classification of Disease, www.who.int/classifications/icd/en/.

interoception — In addition to the usual 'five senses' (hearing, sight, smell, taste and touch), humans also feel internal sensations from our circulatory system, lungs, digestive tract, bladder and bowel. Over-responsive interoception causes discomfort, whereas under-responsiveness might be associated with bladder or bowel dysfunction.

Methylin — See *methylphenidate*

methylphenidate — (branded as Concerta, Methylin, Ritalin) A psychostimulant drug prescribed for ADHD / ADD and used to maintain alertness and attention.

MRI — Magnetic Resonance Imaging is a technique for examining structures inside the body, including brain-imaging. MRI does not carry the same risks as X-Ray imaging and provides greater detail. There may be structural brain differences in people with autism that could, one day, lead to better diagnosis and evaluation.

NICE — The UK National Institute for Health and Care Excellence is one of the leading authorities on health care provision, with Clinical Guidance documents on autism recognition and intervention (publications.nice.org.uk/autism-recognition-referral-diagnosis-and-management-of-adults-on-the-autism-spectrum-cg142).

NIMH — The US National Institute of Mental Health (www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/index.shtml) is one of the leading authorities on development and well-being, with reputable information about autism



recognition and intervention.

NLN — The National Learning Network (www.nln.ie/) is the largest non-Government training organisation in Ireland.

NT — NeuroTypical is a term coined by people with autism to define people without autism, and later to define people without any atypical neurology (such as developmental conditions, dyslexia, ADHD or learning impairments).

obsessive-compulsive disorder (OCD) — An anxiety-driven behaviour in which someone obsessively follows routines or repeats actions to ease the sense of anxiety. *Perseveration* and restricted and repetitive behaviours are a part of autism, although often without apparent anxiety.

OCD — See *obsessive-compulsive disorder*

OTC — See *over-the-counter drug*

over-the-counter (OTC) drug — Over-the-counter medications are drugs which can be bought from a pharmacy without a prescription, although some (such as pain medication) is sold in limited quantities and after questioning about symptoms.

pervasive developmental disorder — A group of five diagnostic categories within the DSM-IV that includes the specific diagnoses of autism, Asperger syndrome, childhood disintegrative disorder and Rett syndrome, and the non-specific diagnosis of pervasive developmental disorder, not otherwise specified (PDD-NOS). PDD-NOS is the most common diagnosis.

PDD — See *pervasive developmental disorder*

PDD-NOS — Pervasive developmental disorder, not otherwise specified. Within the DSM-IV diagnostic criteria, this is a pervasive developmental disorder that does not meet the criteria for one of the specific developmental disorders of autism, Asperger syndrome, childhood disintegrative disorder or Rett syndrome. PDD-NOS is the most frequently diagnosed pervasive developmental disorder.

PEG — Polyethylene glycol (as the prescription-only medication Movicol) is an osmotic laxative that draws moisture into the gastrointestinal tract to soften the bowel contents and relieve constipation. It is found to be gentler and more effective than either non-soluble fibre bulking agents or stimulant-irritant laxatives such as senna extract, especially in chronic constipation associated with IBS.

perseveration — The perseverance with behaviours and thoughts that are linked with a narrow range of interests, or a single focus of interest. A strong focus and drive only becomes “perseveration” when other people decide that the focus is not important enough or the focus is excessive by their standards.

PMR — Progressive muscle relaxation is a method for managing tension than can be an effective intervention for stress, anxiety and persistent headaches or pain. The exercise may



consist of tensing and then relaxing each muscle group — from the tips of the toes to the scalp — while in a comfortable place, or it may also involve visual imagery. PMR is most effective when practised regularly, with benefits that extend to managing anxiety in public places.

proprioception — A sense of your own body within the local environment, or the parts of your body in relation to each other. At the simplest level, proprioception helps you to safely cut things that you are holding with your hand, even when you can't see your fingers, or to bring a fork to your mouth. At a more complex level, it helps you coordinate walking and avoiding obstacles.

PRSI — Pay Related Social Insurance is a system for collecting social and health insurance taken directly from income (in the same way as tax is deducted) and used to fund social welfare and pension payments. Sufficient PRSI credits are required in order to qualify for benefits that are not means-tested.

Ritalin — See *methylphenidate*

Restricted and repetitive behaviours — Stereotyped and repeated actions, or interests that are pursued to an obsessive degree (i.e. to the extent of limiting quality of life). Some apparently 'non-functional' RRBs and rituals have significance and value to the individual pursuing them.

RACE — Reasonable Accommodation at the Certificate Exams are "arrangements that allow students with special educational needs, such as those caused by visual impairments or dyslexia, to access the state examinations on an equal basis with other students." There is detailed information for students and staff at <https://www.examinations.ie/?l=en&mc=ca&sc=ra>

RRB — see *restricted and repetitive behaviours*

self-harm — Deliberate acts that cause injury (including cutting, scratching, biting or hitting yourself) and behaviours around food-control (anorexia and bulimia). Self-harm can act as a form of self-comforting and as an expression of control over mental and emotional distress. Self-harm can be divided into behaviours that have no fatal intent and those that are related to suicide or expressions of suicidal thoughts, for which you should seek urgent help.

self-medication — Using *over-the-counter* drugs, supplements or other substances (legal and illegal) to treat conditions or discomfort that is undiagnosed or is not responding to prescribed treatments. Common self-medication behaviours include the beneficial (diet, exercise and some food supplements), relatively harmless (ineffective supplements or therapies) and the harmful (overuse of pain medication, alcohol, cannabis and other drugs).

SEN — Special educational needs.

Sensory Processing Disorder — Sometimes also called sensory integration dysfunction or SPD is a term pioneered by occupational therapist Dr Anna Jean Ayres. Although SPD is not recognized by all practitioners, there are reports that appropriate occupational therapy improves sensory integration, coordination, tactile sensitivity, anxiety and other signs of poor



neurological integration of the senses.

SNRI — Serotonin-norepinephrine reuptake inhibitor are antidepressant drugs that are also used to treat ADHD, OCD, and some forms of chronic pain.

SOLAS — An tSeirbhís Oideachais Leanúnaigh agus Scileanna (The Further Education and Skills Service) coordinates further education and training. <http://www.solas.ie/>

SSRI — Selective serotonin re-uptake inhibitors are antidepressant drugs that are also used to treat generalised anxiety disorder and OCD.

STEM — In education the Science, Technology, Engineering and Mathematics fields are often seen as a separate stream from the arts, humanities and (sometimes) the life sciences. STEM skills are typically spatial ability, logic and maths rather than language skills. Students can be pressured to choose between either the STEM or the arts and humanities, largely by stereotypes hanging on one specific ability (such as arithmetic).

synaesthesia — A fascinating neurological condition in which one sense triggers another, for instance seeing numbers in colour, tasting words or smelling shapes. Some synaesthetes produce art expressing their experience of connected senses. www.uksynaesthesia.com/

tactile defensiveness — A form of sensory defensiveness to minimise the discomfort from things touching the skin, such as rough textures, wetness or light contact with passers-by. Deep-tissue pressure may be comforting. Typical signs of tactile defensiveness are wearing inappropriately long or thick clothes, or attempting to 'rub out' light touches.

task-switching — Task-switching is an important *executive function* required to complete a planned task, respond to interruptions and manage unexpected outcomes. Task-switching requires a *working memory* of the interrupted and the new tasks, as well as executive function skills to plan a new course of action.

vestibular function — The vestibular system, a fluid-filled labyrinth in the ear, provides both a sense of balance (our sense of 'up') and a sense of motion, and is associated with alertness and attention.

VHI — The Voluntary Health Insurance Board that is a statutory corporation with members are appointed by the Minister for Health, trading under the name Vhi Healthcare (www.vhi.ie/) as Ireland's biggest health insurer.

working memory — Working memory is a limited capacity to hold and manipulate information related to immediate functions, and greater working memory leads to greater *executive function*, the ability to carry out a plan and respond to change. Working memory can be very effectively supplemented with written instructions and images.

