

# Autism Spectrum Disorder: Information Booklet

Amaze (Autism Victoria)



**This package has been compiled by Amaze (Autism Victoria) to provide basic information about Autism Spectrum Disorder (ASD) from a number of perspectives.**

**It is a starting point for families with a newly diagnosed child or adult, as well as agencies, professionals and students learning about ASD for the first time.**

**Once you have read this information package, contact Amaze if you have any other questions or you require more information.**



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Amaze ASD Library	03 9657 1636	<a href="mailto:library@amaze.org.au">library@amaze.org.au</a>	ASD resources
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# What is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that causes substantial impairments in social interaction and communication and is characterised by restrictive and repetitive behaviours and interests.

Individuals with ASD have impairments in the following areas:




## Social Interaction

	In children 	In children 	
May display indifference	Does not play with other children		Joins in only if adult assists & insists

Individuals with ASD may not appear to be interested in joining in with others, or they may want to join in but not know how. Their attempts to respond to social contact may appear repetitive or odd. Alternatively, they may be 'too social'.

In general, individuals often have poor social skills and difficulty understanding unwritten social rules. They often lack understanding of acceptable social behaviour.

## Social Communication

		
Indicates needs by using another person's hands	Echolalic — repeats words back, ie 'echoes' words	Talks continually about one topic


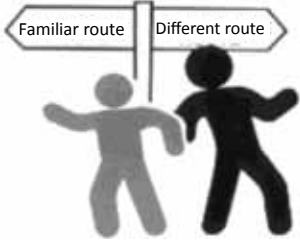

Many individuals have difficulties with verbal and non-verbal communication: some may not speak at all, or have very limited speech, and some individuals may be echolalic (where they repeat what others say).

Some individuals have a large vocabulary but struggle with the social use of language. They might have difficulty understanding jokes or satire, can take things literally, and may have difficulty taking turns in conversation.

Individuals with ASD may also have difficulties with non-verbal communication and using and understanding body language, gesture, facial expression and tone of voice to communicate.

Some individuals have difficulty understanding the feelings of others or that others have different feelings and thoughts to their own. This is known as 'Theory of Mind'.




## Behaviour, Interests and Activities

		
<p>Repetitive activities, interests &amp; behaviours</p>	<p>Preference for routine</p>	<p>Solitary or independent activities or pursuits</p>

Individuals with ASD are often preoccupied with detail and may enjoy lining up or colour-coding items such as blocks and toys. They often exhibit behaviours such as rocking, twirling, flicking and arm flapping.

Individuals may have difficulty in imagining future events or using experiences of past events to apply to current situations. They will usually prefer a predictable environment with expected events and routines. Changes in routines can be very difficult for individuals with ASD.

## Sensory Processing

		
<p>Comforting repetitive self-stimulation</p>	<p>Seeking sensory input</p>	<p>Sensory environment may be overwhelming</p>

Individuals with ASD often have marked differences in their sensory processing, and can be over-responsive, under-responsive or have difficulty in processing sensory information.

Those who are over-responsive may find sound, light, smell, touch and taste overwhelming: they are sensory avoiders.

Those who are under-responsive may seek sensory stimulation from their environment: they are sensory-seekers.

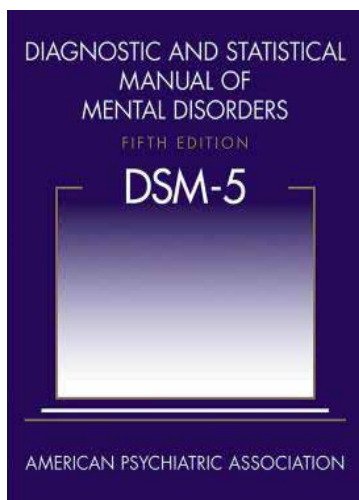
## Every individual with ASD is different

The one thing that individuals with ASD have in common is that every individual is unique!

# How is ASD Diagnosed?

When diagnosing ASD, clinicians and diagnosticians use a number of measures to determine whether or not an individual meets the criteria for a diagnosis. They may conduct observations, take a developmental history, and assess the individual's communication skills, social and play skills, adaptive behaviour, and cognitive skills. Usually a number of professionals are involved in the diagnosis, including a paediatrician or psychiatrist, a psychologist, and a speech pathologist.

One of the items in a diagnostician's tool kit is the 'Diagnostic and Statistical Manual of Mental Disorders' (DSM), a publication of the American Psychiatric Association which includes the diagnostic criteria for many different conditions including ASD.



The DSM is revised periodically to bring it into line with current research and practice. As new evidence about a condition is discovered, the manual changes to more closely reflect new understanding of the condition.

The fourth edition of the DSM (the DSM-IV) was published in 1994, and since this time there have been many studies conducted and thousands of articles published to give us a greater understanding of the disorder. In May 2013, the DSM-5 was released and in it there have been some changes to the diagnostic criteria for ASD, based on expert advice from clinicians and researchers in the field. The proposed criteria were open for public discussion and underwent a number of revisions before the final criteria were settled. The criteria as they appear in the new edition are thought to better capture how we currently conceptualise Autism Spectrum Disorder.

## What are the changes?

The most important change is that the separate disorders that were introduced in DSM-IV will be replaced by a single diagnostic term: Autism Spectrum Disorder.

The individual's *current* level of symptom severity also forms part of the diagnosis, and the new criteria bring a recognition that this can change over time, or in different contexts.



Figure 1—The Triad of Impairments from DSM-IV

These are rated as 'requiring support' (level 1), 'requiring substantial support' (level 2), or 'requiring very substantial support' (level 3), with separate ratings for each of the two major areas of impairment (see below).

The well known 'triad of impairments' (impaired social reciprocity, impaired language/communication, and restricted and repetitive patterns of interests/activities) has been collapsed into two 'domains', which are:

- 1. Impaired social communication and social interaction**
- 2. Restricted, repetitive patterns of behaviour, interests or activities**

DSM-5 acknowledges that while symptoms must be present in the early years of life, they may not become fully evident until the individual is faced with social demands that exceed their coping capacities (such as when they start school and need to work with peers).

## Other Changes

Other changes include recognition of the sensory difficulties and differences experienced by many individuals with ASD.

A delay in language development is no longer a factor in diagnosis.

An ability to officially diagnose another disorder (such as Attention Deficit Hyperactivity Disorder) in addition to ASD is now present.

Generally, people with a DSM-IV diagnosis will not need to be reassessed.

Similarly, individuals with a diagnosis of Asperger Syndrome don't need to give up their 'label' if it is something they identify with.

Some people who don't meet the new criteria for ASD may meet criteria for a new diagnosis - Social Communication Disorder. Social Communication Disorder is not an ASD, but it does include some of those social communication difficulties that are common in ASD, such as impairments in the social use of verbal and nonverbal communication, and difficulties with the pragmatics (practical use) of language. Social Communication Disorder is distinct from ASD as there is an absence of the required number of fixated interests and repetitive behaviours to meet criteria for ASD.

It is as yet unknown whether individuals who meet criteria for Social Communication Disorder will be eligible for funding assistance and support.

The DSM is a living document that reflects current knowledge and understanding. Current thinking has moved a long way from the diagnoses of 'childhood schizophrenia' or 'infantile autism' that were described in earlier editions, and as we learn more about Autism Spectrum Disorder, future editions of the DSM will continue to adapt to meet our ever increasing knowledge of the condition. Individuals and families go through a similar journey when there is a diagnosis of ASD and ask themselves questions about the reasons for the diagnosis. You may find answers to your questions here.

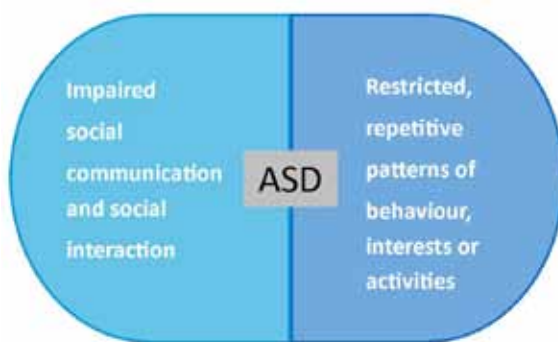


Figure 2— DSM-5 now has just two main areas of impairment - the 2 'domains'



## Common Questions & Answers

<p>Is ASD caused by the vaccinations given to children when they are 18-24 months old?</p>	<p>No.</p> <p>There has been a lot of debate over the role of vaccines in causing ASD, particularly around the Measles/Mumps/Rubella (MMR) vaccine. There are many people on both sides of this debate, and numerous internet blogs, groups and forums supporting either side.</p> <p>To date, scientific research has been unable to find any conclusive link between receiving the MMR vaccine and consequently developing ASD.</p> <p>The research study that originally suggested a link between the two has since been retracted by the journal that published the study, as the researcher's methods were found to be flawed.</p> <p>Large studies have indicated the same rates of ASD amongst vaccinated and non-vaccinated populations indicating no connection between vaccination and ASD.</p>
<p>Is Autism Spectrum Disorder reversible?</p>	<p>Currently, there is no cure for Autism Spectrum Disorder and it is not considered to be reversible.</p> <p>Individualised therapy and effective supports will help to manage the symptoms of ASD and help ensure the individual leads a happy and fulfilling life.</p> <p>However, the diagnosis of ASD will not 'disappear' or cease to be accurate.</p>
<p>Are people with Autism Spectrum Disorder always gifted?</p>	<p>No.</p> <p>Only a small number of people with Autism Spectrum Disorder are gifted in a particular area, such as music, maths or drawing. Portrayals of ASD in some movies and stories of famous people with ASD can lead us to believe that every person with ASD has a special skill, but this is rarely the case.</p> <p>Research indicates that individuals with ASD tend to have an uneven profile of abilities with peaks and troughs, unlike neurotypical individuals who tend to have a fairly even profile of ability across all areas.</p> <p>What this means is that an individual with ASD might find some things relatively easy, and others very difficult. It is important to work to the strengths of each individual and as with neurotypical individuals, encourage them to focus on the areas they enjoy.</p>
<p>Is ASD caused by something parents did or didn't do?</p>	<p>No.</p> <p>ASD is not caused by a particular parenting style, by the actions of parents, or something the mother did while she was pregnant.</p> <p>While we don't know exactly what does cause ASD, we know that these theories and others like 'cold parenting' are completely false.</p>

<p>So what is the cause of ASD?</p>	<p>The cause of ASD is unknown. There is evidence that genes play an important role in its cause and it is believed that there are multiple genes involved. Specific genes for ASD have not been conclusively identified and currently there is no medical or genetic screening or diagnostic laboratory test for ASD. Diagnosis is based on the presence of particular behavioural patterns.</p>
<p>Can individuals with ASD be taught to communicate?</p>	<p>Individuals on the spectrum vary in their communication skills. Some may never develop language, as cognitive or motor processing issues may make speech challenging. Others might acquire some functional language, whilst others still will develop meaningful, fluent, and effective language. Communication skills can be taught using alternative methods: low tech options include signing, symbols, printed word, photos, picture exchange systems or any combination of these, and high tech supports include voice-generating systems and computer-based products. For many individuals these supports will aid the development of language. As ASD is quite a broad spectrum, there are some individuals with ASD who may not develop speech but develop the ability to communicate through these alternative communication methods.</p>
<p>Do all individuals with an ASD also have an intellectual disability?</p>	<p>No.</p> <p>An Intellectual Disability (ID) is diagnosed when an individual scores well below the average in several areas of cognitive ability and adaptive behaviour. Individuals with an ID show impairments across a number of areas, including their verbal skills, non-verbal skills, processing speed, working memory, and adaptive behaviour or life skills. Whilst a large number of individuals with Autism Spectrum Disorder have a co-occurring ID (thought to be around 70%), there are many individuals with ASD who are of average or above average intelligence.</p> <p>Individuals with ASD often display an uneven pattern of abilities. They may score below average in some areas of cognitive ability, such as verbal skills or adaptive behaviour skills, but score in the average range or above average in others, for example working memory or non-verbal skills.</p> <p>The diagram shows that some people may have an ASD without an ID, others might have an ID without having an ASD, and some individuals have both an ASD and an ID.</p> <div data-bbox="783 1355 1348 1624" data-label="Diagram"> </div> <p><b>Diagram 2:</b> some individuals have only ASD, some have only an Intellectual Disability, whilst some have both.</p>
<p>Does ASD co-exist with other conditions?</p>	<p>ASD can occur by itself or in association with other disorders such as intellectual disability, anxiety disorders, ADHD, learning disability, epilepsy, Fragile-X syndrome, mood disorders, sleep disorders and others.</p>



<p>How common is ASD?</p>	<p>ASD affects at least 1 in 100-110 individuals in Australia. ASD is a lifelong condition. Individuals do not grow out of ASD and there is no known cure. More males than females are diagnosed with ASD.</p>	
<p>Is it true that people with ASD don't want to make friends and don't like interacting with others?</p>	<p>No. People with ASD are often unsure how to approach others or develop an appropriate friendship, despite a strong desire to interact with people and have meaningful relationships. Unlike neurotypical people, they may not intuitively learn the social skills required for interacting with others, and instead need explicit instruction on such skills to help them develop an understanding of appropriate social interaction and different kinds of relationships.</p>	
<p>Do people with ASD lack empathy?</p>	<p>People with ASD can struggle to understand that other people have thoughts, feelings and intentions that are different from their own. This is one facet of 'Theory of Mind'. People with ASD may misinterpret another person's intentions and this can be perceived by neurotypical people as a lack of empathy.  People with ASD do not develop these skills in the same way as typically developing individuals, but can learn them through explicit teaching and practice.</p>	
<p>Why do people with ASD exhibit unusual behaviours?</p>	<p>Everyone, whether they have ASD or not, has behaviours. Breathing, talking and moving are all behaviours we engage in as humans. For some people living with ASD, their behaviour is the only way they can communicate with other people. Even if they have good verbal skills, they may find it difficult to communicate with language in times of stress. At these times, their behaviour tells us that they are struggling to communicate.  It is important when supporting a person with ASD, to view their behaviour as communication. Observe them and find out what they are trying to say, then work out how to support them to communicate in a more effective way.</p>	
<p>Will my child always be like this?</p>	<p>Many parents whose child has just been diagnosed with ASD worry that this means that their child will not progress. Although ASD is considered a life-long condition, all children with ASD grow, learn and develop as they get older. The presentation and characteristics of ASD can change throughout the person's life. Life circumstances and life stages, as well as therapy and support, can all change the way individuals with ASD behave and appear to other people. With the right therapy and ongoing support individuals with ASD can learn to compensate for many of their difficulties and use their interests and abilities productively.</p>	

<p>Can children with ASD go to a mainstream school?</p>	<p>Yes, all children with ASD are legally entitled to go to a mainstream school. Some children with ASD may qualify for some extra funding, which the school can use to help the children, for example by employing an integration aide or acquiring help from a psychologist, speech pathologist or other professional. Some children with ASD may qualify to go to an autism-specific school in their region.</p> <p>Children with ASD who also have an intellectual disability may qualify for a Special School or Special Developmental School. If you are a parent, choosing a school for your child is a very personal decision. You may seek advice from other people, but ultimately you will need to decide what is best for your child.</p>
<p>I am an adult and I think I might have ASD - should I get a diagnosis?</p>	<p>With more awareness and understanding in the community around ASD, many adults may wonder whether they have the condition. For many, the diagnosis of a child prompts them to reflect on their own lives and seek further information about a diagnosis for themselves.</p> <p>Some may struggle with secondary issues such as depression, anxiety and social isolation. In these cases a diagnosis may be beneficial to have an understanding of the best way to approach therapy and further support, as well as understanding themselves.</p> <p>Additionally, a diagnosis may also provide the individual with access to other services, resources, employment support and financial support within the community. It may be expensive for adults to obtain a diagnosis and if the individual is well supported and happy a diagnosis may not be necessary.</p>
<p>How can I help someone with ASD?</p>	<p>Anyone can help someone with ASD. It all begins with patience, knowledge and understanding around ASD. An important fact to remember is that every individual on the spectrum is unique and therefore will have both strengths and difficulties. To help someone with an ASD it is fundamental to identify the person's likes and dislikes as well as their key motivators. Simplifying communication and instructions may also benefit the individual. Other ways to help someone with ASD include taking the time to listen and communicate with the person, minimising any stressful scenarios, or reading ASD-related books to obtain a better picture of the disorder.</p>
<p>Can medication be useful with individuals with ASD?</p>	<p>Medication has no specific role in treating ASD itself. However, some individuals with ASD exhibit severe behaviour patterns, high levels of anxiety, they may become depressed, or they may develop epilepsy. In such cases, medication may have a role in the treatment of these specific conditions and should be prescribed by a practitioner familiar with ASD.</p>
<p>What does the future look like for an individual with ASD?</p>	<p>ASD is a lifelong disorder. Most individuals with ASD will require varying degrees of support throughout their lives. With structured support programs sensitive to the unique needs of each individual, those with ASD can live a meaningful and fulfilling life.</p>



# Professionals Involved in Assessment and Diagnosis

If you are worried that you, your child, or other family member, may have Autism Spectrum Disorder often the first step is to speak to your General Practitioner (GP). GPs do not make the diagnosis themselves, but they can refer you to specialists who will carry out an assessment and make the diagnosis.

## Specialists that may be involved in the diagnosis:

### Paediatricians/Psychiatrists:

It is important for a specialist doctor to be involved in the assessment. If the person who may have ASD is an adult, then this will usually be a psychiatrist. If the person who may have ASD is a child or adolescent, then this may be a paediatrician or a child and adolescent psychiatrist.

There are other conditions that may have similar symptoms to ASD, and it is important to determine if someone has ASD or one of these other conditions. Some of these conditions may be treatable. There are also some medical conditions that can occur alongside ASD, and it is important to diagnose and treat these, if possible.

Paediatricians and psychiatrists will also ask detailed questions about the history of the individual and the family. This information can give important clues to the diagnosis and possible causes. Paediatricians or psychiatrists may also order blood tests, including genetic or chromosomal tests. There are currently no genetic tests for ASD itself, but ASD can occur along with genetic or chromosomal conditions, such as Fragile-X Syndrome. Doctors may also order blood tests for levels of nutrients such as iron. Low levels of these nutrients do not cause ASD, but individuals with ASD, especially young children, can often be quite fussy eaters, so they may be missing out on some nutrients. If this is the case, the doctor may recommend supplements to make up for anything that is missing from the individual's diet. These supplements will not treat ASD, but may help with the individual's general health and well-being.

Sometimes paediatricians will conduct tests that give an estimate of children's developmental levels. They will look at whether children have met developmental 'milestones', such as crawling, walking or talking at the same age most children start to do these things. Psychologists (see below) will conduct more detailed developmental tests.

### Psychologists

Psychologists will often conduct tests that assess the developmental or cognitive abilities of individuals suspected of having ASD. These tests are important to determine the relative strengths and difficulties of individuals, as well as how they compare to other people their age on a range of abilities. These tests may

give a summary score, often known as an IQ, and a number of subtest or scale scores. This information is important in making the diagnosis.

People with ASD often have an uneven pattern of abilities: for example they may be relatively good at visual problem-solving, such as jigsaw puzzles, but relatively poor at social understanding and communication.



This information is also important for planning the best way to help individuals with ASD. For example, they may learn better if they are given visual information, such as pictures or visual timetables, than they would if they are given long verbal instructions or explanations.



It is not always possible to get a reliable score for individuals with ASD, especially young children, often due to difficulties in getting them to pay attention and understand and follow instructions. However, psychologists with experience in ASD will use their observations of individuals' behaviour – not just the test scores – to help make the diagnosis and to judge whether the score is likely to be reliable. In some cases an individual's pattern of abilities may be so uneven that the IQ score is not a good summary of the individual's abilities, so it is more important to look at the subtest and scale scores. Some individuals with ASD also have an Intellectual Disability (ID), and if it is possible to get a reliable IQ score, then this score is used to help make this diagnosis.

In addition to the observations psychologists make during the cognitive tests, they may also use standardised observation assessments, such as the Autism Diagnostic Observation Schedule (ADOS). Sometimes they may observe individuals in natural settings, such as at home, school or work. If this is not possible, psychologists usually interview the parents, carers or teachers about the behaviour of individuals they are assessing. They may use a combination of standardised interviews or checklists and informal questioning. If psychologists are assessing adults or adolescents they may also interview the individuals themselves.

## Speech Pathologists

Speech pathologists assess the communication skills of individuals who may have an ASD. They are usually involved in the assessment of young children, but may not always be involved in the assessment of adolescents or adults. Communication does not just involve speech, but also non-verbal aspects of communication, such as gestures, body language and facial expressions. Speech assessments may involve standardised tests of individuals' receptive and expressive language. These tests assess how well individuals understand language and how they express their needs, wants, thoughts and feelings, compared to other people the same age.

Another important aspect of communication that speech pathologists assess is 'pragmatics', or the social use of language, including conversation skills and the non-verbal aspects of communication. Some individuals with ASD may know a lot of words, and may talk a lot about their own interests, but not be able to take turns and carry on a conversation. Speech pathologists may use informal interactions and observations of the individuals, and interviews with their parents, carers or teachers, to gain more information about the individuals' everyday communication skills.

As with the psychologists' tests, it is not always possible to get a reliable score from formal tests, especially with young children who may not be able to sit still and follow instructions.

In these cases information from the parents or carers is especially important. Speech pathologists often also interview parents or carers to get background information, such as when the individual started talking.

## Occupational Therapists

Occupational therapists (OTs) are not always involved in the assessment of individuals who may have ASD, but they may provide input. OTs assess motor skills, everyday living skills and sensory processing.

**Motor skills** include fine-motor skills, such as using pens or pencils and scissors, and gross-motor skills, such as balance, walking, running and coordination.

**Everyday living skills** include self-care, such as dressing and washing.

**Sensory processing** is the way that individuals process information from their senses: sight, smell, touch, hearing, taste and awareness of their own bodies.

Individuals with ASD can often be over-sensitive or under-sensitive to this information, or have a combination of both over-sensitivity and under-sensitivity. For example, they may scream or block their ears when they hear everyday sounds, but not appear to notice when someone calls their name, or they may become very distressed by a light touch, but not react to a heavy fall that would be expected to cause pain.

## Other Professionals

### Neurologists

Neurologists are not usually involved in diagnosing ASD, but paediatricians or psychiatrists may refer individuals for assessments by neurologists to test for other conditions or underlying causes that may be associated with ASD. Neurologists conduct tests of brain activity, such as electro-encephalograms (EEGs), or brain imaging, such as magnetic resonance imaging (MRIs). EEGs are used to diagnose epilepsy, and epilepsy is more common in people with ASD than in the general population. EEGs may also show more subtle differences in brain activity, so if a doctor refers an individual for an EEG, it does not necessarily mean that the doctor thinks that the individual has epilepsy. MRIs give a 'picture' of the brain.

ASD is thought to be caused by differences in the brains of affected individuals, but the technology that is available currently may not show the subtle differences that may cause ASD. For example, technology does not yet allow us to measure how well the cells in the brain (neurones) and the different parts of the brain communicate with each other.

### Audiologists

One of the things audiologists do is test hearing. They are not usually involved in diagnosing ASD, but paediatricians, psychiatrists or GPs will often refer individuals, especially young children, for hearing tests to make sure that the individuals' communication difficulties are not caused by hearing impairments. Some children with ASD may appear to be deaf because they do not respond when people call their name.

Some individuals with ASD also have a hearing impairment. If they do, then hearing aids, cochlear implants or sign language may help with their communication. However, they will still have difficulties with communication that other individuals with hearing impairments do not have, due to their ASD.



# Acronyms and Glossary

**Asperger's Syndrome** A type of pervasive developmental disorder under DSM-IV, now removed in DSM-5.

**Autistic Disorder** A type of pervasive developmental disorder under DSM-IV, now removed in DSM-5.

**Autism Spectrum Disorder (ASD)** A condition affecting social communication, social interaction, behaviour and interests; previously classified under separate categories of Autistic Disorder, Asperger's Syndrome, Pervasive Development Disorder - Not Otherwise Specified (PDD-NOS) and now combined under the one name.

**DSM-5** The Diagnostic and Statistical Manual of Mental Disorders, 5th edition, released May 2013 by the American Psychological Association and taking over from DSM-IV.

**Fragile-X Syndrome** An inherited disorder caused by a defective gene on the X-chromosome causing intellectual disability, enlarged testes and facial abnormalities in males, and with mild or no effects in females.

**Global Developmental Delay (GDD)** A diagnosis given to a child under 5 who fails to meet a number of developmental milestones. Diagnosis of GDD may be given when there are physical barriers to assessment, the child is very young or when clinical severity cannot be assessed.

**ID** A person is said to have an intellectual disability (ID) if they have an IQ (intelligence quotient) below 70 and significant difficulty with daily living skills, including looking after themselves, communicating and taking part in activities with others.

**IQ** Intelligence Quotient - a score derived from one of several different tests designed to assess intelligence.

**Neurodevelopmental** Relating to the development of the brain.

**Neurotypical (NT)** A term used for individuals who meet neurological and cognitive milestones

and are therefore typically developing.

**NDIS** The National Disability Insurance Scheme, being implemented by DisabilityCare Australia (DCA).

**Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS)** A type of pervasive developmental disorder that does not meet exact diagnostic criteria for Asperger's Syndrome or Autistic Disorder under DSM-IV, and now removed in DSM-5.

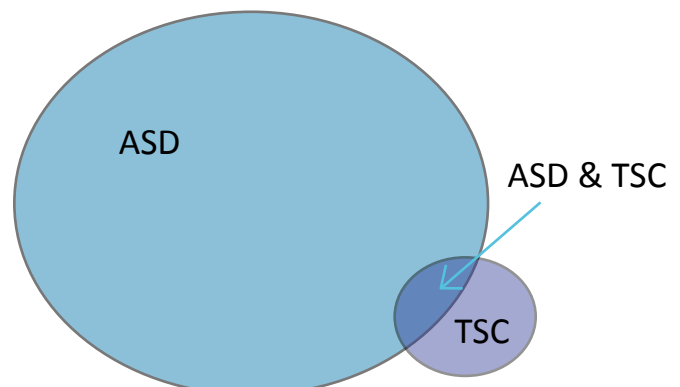
**Social Communication Disorder (SCD)** A new diagnosis in DSM-5 for those individuals with deficits in communication and social communication skills but not satisfying criteria for ASD.

**Social Reciprocity** Playing an equal role in a social event; both initiating and responding to another, eg taking turns in a conversation.

**Social Skills** The ability to interpret and respond to social cues and fit in to social environments.

**Theory of Mind** The ability to understand that other people have beliefs, desires and intentions that are different from one's own.

**Tuberous Sclerosis Complex (TSC)** An inherited disease characterised by blood collecting in the brain, retina and other body tissues, epileptic seizures, intellectual disability, and skin nodules of the face. TSC is less common than ASD with an incidence of around 1 in 6000: whilst 25 to 50% of those with TSC also have ASD, only around 1% of those with ASD also have Tuberous Sclerosis ([www.tsalliance.org](http://www.tsalliance.org)).



# Helpful Websites

## Amaze (Autism Victoria)

[www.amaze.org.au](http://www.amaze.org.au)

The Amaze website – the first place to go to get information on Autism Spectrum Disorder.

## TherapyConnect

[www.therapyconnect.amaze.org.au](http://www.therapyconnect.amaze.org.au)

An online resource to help families understand therapy for young children with ASD.

## Australian State Autism Spectrum Disorder Associations

ACT: Autism Asperger ACT [www.autismaspergeract.com.au](http://www.autismaspergeract.com.au)

NSW: Autism Spectrum Australia (Aspect) [www.aspect.org.au](http://www.aspect.org.au)

NT: Autism Northern Territory [www.autismnt.com.au](http://www.autismnt.com.au)

QLD: Autism Queensland [www.autismqld.com.au](http://www.autismqld.com.au)

SA: Autism South Australia [www.autismsa.org.au](http://www.autismsa.org.au)

TAS: Autism Tasmania [www.autismtas.org.au](http://www.autismtas.org.au)

WA: Autism Association of Western Australia [www.autism.org.au](http://www.autism.org.au)

## National Autistic Society (UK)

[www.nas.org.uk](http://www.nas.org.uk)

The National Autistic Society is the leading UK charity for people with autism (including Asperger syndrome) and their families. They provide information and have a number of useful tip sheets.

## ASD Case Consultant Practitioner (ASD CCP) Program

[www.amaze.org.au/discover/working-with-individuals-on-the-spectrum/professional/](http://www.amaze.org.au/discover/working-with-individuals-on-the-spectrum/professional/)

This state wide program is funded by the Department of Human Services (DHS) to support disability services with training and community development programs that facilitate better outcomes for people with ASD. The program has a large focus on training, regional information sharing and the establishment a community of practice. To find your local ASD Case Consultant Practitioner, please visit the Amaze website.

## National Disability Insurance Scheme (NDIS)/DisabilityCare Australia (DCA)

[www.disabilitycareaustralia.gov.au](http://www.disabilitycareaustralia.gov.au)

The National Disability Insurance Scheme (NDIS) or DisabilityCare Australia is a new way of providing community linking and individualised support for people with permanent and significant disability, their families and carers.

## Department of Education and Early Childhood Development (DEECD)

[www.education.vic.gov.au/autism](http://www.education.vic.gov.au/autism)

Brings together a range of autism-friendly learning and development services for Victorian children, young people and adults. This website includes information, resources and policy on learning, development, education and training in Victoria.

## Raising Children Network

[www.raisingchildren.net.au/autism](http://www.raisingchildren.net.au/autism)

The national Australian Parenting Website. The Autism section of the site provides information about ASD and fact sheets on numerous difficulties faced by parents of children and adolescents with ASD. There is a useful guide to therapies, and a service pathfinder to assist parents to make informed decisions about interventions. There are also parent forums on numerous topics.

## Better Health Channel

[www.betterhealth.vic.gov.au](http://www.betterhealth.vic.gov.au)

Provides health and medical information to help individuals and their communities improve their health and wellbeing. The information provided is quality assured and reliable, up-to-date and easy to understand.

## Olga Tennison Autism Research Centre (OTARC)

[www.latrobe.edu.au/otarc/your-questions-answered/ask-a-researcher](http://www.latrobe.edu.au/otarc/your-questions-answered/ask-a-researcher)

OTARC is Australia's first centre dedicated to research into Autism Spectrum Disorders. The site has a very useful 'Ask a researcher' option.

### ACT NOW

[www.med.monash.edu.au/spppm/research/devpsych/actnow/project.html](http://www.med.monash.edu.au/spppm/research/devpsych/actnow/project.html)

Aims to build skills and capacity across each region in Victoria in the area of Early Childhood (0-6 years) to enable each network of regional service providers to identify ASD and provide a range of evidence-based interventions for young children with ASD and their families. ACT NOW promotes understanding of ASD in the wider community and improves linkages and strengthens partnership. There are a number of useful resources and fact sheets available on the website.

### Autism Help

[www.autismhelp.info](http://www.autismhelp.info)

An initiative of Gateways Support Services (based in Geelong, Victoria). The site provides practical strategies, information and resources to parents, teachers, child care workers and professionals in the field.

### PlayConnect Playgroups

[www.playconnect.com.au](http://www.playconnect.com.au)

Autism-specific playgroups for preschool children with ASD or ASD-like symptoms. They are also very welcoming of young siblings.

### Early Days Workshops

[www.amaze.org.au/earlydays](http://www.amaze.org.au/earlydays)

Free workshops for parents of preschool children with ASD, including an introductory workshop to help newly-diagnosed families navigate the system, as well as skills-based workshops focusing on specific strategies for parenting children with ASD.

### My Time Support Groups

[www.mytime.net.au](http://www.mytime.net.au)

Groups for parents and carers of preschool children with a disability (not specific to ASD), developmental delay or chronic medical condition.

### Positive Partnerships

[www.autismtraining.com.au](http://www.autismtraining.com.au)

A series of online learning modules for parents and carers of school aged children.

### Asperger's Victoria (previously Asperger Syndrome Support Network - ASSN)

[www.aspergersvic.org.au](http://www.aspergersvic.org.au)

A volunteer group of parents, carers, partners, professionals and individuals with Asperger Syndrome, who run a range of support groups and seminars, as well as providing resources such as their quarterly newsletter, fact sheets and library.

### Parent Support Groups in Victoria

[www.amaze.org.au/support-groups](http://www.amaze.org.au/support-groups)

A list of Victorian support groups that have registered with us to let us know they are in operation.

### DiVine

[www.disability.vic.gov.au](http://www.disability.vic.gov.au)

An online community for and by people with a disability covering a wide range of topics. The website is published by the Victorian Government. Send them your own articles or leave comments. DiVine has been designed to meet the highest standards in accessibility.

### Carers Victoria

[www.carersvictoria.org.au](http://www.carersvictoria.org.au)

Provides care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged. Carers Victoria work closely with government and other support organisations to improve the lives of caring families throughout Victoria.

### Association for Children with a Disability

[www.acd.org.au](http://www.acd.org.au)


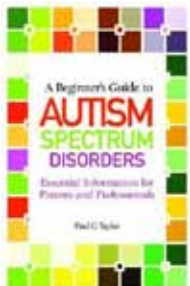
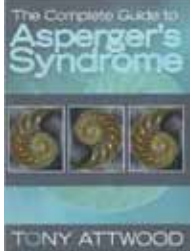



An information, support and advocacy organisation for children with a disability and their families, in Victoria, Australia; a non-profit organisation run by parents of children with all types of disability so they know what it means to have a child with a disability.






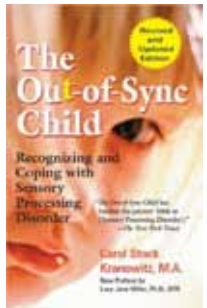
# Suggested Reading List

This is a short list of books that have proved to be very helpful to others wanting to find out more about Autism Spectrum Disorders (including Asperger's Syndrome). The Amaze ASD Library contains these and many more books and resources available to Amaze members - we recommend that you drop in some time and have a look.



## Finding out about ASD



	<p><b>The Australian Autism Handbook</b> By Benison O'Reilly and Kathryn Wicks (2nd edition)</p> <p>The 'only complete guide to every aspect of raising a child with an autism spectrum disorder in Australia' with chapters covering initial diagnosis, self-help, processing grief, early intervention, schooling, puberty and high school, funding and service providers, it is a valuable resource.</p>		<p><b>A Beginner's Guide to Autism Spectrum Disorders: Essential Information for Parents and Professionals</b> By Paul G Taylor</p> <p>A well-written 100 page guide gently introducing Autism Spectrum Disorder - a great start for anybody who has just encountered ASD for the very first time or has a recently diagnosed child. Discusses what ASD is, what a diagnosis might mean to you and your family, what to make of certain behaviours exhibited, as well as strategies that might assist the child.</p>
	<p><b>The Complete Guide to Asperger's Syndrome</b> By Tony Attwood</p> <p>Essential reading for those living or working with a child or adult with Asperger Syndrome. It is written in a clear and concise manner, with plenty of examples, practical suggestions and resource lists. It provides a good overview of Asperger's Syndrome.</p>		<p><b>A Book About What Autism Can Be Like</b> By Sue Adams</p> <p>A picture book aimed at children, trying to provide understanding and appreciation of ASD. It is an excellent introduction to the subject and a good conversation starter, dealing with being different, but also about acceptance.</p>
	<p><b>Since We're Friends – An Autism Picture Book</b> By Celeste Shally</p> <p>A beautiful picture book explaining ASD to children in an easy and accessible way, showing how they can look after and support their friends when they are struggling.</p>		<p><b>Inside Asperger's Looking Out</b> By Kathy Hoopmann</p> <p>Following on from the beautiful 'All Cats Have Asperger Syndrome' comes the follow up trying to depict how an individual with ASD may experience and see the world. Using engaging text material together with wonderful imagery Hoopmann gives us a great insight into how it can feel to live with ASD.</p>

## Common Issues

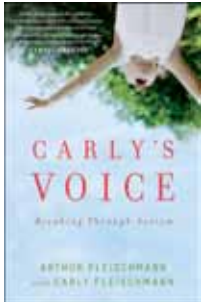

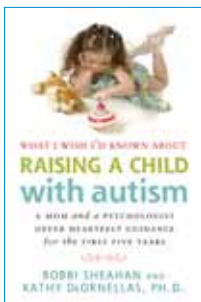
	<p><b>The Incredible 5-Point Scale</b> By Kari Dunn Buron &amp; Mitzi Curtis</p> <p>This book utilises a 1–5 point scale as a tool when encountering problems of social understanding to break down concepts, such as voice volume, the scale starts with 1 being ‘No talking at all’ and 5 being ‘Screaming/Emergency Only’. Gives the individual a visual understanding of specific behaviours and puts them into a social context.</p>		<p><b>The Social Skills Picture Book: Teaching Play, Emotion, and Communication to Children with Autism</b> By Jed Baker</p> <p>Teaches appropriate social behaviour using photos of students engaging in real-life social situations. A good resource for parents and professionals/teachers, with illustrations for the ‘wrong way’ and ‘right way’ to enter a conversation, take turns etc.</p>
	<p><b>Toilet Training for Individuals with Autism or Other Developmental Issues: A Comprehensive Guide for Parents &amp; Teachers (2nd edition)</b> By Maria Wheeler</p> <p>Accessible yet comprehensible, a great place to start if you are looking to toilet train a child who has ASD. Step by step guide from realisation of readiness, via teaching continence, through to night-time training.</p>		<p><b>The Out-of-Sync Child</b> By Carol Stock Kranowitz</p> <p>Many individuals with ASD have sensory sensitivities: explains what they term ‘sensory processing disorder’ to parents in a very accessible way and seeks to provide strategies to help families with the children struggling with sensory input.</p>

## Fiction

	<p><b>The Rosie Project</b> By Graeme Simsion</p> <p>This funny book tells the story of Don Tillman, a successful Genetics Professor who is socially awkward. He believes the solution to all his problems is a wife and his ‘Wife Project’ is a carefully designed questionnaire to find his perfect match. Into his life comes Rosie, not a match, who needs his help to find her real father...</p>		<p><b>The Curious Incident of the Dog in the Night-time</b> By Mark Haddon</p> <p>Winner of the Whitbread Book of the Year 2003 and the Commonwealth Writer’s Prize 2004 for the Best First Book, this story is written from the point of view of Christopher, a 15-year-old boy, and although it is not stated that he has an ASD, the cover tells us that he has Asperger’s Syndrome. A book that will appeal to teenagers but is equally readable by adults and others with an interest in ASDs.</p>
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	<p><b>Mary and Max</b> Directed by Adam Elliot 2009</p> <p>The both sad and warm story of the lonely Mary Dinkle, an 8-year-old living in Melbourne, and her most unlikely pen pal, 44-year-old Max, who is a Jewish man in New York living with Asperger's.</p>		<p><b>Temple Grandin</b> Directed by Mick Jackson</p> <p>The 2010 movie telling the story of Temple Grandin's life from her diagnosis, through school and university years, tapping into her incredible understanding of animals, all with the support of mum and aunt, struggles with misconceptions of peers, anxiety and sensory sensitivities.</p>
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## Personal Experiences

	<p><b>Carly's Voice : Breaking Through Autism</b> By Arthur Fleischmann with Carly Fleishmann</p> <p>This is the amazing story of Carly as told by her father mixed in with her own words. Carly, who had no spoken language, was diagnosed at the age of 2 with autism. With support from her family and therapists, she found her voice and started to communicate via typing at the age of 10.</p>		<p><b>Look me in the Eye: My Life with Asperger's</b> By John Elder Robison</p> <p>Provides a memoir that recounts a life that has been heartbreaking, inspiring and funny in equal measure. After touring with rock band Kiss at the height of their fame, producing special effects for them whilst shunning their company, he finally received a diagnosis at 39. Provides useful insights which will be useful to others with ASD as well as neurotypical people who have contact with individuals with ASD.</p>
	<p><b>What I wish I'd Known About Raising a Child with Autism : A Mom and a Psychologist Offer Heartfelt Guidance for the First Five Years</b> By Bobbie Sheahan &amp; Kathy DeOrnellas</p> <p>Beautiful and funny account of a mother's journey with her daughter and her diagnosis, together with the psychologist that supports the family.</p>		

The Amaze Autism Library is at the offices of Amaze in Carlton and is open during office hours - 9am to 5pm Monday to Friday.

Books and resources are available to members for up to 4 weeks and DVDs up to 2 weeks.

# What does Amaze do?

Amaze provides information, advice and support for individuals, families/carers, professionals and the greater community affected by Autism Spectrum Disorder. We aim to assist throughout the life span, from early childhood, through school year to adulthood.

	<p>National Registered Training Organisation (RTO) providing Certified Training Courses and tailored professional development</p>		<p>National Certification system for organisations and services to promote a high level of ASD competency</p>
	<p>Free phone support for individuals, parents and families</p>		<p>Early Days workshops provide support for parents and carers of children with ASD age 0-6</p>
	<p>The ASD Case Consultant Practitioner Program provides training and support to the professional community</p>		<p>Administration of FaHCSIA 'Helping Children with Autism' funding in Victoria</p>
	<p>Membership – providing benefits for individuals and professionals</p>		<p>A range of information services: Autism Library, online information, fact sheets, quarterly Spectrum magazine, eSpectrum newsletter</p>
	<p>Biennial Victorian Autism Conference (VAC) for individuals, families and professionals</p>		<p>Specialist ASD counselling service to assist individuals, parents and families</p>
	<p>Products to assist individuals with ASD and help promote awareness</p>		<p>In-house Directory of Services containing details of autism-aware services for those affected by ASD</p>

Amaze is responsible for running a number of services and programs on behalf of federal and Victorian state government.

Amaze acknowledges the support of the Victorian Government.



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