Autism Spectrum Disorders: Information Pack

Autism Victoria, trading as Amaze











This package has been compiled by Autism Victoria to provide basic information about Autism Spectrum Disorders 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 ASDs for the first time.

In this pack:

- A parent perspective
- What are Autism Spectrum Disorders?
- Subtypes of Autism Spectrum Disorders
- What we know about ASD
- Myths & Misconceptions
- Frequently Asked Questions
- Getting an Assessment or Diagnosis
- Information about Funding Options
- What does Autism Victoria do?
- Helpful Victorian Websites
- Suggested Reading List

Once you have read this information package, don't hesitate to contact the Autism Victoria office if you have any other questions or you require more information.

A Parent Perspective

Welcome to Holland

By Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this......

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

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What are Autism Spectrum Disorders?

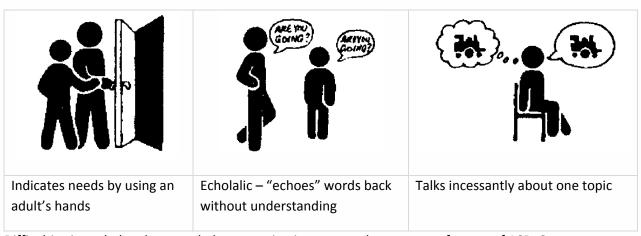
Autism Spectrum Disorder (ASD) is the term used to describe a group of pervasive developmental disorders with core impairments in the following areas:

Social Relationships



Social behaviour for individuals with ASD can range from almost complete indifference to other people, to wanting to join in but not knowing how, or being 'too social'. Some individuals will respond to social contact but not initiate interactions with others. Their attempts at social interaction may appear odd, repetitive, or unusual. They may have poor social skills and often have difficulties understanding the unwritten social rules of friendships and joining in, and can lack an understanding of acceptable social behaviour or an awareness of others' feelings.

Communication



Difficulties in verbal and non-verbal communication are another common feature of ASD. Some individuals with ASD may not speak at all, some might have limited speech or be echolalic (i.e. mimicking words or phrases in a repetitive way), while others are able to speak in full sentences. Some individuals with ASD might have a very large and impressive vocabulary, but struggle with the social use of language. Many display disordered or unusual speech patterns, or talk excessively about a limited range of topics or an area of special interest. Complex instructions, jokes, satire and emotional situations may be difficult for individuals with ASD to understand. Non-verbal communication (such as body language, facial expression or tone of voice) is often very confusing for individuals with ASD, and they often need explicit teaching in how to interpret and understand non-verbal communication.

Imagination / Flexibility of Thought



Individuals with ASD may use toys and objects in unusual or repetitive ways. Objects are often used for sensory stimulation, and may be used for spinning, lining up or flicking. Children on the spectrum tend to find it difficult to play creatively with toys and to join in the pretend play of others. While they may have difficulties joining in the imaginary play of others, individuals with ASD can be imaginative and create elaborate imaginary worlds, but they have difficulty allowing others to join their games and it is usually on their own terms and by their own rules. The imaginative play of individuals with ASD is often restricted, repetitive, and limited in interest.

Restricted repertoire of activity and interest



Individuals with ASD may develop certain routines or "rituals" to help them cope with their confusing environment. These routines and rituals may impact on the individuals' flexibility and as a result they may become very resistant to change. Sometimes individuals with ASD may develop ritualistic body actions or obsessive behaviours to help them cope with sensory or emotional overload. They may develop obsessions with particular objects, places or subjects. They may develop repetitive or stereotyped body actions like hand flapping or toe walking.

Subtypes of Autism Spectrum Disorders

Autism Spectrum Disorders (ASDs) are classified as a group of conditions that vary on a continuum, also referred to as the "spectrum". ASDs are neurodevelopmental disorders that cause substantial impairments in social interaction and communication and are associated with unusual behaviours and interests. There are several diagnostic subtypes of ASD.

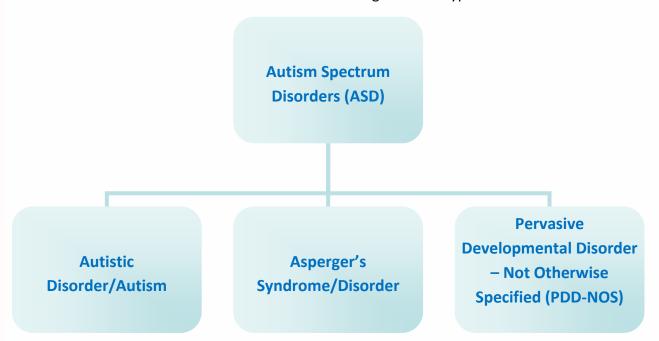


Diagram 1: Autism Spectrum Disorder includes Autistic Disorder/Autism, Asperger's Syndrome and Pervasive Developmental Disorder – Not Otherwise Specified

Autistic Disorder/Autism

In Autistic Disorder, or Autism, the impairments in the social and communication areas are severe and sustained and present before the age of three years (although they may not receive a diagnosis by this age). There is likely to be a restricted range of activities and interests. Autism is sometimes referred to as classic autism. Speech delay is a core feature of Autism. Individuals with Autism may also have an intellectual disability.

Asperger's Syndrome/Disorder

There can be severe and sustained social impairments, but impairments are not as severe in the communication area and language generally develops at the typical age. However, individuals may still have difficulties with the unwritten rules of communication (e.g. turn-taking, engaging in conversation, literal interpretations). There is likely to be a restricted range of activities and interests. The impairments seem less obvious in the very young child, and become more apparent when the individual is in preschool or school. Individuals with Asperger's Syndrome may have an average or above average IQ.

Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)

Individuals may be diagnosed with PDD-NOS if they have some characteristics of ASDs that impact their daily life, but do not meet the criteria for a diagnosis of Autism or Asperger's Syndrome. PDD-NOS is also known as Atypical Autism.

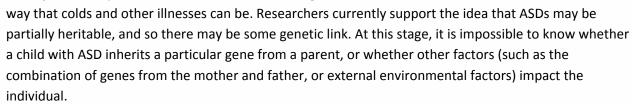
Myths and Misconceptions about ASD

Myth: Autism Spectrum Disorders are reversible.

Reality: Currently, Autism Spectrum Disorders are not thought to be reversible or curable. With individualised therapy and effective supports, symptoms of ASD are managed to ensure the person leads a happy and productive life. However, the diagnosis of ASD will not 'disappear' or cease to be accurate.

Myth: Autism Spectrum Disorders are contagious.

Reality: Autism Spectrum Disorders cannot be 'caught' in the



Myth: People with Autism Spectrum Disorders are always gifted in one area.

Reality: Only a small number of people with Autism Spectrum Disorders 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 ASD has a special skill, but this is not the case. There is no need to be alarmed if your child does not display exceptional skills in an area of their development.

Myth: Children with Autism Spectrum Disorders are always very attractive in appearance.

Reality: Because ASDs do not have physical characteristics like some other disabilities, it is difficult to detect if a person has an ASD from just looking at them. There are many anecdotal reports suggesting that people with ASD (especially children) are unusually attractive in their appearance, but no scientific research supports this.

Myth: ASD is caused by vaccinations given to children when they are around 18-24 months old.

Reality: There has been much 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. To date, scientific research has been unable to find any conclusive link between receiving the MMR vaccine and consequently developing ASD. 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.

Myth: ASD is caused by something parents did or didn't do.

Reality: ASDs are not caused by a particular parenting style, by the actions of parents, or something the mother did while she was pregnant. While we don't know exactly what causes ASDs, we know that these theories and others like 'cold parenting cause autism' are definitely untrue.

Myth: The characteristics of an Autism Spectrum Disorder stay the same throughout a person's lifetime.

Reality: ASDs are considered a developmental disability, meaning they impact development and continue throughout the person's life. However, this does not mean that the presentation of symptoms will remain the same across the lifespan. The presentation and characteristics of ASD can change throughout the person's life as they grow and develop areas of skill and interest.

Myth: People with ASDs don't want to make friends and don't like interacting with others.

Reality: People with ASDs are often unsure how to approach others or develop an appropriate friendship, despite a strong desire to interact with people and have meaningful relationships. They may find it very hard to 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

Frequently Asked Questions (FAQs)

What is the prognosis for an individual with an ASD?

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, many gains can be made and individuals with ASDs can live a meaningful and fulfilling life.

Do ASDs co-exist with other conditions?

ASD can occur by itself or in association with other disorders such as intellectual disability, anxiety disorders, learning disability, epilepsy, Fragile-X syndrome, mood disorders, sleep disorders and others.

How common are ASDs?

ASDs affect at least 1 in 160 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. The ratio is around 4:1 and 8:1 for Asperger's Syndrome.

What causes ASDs?

The cause of ASD is unknown. There is evidence that genes play an important role in the cause of ASD; however it is likely that there are multiple genes involved. Specific genes for ASDs have not been conclusively identified. There is no medical or genetic screening or diagnostic laboratory test for ASDs; diagnosis is based on the presence of particular behavioural patterns.

Do all individuals with an ASD also have an intellectual disability?

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 intellectual disability 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 intellectual disability (thought to be around 70%), there are many individuals with ASD who are of average or above average intelligence.

Individuals with ASD often display an uneven pattern of abilities. They may score below average in some areas of cognitive ability, such as non-verbal skills or adaptive behaviour skills, but score in the average range or above average in others, for example working memory or verbal comprehension.

The diagram below shows that some people may have an ASD without an intellectual disability, others might have an intellectual disability without having an ASD, and some individuals have both an ASD and an intellectual disability.

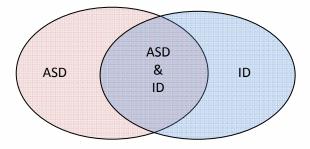


Diagram 2: some individuals have only ASD, some have only an Intellectual Disability, whilst some have both.

Can individuals with ASD be taught to communicate?

Individuals on the spectrum vary in their communication skills. Some may never develop language. Others might acquire in simple language, whilst others still will develop meaningful, fluent, and effective language. Communication skills, including effective language and speech, can be taught using signing, symbols, printed word, photos, verbal communication, picture exchange systems or any combination of these for some individuals on the spectrum. For many individuals these supports will aid the development of language. As the autism spectrum is quite broad, there are some individuals with ASD who may not develop speech but develop the ability to communicate through these alternative communication methods.

Can children with ASDs go to a mainstream school?

Yes, all children with ASDs are entitled to go to a mainstream school. Some children with ASDs may qualify for some extra funding, which the school can use to help the children, for example by employing an integration aide or getting some help from a psychologist, speech pathologist or other professional. Some children with ASDs may qualify to go to autism-specific schools in their region. Children with



ASDs who also have an intellectual disability may qualify to go to Special Schools or Special Developmental Schools. If you are a parent, choosing a school for your child is a very personal decision. You may want ask advice from other people, but ultimately you will need to decide what is best for your child.

(See also Autism Victoria's Information Sheets on schooling online.)

Can medication be useful with individuals with ASD?

Medication has no specific role in treating ASD itself. However, some individuals with ASD may exhibit severe behaviour patterns or high levels of anxiety, develop epilepsy or become depressed. In such cases medication has a role in the treatment of these specific conditions and should be prescribed by a practitioner familiar with ASD.

What if I am an adult and believe I have an ASD, should I get a diagnosis?

With more awareness and understanding in the community around ASD, many adults may wonder whether they have an ASD and consider getting a diagnosis. For many adults the diagnosis of a child with an ASD prompts them to reflect on their own lives and seek further information about a diagnosis for themselves. 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. 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.

How do adults with ASD access day placement, supported accommodation and respite?

The Department of Human Services (DHS) funds all of these services. In order to access them individuals and/or families must contact the DHS – Disability Intake and Response on 1800 783 783. The first step with DHS is to be included on the Disability Support Register (DSR); information about this is available on the DHS website www.dhs.vic.gov.au. Commonwealth Respite & Carelinks Centres provide knowledge about a range of respite services available and how



to access them, further information is available on www.commcarelink.health.gov.au or via phone on 1800 052 222.

How can I help someone with an ASD?

Anyone can help someone with an ASD. It all begins with patience, knowledge and understanding around ASDs. 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 an ASD include taking the time to listen and communicate with the person, minimise any stressful scenarios, read ASD-related books to help grasp a better picture of the disorder.

Getting an Assessment or Diagnosis

If you are worried that you, your child, or other family member, may have an Autism Spectrum Disorder (ASD), 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.

Some or all the following specialists 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 an ASD is an adult, then this will usually be a psychiatrist. If the person who may have an 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 ASDs, and it is important to determine if someone has an ASD or one of these other conditions. Some of these conditions may be treatable. There are also some medical



conditions that can occur alongside ASDs, 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 ASDs themselves, but ASDs 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 ASDs, but individuals with ASDs, 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 ASDs, 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 ASDs. These tests are important to determine the relative strengths and weaknesses 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 ASDs 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 ASDs. 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 ASDS, especially young children, often due to difficulties in getting them to pay attention and understand and follow instructions. However, psychologists with experience in ASDs 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 ASDs 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.

Other Professionals that May be Involved in an Assessment:

Occupational Therapists:

Occupational therapists (OTs) are not always involved in the assessment of individuals who may have ASDs, but they may be involved. 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 ASDs can often be over-sensitive or under-sensitive to this information, or have a combination of both over-sensitivity and undersensitivity. 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 pain.



Neurologists:

Neurologists are not usually involved in diagnosing ASDs, but paediatricians or psychiatrists may refer individuals for assessments by neurologists to test for other conditions or underlying causes that may be associated with ASDs. 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 ASDs 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.

ASDs are 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 ASDs. 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 ASDs, 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 ASDs may appear to be deaf because they do not respond when people call their names.

Some individuals with ASDs 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 ASDs.

Information about funding options

Funding Options

There are various funding options for individuals with an ASD. The individual must meet specific criteria to be eligible and this information differs across organisations and federal/state bodies.

The table below provides a guide for individuals, parents and carers. Please refer to the contact details for further information.

Organisations	Contact	What is this?	Child 0-6 yrs	Primary Age 6-13 yrs	Adolescents 13-15 yrs	Adults 16+ yrs
Helping Children With Autism Package (HCWA) – Autism Victoria Advisors	1300 424 499	Federal funding package for Early Intervention	Apply before age 6	×	×	×
Early Childhood Intervention Services (ECIS)	03 9637 2000	State funded Early Intervention	1	×	×	×
Medicare Benefits (factsheet available from Autism Victoria)	1300 308 699	Subsidised medical costs	1	✓	✓	✓
DEEWR	1300 363 079	Child care rebate	1	×	×	×
DEECD	1800 809 834	Program for students with a disability	×	1	√	(within secondary school capacity)
Association of Independent Schools of Victoria (AISV)	03 9825 7200	Funding for Students with Disabilities	×	✓	✓	(within secondary school capacity)

Continued on next page...

Organisations	Contact	What is this?	Child 0-6 yrs	Primary Age 6-13 yrs	Adolescents 13-15 yrs	Adults 16+ yrs
Centrelink (Carers Allowance)	13 27 17	Federal fortnightly allowance for primary carers of individuals with a disability	•	•	•	✓
Centrelink (Carers Payment)	13 27 17	Federal fortnightly payment for primary carers of individuals with a disability (means tested)			*	✓
Centrelink	13 27 17	Disability Support Pension (DSP) A pension for individuals with a disability who are unable to work full-time	*	*	*	*
DHS (Disability Information & Support)	1800 783 783	Individual Support Package (ISP)	×	✓	✓	✓
DEECD (ECIS)	(03) 9637 2000	Flexible Support Package (FSP)	✓	(Prior to school entry)		×

What Does Autism Victoria do?

Autism Victoria trading as Amaze provides information, advice and support for individuals, families/carers, professionals and the greater community affected by Autism Spectrum Disorders. The information aims to assist throughout the lifespan ranging from early childhood, primary years and adolescence through to adulthood.

amaze knowledge providing learning opportunities	National Registered Training Organisation (RTO) providing Certified Training Courses and tailored professional development	amaze accreditation ensuring quality outcomes	National accreditation system for organisations and services to promote a high level of ASD competency
infoline 1300 308 699	Free phone support for individuals, parents and families	adviceline 1300 598 272	Free phone support for health professionals, education and employment services
1100	Information sessions, workshops, seminars, professional development		Administration of FaHCSIA "Helping Children with Autism" funding in Victoria
amaze fulfilling life's potential	Membership – providing benefits for individuals and professionals	ESPECTRUM WITH STREET	A range of information services: Autism Library, online information, fact sheets, quarterly Spectrum magazine, eSpectrum newsletter
Victorian Autism Conference	Biennial Victorian Autism Conference in Melbourne and around the state		Specialist counselling service to assist individuals, parents and families
	Products to assist individuals with ASDs and help promote awareness		In-house directory of services containing details of autismaware services for those affected by ASDs

Helpful Victorian Websites

Autism Victoria trading as amaze

www.amaze.org.au

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

Early Childhood Intervention Services

http://www.education.vic.gov.au/ecsmanagement/intervention/default.htm

Early Childhood Intervention Services (ECIS) support children with a disability or developmental delay from birth to school entry and their families. ECIS provides special education, therapy, counselling, service planning and coordination, assistance and support to access services such as kindergarten and child care.

Department of Education and Early Childhood Development

www.education.vic.gov.au

The Department of Education and Early Childhood Development brings together a range of 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

http://raisingchildren.net.au/autism

This is the national Australian Parenting Website. The Autism section of the site provides information about ASDs 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

The Better Health Channel 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. Information on the Better Health Channel is provided to help people stay healthy or understand and manage their health and medical conditions. It does not replace care provided by medical practitioners and other qualified health professionals.

Olga Tennison Autism Research Centre

http://www.latrobe.edu.au/otarc/

The Olga Tennison Autism Research Centre (OTARC) is Australia's first centre dedicated to research into Autism Spectrum Disorders. OTARC was established to advance knowledge of the nature and causes of Autism Spectrum Disorders, as well as to develop and study evidence-based strategies for supporting children and families affected by Autism Spectrum Disorders.

ACT NOW

http://www.med.monash.edu.au/spppm/research/devpsych/actnow/project.html

The Autism Secondary Consultation and Training Strategy (ACT NOW) is funded by the Department of Education and Early Childhood Development (DEECD) in Victoria. The project 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 also aims to promote understanding of ASD in the wider community, and to improve linkages and strengthen partnership. There are a number of useful resources and fact sheets available on the ACT NOW website.

National Autistic Society (UK)

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.

Australian State Autism Spectrum Disorder Associations

ACT: Autism Asperger ACT <u>www.autismaspergeract.com.au/</u>
NSW: Autism Spectrum Australia (Aspect) <u>www.aspect.org.au</u>

NT: Autism NT www.autismnt.com.au/

QLD: Autism Queenland www.autismqld.com.au/

SA: Autism SA www.autismsa.org.au/

TAS: Autism Tasmania www.autismtas.org.au/

WA: Autism Association of Western Australia www.autism.org.au/

Alpha Autism

http://alpha-autism.org.au/

Alpha provides support to individuals aged 14 and over to plan for and live the lifestyle of their choice. Every person is supported to develop and individual plan that includes actions to achieve their own personal goals for employment, recreation, daily activities, independent Living Skills Training and Day centre programs.

Autism Help

www.autismhelp.info

This website is an initiative of Gateways Support Services (based in Geelong, Victoria). The site aims to increase awareness of Autism Spectrum Disorder through providing practical strategies, information and resources to parents, teachers, childcare workers and professionals in the field.

PlayConnect Playgroups

www.playconnect.com.au

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

Early Days Workshops

www.amaze.org.au/earlydays

A national series of workshops for parents of preschool children with ASDs. There is 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 ASDs. All workshops are free.

My Time Support Groups

www.mytime.net.au

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

Positive Partnerships

www.autismtraining.com.au

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

Asperger Syndrome Support Network (ASSN)

www.assnvic.org.au

Asperger Syndrome Support Network (Vic) is a volunteer group of parents, carers, partners, professionals and individuals with Asperger Syndrome, with the goal of providing support to those living with Asperger Syndrome. ASSN runs support groups and seminars, as well as providing resources such as their quarterly newsletter, fact sheets, and library.

Parent Support Groups in Victoria

http://www.amaze.org.au/documents/ParentSupportGroups.pdf

Autism Victoria keeps a list of Victorian parent support groups that have registered with us to let us know they are in operation. Use this link to find a support group in your area.

My Connected Community

http://mc2.vicnet.net.au/

my connected community (mc²) is a virtual meeting place. Here you can connect with people who share your interests. Join a community or start your own community with family, friends or colleagues.

DiVine

www.disability.vic.gov.au

DiVine is an online community. It is for and by people with a disability. The website is published by the Victorian Government. DiVine covers a wide range of topics. You can send us your own articles. You can also leave comments. DiVine has been designed to meet the highest standards in accessibility.

Autism Games

http://www.autismgames.com.au/

This site is for parents and teachers of children with moderate to severe autism. The information on this site describes the objectives of the games found on Whiz Kid Games (see below), a games portal for children with autism. The games are a free resource that aims to help children with ASD to develop independent living skills.

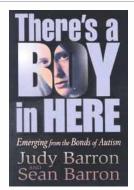
Whiz Kid Games

www.whizkidgames.com/

Whiz Kid Games is the portal through which children with ASD can access games, with parental controls to limit other computer and internet functions. Each game has keywords such as 'special activity' that are reinforced so that in-game learning can be transferred into real world situations.

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 Autism Library contains these and many more other useful books and we recommend that you drop in some time and have a look.



There's a boy in here, by Judy Barron & Sean Barron

Future Horizons, 2002

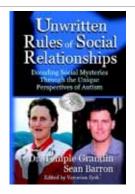
Mother Judy and son Sean both write about Sean's Autism Spectrum Disorder from their own points of view: particular situations are shown from both perspectives which helps the reader to understand what is going on in the mind of someone with an ASD.



The Passionate Mind: How People with Autism Learn, by Wendy Lawson

Jessica Kingsley Publishers

Lawson lays out her theory of Single Attention and Associated Cognition in Autism (SAACA) in simple terms, explaining the disorder in terms of the unique learning style of individuals with an ASD. She suggests that whereas those who are not on the spectrum are able to shift their attention easily from one thing to another, those with an ASD focus very intently on a single theme. Understanding this learning style and accommodating it empower the individual to achieve their full potential. A great book for individuals and families as well as professionals and educators.

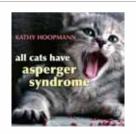


Unwritten Rules of Social Relationships, by Dr Temple Grandin & Sean Barron

Future Horizons, 2004

Grandin and Barron both have an ASD, and in this book, they share 10 important rules of social engagement that they have learned through first-hand experience.

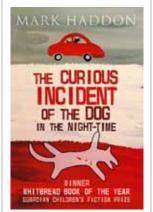
This book will be of benefit to those with a range of developmental, behavioural or learning difficulties.



All Cats Have Asperger Syndrome, by Kathy Hoopmann

Jessica Kingley Publishers, 2006

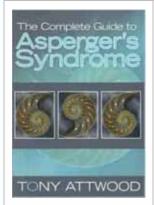
This is a great book to help explain the characteristics of Asperger's Syndrome to children and relatives in a gentle way or to help explain the condition to children themselves. The photos are really lovely.



The Curious Incident of the Dog in the Night time, by Mark Haddon Doubleday, 2003

Winner of the Whitbread Book of the Year 2003 and the Commonweatlth 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 a Although it is not stated that he has an ASD, the cover tells us that he has Asperger's Syndrome.

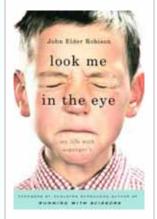
The "curious incident" leads Christopher to try to uncover what happened, resulting in a series of events which are affected by his condition. It is a book that will appeal to teenagers but is equally readable by adults and others with an interest in ASDs.



The Complete Guide to Asperger's Syndrome, by Tony Attwood

Jessica Kingsley Publishers, 2008

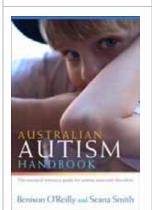
This book is essential reading for those living or working with a child or adult with Asperger Syndrome. It is written in a clear and concise manner, with plenty of examples, practical suggestions and resource lists. It provides a good overview of Asperger's Syndrome.



Look me in the Eye: My Life with Asperger's, by John Elder Robison

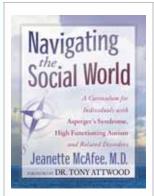
The River's Press, 2007

John Elder Robinson provides a memoir that recounts a life that has been heartbreaking, inspiring and funny in equal measure. He toured with rock bank Kiss at the height of their fame and produced special effects for them whilst shunning their company. He didn't get a diagnosis for his condition until he was 39. Robinson provides some very useful insights about his condition and how he sees the world which will be useful to others with Asperger's as well as neurotypical people who have contact with individuals with Asperger's Syndrome.



The Australian Autism Handbook, by Seana Smith and Benison O'Reilly Jane Curry Publishing, 2008

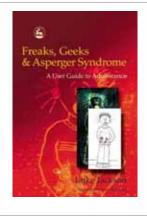
A resource guide written specifically for Australian parents whose children have just been diagnosed with an Autism Spectrum Disorder. It is a practical guide to every aspect of raising a child with an ASD and includes information on assessment and diagnosis, early intervention, the medical theories and school options.



Navigating the Social World, by Jeanette McAfee

Future Horizons, 2002

A curriculum for individuals with Asperger's Syndrome, Autism and related disorders, this resource provides information surrounding some of the key areas that affect people with an Autism Spectrum Disorder. It provides information about a variety of important skills such as how to increase communication skills, recognise and cope with emotions, recognise and prevent stress and develop abstract thinking skills. A good resource that provides both handouts and worksheets as well as knowledge and background.



Freaks, Geeks and Asperger Syndrome, by Luke Jackson

Jessica Kingsley Publications, 2002

Written by 13-year old Luke who has Asperger's Syndrome, this book is great for other young adolescents who are trying to work their way through life. It is a serious book but written in a light-hearted way. The author has 6 siblings, one with ADHD and another with an Autism Spectrum Disorder. The book is beneficial as well as being entertaining.

The Autism Library is at the offices of Autism Victoria trading as Amaze – 24 Drummond Street, Carlton. It is open during office hours – 9am to 5pm Monday to Friday.

Books may be borrowed for up to 4 weeks.

Autism Victoria Trading as Amaze

Office Hours: 9am to 5pm, Monday to Friday				
Main Switch	03 9657 1600			
InfoLine	1300 308 699			
AdviceLine	1300 598 272			
Autism Advisor Line	1300 424 499			
Early Days	1300 307 909			
Family Counsellors	03 9657 1616			
Amaze Knowledge	1300 262 935			
Amaze Accreditation	03 9657 1617			
Fax	03 9639 4955			

Emergency Assistance

NB: We are unable to provide emergency assistance: for urgent help, call:

 Lifeline
 13 11 14

 Parentline
 13 22 89

 Kids Helpline
 1800 55 1800

 Sane
 1800 187 263

Contact us by Email

InfoLine info@amaze.org.au

Autism Advisors teamleader@amaze.org.au
Family Counsellors counsellor@amaze.org.au
Amaze Knowledge info@amazeknowledge.org.au

Training & Education learning@amaze.org.au

Autism Library library@amaze.org.au

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Autism Victoria Inc. ABN 15 600 724 949

Autism Spectrum Disorders: Information Pack

