Autism spectrum disorder (support services)

Summary

- The word ‘autism’ refers to autism spectrum disorder (ASD), including Asperger syndrome.
- ASD can affect a person’s ability to interact with the world around them and lead to repetitive behaviours or a narrow range of interests and activities.
- It can be hard to understand why people on the autism spectrum behave the way they do. Try to remember that the world can be a very confusing place for them and the best way to help is to be supportive and caring.
- Asperger Syndrome is now classified under the single umbrella term, ASD.
- There is no cure for ASD, but by getting advice early and working with your healthcare professional, you can give your child the best possible chance of fulfilling their potential.
- Amaze is funded to help individuals on the autism spectrum, their families and carers who need information about Autism Spectrum Disorder and to understand what supports are available in Victoria. The Amaze InfoLine operates 9am to 5pm Monday to Friday (except public holidays) 1300 308 699

The word ‘autism’ refers to autism spectrum disorder (ASD) and now includes Asperger syndrome. This brain-based condition (where the brain hasn’t developed in the usual way) can affect a person’s ability to interact with the world around them and lead to repetitive behaviours or a narrow range of interests and activities. Individuals on the autism spectrum often have sensory sensitivities – they may be under- or over-sensitive to any of the five senses.

Everyone on the autism spectrum is different and has a unique set of strengths, interests and abilities so trying to understand each person's strengths and needs can take time.

Sometimes it can be hard to understand why people on the autism spectrum behave the way they do. They may in social situations do and say things that make others feel uncomfortable. However, try to remember that the world can be a very confusing place for a person on the autism spectrum and the best way to help is to be supportive and caring.

Although there is no one specific cause, genetic issues and some medical conditions have been identified as possible factors. Someone’s family or social background will never be a reason for developing ASD.

Most people on the autism spectrum are diagnosed in early childhood, but it can be diagnosed at any age by a psychiatrist, developmental paediatrician or psychologist who has experience with ASD.

Read more on the Autism spectrum disorder (ASD) page.

ASD behaviours and symptoms

There is a range of behaviours and symptoms commonly linked with ASD. These may include:

- difficulties with communicating and interacting with other people
- speech and language difficulties
- repetitive and/or behaviours of concern
- strong interest in one topic or subject
- a preference for routines and dislike of change
- unusual reactions to what they see, hear, smell, touch or taste
- intellectual disability (around 50% of individuals on the autism spectrum also have an intellectual disability)
- sleep problems
- attention problems
- anxiety and depression.
Asperger syndrome

Asperger syndrome is a developmental disorder that affects how the brain processes information. It is now classified under the single umbrella term, ASD.

This means that Asperger syndrome will no longer be diagnosed. However, people previously diagnosed with Asperger syndrome, and who identify with this diagnosis, will still be able to refer to their condition as Asperger syndrome.

Read more on ‘Autism-spectrum-disorder - tips-for-parents’ and ‘Autism spectrum disorder and adults’ pages.

Pervasive development disorder (PDD-NOS)

Pervasive development disorder not otherwise specified (PDD-NOS) is a general term for children who may not meet diagnostic criteria for ASD, but who display some characteristics of ASD and there are concerns about their development.

Assessment and diagnosis of autism

A detailed assessment is crucial to making sure an accurate diagnosis is made. It will be carried out by a multidisciplinary team of a paediatrician, psychologist or psychiatrist, and speech pathologist.

Some children will demonstrate signs of ASD by the age of two, but a diagnosis may sometimes not be possible until three or older. There is a significant amount of research indicating that early intervention maximises outcomes and gives children on the autism spectrum the best possible chance of fulfilling their potential.

There are a number of government-funded teams that specialise in the assessment and diagnosis of ASD. Parents can contact these teams directly, but you may need a referral from your GP or paediatrician.

There are also private practitioners and teams who conduct assessments on a fee-paying basis.

The Amaze website provides information on public assessment teams in Victoria.

Support services for people who have autism and their families

A diagnosis of ASD can produce a lot of different feelings and reactions. You may feel an initial period of distress and grief, and this is completely normal. Alternatively, you may experience a feeling of relief as you finally have a diagnosis and you can plan ahead.

There is a range of services and therapeutic treatments available for children and adults who have autism. These include the provision of information and advocacy, assessment, early intervention therapies, help at school, behaviour support, individual support packages, supported accommodation and respite.

Families can also be assisted to learn about autism, to address behaviours of concern and how to access respite.

Research and experience shows that the best treatment approach for ASD is a combination of educational and behavioural strategies that are highly structured and designed to meet the particular needs of each individual. It is important to begin structured intervention as early as possible in the child’s development.

There are a range of different treatment options which you should discuss with your healthcare team. It is also worth doing your own research.

- When searching the internet for information on ASD intervention or therapies, be aware that not all information on the internet is reliable. Check with your doctor or ASD professionals, and be wary of any website that claims a ‘cure’ for ASD. It is a lifelong condition and while there are many therapies and strategies to help support an individual on the autism spectrum, there is no cure.

- The Raising Children Network’s Parent’s guide to therapies available will help you find reliable information about a wide range of therapies and interventions for children on the autism spectrum. Each parent guide sets out what the research says about the therapy, and the approximate time and costs involved.

- Therapy Connect is a resource created by Amaze to help families of young children on the autism spectrum to understand the therapies that are available.

- Other parents who have children on the autism spectrum can be excellent sources of information and support. Amaze has a list of ASD support groups in Victoria. Call Amaze on 1300 308 699.
Changes to who will provide supports to people with autism in Victoria

In Victoria the National Disability Insurance Scheme (NDIS) is available in the Barwon Area and will commence providing individualised support and services for children and adults aged under 65 years in other parts of the state from 1 July 2016. Information on the roll out and how to apply for support from the NDIS is available on the NDIS website.

If you are not currently receiving support you can continue to apply for support from existing State and Commonwealth programs until the NDIS becomes available in your area. See information below on available services and supports.

Developing positive behaviours

Supermarket meltdowns? Mealtime tantrums? Wandering off? Bedtime battles? When you’re the parent or caregiver of a child with a disability, sometimes life can be extra challenging.

There are a number of services that assist parents by teaching them about positive behaviours therapy and practice.

- **Stepping Stones Triple P (SSTP)** has been tailored for parents of children with a disability aged 2–12. It doesn’t tell you how to be a parent. It’s more like a toolbox of ideas. It’s all about making it work for you. Families with children with a disability or developmental delay have free access to selected levels of Triple P’s Stepping Stones parenting program.

- **Aspect Victoria (VIC) Positive Behaviour Support Program** is free to parents/carers of children and young adults diagnosed with autism aged 6 – 25 years of age and living at home. The three tiered program offers:
  - Positive Behaviour Support Workshops - Group training and information.
  - Post Workshop Consultation - Short term additional assistance for families needing support with their individual behaviour support plan following attendance at a workshop
  - **Individual Behaviour Support Coordination** – a ‘wrap around’ team approach provides support to a small number of families with a child or young person with complex needs. Individuals requiring this level of support may be of significant risk of family breakdown.

Challenging behaviours or ‘behaviours of concern’

Behaviours of concern are behaviours that are a barrier to a person participating in and contributing to their community, the behaviours can pose a risk to the health and safety of a person and the community. A person on the autism spectrum may develop behaviours of concern such as self-injurious and anti-social behaviours or dangerous behaviours such as absconding.

A range of services and supports exist to help people on the autism spectrum, their parents, teachers and support staff to get the information and strategies they need to reduce behaviours of concern and develop alternative more positive behaviours.

It is important to determine the function of your child’s behaviour (or the reason why it occurs) to make sure you get help from the appropriate therapist or therapists. For example, if the underlying cause of the behaviour is a breakdown in communication, then a speech pathologist might be needed. If the behaviour is due to difficulties with sensory processing, an occupational therapist might be the best person to work with your child. It could also be that a number of therapists might work together on different areas to address your child’s challenging behaviours.

- Contact the Department of Health and Human Services Disability Intake and Response Service for further information on eligibility criteria and referral pathways for accessing behaviour support services. For direct connection to the Disability Intake and Response Service call 1800 783 783 or TTY 1800 008 149.
- A number of private practitioners and organisations also offer behaviour intervention support on a fee-for-service basis.
- For more information on the behaviour support services or how to find a therapist with experience working with people who have autism visit the Amaze website or the raising children website.

Pre-school years

Get help for you and your family during the early years by accessing a range of early intervention services. These services provide therapies and supports to help young children with autism reach their full potential.

betterhealth.vic.gov.au
Parents and carers of a child on the autism spectrum may also benefit from accessing the following services.

- **Early Days Workshops** – a national ASD workshop program for parents and primary carers. Provides an introductory session and skills workshops on a number of topics – strictly for parents and carers of children ages 0-6 that have an ASD diagnosis or are going through the diagnostic process.
- **Parent Support Groups** – Victorian support groups for ASD and children with disabilities.
- **PlayConnect Playgroups** – ASD-specific playgroups that also welcome younger siblings. Call 1800 790 335.
- **MyTime groups** – groups for mothers, fathers and carers of children with a disability (not specific to ASD), developmental delay or a chronic medical condition. Call 1800 889 997.
- **Respite Care** – your local council or shire services may offer respite care in your home.

**School assistance for children on the autism spectrum**

Preparing a child on the autism spectrum for school can sometimes be a complicated process. Each child has unique strengths and skills and may require a personalised learning and support plan, so the sooner you begin planning the better.

Think about which school might be best and talk to the teachers and staff about your child’s needs. If they are receptive, welcoming and willing to be flexible, book a visit. It is a good idea to go alone on your first visit so you can openly discuss your child’s strengths and needs.

Deciding on the school is only the first step. Staying engaged and providing ongoing support is important so that your child can adjust well to their new environment. Visit the Amaze website for more information on preparing your child for school.

The Victorian Department of Education and Training (DET – formerly DEECD) website also provides information to assist parents of children on the autism spectrum to prepare for the transition to school.

**High school students with autism**

The teenage years can be a difficult time for those on the autism spectrum and their families. Like any teenager, they may have to deal with issues including sexuality, bullying, anxiety, depression and other emotional problems.

It can be hard to know when to start talking about puberty and how to explain some of the changes they are going through. Be as open and as honest as you can and let them know you are there for them all the time, even if they do not want to talk. Visit the Family Planning Victoria website for useful information on sexuality and people with a disability.

Some teenagers on the autism spectrum may be teased and bullied. Find more information on how to support your teenager on the autism spectrum on the Amaze website.

**Leaving school**

Approaching the time to leave school may result in a high level of anxiety for a young person on the autism spectrum and their family as they determine their next steps. There are a number of resources and supports that may be of assistance.

The Department of Education and Training’s Strengthened Pathways Planning for young people with disabilities - Parent Information provides guidance for parents on careers and transition planning for young people with disabilities. Links to relevant information, resources and services are included.

The document can be found at the Department’s website.

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Launchpad is a website that has been created as a resource for young people on the autism spectrum who are leaving school, and their families. Visit Launchpad or Amaze

Adults with autism

Many thousands of Victorian adults are living with ASD in Victoria and across Australia. Some can live independently with minimal help, while others require more support to manage their day-to-day lives.

There is a range of services available to assist adults on the autism spectrum to live as independently as possible and participate in their community. The available services include respite, individual support package, case management, advocacy, employment services and shared accommodation.

Case management sometimes also called service coordination can assist a person with ASD and their family to understand the services available.

For information of services that are available

- Call the Department of Health and Human Services Disability Intake and Response Service call 1800 783 783 or TTY 1800 008 149 for more information on services and supports that may be available or visit the department’s website
- Visit the National Disability Insurance Scheme.
- Respite care – call the Commonwealth Respite and Carelink Centres on 1800 052 222.
- Advocacy – call the InfoLine on 1300 308 699 to find an advocate who can support you in the Victorian health system.
- InfoLine – call 1300 308 699 to find out about different services including employment agencies in your local area.

Where to get help

- Amaze call 1300 308 699
- Commonwealth Department of Social Services, call 1300 653 227
- Department of Health and Human Services Disability Intake and Response Service call 1800 783 783 or TTY 1800 008 149.
- Victorian Department of Education and Training
- National Disability Insurance Scheme

This page has been produced in consultation with and approved by:

Better Health Channel - (need new cp)