

## Autism Spectrum Disorder for Support Workers





In the spirit of reconciliation Premium Health acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respects to their elders past, present and emerging and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

# OUR PROMISE

“

**Premium Quality,  
without compromise.  
It's the Premium Health  
promise.**



**Phillipa Wilson**

Founder & Managing Director of Premium Health

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Contextualised to  
Your Workplace**

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workplaces

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## Welcome to your course and Premium Health.

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The aim of this non-accredited course is to provide a basic introduction to the characteristics of Autism Spectrum Disorder (ASD) and how to support clients with the disorder.

# AUTISM SPECTRUM DISORDER FOR SUPPORT WORKERS

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# WHAT YOU NEED TO KNOW ABOUT YOUR COURSE

## Evaluation of the program

Your feedback is important to us as we use this as part of our continuous improvement cycle. Please undertake our evaluation which will be discussed by your trainer during the course.

## Premium Health's customer service

We offer you an on-going service in relation to first aid information and invite you to call our office on **1300 721 292** or email us on [info@premiumhealth.com.au](mailto:info@premiumhealth.com.au).

For more information about Premium Health's health care, first aid or mental health courses, services and policies, access our website [www.premiumhealth.com.au](http://www.premiumhealth.com.au)

# AUTISM SPECTRUM DISORDER

Autism spectrum disorder (ASD) is a complex developmental disability caused by differences in the brain. This impairs people's ability to learn, behave, communicate and interact with others. ASD is diverse, with no single person with the disorder the same as another.

The clearest definition is that autism - clinically referred to as ASD - is a different way of thinking of an individual, a neurological developmental difference that changes the way an individual relates to the environment and people around them.

Put simply, autism changes the way that people see, experience and understand the world.

For an ASD diagnosis to be made, symptoms need to be evident from childhood and impair daily functioning<sup>1</sup>. Although no two people with ASD are the same, they all will have either one of the following: social and communication impairment and restricted interests and repetitive behaviour.

## SOCIAL COMMUNICATION AND INTERACTION IMPAIRMENT

- Lack of social-emotional responses such as pointing, smiling, showing things to others.
- Lack of non-verbal communication such as nodding and shaking head, using hand gestures.
- Difficulty in developing and maintaining relationships appropriate to developmental level, such as peer play, lack of close friends – this very much depends on the age.
- Delayed speech or unable to speak two words by age two.
- Lack of eye contact when speaking.
- Loss of language skills at any age.

## RESTRICTED INTEREST AND REPETITIVE BEHAVIOURS

- Excessive adherence to routines, patterns or behaviour, distressed at changes.
- Stereotyped or repetitive speech, movements or use of objects, such as rolling wheels before eyes, flapping hands, toe walking.
- Hyper or hypo-reactivity to sensory input such as sound, pain or textures.
- Restricted or fixated interests such as only playing with certain toys or discussing certain topics.
- Aggressive toward other people or toward self.

## The spectrum

ASD is diagnosed according to a checklist in the diagnostic and statistical manual of mental disorders, the DSM. In the past, the DSM categorised people with ASD as having a specific disorder such as: Asperger's disorder, Autistic disorder or Pervasive development disorder not otherwise specified (PDD-NOS).

DSM-5 now combines the three categories into one, which is now called ASD. There are no longer any subcategories to ASD and people will no longer be diagnosed as having Asperger's, Autistic disorder or PDD-NOS, they will all fall under the single term/ diagnosis of ASD.

A typical diagnosis can be made at about 2 years of age, when the individual is not meeting their developmental milestones. But symptoms of ASD can sometimes be subtle and may not become obvious until a child starts school or moves into adulthood. A good example of this is diagnosis rates of ASD in women.



**On average, for every 4 males diagnosed with ASD there is 1 female with the same diagnosis.**

This is because the systems and checks used to measure communication, social skills, interactions and restrictive or repetitive behaviours is modelled off the "classic male ASD symptoms". During developmental years women are better at "hiding" their symptoms, therefore it is common for women to go undiagnosed as their symptoms are put down to something else or completely disregarded. As a result, we see many women with ASD go undiagnosed until early – mid adulthood.

## CHARACTERISTICS OF ASD

Whilst there are some shared characteristics, it's important to remember and respect that ASD presents differently in different people.

ASD is not a physical disability so people on the spectrum look no different to their peers. This can make it difficult for some people to understand why someone with ASD might be behaving or reacting in a particular or unusual way.

Many people with ASD live completely independent lives; others need support in almost all aspects.



Today, ASD can be diagnosed in children aged two years and even younger. Younger siblings of children already diagnosed are being assessed before they are one. Listed below are typical signs of ASD up to 3 years of age.

## SIGNS OF ASD IN INFANTS AND CHILDREN

BY 12 MONTHS	BY 24 MONTHS	BY 36 MONTHS
<ul style="list-style-type: none"> <li>› Does not pay attention to, or is not frightened by new faces.</li> <li>› Does not smile, does not follow moving object with eyes.</li> <li>› Does not babble, laugh and has difficulty bringing objects to the mouth.</li> <li>› Has no words.</li> <li>› Does not turn head to locate sounds and appears not to respond to loud noises.</li> <li>› Does not push down on legs when feet placed on a firm surface.</li> <li>› Does not show affection to primary caregiver, dislikes being cuddled.</li> <li>› Does not crawl, cannot stand when supported.</li> <li>› Does not use gestures such as waving or pointing.</li> </ul>	<ul style="list-style-type: none"> <li>› Cannot walk by 18 months or walks only on toes, cannot push a wheeled toy.</li> <li>› Does not speak; does not imitate actions, cannot follow simple instructions.</li> <li>› Does not appear to know the function of common household objects such as a telephone by 15 months.</li> </ul>	<ul style="list-style-type: none"> <li>› Very limited speech, does not use short phrases, has difficulty in understanding simple instructions.</li> <li>› Has little interest in other children, has difficulty separating from mother or primary care-giver.</li> <li>› Difficulty in manipulating small objects.</li> <li>› Has little interest in 'make-believe' play.</li> <li>› Frequently falls, has difficulty with stairs.</li> </ul>



## PRESCHOOL SOCIAL COMMUNICATION RED FLAGS



- The child generally does not point to or share observations or experiences with others.
- The child tends not to look directly at other people in a social way.
- There may be an absence of speech, or unusual speech patterns such as repeating words and phrases (echolalia), failure to use 'I', 'me', and 'you', or reversal of these pronouns.
- Unusual responses to other people. A child may show no desire to be cuddled, have a strong preference for familiar people and may appear to treat people as objects rather than a source of comfort.
- The child may appear to avoid social situations, preferring to be alone.
- There is limited development of play activities, particularly imaginative play.
- There may be constant crying or there may be an unusual absence of crying.

## BEHAVIOURAL RED FLAGS



- The child often has marked repetitive movements, such as hand-shaking or flapping, prolonged rocking or spinning of objects.
- Many children develop an obsessive interest in certain toys or objects while ignoring other things.
- The child may have extreme resistance to change in routines and/or their environment.
- The child may have sleeping problems.
- The child may be resistant to solid foods or may not accept a variety of foods in their diet.
- There are often difficulties with toilet training.
- The child may be extremely distressed by certain noises and/or busy public places such as shopping centres.



**SCHOOL**

Children are often diagnosed with ASD once they get to school when their social communication and behavioural characteristics mark their development out as different to their peers.

Some of the main social communication and behaviour signs of ASD in middle childhood and adolescence are listed below. These signs often become noticeable when a child reaches school age and has difficulty adjusting to new social situations in a school environment.

- Issues with conversation, perhaps dominating conversations with their favourite topic and not knowing how to take turns.
- Being confused by language and taking things literally – for example, they might be confused by the expression 'Pull your socks up!' and actually pull up their socks.
- Having an unusual tone of voice, or using speech in an unusual way – for example, they might speak in a monotone or with an accent.
- Not being able to interpret the non-verbal communication of peers and adults.
- Being rigid in following rules at school and in sport and games.
- Seeking solitude, and finding being with others very stressful and exhausting.
- Finding it hard to read social cues and the unwritten rules of friendship.
- Having unusual interests and obsessions, no breadth of interests.
- Sometimes there are unusual physical movements, such as touching, biting, rocking or finger flicking.
- Having sensory issues, either heightened or lack of sense of smell, touch, taste, sound and vision.
- Needing to follow routines to feel secure, becoming very upset when expected routines change.
- Having few or no real friends.
- Aggression is sometimes seen, usually as a way of avoiding overwhelming situations.
- Seeking solitude, and finding being with others very stressful and exhausting.
- Anxiety is also common, especially as children enter the teenager years.
- Finding it hard to follow a set of instructions with more than one or two steps.

## Adults with ASD

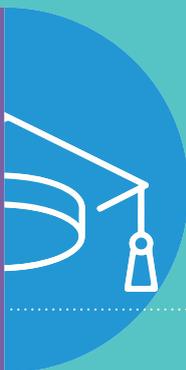
Adult life - with the bosses, co workers, roommates and romantic partners - can be tough enough. Then add the hallmark social and executive-function challenges of ASD.



An estimated 5 percent of adults with ASD have ever been married

Depression affects an estimated **26%** of adults with ASD **3 x the average**

More than half of young adults with ASD remain unemployed and unenrolled in higher education in the two years after high school

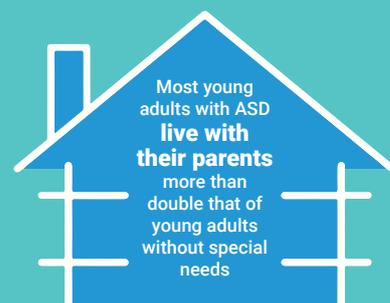


Many young adults with ASD **don't receive any health care** for years after they stop seeing a paediatrician

An estimated one in four to one in five is **unemployed**



Most young adults with ASD **live with their parents** more than double that of young adults without special needs



## ASD SIGNS IN ADULTS

Signs of ASD in adults can be quite different to the signs in a child. Whilst it is common to see similarities, there are some stark differences. This can be put down to very different lifestyles and living situations for the individuals. Numerous individuals who may display the behaviours of ASD, but are not formally diagnosed, learn to cope well with their lives. It is common for adults with ASD to have jobs and satisfying careers, develop meaningful professional and social relationships, be living out of the home with no support and satisfied with their quality of life. However, some adults exhibiting signs of ASD are often aware of being and feeling different.

**Many adults may demonstrate different signs of ASD such as:**

- Problems in obtaining, regularly attending, or sustaining employment or education.
- Difficulty with managing time, completing tasks and staying organised.
- Difficulty making or leading conversations and maintaining eye contact.
- Masking or camouflaging in the crowd or to the backgrounds.
- Extreme interest in one topic and limited interest in others.
- Difficulty in initiating or sustaining social relationships and experiencing social anxiety.
- Challenges with regulating their emotions or reading emotions of others.

- Making involuntary noises, for instance throat clearing.
- Displaying repetitive behaviours such as strange body movements and unusual reactions to the senses of sight, hearing, smell, touch and taste.
- A history of another neuro-developmental conditions (including learning disabilities and attention deficit hyperactivity disorder) or psychiatric difficulties.

As mentioned, we can still see some of the signs of ASD in adults that we see in children, however we need to make further considerations and take additional signs into account. Some adults on the spectrum will experience great challenges in completing their daily activities, whereas others on the spectrum may simply feel like they are different from everyone else. They may have felt like this from childhood and have not been able to identify why, or they may not know that they behave and interact with people differently.

**CAUSES AND PREVALENCE**

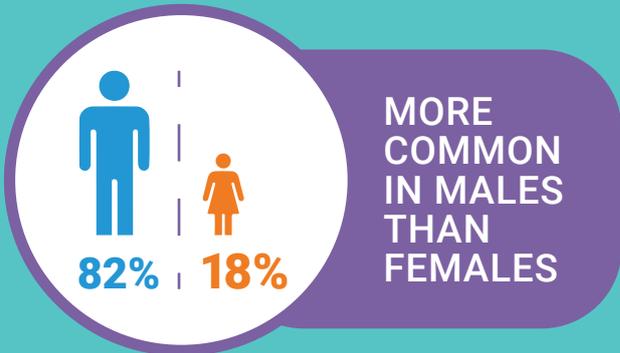
Research shows that about 1 in 100 children have ASD. Currently, there is no single known cause for ASD, however, recent research has identified strong genetic links. ASD is not caused by an individual's upbringing or their social circumstances.

# AUTISM IN AUSTRALIA

## PREVALANCE

# 1 in 100

### AUSTRALIAN CHILDREN



### AVERAGE AGE OF DIAGNOSIS 3-5 YEARS OLD

## WHAT IS THE COST OF AUTISM?

**Cost**  
on average:  
**\$56,000**  
per year

Examples of expenses include:



social services



reduced income



healthcare  
eg. therapies



special education

In children with ASD, there might be early brain overgrowth. This means that the brain grows faster than average therefore different parts of the brain don't communicate with each other in a typical way. Evidence also strongly suggests a genetic basis to ASD. But it's unlikely that one specific gene is responsible. It's more likely that several genes combine and act together. Researchers have found information relating to:

<b>Brain development and ASD</b>	<ul style="list-style-type: none"> <li>➤ In children with ASD, the brain develops differently from typically developing children. The brain tends to grow too fast during early childhood, especially during the first three years of life. And the brains of babies with ASD, appear to have more cells than they need, as well as bad connections between the cells.</li> </ul>
<b>Too many connections between brain cells</b>	<ul style="list-style-type: none"> <li>➤ A young child's brain is developing all the time. Every time a child does something or responds to something, connections in the brain are reinforced and become stronger. Over time, the connections that aren't reinforced disappear – they are 'pruned' away as they're not needed.</li> <li>➤ This 'pruning' is how the brain makes room for important connections – those needed for everyday actions and responses, like walking, talking or understanding emotions. This pruning doesn't seem to take place as much as it should in children with ASD – so information might be lost or sent through the wrong connections. The lack of pruning might also explain why the brain seems to be growing faster in children with ASD than in children with typical development.</li> </ul>
<b>Genetics and ASD</b>	<ul style="list-style-type: none"> <li>➤ Genetic problems seem to play a major part in ASD. These problems can happen in two ways. The first is that something happens during foetal development that alters a gene.</li> <li>➤ The second way is that the child inherits a problematic gene (or genes) from one or both parents. This is why some families have several children diagnosed with ASD, or siblings of children with ASD often show some ASD characteristics. Other family members might also have ASD or show some ASD characteristics.</li> <li>➤ It's unlikely that there's one specific gene that causes ASD. Rather, it might be that several genes combine and act together. Researchers have found many possible genes that might play a role in the development of ASD.</li> <li>➤ It's also possible that different gene combinations might explain the differences seen in ASD – for example, why one child is more sensitive to sounds than another.</li> </ul>
<b>Environmental factors</b>	<ul style="list-style-type: none"> <li>➤ There is no solid evidence to show that ASD can be caused by anything in the environment, like diet (either during pregnancy or once a child is born) or exposure to certain toxins. External factors might trigger ASD in a child who is already genetically prone to developing the condition.</li> </ul>

## DIAGNOSIS

- ASD is diagnosed through an assessment which includes observing and meeting with the individual, their family and service providers.
- Information is gathered regarding the individual's strengths and difficulties, particularly in the areas of social interaction and social communication as well as restricted and repetitive interests, activities and behaviours.
- Such information may be obtained by administering standardised tests or questionnaires.

ASD is usually diagnosed in early childhood, but assessments can be undertaken at any age. There is no single behaviour that indicates ASD.

Currently, there are no blood tests that can detect ASD. Developmental paediatricians, psychiatrists and psychologists with experience in assessing individuals on the autism spectrum are qualified to make a diagnosis.

## Possible outcomes

An early diagnosis followed by early intervention provides the best opportunities for a child with ASD. Early intervention, specialised education and structured support can help develop an individual's skills. Every individual with ASD will make progress, although everyone's progress will be different. Progress depends on several factors including the unique make-up of the individual and the type and intensity of intervention. With the support of family, friends and service providers, individuals with ASD can achieve a good quality of life.

**ASD COMORBIDITIES**

ASD can occur with other genetic conditions. These are called comorbidities. Nearly three-quarters of children with ASD also have another medical or psychiatric condition. Comorbid conditions can appear at any time during a child's development. Some might not appear until later in adolescence or adulthood. Sometimes these comorbid conditions have symptoms that affect how well ASD therapies and interventions work. So, it's important to identify the conditions and treat them separately.

**Anxiety**

People with anxiety have a range of symptoms including tension, restlessness, hyperactivity, worry and fear. For people with ASD, anxiety might show up as self-stimulating more often, asking questions over and over again, hurting themselves, or having trouble getting to sleep. Anxiety is common among people with ASD. Up to 84% of people with ASD have anxiety symptoms. Anxiety can happen at any age, but older children and those with less severe ASD are more likely to be anxious.

**Attention deficit hyperactivity disorder (ADHD)**

Attention deficit hyperactivity disorder (ADHD) can cause people to act before they think and have trouble focusing and sitting still. Generally, all three behaviours happen together but some people can be mainly inattentive. Many people have trouble with sitting still and focusing. But for those with ADHD, this behaviour is extreme and has a big impact on their daily life.

**Bipolar disorder**

Bipolar disorder is a psychiatric condition. People with bipolar disorder have both extreme emotional highs (mania) and extreme lows (depression). The depression can be obvious – the person will probably have low mood, lack of motivation, trouble sleeping and poor appetite. Mania can be harder to spot. Its symptoms include extreme self-esteem, less need for sleep, and being more talkative and active than usual. Children who have bipolar disorder have big and quick changes in mood and behaviour. When they're going through these mood changes, they might also have trouble paying attention, sitting still and behaving appropriately.

**Clinical depression**

Symptoms of depression include low mood, poor sleep and appetite, irritability and a loss of motivation. In children, depression symptoms can also be cranky moods rather than just sadness and low moods.

Depression is common among people with ASD. Symptoms of depression have also been associated with more severe characteristics of ASD, older age and higher verbal IQ.

**Down syndrome**

Down syndrome is a genetic disorder. Most people have 23 pairs of chromosomes. People with Down syndrome (also called Trisomy 21) have an extra 21st chromosome. This causes characteristic facial features, developmental delays, poor muscle tone, potential hearing and vision problems and congenital heart defects. Down syndrome can be identified with tests during pregnancy. If it isn't picked up then, it's usually diagnosed at birth or in early infancy. Studies have shown that up to 17% of people with ASD have Down Syndrome.

**Fragile X syndrome**

Fragile X is a genetic disorder. It's the most common cause of inherited intellectual disability. Most boys with this condition have an intellectual disability, sometimes severe. In the early years this would be noticed as developmental delay. In girls the condition generally looks like a learning disability rather than intellectual impairment. Children with the condition have trouble communicating. Although ASD is relatively common in children with Fragile X (25-33%), Fragile X happens much less frequently than ASD. This means that only about 2% of people with ASD also have Fragile X.

## Other common co-morbidities for people with ASD include:

<b>Gastrointestinal symptoms</b>	<p>The most common gastrointestinal symptoms for people with ASD are chronic constipation, abdominal pain, diarrhoea and faecal incontinence. Other problems can include gastro-oesophageal reflux disease (GORD) and bloating of the abdomen. Autistic children are more likely to have gastrointestinal (GI) problems than typical children are, but no more so than children with other brain conditions.</p> <p>About 40 percent of children with any of a variety of developmental conditions have GI troubles such as constipation, abdominal pain and diarrhoea, compared with about 25 percent of typical children.</p>
<b>Intellectual disability</b>	<p>Intellectual disability can be diagnosed when a child six years or older has an IQ below 70 as well as difficulties with daily tasks. In children under six years, the term 'developmental delay' is used for children with significant cognitive and language delays. Intellectual disability varies from person to person. Children with ASD and intellectual disability might have uneven skills, so there are some things that they're quite good at and others they find hard.</p>
<b>Obsessive-compulsive disorder (OCD)</b>	<p>OCD is a type of anxiety disorder. People with OCD have thoughts that they don't want but can't get out of their heads. They behave in repetitive and compulsive ways to deal with these thoughts. For example, they might wash their hands over and over again, or arrange or count objects in patterns, as a way of cancelling out bad thoughts with good thoughts. OCD is common among people with ASD. People with ASD also tend to have repetitive thoughts and behaviour.</p>
<b>Seizures and epilepsy</b>	<p>Epilepsy is when a person has two or more attacks of abnormal electrical activity in the brain. The nerve cells of the brain release uncontrolled and unpredictable electrical charges and cause odd sensations and abnormal movement or behaviour. These are called convulsions or seizures. When a person has a seizure, there's usually a temporary period of unconsciousness, a body convulsion, unusual movements or staring spells. It can be hard to notice epilepsy in people with ASD because seizure symptoms can be like some ASD characteristics, like failing to respond to your name or doing repetitive, tic-like behaviour. Epilepsy is quite common, and 20-30% of people with ASD also have epilepsy.</p>
<b>Sensory overload</b>	<p>Signs of sensory sensitivities include:</p> <ul style="list-style-type: none"> <li>• avoiding certain textures, tastes, sounds and smells</li> <li>• eating a limited diet</li> <li>• preferring to be naked or being rigid about clothing</li> <li>• placing hands over ears</li> </ul> <p>Up to 76% of young children with ASD might have sensory sensitivities. This is because many children with ASD experience the world very differently from typically developing children. Their brains process information from the senses differently. They can be extremely sensitive or insensitive to touch, sight, smell, taste, sound, pain or temperature. The most common sensory sensitivities are over reactivity to sound and under reactivity to pain.</p>
<b>Sleep problems</b>	<p>The most common sleep problems in children are insomnias – that is, trouble falling asleep and staying asleep – and parasomnias, which include nightmares, night terrors and sleepwalking. Sleep difficulties are common among people with ASD. About two-thirds of people with ASD might have a sleep problem at some time.</p>
<b>Tourette syndrome</b>	<p>Tourette syndrome is an inherited brain disorder. People with Tourette have many movement-based tics and one or more vocal tics. These tics are sudden, repetitive and involuntary. Tourette syndrome is common among people with ASD. One study found that 11% of children and teenagers with ASD had Tourette syndrome (vocal tics and motor tics) and a further 11% had motor tics.</p>

**DIAGNOSIS AS AN ADULT**

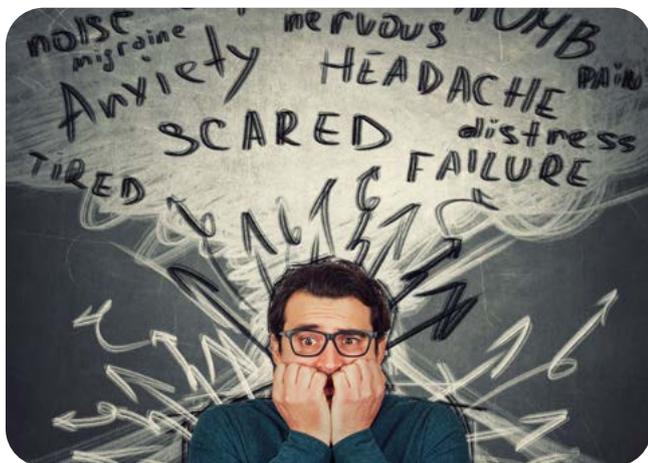
A diagnosis of ASD may offer some benefits socially, economically and mentally to the individual. By receiving a diagnosis, they are able to receive appropriate funding, services and additional support they may need in their workplace and education environments. Their colleagues, friends and family will have a better understanding of their needs and it may allow them to support the person more efficiently. The person may also develop a greater sense of self identity and gain an increased sense of confidence, knowing that they are a part of a large group of like-minded adults.

If an adult seeks an assessment for ASD, they should consult with their GP or qualified health professionals with experience in the assessment and diagnosis of autism such as a psychologist and/or psychiatrist. The process involves gathering information about the individuals medical and health history, developmental and educational history as a child, their experiences at school and noted signs and symptoms relating to ASD. A speech pathologist can be consulted as well to assess the person’s social communication skills.

**The commonly used diagnostic criteria for the diagnosis of ASD throughout Australia are:**

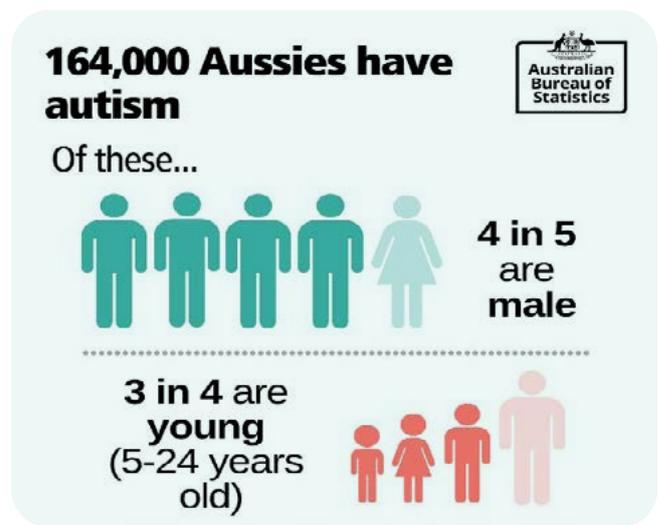
- American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (currently in its fifth edition – DSM-5)
- The World Health Organization’s International Classification of Diseases (currently in its 11th edition – ICD-11)

These require health professionals to assess for the symptoms of ASD and its impact on an individual’s life and to specify the presence and extent of intellectual and language impairment, along with the impact on numerous areas of functioning. This information can help clinicians in making a diagnosis and identification of support needs and considering other associated ASD comorbidities.



**However, obtaining an ASD diagnosis as an adult is not always a straightforward process. There are a number of reasons for this:**

- It can be difficult for adults with suspected ASD to find a specialist psychiatrist to diagnose and treat their condition.
- Most assessment tools used for the diagnosis of ASD in adults and children are similar, however the ways symptoms are assessed against the criteria can be quite different depending on your age.
- Individuals may be unable to recall details from their childhood that would provide clues as to the likelihood of ASD and parents may not be alive or available to contribute to the consultation.



Information source: <https://www.abs.gov.au/ausstats/abs@.nsf/Previousproducts/4430.0Main%20Features762015?opendocument&tabname=Summary&prodno=4430.0&issue=2015&num=&view=>

If an individual does get diagnosed with ASD, it can be quite emotionally demanding for them, therefore, post-diagnostic support is important such as counselling services to suggest what support services, strategies and interventions are available to access, training and workshops about autism and vocational support.

## AGEING WITH ASD

It is reported that 1 in 100 people in Australia are diagnosed with ASD. There is now an emerging awareness that as the population ages the people who were diagnosed as a child with ASD in the 1940's and 1950's, or have been more recently diagnosed as an older adult, are now starting to need additional support.

For many adults with autism, ASD is an essential part of their identity and does not require additional support, however for some other individuals with ASD they may require extra services and support.

Service providers, researchers and families are now recognising the persistent need for a better understanding of ASD as a life-long developmental disability, and not simply as a childhood condition. Individuals who are diagnosed with ASD as children ultimately enter adulthood and many require ongoing support services.

Adults with ASD can face significant challenges, many of which are caused by the fact that our communities are often not set up well to accommodate and accept differences and disabilities. The range of experiences of adult life varies wildly, of course. In many families, a young adult is very dependent on family care and support.



**Until recently, little was known about the prevalence and progression of ASD among the adult population. Researchers have begun to find answers to some frequently asked questions:**

- › What are the likely life course outcomes for young people with ASD moving into adulthood?
- › Can children diagnosed with ASD 'grow out of' the condition as adults?
- › What are the best ways to identify and diagnose ASD in adults for the first time?
- › Do people with ASD have a shorter than average life expectancy?



The world's first nationwide study into the prevalence of ASD among adults was carried out in the United Kingdom in 2007<sup>2</sup> led by the National Centre for Social Research (NatCen) in collaboration with the University of Leicester. Some of the key findings from the study, and their implications, are described below.

- › ASD is as common in the adult population as it is among children, which contradicts the idea that people can eventually 'grow out of' ASD.
- › Rates of ASD were found to be generally constant across adult age groups, meaning there is no evidence that individuals affected by ASD have a shorter than average life expectancy.
- › The presence of ASD was associated with being unmarried, living in social housing and/or in deprived areas, having a lower verbal IQ and holding lower-level educational qualifications.

**MYTHS ABOUT ASD VS TRUTH**

- People with ASD do not want to socialise or make friends.
- Individuals with ASD cannot learn or work.
- ASD is caused by bad parenting.
- People with ASD do not experience different emotions.
- All people with ASD exhibit violent behaviours.

# Myth conceptions vs Truths

As you probably know, there are many myths and misconceptions about autism. By spreading awareness about the realities of autism, together we can create a more inclusive world.

**Myth: Autism is a form of intellectual disability**

**Truth:** While intellectual disability and autism do sometimes co-occur, autism is not an intellectual disability. Many people on the autism spectrum have normal to high IQs but learn differently to others.

**Myth: All autistic people are violent**

**Truth:** People on the autism spectrum are far more likely to be the victims of others' aggression.

**Myth: There is a simple spectrum of autism with 'high functioning' at one end and 'low functioning' at the other**

**Truth:** This is a simplification. The risks are that we overlook the support needed for people described as 'high functioning' and underestimate the potential of people described as 'low functioning'.

**Myth: You can't be autistic because you talk/make eye contact/are a girl**

**Truth:** Autism occurs in all populations and expresses differently in each individual.

**Myth: People on the autism spectrum don't experience emotions**

**Truth:** People on the autism spectrum experience the full range of human emotions, but may show their emotions in their own way.

**Myth: Autism is something to be ashamed of**

**Truth:** Autism, disability or difference, is never anything to be ashamed of. For many autistic people, autism is an important part of their identity and a simple fact like hair colour.

**Myth: "Everyone is a little bit autistic" (when this is said as a means to diminish the challenges faced by people on the spectrum)**

**Truth:** Most people find at least some typically autistic experiences a bit understandable and relatable. Although it is good to try to find ways to connect with people, don't dismiss the isolation, discrimination, stress or disrespect that people on the autism spectrum can experience. Autistic people often feel their problems aren't taken seriously enough, and phrases like the above can contribute to this.

**Myth: Everybody on the autism spectrum has a special skill like Dustin Hoffman's character in Rain Man**

**Truth:** Although every person on the autism spectrum has their own strengths and interests, less than one third have what are known as 'special skills'.

These were developed in conjunction with people on the autism spectrum.



1800 AUTISM (1800 288 476)  
www.autismspectrum.org.au



## EARLY INTERVENTION

There are several different methodologies for early intervention but only one golden rule: be intensive.

The Australian Government's own "Guidelines for Good Practice" recommends a minimum of 20 hours a week of ASD-specific early intervention. Unfortunately, most Australian children currently receive nothing close to this amount. This early intervention has been proven to provide the best outcomes.

Behavioural interventions are grounded heavily in learning theory: they are developed on the belief that most human behaviour is learned through the interaction between an individual and their environment. Behavioural interventions aim to teach and increase targeted positive behaviours and reduce or eliminate inappropriate or non-adaptive behaviours. Applied Behaviour Analysis (ABA) and Discrete Trial Training (DTT) continue to constitute the core features of most behavioural intervention programs.

PBS is for anyone with behaviour difficulties, including those with ASD. The approach can also be used with people with intellectual, learning, developmental and social difficulties. The main goal of PBS is to reduce difficult behaviour.

The idea behind PBS is that all behaviour serves a purpose. Difficult behaviour can be reduced if we know what children are trying to achieve by behaving in particular ways.

The PBS approach aims to teach children more positive and socially appropriate ways of communicating and getting what they want – for example, using words or signs to communicate.

**The key feature of a PBS approach is an individualised plan that is:**

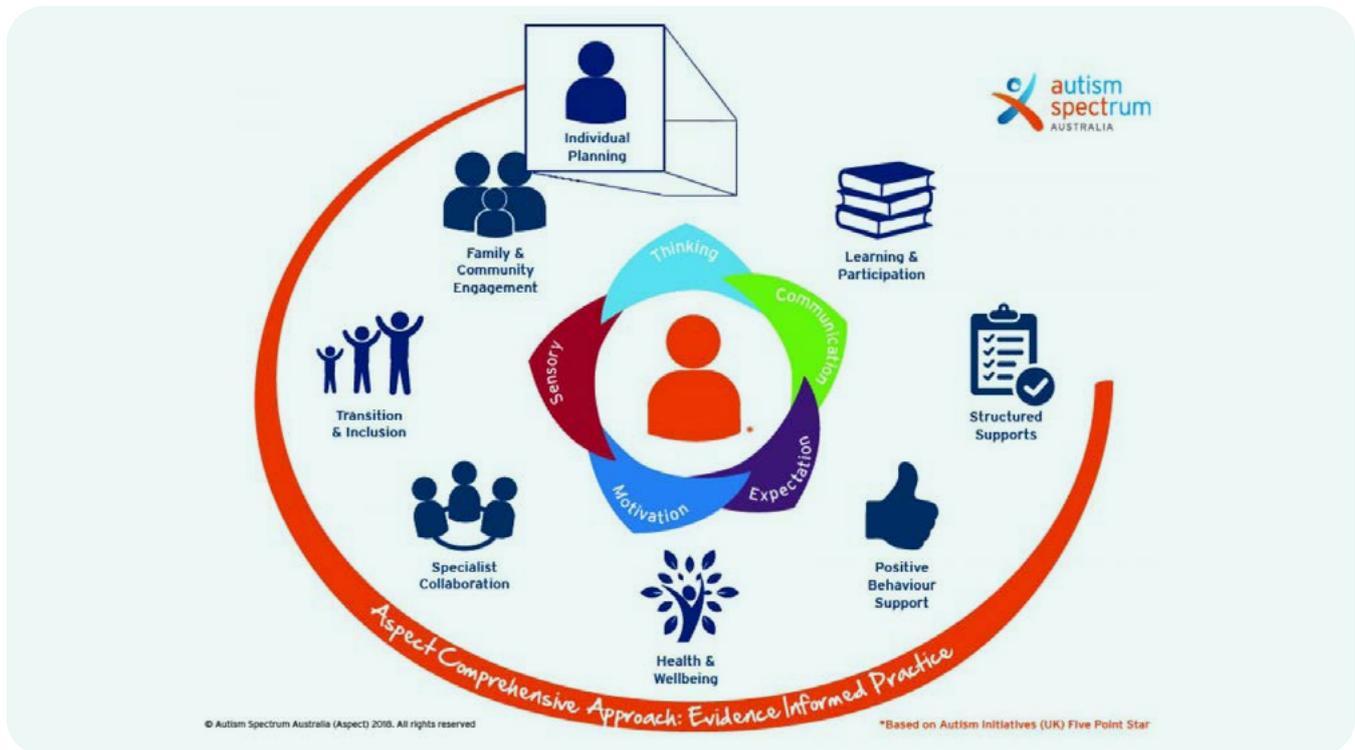
- implemented by everyone involved with a child on a day-to-day basis
- used in the natural environment where a behaviour occurs

## APPLIED BEHAVIOUR ANALYSIS (ABA)

- ABA is often called Early Intensive Behavioural Intervention (EIBI). In ABA programs, each child's strengths and weaknesses are assessed and then a comprehensive program is created for the child. Things that need to be learned – like saying words, learning non-verbal gestures, playing with toys and then peers, washing hands, eating etc. – are broken down into tiny steps and then taught systematically, little by little.
- Children's difficulties are also approached using a slow but steady approach. Many children hate having haircuts or fear supermarkets and these sorts of issues can be improved slowly over time. To be considered ABA, a program must be intensive, with 20 – 40 hours of therapy taking place each week in addition to the family using the same methods and working on the same activities in non-therapy hours.

## POSITIVE BEHAVIOUR SUPPORT (PBS)

- PBS emerged in the 1980s, evolving from ABA. Both PBS and ABA are based on 'learning theory', but PBS developed with a stronger focus on being person centred or family centred. Learning theory suggests that how people behave in a situation depends on their previous experiences of similar situations.
- PBS is an individualised and comprehensive approach that parents and carers use to teach and encourage children to behave in appropriate ways. The approach makes difficult behaviour unnecessary by removing the things that trigger, encourage or reward that behaviour. It also teaches children alternative, more appropriate behaviour to replace the difficult behaviour.



Information source: <https://www.autismspectrum.org.au/how-can-we-help/going-to-school/other-education-services/individual-planning>

### Support services for adults with ASD

Just like anyone, adults with ASD need a network of support services at certain stages of adulthood to enrich their lives. The federal, state and territory governments and the local ASD associations provide a range of support services including employment, accommodation and housing, interest groups, tertiary education, health and wellbeing to assist individuals with with ASD. These services are funded through the NDIS.

### Accommodation and housing

For those individuals with ASD who want to live independently, numerous accommodation and housing support options are available such as specially adapted and modified homes, supported rental housing, group accommodations, in-home support and supported independent living. Specialist Disability Accommodation (SDA) and Support Residential Services (SRS) are examples of services available for adults with ASD to manage their accommodation and housing options.

### Recreation, social and interest-based groups

There are numerous recreations, social and interest-based groups designed for adults with ASD to support their strengths and interests, provide opportunities to meet others, develop friendships and explore shared interests within the group. Interest groups include swimming, yoga, train spotting, gem and mineral collecting, bushwalking, music, games, photography, art or social groups that take part in local events and activities such as workshops on general socialising, going to the movies, having dinners or taking part

in local events. Some of the examples of social and interest-based groups are:

- **Asperger's Victoria** enables peer support groups and educational events. It also provides employment readiness resources.
- **Different Journeys** provides with ASD focused, peer-run social platforms for events like inspirational talks, sporting, creative and gaming activities and special-interest discussion forums.
- **Autism Community Network** is a Sydney-based organisation that organises social groups and information events.
- **Neurodivergent Humans** is a Melbourne-based social club for individuals with ASD.

### Day programs and advocacy services

The state and territory governments also offer some routine-based day programs and advocacy services to assist adults with ASD with their education and learning, for example expressing views, making decisions, finding information, looking for a job, budgeting, shopping, meal planning and in some cases how to live independent lives, and using health and social services.

The national organisation that directly represents the people with ASD and their families in Australia is Autism Asperger's Advocacy Australia. Most TAFE campuses and universities have support staff to assist adults with ASD with tertiary studies and accessing any reasonable adjustments for the learning program.

## Employment

**Disability employment service (DES) provides a range of services to support individuals with ASD with:**

- training in specific job skills and preparing for work
- job-search support such as resume development and interview skills
- on-the-job support and assistance from co-workers and employers
- vocational training and access to other workplace modifications
- school leaver employment support (SLES) is an early intervention approach for Year 12 school leavers which is designed to support transition from school to employment

Mentoring programs is the other way for people with ASD to get experience and advice on finding work.

- the Australian Network on Disability (AND) runs a Positive Action towards Career Engagement (PACE) Mentoring Program for people with a disability
- aspect's Capable Employment Mentoring Program offers one-on-one strengths-based employment support to assist adults with ASD to prepare for, find and maintain meaningful employment

## CARING FOR PEOPLE WITH ASD

An important way to assist people with ASD to learn is to establish routines

- ✓ People with ASD have difficulty anticipating what is about to happen.
- ✓ Inform them of any changes or transitions to the routine.

## Language and communication

### Simplify your language

- ✗ **Don't say:** "Hurry up John you'll have to stop playing the piano now because dinner is on the table and it's getting cold."
- ✓ **Say:** "John, piano finish: dinner."

### Express one idea at a time, saying things in the order they will happen

- ✗ **Don't say:** "We are going to have a BBQ at the park, but we are going to the shops first to buy new cushions for the lounge room."
- ✓ **Say:** "We're going to Kmart (pause, show photo of Kmart brochure). We'll buy cushions (pause, show photo). Then a BBQ at the park (photo)."

### Use direct and specific language

- ✗ **Don't say:** "Be friendly when you see people you know."
- ✓ **Say:** "People look at you. You smile and say 'hello'."

### Pauses and silence

- ✓ Talk when necessary and leave plenty of silences.
- ✓ Use pauses to separate and highlight important words.
- ✓ **Say:** "Tony...Open the door."

### Talk at a normal volume with intonation that varies

- ✓ Use a normal tone of voice.
- ✓ Speak at a normal volume.
- ✓ Speak slightly slower.
- ✓ Leave plenty of silences.

### Use positive statements

The overuse of words: No, don't, stop, wait, not now may trigger challenging behaviours.

- ✗ **Don't say:** "No reading" OR "Stop that"
- ✓ **Say:** "It's bed time now...(pause) Let's get ready."

### Give plenty of time to respond

- ✓ May take longer than usual to comprehend and respond.
- ✓ Can take up to 30-45 seconds to respond.
- ✓ Repeating too quickly can cause anxiety.

### Give specific choices

People with ASD will respond to questions better if they are given a choice.

- ✗ **Don't ask:** "What do you want to eat?"
- ✓ **Say:** "Do you want chips or biscuit?"

## Variations of behaviour

A persistent pattern of deteriorating behaviors is a warning of increased stress due to:

- external factors (change in routine, environment) or
- internal factors (ill health)

**WHEN CARING FOR ADULTS WITH ASD****Assist with managing organisational skills by putting strategies in place**

- › Making written checklists to ensure task was completed.
- › Setting reminders for different tasks.

**When making or changing in plans and strategies – reduce uncertainty**

- › Involve the individual and encourage participation.
- › Create schedule of daily events.
- › Inform of any changes in schedule or long wait times.

**Developing new skill or behaviour**

- › Use motivational reinforcements of interest.
- › Be constant with what works for the individual.

**Acknowledgement of the accomplishments**

- › Celebrate the achievements with others – small or large.
- › Be proud and respect the small steps.

**Breaks and calming strategies**

- › To reduce anxiety.
- › To ensure individual doesn't get overwhelmed with tasks.
- › To boost self-esteem and confidence.

**Potential sensory environment stimuli that might bother the person with ASD**

- › The visual input - fluorescent and bright lights.
- › Auditory input - loud noises.
- › Tactile input - certain surfaces, textures, fabrics.
- › Smells/tastes - strong perfumes or certain food textures.

**Assistance with daily routine activities**

- › Break down the tasks into simple steps - one thing at a time.

**Promote friendships with others**

- › Connecting with similar interest groups.
  - › Attend places such as museums, libraries, or team sports of interest.
-

# What is autism?

Autism is a lifelong neurodevelopmental disability that affects the way that people communicate and interact with others. All autistic people are unique.

However, autistic people may display some of the characteristics in the two main areas below:

## Social communication and interaction

### Finds two-way conversations difficult

- May find it difficult to start, maintain, or end a conversation
- May find it hard to stay on topic

### Needs help to interact with others

- May prefer to be alone
- May want to join in but not know how
- May find it difficult to form and maintain social relationships

### Seems uninterested

- May avoid eye contact
- May not respond to name
- May appear to be in their own world

### Needs help with communication

- May have delayed or limited speech
- May tend to interpret language literally
- May have a large vocabulary but struggle with social use of language

### Difficulty reading social cues or situations

- May find it hard to read body language, facial expressions, and tone of voice
- May need help to understand when a behaviour is appropriate

## Behaviour, interests and activities

### Under- or over-responsive senses

- May have unusual reactions to what they see, hear, smell, touch or taste etc
- May need regular movement breaks

### Prefers structure and routine

- May need structure or routine to help process information
- May need to be prepared and supported to try new things
- May need support and time when transitioning to a new activity, e.g. switching off a video game to go into doctor's office
- May need support with planning tasks and time management

### Narrow interests

- May have an intense interest in one topic
- May have an interest that is unusual
- May have an unusual level of interest in a topic

### Repetitive behaviours & body movements

- May repeat the same action over and over e.g. lining up objects or watching the same movie repeatedly
- May display echolalia (repeating words or phrases)
- May display hand-flapping, spinning, rocking etc. This is also called stimming

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- Infection control
- Managing behaviours with positive support
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