Adult life on the autism spectrum

Autism is now recognised as a life-long condition, and not one that exists only in childhood. People who are diagnosed as autistic when they are children ultimately enter adulthood and many require ongoing support services. As public and professional awareness of the autism spectrum continues to improve, more people are also being diagnosed as being on the autism spectrum when they are adults. In many cases, these individuals may have known for years that they are 'different'; with diagnosis, they gain an understanding of how their characteristic profile of interests, habits, challenges and skills constitutes a recognised condition for which diagnostics and support are available.

There is much less known about autism in adulthood compared to our understanding of and services for children on the autism spectrum. To address this, researchers have begun to investigate the prevalence, experiences and needs of adults on the autism spectrum.

How common is autism in adulthood?

Consistent with the understanding that autism is a lifelong condition, a 2007 UK research study found that the prevalence of autism in the adult population to be similar to that identified in children. In this study, approximately 1 in 100 adults living in UK met the diagnostic criteria for autism.\(^1\) In addition, the rates of autism spectrum disorders were found to be generally constant across adult age groups. We can generalise that rates of autism in Australia will be similar to the UK rates, given that the prevalence of autism in children in Australia is generally similar to that found in the UK and USA. In addition, studies of autism worldwide suggests that there is little variation from one region to another in the proportion of the population who are on the autism spectrum.\(^2\)

Diagnosis for adults

For adults, autism is diagnosed by psychiatrists and psychologists who are qualified and experienced in assessing people on the autism spectrum. An assessment includes observations, standardised tests or questionnaires, and meeting with the individual, as well as their family and service providers if possible. Information is gathered about the
individual's abilities and difficulties, particularly in the areas of social interaction and social communication, sensory processing, and restricted and repetitive interests, activities and behaviours. A comprehensive assessment will highlight areas of strength as well as areas of functioning that may benefit from support or interventions.

There is no single behaviour that indicates autism. Currently, there are no blood tests that can detect autism.

In Australia, as in the UK and USA, professional diagnosis commonly uses the classification provided by the Diagnostic Statistical Manual of Mental Disorders (DSM 5), produced by the American Psychiatric Association. Under the most recent version (DSM 5) there is now a single diagnosis of autism spectrum disorder, with a severity ranking of 1, 2 or 3 allocated according to individual's support needs. An alternative diagnostic tool used for the clinical identification and classification of autism is the International Classification of Diseases (ICD), produced by the World Health Organisation (WHO). The most recent version (ICD-10) provides four separate classifications for Autistic Disorder, Asperger's syndrome, Other pervasive developmental disorders; and Pervasive developmental disorder, unspecified.

Many adults on the autism spectrum who have received a diagnosis after childhood express a feeling of relief in finally knowing why they have felt different from other people for all or most of their life. For many, a diagnosis has enabled them to find the right services and treatments after many years of unsatisfactory therapies, to make contacts with support networks and to develop rewarding social relationships with other people on the autism spectrum.

**Drawing on your strengths to enjoy a quality life in adulthood**

Research is increasingly providing evidence that adults across the autism spectrum and across all styles of cognitive, social, and behavioral functioning, have both the ability and desire to participate in a rewarding life. This includes participating in satisfying work, educational activities and personal and social relationships, and enjoying a reasonable degree of autonomy and independence.

This research has been driven by an increasing focus towards considering how the strengths of autistic people can open up opportunities for them to have equal access to all aspects of adult life.

To date, researchers have looked at the strengths of adults on the autism spectrum in four areas: their cognitive abilities their focus on preferred interests, their personalities and character, and their sensory preferences.
Strengths in interests

Research shows an autistic person's focus on preferred interests can be a strength that offers a range of benefits for that person. Engaging in a purposeful and active way in preferred interests has been shown to help people feel more competent, autonomous and related to others. Autistic people have been shown to have increased enthusiasm, motivation and use more appropriate social interaction language and communication skills when they are asked to speak about the preferred interest. Engaging in special interests is also an effective way used by people on the autism spectrum to manage and reduce anxiety.

Research also shows that while many people on the autism spectrum change their preferred interests over their lifetime, their relatively high intensity of engagement in preferred interests remains throughout their life.

While a traditional view has been that people on the autism spectrum have strengths and preferred interests in natural sciences, spatial design, mathematics, engineering and IT, research now shows that their preferred interests at work and education extend well beyond these fields to include human and social sciences, and creative fields.

A particular strength that has been shown to be related to the pursuit of preferred interests by people on the autism spectrum is the capacity for systematising, i.e., the ability to, and preference for arranging items according to an organized system. High levels of learning, reading and memorising facts are also associated with the pursuit of preferred interests by people on the autism spectrum.

Personality and character strengths

For many years, anecdotal reports have described autistic people as having certain personality strengths, including being fair, authentic and reliable, loyal, free of social or cultural bias, and dedicated to seeking the truth. Recent research reports that the most frequent signature strengths of people on the autism spectrum are open-mindedness, authenticity, love of learning, creativity and fairness. Interestingly, open-mindedness, fairness and authenticity are all considered to be facilitated by the tendency to systematise.

Autistic people have also been found to be make less use of stereotypes.

At Aspect, we consider that the strengths associated with autistic interests and personality can also be strengths for that person in the workplace, in social settings and in the home. These strengths offer a good starting point to find rewarding and suitable work and social opportunities for people on the autism spectrum and where needed, to enable them to enjoy an independent home life.
A recent study examining the attitudes and self-perception of lives of eight autistic adults aged 25 to 63, from their own perspectives, through in-depth, semi-structured interviews suggests that traditional life outcome measures - such as being employed, living independently, and having social relationships - are inadequate for assessing the life outcomes of people on the autism spectrum, because such measures do not take into account the individuals’ own sense of satisfaction with themselves and with their lives.10

Choosing services and supports

Many support services and therapies are available to help autistic adults make the most of their abilities, develop new skills and participate in education, find employment, develop social relationships, and enjoy a degree of independence in their home life.

Choosing services and supports that will best suit the needs of each individual, and where applicable, the needs and role of their family/carers, requires thought, discussion and information.

Questions to consider include:

- Does this program or practitioner respect and incorporate my role and knowledge?
- Can I or we learn how to implement this approach in our everyday life situations?
- Is it clear what type of intervention is offered and why it would help?
- What does the intervention involve, who will be involved in delivering it and how will the approach be introduced?
- Was the approach specifically developed for use with children/adults on the autism spectrum?
- Does this approach benefit all people on the autism spectrum, or is it designed for specific use with one sub-group?
- Is this approach flexible? Does it take into account the differences of individuals on the autism spectrum and their needs?
- Has this approach been evaluated? Is there any research published which supports the safety and effectiveness of this type of intervention?
- How long has this approach been used with people on the autism spectrum?
- Can this approach be used in conjunction with other approaches?
- To what extent will it affect my/our whole family’s lifestyle?
- Is it home-based, centre-based, and can the approach be used and generalised across all situations?
- How does this approach address the individual’s communication, social, behavioural and sensory processing needs?
- How much will it cost?
- How will I know if the approach is working?
Finding help

If you are interested in assessment and diagnosis for autism, your GP can refer you to a psychologist, psychiatrist or a diagnostic assessment service in your area. Alternatively, you can contact Aspect about assessment and autism-related services.

Contact Aspect customer service

Telephone  1800 277 328 or (02) 8977 8377  9am-5pm Monday to Friday
Email     customerservice@autismspectrum.org.au

References


