

What is the issue?

As public and professional awareness of autism continues to improve, a growing number of adults are being diagnosed with autism. These individuals may have known for many years that they are 'different', but perhaps only recently have come to realise that their characteristic profile of interests, habits, challenges and skills constitutes a recognised condition for which diagnostics and support are available (Ford, 2007, Perkins, 2012).

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

Until recently, little was known about the prevalence and progression of autism 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 autism moving into adulthood?
- Can children diagnosed with autism 'grow out of' the condition as adults?
- What are the best ways to identify and diagnose autism in adults for the first time?
- Do people with autism have a shorter than average life expectancy?

What does the research say?

The world's first nationwide study into the prevalence of autism among adults was carried out in the United Kingdom in 2007 (Brugha, 2009) led by the National Centre for Social Research (NatCen) in collaboration with the University of Leicester. Over 7,000 adults were surveyed to determine if they met the diagnostic criteria for autism, and the results were weighted to generate a representative prevalence rate for the adult population as a whole. The sample was then analysed on a variety of demographic factors. Some of the key findings from the study, and their implications, are described below.

1. **Finding:** *Approximately one in every hundred adults living in households in the UK meets the diagnostic criteria for autism. This is broadly the same prevalence rate as within the child population.*

Implication: *The finding that autism is as common in the adult population as it is among children contradicts the idea that people can eventually 'grow out of' autism. However, it also suggests, contrary to popular belief that autism is not in itself becoming more prevalent. It may simply be easier for children now to obtain an autism diagnosis than it was for previous generations.*

2. **Finding:** *Rates of autism were found to be generally constant across adult age groups.*

Implication: *There is no evidence that individuals affected by autism have a shorter than average life expectancy.*

3. **Finding:** *The presence of autism 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.*

Implication: Adults with autism experience a range of social disadvantages, some of which may be avoidable given proper support, education and training.

4. **Finding:** Adults with autism were no more likely to be using services for people with mental or emotional problems than the general adult population.

Implication: Healthcare policy and practice, as currently configured, may not be sufficiently meeting the needs of adults with autism.

Diagnosis

Adults seeking clarification of whether they have autism are usually referred to a clinical psychologist or psychiatrist for consultation. At this consultation a range of tests and interviews designed to assess intellectual functioning, social adaptability, communication skills, and a childhood history of autism traits will be assessed. Obtaining an autism diagnosis as an adult, however, is not always a straightforward process. There are a number of reasons for this:

- It can be difficult for adults with suspected autism to find a specialist psychiatrist to diagnose and treat their condition (Arehart-Treichel, 2008).
- The impairments in social interaction, communication, imagination and mental flexibility experienced by an individual with autism may change from childhood through adulthood (Kan et al., 2008). Most assessment tools are designed for diagnosing autism in children.
- Individuals may be unable to recall details from their childhood that would provide clues as to the likelihood of autism. Parents may not be alive or available to contribute to the consultation.
- Autism in adults may mimic other psychoses (such as social anxiety disorder or obsessive compulsive disorder). It may also co-exist with, and potentially be overshadowed by, conditions such as anxiety, depression, ADHD and various types of personality disorder. In these situations, it may be very hard to delineate specific expressions of autism (Farley et al., 2009).

Life course outcomes

Aspect conducted a comprehensive study into the life course of adults on the autism spectrum. The results from the study showed that adults with autism are often unable to meet their goals and aspirations because there is a shortage of relevant and affordable support (Aspect, 2012).

When high school students with autism are surveyed about their aspirations they report that having a job, as well as a home and family of their own are very important (Aspect, 2013). The reality is that the outcomes for young adults with autism are often quite different. Researchers have observed that young adults with autism are more likely to remain at home with parents or a carer, and are less likely to have lived independently after finishing high school than people with other disabilities (Anderson, 2013, Aspect, 2012, Brugha, 2009).

Employment is often difficult to find and retain for young adults with autism, and those who are employed are often paid minimum wages (Roux, 2013, Howlin, 2013). The results from a recent Australian study showed that 54% of adults with autism who were surveyed were employed, with 33% working in casual employment. Although these figures are encouraging, the employment level is well below the national employment rate (Warren, 2012).

The Organisation for Autism Research in the United States has produced a Guide for Transition to Adulthood. This free, online resource provides suggestions on how to support your child as they finish school and enter adulthood (Gerhardt, 2006). The implementation of DisabilityCare will support Australian schools with programs that provide transition training for students with a disability in the final years of high school. Please note that at the time of writing this information sheet, details of the DisabilityCare transition program and who will be eligible are not yet available.

In summary

For the last few decades autism research has been dominated by studies of child populations, with the result that our understanding of how autism manifests itself into adulthood is relatively limited. It is likely, however, that this research area will gather pace in the next few years as the children and adolescents with autism age, and clinical and community awareness surrounding the condition increases. These changes in community awareness may also prompt adults to come forward for a diagnosis for the first time. The wealth of data on childhood autism that has been gathered will provide a firm foundation for such research, but there is a clear need for more long-term and evidence-based studies of the progression of autism across the life course.

References

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Resources

- We belong - Autism Spectrum Australia (Aspect) Adult survey
<http://www.aspect.org.au/content/we-belong>
- We belong too - Autism Spectrum Australia (Aspect) Adolescent survey
<http://www.autismspectrum.org.au/content/we-belong-too>
- Life journey through autism: Guide for transition to adulthood:
<http://www.researchautism.org/resources/reading/documents/TransitionGuide.pdf>