Adults with autism spectrum disorder

What is the issue?

As public and professional awareness of autism spectrum disorder (ASD) continues to improve, a growing number of adults are being diagnosed with ASD. 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 disorder 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 ASD as a life-long developmental disability, and not simply as a childhood disorder. Individuals who are diagnosed with ASD as children ultimately enter adulthood and many require ongoing support services.

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?

What does the research say?

The world's first nationwide study into the prevalence of ASD 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 ASD, 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 ASD. This is broadly the same prevalence rate as within the child population.

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

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

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

3. **Finding:** 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.

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

4. **Finding:** Adults with ASD 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 ASD.

**Diagnosis**

Adults seeking clarification of whether they have ASD 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 ASD traits will be assessed. Obtaining an ASD 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 ASD 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 ASD may change from childhood through adulthood (Kan et al., 2008). Most assessment tools are designed for diagnosing ASD in children.
• Individuals may be unable to recall details from their childhood that would provide clues as to the likelihood of ASD. Parents may not be alive or available to contribute to the consultation.

• ASD 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 ASD (Farley et al., 2009).

**Life course outcomes**

Aspect conducted a comprehensive study into the life course of adults with ASD. The results from the study showed that adults with ASD 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 ASD 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 ASD are often quite different. Researchers have observed that young adults with ASD 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 ASD, 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 ASD 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 ASD research has been dominated by studies of child populations, with the result that our understanding of how ASD 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 ASD age, and clinical and community awareness surrounding the disorder 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 ASD 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 ASD across the life course.

References


Resources

We belong – Autism Spectrum Australia (Aspect) Adult survey

We belong too - Autism Spectrum Australia (Aspect) Adolescent survey
Please see the Autism Spectrum Australia (Aspect) website.
This report is to be released in October 2013.

Natcen UK adult study: http://www.natcen.ac.uk/

The Health & Social Care Information Centre, Social Care Statistics Report:
http://www.natcen.ac.uk/media/665717/autism%20spectrum%20disorders%20research%20report.pdf

Life journey through autism: Guide for transition to adulthood: