

Girls and women on the autism spectrum

One of the most striking features of autism is the fact that it is diagnosed around four times more often in boys than in girls.¹ However, over the last decade, researchers have started to question whether autism may be more common amongst females than has previously been thought.² Research has found that in the absence of significant intellectual or behavioural problems, girls with autism-like traits are more likely than boys to have a missed diagnosis of autism.^{3,4} So although autism has historically been considered a predominantly 'male' condition, researchers are now also investigating the possibility that autism may manifest differently in females.

Why do more males than females have an autism diagnosis?

Researchers suggest several reasons for the existing 'gender gap' in autism diagnoses:

1. *Current screening instruments may not be adequate for identifying autism in females.* Some researchers have suggested that autism may present differently in females (see the sections below for more about this). However, the criteria, concepts and practices for diagnosing autism currently in use are based on the 'conventional' (male) presentation of autism.^{5,6}
2. *The ascertainment bias:* Several studies have shown that autism is more commonly diagnosed in females who present with classic symptoms of autism and intellectual disability, whereas the autism diagnosis is either missed in females with a higher IQ or with less severe symptoms, or is being made at a later age than boys.³ In cases where girls show different and less severe social and communicative symptoms than boys do, parents, teachers, and health professionals may misinterpret these symptoms as being due to shyness or anxiety. In addition, while males on the autism spectrum tend to show more externalizing behaviours, such as hyperactivity and impulsivity, females on the autism spectrum tend to contend with more internalizing behaviours, such as anxiety and depression.⁷

Girls with 'internalising' problems are referred to professionals less often than boys with similar problems, possibly because these behaviours are considered 'normal' in females or are misinterpreted.³ This misinterpretation of symptoms could also lead to misdiagnosis.

Females with autism-like traits are more likely to be misdiagnosed with conditions such as language delay, anxiety, avoidant personality disorder and eating disorders.^{8, 9, 10}

However, once the diagnosis has been established, studies show that there are few differences in the type or severity of other conditions accompanying autism in girls and boys.¹¹ This indicates that the ascertainment bias is a real problem in the identification of females on the autism spectrum.³

3. The *camouflage hypothesis*, which is related to the ascertainment bias, suggests that compared to males on the autism spectrum, females on the autism spectrum may be better able to, or show a greater tendency to compensate for or adapt to some of the symptoms of autism.¹² This behaviour is also called '*masking*'. As a result, the behaviours of these girls do not cause issues that might lead teachers, parent and medical professionals to consider a possible autism diagnosis.

Research shows that there are number of ways in which girls and women on the autism spectrum, either intentionally or unconsciously, 'mask' their limitations in social understanding, social communication and social imagination.¹²

- As they grow in self-awareness and recognition of their 'differences', girls may make greater efforts to avoid drawing attention to themselves, for example by being quiet, well behaved and compliant at school.
- Girls may be more able to follow social actions through observation. They may be quicker to apologise and appease when they make a social error, increasing the likelihood of their anomalous behaviour being overlooked or forgotten by others.
- Girls are often more socially aware and socially driven, and are more likely to seek out play and interaction opportunities (whilst often being 'led' by peers rather than initiating activities themselves). They may have one special friend with whom they share an intense, sometimes dependent, relationship.

Is autism different in females and males?

It has recently been recognised that the behavioural characteristics of autism are different in girls and women than in boys and men.¹³ However, an analysis of 20 separate studies investigating gender differences in autism symptoms identified that overall, there were few differences between males and females in the *severity* of their symptoms.³ For example:

- Males and females on the autism spectrum showed similar symptom severity in social behaviour. However, some differences were also noted:
 - Girls on the autism spectrum show more interest in social relations.¹⁴

- While girls on the autism spectrum show more imaginative play than affected boys for these girls 'pretend play' may involve simply imitating or repeating play or social situations they have previously encountered.¹⁵
- Girls on the autism spectrum also appear more able to demonstrate complex emotions than boys.¹⁰
- Males and females on the autism spectrum showed similar symptom severity in communication.
 - However, compared to boys on the autism spectrum, girls on the autism spectrum more frequently engage in echolalia - when a person repeats what was just said to them. At a young age this may be mistaken as more advanced communication skills.¹³
- In general, girls showed less restricted interests and behaviours and stereotypes than boys. However, the intense special interests often found in girls on the autism spectrum (such as animals, celebrities and fiction franchises) tend to more closely align with the 'mainstream' than the corresponding interests of boys on the autism spectrum.¹²
- Girls on the autism spectrum exhibited more sleep problems and greater anxiety or depression than boys.¹⁶

Thus, it is possible that due to the different ways that autism presents in females and males, combined with the camouflaging behaviour of females and the ascertainment bias, parents, teachers and clinicians may fail to recognise a range of behaviours, as well as issues such as anxiety and depression, as underlying signs of autism in females.

The life experience of women and girls on the autism spectrum

The growing body of research on the lived experience of women and girls on the autism spectrum indicates that there is not so much a unique female profile of autism, but rather, women experience life on the autism spectrum in a range of subtle and subjective ways that differ from the experiences of men who are on the autism spectrum.¹⁸

- For example, Aspect's large-scale 2013 *We Belong* research project, which documented the life experiences, aspirations and support needs of 313 adults with Asperger's Disorder and high-functioning autism, including 91 women in this study, there were few gender differences. Women and men tended to attain comparable educational qualifications, experienced similar rates of (un)employment issues, and had similar independence and daily life support needs. However, the study found that there were some subtle differences between the male and female experiences.¹⁸
 - For example, the women on the autism spectrum were less engaged socially than were the men on the autism spectrum.
 - The women appeared to more content in their own company and less driven by the desire for friendships and romantic relationships, compared with the men.

- Research has also found that the social communication traits of women on the autism spectrum may make it more difficult for them to join and enjoy female peer groups than is the case with men on the autism spectrum, whose social groups may be less subtle and more forgiving than those of females.¹⁹
- A higher proportion of women on the autism spectrum report having a mental health condition than do their male counterparts.¹⁸
- Women and teenage girls on the autism spectrum also report experiencing a tension between being their true 'autistic' self and their perceived pressure to conform within traditional feminine roles (the wife, the mother, the girlfriend).¹⁹

Research suggest that women on the autism spectrum may find the demands and disappointments of social communication more emotionally and psychologically burdensome than do men on the autism spectrum.

- The effort involved in perpetual social mimicry and repression of integral 'autistic' behaviour can be mentally and emotionally exhausting and lead to the high incidence of mental health problems for girls and women on the autism spectrum.
- Furthermore, in a cycle of unhappiness, this experience may then exacerbate social isolation, rather than improve their social connections.¹⁸

Supporting the 'camouflage' hypothesis, women on the autism spectrum commonly report making a deliberate effort to learn and use 'neurotypical' social skills, describing this as 'putting on a mask'.

- This learned behaviour can be based on careful observation of peers, reading novels and psychology books, imitating fictional characters, and trial and error in social situations.^{19, 20}
- These women also report that they prioritise 'fitting in' above their own needs, and that this had led them to be manipulated and abused by others. In fact, it is suggested that this 'masking' behaviour may mean that women on the autism spectrum are less likely than men to have been offered support to improve their social skills and build friendships during their time at school.¹⁸

Given the likelihood that there is a significant degree of missed and mis-diagnosis of autism in the female population, the disadvantages that women on the autism spectrum report as resulting from having received a late diagnosis of autism are even more pertinent and concerning.

- In Aspect's *We Belong* study, participants whose autism had long gone unrecognised lamented the lack of support and compassion shown for their needs, particularly during their school years, but also continuing into the workforce and other areas of adult life.¹⁸
- In some cases, this was only compounded by the internal confusion and distress of not understanding why they were 'different'.¹⁸ This is likely to be a contributing factor to the level of mental ill-health experienced by women of the autism spectrum.

Adults on the autism spectrum who have received a diagnosis after childhood commonly express relief in finally knowing why they have felt different from other people for all or most of their life. For many people on the autism spectrum, 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 others who are on the autism spectrum.

Into the future

Future research is likely to concentrate on developing a more systematic understanding of the female presentation of autism and raising awareness amongst professionals involved in early identification and diagnosis. A new screening tool '*The autism spectrum screening questionnaire-revised extended version (ASSQ-REV)*', which is sensitive to female features of autism, is currently in development.²¹

References

1. Whiteley P, Todd L, Carr K, Shattock P. Gender ratios in autism, Asperger syndrome and autism spectrum disorder. *Autism Insights*. 2010 Jan 1;2:17.
2. Zwaigenbaum L, Bryson SE, Szatmari P, Brian J, Smith IM, Roberts W, Vaillancourt T, Roncadin C. Sex differences in children with autism spectrum disorder identified within a high-risk infant cohort. *Journal of autism and developmental disorders*. 2012 Dec 1;42(12):2585-96.
3. Van Wijngaarden-Cremers PJ, van Eeten E, Groen WB, Van Deurzen PA, Oosterling IJ, Van der Gaag RJ. Gender and age differences in the core triad of impairments in autism spectrum disorders: a systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*. 2014 Mar 1;44(3):627-35.
4. Lai MC, Baron-Cohen S. Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*. 2015 Nov 30;2(11):1013-27.
5. Andersson GW, Gillberg C, Miniscalco C. Pre-school children with suspected autism spectrum disorders: do girls and boys have the same profiles?. *Research in Developmental Disabilities*. 2013 Jan 31;34(1):413-22.
6. Dworzynski K, Ronald A, Bolton P, Happé F. How different are girls and boys above and below the diagnostic threshold for autism spectrum disorders? *Journal of the American Academy of Child & Adolescent Psychiatry*. 2012 Aug 31;51(8):788-97.
7. Altman L, Turk J. 1.20 Comparison of autistic profiles in young females and males with autism spectrum disorder: A review of the literature. *Journal of the American Academy of Child and Adolescent Psychiatry*. 2016 Oct 1;55(10):S106.
8. Hambrook D, Tchanturia K, Schmidt U, Russell T, Treasure J. Empathy, systemizing, and autistic traits in anorexia nervosa: a pilot study. *British Journal of Clinical Psychology*. 2008 Sep 1;47(3):335-9.

9. Coombs E, Brosnan M, Bryant-Waugh R, Skevington SM. An investigation into the relationship between eating disorder psychopathology and autistic symptomatology in a non-clinical sample. *British Journal of Clinical Psychology*. 2011 Sep 1;50(3):326-38.
10. Head, A., McGillivray, J., & Stokes, M. The female profile of autism: An examination of friendships. Paper presented at the First Scientific Meeting of the Australasian Society for Autism Research (ASfAR), Sydney, 6 December 2012.
11. Lugnegård T, Hallerbäck MU, Gillberg C. Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome. *Research in developmental disabilities*. 2011 Oct 31;32(5):1910-7.
12. Gould J, Ashton-Smith J. Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. *Good Autism Practice (GAP)*. 2011 May 31;12(1):34-41.
13. Kirkovski M, Enticott PG, Fitzgerald PB. A review of the role of female gender in autism spectrum disorders. *Journal of autism and developmental disorders*. 2013 Nov 1;43(11):2584-603.
14. Attwood T. *The complete guide to Asperger's syndrome*. Jessica Kingsley Publishers; 2007.
15. Knickmeyer RC, Wheelwright S, Baron-Cohen SB. Sex-typical play: masculinization/defeminization in girls with an autism spectrum condition. *Journal of autism and developmental disorders*. 2008 Jul 1;38(6):1028-35.
16. Hartley SL, Sikora DM. Sex differences in autism spectrum disorder: an examination of developmental functioning, autistic symptoms, and coexisting behavior problems in toddlers. *Journal of autism and developmental disorders*. 2009 Dec 1;39(12):1715.
17. Lai MC, Lombardo MV, Auyeung B, Chakrabarti B, Baron-Cohen S. Sex/gender differences and autism: setting the scene for future research. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2015 Jan 31;54(1):11-24.
18. Baldwin S, Costley D. The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism*. 2016 20(4): 483-495.
19. Bargiela S, Steward R, Mandy W. The experiences of late-diagnosed women with autism spectrum conditions: an investigation of the female autism phenotype. *Journal of autism and developmental disorders*. 2016 Oct 1;46(10):3281-94.
20. Cridland EK, Jones SC, Caputi P, Magee CA. Being a girl in a boys' world: investigating the experiences of girls with autism spectrum disorders during adolescence. *Journal of autism and developmental disorders*. 2014 Jun 1;44(6):1261-74.
21. Kopp S; Gillberg C. The Autism Spectrum Screening Questionnaire—Revised Extended Version (ASSQ-REV): an instrument for better capturing the autism phenotype in girls? *European Child & Adolescent Psychiatry*. 20():S12, Jun 2011.