



Girls and Autism: Flying Under the Radar

*A quick guide to supporting girls
with autism spectrum conditions*



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Girls and Autism: Flying Under the Radar

A quick guide to supporting girls with autism spectrum conditions
by Jo Egerton and Barry Carpenter, with the ASC and Girls Forum, National Association of Head Teachers



This guide aims to:

- + introduce the debate around autism and gender
- + identify key issues for girls with autism spectrum conditions
- + provide practical school-based support strategies
- + share family, professional and academic perspectives.



Autism and girls – what is the problem?

Autism spectrum conditions (ASC) are 'neurodevelopmental', meaning that the brain and central nervous system develop and function atypically. The American Psychiatric Association (APA 2013) diagnostic term is 'autism spectrum disorder' (ASD). However, the umbrella term, ASC, is considered by many to be less stigmatising as it embraces not only impairments, but strengths as well. (Following this section on diagnosis, this booklet will generally use the term ASC.)

A diagnosis of ASD is based on core behaviours appearing in early development (usually before three years of age):

- Impaired development in social interaction and communication
- Restricted and repetitive interests and activities.

Although behavioural-cognitive traits associated with ASC are found in the general population, it is the severity, intensity and co-occurrence that lead to a diagnosis.



Prior to 2013, these behaviours were thought of as a clustered 'triad of impairments' (Wing and Gould 1987). By the time the APA revised its diagnostic criteria in 2013, researchers were questioning the relationships between these core traits – were they representative of both males and females with ASD; to what extent should they be considered separately (Happé *et al.* 2006)?

ASD has a range of behavioural presentations. In addition to the core traits, individuals with ASD may have other characteristic cognitive, behavioural, emotional, motor and sensory issues. They are influenced by neurobiology, environment, genetic and epigenetic

factors, developmental trajectories and/or co-occurring conditions (for example, Down syndrome, attention deficit hyperactivity disorder (ADHD)). In approximately 55% of cases ASD co-occurs with learning disability (Charman *et al.* 2011).

ASD prevalence is approximately 1 in 100 (National Autistic Society 2013). There is a very pronounced gender difference – the ratio of females to males is typically reported as 1:4. However, this is an average figure. Among intellectually able individuals with ASD, the ratio of girls to boys is significantly lower – approximately 1:10 – whereas for groups with ASD and moderate to severe learning disabilities, the ratio rises to approximately 1:2 (Dworzynski *et al.* 2012).

This extreme gender difference has only recently been questioned and alternative explanations considered, including:

- Gender bias in existing screening and referral processes, diagnostic criteria and tools
- Protective and compensatory factors in females
- Different gender-specific ASC profiles.

PONDER POINT

Is the typically reported gender ratio a true reflection of the ASD population in your school? Are there girls – especially among intellectually able pupils – who have high levels of ASD traits yet do not have a diagnosis?

'Because our diagnostic systems and stereotypes of ASD are based on males, we just don't know how many girls with very high autistic traits are out there, unrecognised. We need to know, and we need to know if they are suffering in silence or managing to compensate.'

Francesca Happé, Professor of Cognitive Neuroscience and Director of the MRC Social, Genetic and Developmental Psychiatry Centre at the Institute of Psychiatry, Psychology and Neuroscience, King's College London



Girls under the radar

In 1944, Hans Asperger (trs. Frith 1991) wrote that the 'contact disturbances' experienced by the girls in his group were 'reminiscent of autism' without showing the 'fully formed' autism seen in the boys. Similarly, today an ASC explanation for autism-like difficulties in girls is often discounted because their behaviour conflicts with the stereotype of ASC core characteristics and associated features.

'She is too sociable'

Intellectually able girls and women with ASC have better social integration skills than boys and men with these traits. Despite social-communication difficulties similar to or at higher levels than males, females with ASC are more inclined towards sociability, emotionality and friendship. However, in contrast to the

intuitive socio-emotional understanding of their neurotypical (ie typically developing) peers, they appear to construct social connections based on analytical thinking (for example, systematisation). In every social situation, instead of socialising with little effort, they struggle to conform and to generate acceptable responses and behaviours. Their strategies may include



rote-learning conversational phrases, imitating social behaviours (for example, from TV soap operas), following social scripts, and 'masking' or 'camouflaging' their innate ASC behaviours.

Lai and colleagues (2015) observe that in comparison with males with ASC, women and girls on the autism spectrum show:

...better expressive behaviors (reciprocal conversation, sharing interests, integrating verbal/nonverbal behavior, imagination, adjusting behavior by situation)... different manifestations of friendship problems (better initiation but problematic maintenance, overlooked rather than rejected by peers, better self-perceived and parent-reported friendship)...

All young people, whether or not they have ASC, experience gender-related differences in upbringing (for example, role models, expectations, socialisation) within and outside the family. From a young age, they are given gender-associated cues and experiences (Cheslack-Postava and Jordan-Young 2012). With their daughters, mothers show increased sensitivity, more frequent interactive styles, and more social behaviours (such as eye contact, vocal response to questions) than with their sons. This gender differentiation may have an impact on gender-associated differences in ASC. Siller and Sigman (2002) observed:

...among children with autism, levels of synchronization between caregiver interactions and child's focus of attention during play were associated with gains in joint attention and language up to 16 years later.

'Autism without learning disabilities in girls is very rare'

Key factors make it more difficult for clinicians to recognise ASC in girls. These include expectations (the accepted

1:4 girls:boys ratio), and the criteria, derived from observing autistic males, that are currently used to identify ASC. Appropriate diagnosis, therefore, relies on very experienced clinicians who are 'able to see and think beyond the lists of criteria in the various classification systems currently available' (Gould and Ashton-Smith 2012). As Dworzynski and colleagues (2012) note:

Even gold-standard diagnostic instruments rely on the clinician to judge whether observed or reported behaviors are different in quality or quantity/intensity from those expected in typical development or relative to the child's developmental level. As such, gender biases in diagnostic criteria, instruments, or processes may be difficult to uncover.

'She has the same interests as her friends'

The special interest topics of girls with ASC may seem to differ less from those of neurotypical girls than do those of boys with ASC from neurotypical peers. A clinician who hears a child talk on and on about electricity pylons or trains may think of ASC, but hearing about a boy band or horses may not ring alarm bells. Girls' interests, for example, may have a more nurturing and social focus (such as working with animals, compiling celebrity facts or exhaustive photo albums); boys are more likely to focus on technical hobbies and facts. For both, there is a tendency to objectify, collect and systematise. Gould and Ashton-Smith (2012) write:

It is not the special interests that differentiate them from their peers, but the quality and intensity of these interests and the length of time spent on these... So, careful questioning on interests and routines is important...

'She does not have repetitive behaviours'

Women with ASC present in wide-ranging and subtle ways and have been observed to have fewer repetitive, ritualistic behaviours (for example, abnormal posture and gait, hand flapping, tremor, dystonic posturing of hands, fingers, etc) than boys and men with ASC.

'There is a real issue of inequality in autism research; many studies explicitly exclude women and girls (because they expect low numbers), so we continue to base our knowledge of autism on findings from men and boys.'

Francesca Happé, Professor of Cognitive Neuroscience and Director of the MRC Social, Genetic and Developmental Psychiatry Centre at the Institute of Psychiatry, Psychology and Neuroscience, King's College London



Case study: Charlotte

Felicity Sedgewick, PhD student, Centre for Research in Autism and Education, University College London (see also Sedgewick et al. 2015)

Charlotte (not her real name) is a quiet, well-behaved 14-year-old girl in a mainstream school. She has some teaching assistant support for dyslexia, but is in the middle sets for all her subjects. She has a tendency to sit at the back of class, almost never puts her hand up or answers questions, and has a best friend. This is not a particularly unusual profile, and in many ways Charlotte would not stand out.

However, Charlotte has a diagnosis of autism, and many of these behaviours are masking the more significant underlying issues she is facing.

Sitting at the back of class allows her to observe her peers and plan her reactions according to what she sees other people doing, as she struggles to work out appropriate social behaviours on her own – she will always be the last to laugh at a joke, as she waits until she is sure that everyone else is laughing. Her good

behaviour stems from an over-reliance on rules and a literal interpretation of instructions. Her reluctance to answer questions comes from her strong perfectionism, as she does not want to attempt something she might get wrong, and even if she does know the answer, she feels too shy to open herself up to attention from her peers. Her best friend has significant learning support needs and is developmentally younger than Charlotte, and so puts her under fewer social demands than the other girls in her class. It is common for children with ASC to make friends with older or younger people who are either more understanding or less demanding than same-age peers.

Altogether, Charlotte feels as though she is struggling at school – she feels isolated, and she is permanently anxious about the quality of her work. Despite this, she is expected to achieve good results and go to university – she just needs more support to access the social world of her peers, to develop the self-confidence to approach the challenges of school life, and to not be missed through her lack of challenging behaviours. She may be quiet, but she is not automatically 'ok'.

Diagnostically overshadowed – girls and ASC

There are likely to be many girls with ASC in schools whose needs are not identified

or understood. Girls with significant ASC experience more barriers to diagnosis than boys with similar levels of impairment. Researchers have found higher levels of misdiagnosis, delayed diagnosis, difficulty in accessing diagnosis, and lack of diagnosis for girls and their families.



Diagnostic overshadowing/ misdiagnosis

Knowledge about the ASC profile of girls and women is very limited. Their underlying ASC may be overshadowed by coexisting conditions (for example, ADHD) and/or secondary symptoms such as mental health disorders (eating, anxiety, obsessive-compulsive, conduct, paranoia, depressive, personality or sleep disorders). This can result in referral to non-ASC services that may miss the root cause of ASC-associated difficulties. Misdiagnosis can lead to inappropriate treatment and management of the problem, and to continuing negative life impacts and bleak outcomes.

Delayed diagnosis

Many intellectually able women with ASC have received late diagnosis. As a result, they have recalled, prior to diagnosis, a lack of support and compassion from others, psychological confusion and distress due to their unexplained differences, and exclusion and victimisation by peers and teaching staff.

Lack of diagnosis

Many girls are never referred for diagnosis, as their ASC traits – ameliorated by masking and unrecognised due to male stereotyped expectations – go unacknowledged (Dworzynski *et al.* 2012).





Research in both the UK and USA shows that girls are significantly less likely to be diagnosed with ASC than male peers with similar levels of ASC traits (Baldwin and Costley 2015; Cheslack-Postava and Jordan-Young 2012).

PONDER POINT

How can we adjust our systems to ensure we identify and reflect on unexplained clusters of symptoms/ behaviours in girls – including insights from the young person and their family?

Girls with ASC need to receive early diagnosis and access to specific education, social, health and community services. Schools' good knowledge of ASC indicators in girls and vigilance in identifying these pupils not only lead to earlier referral but earlier action. Schools

need not wait for a diagnosis. If ASC is suspected, teachers and SENCOs can adopt evidence-based learning, social and environmental support strategies.

'Many SENCOs believe the one girl to four boys scenario for ASD; they do not think past that. We have an undiagnosed population here, who are currently not getting the best from our education system.'
Professor Barry Carpenter CBE, Chair, ASC and Girls Forum

'A diagnosis is the starting point for girls and women to accept, understand, acknowledge and celebrate their individual portfolio of characteristics.'
Sharonne Horlock, SENCO, Impington Village College, Cambridgeshire



Raising girls with ASC and why it is different

Carrie Grant, mother of three girls with ASC, singer, vocal coach and TV presenter

Like most parents with girls on the spectrum, particularly the high functioning end, we've had the usual comments, 'Are you sure she is autistic? She makes eye contact?' and 'But she seems normal.'

What my girls carry is an overwhelming level of unseen anxiety. Their daily minefield of worries takes up a large portion of their headspace, and the concentration required to keep everything hidden takes up anything that is left! With all capacity used up, they are prevented from listening properly or learning effectively.

What can you do to help to lower this anxiety? Recognising it goes a long way! Becoming aware of the things that heighten anxiety like homework or the threat of detention. Autistic girls hate getting it wrong – they want to be seen as smart and popular.

My teenager wears make-up, has her skirt rolled over and is obsessed with social media, just like her friends... except that often she does not understand the nuances of teenage

girls' conversation. Boys can trade information, swap opinions, but girls talk about feelings, finish each other's sentences and seem to have unwritten rules about how to fit in.

What you can do to help these amazing (but often hidden) girls is to look beyond the exterior and understand that they are often feeling like isolated misfits who will never be like the other girls around them.

Boys with ASC possibly feel the same unless they go down the emo/geek route, which is often also a girl route – more isolated, more lonely.

A friend, and mother of a boy with ASC, describes her son as desperate to be sociable, a truth-seeker with a fearless sense of justice, super-perceptive about people but lacking conversational understanding. He and my daughter share similar challenges – the acute, sky-high anxiety with circular impacts on sleep, explosive outbursts and meltdowns. My friend's son manages his comprehension difficulties and others' code-speak, jokes and lack of logic through compulsive cross-checking and questioning. The consequences of his need to visualise, understand and predict unfamiliar situations minutely are extreme tiredness, anxiety and depression.

Girls, ASC and emotional well-being

The social impairments, isolation and social exclusion of girls and women with ASC are most likely to fall 'under the radar' in schools and workplaces. At school, girls with ASC are more likely to receive targeted support for learning and behavioural needs than for improving social skills and building friendships.

There is researcher debate about whether mental health stands out as a significantly gender-associated risk for girls and women with ASC. As well as anxiety, some researchers have found that intellectually able girls and women with ASC have significantly more thought and attention problems than their male

counterparts, higher average fear scores, and a tendency towards self-deprecation, withdrawal, atypical depression and self-harm. Baldwin and Costley (2015) reported high levels of mental health problems among Australian women with ASC, noting:

...it appears that many women with ASD either do not or cannot access satisfactory professional support to help them regulate or improve their mental health and wellbeing...point[ing] to the need for specialised counselling, psychology and social support services...

'There is a pervasive lack of recognition and understanding of the often subtle behaviours which relate to ASC, particularly for girls. Girls can become increasingly unwilling to attend school, participate in learning activities or work collaboratively. Their actions are misinterpreted by adults and peers. Girls who are exhausted from maintaining a social pretence may choose to exclude themselves through school refusal or truancy or may be excluded formally due to misunderstood behaviour issues.'

Sharonne Horlock, SENCO,
Impington Village College,
Cambridgeshire



PONDER POINT

If girls diagnosed with ASC have social understanding issues, additional difficulties and behaviour problems, what impact might this have on school exclusion for undiagnosed girls?



How ASC girls socialise with mainstream peers

*Felicity Sedgewick, PhD student,
Centre for Research in Autism and
Education, University College London*

Girls with ASC can have social behaviours and friendships that look very different to both those of autistic boys and non-autistic girls. For example, girls may mimic the behaviours, interests and even speech patterns of people they are friends with in an attempt to fit in and to be accepted. They may also memorise information about their friends' interests, or learn 'scripts' so that they can talk to new people.

Girls with ASC may become fixated on one person in particular, and focus on making that person their best – and only – friend. This can be very intense for both people and can sometimes lead to a falling-out. Girls with ASC find recognising and managing conflict much more difficult than non-autistic girls do, impacting on their ability to repair and maintain friendships. Alternatively, some girls will form many casual friendships, but not stick to one group, and have no close friends with whom they spend most of their time.

It can be difficult for staff to support the social lives of ASC students

alongside their studies, but it is a crucial aspect of school life and personal development.

Girls with ASC may take literally whatever is said to them, leaving them vulnerable to being manipulated; their less developed social awareness can leave them open to gossip and exclusion. It is important for school staff to notice these behaviours and to intervene or explain.

Girls who have just one or two very intense friendships may need help widening their circle and understanding why this matters. Explaining that most people have several friends so that no single person gets overloaded or bored, and helping them find other young people with shared interests, can be a good form of support.

Girls who appear to be friendly with almost everyone, but who have no close friends, may need support in spending more time with peers. However, they may be happy with their less demanding, casual friendships.

The best course of action is to let each girl choose what sorts of friendships she prefers and to try to help her make and keep the friends she wants to have.

Supporting learning for girls with ASC

Among intellectually able adolescents with autism spectrum conditions there is some evidence that girls and boys have different learning profiles. Specific cognitive skills may vary by gender. For example, while boys are likely to show superior attention to detail, visuo-spatial skills, and inhibitory control,

girls have higher skills in information processing, multiple conceptual tracking, divided attention and cognitive flexibility (Rubenstein *et al.* 2015).

Below, Sarah Wild, Headteacher at Limpsfield Grange School for girls with autism, Surrey, shares key advice for supporting the learning of girls with ASC in schools.

'We are different from the boys.' (Limpsfield Grange girls with ASC)

Key advice for mainstream class teachers/ teaching assistants (TAs)

LEARNING

Possible characteristics of girls with ASC – how you can support them

- Difficulties with abstract concepts and auditory processing – make learning concrete, contextual and visual
- Likes routine, dislikes change – structure all transitions (for example, in and between lessons, after school holidays)
- Quiet, shy, awkward, compliant, passive – praise and reward (if they can accept this)
- Not asking for help, or being avoidant, to mask difficulty – check understanding often
- Explosive outbursts or meltdowns – understand and address fears, triggers and sensory overload
- Perfectionist – build flexibility in making mistakes and re-drafting work
- Very determined and likes to be in control – offer guided choice
- Fine motor or sensory difficulties – make reasonable adjustments; for example, allowing touch typing instead of writing by hand

Key advice for senior leaders

USING SCHOOL SYSTEMS, BUILD WHOLE-SCHOOL ASC KNOWLEDGE, SKILLS AND COMPETENCY IN...

- Creating an 'enabling' school environment
- Understanding the presentation of girls with ASC, their strengths and special interests
- Analysing and supporting behaviours
- Understanding the impact of impairments (for example, social imitation causing exhaustion during the day)
- Identifying rising anxiety or mental health issues
- Working with families to generalise girls' social understanding across different environments

SPECIFICITY: GIRL-ORIENTED PROGRAMMES

Girls with ASC may need:

- To build their own age-appropriate understanding of ASC, sensory sensitivities and anxieties and how to manage them

- Enjoys reading, has a good imagination, etc – incorporate their special interests into learning

SOCIAL

Girls with ASC may...

- Mirror behaviour
- Affect different personalities and may not have a strong sense of identity
- Be socially immature and vulnerable
- Try to impose scripted, controlling play on peers

How you can support them...

- Select a partner(s) to model behaviours
- Use video, role play, social scripts to show how to respond appropriately
- Provide structured activities for social time
- Encourage and model reciprocity

EMOTIONAL

Girls with ASC may...

- Need to feel that someone ‘gets’ them
- Camouflage emotions or mask symptoms at school
- Be exhausted from the pressure of constant social imitation/mirroring
- Experience anxiety more intensely than others
- Shut down or cry over small things due to sensory/emotional overload
- Hate injustice

How you can support them...

- Use social stories and factual evidence to explain fears
- Where appropriate, confirm that their reaction or feeling is ‘normal’
- Tell them it will be ok

- Extra-curricular provision and resources to match ASC special interests
- A social language programme to navigate social rules, with peer mentoring schemes for friendship and bullying issues
- Personal, social health and economic education specificity to facilitate:
 - o sex and relationship education: adolescence is unpredictable; bodily changes heighten anxiety due to perceived lack of control
 - o independence – to reduce vulnerability
 - o privacy awareness, personal space and touching rules
 - o permission to say ‘No’: self-advocacy
 - o awareness of e-safety and grooming: girls with ASC are more vulnerable to complying with a demand and more likely to respond to communication
 - o self-image, self-esteem, assertiveness and confidence
 - o gender identity
 - o emotional well-being and mental health
 - o developing vocational interests and leisure activities
- Careers information, advice and guidance specificity: girls who are systematisers may prefer male-dominated occupations, where the need to follow rules is high. Girls may need to:
 - o see the big picture of career pathway options
 - o celebrate the right to choose their own path, despite ‘female’ cultural influences



ASC and girls – the future

These are early days in identifying gender-related ASC differences for girls and women, and therefore while new pathways of inquiry have opened up, evidence is currently sparse, fragmented and inconclusive. As professionals and researchers working together with girls and young women with ASC, we need to work towards clarity and consensus.

Girls and women with ASC need to be recognised, enabled and effectively equipped so they can make the life choices they choose and benefit from them. It is their human right.

Much knowledge of the ASC experiences of women and girls to date is autobiographical and anecdotal. As diagnosed females have been assessed as having ASC using recognised autistic male-derived diagnostic criteria for ASC,

their characteristics and experiences fit closely with this profile. Going forward, it is important to compare how males and females with autism differ respectively from neurotypical males and females, as well as from their same-gendered peers with ASC. This may reveal that girls and women have a different set of atypical features from boys and men.

New knowledge about gender differences in relation to types, ranges, severity and development of ASC characteristics in girls and women is important both educationally and clinically. It will highlight priorities and generate more valid and effective interventions for girls and women with ASC, and enable a more fulfilling future. Intellectually able females with ASC are often well qualified, motivated and ambitious. They have valuable skills needed in the labour market. However, many are unemployed, under-employed or over-educated for the jobs they do. This can be changed with evidence-based workplace adjustments and accommodations that will enable women with ASC to contribute their potential.

'Our challenge in schools is to evolve a curriculum and pedagogy which are responsive to our new understanding of girls with ASC and their specific needs. This will involve a process of inquiry, to investigate and explore, for and with the girls, how best their needs can be met.'

Professor Barry Carpenter CBE,
Chair, ASC and Girls Forum



Further information

Links

The girls of Limpsfield Grange School have shared what it means to be a girl with ASC:

- 'Limpsfield Grange Girls with Autism' (YouTube): www.youtube.com/watch?v=oZhZ0k1lyF8
- The students of Limpsfield Grange and Vicky Martin (2015) *M is for Autism*. London: Jessica Kingsley.

Further reading

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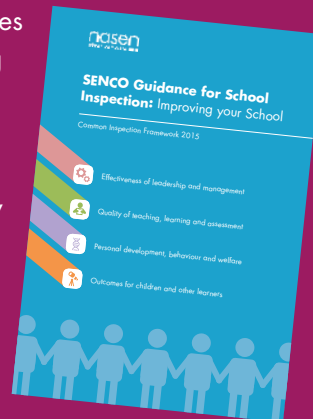
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SENCO Guidance for School Inspection: Improving your School

Written in 2015, this nasen guidance promotes school improvement for SEND by highlighting the dimensions of the Common Inspection Framework (CIF) with particular relevance to those pupils with special educational needs and/or disabilities and is organised by easily accessible sections.

- An introduction including an overview of the remit of the CIF and implications for teachers, the SENCO and school leaders
- Five sections, four relating to the areas of judgement as defined by the CIF and one of practical resources for use by the SENCO and school
- Clear explanations of each section, with ideas for appropriate sources of evidence to support each area of judgement
- Aspects which will be considered during inspection and how they relate to considerations for school self-evaluation



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