Girls on the Autism Spectrum: flying under the radar

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Girls and Autism: Flying Under the Radar

A quick guide to supporting girls with autism spectrum conditions
Girls and Autism
Flying under the radar

A Nasen miniguide written by
Jo Egerton & Barry Carpenter with members of
the National Association of Head Teachers’ ASC and Girls Forum
http://www.nasen.org.uk/resources/?tag=miniguides
ASC and Girls Forum

- hosted by the **National Association of Head Teachers**. (Chaired by Professor Barry Carpenter, CBE.)
- April 2016 – Mini-guide sponsored by nasen
- November 2016. – House of Lords Debate.
- This resulted in the Call to Action
- March 2017, DfE committed to include Autism in Girls as part of new ITT AS component.
- April 2017, Meeting with Cheryl Gillan, Chair, All Parliamentary Group on AS
- June 2017 Campaign planning, supported by NAS and AET
- July 2017. New Book agreed “Girls and Autism” (Routledge)-(To be published 2\textsuperscript{nd} April 2019.)
- January 2018, National Conference on Mental Health, organised jointly by NAHT and Royal College of Psychiatrists

Girls and Autism
Educational, Family and Personal Perspectives
Edited by Barry Carpenter, Francesca Happé and Jo Egerton
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.
Gender and autism

- ASD prevalence is approximately 1 in 100
- The gender ratio of females to males is typically reported as 1:4.
- Among intellectually able individuals with ASD – approximately 1:10
- In groups with ASD and moderate to severe learning disabilities – approximately 1:2

(Dworzynski et al. 2012; National Autistic Society 2013)
‘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, Ph.D.
Chair, National Association of Head Teachers’ ASC and Girls Forum
Where are the ‘lost girls’ with autism?

• Diagnostic overshadowing / misdiagnosis
• Delayed diagnosis
• Lack of diagnosis
‘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.’

Professor 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
Gender related factors

“We need to be aware that our understanding of the autistic brain so far is disproportionately based on autistic males.”

Meng-Chuan Lai (2019 – in press)

“What do we know about the neuroscience of autism in girls and women?”

In Carpenter, B., Happé, F. and Egerton, J. (Eds)
Girls and Autism: Educational, Family and Personal Perspectives
London: Routledge
Girls are typically diagnosed later than boys (NAS 2012) often after a secondary mental health condition.

Rae, T. and Carpenter-Hershey, G., 2019- in press.)

Autistic girls, particularly girls with HFA/AS, appear to develop coping mechanisms that mask their problems, such as becoming observers or social chameleons, or by internalising aggression and anxiety (Solomon et al, 2012).
“Girls on the Autism Spectrum are mimicking and camouflaging.....its like trying to be an Actor 24 hours a day....your brain is ‘wired differently’....and it can all lead to mental health problems.”

from and interview with Robyn Stewart, August 30th , 2016.
Personal hygiene and grooming activities such as daily washing, hair-brushing and choice of clothes are sensory challenges that may be neglected as a result, and may be particularly isolating for girls due to stereotypical gender expectations around appearance (Nichols et al. 2009).
“It’s not an illness. It’s just how I am.” “I want to make friends but I just don’t know how.” “I always felt like I was in a dark corner of a library that no-one went in.”

A pupil at Limpsfield Grange School.
“I’ve been pushed into a room and I’m stuck. I can see through the windows but I can’t open them and I don’t even know if I can see the same objects, people and colours as you. I’m just not sure. I’m locked in and I don’t have a key to get out.”

From a woman with Autism

• I had strong interests, but they were all people based. The biggest interest was with the actress Kate Winslet. I watched all her films, collected all her photos, memorised her interviews, and learnt everything about her life. For 10 years I could only think about Winslet and babies. I became interested in babies after Winslet had a child. I read parenting magazines and took detailed notes every time I saw a baby in my baby spotting diary.

• Personal Correspondence via www.barrycarpentereducation.com
“A young girl with autism may, for example, collect hundreds of identical pictures of her favourite pop star or develop an unusually encyclopaedic knowledge of fashion.”

Supporting Girls with Autism

1) Listen to parents
2) Talk to the child
3) Social anxiety
4) Calming toys
5) Introduce scripting
6) Support
“Why do I feel so different to everyone else?

I’m just trying to be normal.

How do I get normal?”
Masking

- Watching
- Suppressing
- Replicating
- “Passing” as NT
- Exhaustion
- Meltdowns /Shutdowns
- Isolation
‘Charlotte’ – What the teacher sees

Case study contributed by Felicity Sedgewick
PhD student, Centre for Research in Autism and Education, University College London

- A quiet, well-behaved 14-year-old girl in a mainstream school
- Some teaching assistant support for dyslexia
- In middle sets for all her subjects
- Sits at the back of class
- Almost never puts her hand up or answers questions
- Has a best friend
Charlotte – the reality
Case study contributed by Felicity Sedgewick
PhD student, Centre for Research in Autism and Education, University College London

- Charlotte’s behaviours – mask underlying autistic issues
- Sits at the back of class – so she can ‘work out’ what social behaviours to use by copying peers
- Good behaviour – relies on rules to make her feel safe
- Reluctance to answer questions – needs to know she can give the perfect answer (perfectionist)
- Shyness – doesn’t want to draw attention
- Best friend – developmentally younger, so fewer social demands
- Predicted to achieve good results – she feels she is struggling
- The reality – she feels isolated and permanently anxious
“Anxiety – a wild, savage beast …”
Tools for identifying anxiety

Anxiety: Where do I feel it in My body?

- Head feels fuzzy
- Sometimes I cry
- Heart beats faster
- Sweaty hands
- Butterflies in Tummy
- Need to go to the toilet more

What kind of things make me feel anxious?
- School
- Tests
- Parties
- Food
- Mum and Dad fighting

<table>
<thead>
<tr>
<th>How I feel</th>
<th>What I can do</th>
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<tbody>
<tr>
<td>5</td>
<td>Panic has set in!</td>
</tr>
<tr>
<td>4</td>
<td>I know this stuff but I can’t remember.</td>
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<tr>
<td>3</td>
<td>This test is so hard!</td>
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<tr>
<td>2</td>
<td>Okay-I have questions I might double check.</td>
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<tr>
<td>1</td>
<td>Calm- I know this</td>
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In a study by Moyse (2015) four key areas in which the hidden curriculum appeared to create difficulties for the girls were identified: 
-class rules;
-working collaboratively;
-completing tasks;
-and other interactions with peers.
“Meltdowns are not fun. It’s like being stuck on a rollercoaster for eternity .... In the dark with flashing lights. Everything stops making sense.”
Daily check ins:
5 mins problem identification
5 mins problem solving
5 minutes moving on

Sarah Wild, Headteacher, Limpsfield Grange School.
‘We’ve had the usual comments…

“Are you sure she is autistic? She makes eye contact?”

‘Look beyond the exterior and understand that [these girls] are often feeling like isolated misfits who will never be like the other girls around them.

‘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...

The daily minefield of worries… the concentration required to keep [her autism] hidden… takes up all capacity…

Broadcaster, Carrie Grant
Girls with Autism ... the future.

- “Research is urgently needed to establish rates of autism and associated needs in disadvantaged and marginalised groups such as pupils excluded from school, young people in the criminal justice system, the trafficked and homeless. It is very likely that in these groups, there are raised proportions of girls on the autism spectrum, who are un- or mis-diagnosed, misunderstood, and highly vulnerable.”

  Happe, F. (2019 – in press)

  “What does research tell us about girls on the autism spectrum?”

  In Carpenter, B. Happe, F. and Egerton, J.

  Girls and Autism.

  London: Routledge
“Just because the girls aren’t obsessed with Thomas the Tank Engine or lining things up in neat rows doesn’t mean they are not on the spectrum. Just because they can make eye contact, have a reciprocal conversation with someone for five minutes and exchange small pleasantries doesn’t mean they are not autistic. It means they’ve learned to do it. We have to redefine what we think autism is.”

“Where are the ‘lost’ girls?”
‘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.’

*Girls and Autism: Flying under the radar* (nasen miniguide)