The Hidden Face of Autism: Understanding the characteristics and needs of girls and women on the autism spectrum

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Part 1
Autism – an evolving construct
Autism: the 20\textsuperscript{th} century view

A \textbf{rare and severe} neurodevelopmental disorder, \textbf{usually associated with intellectual disability and delayed language development}, and \textbf{categorically distinct} from normal development and from other disorders.
Myth 1 – autism is rare

Under current diagnostic conventions, autism occurs in:

• 1-2% of children (Baird et al., 2006; Centers for Disease Control, 2014)
• 1-2% of adults (Brugha et al., 2016)

Myth 2 – most people with autism have intellectual disability

50-70% of people diagnosed with autism have an IQ in the normal range, and fluent language

Centers for Disease Control, 2014; Loomes et al., 2017
Myth 3 – autism is just about having difficulties

- Social relating
- Social communication
- Inflexibility
- Sensory processing

- Open-mindedness
- Pattern detection
- Expertise
- Detail-focused processing
Myth 4: autism is a categorical disorder
Myth 4: autism is a categorical disorder
Autism: the 20\textsuperscript{th} century view

A \textbf{rare and severe} neurodevelopmental disorder, \textbf{usually associated with intellectual disability and delayed language development}, and \textbf{categorically distinct} from normal development and from other disorders.
Autism: the new consensus

A relatively common, neurodevelopmental condition, usually associated with normal-range IQ, that represents a form of natural human variation, bringing both challenges and strengths.
Part 2
The Female Autism Phenotype
The diagnostic bias against girls and women on the autism spectrum

Autistic girls and women are less likely to get an autism assessment...

(Loomes et al., 2017)

...and if they do, they receive this later on average than equivalent males

(Giarelli et al., 2009)
The diagnostic bias against girls and women on the autism spectrum

And even when they do receive an assessment they are less likely to meet current diagnostic criteria, compared to males with equivalent levels of autistic traits

(Dworzynski et al. 2012; Russell et al., 2011)
Under-ascertainment of autistic females

- Bias against receiving assessment
- Bias against meeting diagnostic criteria

Individual characteristics
Why is there a diagnostic bias against autistic females?

Thanks to Tania Marshall
DSM-5 account of ASD (p.57) “girls without intellectual impairment or language delay may go unrecognized, perhaps because of subtlere manifestation of social and communication difficulties”
The female autism phenotype

1 - Social motivation

On average, autistic girls and women are more interested in the social world

Hiller et al., 2014; Head et al., 2014
The female autism phenotype
2 - Special interests
The female autism phenotype
3 - Co-occurring emotional and behavioural difficulties

Mandy et al., 2012; Westwood et al., 2017; Huke et al., 2013
Anxiety and Depression

Investigated in Millennium Cohort Study

• Longitudinal survey of 19,244 families
• 579 Children with reported autism diagnosis by age 14 years
• Male-to-female ratio = 3.5 to 1
• Completed parent-report mental health measures at multiple time points (Aged 3, 5, 7, 11 and 14 years)
The Female Autism Phenotype
4 - Later symptom onset?

• Measured in ALSPAC aged 7, 10, 13 and 16 years
• 9744 participants: males (n=4,784) and females (n=4,960)
• Data modeled using:
  • Latent growth curve analysis
  • Growth mixture models

Jon Heron (Bristol) and Liz Pellicano (UCL, IoE)
AT growth for males and females

Multi-group (i.e., male and female) latent growth curve model with intercept, slope and quadratic term. CFI=.99; TLI=.99; aBIC=145190.6; RMSEA=.024 (upper bound=.033).
The female autism phenotype

5 - Camouflaging

“Putting on my best normal”
Hull et al., 2017

“Masking encompasses the aspects of camouflaging that focus on hiding one’s ASC characteristics and developing different personas or characters to use during social situations”

“Compensation developing explicit strategies to meet the social and communication challenges resulting from an individual’s ASC”

Reflecting: Wing (1981); Gillberg, 1991; Mandy et al., 2012; Lai et al., 2016; Livingston et al., 2017; Dean et al., 2016; National Autistic Society ‘Autism in Pink’ project.
Camouflage
<table>
<thead>
<tr>
<th>Who camouflages?</th>
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<tbody>
<tr>
<td>Autistic people camouflage more than non-autistic people (Hull et al., 2018)</td>
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<tr>
<td>There is substantial variability amongst autistic people in how much they camouflage (Lai et al., 2016; Livingston et al., 2018; Hull et al., in prep)</td>
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<tr>
<td>- Autism trait severity (Hull et al., in prep)</td>
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<td>- IQ (Livingston et al., 2018)</td>
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<td>- Executive function (Livingston et al., 2018)</td>
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Sex/gender and camouflaging

Do autistic females camouflage more than autistic males?
• Yes! But this is only a medium/large sized effect ($d = 0.6 – 1.0$)
• This finding fits with other methods of measuring camouflaging (Ratto et al., 2017; Dean et al., 2016; Lai et al., 2016)
Fig. 1 Thematic map of the three stages (motivations, camouflaging, and consequences) of the camouflaging process. Themes are indicated by rectangles; subthemes by ovals.
Why do people camouflage?

• “Camouflaging helps to survive in school and college and it is important for keeping jobs” F27
• “I want to avoid the bullying mostly” F48
• “It enables me to be with other people in a way that is relatively comfortable for me and for them” F56
Fig. 1 Thematic map of the three stages (motivations, camouflaging, and consequences) of the camouflaging process. Themes are indicated by rectangles; subthemes by ovals.
What are the consequences of camouflaging?

• “It’s exhausting! I feel the need to seek solitude so I can ‘be myself’ and not have to think about how I am perceived by others.” O30

• “I went for so long without being diagnosed because they didn’t know that I could pretend to be normal!” F20

• “People need to learn how to drop the camouflage when in situations such as medical assessments or dealing with support professionals” F28

• “I feel as though I’ve lost track of who I really am, and that my actual self is floating somewhere above me like a balloon” F22
Costs of camouflaging

Good social skills despite poor theory of mind: exploring compensation in autism spectrum disorder

Lucy Anne Livingston,1 Emma Colvert,1 the Social Relationships Study Team, Patrick Bolton,2 and Francesca Happe1

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Higher camouflaging is associated with higher anxiety
Understanding the Reasons, Contexts and Costs of Camouflaging for Autistic Adults

Eilidh Cage¹ • Zoe Troxell-Whitman¹
Higher camouflaging is associated with higher suicidality
Autism: the new consensus

A relatively common, neurodevelopmental condition with a gender-specific presentation, usually associated with normal-range IQ, that represents a form of natural human variation, bringing both challenges and strengths.
This talk included consideration of social camouflage in autism.

Our group have recently developed a self-report measure of social camouflage in teens and adults, called the Questionnaire of Camouflaging Autistic Traits (Q-CAT)

The Q-CAT is free to use.

If you would like a copy, please email Dr Will Mandy

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