

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 20th century view

A rare and severe neurodevelopmental disorder, usually associated with intellectual disability and delayed language development, and categorically distinct from normal development and from other disorders.

Myth 1 – autism is rare

Under current diagnostic conventions, autism occurs in:

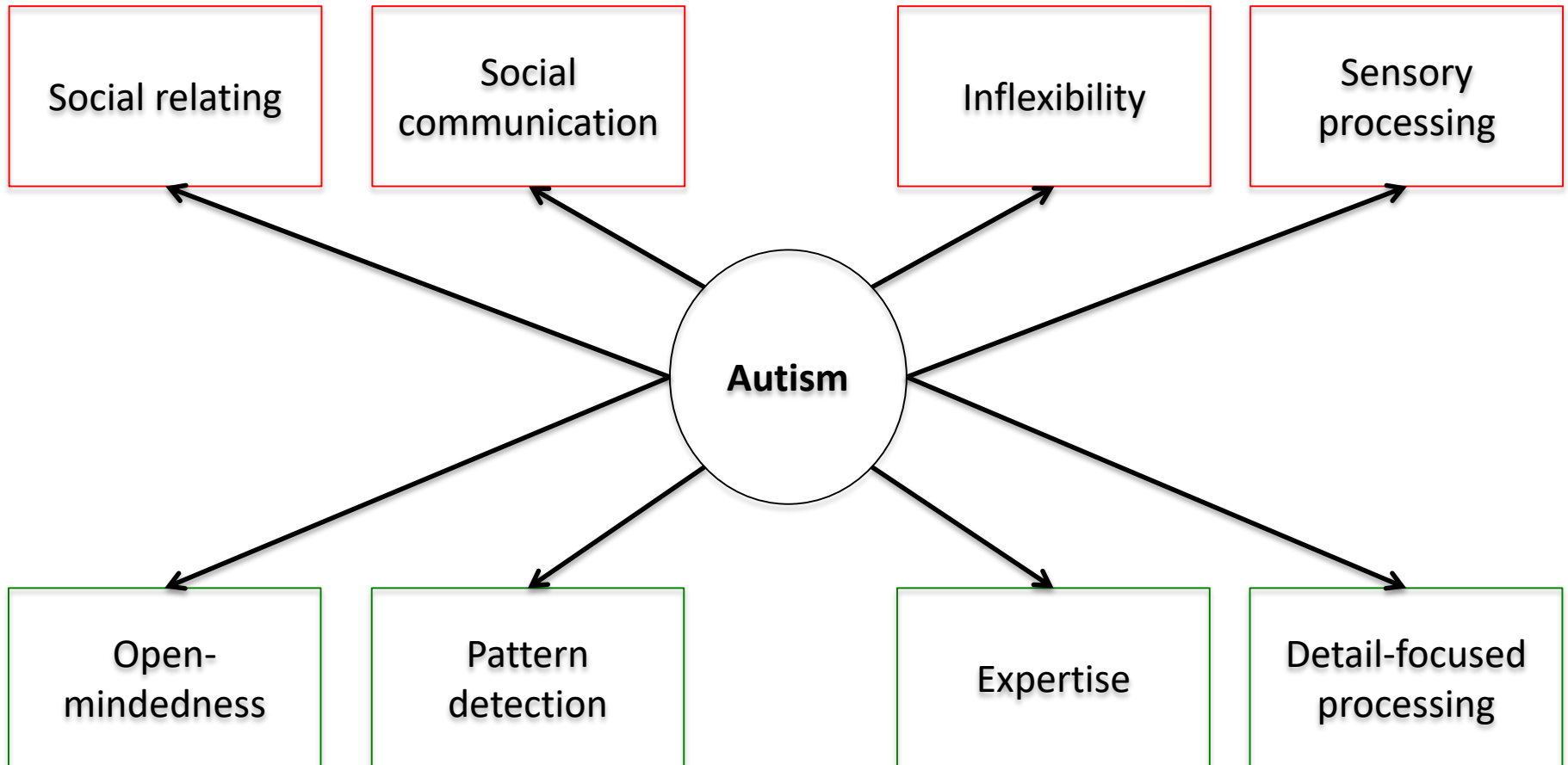
- 1-2% of children (Baird et al., 2006; Centers for Disease Control, 2014)
- 1-2% of adults (Brugha et al., 2016)

Myth 2 – most people with autism have intellectual disability

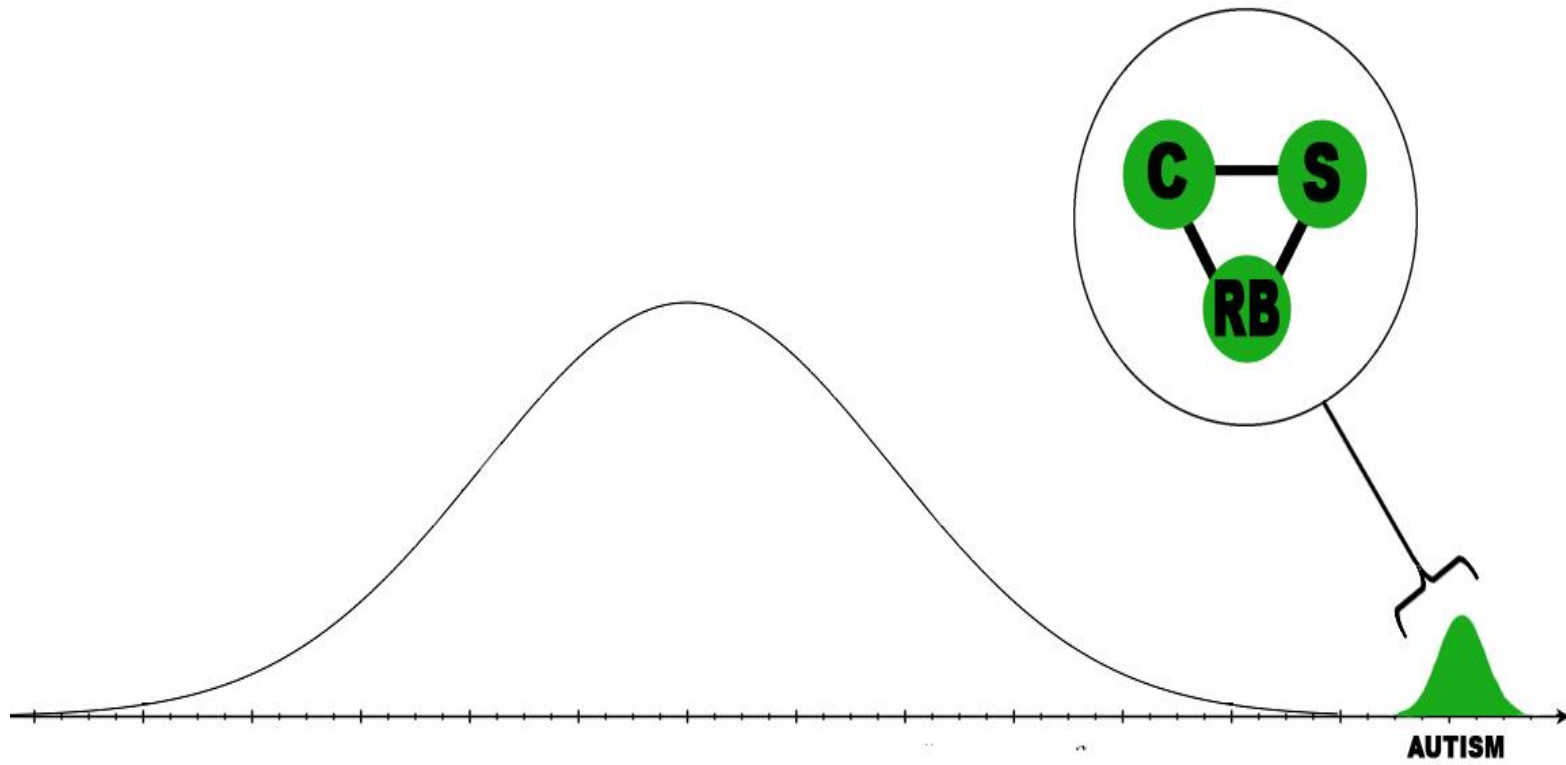
50-70% of people diagnosed with autism have an IQ in the normal range, and fluent language

Centers for Disease Control, 2014; Loomes et al., 2017

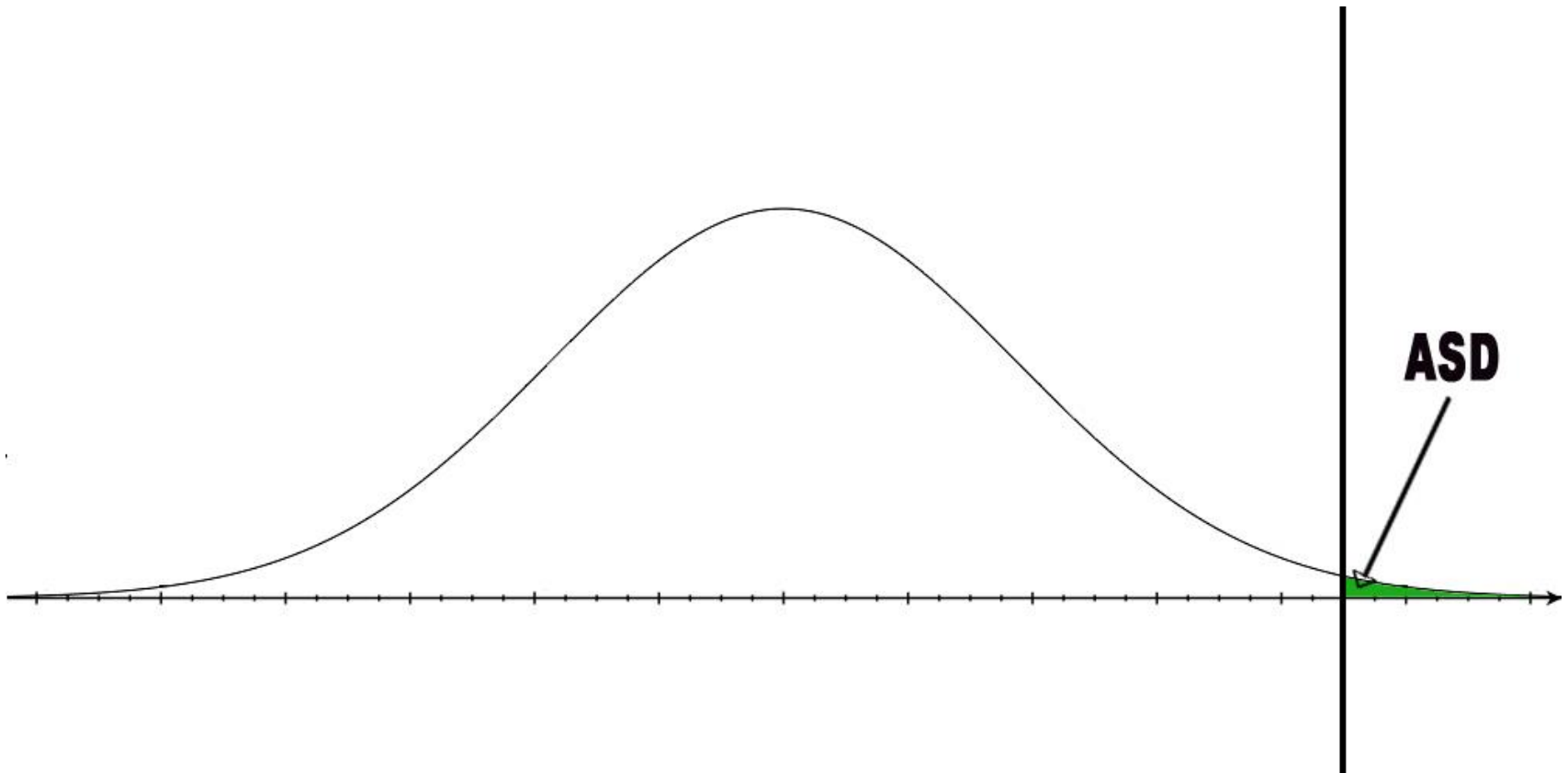
Myth 3 – autism is just about having difficulties



Myth 4: autism is a categorical disorder



Myth 4: autism is a categorical disorder



Autism: the 20th century view

A rare and severe neurodevelopmental disorder, usually associated with intellectual disability and delayed language development, and 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)

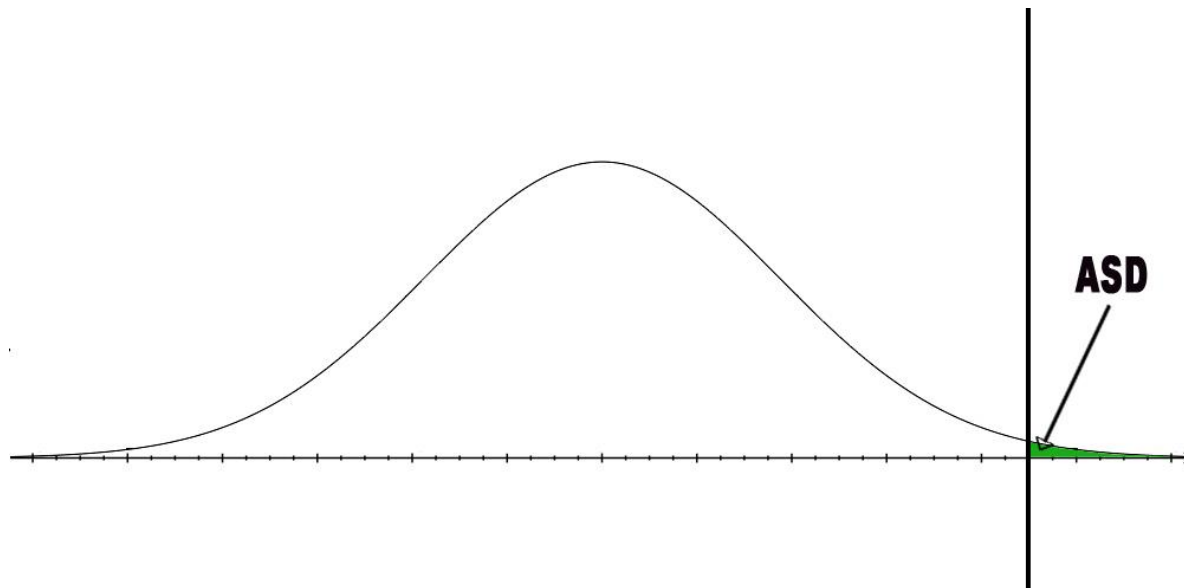
...and if they do, they receive this later on average than equivalent males

(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

The diagram consists of a central green oval at the bottom containing the text 'Individual characteristics'. Two white arrows with black outlines point upwards from the top of this oval towards two red-bordered boxes above. The left box contains the text 'Bias against receiving assessment' and the right box contains 'Bias against meeting diagnostic criteria'. The entire top section is enclosed in a larger light-brown box with a thin blue border.

Why is there a diagnostic bias against autistic females?



Thanks to Tania Marshall

DIAGNOSTIC AND STATISTICAL
MANUAL OF
MENTAL DISORDERS

FIFTH EDITION

DSM-5

AMERICAN PSYCHIATRIC ASSOCIATION

DSM-5 account
of ASD (p.57)
*“girls without
intellectual
impairment or
language delay
may go
unrecognized,
perhaps because
of subtler
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



$$\begin{aligned} &= 2\pi \int_0^{\sqrt{3}} x\sqrt{1+(2x)^2} dx \\ &= \frac{2\pi}{8} \int_0^{\sqrt{2}} (1+4x^2)^{1/2} (8x) \\ &\quad \pi \left[(1+4x^2)^{3/2} \right]_0^{\sqrt{3}} \end{aligned}$$



The female autism phenotype

3 - Co-occurring emotional and behavioural difficulties



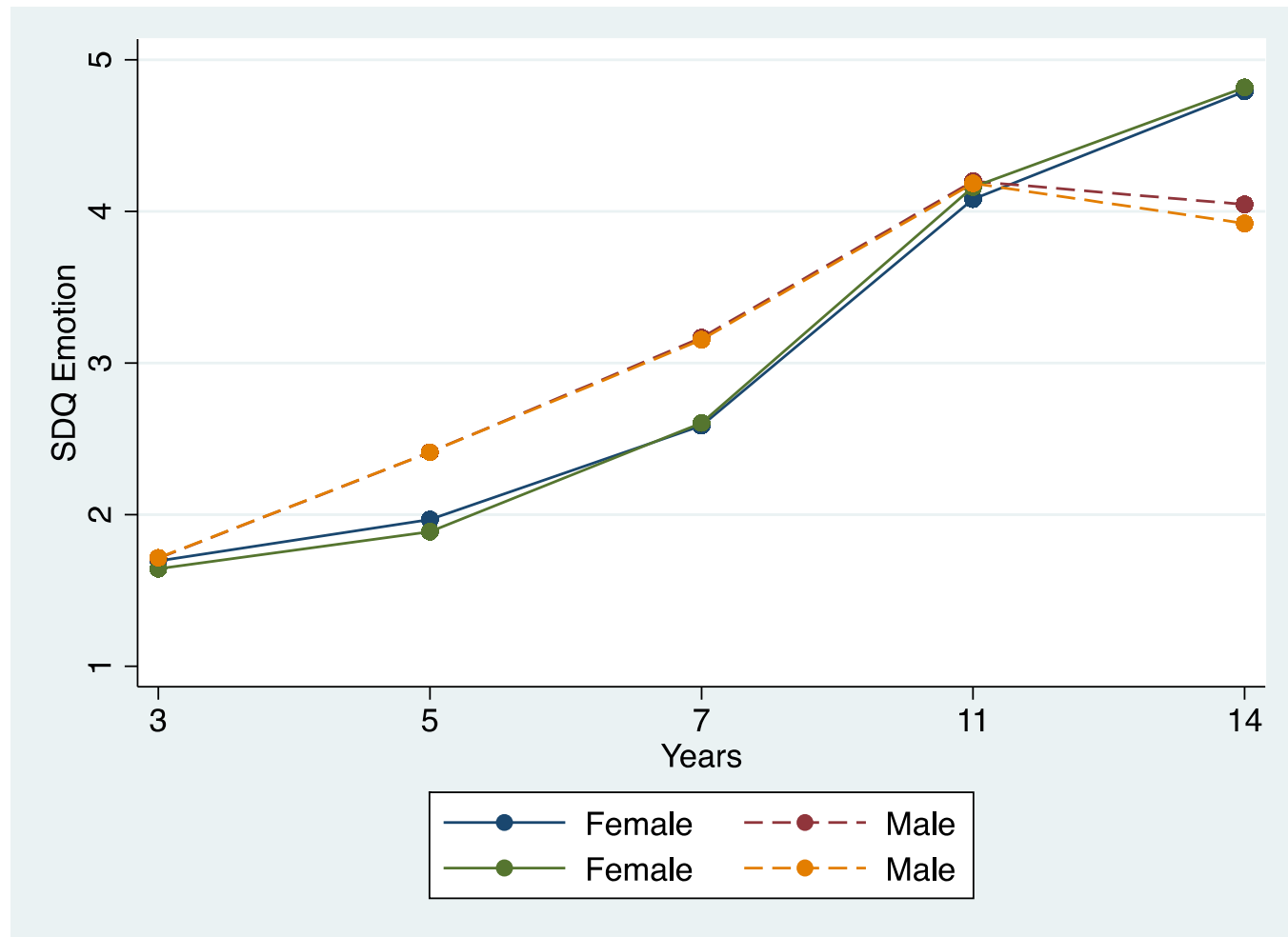
Mandy et al., 2012; Westwood et al., 2017; Huke et al., 2013

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)

Anxiety and Depression



The Female Autism Phenotype

4 - Later symptom onset?

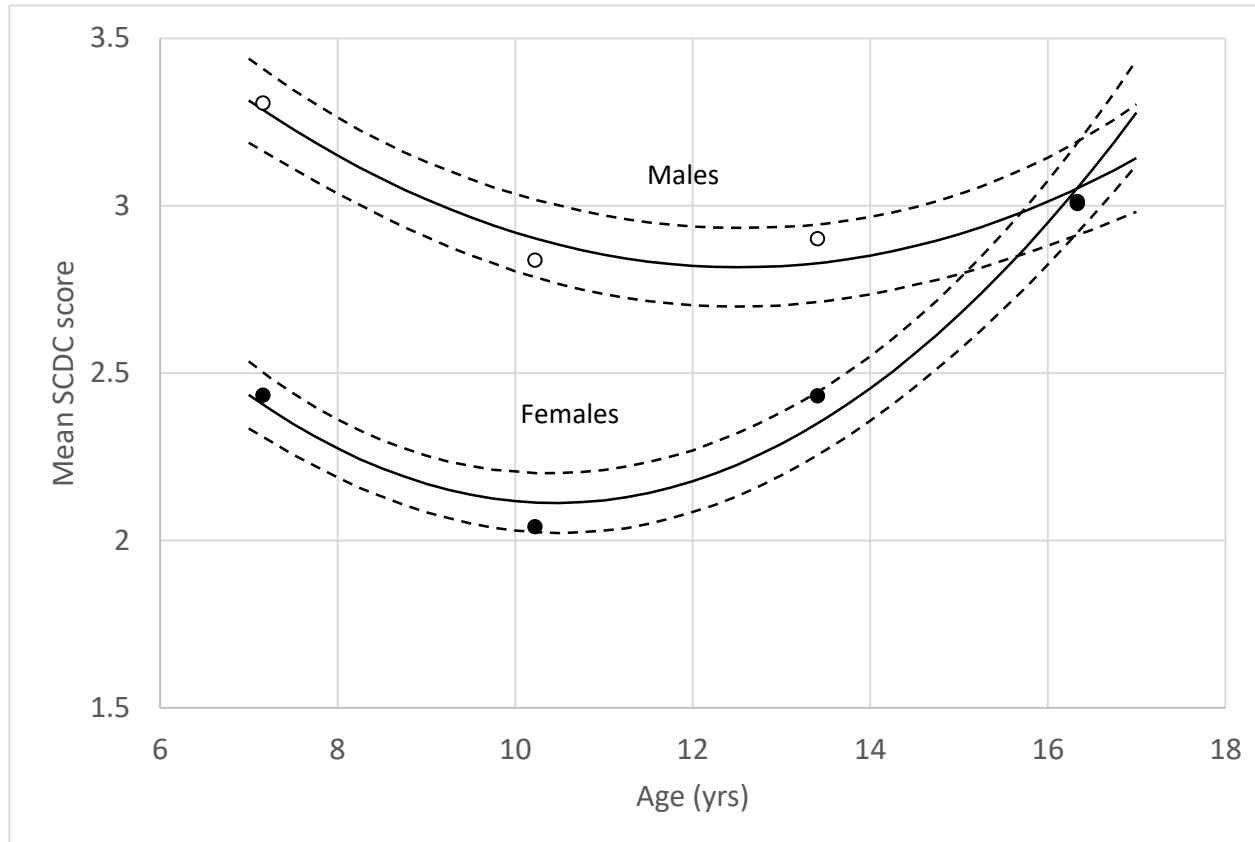


- Measured in ALSPAC aged 7, 10, 13 and 16 years
- 9744 participants: males (n=4,784) and females (n=4,960)
- Data modeled using:
 - Latent growth curve analysis
 - Growth mixture models



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”

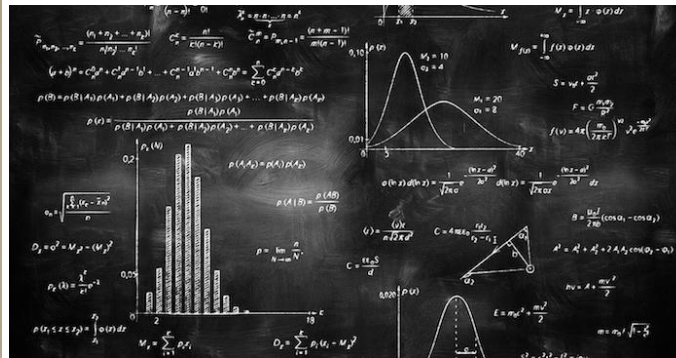
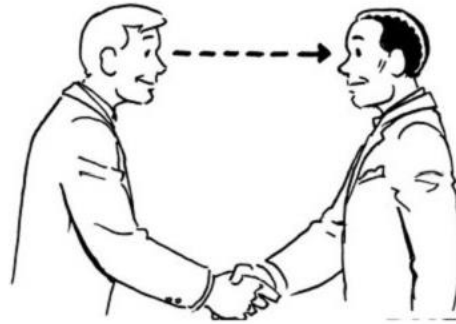
Hull et al. ,2017

“**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



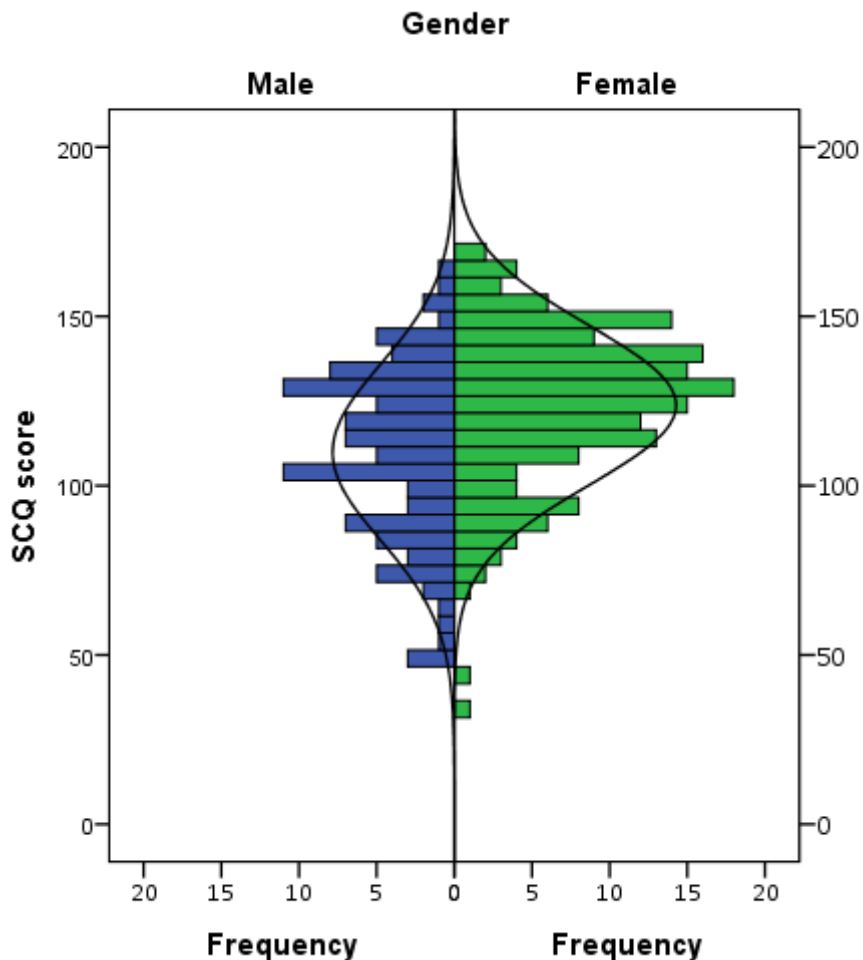
Who camouflages?

Autistic people camouflage more than non-autistic people (Hull et al., 2018)

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)

- Autism trait severity (Hull et al., in prep)
- IQ (Livingston et al., 2018)
- Executive function (Livingston et al., 2018)

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)

Hull et al., 2017

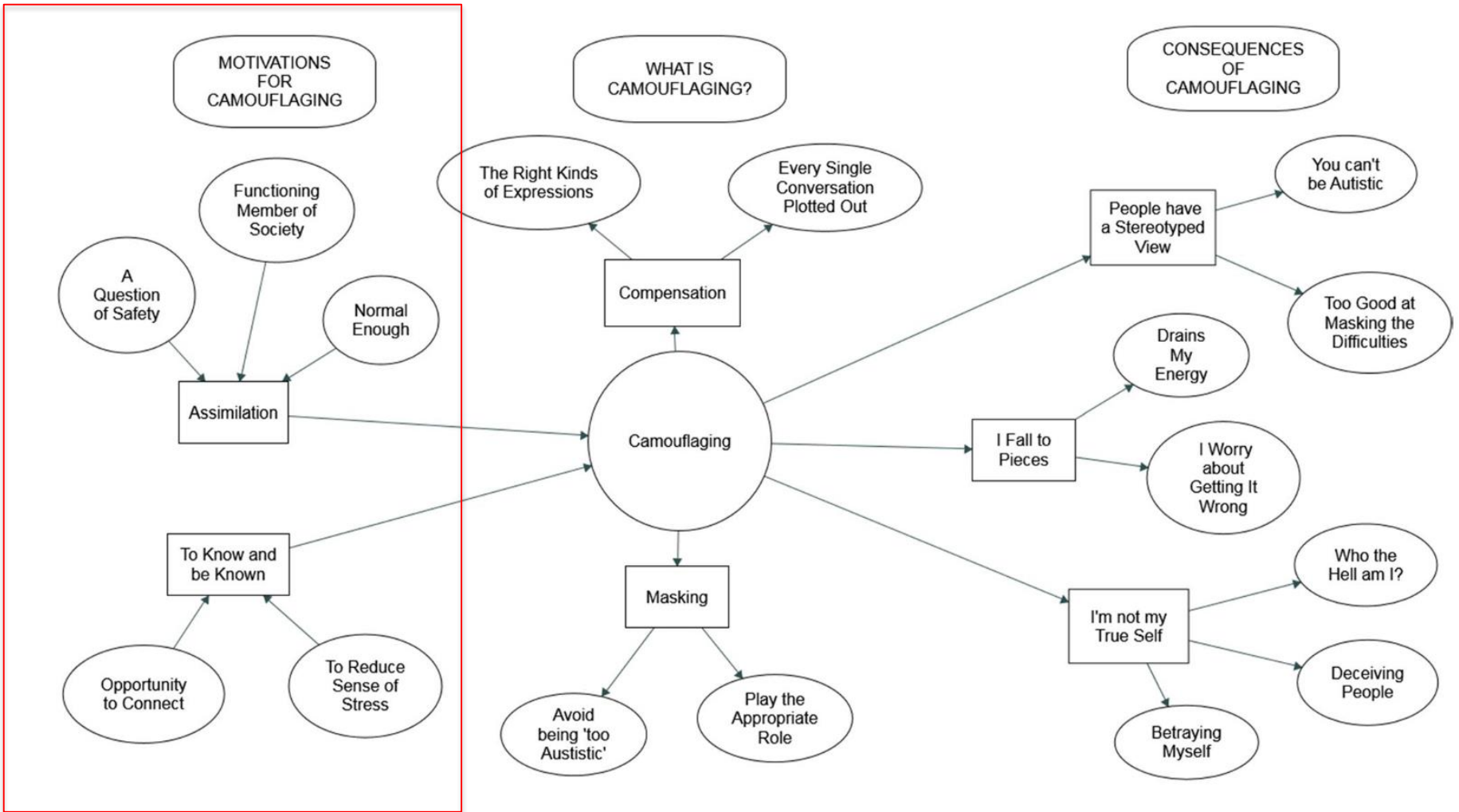


Fig. 1 Thematic map of the three stages (motivations, camouflaging, and consequences) of the camouflaging process. Themes are indicated by rectangles; subthemes by ovals

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

Hull et al., 2017

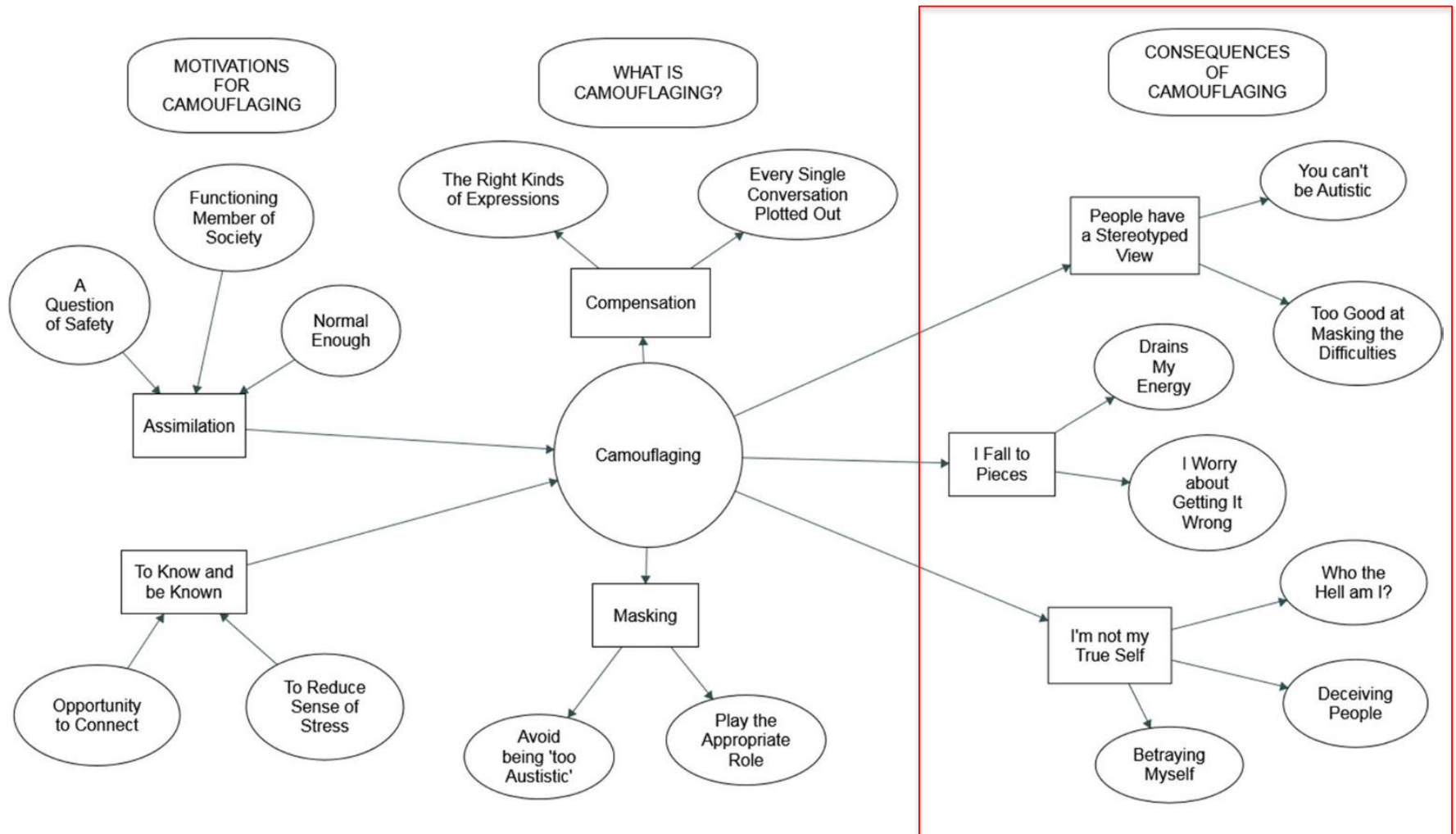


Fig. 1 Thematic map of the three stages (motivations, camouflaging, and consequences) of the camouflaging process. Themes are indicated by rectangles; subthemes by ovals

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 camou age 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 Happé¹**

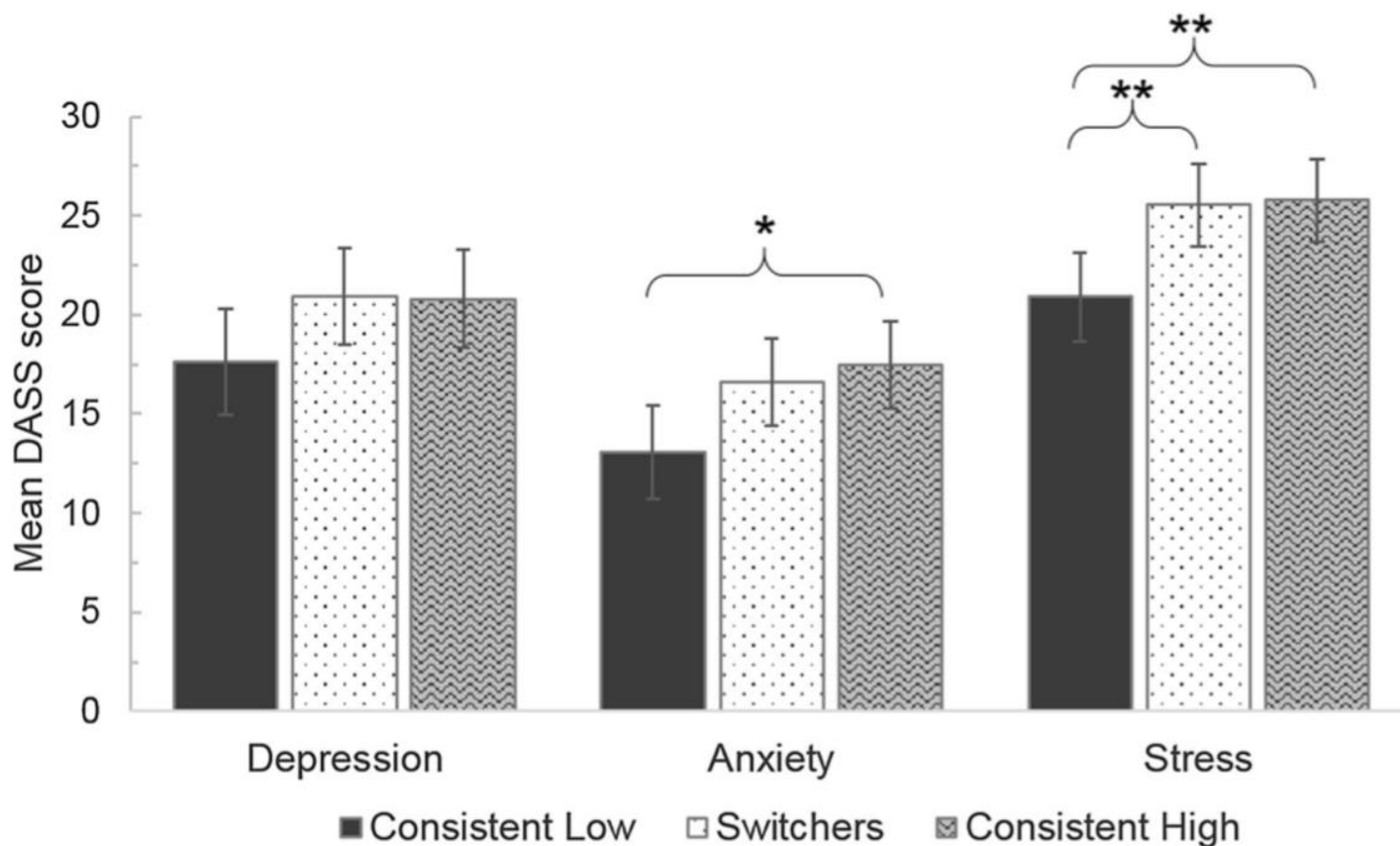
¹Social, Genetic and Developmental Psychiatry Centre, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London; ²Department of Child and Adolescent Psychiatry, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK

Higher camouflaging is associated with
higher anxiety



Understanding the Reasons, Contexts and Costs of Camouflaging for Autistic Adults

Eilidh Cage¹ · Zoe Troxell-Whitman¹



RESEARCH

Open Access

Risk markers for suicidality in autistic adults



Sarah Cassidy^{1,2,3*} , Louise Bradley², Rebecca Shaw^{2,4} and Simon Baron-Cohen^{3,5}

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 camouflaging in autism.

Our group have recently developed a self-report measure of social camouflaging 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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