Autism – an evolving construct

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Plan

• Autism – the old model and the new model
• DSM-5
  – Triad to dyad
  – The end of Asperger’s syndrome
The birth of autism

Leo Kanner (1894-1981)

Donald

“happiest when left alone, almost never cried to go with his mother...wandered about smiling, making stereotyped movements with his fingers...spun with great pleasure anything he could seize upon to spin....Words to him had a specifically literal, inflexible meaning....When taken into a room, he completely disregarded the people and instantly went for objects”
“Since 1938, there have come to our attention a number of children whose condition differs so markedly...from anything reported so far, that each case merits...a detailed consideration of its fascinating peculiarities.”

1. “Inborn autistic disturbances of affective contact’
2. “Powerful desire for...sameness”
Autism: the 20th century view

A rare and severe neurodevelopmental disorder that mainly affects males, usually associated with intellectual disability and delayed language development, and categorically distinct from normal development and from other disorders.
Myth 1: autism is rare

See also Brugha et al., 2011
Myth 2
“Most people with an autism have a learning disability”

50-70% of people diagnosed with autism have an IQ>70

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

Keyes et al. (2012)
California 1992 - 2003
Under-representation of ID in autism research

All autism studies published in autism Journals (IF>3) in 2016: 229 studies (N=85,429) of which 119 reported info on IQ/ID

<table>
<thead>
<tr>
<th>Field</th>
<th>Total N</th>
<th>Studies where over 75% of sample had No ID</th>
<th>Studies where entire sample had No ID</th>
<th>Mean participant IQ, (n)</th>
<th>Estimated % of ASD participants without ID ^1, (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>8</td>
<td>5</td>
<td>4</td>
<td>83 (8)</td>
<td>90 (60, 100)</td>
</tr>
<tr>
<td>Biology</td>
<td>21</td>
<td>19</td>
<td>12</td>
<td>101 (21)</td>
<td>97 (91, 100)</td>
</tr>
<tr>
<td>Epidemiology</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>-</td>
<td>90 (57, 100)</td>
</tr>
<tr>
<td>Psychology</td>
<td>58</td>
<td>50</td>
<td>31</td>
<td>93 (57)</td>
<td>97 (93, 99)</td>
</tr>
<tr>
<td>Social</td>
<td>10</td>
<td>8</td>
<td>5</td>
<td>97 (6)</td>
<td>89 (83, 95)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>17</td>
<td>14</td>
<td>3</td>
<td>94 (10)</td>
<td>88 (80, 94)</td>
</tr>
<tr>
<td>Overall</td>
<td>119</td>
<td>99</td>
<td>57</td>
<td>92</td>
<td>95 (92, 98)</td>
</tr>
</tbody>
</table>

Russell, Mandy....& Ford, (under review)
Myth 3: Autism is a categorical disorder

Autism as a category distinct from other disorders and from typical development
The dimensional syndrome model
Autistic traits: a key risk factor in developmental psychopathology

- Conduct problems (e.g., Mandy et al., 2013)
- Anxiety (e.g., Pickard et al., 2017)
- Depression (e.g., Lundstrom et al., 2012)
- Hyperactivity/inattention (e.g., St Pourcain et al., 2011)
- Peer problems (e.g., Skuse et al., 2009)

Risk was observed across the full AST severity gradient (Skuse et al., 2009)
Myth 4: Autism is a male condition

Autistic females are more likely to be:

- Overlooked (Loomes et al., 2017)
- Misunderstood (e.g., Wikramanayake et al., 2017)
- Diagnosed late (e.g., Mandell et al., 2005)

We have tended to underestimate the number of autistic females, compared to males.

DSM-5 states the male-to-female ratio is 4-to-1

Really it is 3-to-1 or lower (Loomes et al., 2017)
The female autism phenotype

Thanks to Tania Marshall for the picture
Higher Social Motivation
(e.g. Hiller et al., 2014)

The Female autism phenotype
The Female autism phenotype

Higher Social Motivation
(e.g. Hiller et al., 2014)

More typical, and gender-stereotyped, interests
(e.g. Hiller et al., 2014)
Higher Social Motivation
(e.g. Hiller et al., 2014)

More typical, and gender-stereotyped interests
(e.g. Hiller et al., 2014)

Greater vulnerability to emotional difficulties (including eating disorder)
(e.g. Mandy et al., 2012; Mandy & Tchanturia, 2015)
AN and ASC

Prof Christopher Gillberg (1985)

For review of the Gothenburg studies, see Huke et al., 2013

Table 4  Categorical prevalence of autism spectrum disorders in eating disorder populations

<table>
<thead>
<tr>
<th>Study</th>
<th>Prevalence rate of autism spectrum disorders (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Råstam (1992)</td>
<td>8</td>
</tr>
<tr>
<td>Gillberg et al. (1995)</td>
<td>37</td>
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<tr>
<td>Wentz Nilsson et al. (1998)</td>
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<tr>
<td>Wentz Nilsson et al. (1999)</td>
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<td>Råstam et al. (2003), Study 1</td>
<td>20</td>
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<tr>
<td>Råstam et al. (2003), Study 3</td>
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<tr>
<td>Wentz et al. (2005)</td>
<td>23</td>
</tr>
<tr>
<td>Anckarsäter et al. (2011)</td>
<td>28</td>
</tr>
</tbody>
</table>

NB. It must be noted that the comorbid disorders are also included in the analysis of Gillberg et al. (1995) (cluster C personality disorder).
But we need to be cautious...

The Minnesota Starvation Experiment (Keys et al., 1950)
The link between autism and AN

Use of gold standard measures (e.g., Westwood, Mandy Tchanturia, 2017)

Use of historical report (Vagni et al., 2016)

Findings in recovered samples (e.g., Anckarsäter et al., 2011)

20 to 30% of women with AN are autistic
The Female autism phenotype

- Higher Social Motivation (e.g. Hiller et al., 2014)
- Greater capacity to ‘camouflage’ autistic difficulties (Lai et al., 2011)
- More typical, and gender-stereotyped, interests (e.g. Hiller et al., 2014)
- Greater vulnerability to emotional difficulties (including eating disorder) (e.g. Mandy et al., 2012; Mandy & Tchanturia, 2015)
What is 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 gaps resulting from an individual’s ASC Body language”

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
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
Plan for the talk

• What is camouflaging?
  – And how can we measure it?

• Who camouflages?
  – Do autistic females camouflage more than autistic males?

• Why do people camouflage?

• What are the consequences of camouflaging?
  – To what extent is camouflaging a good or bad thing?
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

Quantifying and exploring camouflaging in men and women with autism

Meng-Chuan Lai¹,²,³,⁴,⁵, Michael V Lombardo⁴,⁶, Amber NV Ruigrok⁴, Bhismadev Chakrabarti⁴,⁷, Bonnie Auyeung⁴,⁸, Peter Szatmari¹,²,³, Francesca Happé⁹ and Simon Baron-Cohen⁴,¹⁰; MRC AIMS Consortium

Higher camouflaging is associated with depression, in men but not women
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
Costs of camouflaging

Q-CAT scores are associated with:
• Depression (as measured by PHQ-9)
• Generalised anxiety (as measured by the GAD-7)
• Social Anxiety (as measured by the LSAS) (controlling for autism trait severity)
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.
Plan

• Autism – the old model and the new model
• DSM-5
  – Triad to dyad
  – The end of Asperger’s syndrome
The end of the triad

Reciprocal Social Interaction

- Communication
- Repetitive interests, activities and behaviours

Autism (1980-2013)

Social communication

Repetitive behaviour and sensory interests

Autism (2013-?)
The lumping of ASD in DSM-5

- Autism
- Asperger’s disorder
- PDD-NOS

Autism Spectrum Disorder
Against merging AsD and AD

“I think it’s probably easier for [my son] when he’s older to say he’s got Asperger's rather than autism because of what people are going to think about it at work and things like that.”

“To lump the two into the same category just seems unfair to [my son]. In that respect I wish there were more categories because [he’s] got mild Asperger's as opposed to full-blown Asperger's”
James has autism: what might he be like?

1. Intellectually impaired - 18%
2. Anxious - 11%
3. Difficult to manage - 57%
4. Clever - 12%
5. Kind - 1%
6. Scary - 1%
James has Asperger’s: what might he be like?

1. Intellectually impaired: 4%
2. Anxious: 18%
3. Difficult to manage: 40%
4. Clever: 38%
5. Kind: 0%
6. Scary: 0%
• Autism continues to evolve as a diagnostic entity
• DSM-5 largely captures the most important of these changes...
• As will ICD-11