

# Restrictive eating and life on the autism spectrum

Mair Elliott & Will Mandy

[w.mandy@ucl.ac.uk](mailto:w.mandy@ucl.ac.uk)

@willclinpsy

# Outline of the talk

- ① Autism: the old view versus the new view
- ② Autism and Anorexia Nervosa (and other restrictive eating problems)
- ③ Assessing females with restrictive eating problems to see if they are autistic
- ④ Helping autistic females with anorexia

# What's in a name?

Person first – ‘a person with autism’

V

Identity first – ‘an autistic person’

Martin: *‘I’m an autistic person, but a person with OCD and generalised anxiety disorder’*

*Original Article*



# **Which terms should be used to describe autism? Perspectives from the UK autism community**

**Lorcan Kenny<sup>1</sup>, Caroline Hattersley<sup>2,3</sup>, Bonnie Molins<sup>2</sup>,  
Carole Buckley<sup>4</sup>, Carol Povey<sup>2</sup> and Elizabeth Pellicano<sup>1,5</sup>**

Autism

1–21

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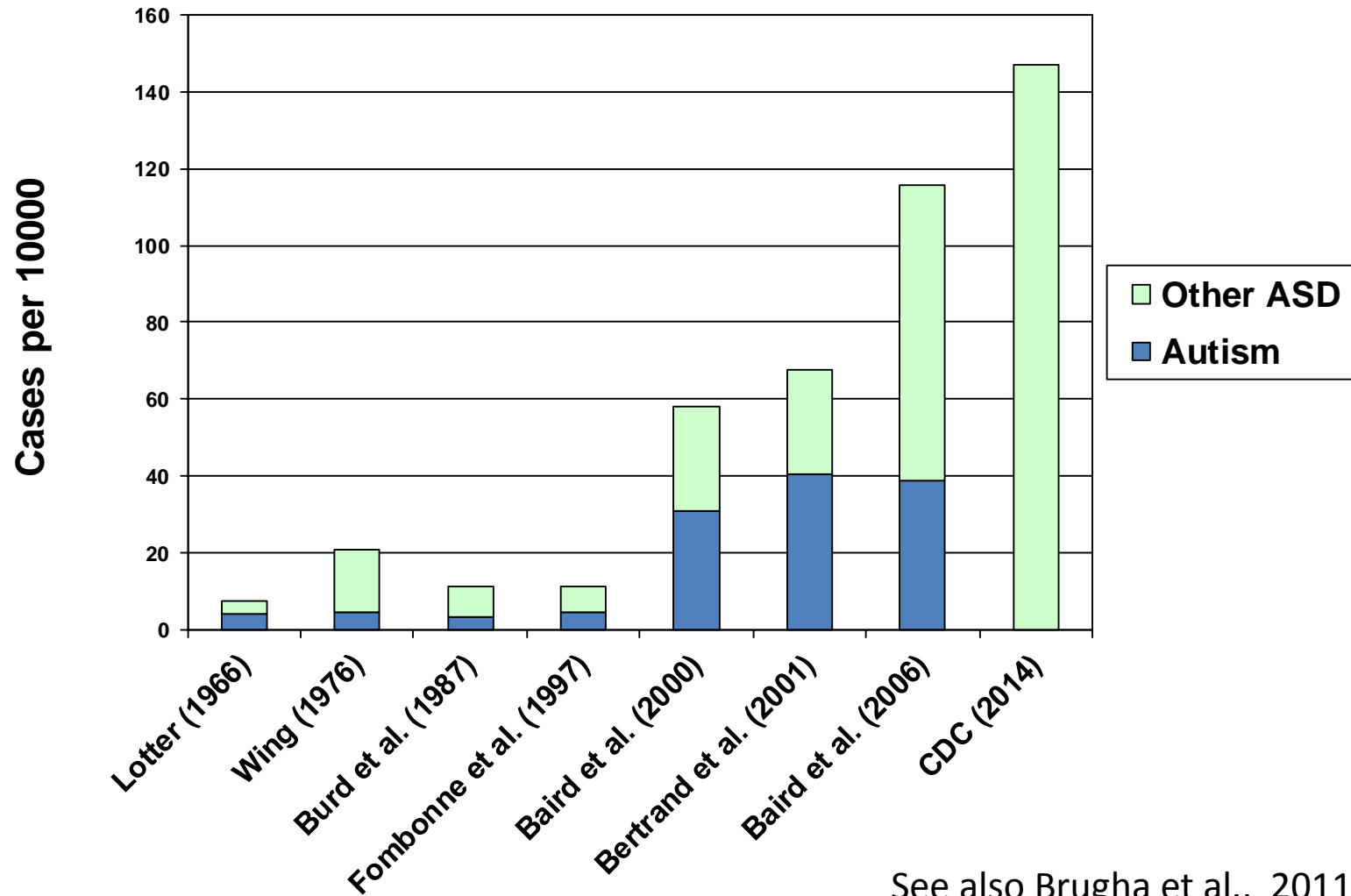
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# Autism: the 20<sup>th</sup> century view

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.

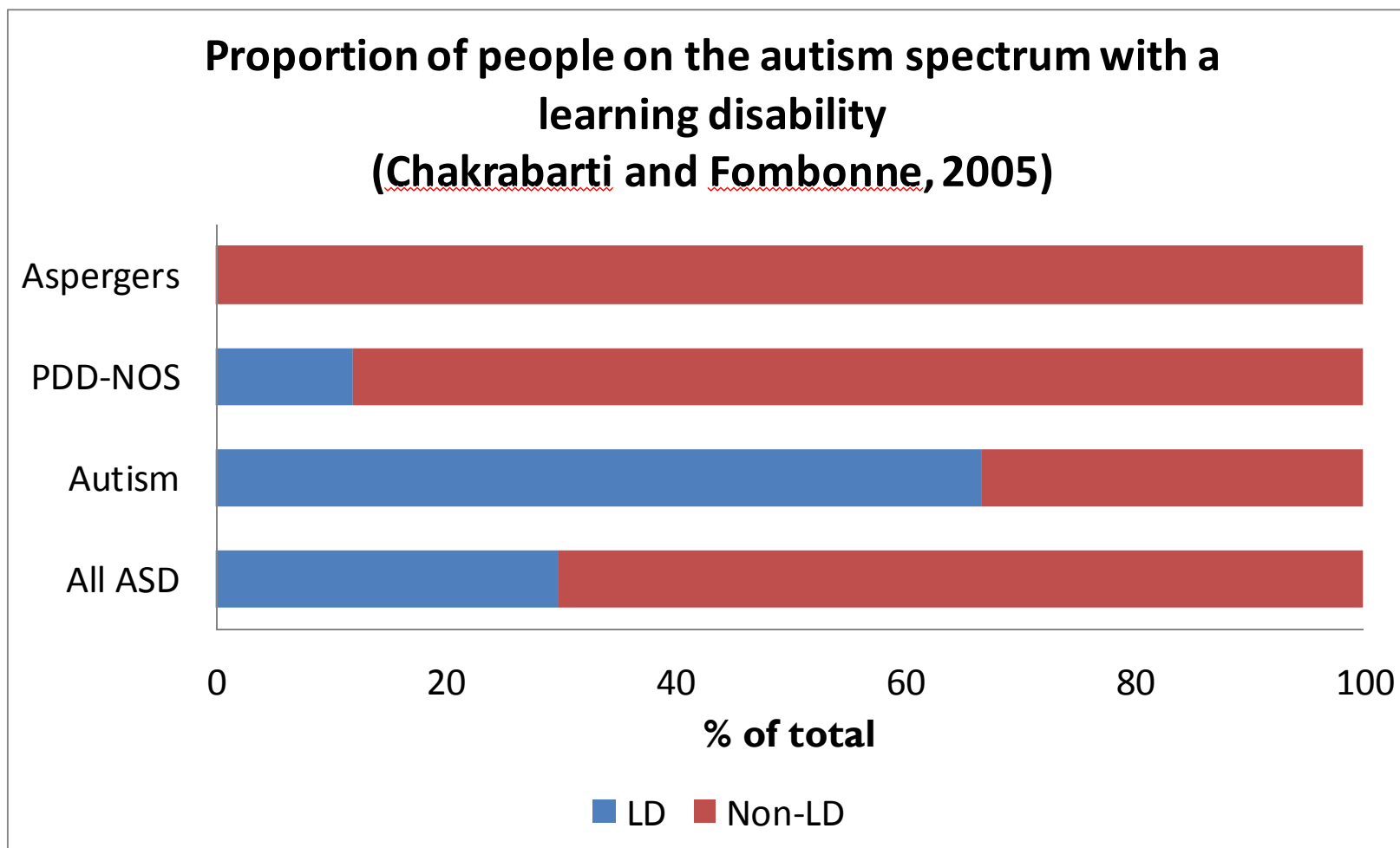
# Myth 1: autism is rare



See also Brugha et al., 2011

## Myth 2

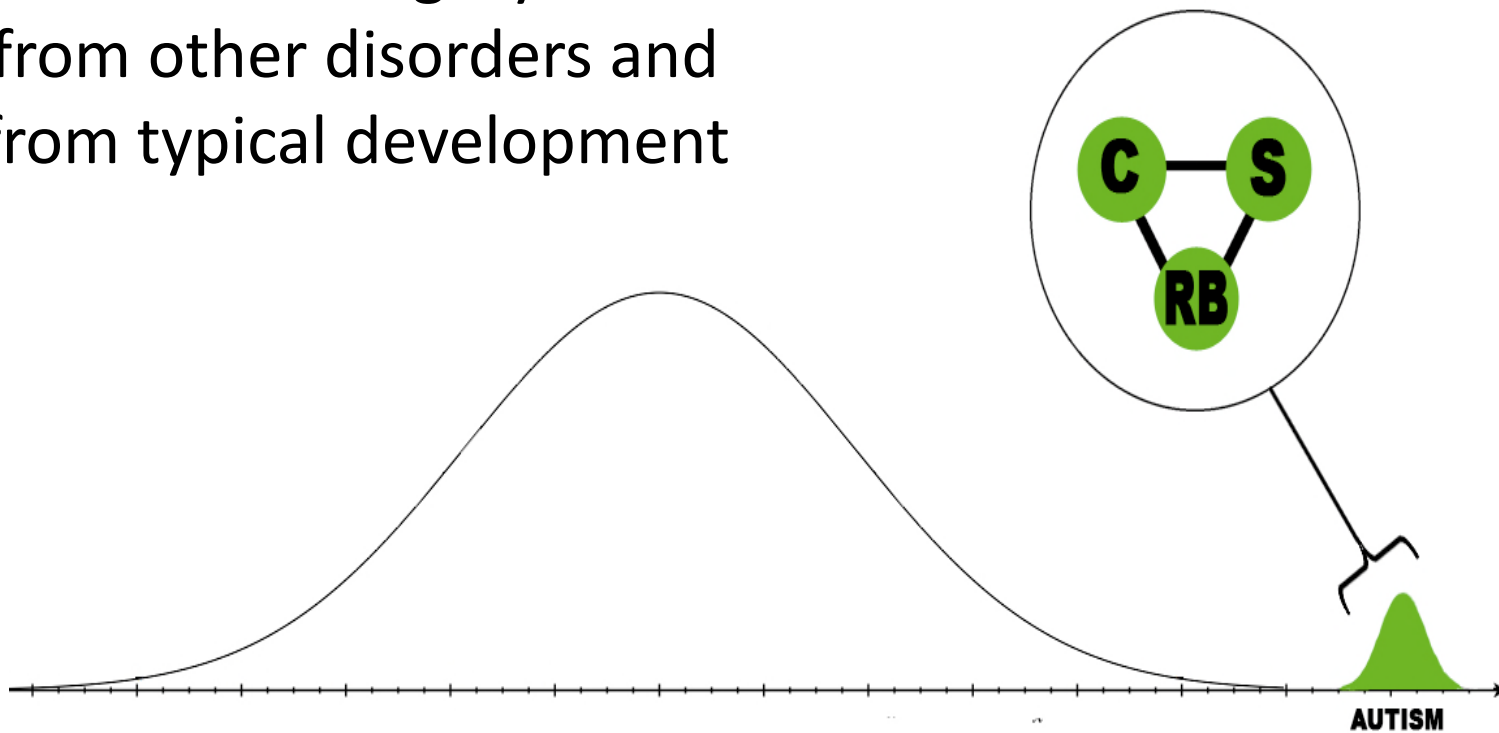
“Most people with an autism have a learning disability”



# Myth 3:

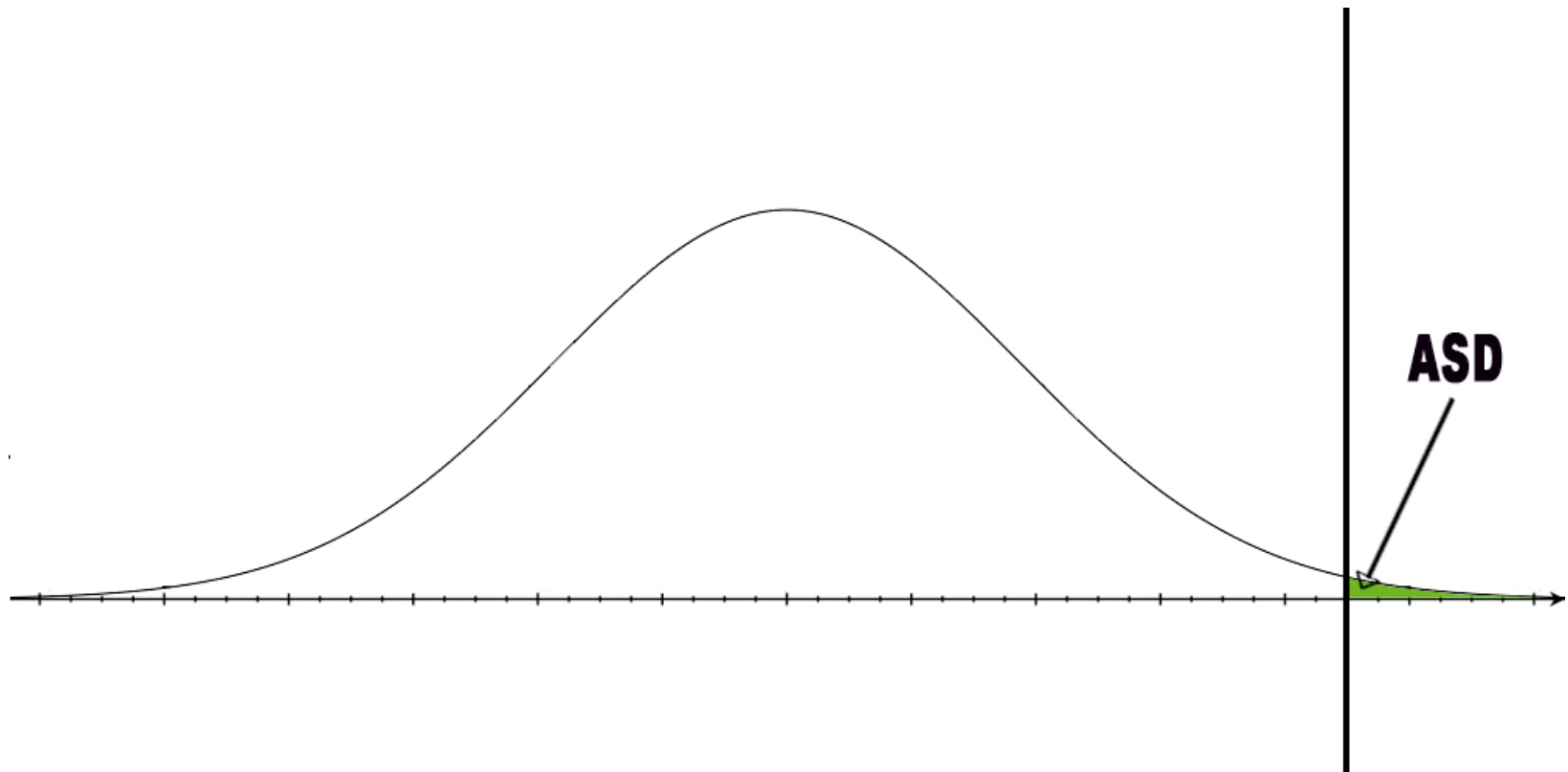
## Autism is a categorical disorder

Autism as a category distinct  
from other disorders and  
from typical development





# The dimensional syndrome model



# 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

# Camouflage

The **masking** of autism behaviours in social  
situations  
and/or  
the performance of behaviours to **compensate** for  
difficulties associated with autism

“Putting on my best normal”

Hull et al. ,2017

Reflecting Mandy et al., 2012; Mandy & Tchanturia,  
2015; Lai et al., 2011; Lai et al., 2015; National Autistic  
Society ‘Autism in Pink’ project

# Camouflage

## Masking

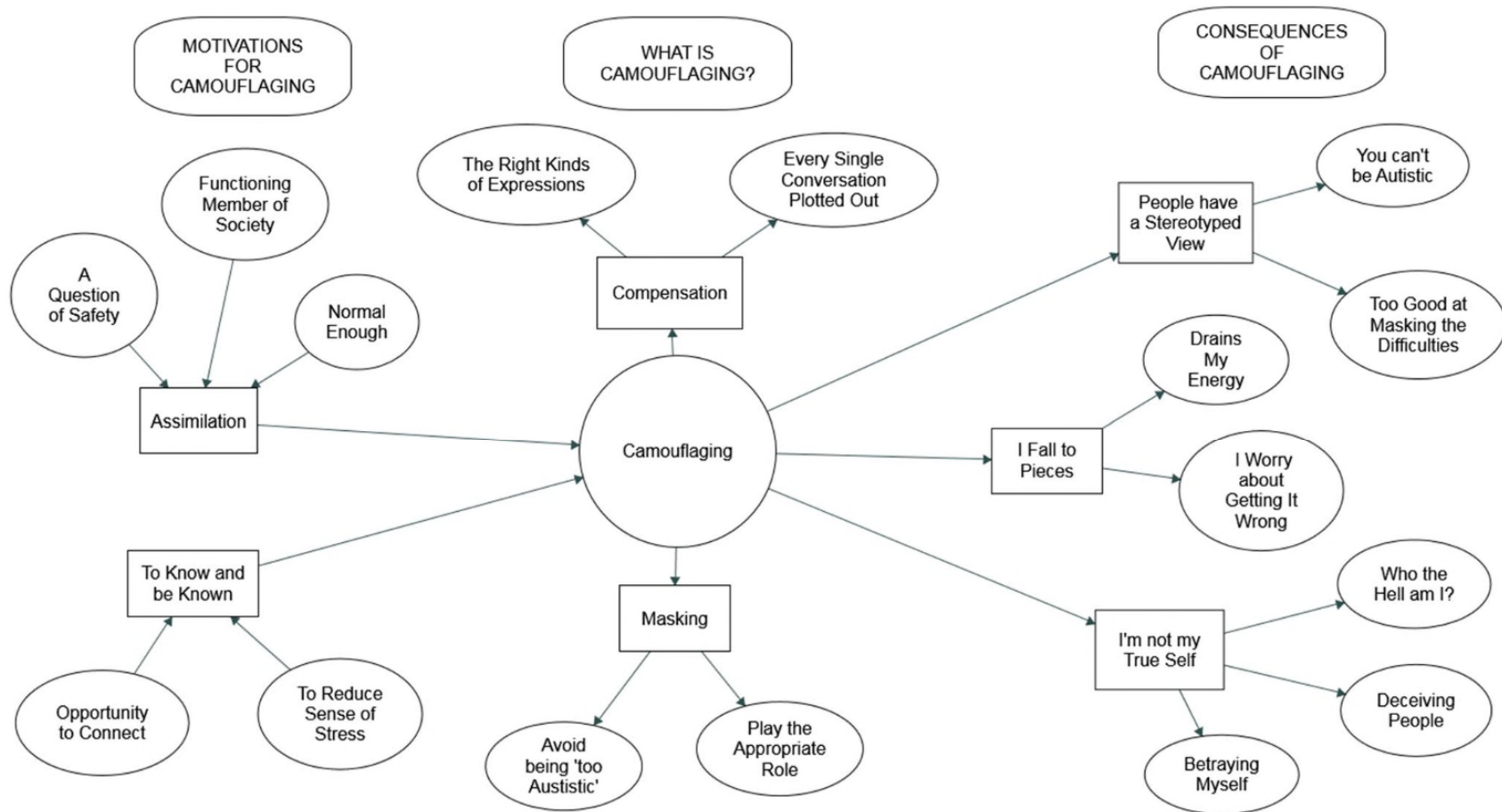
- Consciously deciding to suppress stimming
- Instinctive mimicry of others

## Compensation

- Copying popular peers in how they dress, use gesture, how they talk, etc.
- Implicit learning from social experience

# Hull et al., 2017

J. Autism Dev. Disord.



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

# 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.

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# Anorexia Nervosa

- Diagnosed when a person becomes significantly underweight due to restricted eating, reflecting an intense fear of putting on weight and a distorted body image (APA, 2013)
- Onset typically in adolescence and early adulthood
- Affects over 10 females to 1 male
- High rates of mortality

# 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

Study	Prevalence rate of autism spectrum disorders (%)
Råstam (1992)	8
Gillberg et al. (1995)	37
Wentz Nilsson et al. (1998)	31
Wentz Nilsson et al. (1999)	18
Råstam et al. (2003), Study 1	20
Råstam et al. (2003), Study 3	18
Wentz et al. (2005)	23
Anckarsäter et al. (2011)	28

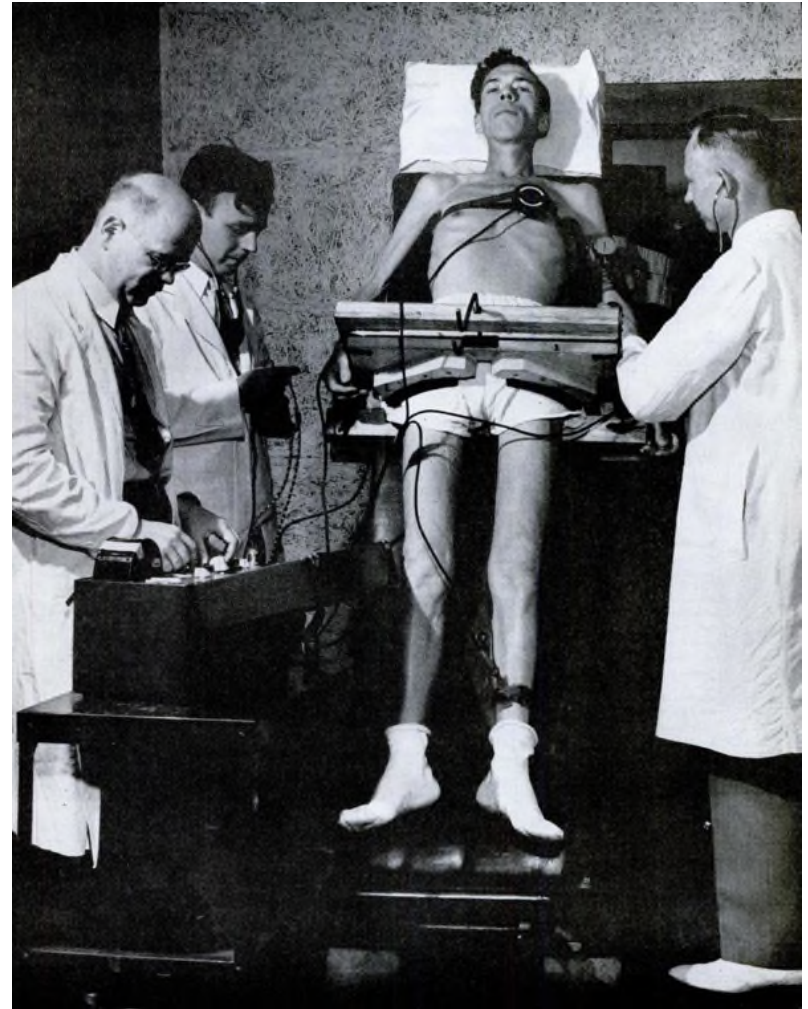
NB. It must be noted that the comorbid disorders are also included in the analysis of Gillberg et al. (1995) (cluster C personality disorder).

# But we need to be cautious...

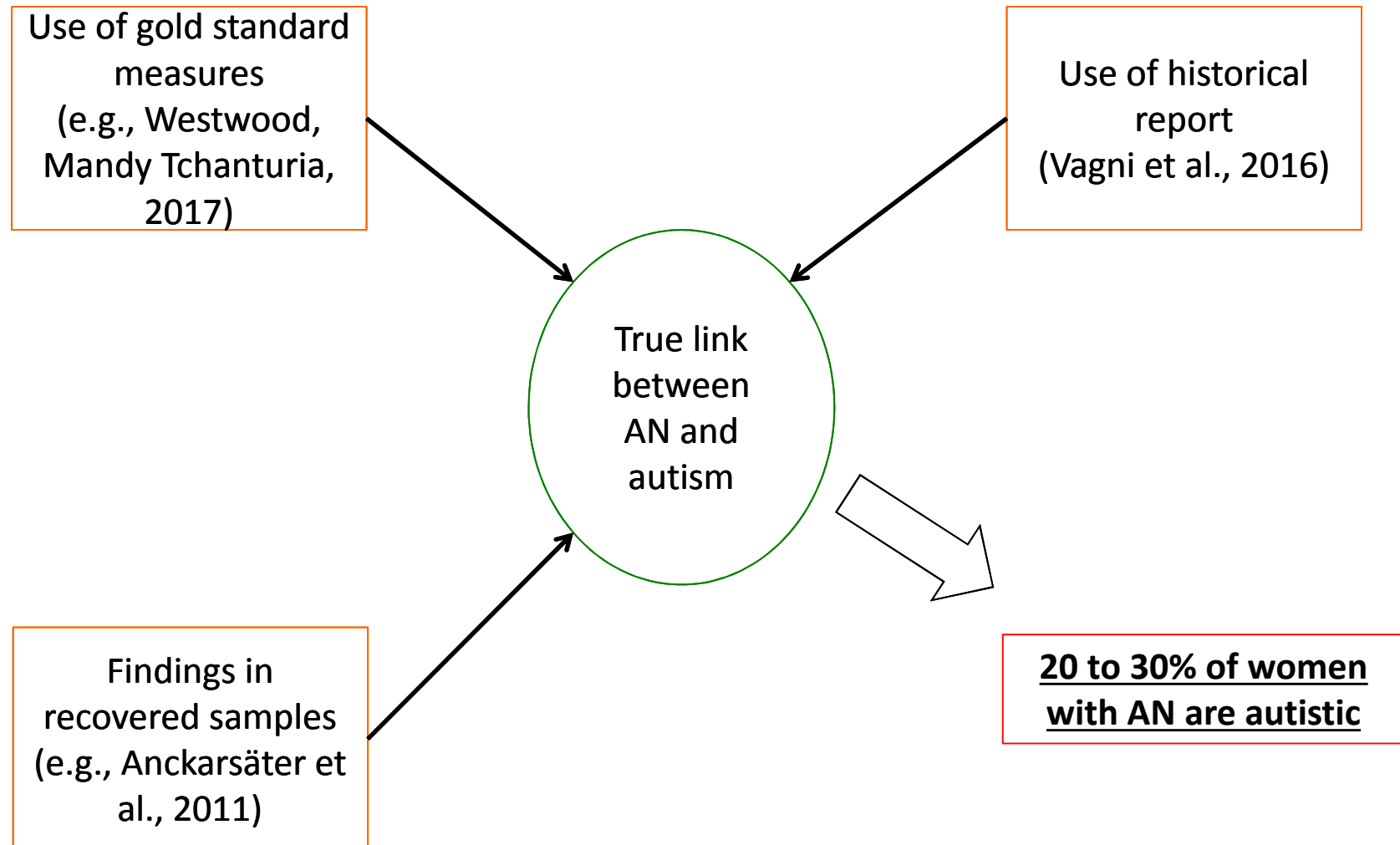


Dan Miller during the twenty-fourth week of starvation, and during the recovery period. Miller's 24.5 percent weight loss was typical. *Courtesy of Henry Scholberg*

The Minnesota Starvation  
Experiment (Keys et al., 1950)



# The link between autism and AN



# Care implications

- Women with AN in the context of autism:
  - Usually their autism is unrecognised
  - Experience the worst outcomes amongst AN patients (Wentz et al., 2009)
  - Benefit the least from current interventions (Tchanturia et al., 2016; Stewart et al., 2016)
  - Are not acknowledged, let alone accommodated, by current AN / ED guidelines (Kinnaird, Norton, Tchanturia et al., 2017)

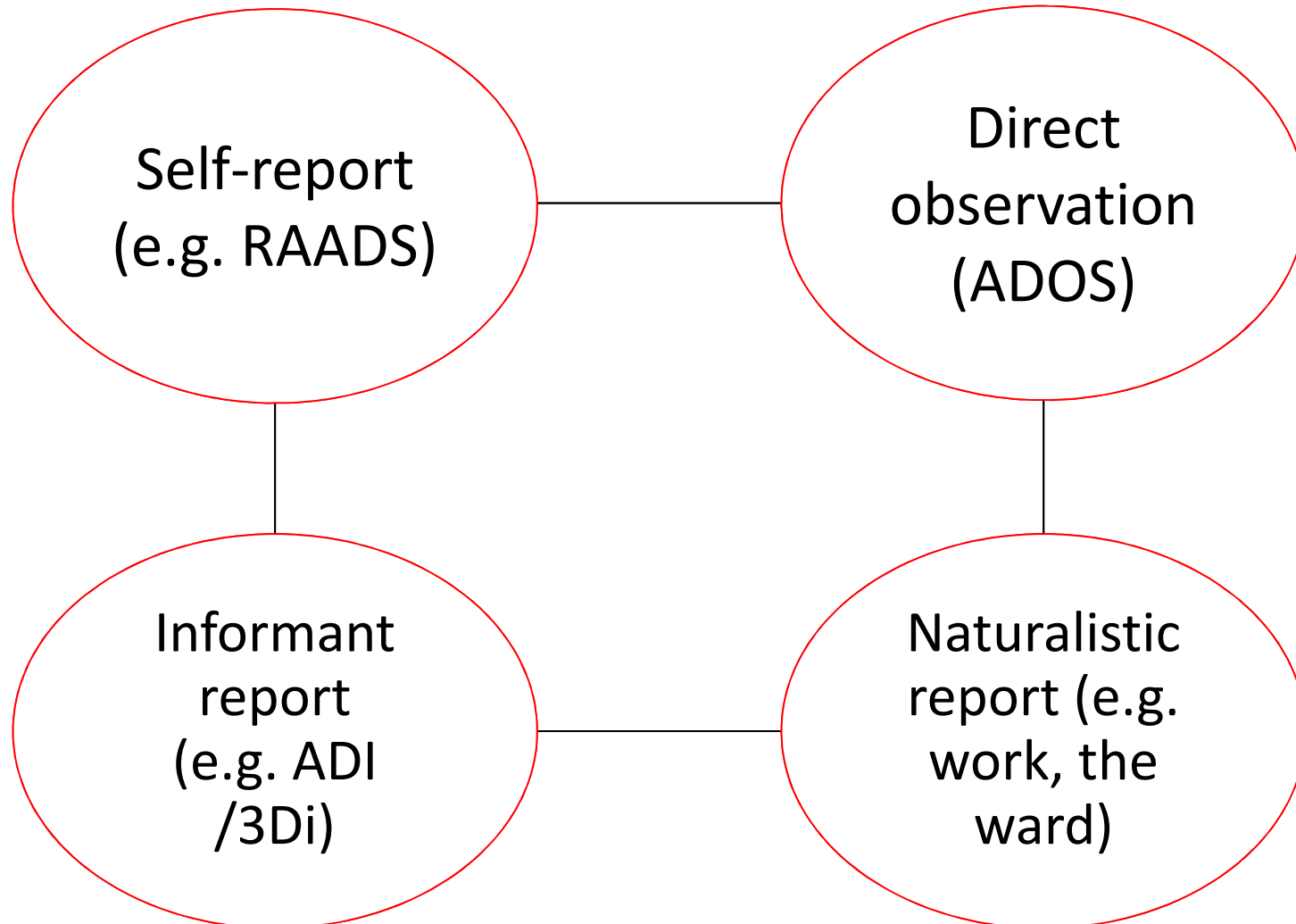
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# Autism assessments in eating disorder services

- Assessments for autism, and for autistic traits, should be routine and common in eating disorder services
- Specific team members should be trained up and specialise:
  - ADOS
  - Ritvo Adult Autism Diagnostic Scale
  - 3Di-Adult

# Multimodal assessment





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# AUTISTICA

Recently funded us to investigate AN in autistic women, to help inform improvements to care.

We seek to understand two types of barrier that currently impede good-enough treatment in this area:

- 1. What are the Practical barriers to accessing and benefitting from services**
- 2. What are the theoretical barriers to successful treatment**

Phase 1 – qualitative study with autistic women, parents and professionals



Phase 2 – quantitative study, testing ideas generated in Phase 1

### **Practical barriers to accessing and benefitting from services**

How can ED services become more autism friendly?

e.g., sensory issues, group treatments

### **Theoretical barriers to successful treatment**

Is AN in autism different from AN in non-autistic people?

Some potential differences:

- Less emphasis on weight and shape concerns
- Greater emphasis on obsessions, focused interests, perfectionism?
- Alexithymia
- Sensory processing

Watch this space...(and please get involved!)

**AUTISTICA**



Meng-Chuan  
Lai  
Simon Baron-  
Cohen



Meng-Chuan  
Lai



David Skuse  
Marianna Murin  
Rebecca Chilvers  
Rachel Bryant-  
Waugh

Great  
Ormond  
Street  
Hospital  
Charity



Rachel Hiller



Liz Pellicano  
Robyn Steward



Kate Tchanturia  
Heather Westwood



John Fox  
Catherine Jones  
Charlie Babbs



Sarah Bargiela  
Laura Hull  
Hannah Pickard  
Janina Brede

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

[w.mandy@ucl.ac.uk](mailto:w.mandy@ucl.ac.uk)