

Restrictive eating and life on the autism spectrum

Mair Elliott & Will Mandy

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 Kenny¹, Caroline Hattersley^{2,3}, Bonnie Molins²,
Carole Buckley⁴, Carol Povey² and Elizabeth Pellicano^{1,5}**

Autism

1–21

© The Author(s) 2015

Reprints and permissions:

sagepub.co.uk/journalsPermissions.nav

DOI: 10.1177/1362361315588200

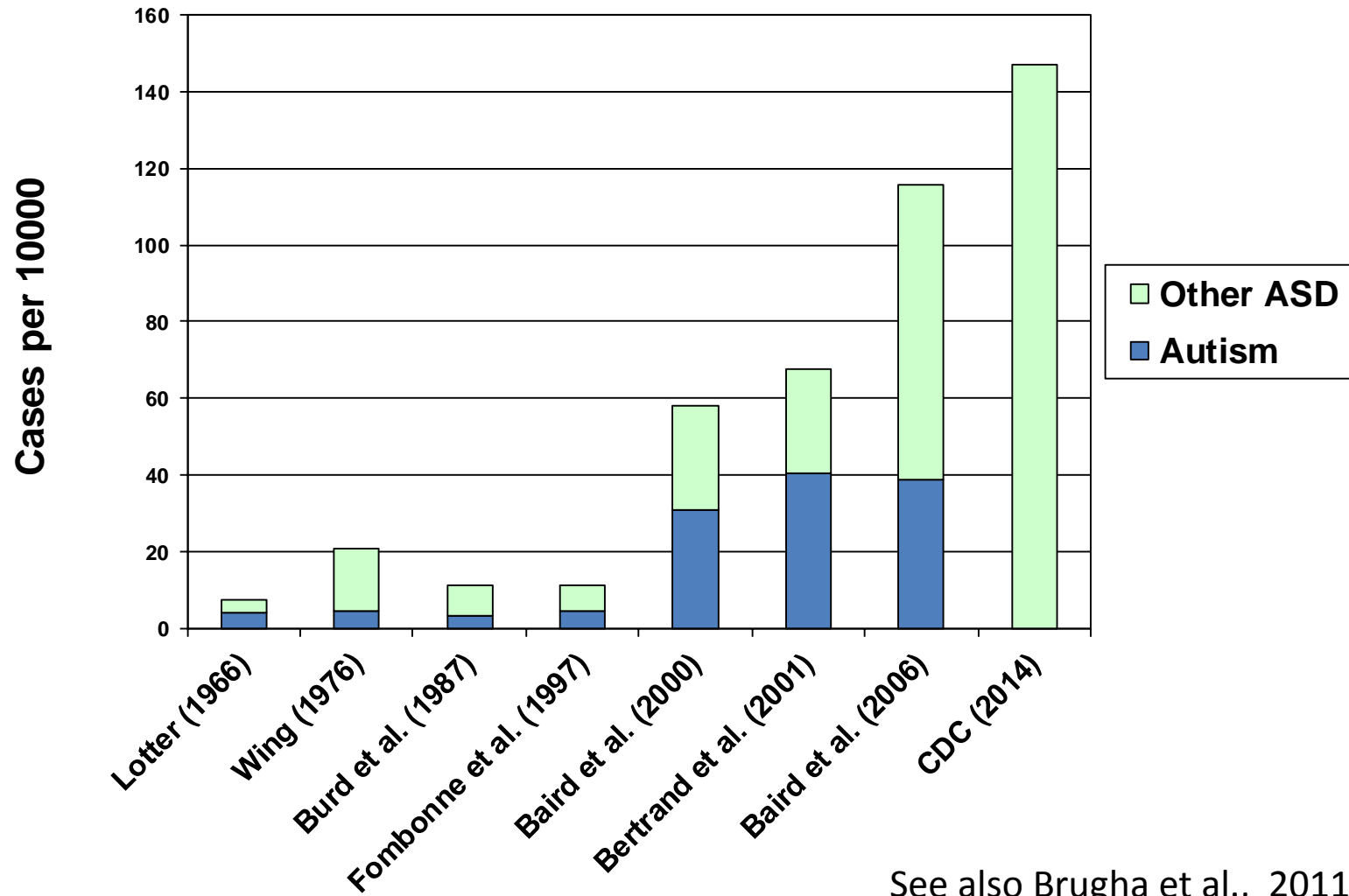
aut.sagepub.com



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.

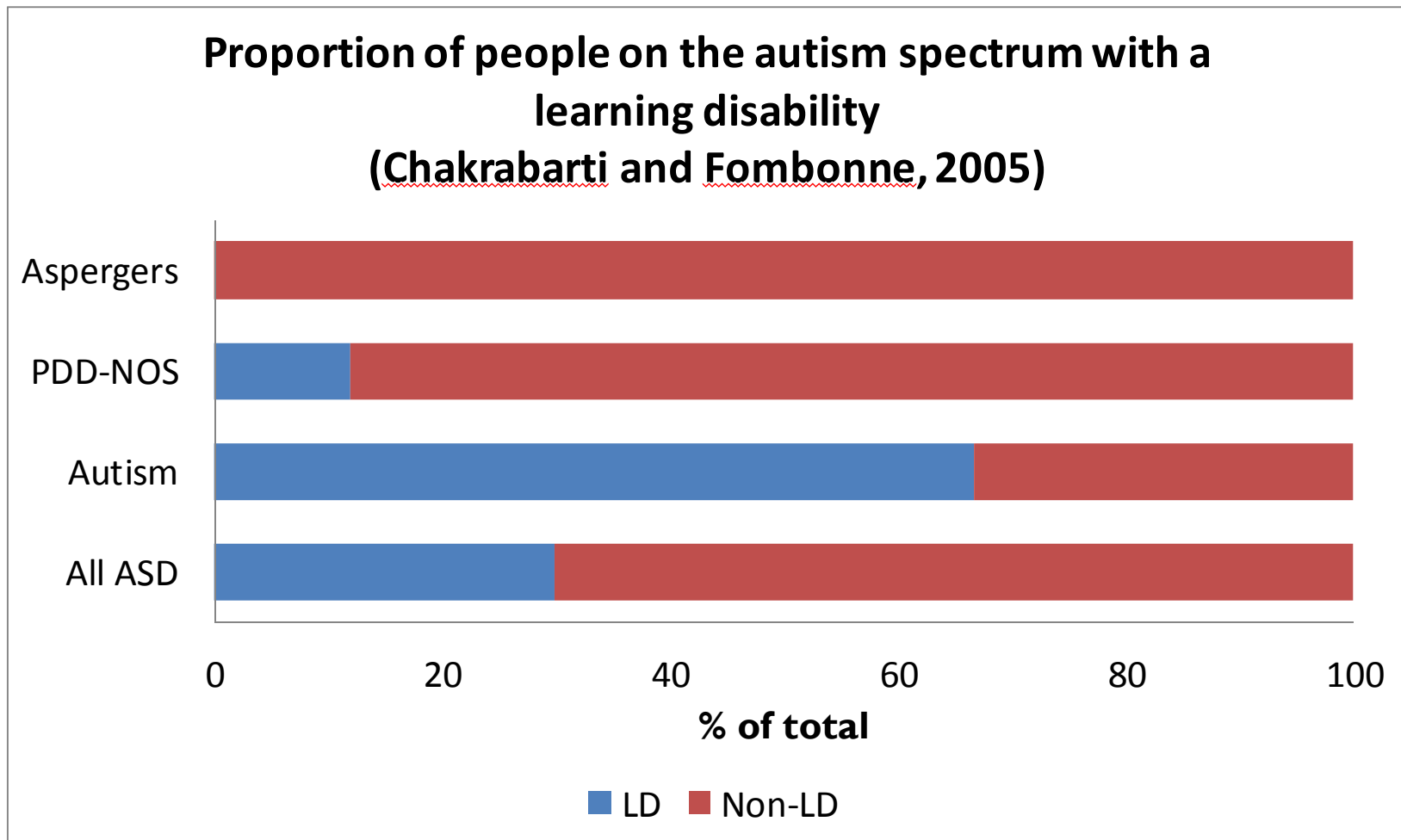
Myth 1: autism is rare



See also Brugha et al., 2011

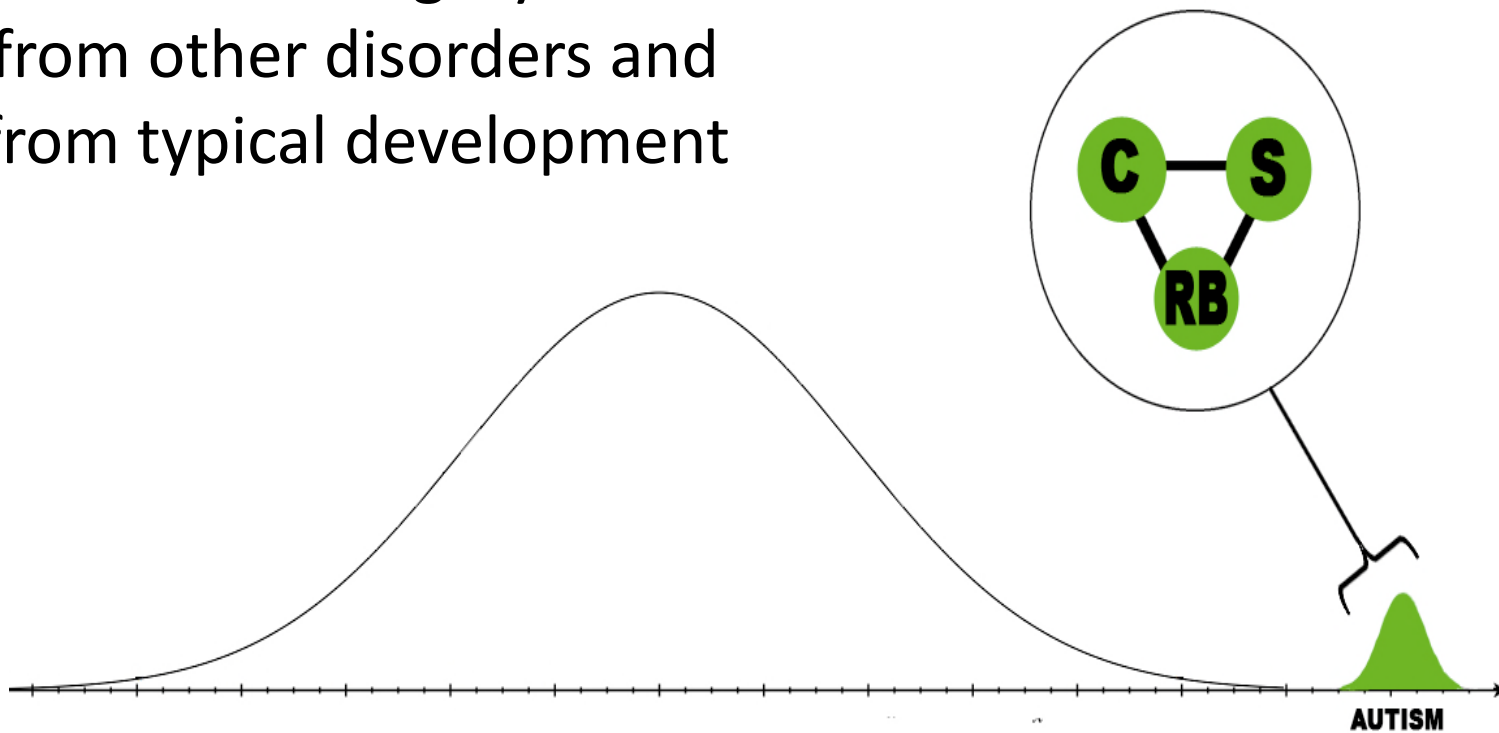
Myth 2

“Most people with an autism have a learning disability”

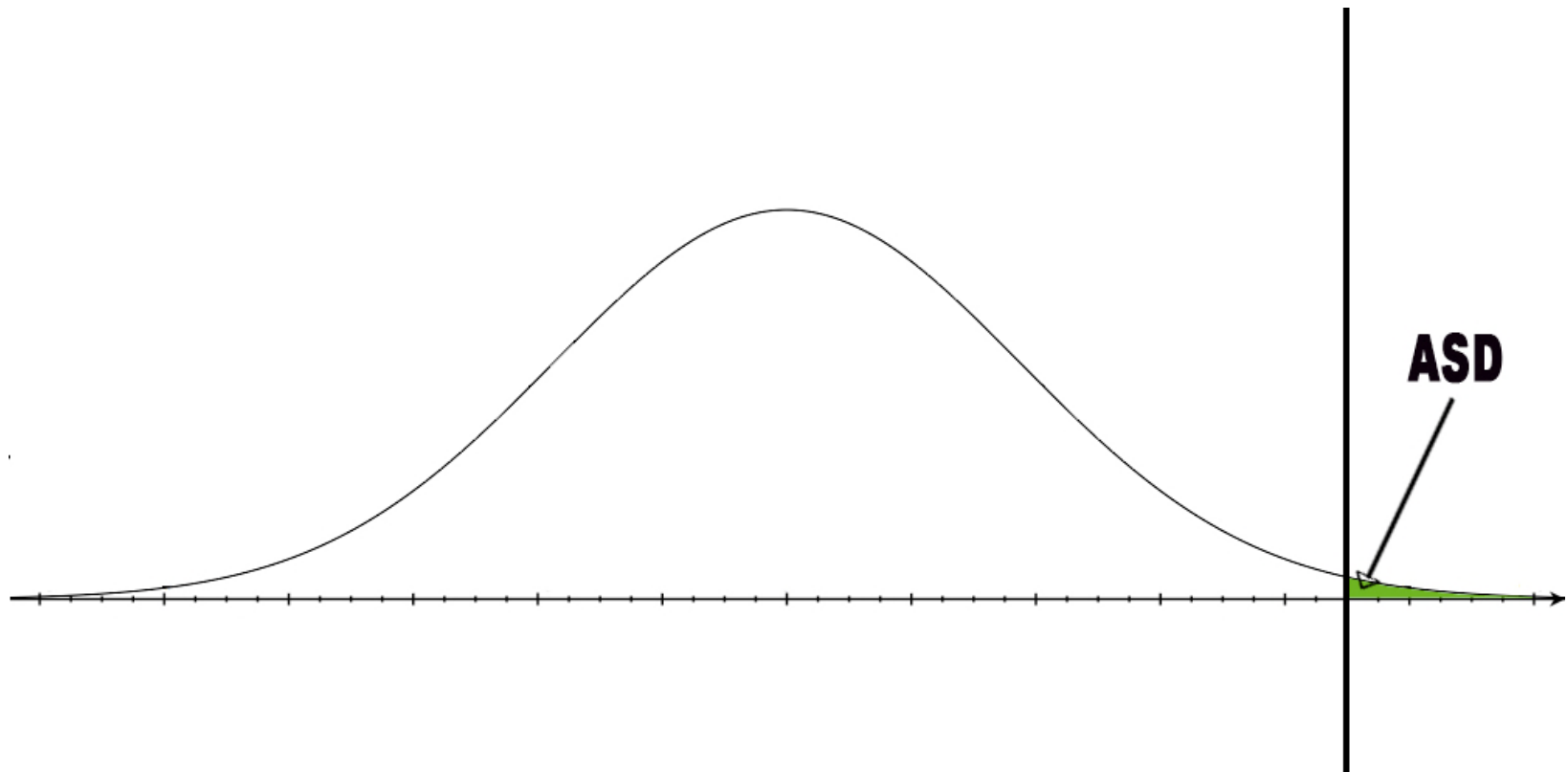


Myth 3: Autism is a categorical disorder

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

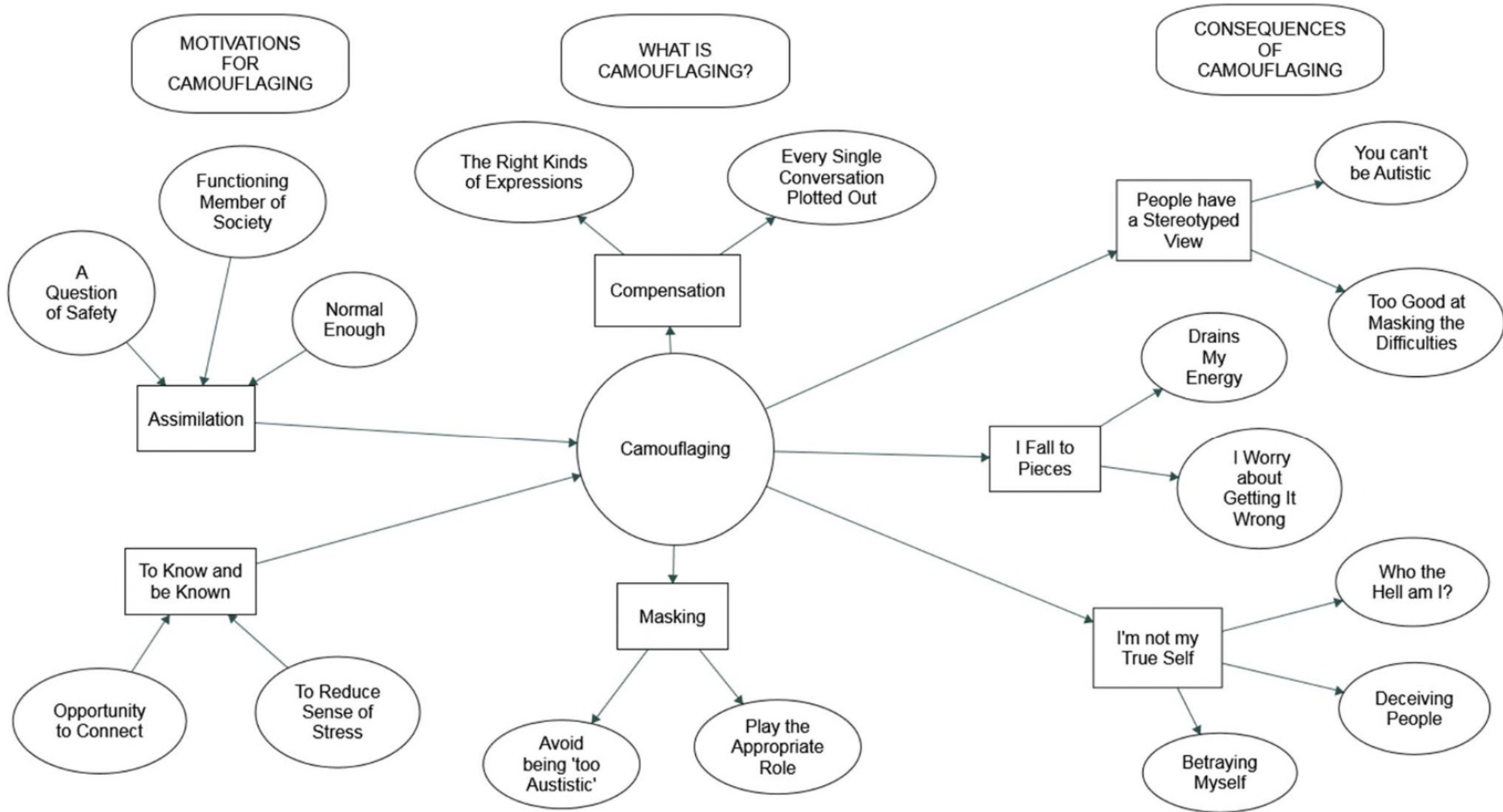


Fig. 1 Thematic map of the three stages (motivations, camouflaging, and consequences) of the camouflaging process. Themes are indicated by rectangles; subthemes by ovals

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.

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

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

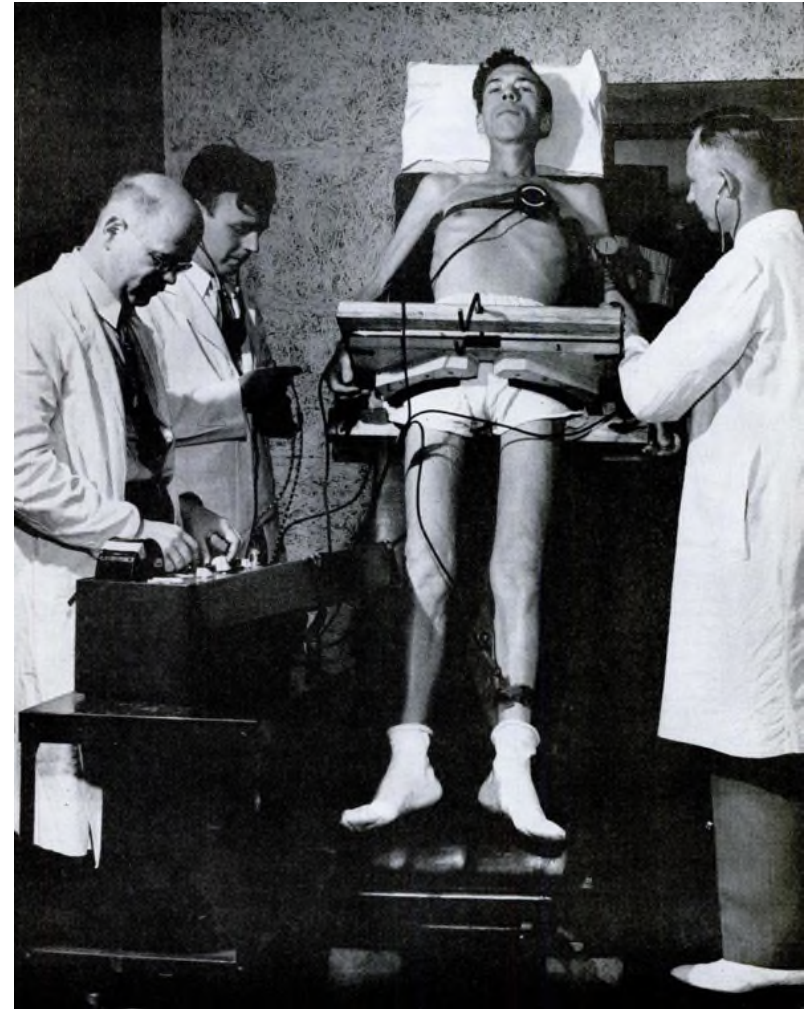
NB. It must be noted that the comorbid disorders are also included in the analysis of Gillberg et al. (1995) (cluster C personality disorder).

But we need to be cautious...

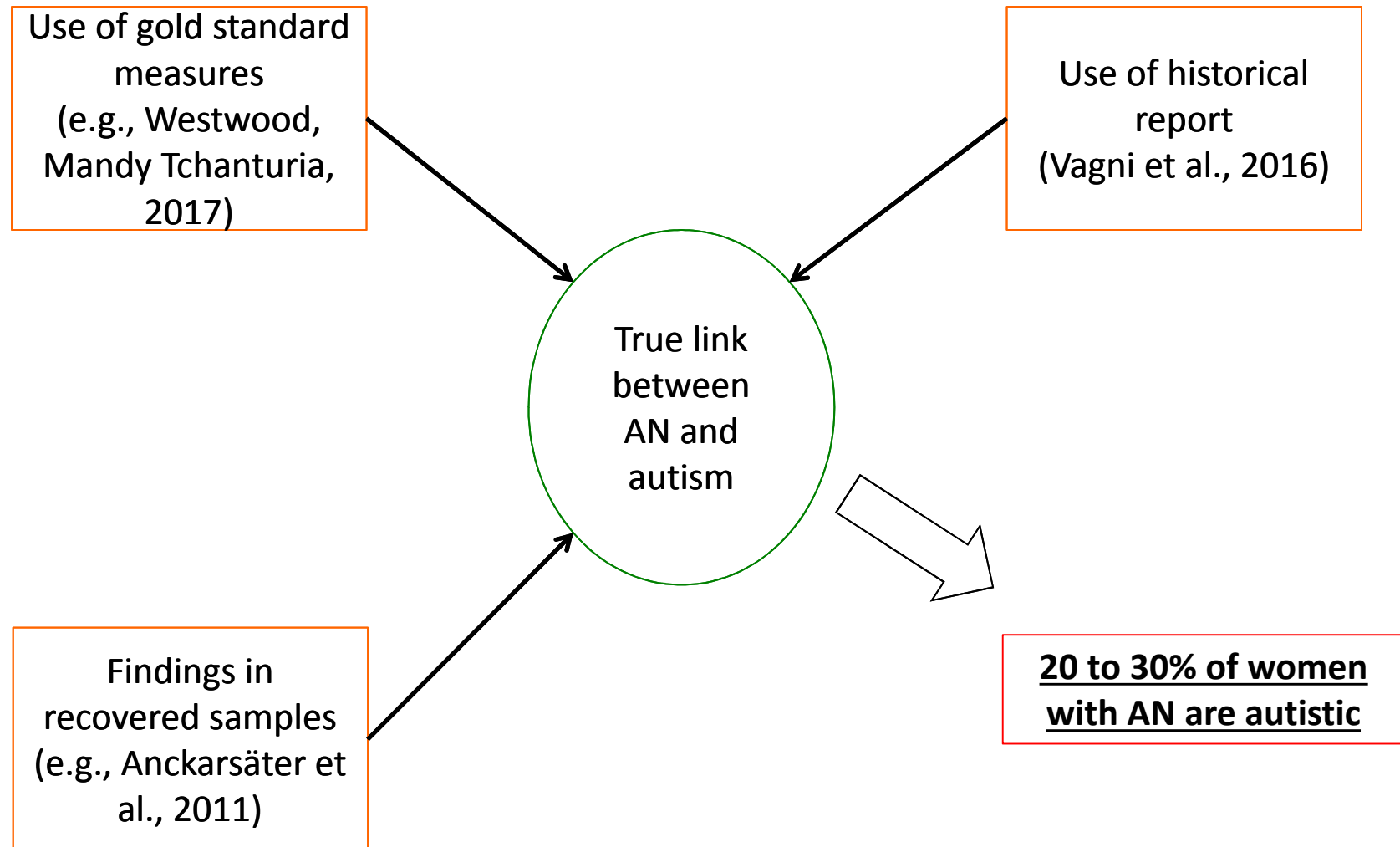


Dan Miller during the twenty-fourth week of starvation, and during the recovery period. Miller's 24.5 percent weight loss was typical. *Courtesy of Henry Scholberg*

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)

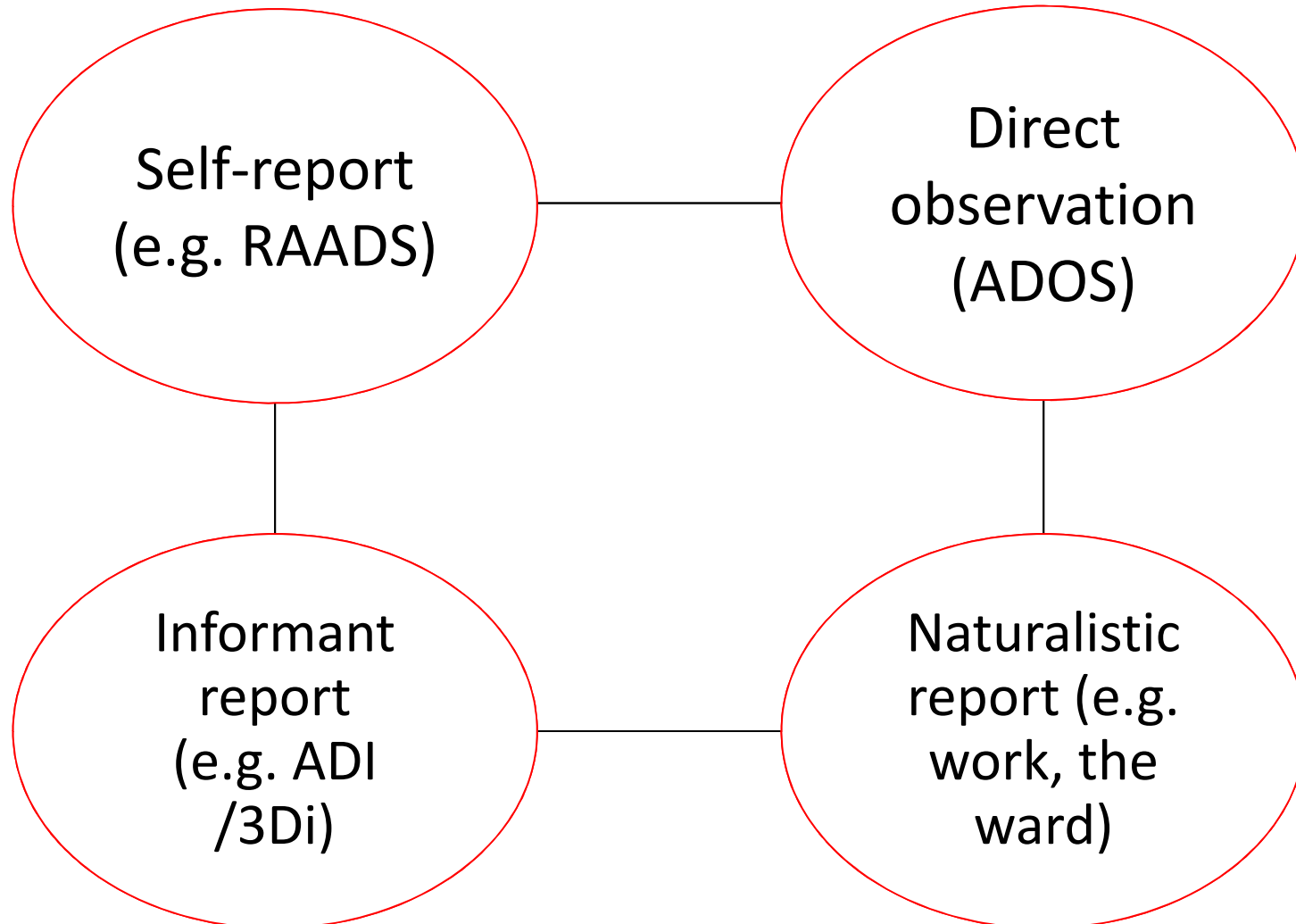
Outline of the talk

- 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

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



Outline of the talk

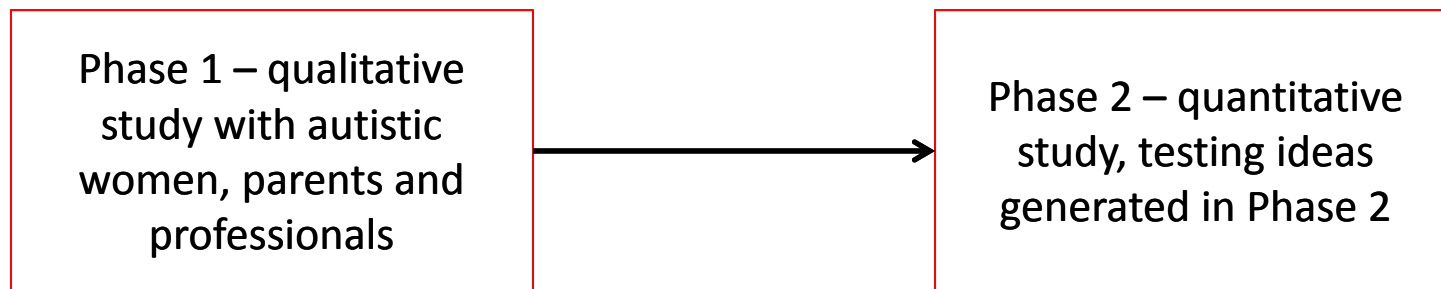
- ① Autism: the old view versus the new view
- ② Autism and Anorexia Nervosa (and other restrictive eating problems)
- ③ Assessing females with restrictive eating problems to see if they are autistic
- ④ Helping autistic females with anorexia

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**



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



Great
Ormond
Street
Hospital
Charity

David Skuse
Marianna Murin
Rebecca Chilvers
Rachel Bryant-
Waugh



UNIVERSITY OF
BATH

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