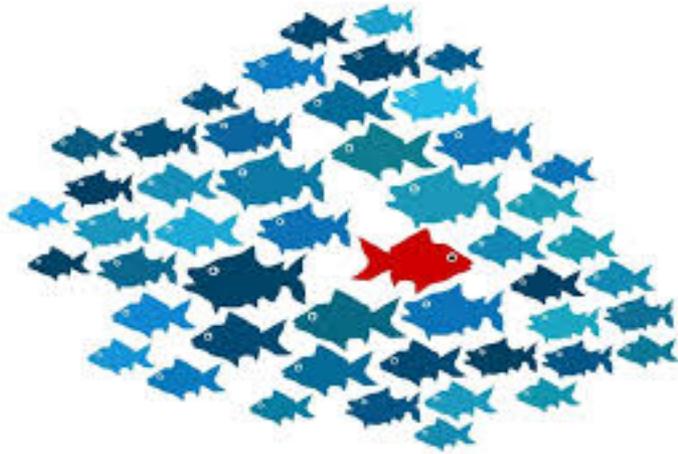


Breaking the Mould

Dr Will Mandy

UCL Department of Clinical
Psychology



Breaking the mould

“To do thinks differently to what has been done before or what is usually done”

We need to continue to evolve in:

1. How we understand autism
2. Understanding of what is the right support for autistic people

Plan of the talk

1. Autism – an evolving construct
2. Autistic girls and women
3. Mental health problems of autistic people
4. Autistic homeless people

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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”

Kanner (1943)

“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 of childhood, 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:

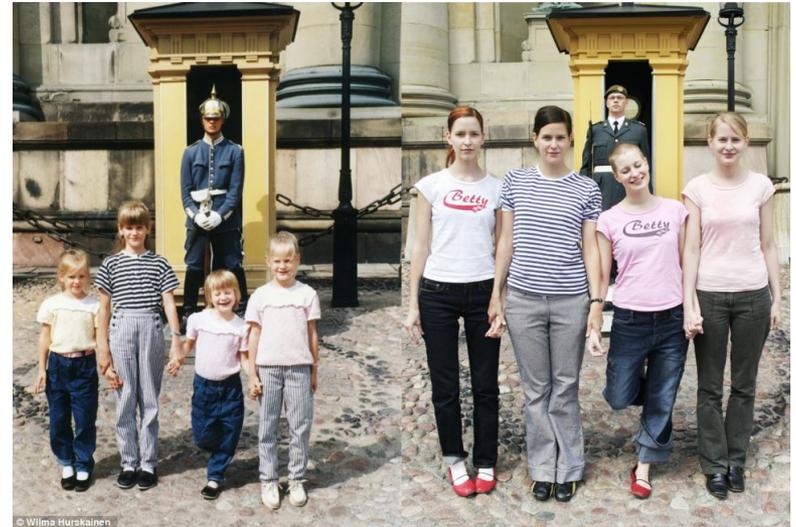
- 1-2% of children (Baird et al., 2006; Centers for Disease Control, 2014)
- 1-2% of adults (Brugha et al., 2016)

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

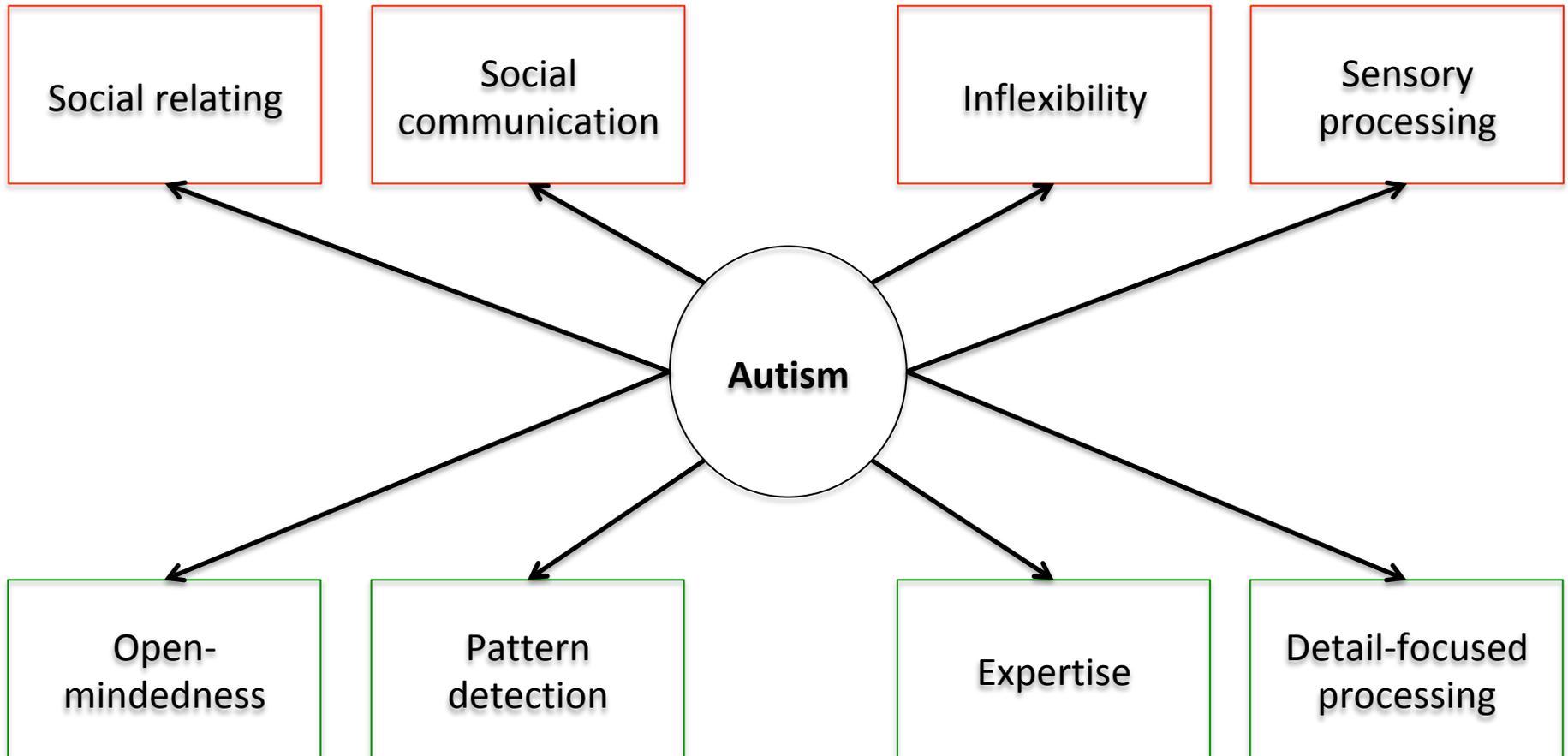
Centers for Disease Control, 2014; Loomes et al., 2017

Myth 3 – autism is a childhood condition

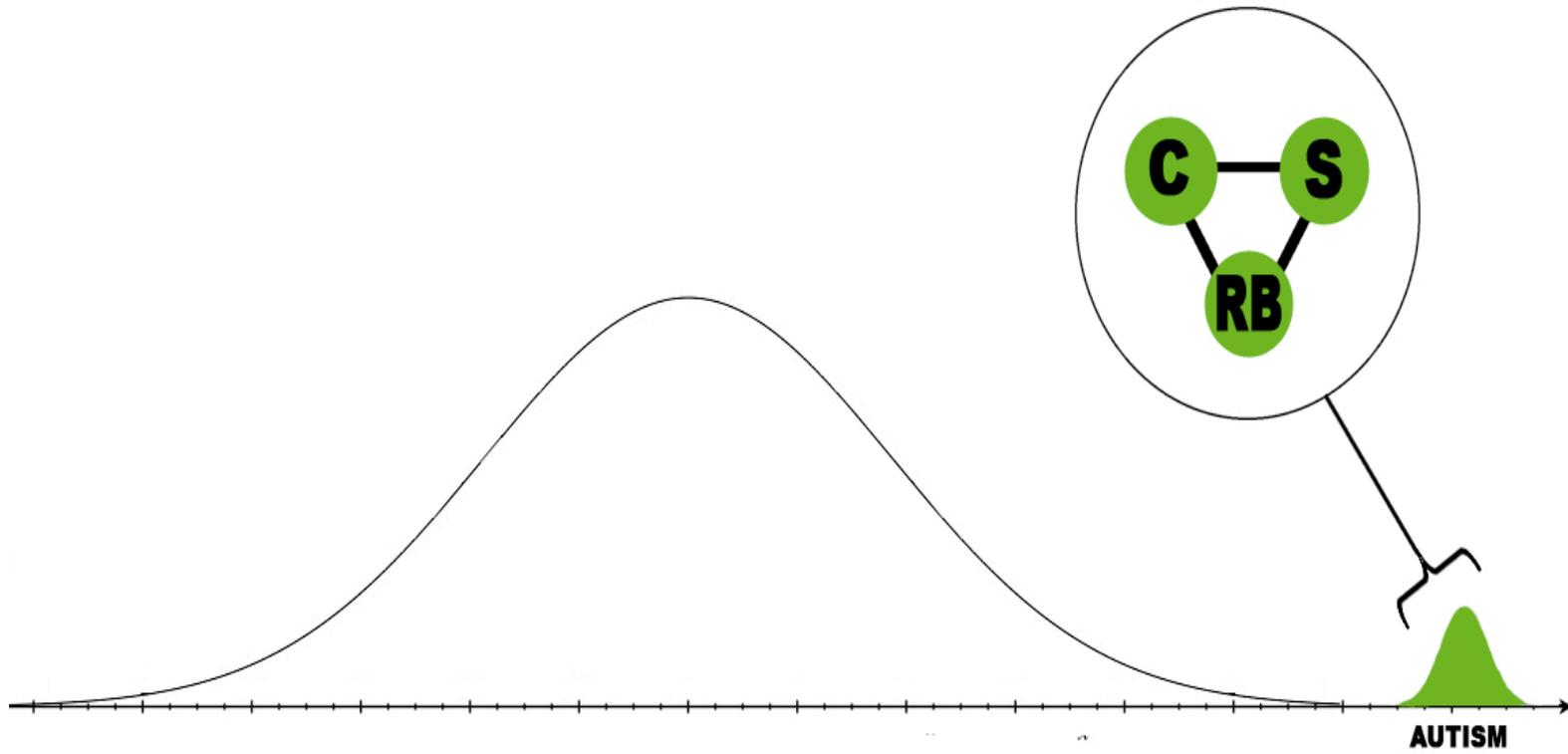


Most people are adults....
Most autistic people are adults...

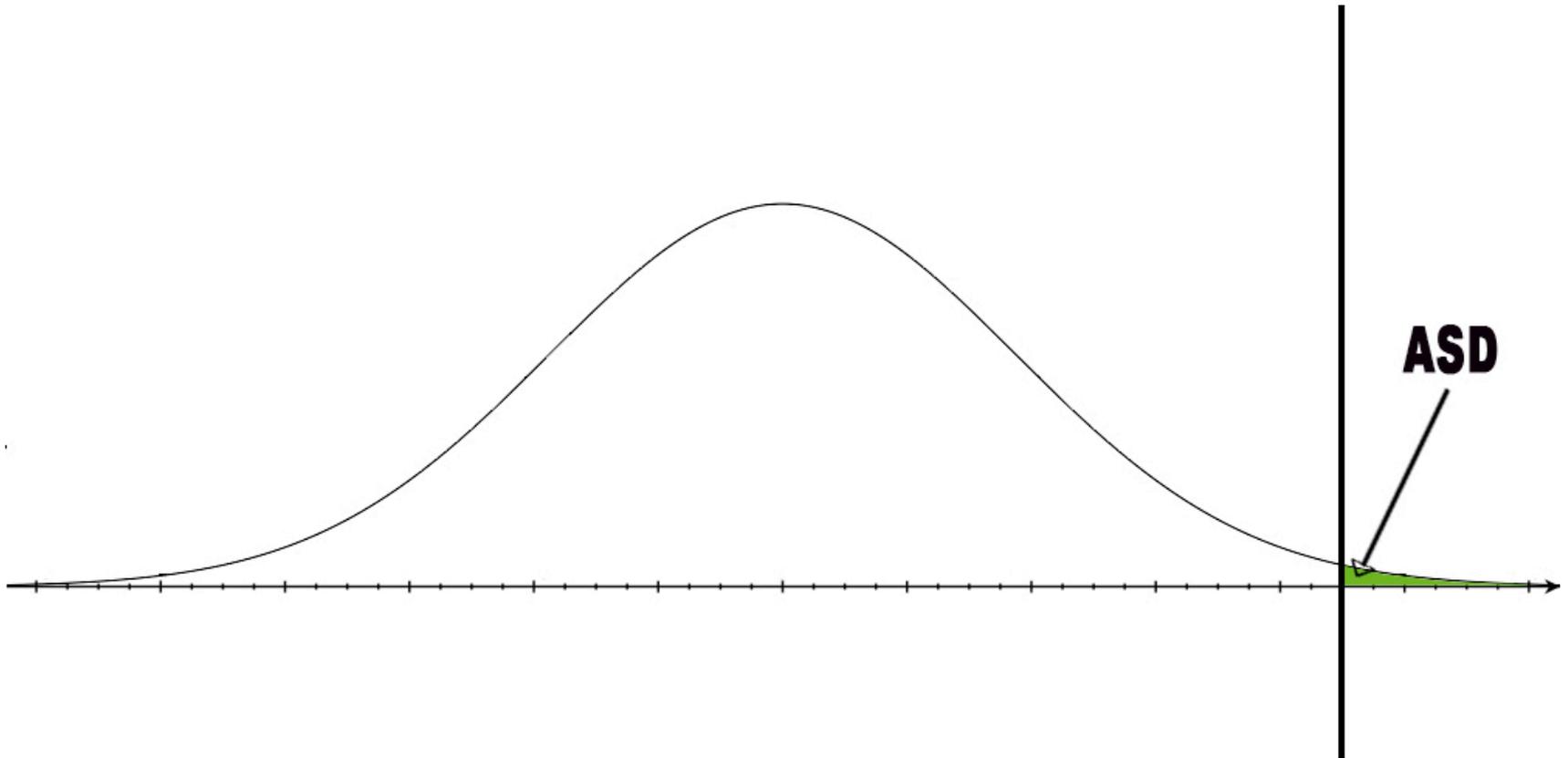
Myth 4 – autism is just about having difficulties



Myth 5: autism is a categorical disorder



Myth 5: 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 early 21st Century view

A relatively common, neurodevelopmental condition that is present across the lifespan, usually associated with normal-range IQ, that represents a form of natural human variation, bringing both challenges and strengths.

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The next step...



Recognising gender differences on the
autism spectrum

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

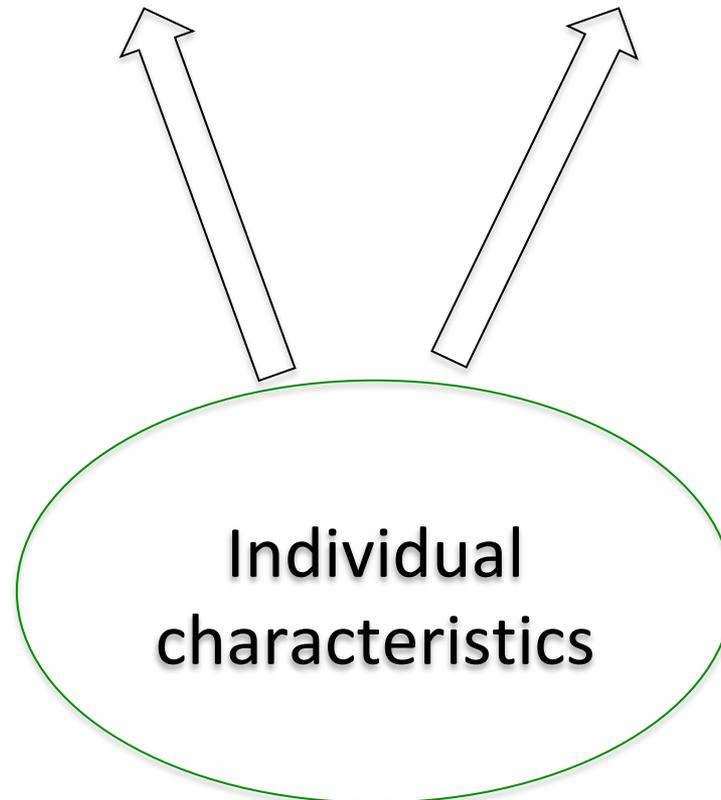
And even when they do receive an assessment **they are less likely to meet current diagnostic criteria**, compared to males with equivalent levels of autistic traits

(Dworzynski et al. 2012; Russell et al., 2011)

Under-ascertainment of females with autism

Bias against
receiving
assessment

Bias against meeting
diagnostic criteria



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

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

Special interests



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



The female autism phenotype

Camouflaging

“Putting on my best normal”

Hull et al. ,2017

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

“**Compensation** developing explicit strategies to meet the social and communication challenges associated with an individual’s autism”

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.

Some things I'm learning about camouflaging

Girls and women camouflage more than boys and men...
(but don't forget camouflaging is a big part of male
autistic experience too!)

It can have beneficial effects

"Camouflaging helps to survive in school and college and it is important for keeping jobs" F27

"It enables me to be with other people in a way that is relatively comfortable for me and for them" F56

But there is another side to camouflaging too...

Some things I'm learning about camouflaging

The negative aspects of camouflaging:

"I want to avoid the bullying mostly" F48

"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

Camouflaging is associated with higher self-reported anxiety and depression

Livingstone et al., 2018

Hull et al., (in prep)

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

The link between AN and autism

- ~20% women being treated for AN are autistic (Huke et al., 2013; , Anckarsäter et al., 2011; Westwood et al, 2017; Vagni et al., 2016)
- These women are usually undiagnosed
- They 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)

ED services are not always 'autism friendly'



"I used to like to sit in the same seat, just because I knew where it was, and every day a different staff member would go and sit there. And they wouldn't understand why I was getting upset."

Participant 1

"It was really frustrating, because it made me feel bad because they acted like I was doing something naughty and that I was doing it on purpose to try and burn calories, and I wasn't. And I didn't want to do that."

Participant 10



Do we need new treatment approaches for eating disorders of autistic people?



“I think I was lonely a lot after [my only friend changed school] and that affected it. I could just get engrossed in food and exercise and just forget about everything else.”

Participant 8

“I’ve always been a really fussy eater. There are lots of things that I won’t eat, like textures or strong flavours and things like that.”

Participant 13

“I didn’t know what a special interest was until I was diagnosed with autism, but it’s something that occupies my mind and keeps me calm but is also intensely enjoyable.”

Participant 14

“I’m not very good at judging my own emotions or physical sensations. I don’t really fully understand my thirst and hunger responses, or my fullness responses, so that really influences my eating because I can binge or miss meals very, very easily.”

Participant 10

“The anorexia very much helps me to control what to expect and to control my routine.”

Participant 4

To help autistic people with eating disorders we need to:

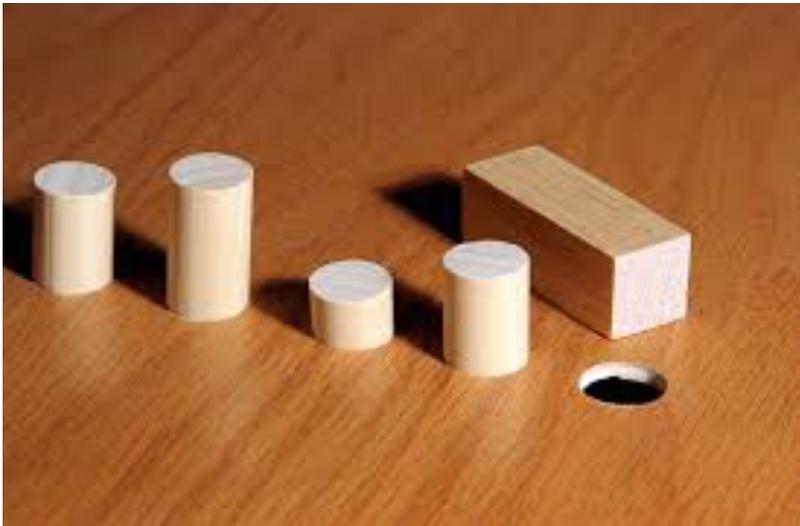
Change the way services are delivered...have an autism-specific pathway

Change the way we think about causes of eating problems

Change the way we treat eating disorders of autistic people

What about other mental health services?

- Autistic people, often undiagnosed, frequently present to mental health services in need of help (e.g., Wikramanayake et al., 2018)



How autism friendly are those services?

How appropriate are the treatments they are receiving?

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Autism and homelessness



Are autistic people at higher-than-average risk of becoming homeless?

- We screened the entire caseload (born in UK / Eire) of an inner-city homelessness service
- We assessed for autistic characteristics using a specially-designed key worker interview

The prevalence of autistic traits in a homeless population

Alasdair Churchar^{1*} , Morag Ryder^{1*}, Andrew Greenhill² and William Mandy¹

- 106 people screened, 13 showed strong evidence of meeting criteria for autism
- A further 9 showed high autism traits
- Only one person in this sample actually had a prior diagnosis of autism

Autistic homeless invisible on our streets



Autism specific pathways to homelessness and needs

Compared to non-autistic homeless people, autistic homeless people:

- Use less substances
- Are more socially isolated

People with autism who are homeless may:

- Decline to move into accommodation due to being unable to imagine what it is like or find it difficult to manage with change
- Abandon accommodation due to sensory over or under stimulation or difficulties managing with change (e.g., change of rules)

Westminster's experience – embedding autistic spectrum awareness into rough sleeping services

- They having been ‘thinking autism’ since 2014 and have put in place a number of no/low cost actions that can be easily replicated
- Promoting awareness with bitesize training, info leaflets and an advice clinic with our Autism Assessment service lead
- Screening question on our assessment form
- Giving thought to which accommodation services work well for autistic people – typically smaller, quieter, personalised, who have permission to work creatively and do things differently to keep people indoors (e.g. where conventional key working, welfare checks etc. cause big conflicts)

Conclusions

- Our concepts of what autism is, and who is autistic, are always changing
- We need to adapt diverse services to support autistic people
- This can be done effectively and can save money...but the journey towards 'autism-friendly' services is only just beginning...



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
Charli Babbs



Sarah Bargiela
Laura Hull
Hannah Pickard
Janina Brede
Alasdair Churchard
Morag Ryder



Jon Heron
Beate St Pourcain

Want to know more?

Camouflaging questionnaire – CAT-Q

Contact Laura Hull laura.hull.14@ucl.ac.uk

Eating disorder work

Contact Janina Brede janina.brede@ucl.ac.uk

Homelessness work (including tool kit)

Contact Alasdair Churcharad

Alasdair.Churcharad@oxfordhealth.nhs.uk