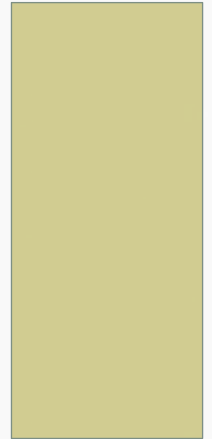


WOMEN AND AUTISM: MISDIAGNOSIS OR MISSED DIAGNOSIS?

NICOLA GILLAN, BASS
AUTISM TODAY - DECEMBER 5, 2019



AIMS

- Overview of conversations about autism and women in media and online, in research and in clinical services
- Consider how these conversations and findings impact autistic women and clinical services

HISTORIC CONTEXT

“

It is fascinating to note that the autistic children we have seen are almost exclusively boys.

- *Asperger, 1944; Frith, 1991, p.84*

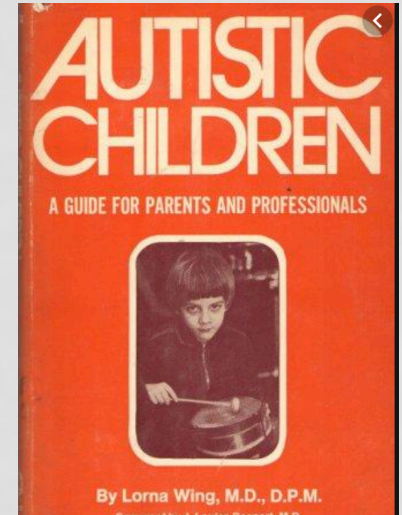
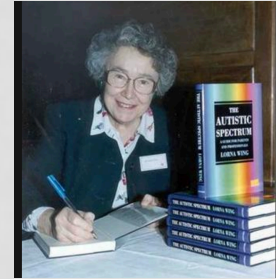
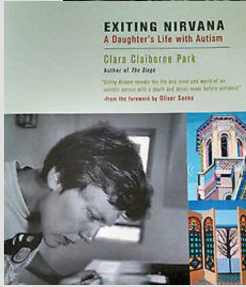
Autism has been a 'male' disorder – from Kanner and Asperger to 'extreme male brain' -

Kanner's original study was 3:8 f:m (n=11)

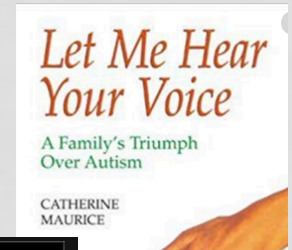
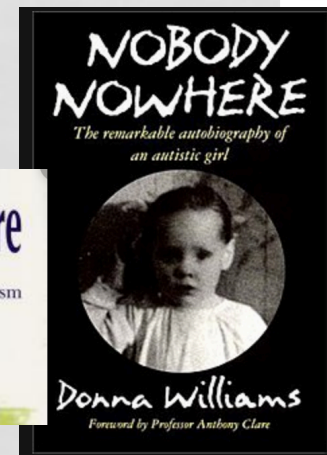
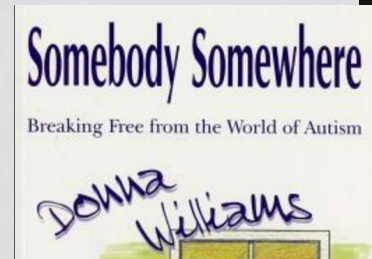
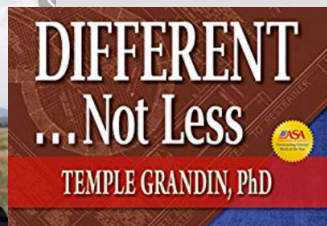
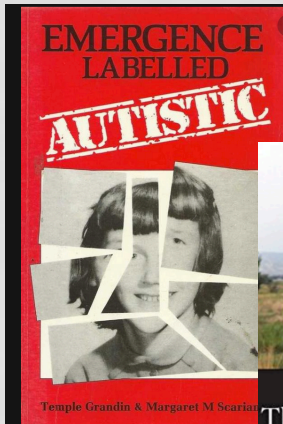
Autism was linked to ID and genetic disorder (more likely to be male)

Does this mean that autistic women were missed?

Yes...



Since the 1960s, women around the world have shaped understanding of autistic experience, interventions, theories and research



WHERE ARE WE NOW?

- Current ratio of male-to-female diagnosis is 4:1 (Halladay et al., 2015).
- Population-based data show that females are often diagnosed at later ages (Begeer et al., 2013; Giarelli et al., 2010; Rutherford et al., 2016; Shattuck et al., 2009)
- In large clinical UK study (Wilson et al., 2016), 72% men, 66% women referred to specialist clinic diagnosed with autism.
- 42% of autistic women report they were diagnosed with another condition first (National Autistic Society)
- Girls report traits on measures, but less likely to receive diagnosis (ALSPAC, Russell, Steer & Golding, 2011; Dworzynski, Ronald, Bolton & Happe, 2012)

Now:

Recognition that autistic women have been overlooked.

Increased autism awareness and change in perception of autism

Mental health and autism less stigmatised

Autism as identity, not only an impairment

Use of internet to share ideas and experience

Third wave feminism



Greta Thunberg: Why She Called Aspergers Her Superpower

Autism is a feminist issue

"You're Just Kooky": Why Women With Autism Aren't Taken Seriously

JESS COMMONS

Misdiagnosis Is All Too Common for Women with Autism

Suffering through a misdiagnosis.

JOURNAL ARTICLE

Quirky Citizens: Autism, Gender, and Reimagining Disability

Why I Fake Being 'Normal' — and Other Women with Autism Do, Too

Attacks on Greta Thunberg expose the stigma autistic girls face

AUTISM

The Missing Autistic Girls

In the past two decades, autism diagnoses

Autistic Girls and Women: Signs We Might Be Missing

BY BONNIE EVIE GIFFORD ON 26 MARCH 2018

Autism: Identity or Disability?

OPINION / VIEWPOINT

Women with autism hide complex struggles behind masks

BY WILLIAM MANDY, ROBYN STEWARD / 20 SEPTEMBER 2016

MENTAL HEALTH

Autism—It's Different in Girls

Different for girls: understanding autism

Why It's Harder for Girls to Get an Autism Diagnosis

Why Many Autistic Girls Are Overlooked

Things I hear as a woman with autism: 'You don't seem autistic to me'

Thousands of autistic girls and women 'going undiagnosed' due to gender bias

THE AUTISM DILEMMA FOR WOMEN DIAGNOSIS

October 26, 2018

By: [Organization for Autism Research](#)

The costs of camouflaging autism

Avon and Wiltshire



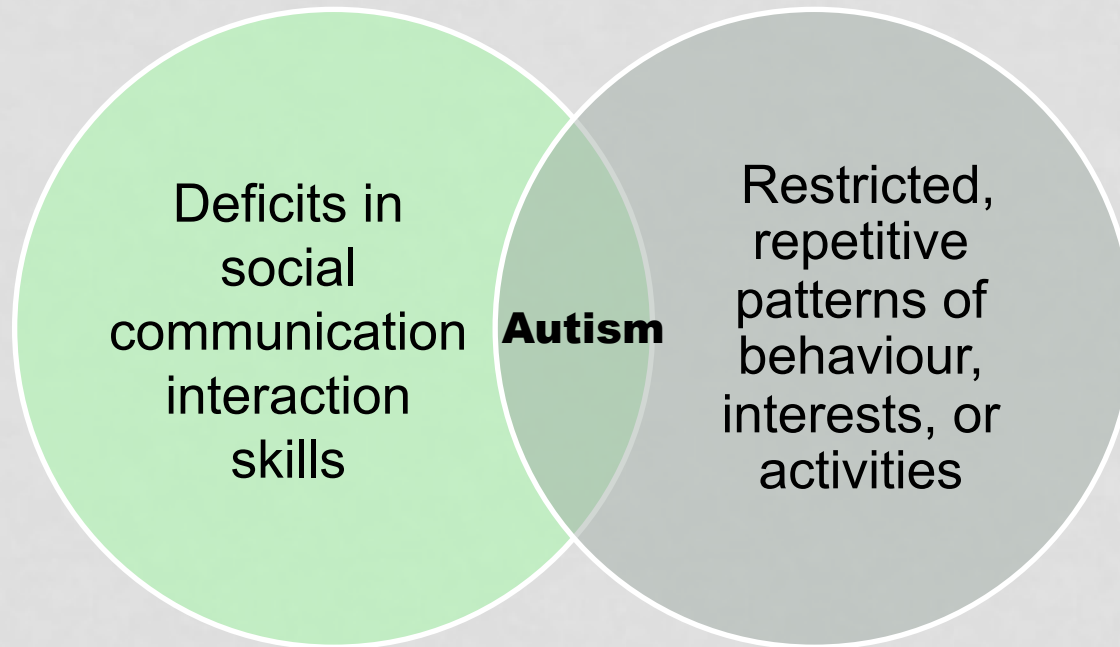
Mental Health Partnership NHS Trust

WHAT ARE THESE DIFFERENCES?

Anecdotally, autistic women describe:

- Social interaction and Communication
 - Perceived as “just being shy”
 - Greater awareness of the need for social interaction
 - Tendency to imitate others (copy, mimic, or mask) in social interactions
 - Tendency to “camouflage” difficulties by masking
 - Better imagination
 - Better linguistic abilities
- Restricted, repetitive patterns of behavior, interests, or activities
 - Restricted interests tend to involve people/animals rather than objects

Lai et al., 2015



Deficits in
social
communication
interaction
skills

Autism

Restricted,
repetitive
patterns of
behaviour,
interests, or
activities

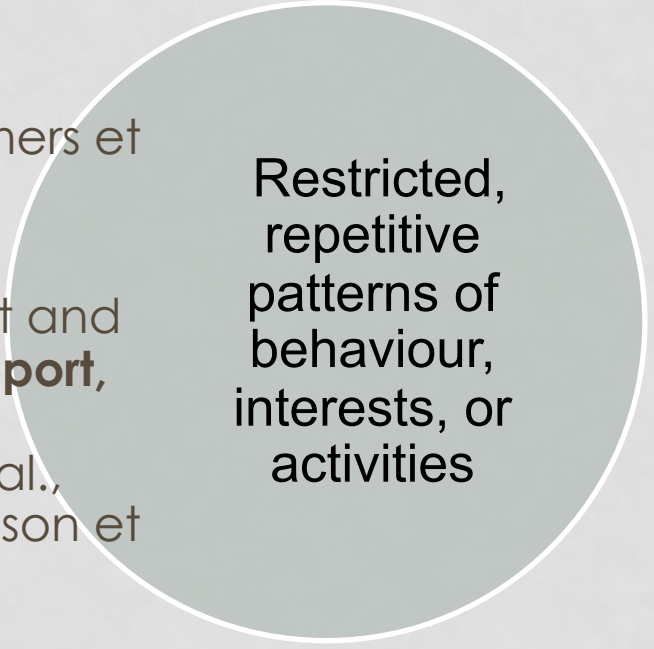


Deficits in
social
communication
interaction
skills

- **No difference** in social understanding, **but different pattern of impairment.** (Hiller et al., 2014)
- Adult females had **fewer current socio-communication difficulties** (Lai et al., 2011; Zwaigenbaum et al., 2012)
- **Females had overall more impairments** in social communication, cognitive and adaptive abilities, this was mediated by IQ. Ability and difference changed in relationship with verbal ability (and potentially age). **In those with fluent speech, females had better social skills** compared to males (Frazier et al., 2014)
- Males and females with autism showed **similar social communication symptom severity** on (Mandy et al., 2012; Solomon, Miller, Taylor, Hinshaw & Carter, 2012; Holtmann, Bölte, & Poustka, 2007; Mussey, Ginn & Klinger, 2017; Van Wijngaarden-Cremers et al, 2014 ; Wilson et al., 2016).

Women with autism without ID tend to have the same severity and number of social communication difficulties as men, though they might have better non-verbal skills.

- Meta-analysis of 20 studies - girls **showed fewer** restricted interests and behaviours, and **fewer stereotypies** than boys. (Van Wijngaarden-Cremers et al, 2014).
- Females **had fewer** restricted patterns of interest and behaviour **in childhood and adulthood in self report, parent report and direct observation** (Coffman, Anderson, Naples & McPartland, 2015; Hillier et al., 2014; Frazier et al., 2014; Mandy et al., 2012; Wilson et al., 2016)
- Adult females with **showed more lifetime sensory symptoms** (Lai et al., 2011)
- Adults are more likely to present with a lack of flexibility in their behaviour, as well as fixated interests. (Carrington et. al., 2019)



Restricted,
repetitive
patterns of
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Women have RRBI, but less. Women may have more sensory symptoms.

“There is disagreement on sex-specific presentations of nearly every behavioral measure, including social aspects, communication, stereotyped and repetitive behaviors, cognition, motor scores, hyperactivity, externalizing and aggressive behaviors, executive function, processing speed, visuospatial skills, and theory of mind” (Ferri, 2018)

So, are autistic women overlooked because of bias in assessment tools? Or by other behaviours, like camouflaging?

No difference in measures

- No m:f differences found on the ADI-R, ADOS, CBCL. (Holtmann, Bölte, & Poustka, 2007)
- No m:f differences in ADI (Lai et al., 2011)
- No m:f difference reported in DISCO abbreviated – though difference between adult and child profiles reported (Carrington et. al., 2019)
- No m:f difference on ADOS reciprocal social interaction or communication scores (Mandy et al, 2012)
- ADOS Module 4, no m:f difference (Mussey, Ginn & Klinger, 2017)

Some difference

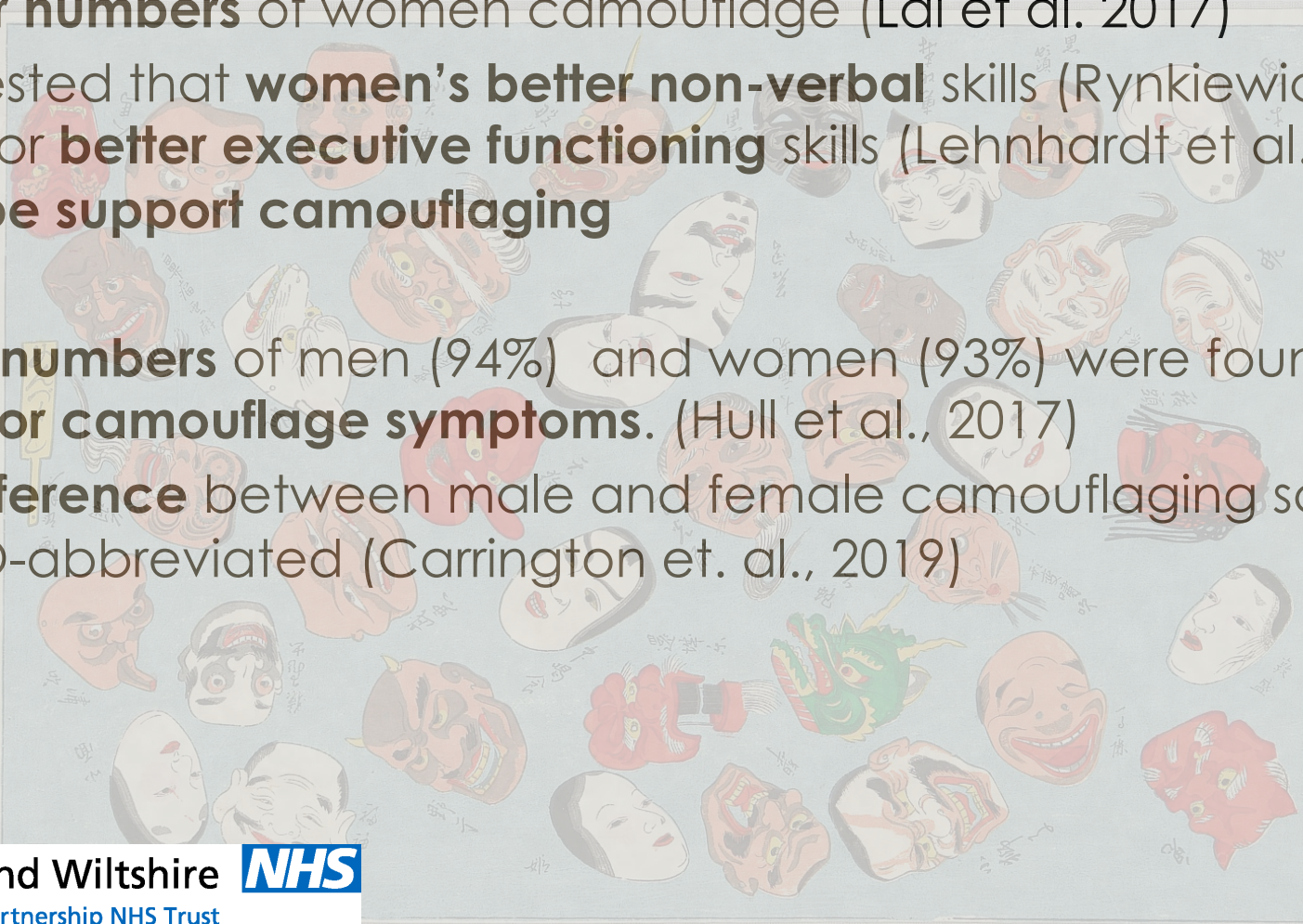
- In parent report (3DI, SDQ), and observational RRBI (ADOS RSB) males showing greater impairment than females. (Mandy et al, 2012)
- Four ADI-R questions differentiated m:f.(circumscribed interest, insistence on sameness, imaginative play, facial expression) (Beggiato et al., 2016)

So, measures are able to capture male and female autistic behaviours, though, autistic women *may* score differently on some items – this may reflect different profile of skills



CAMOUFLAGE

- Two studies of autistic women provide good descriptions of behaviours (Bargiela et al., 2016; Tierney et al., 2016)
- **Higher numbers** of women camouflage (Lai et al. 2017)
- Suggested that **women's better non-verbal** skills (Rynkiewicz et al., 2016) or **better executive functioning** skills (Lehnhardt et al., 2016) **may be support camouflaging**
- **Equal numbers** of men (94%) and women (93%) were found to **mask or camouflage symptoms.** (Hull et al., 2017)
- **No difference** between male and female camouflaging scores on DISCO-abbreviated (Carrington et al., 2019)





From personal accounts and media focus, we know that there are clear messages about differences for autistic women.

We know autistic women have been missed, we know they tend to be diagnosed later and there may be some differences in their experience.

From research, we know that there is some evidence for a differences in symptom profile. While this tends to be fewer repetitive behaviours and better non verbal communication skills, this is not clear.

We know that measures are able to capture female and male symptoms and behaviours, but these may not capture some behaviours well or at all (i.e. camouflaging)

We know that autistic women describe camouflaging, as do autistic men – particularly as adults.

So, how does this reflect the conversations in clinical services?

- With increased awareness, more people seeking autism specialist diagnostic and support services – both men and women
- More women being diagnosed
- Diagnosis, in current system, leads to treatment, allows service access
- High risk of misdiagnosis - this can be harmful!
- Increased number of people highly distressed to not receive autism diagnosis



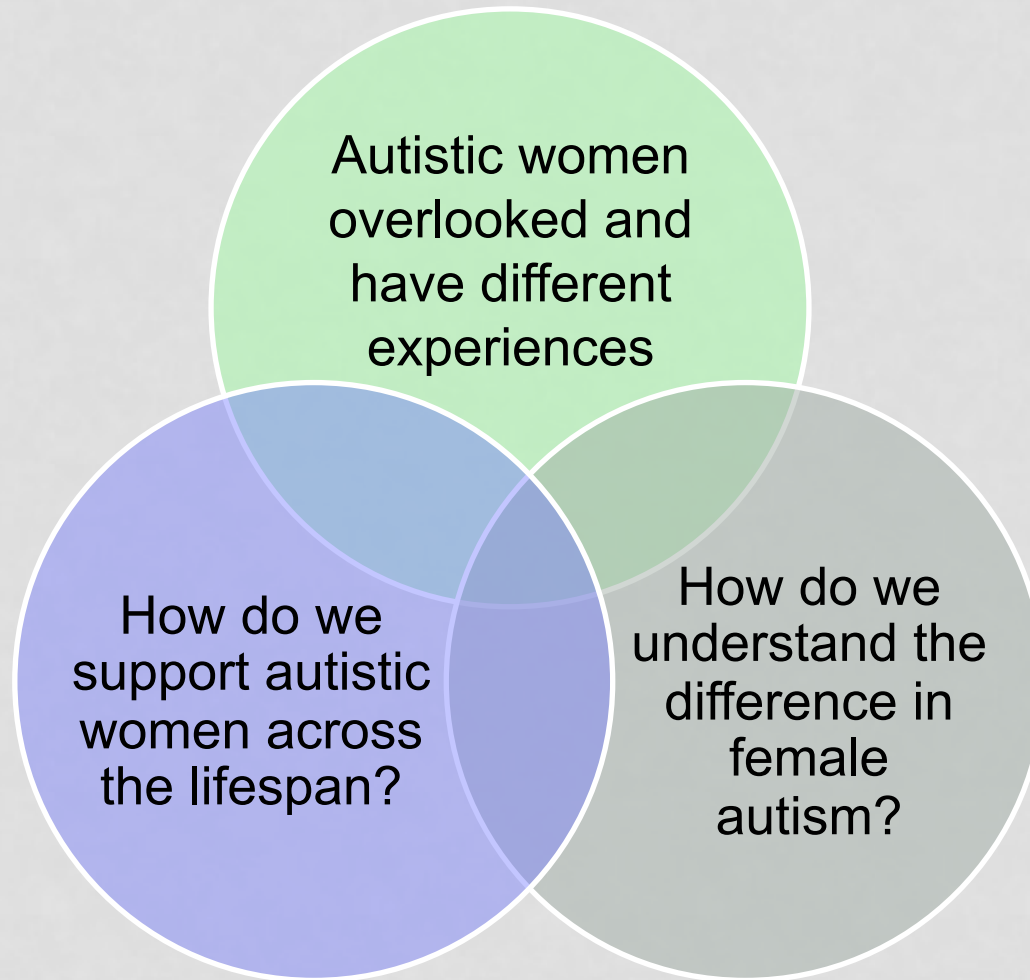
As clinicians, what do we do?

Need to consider how these conversations about difference in experience and phenotype reflect the unmet needs of autistic women

Clinicians and diagnosticians need to build knowledge and think critically about diagnosis and differential diagnosis

Need to respond to urgency of increased demands for service without compromising quality in assessment and support

Join these wider conversations! Ask questions, offer experience and observations



From personal accounts and media focus, we know that there are clear messages about differences for autistic women

We know autistic women have been missed, we know they tend to be diagnosed later and there are differences in their experience.

This does not seem to be explained by variation in autism symptoms, bias in measures or camouflaging behaviours.

- There is some evidence for a differences in symptom profile, but this is very unclear
- Measures are able to capture symptoms and behaviours in female and males
- Camouflaging is an autistic experience
- Need to keep trying to understand factors that may contribute

There is increased demand for clinical assessment services

- Clinicians and diagnosticians need to build knowledge and think critically about diagnosis and differential diagnosis
- Need to be innovative in building quality services that meet unmet needs of autistic women

THANK YOU

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