

Welcome to

Understanding Women with Autism

10.00 Introduction to conference

Mark Goldsborough

mgoldsboroughblog.wordpress.com



Gender differences on the autism spectrum

Dr Will Mandy

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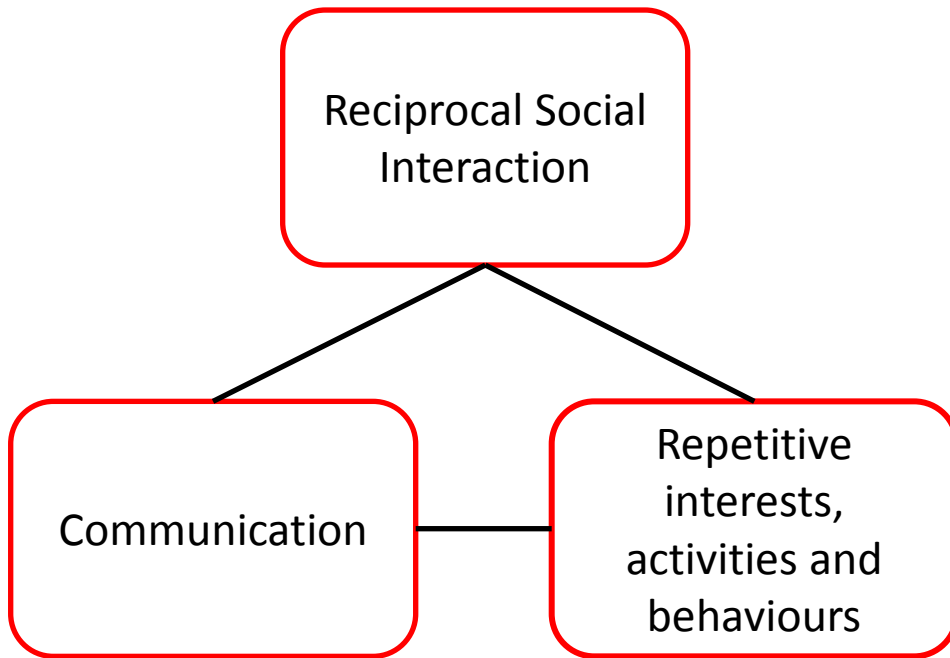
Outline of the talk

- A (very) brief introduction to ASD
- Four boys to every girl on the spectrum?
- Does ASD present differently in males and females?
 - Clinical impressions
 - Empirical findings
- Is Anorexia Nervosa the female Asperger's?
- Clinical implications

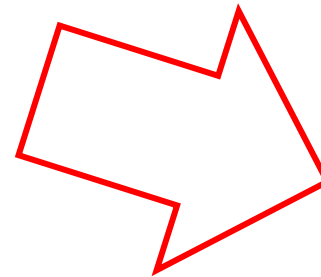
Autism: the old view

A rare, neurodevelopmental disorder with a triad of symptoms, usually associated with intellectual disability, and categorically distinct from normal development and from other disorders.

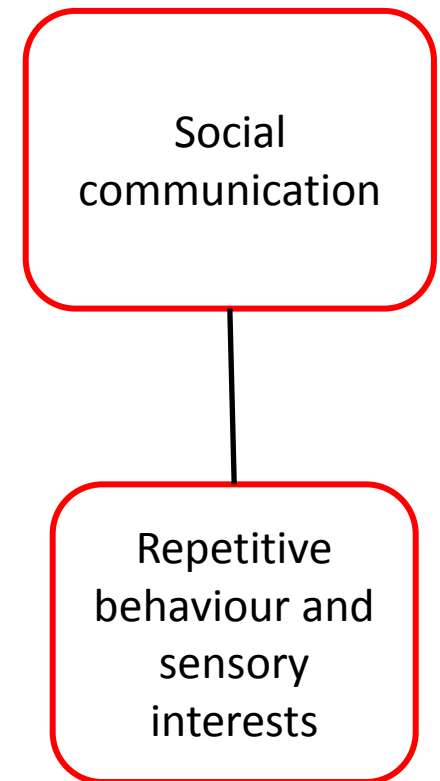
Myth 1: ASD is a triad



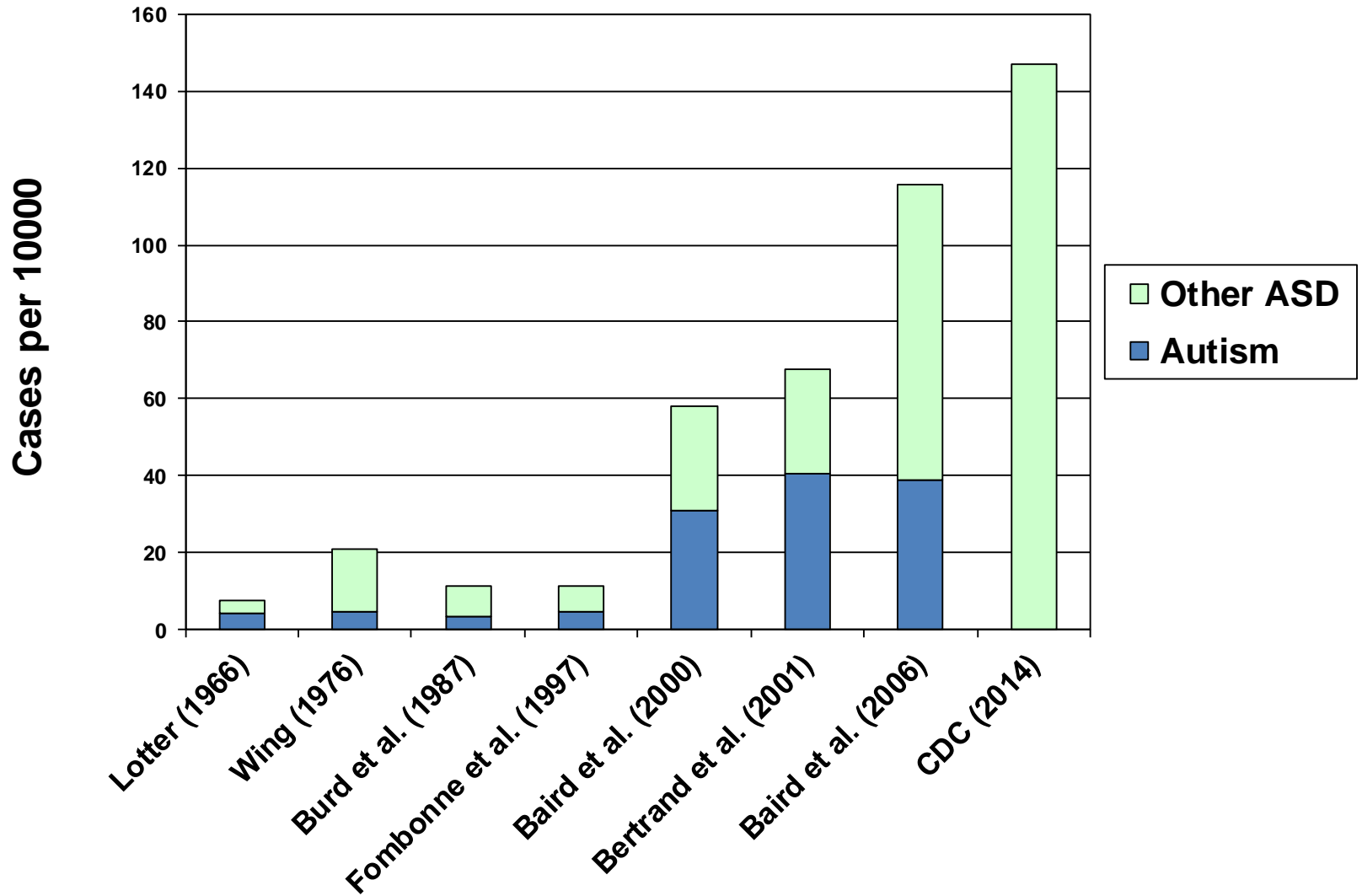
Autism (1980-2013)



Autism (2013-?)

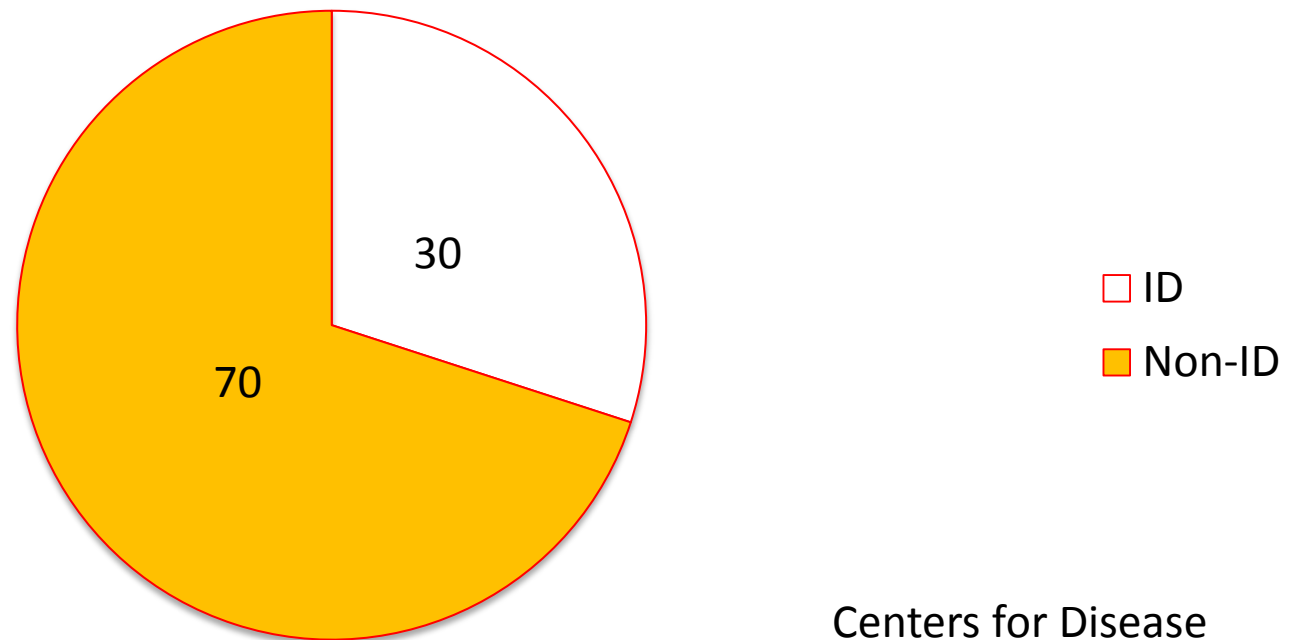


Myth 2: autism is rare



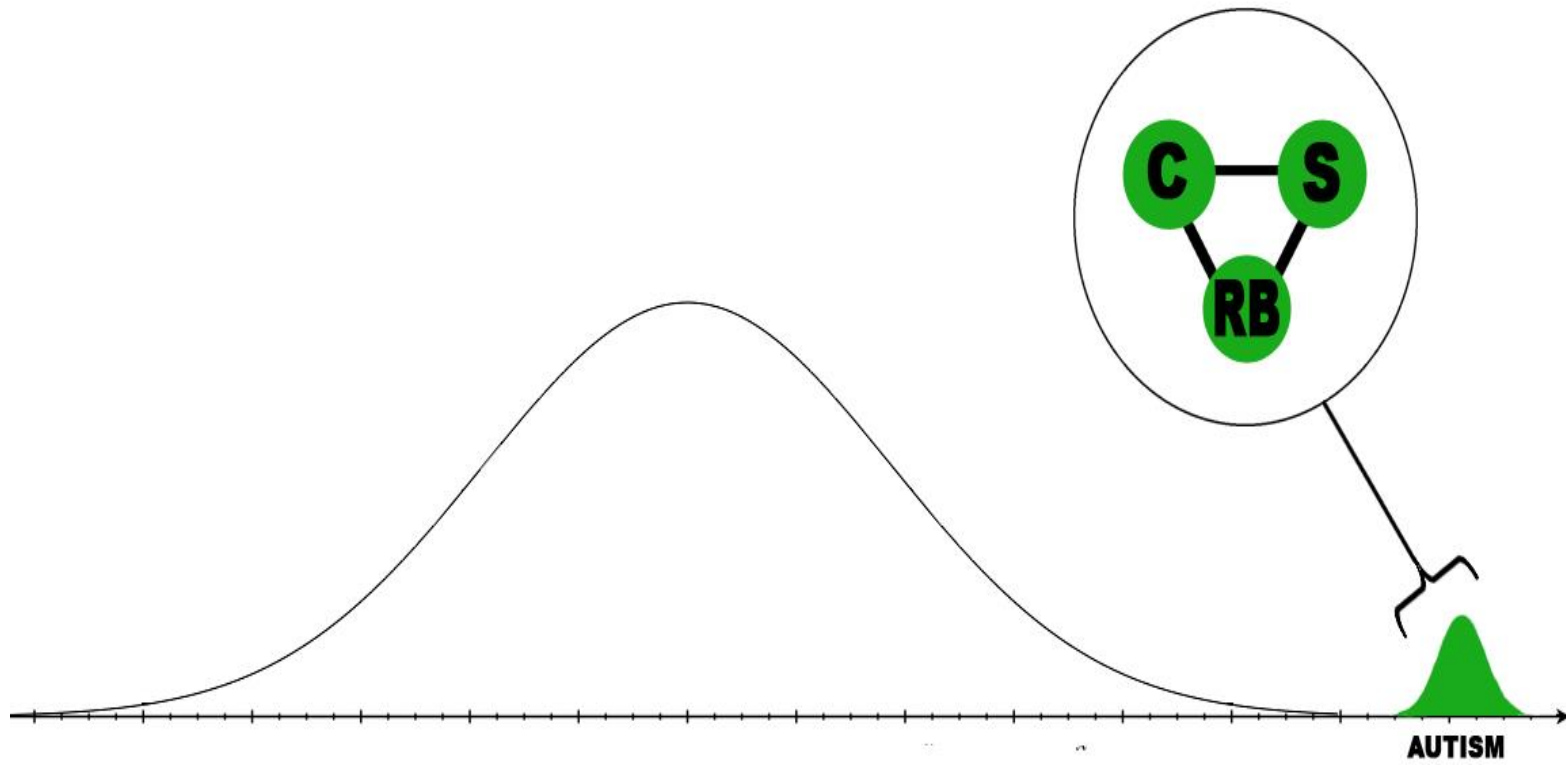
Myth 3: autism is usually associated with intellectual disability

Percentage of children with ASD, with and without intellectual disability (ID)

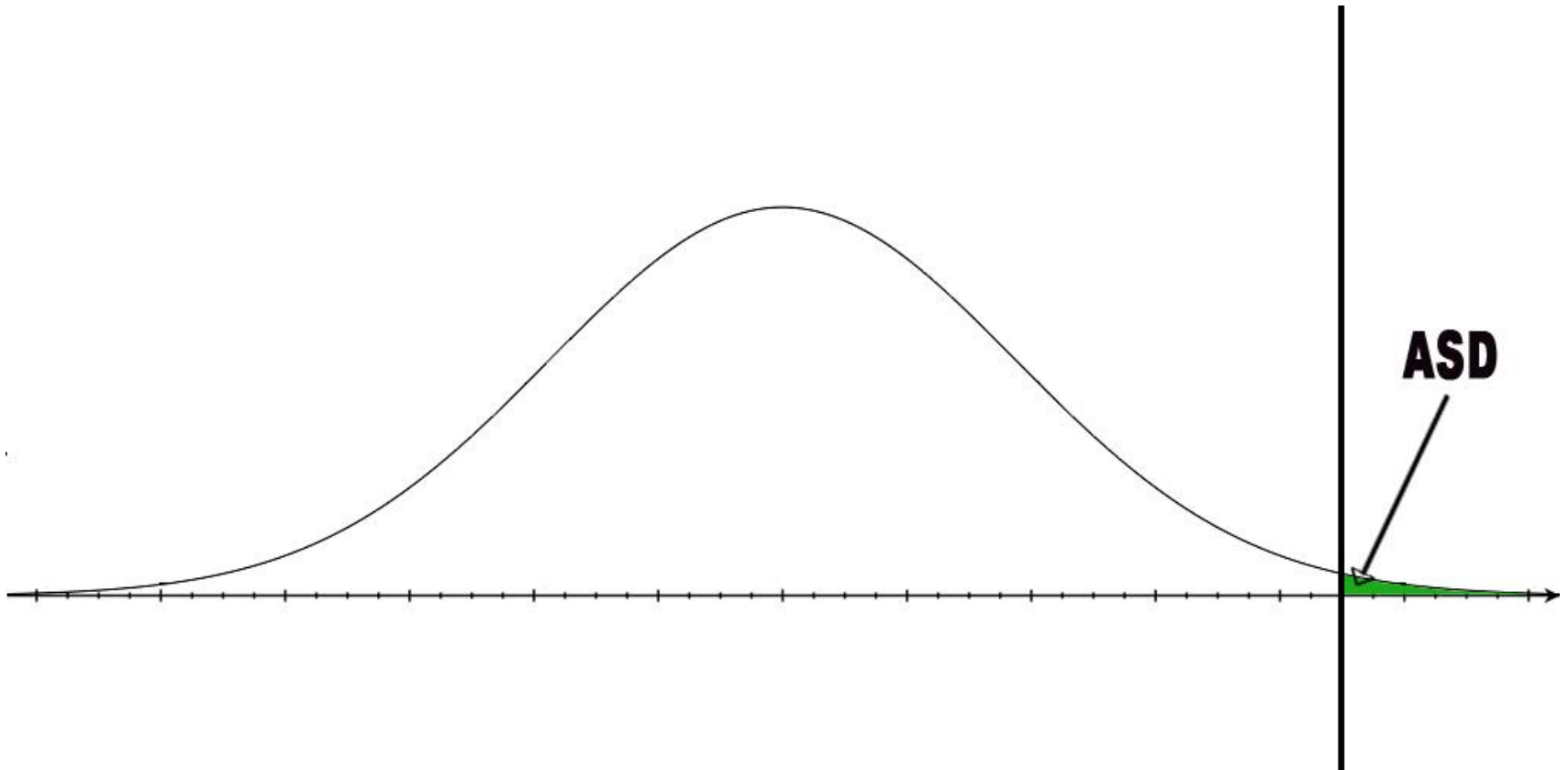


Centers for Disease
Control, 2014

Myth 4: autism is a categorical disorder



Myth 4: autism is a categorical disorder



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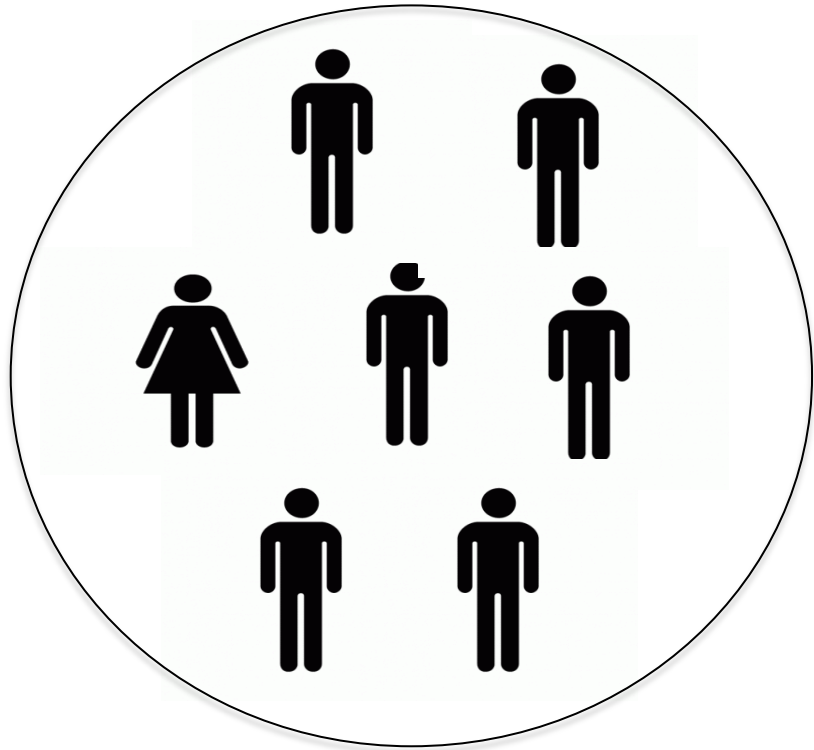
Autism: the new consensus

A relatively common, neurodevelopmental disorder with a dyad of symptoms, usually associated with normal-range IQ, and representing the extreme of trait distributions that extend throughout the general population.

Outline of the talk

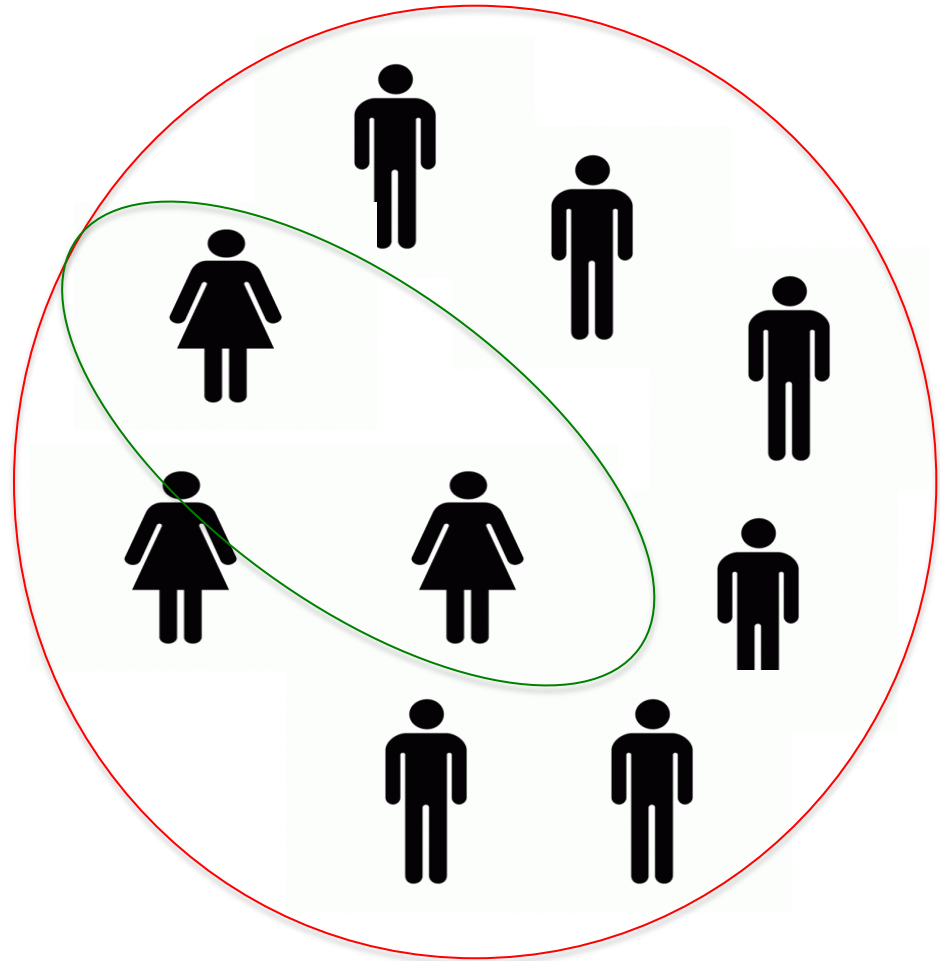
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The gender ratio in ASD



Clinical Samples

Non-referred samples



Is there a female-typical autistic presentation of that does not fit with our current male-biased ideas of what ASD looks like?

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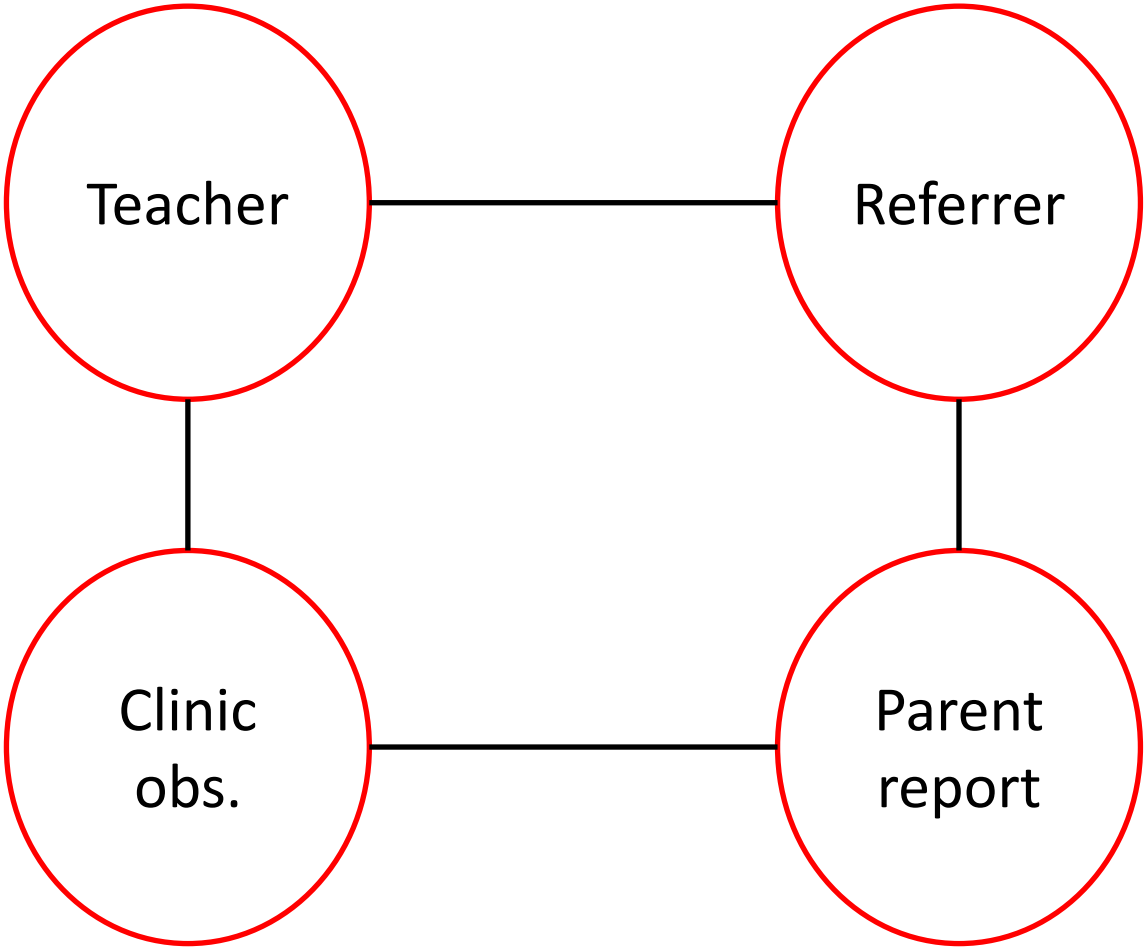
	Age	Previous professional involvement	School concerns over ASD	Friends	SCDC observations	Diagnosis
1	6	None (referred due to maternal concerns)	No concerns – perceived as well behaved and compliant	None – although would copy other children and was tolerated by other girls in her small village primary school	Very little expression of enjoyment; no facial expression or tonal expression; literal and difficulties with imagination; minimal social insight	Atypical Autism (due to lack of stereotyped, repetitive behaviour)
2*	13	CAMHS offered family therapy. Seen to have 'good social skills'	Noticed social and communication difficulties. Seen in context of LD and anxiety	Attempts peer interaction, but has trouble with social skills. Isolated and frustrated	+ Conversation and use of gesture fine. - Facial expressions, insight, social overtures.	Atypical Autism (no repetitive and stereotyped behaviour)
2*	9	None	No concerns over ASD – although she was perceived as volatile and difficult to manage	Part of a group of friends; limited reciprocity; relationships heavily based on shared activities	+ use of gesture and facial expression fine; garrulous - one-sided interactions; limited social insight; lack of imagination	Aspergers

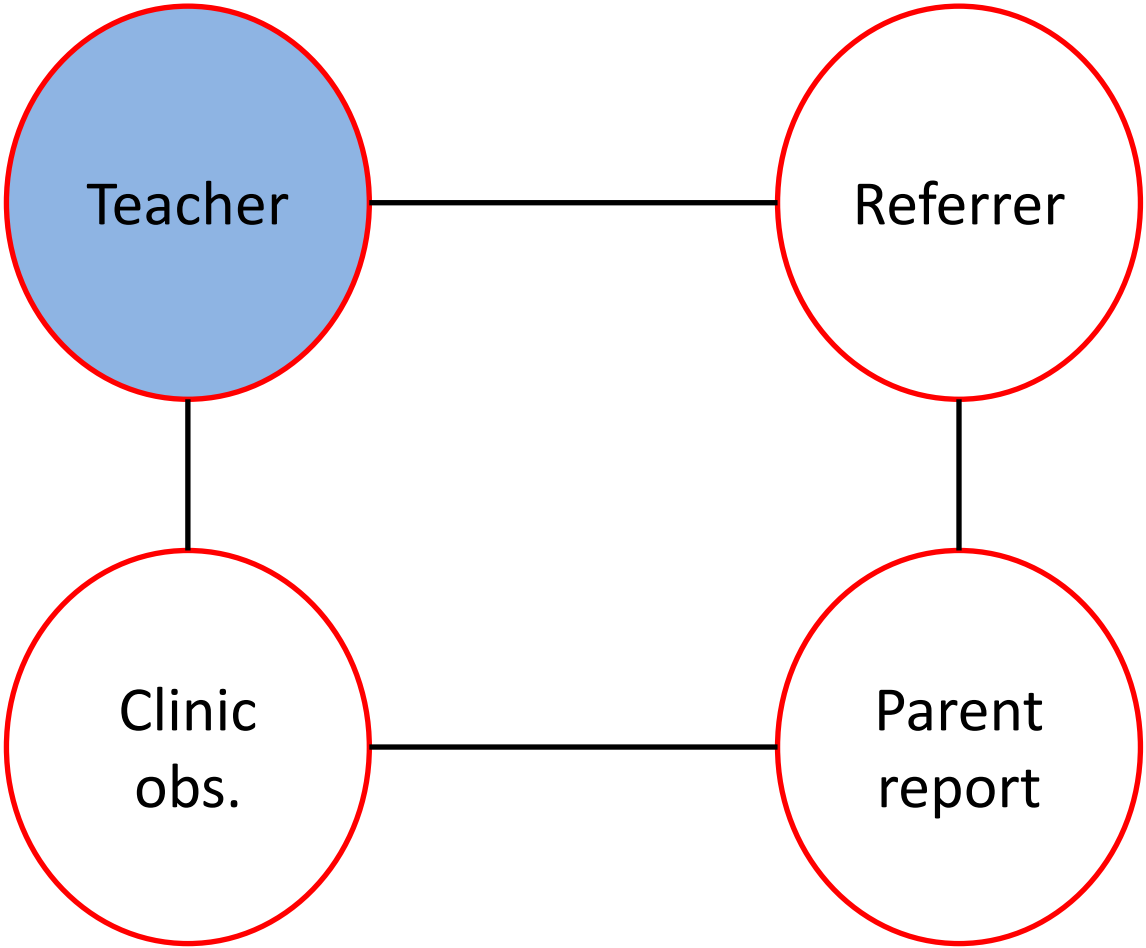
Clinical Observations – some themes

1. Females have fewer repetitive and stereotyped behaviours
2. Sense that social communication difficulties can be more subtle in girls than boys...and that this partly reflects their greater social motivation and compensation
3. Girls present with more internalising and fewer externalising behaviours compared to males
4. Girl's internalising problems sometimes mask their social communication difficulties

Quantitative study

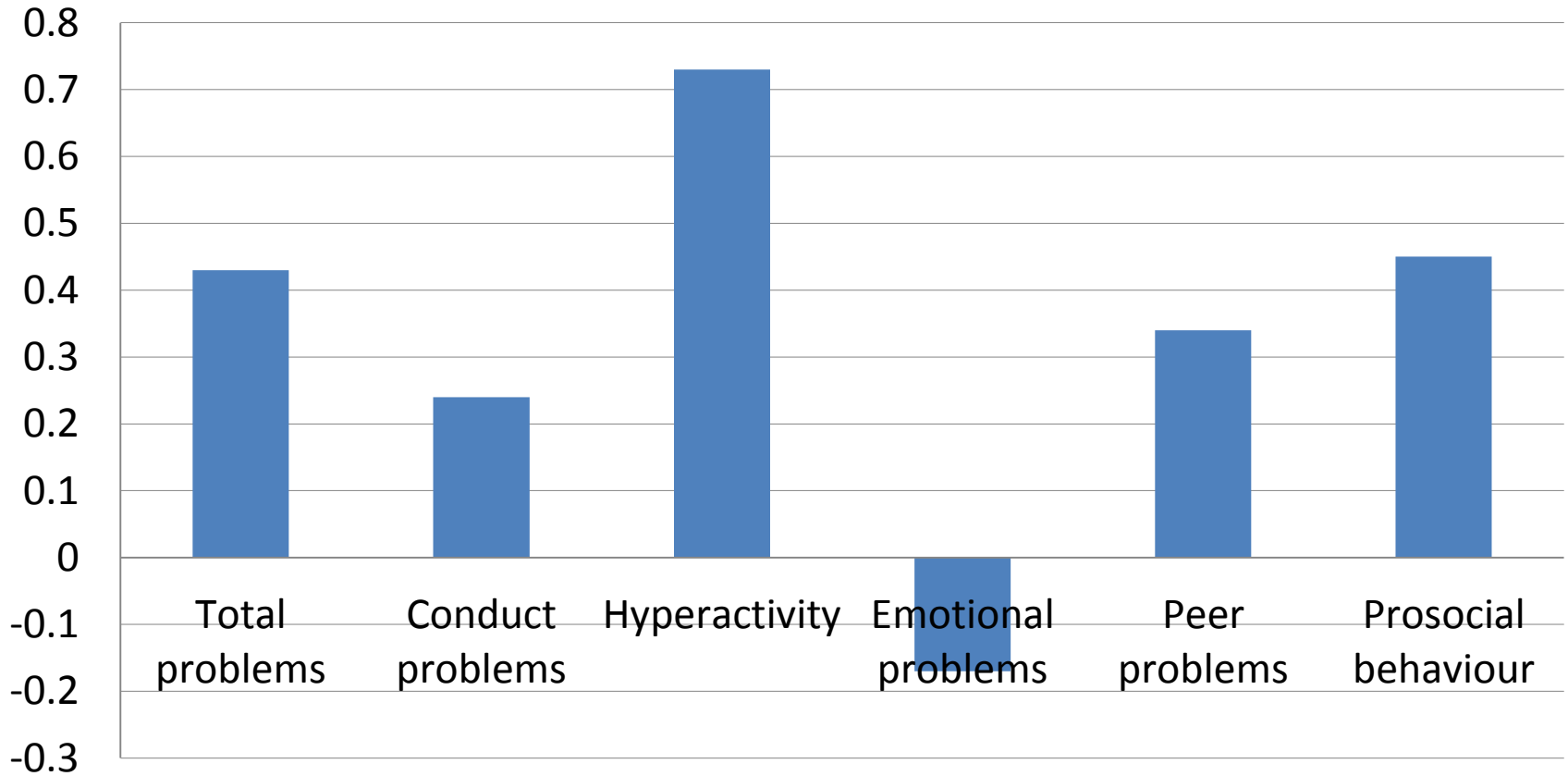
- 325 higher-functioning (mean VIQ=93) young people (mean age=9.8 years; range = 3 to 18 years) with an ASD
- Males (n=273) and females (n=52) matched for age and VIQ.
- Compared according to core ASD symptoms (3Di and ADOS); and adaption and psychopathology (SDQ).

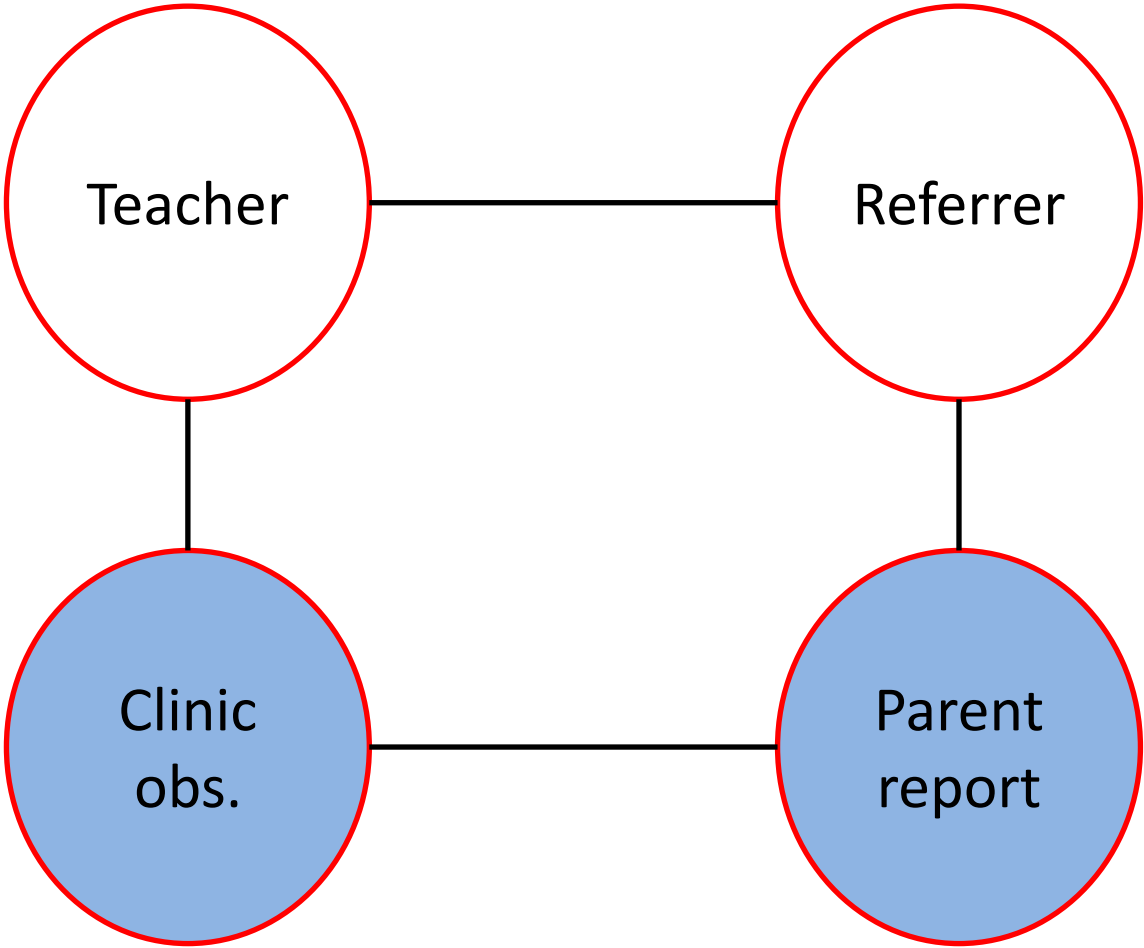




Teacher report

Comparison of ASD males and females on SDQ

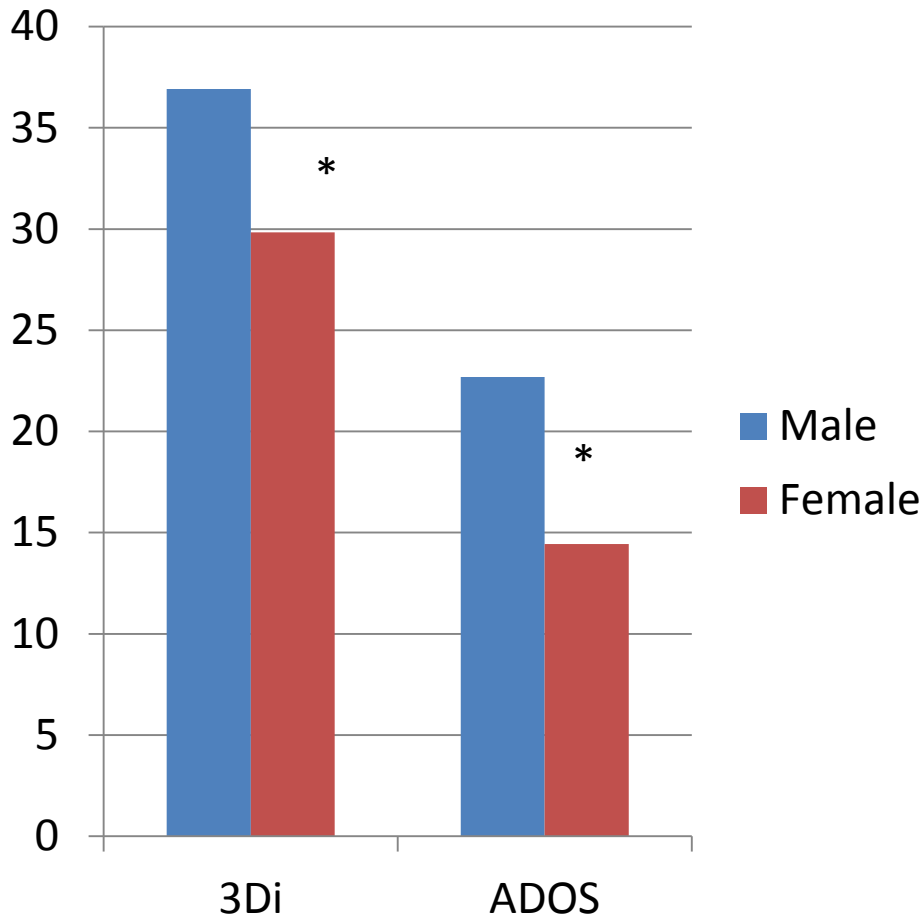




Parent report and clinical observation

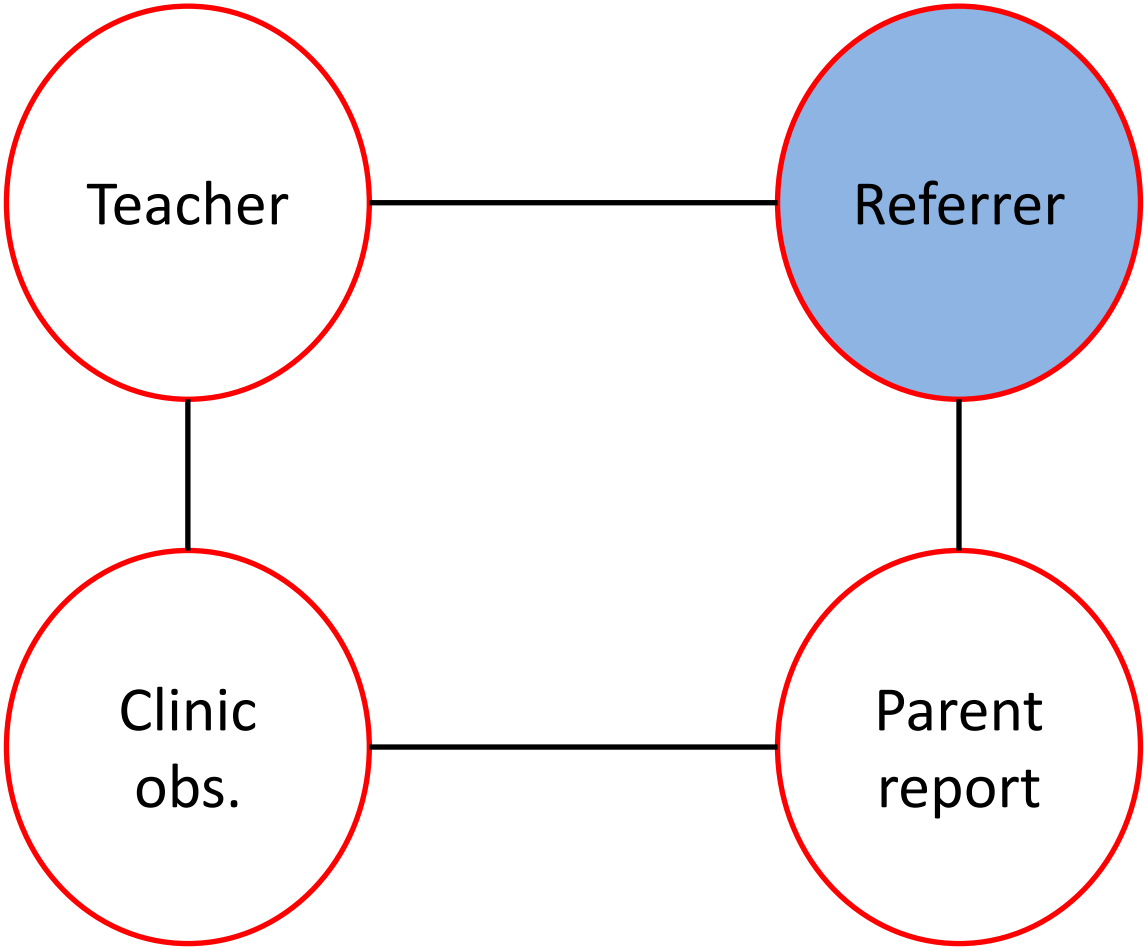
- No difference in degree of social communication impairment between males and females.
- No difference in parent-reported 'prosocial behaviour' and 'peer problems'
- Parents report more internalising problems for girls, although rates were high for both genders.

Parent report and clinical observation



In particular females were less likely to:

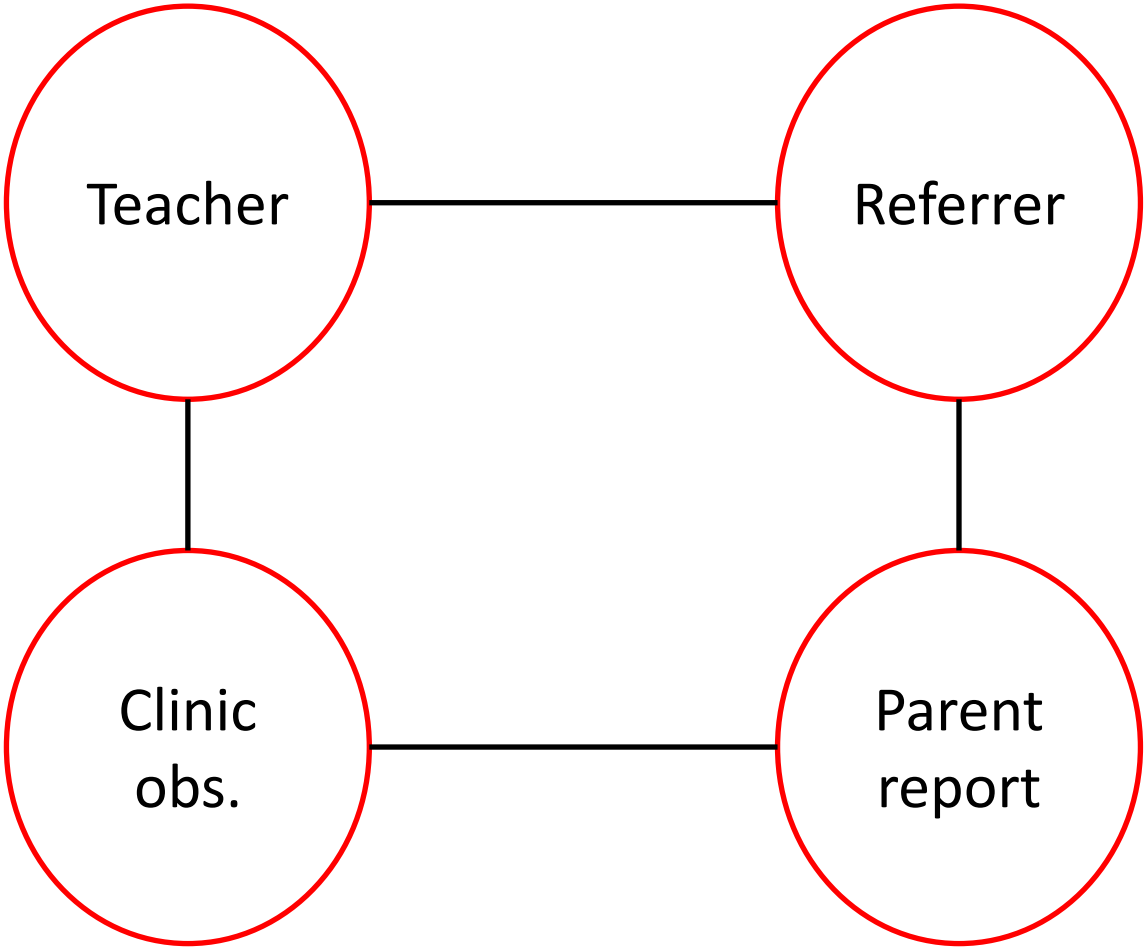
- show 'oddly formal play'
- have a large store of factual information.



Previous clinical impressions

Presenting problems described by referrer

		Females	Males
		N=25	N=25
Motor Problems	Coordination / dyspraxia	1 (4%)	9 (36%)*
Affect problems	Affect regulation	1 (4%)	0 (0%)
	Depression	5 (20%)	0 (0%)*
	Anxiety	6 (24%)	0 (0%)*



ASD in females

Compared to males, females with ASD have:

- fewer and qualitatively different repetitive behaviours
- equivalent levels of social and communication difficulties
- less obvious difficulties with socialising and behaviour regulation at school
- higher levels of internalising difficulties

ASD in females – clinical hypotheses

- More subtle social difficulties...the ability to mask difficulties better than boys
- More socially motivated, and more often aware of what is lacking
- More skilled in one-to-one interaction than boys...often protected by a single friendship
- More likely to be misunderstood at initial presentation to services

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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 morbidity

AN and ASD



Prof Christopher Gillberg (1985)

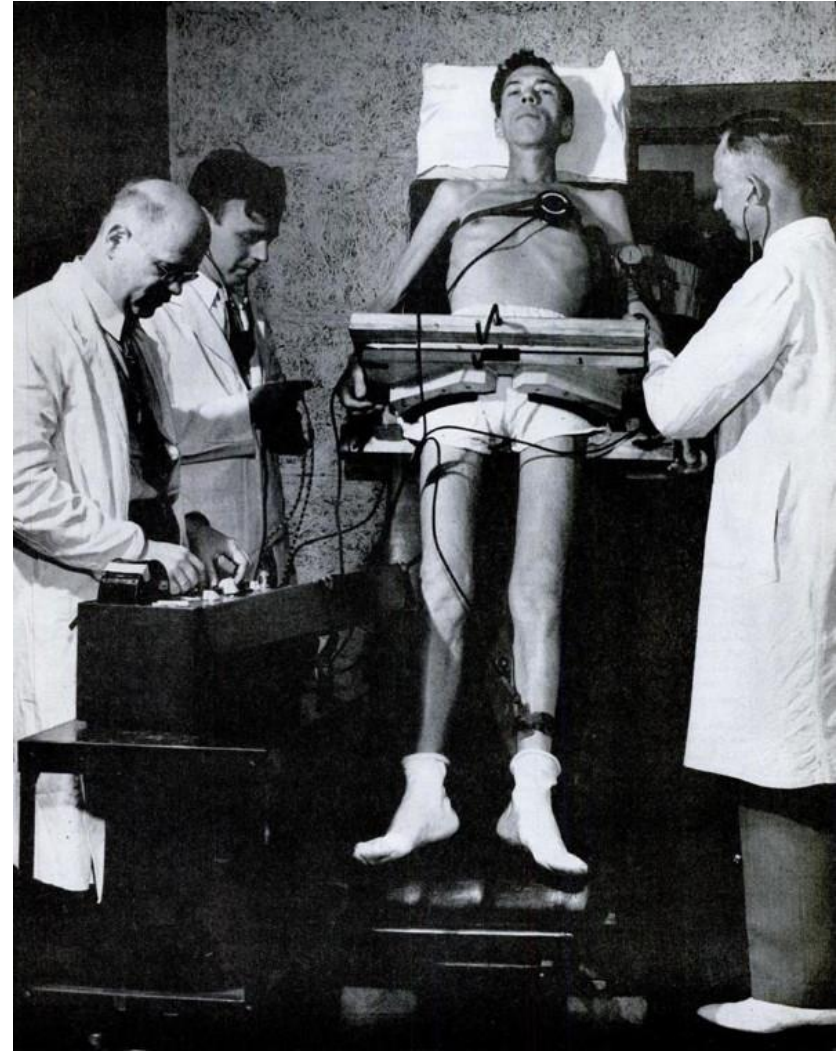
- Around 25% of women with AN meet criteria for ASD (Anckarsat et al., 2012)
- Autistic traits associated with AN (Hambrook et al., 2008)
- People with AN show ASD-like cognition
 - Poor ToM
 - Impaired set-shifting
 - Weak central coherence

But there is a problem...



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)



Controlling for the effects of starvation

- Adolescents with early onset AN, when assessed using standardised parent report, show high levels of non-social ASD traits (Pooni et al., 2012)
- In recovered people with AN, set-shifting and detail focused processing persists, but ToM problems do not (Oldershaw et al., 2010)
- Around 60% of females with social and flexibility problems in the context of anorexia meet ADOS criteria for ASD

Some clinical implications

- Females with ASD are at elevated risk of being missed by services
- They can present to non-ASD services due to co-occurring conditions (e.g. Anorexia)
- Assessment should include:
 - multimodal assessment
 - Observation in different contexts (e.g. clinic and school)
 - Look beyond anxiety and depression, and other co-occurring conditions
 - standardised interview and observation tools
 - Focus on social communication difficulties – don't be put off by lack of RSB

Some features of assessment we find useful

What to look for:

- Insight into relationships and the individual's roles in those relationships
- Evidence of learnt social behaviour and compensation
- When talking to school does 'she has no difficulties' really mean 'she causes us no difficulties'
- Lack of friendships...or reliance on one friendship
- Consequences of breaking down of these friendships, and of change generally
- Are RSB's masked by being more normative and social in nature

Summary

- There are more similarities than differences between males and females on the autism spectrum...
- ...along with some subtle but significant differences
- These may delay or prevent diagnosis, or lead to problems in females being mislabelled.

Understanding Women with Autism

Tea Break

Please be back for 11.30

Up Next: Robyn Steward

Lived perspective

By Robyn Steward

Autism trainer, Author, broadcaster



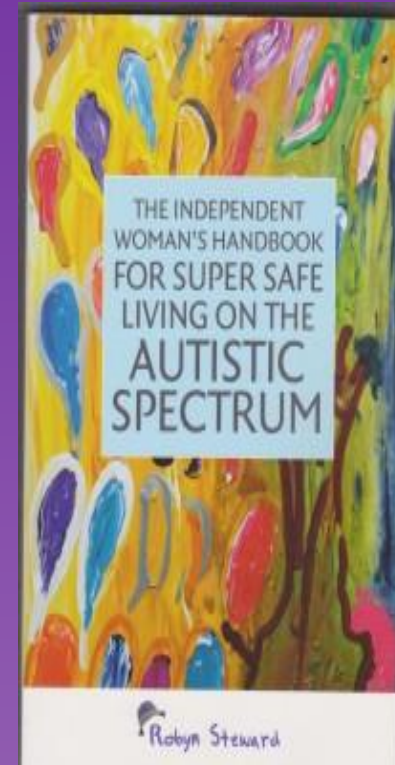
Robyn Steward

Consultant • Trainer • Mentor • Speaker • Artist

The Autistic Spectrum from a person not just a textbook!

Who I am

- Trainer
- Mentor
- Consultant
- Author
- Broadcaster
- Artist
- Musician



Topics

- Life from this viewpoint
- Diagnosis
- Post diagnosis support
- Questions?



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Topics

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Life from this viewpoint



Circa 2002



Circa 2012

Topics

- Life from this viewpoint
- **Diagnosis**
- Post diagnosis support
- Questions?

Diagnosis

- Missed
- Late
- Inaccurate or incomplete diagnosis

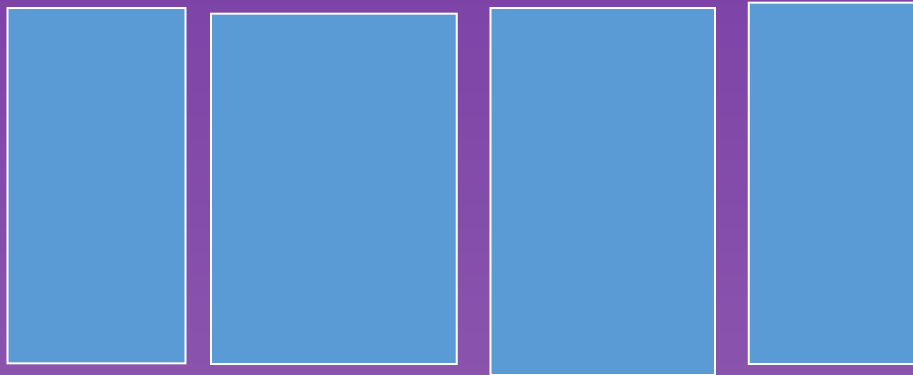


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Diagnostic package



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Topics

- Life from this viewpoint
- Diagnosis
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The Autistic Spectrum from a person not just a textbook!

So what?.....



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Consultant • Trainer • Mentor • Speaker • Artist

The Autistic Spectrum from a person not just a textbook!

For the individual

- Can answers questions about past experiences
- Builds on sense of self
- Allows access to others
- Allows context in which to learn about autism.
- Possible better coping strategies



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For people around the person

- Answers questions about past experiences
- Informs treatment and support
- Allows specific supports to be put in place
- Changes statutory duties?



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Topics

- Life from this viewpoint
- Diagnosis
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Q and A and contact Details

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robyn@robysteward.com
- 07956511903

Thank you!

Understanding Women with Autism

Up Next: Tiago Pinto

SEE BENEATH THE SURFACE

Autism Spectrum Disorder, Personality Disorder,
Comorbid conditions
or
something else?

Tiago Pinto
Clinical Psychologist
11/09/14

Overview

- **Females with ASD - different presentation from males?**
- **Diagnostic tools - what are they looking for?**
- **Gaining an accurate Diagnosis**
- **Common Co-Morbid Conditions**
- **What to treat first?**

ASD (DSM5)

- ASD now encompasses the previous DSM-IV autistic disorder (autism), Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder (PDD) not otherwise specified.
- Single condition with different levels of symptom severity with **two core domains**
- ASD is characterized by 1) deficits in social communication and social interaction and 2) restricted repetitive behaviours, interests, and activities (RRBs).
- Both components are required for diagnosis of ASD, social communication disorder is diagnosed if no RRBs.

ASD (DSM5)

- Individuals with ASD must show symptoms from early childhood, even if those symptoms are not recognised until later.
- This criteria change encourages **earlier diagnosis** of ASD
- Allows people whose symptoms may not be fully recognised until social demands exceed their capacity to receive the diagnosis.

Females vs Males

- Current Ratio

**Males : Females is 8:1 in Asperger syndrome,
and 4:1 in Autism**

- Is there a genetic predisposition in boys?
- Do biological factors, such as testosterone, increase risk?

OR
females are under-detected?

Females with ASD different presentation?

- Wing (1981) – females are *superficially* more sociable than males.
- Kopp & Gillberg (1992) – females less interested in objects or parts of objects.
- Wolff (1995) – females have fewer special interests.
- Kopp (2003) – special interests include animals, drawing, cultures, comics, sports, fantasy books, pc games.

Females with ASD different presentation?

- Faherty (2002) – girls are enamored with princesses, fantasy kingdoms, animals, unicorns, etc.
- Attwood (1999) – Girls are mothered by other female peers?
- Girls may have imaginary friends/talk to dolls.
- Girls may ‘role play’ or imitate other personas.
- Gillberg (2003) – girls hidden by other disorders e.g. anorexia

Females with ASD different presentation

Kopp and Gillbert (2010), Koop et al (2010)

Girls appear:

- “passive” “avoidant”, and “hypoactive” – leading to under recognition,
- more verbally communicative (leading to superficially better social skills),
- less violent (leading to low rates of clinical referral),
- With time becoming more demand avoidant, and in some aspects, less rigid and over-confused (leading to non-consideration for a diagnosis of ASD)

Girls Vs Boys

Noticeable differences include:
Gilbert and Kopp (2010)

- Voice or speech: 50% girls vs 20%boys
- Motor tics: 40% vs 15%
- Deviant style of gaze: 50% vs 30%
- Lacks best friend: 30% vs 70%
- Follow other children like a shadow: 40% vs 10%

Girls vs Boys

Baron-Cohen S, Lai M-C, Lombardo MV et al (2012) Cognition in Males and Females with Autism: similarities and differences; concluded:

- performance in the social-cognitive domain is equally impaired in male and female adults with ASD.
- found striking sex difference in current interactive behaviours on the ADOS, with milder interpersonal features in woman with ASD compared to men.
- Strengthening the argument for superficial camouflaging of social-communication difficulties in females with ASC.

Under-detected, hidden, meshed?

Baron-Cohen S (2013) Anorexia and Autism

- Autism and anorexia appear to be completely different both have common features, including:
 - A fascination for detail
 - A tendency to focus on oneself
 - Inflexible behaviours
 - Rigid attitudes
 - As far as social perception is concerned, **anorexia and autism** both share similar changes in structure and function of brain regions.
- Depression
- Bipolar disorder
- Anxiety disorders (social anxiety)
- Personality disorders

Personality Disorders

- **Schizoid PD**

- No interest in forming close relationships
- No interest in sexual relationships or intimacy
- Relationships feel as interfering with freedom
- Solitary and inward looking
- “Loner”

- **Narcissistic PD**

- Fragile self-esteem → dependent on others to recognise worth and needs
- Putting own needs over others “I don’t get what I deserve”
- Selfish, resenting behaviour

- **Borderline PD**

- No sense of who you are → very changeable
- Intense emotions, mood swings → Stormy relationships,
- Fear of being alone → clinging to relationships
- Brief psychotic episodes
- Self harm and suicide attempts, Impulsive actions

Diagnosis

- Do standardised assessment tools pick up females?
- Importance of peer observation and information.
- Theory of Mind, cognitive assessments.
- see beneath the the surface.

ADOS-2 ADI-R

- ADOS-2 and ADI-R Golden standards for a diagnosis of ASD (plus own clinical judgement and MDT discussions) + DISCO
- ADOS-2 highly structured observational assessment; activities to observe behaviours relevant to ASD; use of presses relevant to reciprocal social interaction, communication, imagination/creativity, stereotyped behaviours and restricted interests.
- ADI-R completed with caregiver, semi structured interview schedule, DSM-IV/ICD-10 autism, exploring early development' milestones, communication, social development, play, interests, behaviour.

ADOS-2 ADI-R

- Reliable tools good sensitivity and specificity data
- However do not take into account male vs female bias

Lai M-C, Lombardo MV, Pao G, Ruigrok ANV, Wheelwright SJ, et al. (2011) A behavioural Comparison of Male and Female Adults with High Functioning Autism Spectrum Conditions;

- Study suggest rather weak evidence to support use of ADOS mod 4 for female adults with ASD as a tool of diagnosis.
- Study suggests tell-tale signs among females – good camouflage include speaking and/or writing too much, difficulties with switching attention (more research needed).

Specific Female ADOS?

See beneath the surface

- Diagnosis – important – spend time with the person, understand what is underneath not just in the surface (not just ED or aggressive behaviour, talk with the person and systemically understand the presentation, use recommended tools as well as your clinical judgement, history)
- not 20 mins talk with psychiatrist or did a WASI-2, “spikey” profile performance IQ vs verbal IQ
- diagnosis and early intervention may avoid development of future comorbidities
- AWARENESS of ASD female.

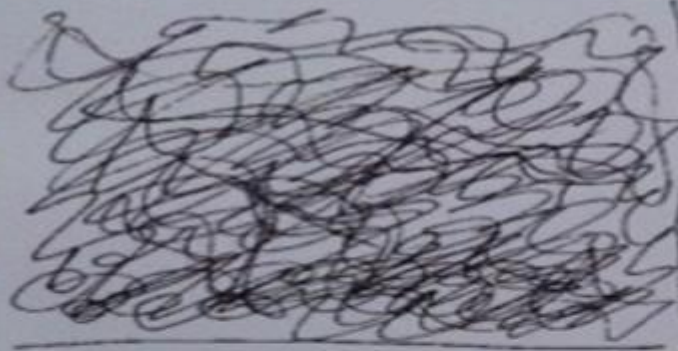
See beneath the surface

www.unitedresponse.org.uk

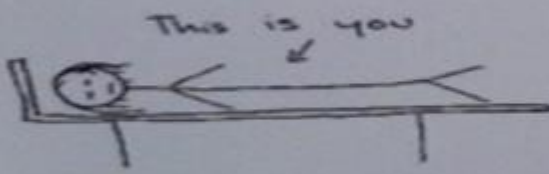
www.postcardsfromtheedges.org.uk

Charity supporting young people and adults with a wide range of disabilities.

Presentation Feb 2014 House of Commons



← And this is the ugly pile of illness that covers you.
I love the you that's under the pile.



This is you
↓



Why don't you hear me?
Where are you?
What's happened to you?
Mum!!!

Marysia - Mum

See beneath the surface

- Social anxiety – leading to drinking
- Not able to understand oneself and others – dynamics of conflict and feeling inferior – I am useless – Low self – esteem; depression
- reinforced by bullying – parents: what is wrong with you? depression, suicide, poor coping strategies
- Autism – invisible – making it visible – eating disorder – control factors

Autism in Pink Project 2014 “Nothing about us, without us”

It is essential that the public becomes more aware of ‘**Masking**’, which appears to take place more in women with autism than men.

The qualitative research showed that **many of the participants go to great lengths to compensate for and cover up some of their autistic characteristics by suppressing them, mimicking other people, and using logic rather than instinct to work out social situations.**

This means that people are not aware of the difficulties that they might be experiencing (...). It also means that women with autism are constantly putting a lot of extra energy into their interactions, which is exhausting.”

Autism in Pink Project 2014 “Nothing about us, without us”

Case studies from the group:

Emily only received a diagnosis of autism three years ago, after spending most of her life feeling different from others but not understanding why. She attributes her late diagnosis to a lack of understanding of the way that autism affects females.

Emily struggles with social situations and says she feels "a bit like an alien", even when she's surrounded by loved ones.

Emily said: *“There are lots of stereotypes surrounding autism which can make it difficult for others to understand how the condition affects me as an individual and as a woman.”*

“Breaking the silence”

A collection of personal writings and drawings by women with autism

Address me directly.

Understand you are not the expert on me, I am.

The media & Hollywood tar us with the same brush. We're all unique.

If we fall in love or enjoy something, don't problematise it as an obsession.

Society's negative attitudes are more disabling than our differences.

Milestones such as raising a family, driving & University isn't beyond us.

P.S. *not* everyone wants a cure!

AUTISM



A

Understand you are not the expert in me, I am.

T

I

S

M

Autism from the inside out postcard by Amy Simmons

Mum2Aspergirl

21 July 2014

Ann Memmott wrote a new note:

"She's definitely not autistic! I'd know if she was!"

- "Autism in women is nothing like autism in men. (...) Think of a stereotype of autism; the geeky anorak bloke with really awkward body language, a tendency to rock, flap or make a strange noise from time to time. totally abrupt manners, (...) it's exactly what many people look for in a woman to work out if she is autistic. They'll never spot us that way! (...) Autistic women are the most amazing actors, at massive personal cost to us.
- We can handle 'being normal in appearance and manner' because we made people our specialist subject. We studied and studied, learned and learned, practised and practised...for days, weeks, months, years....including practising how to do eye contact, hugs with friends, etc. Even if it hurts us sometimes/always.
- And we got so good at mimicking 'normal women'(...) that we can pass for 'normal'. Even in front of friends. (...)

Ann Memmott wrote a new note:

"She's definitely not autistic! I'd know if she was!"

- We hope no-one notices our need for detail. We hope no-one notices our need to have a drink to steady our sensory system in public.
- We hope no-one notices us leaving regularly to recover, saying it's to 'go for a walk' or 'go to the toilet' or whatever else.
- We hope no-one notices us arriving late and leaving early at social events.
- We hope we don't stim or say something stupid, so we learn stock phrases that will get us out of trouble a lot of the time, and learn to keep our hands still, etc.
- We practise not talking about our favourite subjects for hours.
- We have intense interests that seem really 'normal', e.g. celebrities, ponies etc - and hope no-one notices that we are utterly obsessed with rules, data, lining the stuff up, collecting one of each colour...
- But the strain on us from covering up 100% of our autism is so intense that it leaks out in other ways.

Ann Memmott wrote a new note:

"She's definitely not autistic! I'd know if she was!"

- We may end up with extreme anxiety or depression from the strain.
- We may end up with high blood pressure and other health-related issues.
- We may end up with anorexia or eating disorders.
- We may end up self-harming as a desperate way of coping.
- We may end up utterly alone, unable to make a single really good friendship (...).
- But it's all an act. (...)
- We can't see body language, or eye contact, or face expression.
- We can't cope with the social 'overload' in crowds.
- We can't handle the sensory overload in busy, noisy places under intense lighting.

Ann Memmott wrote a new note:

"She's definitely not autistic! I'd know if she was!"

- Our brains are autism-design, not standard-design. And what we learn to do is live a life of pretending they are not, at massive exhaustion and massive personal cost.
- So many of us are told, "There's no way you are autistic", and are denied a diagnosis.
So we just think we're substandard instead(...). Hundreds of thousands of us in the UK have had to hide, or have no diagnosis and maybe no clue that they even are autistic. (...)

Rosie's case

- **30 y.o.**
- **Aspergers; Anorexia Nervosa; Alcohol Misuse; Borderline Personality Disorder inc. Suicide attempts**
- **Problem** Accepting diagnosis of Aspergers
- **Life Pattern:** always feeling being different and not knowing why; nobody understands me; people don't like me; I can't fit in in society; feeling left out; I am odd; I am stupid; I am useless; I destroy my family. I was bullied at school for being different and not fitting in. Given a lot of labels when she was a child.
- **Problem** Eating disorder since the age of 12
- **Life Pattern:** eating disorder serves a purpose for Rosie – Rosie has made the assumption that "If I am thin people will know that I am different"; If I am thin and I have a problem my parents will care for me. I will always need to be looked after. I will not be able to grow up. If my parents think I am ok they will forget me.

Rosie's case (cont)

- **Problem** Low mood/ Depression
- **Life Pattern:** Started when she experienced bullying at school. Withdrawing and isolating in room. Ongoing thoughts of you are useless; you don't have a purpose in life, what is the point of living. Several suicide attempts.
- **Problem** Risky behaviours
- **Life Pattern:** Misuse of alcohol, promiscuous sexual partners, "waking up in my flat in a pile of vomit with a stranger by my side", drinking helped me feel relaxed and fit in.

Rosie's case (cont)

Developmental Origins

- Mother (history of eating disorders) /Father (absent); one older brother and one younger sister.
- Family moved together to a different city when Rosie was 7 – Rosie did not want to move
- Rosie always felt different. Was severely bullied at secondary school.
- In Secondary school binge drinking starts, self-harm, promiscuous sexual behaviours.
- Parents could not cope with Rosie's presentation, Rosie started in the system, special schools, psychiatric admissions.
- Teenage years until 3 years ago: ongoing self-harm; suicide attempts; drinking
- Restrictive eating from age of 12 – I was never happy with weight. I see myself as an elephant.
- OCD starts – praying for up to 3 hours a night, having to touch jackets in a certain way.

Rosie's case (cont)

Core Cognitions & Distortions

- **Parents** – “I want my parents to love me”; “I don’t want periods, I want to be a child”; “If I grow up my parents will stop loving me”; “I destroy my family”
- **Others** – “If I try to talk to people, they will make fun of me”; “If I am thin people will know I am different”; “people will look after me if I am ill”; “If I am ok people will forget about me” ; “people hate me and don’t want to spend time with me”
- **Self-** “I don’t have a purpose in life, I shouldn’t be alive” ”; “If I gain weight I am a bad person”; “I am unlovable; ugly ; fat and stupid”

Rosie's case (cont)

- Late diagnosis of ASD - 20
- Not knowing why different? – IMPACT Core belief – I'm useless and worthless
- Unable to form relationships – why? – IMPACT – Alcohol misuse, Bullied
- What is wrong with me? – making difference visible – Eating Disorder
- Cant cope – SH and SI
- What's the point

Help me

What to treat first? No intention of treating ASD, but to look into how ASD has influence life story, has played a huge part in feeling low, not knowing what is wrong with me, how it meshed and shaped MH problems.

So...

- Psycho-education
- Small group work – Social skills, anxiety management (adapted CBT work), friendships and relationships,
- Self esteem. Image and social expectations
- If needed and possible some indepth work: DBT or Schematherapy , not for the ASD but for the mh presentation
- Work as an MDT – liaising with other agencies
- Looking at strengths, focus on the strengths– Drama, art, observation!
- Be careful with taking everything literally (*aliens*).

Ashwood



Real Care Pathways; Real Outcomes

A quote from Rosie

“ I always wanted to be accepted and feeling accepted, trying to fit in, but maybe its time for the world to accept me for what I am”

Rosie, 04/09/14

Thank you

To Dr Fiona J Scott – Autism Research Centre – University of Cambridge – ongoing support, research data, ADOS-2, ADI-R.

Thank you for listening!

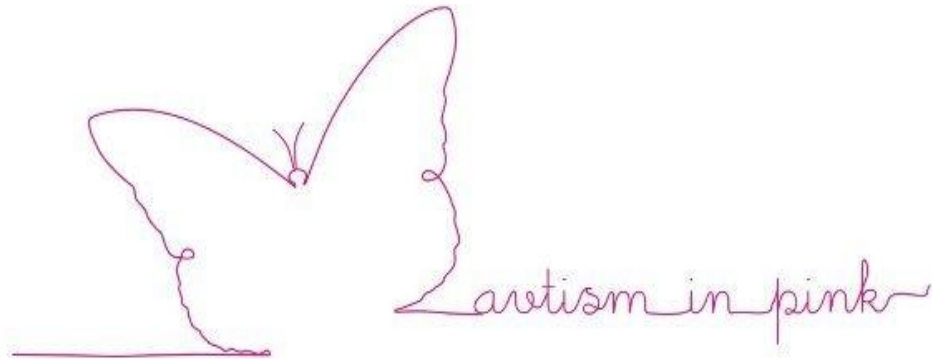
Contact me

tiagopinto@brookdalecare.co.uk

Understanding Women with Autism

**Lunch Break
Please be back for 2.00**

Up next: Sylvia Kenyon



Women with Autism: Vulnerable Women in Society

Overview:

- Autism in Pink Background
- Vulnerability and giving support in general

Themes:

1. Masking -
 2. Stereotyping
 3. Spiky profile
 4. Sensory and processing differences
- } affect our perception of what is going on

Relevant to what we perceive as the support that a woman with autism might need in all possible areas of vulnerability

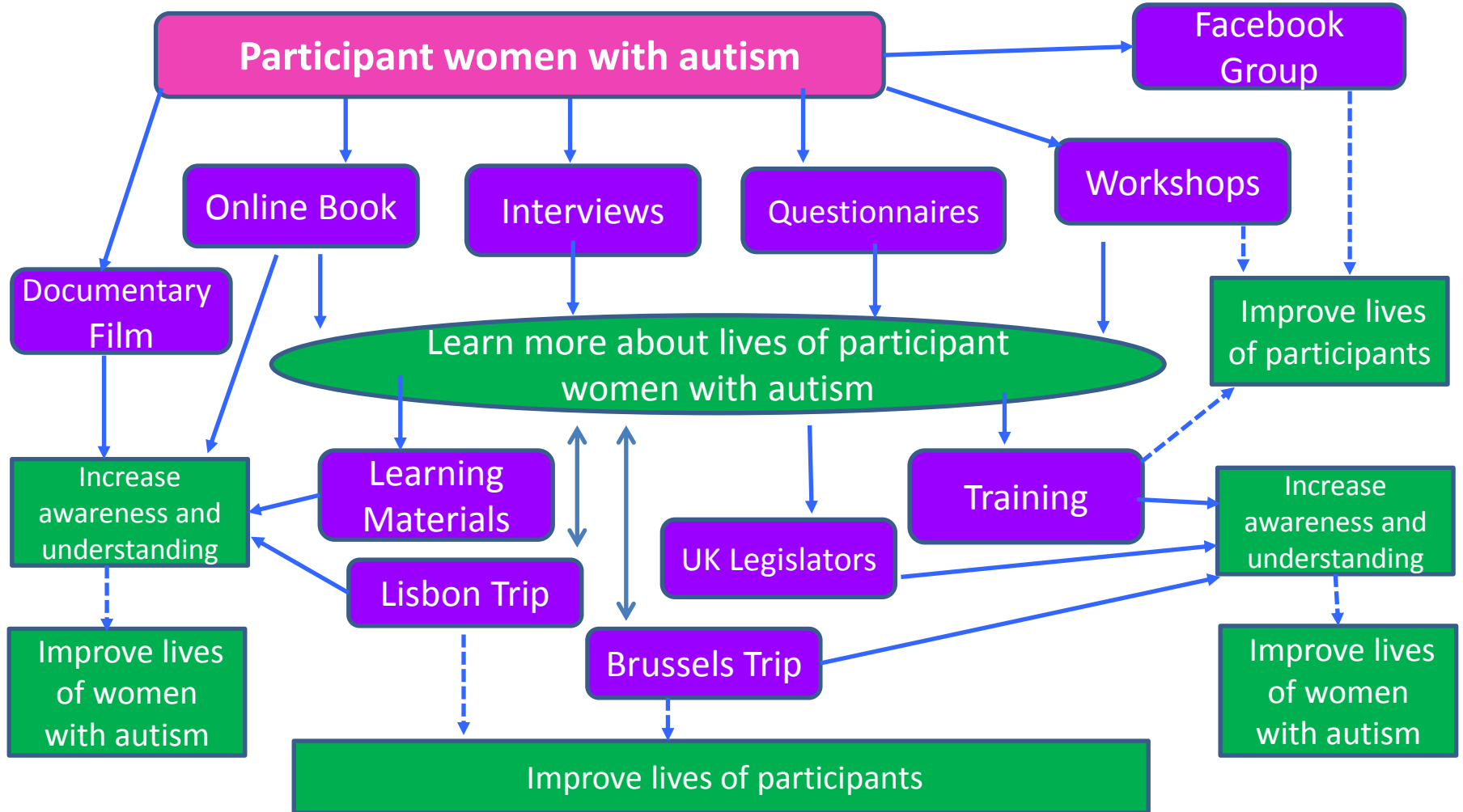
- Areas of Vulnerability:
 1. Relationships
 2. Financial Management

Autism in Pink

www.autisminpink.net.uk

- Funded by EU Lifelong Learning Programme
- 46 women from EU aged 18-40
- 12 from UK
 - 10 Asperger syndrome , 1 atypical autism, 1 autism
 - 4 employed: 1 FT, 2 PT, 1 self employed
 - 5 in ed: 1 in specialist/mainstream, 4 mainstream (3 degree/PG)
 - 4 unemployed, 2 seeking employment
 - 5 living with family, 2 with partner, 5 alone

Autism in Pink



Vulnerability and support

Themes

1. Masking



Masking

Hides / Covers up /
Compensates

By

Using logic

Mimicking

Suppressing

Fitting in / Appearing 'Normal'

BUT

Misjudgement by others

Masking

That doesn't
make sense – it
must mean
something else

Using Logic

That makes
more sense –
it must mean
that

“Opening a can of
worms...”



“Creating an
unpleasant or
difficult situation...”

Masking

Conscious processing to hide, cover up, compensate

Using Logic

Mimicking

Suppressing

Fitting in better

More effort and energy required

Takes longer

Can't be true selves

Make more mistakes

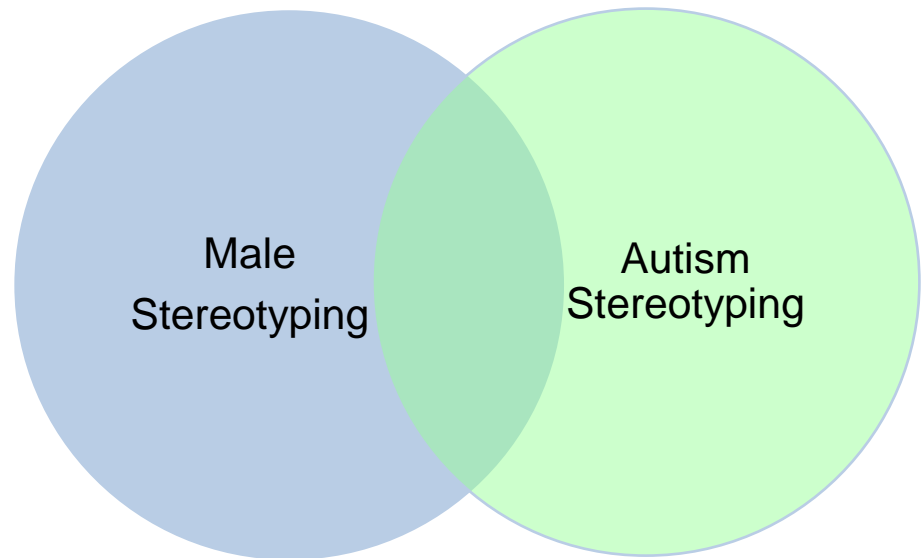
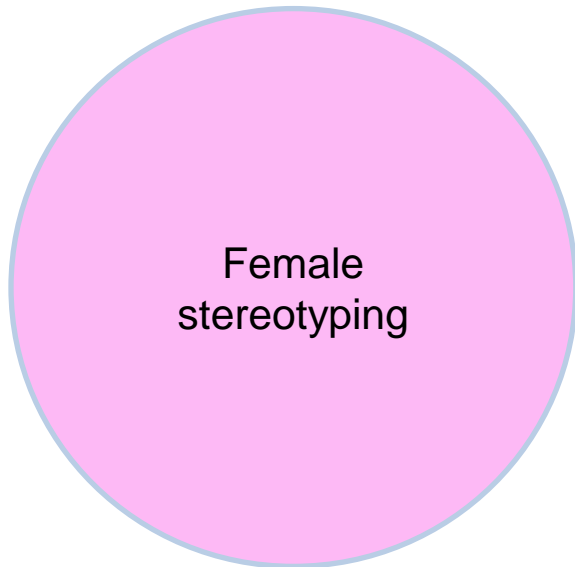
Misjudgement by others

'not autistic, doesn't need support'

Rude, slow, unintelligent, shy, unconfident, depressed, obstructive, selfish, doesn't listen

Themes (ctd)

2. Stereotyping

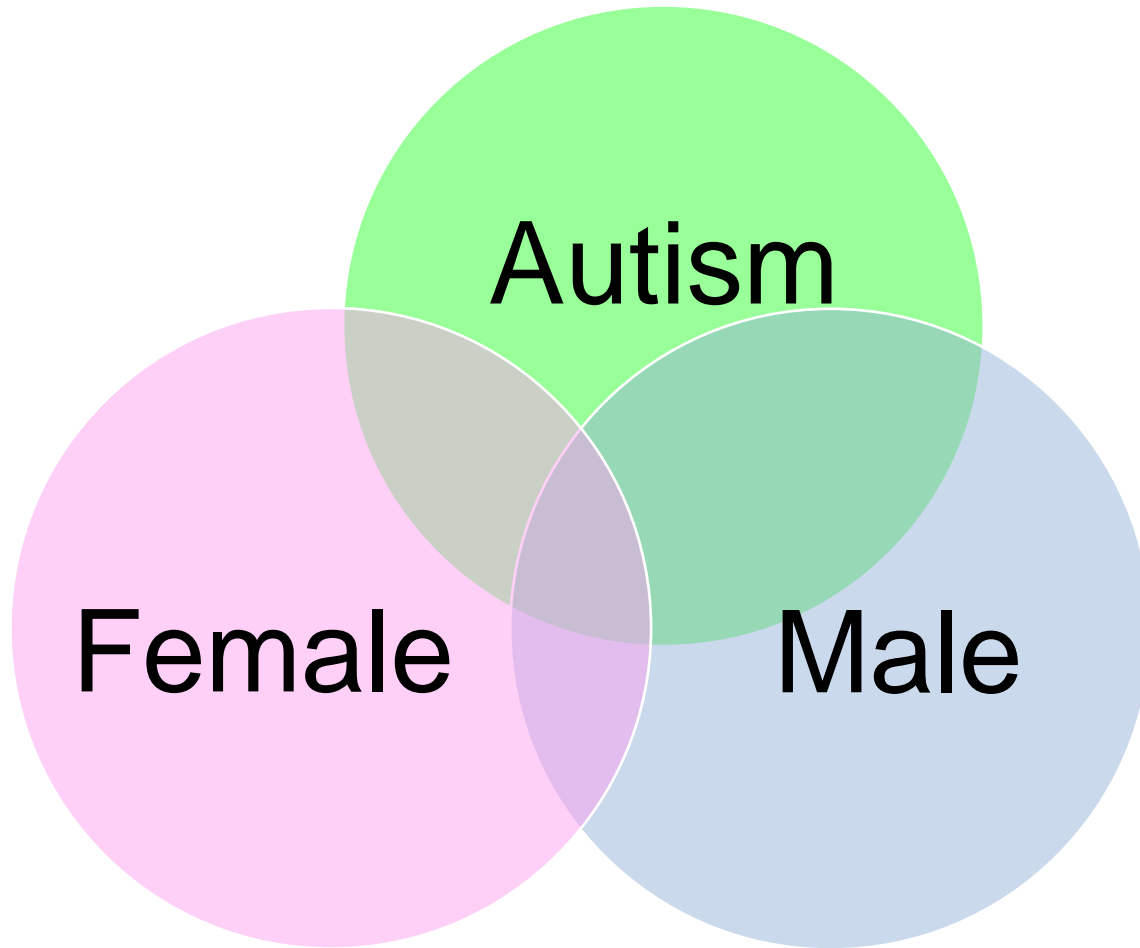


Not fitting the female stereotype



“Men and women are judged differently when it comes to appearance....Men who appear grungy, archaic in their fashion sense, or just eccentric are usually excused for this shortcoming.... But a grungy, unkempt, or strange-looking woman is a spectacle.” (Grandin, 2005)

Reality



Themes (ctd)

3. Spiky profile



Themes (ctd)

4. Sensory and Processing Differences

- Heightened sensitivity to sensory stimuli eg noise / sound, heat, touch, taste, sight/light – can be uncomfortable or painful
- Reduced sensitivity to sensory stimuli
- Difficulty in identifying sensory feelings
- Difficulty in screening out sensory stimuli
- Overload, bombardment
- One sense at a time
- Delayed processing
- Default processing of detail rather than whole picture
- Handles objects for simple sensations
- Fascination with sensory stimuli
- Perceptual problems - scale, sight, perspective



Vulnerability to Misjudgement and Misinterpretation

She's got a degree – she doesn't need support

You can't be autistic, you're a woman – anyway your eye contact is fine

She's so rude and unsociable – she thinks she's better than everyone

Autism? That's ridiculous – she's got kids!

Asperger syndrome? What are they talking about? She's just a bit shy

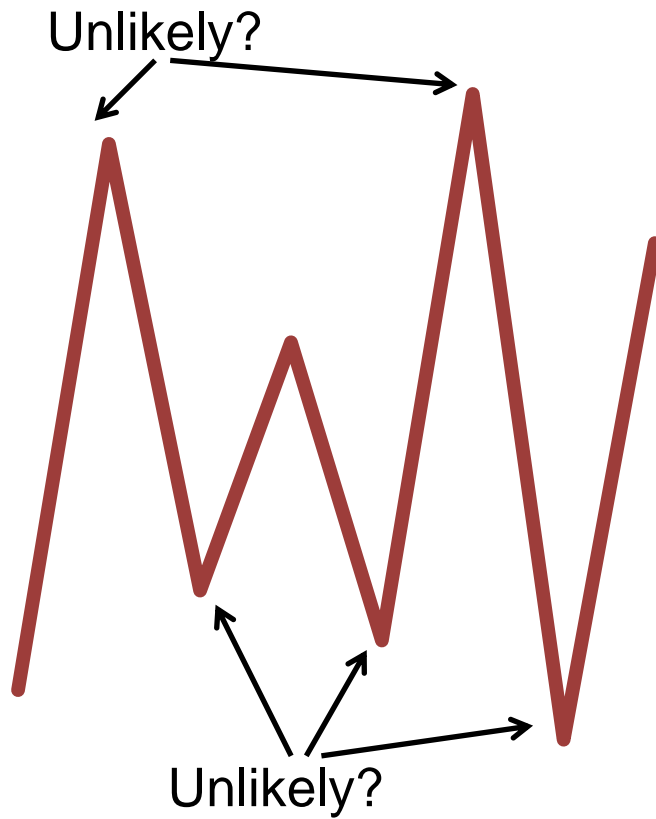
She's self-obsessed, doesn't care about anyone else

She's not bright enough to ever have a decent job

Support?

- Many women with autism remain undiagnosed or are misdiagnosed.
- They may get some support but without the diagnosis of ASC there is little chance of the support meeting their needs.
- Even with a diagnosis, no support, inadequate support or inappropriate support are not uncommon

Spikey Profile



Spikey Profile + Masking



Relationships

Some Difficulties / Issues:

- Get into 'wrong relationships'
 - Seen as easy target – may attract people with bad intentions, or intentions not inline with own intentions
 - Tend not to initiate
 - Accept initiation / approach of others
- Allow 'wrong relationships' to continue

Strategies

to help with relationships

As concrete and specific as possible

- Mentor / advocate / support worker / counsellor:
 - advice, suggestions
 - assistance in understanding the situation
 - accompany
- Activities of interest
- Technology
- An escape strategy / plan B

Input from mentor / advocate

With the help of her advocate one member of the group resolved a problem with men approaching her while waiting for the bus.

Before



After



Financial Management

Some Difficulties / Issues:

- 'Money' is often intangible
- To buying, ideally one would need to bring various strands together
- Organisational aspects
- People aspect leads to vulnerability
 - Not understanding instructions
 - Naivety can lead to exploitation
 - Avoidance of interaction

Strategies

to help with financial management

- Try to make sense of money in line with interests or something that motivates
- Mentor / advocate / support worker
- See money management as logic-based numbers task
- Use money charts or budgeting system
- Look for / as for neutral autism friendly information

Summary

- Understanding of individual
- Awareness of masking, stereotyping, spiky profile
- Other issues
- Autism as possible root
- Concrete support

Understanding Women with Autism

Up Next: Sue Hahn

Real Outcomes for Women on the Spectrum

Sue Hahn

Head of Diagnostic Services
Brookdale Care

What do we mean by real outcomes?



We need to identify needs through assessment and diagnosis

Wendy Lawson believes:

Girls on the spectrum may be under diagnosed, if they have obsessive interests they are more likely to be socially acceptable than the obsessions of boys with autism “so people don’t pick up on our social difficulties.”

ADOS-2 and ADI-R

- Describe and note need for exploration
- Get evidence
- Get a balance between looking for autism and uncovering it
- Need for open ended questions and digging deep

Principles for all staff working with adults with autism

- work in partnership with adults with autism and, where appropriate, with their families, partners and carers
- offer support and care respectfully
- take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care.

Have an understanding of the:

- nature, development and course of autism
- impact on personal, social, educational and occupational functioning
- impact of the social and physical environment.

All staff working with adults with autism should

be sensitive to issues of sexuality, including asexuality and the need to develop personal and sexual relationships.

In particular, be aware that problems in social interaction and communication may lead to the person with autism misunderstanding another person's behaviour or to their possible exploitation by others.

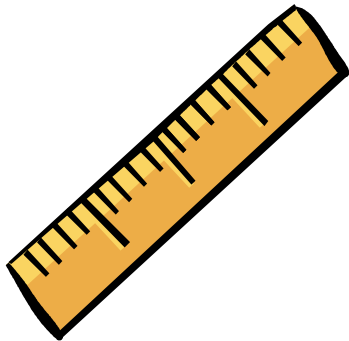
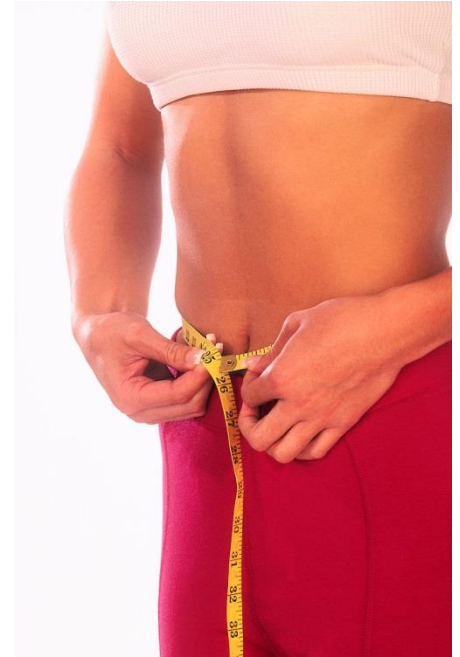
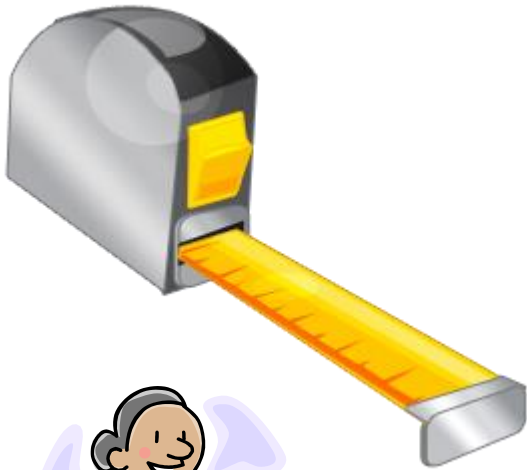
And

- aim to foster the person's autonomy, promote active participation in decisions about care and support self-management
- maintain continuity of individual relationships wherever possible
- be aware of under-reporting and under-recognition of physical disorders in people with autism
- be vigilant for unusual likes and dislikes about food and/or lack of physical activity

Autism in adults

NICE clinical guideline 142 (2012)

How can we measure?

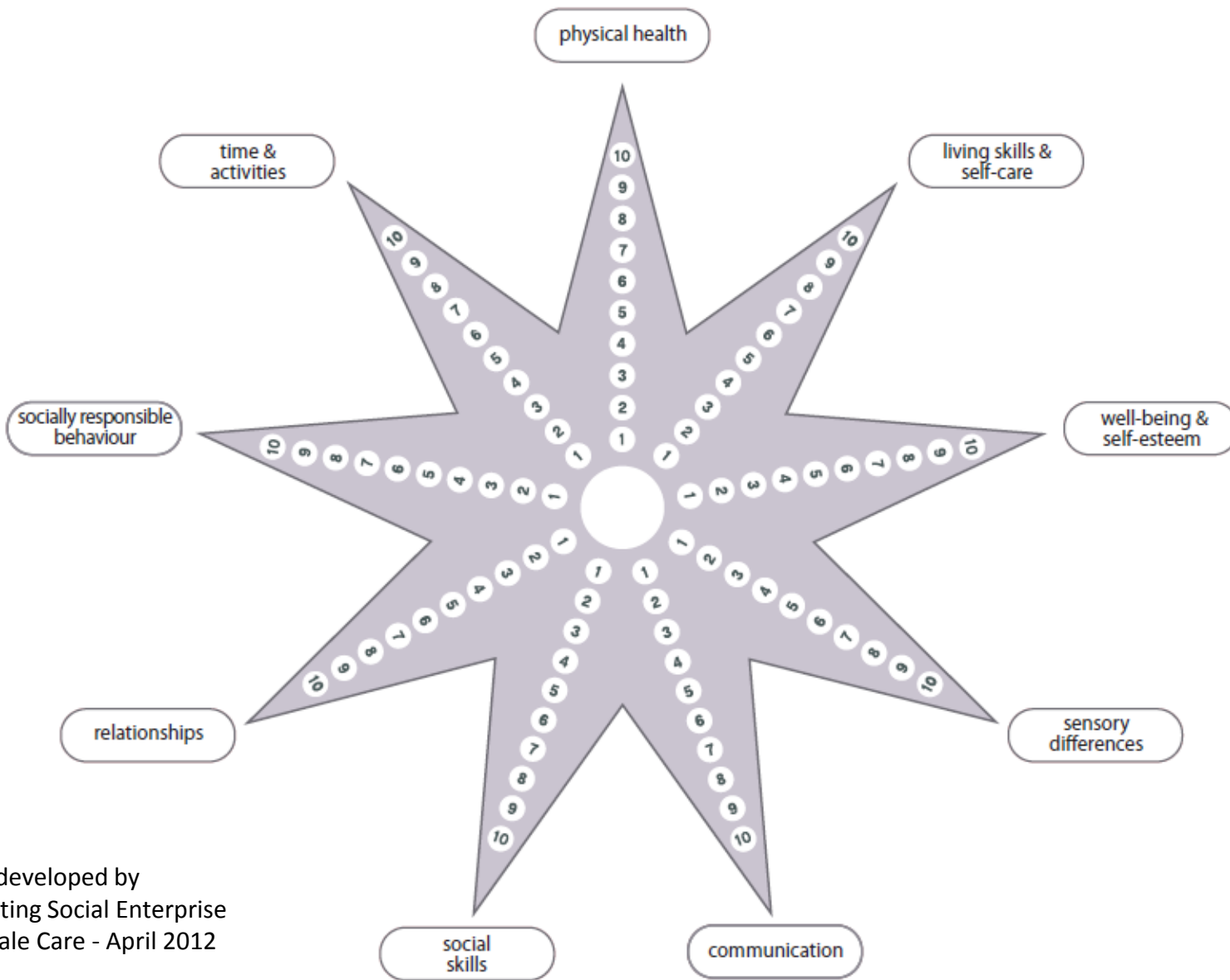


Spectrum Star

Developed by:

Brookdale Care and Triangle Consulting Social
Enterprise Ltd

The Spectrum Star



Spectrum Star developed by
Triangle Consulting Social Enterprise
Ltd and Brookdale Care - April 2012

Brief description of one scale

1 Physical health

- *Doctors*
- *Treatment*
- *Healthy meals*
- *Exercise*
- *Sleep routines*

Choice and self-reliance

- 10** I look after my own physical health well and don't need support from an autism service
- 9** I look after my own physical health well with occasional reminders from a service

Learning for yourself

- 8** I have learnt some ways to look after my health and I'm learning more
- 7** I am starting to look after my health myself

Stable

- 6** My basic health needs are met. I follow the doctor's advice but do not manage my health by myself
- 5** Nearly all of my basic health needs are met and I do what doctors tell me to do most of the time

Accepting some support

- 4** I receive treatment or other help when I'm ill but it can occasionally result in distress or conflict
- 3** I receive treatment or other help when I'm ill but sometimes resist or reject this help

Autism is a major barrier

- 2** My basic health needs are not met but I occasionally permit someone to help me
- 1** My basic health needs are not met. I might refuse help or the help I get is unsuitable, or both

Spectrum Star developed by
Triangle Consulting Social Enterprise
Ltd and Brookdale Care - April 2012

All the scales points are described

1 Physical health (detail)

This scale is about how well you look after your physical health. It covers developing healthy living habits such as eating healthy food and taking exercise. It also covers seeing the doctor when you need to and taking any medication or other treatment that is necessary. If you have a physical disability or chronic illness, this scale is about taking steps to manage things in the best way possible.

9 - 10 Choice and self-reliance

- You look after your physical health well by yourself
- You make and attend appointments with the dentist, optician, GP and other health professionals by yourself, as needed
- If you have physical health problems, you are aware of them and they are well managed. You take your medication by yourself and follow doctors' advice most of the time
- You have a fairly healthy lifestyle and mostly eat healthy meals, take exercise and sleep well enough
- Choose 9 if you need occasional reminders from a service. Choose 10 if you look after your health well without a service and reminders or support are provided by family or friends, if needed

7 - 8 Learning for yourself

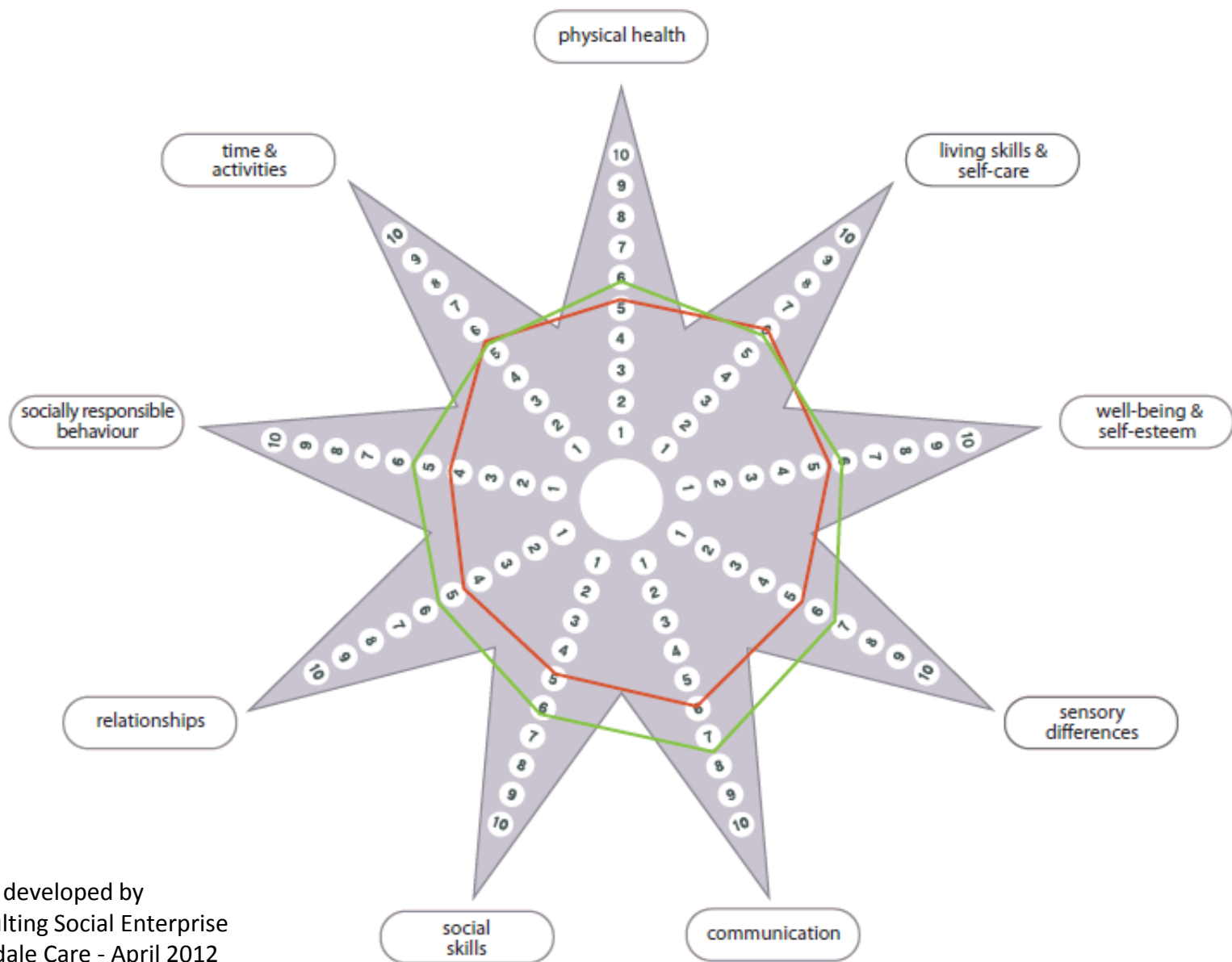
- You are learning ways to manage your health better. You go to the doctor when you are ill and you take the medicine or other treatments the doctor prescribes
- Through experience you are learning for yourself that you feel better when you take care of your health so you sometimes choose healthier food, exercise and sleep routines
- Changing routines and habits and learning to do things by yourself is difficult so it helps to have skilled support and encouragement
- Choose 7 if you are just starting to take responsibility for your own health and have a lot to learn. Choose 8 if you have already learned a lot but still need support

5 - 6 Stable

Under-pinned by a model of change

- **Choice and self-reliance – dark green stage (9-10)**
- **Learning for yourself – the light green stage (7-8)**
- **Stable – the yellow stage (5-6)**
- **Accepting some support – the orange stage (3-4)**
- **Autism is a major barrier – the red stage (1-2)**

At 6 people's needs are met in ways that work for them in a supportive environment – for some the goal may be maintenance at this point



Spectrum Star developed by
 Triangle Consulting Social Enterprise
 Ltd and Brookdale Care - April 2012

Using the Star as the basis for a support plan

- The completed Star is visual and shared
- The worker and service user can look at the shape together and ask:
 - What is going well? Are there things that can be learnt from that and applied to other areas?
 - Where are there most problems?
 - What are the priorities to put in a support plan and for the workers and service user to address?
- Completed a second Stars at review shows both progress and areas that may be stuck

Interventions and Activities

- Need to be meaningful to the individual
- Based on abilities
- Develop existing skills and interests

And finally

Wendy Lawson says:

“there needs to be a more feminist approach to autism which is often seen as owned by men,”

and that doctors and treatment programs need “an understanding of how autism is experienced by females.”

Thank you for listening, please feel free to ask any questions.

Sue Hahn

Head of Diagnostic Assessments

Brookdale Care

shahn@brookdalecare.co.uk

Understanding Women with Autism

**Thank for attending our conference,
we will forward your Certificate of
Attendance to you.**