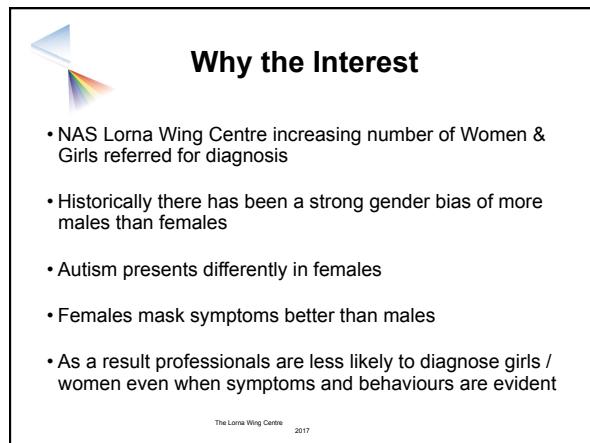


Autism in women: significantly under-diagnosed

Dr Judith Gould
Consultant Clinical Psychologist
The NAS Lorna Wing Centre for Autism

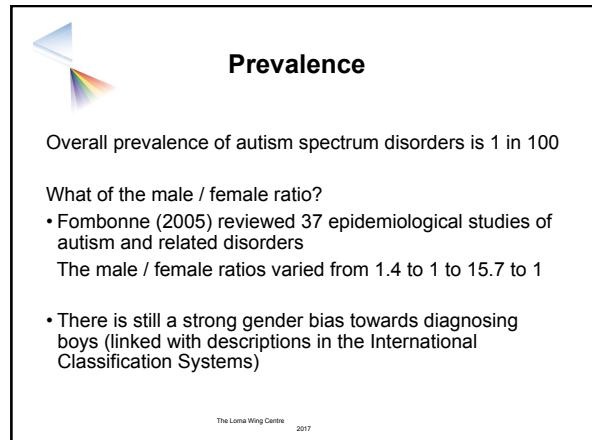
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Why the Interest

- NAS Lorna Wing Centre increasing number of Women & Girls referred for diagnosis
- Historically there has been a strong gender bias of more males than females
- Autism presents differently in females
- Females mask symptoms better than males
- As a result professionals are less likely to diagnose girls / women even when symptoms and behaviours are evident

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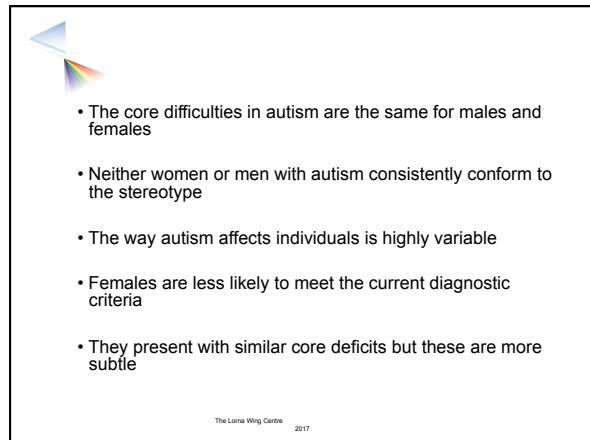
Prevalence

Overall prevalence of autism spectrum disorders is 1 in 100

What of the male / female ratio?

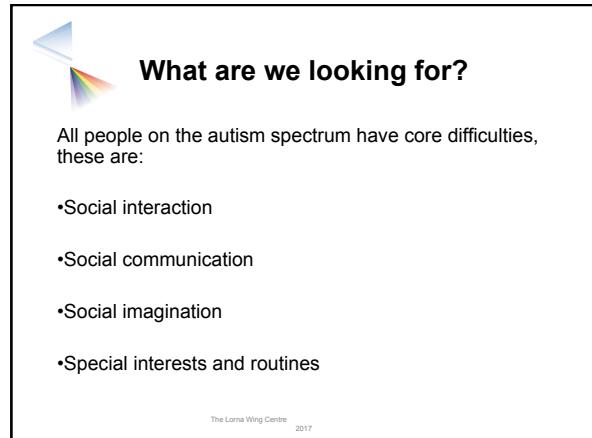
- Fombonne (2005) reviewed 37 epidemiological studies of autism and related disorders
- The male / female ratios varied from 1.4 to 1 to 15.7 to 1
- There is still a strong gender bias towards diagnosing boys (linked with descriptions in the International Classification Systems)

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- The core difficulties in autism are the same for males and females
- Neither women or men with autism consistently conform to the stereotype
- The way autism affects individuals is highly variable
- Females are less likely to meet the current diagnostic criteria
- They present with similar core deficits but these are more subtle

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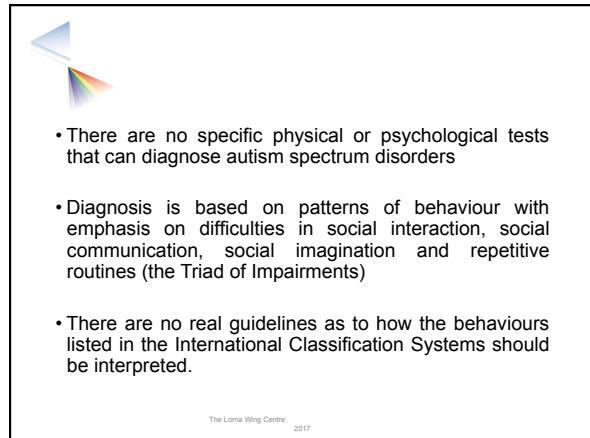


What are we looking for?

All people on the autism spectrum have core difficulties, these are:

- Social interaction
- Social communication
- Social imagination
- Special interests and routines

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- There are no specific physical or psychological tests that can diagnose autism spectrum disorders
- Diagnosis is based on patterns of behaviour with emphasis on difficulties in social interaction, social communication, social imagination and repetitive routines (the Triad of Impairments)
- There are no real guidelines as to how the behaviours listed in the International Classification Systems should be interpreted.

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Difficulties around diagnosis of Women & Girls

- The International Diagnostic criteria do not give examples of behaviour experienced by Women & Girls
- DSM 5 provides some acknowledgement of differences in females and say "females without intellectual disability due to a subtler manifestation of symptoms may go unrecognised"
- A wider perspective on gender roles is needed regarding social, communication, imagination dimensions in addition to special interests and rigidity of behaviours
- The right questions need to be asked as often the person has adopted a social role based on intellect rather than social intuition.
- Societal expectations are different for females than males

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At the Lorna Wing Centre How we diagnose

- The recognised diagnostic tools have not currently been validated in line with the female presentation of the condition
- This is more evident in adult females
- Utilisation of extreme cut-offs for diagnosis may fail to identify many affected females
- Be aware if the person referred has had many previous diagnoses
- Be aware if there are many other family members affected

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At the Lorna Wing Centre How we diagnose cont.

- It has been recognised that female presentation of the behavioural profile has to be recognised
- Questions in the Diagnostic Interview for Social and Communication Disorders (DISCO) highlight the differences in the Women & Girls for all aspects of the Triad and routines/interests. A dimensional approach rather than cut-offs is more effective in diagnosing females
- We need to look at current ratings of behaviour in diagnosis and not so much on early development
- Females self-report more autistic traits in adulthood – they appear less impaired in structured/clinical settings

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Diagnosis in Females

Social Interaction

- Women/Girls are more able to follow social actions by delayed imitation. They observe others and copy them – masks symptoms
- They are on the periphery of social activities
- Women/Girls are more aware and feel a need to interact socially
- Women/Girls want to conform and identify with peers
- Women/Girls find it easier to interact with adults rather than their peers
- They are often over eager and intense which can lead to social rejection

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Social Interaction cont.

- When involved in social interaction are often led by peers rather than initiating contact
- Women/Girls are more socially immature, shy and passive than typically developing peers
- In primary school more likely to be 'mothered' by other girls but bullied in secondary school
- Parents often 'engineer' or 'organise' friendships
- Women/Girls are more often more socially inclined than males and may have one special friend

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Social Interaction cont. Gender Identity

- Identity relates to self-image, self-esteem and individuality. How you perceive yourself in relation to others. Women and girls tend to internalise their problems and often are unaware of their personal identity
- Gender identity in women and girls on the autism spectrum can be confusing and adds to difficulties in social interaction which needs to be teased out
- Currently there is much interest and research carried out on this topic

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Social Communication

- Little difference in acquiring speech in males and females
- Females generally have superior linguistic abilities to males of a similar cognitive level
- In society females are expected to be social in their communication but they do not 'do social chit-chat or make meaningless comments to facilitate social communication'
- Little idea of social hierarchy and how to communicate with people of different status

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Social Imagination

- Females have better imagination as children have more pretend play
- Many have a rich and elaborate fantasy world with imaginary friends but have difficulty separating reality from fantasy
- Females escape into fiction and some live in another world
- When involved in solitary play they have a 'script' and may reproduce a real event or a scene from a book or film

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Social Imagination cont.

- There is a lack of reciprocity in their social play and they can be controlling or domineering
- Social imagination does not relate only to pretence or symbolic activities – it is the ability to use imagination in a social sense
- Imaginative activities in childhood are pre cursors of the ability to predict a range of possible consequences arising from past and present events

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Social Imagination cont.

- The ability to foresee the consequences in social and practical terms of one's own and other's actions and act appropriately is often a problem
- This is especially the case for women on the spectrum
- Safety for women can be a major issue
- Many are vulnerable to both verbal and sexual abuse in their attempt to fit into society
- Women and girls cannot imagine risk – so do it anyway

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Special Interests and Routines

- The male stereotype of autism has clouded the issue in diagnosis
- Research has shown there are significant differences in this area between males and females
- Males are more hyperactive and aggressive and have interests in technical hobbies and facts
- Females are more passive and collect information on people rather than things
- Females have fewer stereotyped mannerisms

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Special Interests and Routines cont.

- The interests of women & girls in the spectrum are similar to those of other girls – animals, soaps, celebrities, fashion
- Perfectionism is frequently seen in females
- Angry/confused when things are not how they are supposed to be according to the learned rules
- It is not the special interests that differentiate them from their peers but it is the **quality** and **intensity** of these interests

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Unusual Responses to Sensory Input

- Over and under reaction to sensory input is an important feature for all on the autism spectrum and is now included in the DSM 5 Diagnostic Criteria
- Common in females and maybe is not different in males and females – anecdotal and clinical accounts
- Self-report regarding sensory issues is essential as often parents/informants are unable to provide this information

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Gender Differences

- Questions in the Diagnostic Interview for Social and Communication Disorders (DISCO) Wing et al 2002 highlight the differences in the girls for all aspects of the Triad and routines / interests and sensory issues
- Training in the use of the DISCO enables clinicians to have wider perspective on the female presentation of the autism spectrum

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Referrals to the Lorna Wing Centre

- Most likely through Mental Health Services
- Some of the co-morbid diagnoses are:
 - Obsessive Compulsive Disorder
 - Eating Disorders
 - Personality Disorders
 - Selective Mutism
 - Anxiety and Depression – chronic anxiety often leads to physical health problems
- More recently the referrals are for daughters of women with Asperger Syndrome
- Taking an appropriate developmental history reveals the possible underlying problem of an ASD with an additional diagnosis or mis-diagnosis

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One view from a women with Asperger Syndrome

Fear is the core emotional trait, fear triggers unpredictable anxiety

Reason for fear:

- Sustained and untreated inability to connect, understand and work out situations and people
- The not knowing, the inability to reach for their own feelings or to verbalise things and being unable to understand what is expected of them
- Not being able to work out a sequence of events or to predict people or situations
- The inability to know when they can trust people
- The paralysing fear can fully control them and internally disorganise them to the extent that it becomes easier to disconnect from their surroundings

Sofia Lake – 'A constant feeling of not knowing' 2014, Author House

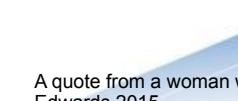
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The Importance of Diagnosis

- It is recognised that for females a late diagnosis is the 'norm'
- A late diagnosis reflected the 'hidden' nature of the condition
- A diagnosis is the starting point in providing appropriate support
- An explanation of the person's difficulties relieves confusion as to why they cannot fit in and results in reducing self-blame
- A timely diagnosis can avoid the difficulties women and girls experience throughout their lives
- Diagnosis can lead to assessment of needs in education, leisure, housing, social relationships and employment

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A quote from a woman with Asperger Syndrome, Olley Edwards 2015.

"The autism spectrum is vast and beautifully complex, some individuals are easily identified, but for others their autism is a prism, it is present, but yet it remains transparent until the appropriately trained clinician shines their knowledge and light onto it, it is only then that the colours and complexities can be seen and understood.

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