Missed or Mis-diagnosis…
Girls and Women on the autism spectrum

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Why the Interest

- NAS Lorna Wing Centre increasing number of Women & Girls referred for diagnosis most likely through mental health services
- 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

What are we looking for?

- on the autism spectrum have core difficulties, these are:
  - Social interaction
  - Social communication
  - Social imagination
  - Special interests and routines

Difficulties around diagnosis of Women & Girls

- 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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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
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

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

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

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

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

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
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

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

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

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

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

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.*"
Educating girls on the autism spectrum - a very under-researched field

- Very few ‘diagnosed’ girls go through the education system compared to boys.
- These are - “Tentative suggestions and extracts from literature to substantiate anecdotal assumptions that still have to be validated by academic research.
- Teaching and developing social and communication skills is fundamental to a successful and happy school career for girls and has implications for later life.
- “Being an autistic woman has been pivotal to everything that’s happened to me. If I’d been an autistic man, my story could have been very different.” (Postgate)

Girls with a diagnosis of autism in mainstream - often undiagnosed.
Girls with a diagnosis of autism - often in special schools - male dominated (4-1 or 10-1)

“I want to go to another school”

Many girls on the autism spectrum are not being identified and diagnosed

Gillberg 2010 - without the skills of an experienced clinician the diagnostic criteria used may not pick up girls

- Lacks best friend (30% girls vs 70% of boys)
- Follows other children like a shadow (40% girls vs 10% of boys)
- Demand avoidance (65% girls vs 20% of boys)

Gillberg 2010 – Diagnosed with autism – 4 boys to 1 girl, should that be 1.5 boys to 1 girl?
Diagnosed with AS – 12 boys to 1 girl, should that be 4 boys to 1 girl?

PDA – Should there be an equal number of boys and girls diagnosed?

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Important issues in the education of girls with an autism spectrum condition – the ‘hidden curriculum’

- Social understanding
- Social communication
- Teaching independence and reducing vulnerability
- Self image, Self esteem and confidence building
- Gender identity
- Sex education
- Emotional wellbeing and fostering mental health
- Cultural expectations and the right to choose one’s own path
- Vocational training, hobbies and interests
- Positive role models

Why is Social understanding & social communication such an important area for girls?

- Many girls care what their peers think and worry about this.
- Initiate other girls in order to initiate social contact but can’t hold reciprocal friendships which is distressing.
- Many girls are not good at empathy and conversation and they find themselves locked out, more so than boys. (Lainhart, 2009)
- Many girls want to connect with people outside their families.
- Some girls tend to ‘over emphasise’ and can’t disassociate from other’s grief, anger, anxiety or joy.
- Difficulties in social understanding result in anxiety, depression, isolation and feelings of failure

Social understanding & communication – Why is it more difficult for girls on the autistic spectrum to acquire these skills despite greater social abilities than boys?

- Typical girls relationships are more complex than typical boys generally
  - Teenage girls relationships - primarily based on ‘talking’ and intimate social communication
  - Boys relationships - more often based on ‘doing’
- Girls with ASD’s are going to have a much harder time with the level of communicative skill and social understanding required to fit in with female social groups.” (Nichols et al, 2005)
- Girls and boys also fight and bully differently e.g. gossiping or exclusion.
- Three is not company for girls!!
- As girls with an autism spectrum condition are in the minority, the likelihood is that they will try to make friends with ‘non-autistic’ girls.
All girls on the autism spectrum are different.

Some are more motivated to spend time with peers and make connections. Some want a single friend to talk to. Others may only want to play a computer game wordlessly beside a peer.

Girls need the support to develop the skills needed to achieve her own potential individual social interests.

For girls on the autism spectrum, book groups and hobby related clubs let girls socialise in their own way and their own time.

What is the ideal social life for a girl on the autism spectrum?

- Only a small social life
- Someone in my world
- Time alone
- 1-1 social contact
- Shared interest talks
- Email, texting, phone

Starting block much lower – understanding friendships/relationships

- What are they for?
- What are the rules?
- How do I get one?
- What is a friend?
- What’s in it for me?
- Is it worth it?

(Hendrickx, 2008)

Despite being less interested than girls generally in having and maintaining friendships, many girls with an autism spectrum condition do want social contact, especially with other girls.

“...who share the similar interests and experiences, understand their difficulties, are respectful, are appreciative of their strengths, and are tolerant of their weaknesses”. (Nichols et al, 2009)

Friends are “...people I enjoyed passing a few hours or minutes with”. (Liane Holliday-Willey)

They do not necessarily want to spend a lengthy time with a friend discussing serious topics or feelings, they would prefer to spend shorter periods of time talking about common interests such as art, TV, movies, music, books or favourite actors etc. (Nicholls et al)

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Programmes to help develop social understanding & social communication for girls

- Strategies to teach girls social understanding
  - Direct instruction
  - Scripting
  - Role play
  - Mirroring
  - Drama - expressive arts
  - Peer tutoring
  - Peer and adult mentoring – providing female role models
  - Scrap books and picture albums
  - Watching films or soap operas
  - Girls need other girls to practice/reflect on vocal tone, expression, gesture use, body language.

Teaching strategies geared towards girls

Visual supports, schedules and routines. (like boys)

- Use teaching methods that play to their strengths

Modelling of people – point out what the model is doing and let her emulate this.

Video modelling – Video the behaviour you want her to learn and replay, rewind and pause to explain clearly what you want her to learn.

Role play or drama – particularly good for social skills, dangerous events and situations that don’t occur frequently or arise naturally.

Write narratives about social situations. Explain factually why.
Teaching strategies geared towards girls – Facts and information as opposed to sentiment.

- Social scripts – what to say and do in specific situations.
  - To answer the phone, buy a bus ticket, how to respond to teenage chat.
- Power cards – uses a girl’s special interests to teach appropriate behaviour.
  - The card explains how a favourite character would behave or handle a situation.
  - Then encourages the girl to act in the same manner in a similar situation.
- Television and movies – an excellent teaching tool for girls.
  - Point things out and talk about them.
  - Ask what she thinks the character should do.
  - Ask why the character is acting in a particular way.
- Books and the internet – Many teenage girls with an ASC like to read.
  - Prefer to read instructions rather than being told.
  - This applies strongly to personal hygiene, puberty issues and sex education. (Nichols et al. 2009)

In conclusion – important teaching points for girls

Four important teaching points for girls on the autism spectrum:

- “Not being ‘typical’ is just fine – in fact, it can be/ is an asset!!
- The most important relationship skills are actually friendship skills, and the best basis for friendships is common interests.
- Common special interests are the most important social tool and basis for social contacts for people with AS.
- When it comes to the basic facts and problems with sex, ignorance is a very bad thing.” (McIheoo-Myers, 2007)

Social/sexual issues – dealing with puberty

- Social/sexual issues
  - Puberty and body changes
  - Personal hygiene
  - Modesty and privacy
  - Emotional changes
  - Practical issues in planning, back up systems
- Address this long before due to happen - prepare, practice, plan
  - Prepare her for the changes and requirements - step by step to follow
  - Practice using social stories and checklists
  - Develop her self help skills
  - List hygiene rules
  - Rehearse problem solving scenarios
- Social stories, scripts

Sex education for girls

- Need discrete classes for girls as prior knowledge seldom exists and their learning needs are greater.
- Girls on the autism spectrum have fewer opportunities for social contact therefore sources of sexual learning are different:
  - Receive less information from peers.
  - Male to female ratio – girls in specialist settings spend most of their social time with boys.
  - Girls are more closely supervised, often with more limitations or rules.
  - Girls with an autism spectrum condition develop independence more slowly therefore rely on care givers.
  - Girls may experience less privacy than peers or live in group settings which is very different from typical living arrangements.
- Need to directly teach boundaries (and rules) as lack of social skills inhibit this development.

Independence verses vulnerability

Teaching Independence to enable social opportunities

- Many adults complain that they were/are overly protected and treated like children.
- Staff “do things for them” instead of giving them the skills to do things.
- Young women are often immature, naive, gullible, and easily deceived.
- Many girls want to be accepted so may be coerced into things.
- Many women maintain their childlike tone of voice which increases vulnerability. (Attwood)
- Most important part of any curriculum is to equip our female students with the skills needed to be independent.

Vulnerability vs. over protection

- We need to teach girls with an autism spectrum condition the skills to protect themselves and give them the confidence to use these skills.

Facilitating social independence through reducing vulnerability

Abuse prevention curriculum:
Use role play, provide knowledge, practice scenarios

- Social skills – ability to recognise and deal with inappropriate behaviours.
- Social communication – ability to communicate ones wants and needs and request attention from another.
- Emotional awareness – being aware of own and others feelings including being anxious, fearful, uneasy.
- Sex Education – knowledge is a very powerful protective tool and will help her identify and report inappropriate behaviour.
- Privacy awareness – social concepts therefore difficult – need an understanding of private places, private behaviour, what not to talk about etc.
- Personal space, touching rules and boundaries – cultural concepts therefore difficult – need to understand boundaries for self and others, saying no, not stalking or intimidating.
- Permission to say “no” – a real issue for girls who are passive and like to please.
- Self advocacy – Teach how to report when she is feeling intimidated.
Facilitating cyber independence & social networking through reducing vulnerability

The internet is very popular, especially with sharing special interests, and many do so for longer and with greater intensity than their typically developing peers. (Nicholls, 2009)

Girls are particularly vulnerable to complying when told to do something
Girls are more likely to respond to communication.
This therefore needs to form part of the curriculum taught at school

Autism and societal expectations of girls and women

“Women are affected by autism in the same way as their male counterparts; however, they are doubly challenged by the added assumptions that society places on their female gender.”

“Problems related to the autism spectrum are combined with society’s expectations of women. How one looks, what one wears, how one is supposed to relate socially, that a woman is supposed to have natural empathy for others, expectations about dating and marriage.”

Autistic woman quoted in Faherty’s social group (2002).

Girls are highly skilled in navigating the technology (email, chat rooms, blogging, googling and gaming)

Girls can give too much information on social networks e.g. Facebook

Gender and identity issues reported to be experienced by girls and women.

- Some autistic women report experiencing issues regarding gender identity.
  “Most girls at 11 have developed gender identity and start relating to other girls differently from boys but this type of relating may be delayed or non-existent for girls with ASD.” (Durian, 2002)
  “Many young women with ASD may appear to have more male-like characteristics, which consequently can separate them from bonding with other females.” (Zaks, 2006)
  “This conflict with gender identity can have a negative impact on the developing self esteem.” (Lonsdale, 1997)
- Many female writers believe that self esteem and identity are intrinsically linked.

Girls on the autism spectrum - a minority group and issues around ‘segregation’

- Many women state the unique challenges of being a ‘minority’ within a unique group in society.
- Special Schools are male dominated - therefore opportunities to meet girls with some common interests are far less common than boys.
- Minimal opportunities to meet a range of girls and therefore do not develop the social skills needed to mix with mainstream peers. (Atwood, 2007)
- Women tend to learn from other women/girls yet there are not many of them so it becomes a ‘double whammy’. (Faherty, 2007 in Atwood)
- Difficulty in reaching ASD girls potential and it is societal gender expectations that interfere with this. (Nicholls, Tetenbaum & Perlis, 2009)

Building self esteem and confidence

- An important component of an appropriate educational programme.
- Need to help girls develop and internal sense of self.
- Build on individual strengths.
- Praise, acknowledgement, reward – capitalise on their strengths.
- Help girls understand their gender and identity.
- Understand and facilitate the need for ‘recovery’ or alone time.

Developing girls self esteem - the basics we need to teach girls

- To feel valued, safe and cared for.
- To feel influential – to feel that she can affect her world through decision-making and assertiveness.
- To feel a sense of self control – has coping skills she can rely on, and learning to develop “positive self talk”
- To experience success and achieve goals.
- To develop independence and self reliance.
- To have good self knowledge.
- To have fun and enjoyment, emotional wellbeing.
- We need to directly teach all these skills as they are very important for their future wellbeing. (Nicholls et al, 2009)
Emotional wellbeing and fostering mental health

- "The emotional instability and moodiness of adolescent girls in general can be amplified for girls with ASD." (Einspger & Wendel, 2007)
- It has been found that as children approached adolescence, increased signs of depression are also observed... and that females may be particularly vulnerable due to:
  - Hormonal changes (Brenton et al, 2006)
  - Greater expectations to succeed academically and socially (Cohen-Sandler 2005)
- Attwood states that girls with an autism spectrum condition can be at a risk of reactive depression due to:
  - Coming to the realisation that they are different from their peers.
  - A general lack of acceptance by their peers and/or bullying.
  - A greater awareness of the daily social difficulties they experience.
- This can result in depression, negative self perception, de-motivation, feelings of worthlessness, hopelessness and self harm.

Girls on the autism spectrum and issues with eat

- Many young children on the autism spectrum have issues with food – texture, colour, pica, food fads etc
- Parents of girls on the autism spectrum have reported the following and should their form part of the ‘hidden curriculum’ taught at school:
  - Cannot tell when she is hungry nor recognise signs of hunger.
  - Cannot tell when she is full and confuses full and hungry.
  - Drinks excessive amounts of fluids.
  - Forgets to eat or drink or refuses to in unfamiliar surroundings.
  - Obsessed with rules about food and food consumption or preparation.
  - Rigid and restricted eating patterns. (Nicholls et al, 2009)
- Attwood states: 18 – 23% of adolescent girls with anorexia also present with signs of Asperger Syndrome. (Gillberg & Billstedt, 2000)

Emotional wellbeing and fostering mental health

- Girls tend to use social intimidation, threaten, name call and tease – more subtle.
- Includes social intimidation – you can't play with us, we won’t be your friend etc.
- Girls with an autism spectrum condition may not understand that they are being bullied due lack of social understanding, but when they do, it seems to upset them far more than boys.
- Girls bullied over time become depressed and emotionally traumatised (Miller, 2003) and more agitated at home and mostly. (Guiran, 2002)
- When teaching a girls how to react to bullying... use role play (Gray, 2004) Use video to record the correct way to respond to bullying and play repeatedly.
- Girls also appear to experience more social anxiety. (Lainhart, 2009)

Social anxiety - girls on the autism spectrum have reported that:
- They notice the gap between their intellectual abilities and what they can achieve in day to day life.
- The future looks very scary.
- The future looks very scary.
- Frequent worrying, not being able to ‘switch off’.
- Feeling restless, irritable, overly concerned about their performance.
- Over-critical of themselves and a perfectionist.
- Needing to take control wherever they can.

Cognitive Behavioural Therapy as a subject on the curriculum?
- Identify situations that are stressful.
- Identify how their body responds when experiencing particular emotions.
- Physical awareness - differentiates between a feeling (nervous) and an internal physiological state (upset stomach).
- Coping skills training.
- Relaxation techniques plus yoga, tai chi, dancing etc.
The aim of education is to equip students to have a quality adult life - satisfying relationships

- The criteria for the perfect partner or friend for a person with an autism spectrum condition:
  - ‘Me’ in the preferred gender
  - 1:1 interaction, not groups
  - Limited, not constant contact – perhaps once a week
  - Accepts you for yourself
  - Shares interests
  - Valued for knowledge
  - Meets needs
  - Comfort zone maintained – does not add to stress. (Hendrickx 2008)

- McIlwee Myers (2007) maintains that the reality of what relationships entail for girls with an ASC should be taught realistically, factually and logically e.g.
  - Dating and meeting people
  - Sharing living space
  - What relationships involve
  - Not getting enough ‘alone’ time
  - Nichols, Tetenbaum & Perlis – The ASD girls curriculum.

Teaching girls on the autism spectrum to deal with cultural expectations

Rousso & Wehmeyer (2003) “…an attractive appearance for a young woman in our society is linked to intelligence, kindness and overall influence. Yet young women with ASD may be ambivalent about appearance.

The decision on what clothing to wear may be influenced by their sensory needs or by their need for repetition and consistency (or practicality) rather than the latest fashion fad. (Attwood, 1999)

“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)

Women on the spectrum who do not conform are viewed as “…childish, disorderly, or rebellious and not accorded respect or taken seriously.” (Grandin, 2005)

Address these issues as part of the curriculum and strategies to overcome or compensate for them.

Girls face unique challenges with regard to:

- Social and cultural expectations of behaviour
- Degree of vulnerability
- Obtaining independence
- Puberty and menstruation
- Opportunities for adulthood

Additional issues to be addressed and skills to be taught:
- Female friendships and girl bullying
- Puberty
- Body image and gender
- Safety
- Hygiene
- Self-perception and confidence
- Relationship and sexual health
- Coping with the culture of gender
- Overcoming emotional barriers
- Leisure

Summary - educating girls with an autism spectrum condition

Understanding that it is ok if girls do / or do not want to be part of the “typical” culture and its requirements.

“There are rules about what women need in the way of relationships that are pretty clearly communicated in our culture” “…these rules should not be applied willy-nilly to girls with AS.”

“Girls with AS, even more so than boys with AS, are often bombarded with variations on the idea that being more social and being a better person are the same.”

Finding people with shared interests is more important “…data shows us that people who have much in common are most likely to get along.” (Attwood, 2007)

“You don’t find true love by being a fake; you find him by living and being the best version of you that you can achieve.”

“Romantic love is not necessary to human happiness so it is ok not to feel it” (McIlwee Myers, J. in Attwood, 2007)
"The future for girls with ASD is unlimited and boundless. As parents and professionals, we cannot let our own fears and lack of knowledge inhibit our girl's growth and independence." (Wagner, S. 2007)

We need a flexible, unconventional, person-centred and responsive model in all provisions that educate and include students with an autism spectrum condition.

"We need schools where difference is valued and there is less emphasis on conformity and greater focus on harnessing strengths in order to enable all, students and staff alike "...to be the best they could become."

"Wouldn't such a system be one in which all could flourish?"

Understanding and getting it right for children with ASD can be a way of getting it right for everyone." (Jordan, 2008)