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Autistic Girls: Barriers for Diagnosis Sarah Hendrickx

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Introduction

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- Author of Women & Girls with ASD (JKP)
- Two autistic children, several autistic partners (not all at once)
- 1000+ clinically supervised and non-clinical autism assessments carried out
- Youtube Women and Girls talk seen by 280,000+ people
- **By the time I was diagnosed at age 43 years:**
- Masters degree in autism
- 5 autism books published
- 1000+ autism training delivered
- Managed autism mentoring project
- Partner diagnosed autistic
- Many family members diagnosed or suspected
- History of mental health and sensory differences
- **It took so long because there was no version of autism for females like me**

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What happened to the girls?

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Gender rarely considered in autism research

- + Original Kanner and Asperger studies were male children
 - + Diagnostic criteria evolved from research – changed over time
 - = Diagnostic criteria default establishes 'male' profile
- Leads to: Belief that autism is mainly male
- Therefore: Clinicians are taught that autism is mainly male
- + Clinicians don't consider autism as possibility for females
 - + Females don't always fit traditional 'male' profile
- Therefore: Few females are diagnosed + autism remains mainly male diagnosis
- Leads to: Few females to participate in research, therefore little research
- = ***View of few females perpetuates clinically and in research due to missed and mis-diagnosis***

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Autism Gender Research

- 2.5:1 male:female autism ratio (Gould)
- Diagnosed later than boys (+3yrs)
- More likely to get mental health diagnosis (first)
- Early & precocious speech – may mask social & comms diffs
- M & F with autism more 'androgynous', gender incoherence
- Less rigid and restrictive interests; more social difficulties
- Better social skills than autistic boys in childhood; poorer social skills than autistic boys in teens – nuanced social world for female teens
- Parents comparing 'normal' daughters to diagnosed autistic sons
- High number 'invisible' adult women seeking diagnosis – negative experience

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Applying the criteria to girls

Social interaction

Mimicry and copying - masking
 'Shy', 'on the edge'
 Mask difficulties very well
 Watch everything/everyone
 Systematic brain applied to social world – 'rules of people'

Peer relationships

Not intuitive – seek inclusion on own terms
 Other girls 'mother' and lead
 Can be bossy/passive – not reciprocal
 Can be obsessed with friend
 Seeks exclusivity with friend
 Clown/intense – 'smile it might never happen'

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Applying the criteria to girls

Restricted interests

- People based
- 'Little Psychologist' – not 'Little Professor'
- Animal based
- TV, celebrity based
- Appear 'normal' in topic – but are more intense

Routines

- 'Sensitive', 'Perfectionist', 'Particular'
- Collecting – rubbers, pics, badges, stones
- Seen as positive trait in girls?
- Less aggressive than boys when faced with change?
- Shutdown rather than meltdown (less visible)



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Applying the criteria to girls

Sensory behaviours

- Stroking, touching – 'normal'
- Soft toys – 'normal'

Imagination

- Fantasy worlds – as an escape from real life
- Take on persona of animals/characters
- Dolls/teds – literal names
- No original narrative play – replicating TV or real-life

Activity Choice

- Reading
- Construction
- Collecting, sorting, tidying
- Colouring, drawing
- Making, experiments
- Animals and bugs



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Tips for Successful Diagnosis

- Don't compare your daughter to diagnosed autistic sons
- Check knowledge and tools used by diagnostician – ADOS should not be sole tool used (Gould)
- Consider private diagnosis by female autism specialist clinician
- Provide extensive evidence:
 - Across lifespan
 - All aspects of diagnostic criteria
 - Family history – included 'suspected' members
 - Intensity of interests – not just topics
 - Play – observe in detail what she is doing, how and why
 - Sensory profile – food, touch, smell, noise, clothing – avoidance and seeking

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