

# Autistic conditions in girls: clinical perspectives on diagnosis, assessment and intervention



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## Background information

- ◆ Almost all of the very few early studies published on girls with ASD have focused on the low functioning group with IQs in the retarded range
- ◆ There has only been a handful international in-depth descriptions of intellectually more high-functioning females with ASD (Bölte et al. 2011; Holtmann, Bölte & Poustka, 2007; Kopp & Gillberg, 1992, Kopp, Berg-Kelly & Gillberg, 2010; McLennan, Lord & Schopler, 1993)
- ◆ Very few have attempted to address the issue of whether or not the reason for the much higher male: female ratio in clinical cohorts might be a different phenotype in girls (Kopp & Gillberg, 1992)

## *To hypotheses*

(Kopp & Gillberg, 1992)

- Some crucial aspects of the core deficit in autism often described as qualitative impairment in social interaction could be more common in females than previously believed
- The reason for underreporting females in the past has been the overreliance on the male prototype of autism

Girls with social deficits and learning problems:  
Autism, atypical Asperger syndrome or a variant of these conditions

Kopp, S., and Gillberg, C. (1992)

- The target group consisted of 6 girls, 6-10 years of age, with previously undetermined diagnosis
- All girls were high-functioning in that they had IQs in the 60-100 range and spoke in complicated sentences (one girl <70)
- The six girls all fulfilled criteria for autistic disorder (DSM-III-R)
- All but one of the girls scored under 67 on the ABC (Krug et al. 1980)
- All the girls had been seen by experts in the field long before a diagnosis of autism was made
- None of the girls exhibited aloofness
- The type of social impairments shown by these girls tended more to "clinging" to other people, especially to their mothers

Girls with social deficits and learning problems:  
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Kopp, S., and Gillberg, C. (1992)

## *Conclusions*

- Girls with core autism deficits, similar or identical to those seen in boys, may not have quite the same behavioural phenotype as in boys
- These girls would not be suspected of suffering from autism and therefore, of course, not even considered for a diagnosis of that kind
- Girls socialinteraction/communication deficits may go unrecognized because of their non-aggressive and non-domineering behavioural style

# The Girl Project

1999-2001

(S.Kopp, C. Gillberg)



The project was supported by the Swedish Autism Society and the Swedish Association for Disabled Children and Young People

The project was funded by  
The Swedish State Inheritance Fund

## Girls with social and/or attention deficits, a descriptive study of 100 clinic attenders

Kopp, S., Berg-Kelly, K., & Gillberg, C. (2010)

- ◇ 100 clinically referred girls 3-18 years, with no prior suspicion of learning disorder 3-18 and 60 non-clinically referred schoolgirls from the community 7-16 years participated in the project.
- ◇ All were given meticulous comprehensive neuropsychiatric assessment that included examinations by child psychiatrist, psychologist, social worker, educationalist and physiotherapist

Girls with social and/or attention deficits,  
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Kopp, S., Berg-Kelly, K., & Gillberg, C. (2010)

*Main diagnoses*

- 46 Autism spectrum disorders (ASD)
- 46 ADHD
- 3 Tourette disorder
- 5 other diagnoses

(1 ADHD NOS, 1 Intermittent Explosive Disorder, 1 Mild Mental Retardation,  
1 Learning Disorder UNS, 1 Sleep Disorder)





## “Special” interests in girls with ASD

Kopp & Gillberg (2011)

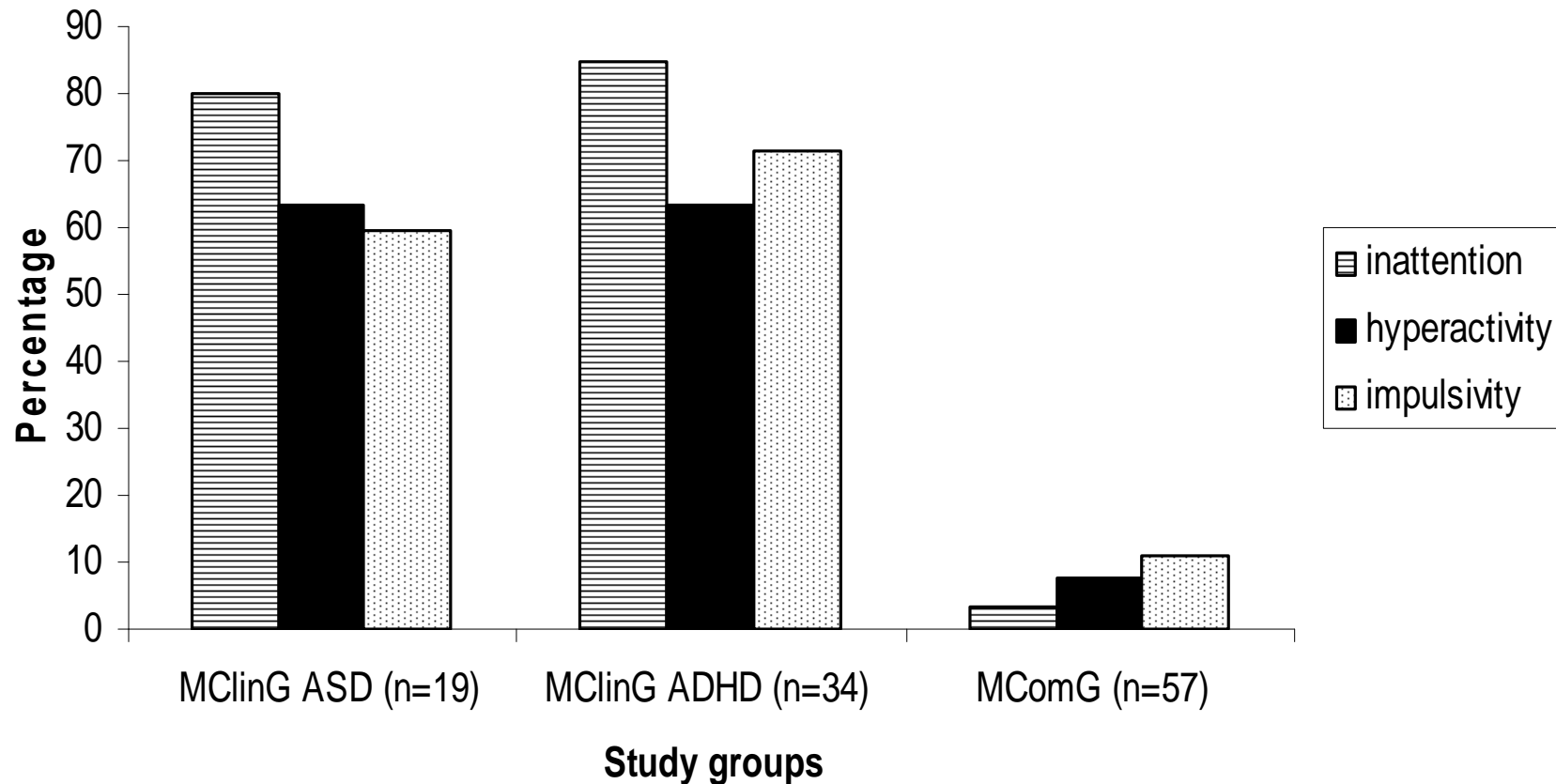
Usually the girls interests were reported in the context of “social” interest, often relating to animals, foreign cultures, fairy-tales figures, famous people, comic strip personalities

Many girls were extremely interested in painting, pottering, collecting, reading, beauty products, and clothes

Some others were very interested in physics, such as horse-riding and ice-dancing



Comparison between the ADHD DSM-IV symptom criteria,  
inattention, hyperactivity and impulsivity  
in the ASD, ADHD and Community school age groups



There was a tendency for fewer symptoms for impulsivity  
( $p = 0.06$ ) between the ASD and ADHD groups of girls

# Girls with social and/or attention deficits, a descriptive study of 100 clinic attenders

Kopp, S., Berg-Kelly, K., & Gillberg, C. (2010)

## Additional diagnoses in the school age groups of girls

<b>Additional Diagnoses</b>	<b>Girls with ASD n=20</b>	<b>Girls with ADHD n=34</b>	<b>Community girls n=57</b>	<b><i>p</i>-value ASD vs ADHD</b>	<b><i>p</i>-value ASD vs Community girls</b>	<b><i>p</i>-value ADHD vs Community girls</b>
<b>Oppositional defiant disorder at home</b>	<b>11 (55%)</b>	<b>22 (65%)</b>	<b>0</b>	<b>.67</b>	<b>&lt;.001</b>	<b>&lt;.001</b>
<b>Oppositional defiant disorder at home and at school</b>	<b>3 (15%)</b>	<b>13 (38%)</b>	<b>0</b>	<b>.130</b>	<b>.032</b>	<b>&lt;.001</b>
<b>Depression (actual)</b>	<b>7 (35%)</b>	<b>11 (32%)</b>	<b>2 (3%)</b>	<b>1.0</b>	<b>.002</b>	<b>&lt;.001</b>
<b>Multiple anxiety diagnoses</b>	<b>7 (35%)</b>	<b>6 (18%)</b>	<b>3 (5%)</b>	<b>.27</b>	<b>.004</b>	<b>.126</b>
<b>Specific phobia</b>	<b>8 (40%)</b>	<b>7 (21%)</b>	<b>4 (7%)</b>	<b>.22</b>	<b>.002</b>	<b>.116</b>
<b>Obsessive-compulsive disorder</b>	<b>7 (35%)</b>	<b>11 (32%)</b>	<b>3 (5%)</b>	<b>1.0</b>	<b>.004</b>	<b>.002</b>
<b>Sleep disorder</b>	<b>8 (40%)</b>	<b>16 (47%)</b>	<b>10 (17%)</b>	<b>.83</b>	<b>.090</b>	<b>.006</b>

Mean number of additional diagnoses ; 3.9 (SD 1.9) f in the ASD group, 2.8 (SD 1.6) in the ADHD group  
Chi-square test and Fishers exact test used

## Developmental coordination disorder and other motor control problems in girls with autism spectrum disorder and/or attention-deficit/ hyperactivity disorder

Kopp, S., Beckung, E., & Gillberg, C. (2010)

### *Results*

- ❖ Developmental coordination disorder (DCD) was prevalent in 25% of school age girls with ASD
  
- ❖ 53% of schoolage girls with ASD did not participate in physical education

# Reading Comprehension, Word Decoding and Spelling in Girls with Autism Spectrum Disorders or AD/HD: Performance and Predictors

Åsberg, J., Kopp, S., Berg-Kelly, K., & Gillberg, C. (2010)

## *Results*

- \* 8/20 (40%) girls with ASD had at least one reading and/or writing disorder
- \* Reading comprehension was highly correlated to autistic symptoms

## Functional characteristics in school age girls with ASD and ADHD and in Community girls

	<b>ASD 7-16 years n=20</b>	<b>ADHD 7-16 years n=34</b>	<b><i>P-value</i> Mann Whitney U-test</b>	<b>*Community girls 7-16 years n=57</b>
<b>Full scale IQ (SD)</b>	99 (12.5)	97 (10.7)	.706	108 (11.9)
<b>Median (min, max)</b>	102 (80, 120)	97 (83, 121)		108 (74, 130)
<b>VABS DLS (SD)</b>	65 (23.3)	75 (15.6)	.023	99 (9.3)
<b>Median (min, max)</b>	61 (24, 129)	72 (48, 103)		98 (77, 129)
<b>GAF (SD)</b>	35 (6.4)	46 (5.3)	<i>&lt;.001</i>	86 (8.0)
<b>Median (min, max)</b>	35 (25, 50)	45 (35, 60)		85 (65, 98)

*\*All p-values < .01 between the Community girls and the main diagnostic groups*

## School situation and treatment history in the different study groups

<i>School situation and treatment history</i>	Girls with ASD n=20	Girls with ADHD n=34	Community girls n=57
Underachievement in math*	8 (40%)	17 (50%)	0
Underachievement in reading*	6 (30%)	14 (41%)	0
Number(%) of bullying	12 (60%)	17 (50%)	4 (7%)
Counseling at or before age 4	8 (40%)	11 (32%)	0
Counseling ever	20 (100%)	29 (85%)	6 (10%)
Child Adolescent Psychiatry no. (%)	13 (65%)	17 (50%)	2 (3%)

Girls with social and/or attention deficits, a descriptive study of 100 clinic attenders  
Kopp, S., Berg-Kelly, K., and Gillberg, C. (2010)

\*Not reaching grade-adequate goals reported by teachers

## Instruments used for assessment of girls with ASD (and ADHD)

- ⊖ Anamnesis (life history) and a thorough hereditarian report
- ⊖ Tests for IQ , executive functions and theory of mind
- ⊖ ADI-R /DISCO
- ⊖ ADOS-G
- ⊖ ABC- ckecklist
- ⊖ Autism Spectrum Screening Questionnaire (ASSQ)
- ⊖ Vineland Behaviour Scale: Daily Living skills (DLS)
- ⊖ Global Assessment of Functioning (GAF)
- ⊖ Questionnaires for ADHD, depression, anxiety, obsessive-compulsive disorder and eating disorders to parents (or semistructured schedule K-SADS, CAPA),
- ⊖ Questionnaires for teachers especially for ADHD and ODD
- ⊖ Motor test
- ⊖ Reading and writing tests
- ∅ Medical examination, chromosomal analysis
- ⊖ Family stress





## Screening instruments

- There are a number of screening instruments for ASD available for research and clinical practice (Campbell, 2005)
- Most of these appear to have been modelled around the phenotypes first delineated by Kanner (1943) and Asperger (1944)
- ASSQ was developed to screen for Asperger syndrome /HFA in the general population of school age children (Ehlers & Gillberg, 1993; Ehlers, Gillberg & Wing, 1999)

## The most striking gender differences of the ASSQ-REV items



The item **“lacks best friend”** was significantly more endorsed in boys than in girls

Four other items were more endorsed in girls than in boys

the item **“interacts mostly with younger children”**

the item **“avoids demands”**

the item **“has a different voice/ speech”**

the item **“difficulties in completing daily activities because of compulsory repetitions”**

Different items of the combined ASSQ predicted differently between ASD and non-ASD in the girls' and boys' groups

*Good predictive items for girls with ASD were;*

“is very determined”

“has a different voice”

“avoids demands”

“deviant gaze”

“ self-care problems”

*Good predictive items for boys with ASD were;*

“poor at games”

“robotlike language”

“eating problems”

The Autism Spectrum Screening Questionnaire (ASSQ) - Revised Extended Version (ASSQ-REV): an instrument for better capturing the autism phenotype in girls?

Kopp, S. and Gillberg, C. (2011)



- The results support the use of at least some of the new ASSQ-GIRL items for screening and clinical purpose
- The ASSQ-REV response profiles differed markedly between the two sexes
- It appeared to be more valuable to look at the response profile than to solely look at the sum score
- To avoid demands might be a crucial item for girls with disability
- Further and larger studies are certainly needed for interpreting the clinical appearance of gender differences in ASD

## Is there a female phenotype in autism?

### **A suggestions is to be sensitive to a girl;**

- who avoids demands
- who is very determined
- who interacts (mostly) with younger children
- who is carefree or over meticulous with regard to physical appearance and dress
- who acts or lives different parts (animals, TV-stars)
- who has a different voice or speech
- who often has intense girl-oriented interests

## Concluding remarks

- A few years ago as well as today girls with ASD receive this diagnosis too late
  - More than every second school age girls with ASD had been bullied
  - School age girls with ASD with IQ in the normal range girls showed academic failure and truancy far from reported results in the Community girls
  - Girls with ASD had many additional diagnoses including developmental coordination disorder and reading disorder
  - The degree of functional impairments (GAF) was severe for girls with ASD and indicate the burden for the parents and the need for early detection
  - The majority of parents to schoolage girls with ASD had consulted a professional for problems already during preeschool years. The fact that no conclusive diagnosis was given cries for improved competence for early detection in girls
  - Our results support the use of at least some of the new ASSQ-GIRL items for screening and clinical purpose
  - The findings indicate that whenever girls present with social and attentional impairments, a diagnosis of ASD or ADHD needs to be considered or a combination of these disorders
- More research and larger studies on girls with autism is obviously needed

Thank you for your attention !

