

## Autism in girls

### PERSPECTIVES

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**Many girls with autism remain undetected by the health service. The absence of a diagnosis can have far-reaching negative consequences for their health, education, employment and independence. How many more autistic girls will we overlook?**



Illustration: Kristin Berg Johnsen

In her autobiography *Kunsten å feike arabisk* [The Art of Faking Arabic], Lina Liman shares her experience of having autism spectrum disorder. She realised that she had the condition at the age of 31 years, after listening to a radio programme about women with autism.

Autism spectrum disorder is a complex neurodevelopmental disorder that encompasses a broad diversity of individuals. Leo Kanner and Hans Asperger played an important part in describing the condition. Kanner's works were published in 1943, and Asperger wrote 'Die Autistischen Psychopathen im Kindesalter' [Autistic psychopathy in childhood] in 1944. In the 1980s, the definition of autism was extended to include a broader spectrum of characteristics, and in 1994, Asperger's syndrome, which is regarded as a milder form of autism, was formally included in the diagnostic manuals [\(1\)](#).

In 2013, significant changes were made in the classification of autism in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). This diagnostic manual is published by the American Psychiatric Association. In this revised edition, the subcategories were removed, and the term 'autism spectrum disorder' was introduced on a graded scale.

Corresponding changes were also made in the International Classification of Diseases (ICD-11), which is the World Health Organization's standard classification for medical conditions. The manual has yet to be implemented in Norway [\(1\)](#).

**«The understanding of autism spectrum disorder has historically been influenced by research that has primarily focused on boys»**

The understanding of autism spectrum disorder has historically been influenced by research that has primarily focused on boys. In previous studies, the ratio of autistic boys to girls was reported as 4:1 [\(2\)](#). In a large-scale study from 2022, this ratio was adjusted to almost 4:3. The researchers also concluded that around 80 % of girls with autism remained undiagnosed at the age of 18 years [\(3\)](#). A Norwegian study from 2019 determined that the number of children with the condition varied considerably between counties. The authors also concluded that in counties with low diagnostic figures, there was reason to believe that girls in particular remained undiagnosed [\(4\)](#).

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## Autism in girls

Studies of girls with autism spectrum disorder have shown that they have various clinical, cognitive and biological characteristics that are associated with underdiagnosis and delayed diagnosis [\(5\)](#). Forms of clinical expression vary considerably. Studies based on qualitative methods, information from interest groups and our own clinical experience have revealed that the symptoms of autistic girls with a full-scale IQ over 70 manifest themselves in distinctive ways when compared to autistic boys, even though there are clear similarities [\(6–8\)](#).

Autistic children and adults have difficulty adapting to social expectations. Many girls in this group have a strong desire to be social but can nevertheless feel alienated. Even with an advanced vocabulary they can strive to understand the nuances of language, which may lead to misunderstandings and poor self-confidence. They can be perfectionists and at the same time socially immature. Situations that they perceive as unfair can trigger strong reactions, and the girls have a tendency to fixate on negative thinking.

Special interests are part of the behavioural profile in people with autism spectrum disorder. Compared with autistic boys, these types of focused passions in autistic girls may be more socially focused. They may include interests such as language, animal welfare and politics. Many have artistic abilities, a vivid imagination, and express themselves better through art than through 'normal' social communication. Their interest goes much deeper than that of their peers.

Difficulties with organising and repetitive behaviour are common in people with autism spectrum disorder. They repeat the same activity several times to soothe themselves and relieve stress. For girls with autism spectrum disorder, this may mean watching a favourite film or listening to the same audiobook repeatedly. They often need time to process information and move from one thing to another. Many autistic girls find the completion of tasks especially stressful, which can make them appear unreasonable and rigid.

People with autism spectrum disorder are generally sensitive to sound, light, taste and smell, and many are bullied when they struggle to cope with everyday life because of this.

Teenage girls are often interested in fashion, but autistic girls may have challenges in wearing trendy clothes due to their sensitivity to textiles. They can feel different and less accepted by their peers as a result.

Identifying emotions and body language is also difficult. This can affect mood, pain threshold, stress tolerance and hygiene. Many describe great frustration with simple tasks such as showering and haircare, and some also struggle with enuresis and (more rarely) encopresis. When stressed, many turn to self-stimulating techniques, such as using fidget toys.

Especially typical for girls with autism spectrum disorder is the development of compensatory skills and sophisticated methods to mask their autism and conceal their differentness. Masking usually occurs outside the home, for example at school, where they control their vulnerabilities only to 'explode' at home. They may have outbreaks of anger or a need for social withdrawal when overstressed. These stress reactions can lead to rejection and prejudice by those who do not know the background for their difficulties.

***«Especially typical for girls with autism spectrum disorder is the development of compensatory skills and sophisticated methods to mask their autism and conceal their differentness»***

Women with autism also have a greater diversity in terms of sexual identity, and those who have a homosexual orientation are more exposed to adverse sexual experiences (9).

People with autism have a considerable degree of comorbidity, and those with autism spectrum disorder have an increased risk of concomitant disorders such as anxiety, ADHD, depression, sleep disorders, suicidal behaviour, irritable bowel syndrome and eating disorders. Problems with motor coordination and sensory hypersensitivity can also affect daily life (10–13).

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## Assessment and treatment

Assessment of autism spectrum disorder in child and adolescent psychiatry involves following guidelines drawn up by both regional health trusts and the Norwegian Society of Child and Adolescent Psychiatry (14, 15).

The medical history, which includes observations and information from next of kin, is a fundamental part of the assessment. Family members often have similar challenges. A wide-ranging medical examination should be undertaken, and it is important to assess cognitive abilities and adaptive skills.

Two essential tools in the assessment are the revised edition of *Autism Diagnostic Interview* (ADI-R) and *Autism Diagnostic Observation Schedule* (ADOS). The former is a parent interview that identifies symptoms of autism (16), while the other is an examination based on play and verbal responses (17). Autistic girls can sometimes show atypical features that are not always captured by these tools (18).

Many autistic children and adolescents have comorbid disorders, which underlines the importance of differential diagnostic mapping (19). In this context, the Kiddie-SADS-PL (*Kiddie Schedule for Affective Disorders and Schizophrenia*) tool is recommended. This is a semi-structured interview that aims to systematically identify a number of psychiatric disorders in children and adolescents (20).

Several other questionnaires are used to evaluate symptoms associated with autism (21).

The revised and expanded version of the *Autism Spectrum Screening Questionnaire* (ASSQ-REV) is specifically designed to capture autism spectrum disorder in girls. In a study from 2011, it was noted that certain items in the questionnaire, such as 'very determined', 'avoids demands' and 'careless with physical appearance and dress' were especially typical of autistic girls. It was recommended that these questions be incorporated into the assessment to improve the possibility of identifying girls with autism spectrum disorder (22).

In terms of treatment, no medication exists that cures the condition, but risperidone can be useful for controlling irritability. ADHD drugs can be considered if ADHD is a secondary disorder. Anxiety and depression are treated according to normal guidelines, and melatonin products can be used for sleep problems (15).

Apart from medicines, therapeutic approaches such as forms of cognitive behaviour therapy and psychoeducation can be beneficial. Support at school, in the workplace and in the familial network can also help. Group therapy is an effective way to share experiences and promote cohesion. It is essential to be aware of sexual identity and offer counselling to promote a healthy sexual development (14, 15).

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## Conclusion

Autism spectrum disorder affects both sexes, but many autistic girls are discovered late, or not at all. In her book, Lina Liman has put into words how it felt to have an answer to the puzzle of her own self: 'Part of me died. Another part of me finally, finally started to live' (23).

As a child and adolescent psychiatrist, I have met a number of girls and women like Liman, who have struggled to understand their own being. The diagnostic process has often been challenging but has also given them a sense of relief.

It is essential to see the unique characteristics and special challenges of both girls and boys with autism spectrum disorder. However, autism must not be perceived only as a pathological phenomenon, but also as a component of human diversity. We must actively help them to realise their potential as autistic people. And not least, we must identify the girls that pass under the radar so that they avoid 'faking Arabic'.

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