

# **ADOLESCENT GIRLS WITH AN AUTISM SPECTRUM DISORDER:**

Presentation, challenges and support needs in the mainstream education  
system

Summary of research findings  
for the Honours degree  
of Bachelor of Health Sciences

by

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## **ACKNOWLEDGEMENT**

My very special thanks go to the girls and their parents who participated in this project, and who so willingly shared their invaluable experiences, knowledge and insights. It is my hope that the information you have shared about your life as a girl with ASD will inform those who work with girls in the future. None of this would have been possible without your input.

“As a woman with Asperger syndrome and as an academic in the field of pervasive developmental disorders, I can say with a good deal of authority that there is not nearly enough information on the unique ways in which autism spectrum disorders (ASDs) affect females. Considering that the penalty females pay for flying under the radar is years of vulnerability and confusion that consequently leaves them susceptible to additional comorbid emotional, physical, and neurological issues, one must conclude that more information on girls with ASDs is needed post haste.”

(Liane Holliday Willey (cited in Ernsperger & Wendel 2007, p. v))

## BACKGROUND

- Girls with ASD are diagnosed significantly less than boys, at a rate of 4:1 (Attwood 2006).
- Sensory issues and anxiety add to the difficulties girls with ASD experience.
- During adolescence, girls with ASD are at increased risk of not fitting in, feeling alienated from their age level peers and experiencing bullying and harassment.
- More informed knowledge of the difficulties experienced by adolescent girls on the autism spectrum is essential to improve the provision of strategic and appropriate support.

## INITIAL AIMS

- To document the literature about adolescent girls with ASD.
- To provide insight and ideas from girls, their families and schools.
- To outline a range of strategies to support girls with ASD in the education system.

## LITERATURE REVIEW

A comprehensive review of literature, including recent research, clinical and autobiographical accounts, about adolescent girls with ASD resulted in the following conclusions:

- **Adolescent girls with ASD are less identifiable and diagnosed later than boys, and may not receive appropriate support.** This is partly due to bias in the diagnostic criteria, the belief that ASD is a “male disorder”, the knowledge and expectations of clinicians, parents and professionals - the interpretation of behaviours, and levels of awareness and concern of parents, educators and clinicians influence clinical diagnosis of girls with ASD. Girls are frequently diagnosed with other disorders.
- **Adolescent girls with ASD experience sensory issues, communication difficulties and social difficulties.** Girls exhibit the same symptoms of ASD as boys, but they are influenced and moderated by socio-cognitive processes. The presentation of symptoms in girls is often less obvious, less atypical and less overt. They can appear socially integrated due and seem to have mature language skills due to their ability to imitate their peers and adults and their desire to “fit in” and not be noticed as different. Analysis reveals this is not so, and frequently their ASD becomes more evident in early adolescence when social language and relationships become more complex.
- **Adolescent girls with ASD experience bullying and / or exclusion.** Kopp (2011) found that more than one in two girls with ASD had been bullied. Adolescent girls’ bullying techniques are more covert than boys, less physical and harder to observe. Girls’ bullying includes social intimidation and social

exclusion, threats, name calling and teasing. The long-term effects of bullying and extended periods of feeling excluded can significantly affect outcomes for girls.

- **Adolescent girls with ASD experience internalising difficulties such as significant anxiety, which in some cases leads to depression.**

In most girls and boys with ASD, comorbid psychiatric or behavioural disorders are quite common. Anxiety was found to be higher in adolescent females with ASD than in adolescent males with ASD, there was no difference in depression scores, but internalizing scores were significantly higher. Girls with ASD scored higher in all areas than typical girls. Other internalising disorders can also develop due to stress and anxiety. For example, Pathological Demand Avoidance (PDA) occurs as a result of social anxiety. It was also found that, as well as anxiety, girls with ASD frequently experienced depressive conditions sleep problems, OCD and Opposition Defiance Disorder (ODD).

- **Adolescent girls with ASD require informed, specialised and focused support at school to address these challenges, and to minimise their potential social, emotional and academic impact.**

Education and training in ASDs across the spectrum, particularly at the higher functioning level, is essential for all educators at all levels in mainstream schools to ensure referral and appropriate support (Attwood et al. 2006, p. 22).

Unfortunately, many educators are unaware of the way girls with ASD present and therefore are not aware of their unique needs. For adolescent girls with ASD in mainstream schools, the number of teachers involved and frequent changes of subject teachers results in teachers not being effectively informed or trained and in them using unsuitable teaching strategies in the classroom. This can result in

“socially isolated, lonely, potentially depressed individuals who will not be able to capitalize on their high potential” Wagner (cited in Attwood & Grandin 2006, p. 22).

## RESEARCH

57 participants were involved in this research project. There were 24 girls with ASD between the ages of 10 and 20 years, 24 parents /caregivers, and 9 school representatives.

Each participant completed a semi-structured interview with the researcher or responded to email questions.

The guiding questions were the same for all the participants and covered diagnosis, sensory, communication, academic, social / emotional issues and self-determination.

All interviews were transcribed by the researcher, and the results analysed to determine common findings under the following headings: Diagnosis, Sensory Processing / Motor Skills, Special Interests, Communication, Academic Strengths and Challenges, Social / Emotional and Self Determination.

## RESULTS

The results supported the findings of the Literature Review. The three main themes or issues which were found to have the most impact on the ability of the participants to succeed at school were:

1. Internalising Symptoms (Anxiety and Depression)
2. Difficulties with Peer Relationships (including Social Communication) and
3. Bullying (including Exclusion).

All these are interlinked as can be seen below.

### **Diagnosis**

- It was found that most girls missed out on early diagnosis and were diagnosed at a later age than boys (Average Age was 9.6 years) and so missed out on early and appropriate interventions.
- 79% had a prior diagnosis other than ASD. 92% had another diagnosis as well as ASD, and 62% had more than one diagnosis apart from ASD.
- All participants found that receiving a diagnosis was positive and 59% received improved support at school as a result of being diagnosed.

### **Sensory Processing / Motor Skills**

- All the participants had some sensory processing difficulties
- Many also reported fine motor, balance and coordination problems.

### **Special Interests**

- All the girls had special interests. These interests were many and varied, and most were common to all girls. It was the intensity and endurance of the interests that differed from typical girls.
- An interest in animals, birds and insects was common, and 25% were collectors of a range of changing things.
- Almost all the girls enjoyed reading.

### **Communication**

- The two main areas of difficulty identified were following multiple instructions and expressing emotions.
- Over half (63%) of the participants had difficulty communicating with peers or teachers. 38% had difficulty communicating with both peers and teachers.

## **Academic Strengths and Challenges**

- Many had other diagnoses that positively or negatively affected the academic success.
- Following written instruction and group work were reported as problems by 25%.

## **Social / Emotional**

### 1. Bullying, Exclusion and Peer Relationships

- Only 2 participants who attended mainstream schools did not report bullying / exclusion. 11 had experienced both bullying and exclusion.
- Several parents commented their daughters would not recognise bullying or report it at school.

### 2. Peer Relationships

- Peer relationships were reported to be concern for most (16) of the participants. Of those who did not report concerns (8), five reported difficulties communication with their peers.
- Supportive peer groups and tolerance at school, did not necessarily equate to friendships.

### 3. Mental Health

- All except one of the participants experienced anxiety.
- 50% experienced depression.
- 33% experienced significant physical symptoms during anxiety attacks.

## **Self Determination**

- 58% of the participants felt positive about their future, and only one felt completely negative. 3 were ambivalent.
- Most had some idea about a future profession.

## MAIN FINDINGS, IMPLICATIONS

### **Diagnosis**

- Obtaining an accurate diagnosis was difficult.
- Receiving a diagnosis was seen as positive, both personally and in regard to the understanding of others.

### **Sensory Issues**

- Sensory overload impacted all the participants.
- Most had developed strategies to cope at school.
- However, some required on-going support.
- Some participants reported a lack of awareness of school staff, and a resultant lack of support.
- The research also found girls camouflage difficulties at school, resulting in a build up of stress and anxiety.

### **Social**

All participants reported this as a major concern.

- Few had “real” friendships with peers at school.
- Both making and maintaining friends was reported to be difficult by those over 13 years. They were aware of their lack of real friendships and wanted to develop them. They lacked the skills to do this.
- Social difficulties impacted how girls felt about attending school.

### **Communication**

Issues arising included:

- Communication with peers
- Making conversation with peers



- Communication with teachers
- Following multiple verbal instructions
- Expressing feelings and emotions

### **Bullying and Exclusion**

- Verbal bullying and teasing was not always recognized as bullying.
- Reported bullying stopped in most cases, but some changed schools.
- Exclusion was more ongoing. Social intimidation and social exclusion can negatively impact self-esteem, self-confidence and emotional well-being.

### **Emotional / Mental Health**

- Anxiety was often hidden at school but affected school attendance and success.
- Depression was usually linked to loneliness and feelings of being different
- Activities such as reading, writing, drawing, music, computer games or TV shows were used at home to ease anxiety and depression.

### **Academic / Self Determination**

- Academic success and self-determination were affected by all the factors discussed above. Although, some of the other diagnosed learning strengths and difficulties clearly had an affect on academic achievement, and consequently self-confidence and self esteem, if support strategies are implemented to maximise social success and emotional well being, this impact could be reduced.
- Self-determination involves the ability to self regulate and self manage one's own behaviour, be less dependent on others, express preferences and make choices. Positive self-esteem, awareness of personal strengths and talents, stress management, self-regulation, and conflict resolution

are the attributes needed for the development of self-determination and will minimise the effects of anxiety and depression. Education of girls with ASD should also develop the skills to make decisions, solve problems and set personal goals.

#### SUGGESTED STRATEGIES TO SUPPORT ADOLESCENT GIRLS WITH ASD IN MAINSTREAM SCHOOLS.

There suggestions include strategies the participants have found helpful and strategies suggested in the literature.

#### **Diagnosis**

1. Educators and diagnosticians need to be informed and share knowledge about the female phenotype to develop a framework and enable the identification and appropriate support of girls with ASD.

#### **Sensory Issues**

1. Developing teacher awareness of indicators of sensory overload so they can defuse the situation before the stress escalates and becomes unmanageable.
2. Teachers, parents and students working together to develop adaptive self-regulation strategies to stop sensory overload causing stress was also found to be useful. Strategies should be mutually determined and implemented.
3. Developing a range of accommodations to stop stress being caused by sensory overload is essential.
4. Teachers removing or minimising sensory triggers, or allowing the girls to remove themselves from stressful situations.
5. Some other strategies are aromatherapy, yoga breathing, music, reading, writing and the use of fidgets and stress balls.

## **Social**

1. Developing and maintaining well planned peer support structures
2. Organising and implementing effective social skills groups
3. As social interactions with peers can be negatively affected by poor social communication skills caused by the inability to process information quickly and reciprocate appropriately. Social skills support strategies will also support the development of social communication skills, conversational skills and the ability of adolescent girls with ASD to communicate thoughts and feelings
4. Providing direct instruction of social and conversational skills to develop the ability to communicate with peers and teachers.

## **Communication**

1. Regular sessions with a counselor or trusted staff member who can provide support in a range of situations and help develop communication skills. A trusted person to talk to can help in many areas not just communication. Strategies such as cognitive restructuring, including measuring emotional intensity and alternative ways to express emotions, and affective education, including comic strip conversations and relaxation techniques to help people with ASD express feelings appropriately and reduce anxiety. Some of these strategies could be used in social skills groups or individual counselling sessions.
2. Providing written instructions to reinforce verbal instructions, and ensuring these visual instructions and assignments are presented in a form that is clear and explicit.

3. Providing verbal prompts to ensure that girls are actually tuned in to what is being said and checking that they are not over-whelmed by the general classroom noise. This will minimise the effects of auditory sensory overload and auditory processing issues that are common for girls with ASD.
4. Tactfully checking for understanding of verbal and written instructions and assignment requirements. This is critical, as adolescent girls with an ASD will often not say they do not understand and will not ask for help.

### **Bullying and Exclusion**

Some strategies to minimise bullying and exclusion, and support adolescent girls with ASD to recognise, report and manage it include:

1. Implementing a range of pro-active strategies to prevent bullying and exclusion, implementing interventions to address bullying which are adapted to suit the students and the type of bullying occurring, small group or 1:1 education about bullying, and learning strategies to deal with bullies
2. Ensuring teacher vigilance
3. Using a supportive peer group
4. Identifying a trusted staff member to talk to
5. Providing a “safe” place, including during breaks.

### **Emotional / Mental Health**

1. Establishing a safe haven / quiet place for students to access at recess and lunch.
2. Providing a legitimate exit strategy from classes to a designated quiet area
3. Regular meetings with a counselor or trusted staff member.

4. A supportive peer group.
5. Girls' groups which discuss understanding and expressing emotions, develop an awareness of personal strengths and talents, stress management, self-regulation, and conflict resolution will minimise anxiety and depression and will help develop and maintain self confidence and self esteem.
6. Promoting adaptive coping strategies through social skills training, self-regulation, relaxation and personalised accommodations.
7. Use of fidgets, stress balls, listening to music and aromatherapy.

#### **Academic / Self Determination**

1. Educators need an in depth knowledge of the cognitive ability, learning style and the skills, abilities and challenges faced by each individual girl
2. Implementing accommodations to support any learning difficulties, theory of mind and executive functioning deficits.
3. Reduced homework.
4. Extra time to complete assignments.
5. Pre-teaching of content.

#### **CONCLUSION**

- Girls share many of the same difficulties as boys.
- These difficulties manifest differently.
- There are difficulties specific to females.
- Diagnosis, support and intervention are impacted by lack of knowledge.
- This affects girls socially, emotionally and academically.

The participants displayed a depth of self-awareness and self-acceptance.

Some of the participants reported that receiving a diagnosis had improved their understanding and acceptance of themselves.

The majority had a positive outlook despite their reported difficulties.

Areas for future research could include sensory integration difficulties and their impact on anxiety, social and communication difficulties at school. The effects of bullying and exclusion, internalising problems experienced by girls and research into the effectiveness of some of the strategies suggested as supportive of adolescent girls with ASD in education facilities (for example peer group support and safe havens for both bullying and sensory overload) could assess the value of the strategies.

#### Future Outlook

Support to address the challenges experienced in a school environment and build on the positive outlook of adolescent girls with ASD is not costly, and does not require a lot of resources. It requires the awareness of school and educators to the needs of adolescent girls with and ASD and their willingness to address these needs.

- **Girls were found to be self aware, optimistic and resilient.**
- **These strengths are the positives that, with future research, will improve understanding and outcomes for adolescent girls and women with ASD.**