Spotlight on Girls with Autism



A comprehensive guide to greater visibility, better understanding and improving support for autistic girls by Yellow Ladybugs together with the Department of Education & Training Victoria, in collaboration with autistic females, parents, teachers, allied health professionals and academic researchers.







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Stock imagery using models are used throughout this document for illustrative purposes only.

This document has used person-first language (girls with autism) and identity-first language (autistic girls) interchangeably to respect the various views in the community.







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is guide aims to

Introduce the female presentation of autism



Recognise the key issues facing girls with autism at school



Provide practical school-based strategies



Share personal, professional and academic experiences

Autism is the lens through which a person on the spectrum sees and processes the world.

The autistic brain develops differently from conception and this can affect the individual's language and communication, cognition, sensory processing, motor control and social behaviours.

Official figures show that about 1 in 68 children have an autism diagnosis¹, with emerging research suggesting rates of autism could be around 1-2 percent. Statistics show that boys are almost four times more likely to receive an accurate autism diagnosis than girls – a prominent gender difference.

Accurate rates of autism in girls are harder to measure.

The challenge of receiving a proper diagnosis for their daughter is an early hurdle faced by many parents.

Boys are often diagnosed in early childhood, whereas

girls often receive their diagnosis later, with an average ² age of diagnosis being nine.

This difference in diagnosis ratios has been attributed to

Girls with autism presenting differently³ Gender bias in existing screening tooks and diagnostic criteria

Existing stereotypes about how autism presents

Cack of clinician's training and experience in recognising autism in girls

This practical guide has been developed to support their autism autistic girls at school and uses the lived experience of autistic girls and momen, together with input from teachers, psychologists and other key professionals. For a list of resources, go to page 14.



Girls often get diagnosed later

⁽Centers for Disease Control and Prevention, 'Autism Spectrum Disorder – Data and Statistics', US Department of Health and Human Services, accessed 24 April 2017). ²(Ormond, S., Brownlow, C., Garnett, M.S., Rynkiewicz, A. & Attwood T. (2017). Cox, I., McGillivray, J., Manjiviona, J., Bulhak-Paterson, D.T. & Stokes, M.A. (2017). ³ Jamison, R., Bishop, S. L., Huerta, M., & Halladay, A. K. (2017).



The Hidden Presentation

Although there are some shared traits in both boys and girls with autism, girls often present differently. This can result in girls being

misdiagnosed, misunderstood, or missed completely. Because girls with autism are less identifiable and diagnosed later than boys they may not receive appropriate and timely support.²

Girls with autism may be better at masking their difficulties in order to fit in with their peers, and, in general, they present with a more stable profile of adequate social skills.⁵

Girls tend to have more cognitive resources to mask their autism, including better language and imitation skills, and a stronger ability to blend in socially than their male counterparts.

Girls with autism are often less noticeably different or disruptive than boys with autism.⁶

These dynamics help explain why girls tend to fly under the radar and why so many misconceptions currently exist around girls with autism.

Case Study

My <mark>son was quite</mark> easily diagnosed with who really understood the subtle ways <u>a</u>ut<u>is</u>m at five years old. It was "outwardly girls with autism may present.

obvious" to me and his teachers, that he Once we dug deeper, we were able to see displayed the more common traits linked to other traits that were less obvious. Her autism e.g., repetitive and rigid behaviours,

sensory sensitivities were not so apparent, anxiety and lack of receptive language. but equally in need of support. If we had an Whilst the path to diagnosis was easy for my earlier diagnosis, I am certain her learning son, the journey to diagnosis for my daughter needs would have been better supported. was filled with doubt, lack of expertise and

recognition. She was oft en dismissed as Natalie, Mum to Girl 9 years old and being 'just shy' and 'fine', and when I raised Boy 7 years old, both with an Autism diagnosis. concerns over her troubles connecting with peers and her hidden anxiety, I was turned away again and again. It wasn't until she was in grade two, and her learning was beginning to be impacted, that we really had prish for answers and sought out an expert

Misconceptions



she can't be autistic she is too social??

she doesn't have repetitive behaviours or obscure interests?



These statements are not true.

she is just shy?



It is not the special interests that differentiate girls from their peers, but the quality and intensity of these interests and the length of time spent on these. Through my observation, I have found girls do have fewer repetitive behaviours than boys, however they do exist and are more subtle in their presentation.

For example, girls tend to twirl their hair, or use other stimming behavior such as twirling, humming or picking their nails. Girls do also enjoy special interests to the same intensity as boys, but often have more common topics such as animals, music, people or fashion.

Danuta Bullhak-Paterson, Clinical Psychologist I got so used to holding it together at school or copying others just to blend in. The trouble is, I would then have shutdowns or fall apart at home – exhausted from keeping up my charade. I may have seemed 'fine' but in reality, I really needed more support.

Sarah, 30 years old

People just think I'm naughty and lazy but I'm not. Sometimes I don't know where to start and my brain feels too busy.

Emma, 8 years old

special interest (commonly animals, people, nature, books, art)

She may be described as being either 'extremely shy' or not aware of 'social boundaries'

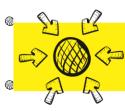
She may contain her anxiety in public but then melt-down or shut-down once home She may be overly dependent or reliant on one friend who may play a nurturing and protective role, and have trouble coping without them

She may be extremely interested in socialising, but unsure how to approach

making connections

She may have sensory sensitivities (e.g., noise, food, clothing, temperature) play with peers and have great difficulty with reciprocal play

- She may interpret language literally She
- may be more fluid in her gender identity (e.g., prefers less 'girly' clothes or be extremely 'girly')
- She may be **extremely empathetic**, nurturing and sensitive
- She may have a great attention to detail
- She may appear to have a good imagination⁸
- She may be a **perfectionist** in some areas and at the same time be disorganised with basic



Common Traits in Girls

She may display **extreme focus** on her She may **exhibit extreme reactions** to minor events (e.g., changes to the classroom routine) and have difficulty controlling her emotions

She may be very controlling in social routine tasks She may prefer playing with boys in physical activities and may be perceived as being a 'tomboy'. This may be because she sees girls as too socially demanding.



Internalising and Hidden Anxiety pg8 Peer Relationships pg9 Bullying and Exclusion pg10 Teamwork _____ pg11 (a) Completing Tasks and Executive Functioning pg12

> To better understand and support these challenges, go to the relevant page.

Class Rules

pg13

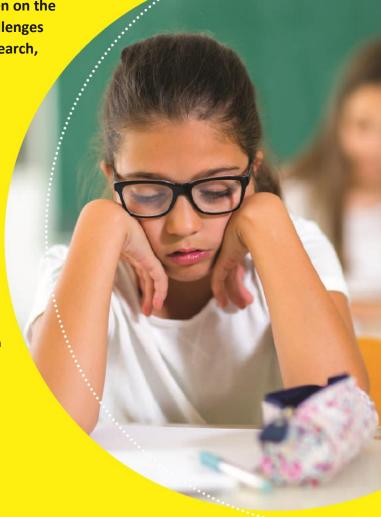
This list has been developed with the help of clinical psychologists Dr Danuta Bulhak-Paterson, and Dr Janine Manjiviona. This is for information purposes only, and be used as a diagnostic checklist. Please refer to a clinician for further information.

Common Challenges

Whilst there are many challenges faced by all children on the spectrum, the following outlines those common challenges faced by autistic girls attending school, based on research, practitioner insight and the lived experience.

The hidden curriculum

Research shows that girls with autism are oft en harder to identify. Apart from the typical language, communication, cognitive, sensory processing, motor control and social challenges, navigating the 'hidden curriculum' is an oft en overlooked or unknown challenge faced by autistic girls. The hidden curriculum is about the aspects of the school day that sit outside the boundaries of traditional lessons, but aspects that are critical to the positive experience of the classroom environment. Girls with autism may not learn intuitively so must be taught rules and school culture. However, their coping mechanisms of masking and internalising difficulties and anxieties make them vulnerable to not having their needs met in school, even with a formal diagnosis.³



³ (Moyse, & Porter 2015) ¹⁰ (Charman et al. 2011; Szatmari 2011)





Knowledge of this hidden curriculum is vital. When teachers understand the need to address this, they can then eff ectively teach the known curriculum in a way that girls with autism can understand.10

Case Study

I am now paying the price as an adult, having gone through school as an undiagnosed autistic girl and feeling isolated and trying to be anyone else other than myself just to fit in. I am now working with a psychologist to undo 20 years of emotional damage and abuse that I've inflicted on myself. The damage of believing the labels given to me over the years by my peers and teachers that I was rude, naughty, lazy and odd. If only they knew the toll it was taking on me and how these labels have negatively shaped how I view myself now as an adult. I don't want my daughter to go through the same thing. I want her

to feel like she can be herself and be proud of who she is. I want teachers to be able to understand her and look beyond the surface and realise the immense power they have to shape her future selfworth.

> Teresa, mum to girl 13 years old. Both have an Autism diagnosis



Internalising and Hidden Anxiety

Girls with autism oft en internalise or "mask" their difficulties (e.g., sensory, social, communication) resulting in symptoms of anxiety and depression.⁴

Studies have shown that anxiety is higher in autistic females than in autistic males. 12

Tips and Strategies

Check in with her regularly. It's best to be discreet and off er her a variety of ways she can approach you. For example, in early years, a visual sign that girls can use to identify that she needs help is eff ective, and in older years being allowed to email the teacher directly can improve communication.

Get to know her. Understand her individual triggers for anxiety and dig deeper if they are not obvious - she may be camoufl aging them. It is also worth checking in with parents as they will have great suggestions as to what is helpful for their daughter.

Establish a safe haven or quiet place for her to access in the classroom or on the playground and provide her with a discreet exit strategy to access these when needed.

Allow her to have her comfort items close to hand e.g., fi dget or sensory tools, soft toys.

It can be diffi cult for staff to support the social lives of autistic girls alongside their studies, but it is a crucial aspec of school life and personal development. Alex

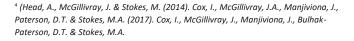
Grade 5 Teacher

Views fr om Teacher, Practitioner and Autistic **Female**

Teacher It's really important to understand her individual triggers and signs of anxiety. It may not be obvious at first, but you almost need to be a good detective to find the clues and see what's going on under the surface.

Practitioner Anxiety can impact learning, and can be seen in subtle presentations e.g., nail biting, twirling of hair, flicking of nails. Ongoing and untreated anxiety can result in signifi cant issues such as school refusal and more serious longer term mental health consequences.

Autistic Female My anxiety is silent. You wouldn't even notice a change on the outside. But when I get stress tasks. I am of



(2017).) 12(Attwood 2007; Kopp 2010; Kopp, Kelly & Gillberg 2010; Kreiser & White 2013; Solomon et al. 2012)

Peer Relationships

Social communication differences and a possible lack of understanding of the 'hidden curriculum' impact on the peer relationships of girls with autism.⁵

Girls with autism often find forming friendships difficult. They want to experience friendship in the way their peers do but they may not have the innate skills to make the relationships work. ¹⁴ Autistic girls mask this challenge as they are more able to follow social actions by imitation, observation and copying other children. ¹⁵

Views from Teacher, Practitioner and Autistic Female

Teacher In my experience, girls with autism can have many different types of relationships. I have seen girls be very attached to one person, or have difficulty establishing any friendships at all. Then there are the girls who float between groups, known as the 'floater'. They appear to have many friends, but if you look closer, they never spend enough time with any particular group to establish meaningful connections.

Practitioner Girls are often more aware of and feel a need to interact socially. They are involved in social play, but may be led by their peers rather than initiating social contact. In our society girls are expected to be social in their communication, therefore there may be more challenges in this area that need support. Whilst you may help them widen their friendship circle, it's important to remember they may be happy with their less demanding, casual friendships.

Adult Female with Autism Interacting is mentally draining. At school I was often misunderstood as being defiant or insensitive. Most

of the time, I was simply processing conversations differently. What came naturally to my peers, I struggled with. I spent a lot of energy trying to understand and process the words people were saying, the context they were being spoken in, the tone, facial

expressions, physical gestures, and body language to even get close to working out their feelings, and intentions. At the same time, I had to

formulate how I was feeling, and how I was going to reply. There were so many nonverbal cues that went over my head, and I

am sure many of those led to many of my social struggles. I was very bright, but because of these hidden processing differences, many of my peers and teachers assumed that I had chosen to misinterpret instructions or not act what was socially acceptable. This was my hidden disability.



Tips and Strategies

W ork with her to choose a classroom and playground buddy so she has a built in ally or 'go to person' that can support her in unstructured times.

C reate a culture at the school that promotes inclusion for all e.g., set up a friendship bench, reading nook or lunchtime clubs that provide more opportunities for semistructured play during social times.

P rovide explicit teaching about how she can join groups, how she can check to see what the children are playing, how to leave a group if she no longer wants to be a part of the game e.g., use social stories.

U nderstand she might find it easier to connect with students who are older or younger than herself rather than students her own age. Allow her to access all play areas if she wants to.

G irls who have just one or two very intense friendships may need help widening their circle and understanding why this matters.

D.T. & Stokes, M.A. (2017).) ¹⁴(Attwood 2007; Beteta 2009) ¹⁵(Attwood 2007, Head, A., McGillivray, J. & Stokes, M. (2014).)

⁵ (Head, A., McGillivray, J. & Stokes, M. (2014). Cox, I., McGillivray, J., Manjiviona, J., Bulhak-Paterson,

3

Bullying and Exclusion

Help them find other young people or peers with shared interests.

Studies reveal a majority of girls with autism experience bullying and/or exclusion.

Kopp (2011)⁶ found that more than 50% of girls with autism had been bullied. Girls' bullying techniques are often more covert than boys, less physical and harder to observe. Girls' bullying includes social intimidation and social exclusion, threats, name calling and teasing. The longterm emotional impact of bullying and extended periods of feeling excluded can detrimentally impact on outcomes for girls and contribute to low self esteem, anxiety and depression.¹⁷

Views from Teacher, Practitioner and Autistic Female

Teacher The fear of being bullied or feeling different but I also had many unique strengths. Yes I had

challenges, can lead to girls choosing to isolate themselves. On

the other hand, some girls with autism may not even If we had been able to tap into those understand bullying as a concept or recognise when more at a younger age, I think they are being bullied. This may diminish their ability I would have felt more confident to seek help.

and supported.

Practitioner Girls with autism can be very empathetic, Mary, Year 12 student to a point where they can take on the emotional pain of others. They can often hold onto things that upset them longer, because they feel more intensely. It's important to acknowledge this and support them.

The best thing teachers can

Autistic Female I was often overlooked or ignored do for girls with autism is to find in class, but it was even more obvious how different out how they learn best. Allow girls

I was in the playground. Girls either were mean to

me, or completely ignored me. This is where I felt

to work to their strengths and nurture

completely ostracised, and needed more support an environment which embraces during unstructured times.

uniqueness. Victoria, Grade 2 teacher

Tips and Strategies

E nsure she has a 'safe' person and place (e.g., teacher, principal, support staff, trusted friend) she can access if she is being bullied or excluded.

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⁶ (K<mark>o</mark>pp 2011) ¹⁷(Attwood 2007; Attwood & Grandin 2006; Cridland, et al. 2013; Jackson 2002: Solomon et al. 2012)

- E mpower her to access this support group through a variety of methods (e.g., verbal, written, direct or indirect requests) when needed. A 'Bully Box' held at the office for students to anonymously report situations can be helpful for her to use if she is not comfortable revealing her identity.
- B e aware of the different types of bullying. It can be less obvious for females and often takes more 'covert' forms (e.g., hidden or out of sight actions, including making up stories to get someone in trouble or spreading rumours).
- A ctively promote positive, inclusive attitudes through a whole school approach that actively involves students, staff and parents.

One of the most significant challenges that autistic girls in mainstream schools face is the requirement for consistent – and almost continuous – social interactions with their teachers and peers.

In classes where children are expected to cooperate and collaborate, girls with autism need to be presented with alternatives to help them focus on the education task at hand, without being distracted and stressed by the concept of managing the complicated social interactions as well.

By managing these interactions, stress levels and anxiety in girls with autism can be greatly reduced – a shift in approach

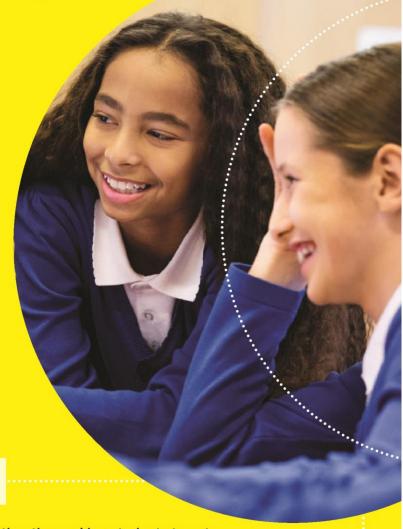
that can have a significant impact.¹⁸

Views from Teacher, Practitioner and Autistic Female

Teacher I find that if I bring some structure to the unstructured situations or provide a range of activities for my students at break and lunch times, and provide clear guidelines for group work, it really helps to alleviate anxiety.

Practitioner Girls with autism may have trouble following group discussions, and may be better at smaller groups. It's also important to allow her to take a role in the group that she is comfortable with and will succeed in

Autistic Female I preferred to work alone, and when I was put in groups, I was often placed in a role I was not comfortable with. I would have happily been the note taker or time keeper, but being asked to present to the class was not ideal and caused immense anxiety.





Tips and Strategies

- Facilitate the allocation of groups rather than asking students to get themselves into teams. This will reduce the anxiety of not being picked or chosen.
- Allocate specific roles within the group and play to her strengths e.g., she may prefer to be the note taker or writer if she is anxious about public speaking.
- Balance the amount of group work in the day with individual work to allow her downtime.

Completing Tasks and Executive Functioning

achievements.

=>

Autistic girls have a diff erent profile of cognitive skills that must be recognised and accommodated when they are undertaking academic work at school and home. One aspect of the profile is impaired Executive Function.⁷ Autistic girls may have difficulty planning, organising and prioritising, have a need for supervision and guidance and need help determining what is relevant and redundant. They may need help with time perception and time management. Impaired Executive Function can significantly impact the ability of autistic girls to learn and engage in busy school environments.²⁰

Views fr om Teacher, Practitioner and Autistic Female

Teacher The oft en hidden or invisible need in the classroom is helping our girls with their executive functioning. The minds inner 'personal assistant' is oft en in need of help to support our girls with organisation to help girls reach their full potential. Practitioner Many girls struggle with issues with planning and prioritising, and can be misunderstood as being lazy or as simply procrastinating. If you dig deeper, you may see that she is overwhelmed and simply freezes and does nothing. On the other hand, many autistic girls can be perfectionists and have a real strength in this area.

Autistic Female During my later years at school when it came to completing more complicated tasks, I would oft en

interests were and use them to would have had motivate and engage me.
Sally, Year 9 student

Tips and Strategies

P rovide her with clear written or visual instructions to reinforce what you have said.

Regularly check for understanding of verbal and written instructions as she may not ask for help.

Give her the big picture. For instance she may benefit from understanding the end result

Class Rules

A key area, in which the hidden curriculum appears to create difficulties for autistic girls is class rules.8 Autistic girls identify difficulties with authority and rules, stating that rules had to make sense to them

ask for clarifi cation more oft en than my peers. Because of this, I had the reputation of being precise and detail orientated amongst my peers, but the fact was that I struggled with starting and completing a task without knowing all the moving parts. I would oft en get bogged down in the detail, not being able sift through what was relevant and important and as a result I would rarely fi nish work on time. I was then oft en misunderstood as being a procrastinator or lazy by my teachers. If only I had known that my executive functioning was a big part to play

and be consistently applied, otherwise this caused confusion,

better have loved my teachers strategies to to know what my current special support this, I believe I

before beginning her work.

Help her understand time. For example use an analogue clock so she can see time passing and plan how to use it. Also break tasks into smaller steps and help her determine the time needed to complete step.

prompts, including colour codes for each subject or picture sequences.

frustration and increased anxiety.

(Attwood 2007) ²⁰(Manjiviona, J. 2003)

Views from Teacher, Practitioner and Autistic Female

Teacher I have found that girls with autism often have a strong sense of fairness, justice and a desire to abide by the rules. This has led to many conflicts with their peers who may not feel the same. This can cause anxiety amongst the class, so it's important to manage.

Practitioner I have seen girls with autism who easily get distracted by their surroundings, which can impact on their ability to focus and follow what is expected.

Autistic Female I have never responded well to authority and would often question teachers at school on the rules. I didn't do this to be disrespectful, I just processed this differently and needed to understand 'why' the rules were in place and also see the record fairly.



- $\overset{
 ightharpoonup}{\longrightarrow}$ H elp her understand why the rules are in place and be ready to provide a logical reason rationale that she can understand and relate to.
- B e clear consistent and explicit. Avoid idioms, metaphors and figurative language e.g., say what you want to happen - if you say "your desk is getting very messy" she may not pick up the implied meaning that you expect her to clean it up.
- E xplain the unwritten rules to the class and ensure she understands them. wished that a teacher could have gone up to a nice little boy or girl in my class and encourage them to invite me to join them at kickball or skipping or tag. I struggled in the classroom as well. I was often described as being 'naughty' by my teachers and while I didn't mean to be disruptive I found it so hard to sit still in uncomfortable chairs with lots of things happening for long periods of time. I used to move around the classroom a lot as a way to stay calm and focused but my teachers thought I was being purposely disruptive when in fact I wasn't. These were the strategies I was using to help me learn and be a better student.

Chloe Hayden, diagnosed with Asperger Syndrome at the age of 13.

Case Study

I'm nineteen-years-old now and I've finished doing sixteen years at school. I've come out the other side but I'm not going to lie, it was hard! I struggled a lot with friendships and while it may have seemed that I didn't want to play with the other kids in the playground, the fact was that I simply didn't know how to start a conversation or enter a play situation. I felt silly, and awkward, and I felt like I was intruding if I tried and go up and play with someone on my own accord. I also struggled with knowing what to say as their language was strange to me and their ways of communicating were different than my own. So I was the child who spent their lunch time crying in the bathroom, because I so, so desperately wanted to make friends, but didn't know how. Looking back now I





- What Every Autistic Girl Wishes Her Parents Knew - Inc. Autism Woman's Network (Edited by Emily Paige Ballou, Kristina Thomas & Sharon daVanport
- Girls Under the Umbrella of Autism Spectrum Disorders - Lori Ernsperger & Danielle Wendel
- Women and Girls with Autism Spectrum Disorder: Understanding Life Experiences From Early Childhood to Old Age - Sarah Hendrickx
- Aspergirls Rudy Simone
- Aspergers and Girls Catherine Faherty, Jennifer McIlwee Myers, Lisa Iland, Ruth Snyder, Temple Grandin, Teresa Bolick, & Tony Attwood
- The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations - Brenda Smith Myles, Melissa Trautman, & Ronda L. Schelvan



Autobiographies

- Pretending to Be Normal: Living With Asperger's Syndrome - Liane Holliday Willey
- Congratulations! It's Asperger Syndrome! len Birch
- Finding a Different Kind of Normal -Jeanette Purkis
- Thinking In Pictures: My Life With Autism -Temple Grandin
- Life Behind Glass: A Personal Account of Life With Autism Spectrum Disorder -Wendy Lawson

For Girls

- M is for Autism Students of Limpsfield Grange, Vicky Martin
- How To Be Human: Diary of an Autistic Girl -Florida Frenz
- Me and My Brain: Ellie's Story Antoinette Preston
- The Asperkid's [Secret] Book of Social Rules: The Handbook of Not-So-Obvious Social Guidelines for Tween and Teens With Asperger Syndrome - Jennifer Cook O'Toole
- Asperger's Rules!: How To Make Sense of School and Friends - Blythe Grossberg
- The Aspie Teen's Survival Guide: Candid Advice for Teens, Tweens, and Parents, From a Young Man with Asperger's Syndrome - J.D. Kraus
- Middle School: The Stuff Nobody Tells You About - Hayley Moss



Further Resources

Further resources and information can be found at www.yellowladybugs.com.au



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A Positive Future

Creating greater awareness of the unique challenges autistic girls face - both at school and at home - opens the door to better understanding, support and ultimately, to the educational, social and emotional well-being of these students.

The current obstacles facing girls with autism are many and varied - but they can be overcome with deeper knowledge, more effective support systems in place, open and honest communication between schools and families, and strategies that encourage families and schools to work together towards positive outcomes. Teachers and support professionals can be powerful allies in helping autistic girls feel understood, safe and accepted at school.

School is an important step in the lifetime journey of girls with autism. Having a positive, validating educational experience can help provide the foundations for her to thrive.



