

Autistic Girls



(A guide to understanding and supporting internalised presentations of autism in Bolton)

This resource has been co-produced with professionals from Bolton Educational Psychology Service, Ladywood Outreach Service, Speech and Language Therapy, Bolton Social Communication and Interaction Panel (BSCIP), The Nest nursery, teachers from Bolton Schools and most importantly with the guidance and support of a group of fantastic autistic young people and their parents, who you will meet in this resource.

Introduction

This resource aims to increase awareness of how autism can present differently, specifically when considering gender differences. We have gathered information that focuses predominantly on autistic girls, but it is important to consider that other genders including boys and non-binary people may present with a similar 'internalised' profile of autism. We want to help professionals identify young people who may present in this way, and support them with strategies and resources when exploring a possible or given diagnosis of autism for these individuals.

Identity-first language

Within this resource, we have used identity-first language (i.e. "autistic people" rather than "people with autism") as this is in line with a range of Greater Manchester autism standards and strategies. Research by Kenny et al. (2015)¹ also highlights identity-first language as the preferred choice of over 3,000 autistic people surveyed and 'autistic' was also the preferred language choice of our young autistic people involved in this project. It is important to note that people's preferences do differ in relation to language choices, so it is always important to ask what the individual feels comfortable with.

Diagnosing autism in girls

Under the current diagnostic criteria (DSM-5)², an autism diagnosis is given to an individual who experiences (from early childhood and to the extent that these difficulties limit everyday functioning):

- Difficulties with social communication and interaction
- Restricted and repetitive patterns of behaviours, activities or interests

Autistic people also often present with sensory processing differences and may also have co-occurring difficulties within learning, attention, motor skills, emotional regulation and speech and language skills.

Research by Loomes et al. (2017)³ indicates that boys are three times more likely to be diagnosed as autistic than girls. Autistic girls are also, on average, diagnosed 2-3 years later than boys (Russell et al., 2021)⁴ and as a consequence are more likely to be misunderstood, misdiagnosed and develop associated mental health difficulties. Girls who have co-occurring learning difficulties are much more likely to be diagnosed earlier in life and it is reported therefore that many, more cognitively able autistic girls can 'go under the radar' for a variety of reasons.

Why might girls be being missed for diagnosis?

- Autistic girls are often better at **masking**, **mimicking or camouflaging** their differences and may not present with the same behavioural presentations as boys within the school environment.
- Professionals may see autism as a 'male condition' and screening and assessment tools are used which are often founded on male-centred research populations and may therefore be aimed at stereotypically male presentations of autism. Due to this, wider contextual information towards a diagnosis is often much more important for girls.
- Girls are **often misdiagnosed** as having anxiety, depression, auditory processing difficulties, ADHD, eating disorders, OCD, selective mutism, personality disorders etc.
- Girls have **different social experiences** growing up which may mean they develop better awareness of social skills (e.g. use of eye contact, social greetings etc.). They may therefore appear outwardly to form more friendships and cope better in social situations, despite struggling internally.

How might autistic girls present differently?

It is important to note that all autistic people are different and they may also have co-occurring needs which may affect their language, social interactions, emotional regulation and other aspects of learning. Each person should be considered as an individual, but some common traits identified in autistic girls may be seen as follows:

Speech, Language and Social Communication



- May be very chatty and articulate or may also struggle with expressive and receptive language and be very quiet or show traits of selective mutism.
- May imitate language or speech intonation that they have seen on ty, in films. or from books within their speech (also known as echolalia).
- May have difficulty shifting attention to tune into instructions when focussed on a preferred activity.
- May struggle to make inferences about meaning or feelings when listening to or observing others.
- May have learnt to give some eye contact but may still feel uncomfortable to do so. They may therefore look towards an adult but not make eye contact e.g. look at nose instead.
- May misunderstand social norms e.g. appearing rude when communicating but not understand social rules, inferred meaning or etiquette within their communication.

Friendships

- May have one very strong, loyal or special friendship or may flit between or be on the edge of social groups regularly or be more socially isolated.
- May feel friendships are very important to them but struggle to maintain them or may not be interested in social activities at all and prefer their own company instead.



- May be uncomfortable with conflict or struggle to know what to say in social situations so may practice or imitate others or rehearse scripts. This can lead to difficulties understanding and interacting with peers.
- May struggle with group dynamics and following other people's way of doing things or changes in rules in a game for example or they may just prefer to play in their own way/on their own.

Learning and Interests



- May be very academically able e.g. be an avid reader, writer, mathematician etc.
- May have repetitive behaviours that are more subtle to recognise e.g. re-reading the same books or re-watching the same films and may also present with perfectionist tendencies (but may also have co-occurring learning difficulties).
- May have intense interests and passions but these may be deemed more socially acceptable than those associated with stereotyped autistic profiles e.g. celebrities, books etc.
- May be very creative and interested in fantasy ideas.
- May have a strong sense of social justice and fairness.
- May have difficulties with organisation, breaking down tasks or interruptions to their intense focus on an activity (attentional shifting).
- May struggle to process lots of instructions and plan actions and may therefore need additional processing time and support (e.g. may feel like they have 'too many tabs open').



How might autistic girls present differently?

What is masking?

"Trying to do what the other girls are doing to pretend to fit in"

Beth (age 11)

Emotional Wellbeing:

- May be very anxious but may mask or camouflage this in school to avoid being seen as different.
- May feel their own and other's emotions strongly and be hyper empathetic but struggle to articulate how they and others might feel.
- May become strongly attached to animals or other objects e.g. toys.
- May shut down, go quiet or need time away due to sensory or emotional overload. This may present as situational mutism or not participating in lessons.
- May be **masking** through the day and present as quiet and compliant at school but present very differently emotionally at home as they are exhausted from masking and are now in their safe space.
- May also struggle with transitions, school attendance and anxiety and marked differences may be seen in behaviour with the transition to secondary school.

Physical, Medical, Sensory Needs:

- May be very observant to their environment and may show strong sensory sensitivities e.g. diet, noise, textures, smells.
- May struggle with sleep and self-care routines due to sensory needs.
- May struggle wearing different clothing textures or be sensitive to e.g. labels in clothes.



- May often struggle during puberty with additional sensory, hormonal and emotional difficulties to process alongside struggling to understand and process physical changes to their bodies.
- May be misdiagnosed with anxiety, eating disorders, OCD or sensory processing difficulties and/or have associated difficulties with self harm.

Why is it important we understand how autistic girls may present differently?

"In the past ten years, there has been an increase of research on girls and women with autism, and it has become clear that they can present differently from their male counterparts in many ways. Research demonstrates that these girls and women are highly vulnerable to anxiety, depression, and other mental health conditions. While this less obvious presentation of autism seems to be most common in females, it can also apply to clients throughout the gender spectrum. Girls and women are more likely to use masking strategies to compensate for their intrinsic differences. Receiving a proper diagnosis can be lifechanging, so all clinicians working on an autism pathway, including BSCIP, ensure that they are updated on the ways to recognise the subtle presentations of autism, particularly, but not exclusively in women and girls."

Bolton Social Communication and Interaction Panel (BSCIP)

What do our parents of autistic young people want you to know about supporting their children?

"Be aware that a child's day starts before school and sensory pressures such as dressing, the bus and corridors can be really challenging. What matters to us and them is taking time to get to know them and don't expect too much too soon" - Sarah (Ellen's mum)

"Some autistic girls present as the 'swan analogy': graceful on the surface but frantically paddling beneath the water. This presents as a stark contrast between them as a model student by day in school and then in the evening at home, needing to emotionally offload and regulate from all of the pent up stress of masking all day." - Dawn (Beth's mum)

Meet our young autistic people

Ellen (they/them) (16 years old)

Ellen is described as:

A creative, strong, resilient person who is extremely caring with friends and family and who is passionate about equal rights. When they are older, Ellen wants to open a shop selling 3D model dolls in Manchester.

Ellen likes:

Having time to talk about their interests, which include: writing poetry, reading and designing 3D dolls. They prefer when people just say what they mean rather than using implied or polite language, as that can be difficult to understand. At school and college, they like teachers who get to know them, who anticipate their needs (such as their sensory triggers), show they care, make them feel safe and 'shiny', give them space when they need it and give extra thinking time for questions.

Things that Ellen finds tricky:

Ellen has sensory sensitivities that can make college feel overwhelming. Being out in the rain, sounds like the fire alarm or smells like perfume can make it hard to focus and stay calm and when lots of new things happen, this can lead to Ellen feeling 'shut down.' Ellen has lots of good friends but shared they can feel anxious navigating friendships and not knowing when they have 'messed up' in conversations. Ellen is also non-binary and doesn't like it when people don't make an effort to use their correct pronouns.

Things that help Ellen:

Ellen's mum shared that communication with school was key. Staff that made a difference were those who read pupil passports, understood Ellen's needs and allowed supports such as use of ear defenders, noise warnings and access to a quiet spaces when needed. Having a smaller form and a quieter space to hang out with friends at break was also helpful. Ellen preferred choosing their own 'key person' that they felt safe with and they shared it would be helpful if that person could be a key person even when changing year groups.

"Ellen has a beautiful personality. They would share their last slice of cake with you!"

Sarah (Ellen's mum)

Anonymous (she/her) (15 Years old)

Anon is described as: Creative, witty, compassionate and good at problem solving. She has a passion for graphic design and is skilled using a range of Adobe software to create her work. She feels that she is generally calm and copes well in school because school are really supportive.

Anon likes: Days at school with maths, graphics and computer science and time hanging out with her friends.

Things Anon finds tricky: Sometimes friendships or talking about things that are upsetting can be difficult. She personally feels better when people aren't aware of her diagnosis but feels it's really important that people understand autism so that autistic people can access the support they need as individuals.

Things that help Anon: Having a kind, caring, fun teaching assistant on hand to help, when teachers are calm and don't shout and when adults get to know her well. She doesn't feel like she needs or wants lots of extra accommodations in school but she did enjoy lockdown (mostly as she didn't have to wake up as early!)

Meet our autistic young people

Beth (she/her) (11 years old)

Beth is described as:

A confident, assertive, enthusiastic and resilient person. She is very empathetic and feels she is good at reading other people and sensing their 'emotional vibes' to recognise they might need help, even though she finds understanding emotional cues in language tricky. Beth has a strong sense of justice and wants to advocate for others in her role on the school council. When she is older, Beth wants to be a writer and illustrator.



Beth likes:

Writing historical fiction often about Elaveana the Celtic Warrior princess and her horse. She loves drawing, art, reading, playing the cello and teaching her dog Bailey (who really helps her at home!) new tricks. Up to now, Beth and Bailey have raised £1215 doing tricks for Children in Need. Beth likes public speaking and gave a fabulous talk about autism in assembly at her primary school to help raise awareness.

Things that Beth finds tricky:

Beth doesn't like it when her routine changes or lessons change without warning, and she likes it when people follow the rules. She finds it difficult if people aren't aware of the support she is entitled to, such as extra time for tests. She finds busy bus queues, loud noises, strong smells and understanding people's tone or taking turns when speaking tricky too. She doesn't like people telling her 'don't worry' and she struggles with the feel of some clothes and object textures (plastic toys like fidget toys aren't for her!). She feels she has some good friends now, but when she was younger she felt isolated and as if she didn't belong, or that people didn't like her, so she felt she needed to mask to fit in.

Things that help Beth:

Beth has an exit pass and toilet pass she can use, as well as extra support in the bus queue from an adult if she needs it. She finds being involved in lots of clubs at lunch helpful. Beth has a communication passport and had support from Speech and Language Therapy to practise social communication skills too. Beth finds it helpful when teachers are understanding of different social communication styles, let her use her passes without questioning and when teachers take the time to understand her difficulties and support with her anxieties. She is aware of challenges experienced by autistic girls and wants to channel her own experiences into making a difference in the lives of others.

What do our young people want you to know about their experiences of being autistic?

Beth: "People need to know we are different and more sensitive (especially when going through puberty too). It's not helpful to be told off, as it makes me more emotional. It sometimes takes me longer to process things, but I am still human, and I don't want to be seen as weird or criticised for being different."

Ellen: "Sometimes I feel like everyone got a manual for life and I didn't and the world can feel complicated, icky and loud. I'm me, I'm not just a label!"

How can we support autistic girls?

Support for autistic girls can be implemented at individual and systemic levels across school. We asked our autistic young people and their families about how school staff have and could help them best.

When speaking to our young people, it was clear that an understanding of their needs needed to radiate further than just the school SENCO or form teachers and they felt ALL staff including reception staff, teaching assistants, lunch staff etc. should be aware of autistic difficulties and differences so they could support them better.

All staff could help by:

- Taking time to get to know the pupil as an individual and understand and celebrate their interests and positive qualities as well as their difficulties or triggers. Taking time to engage with an autistic girl's special interest is a great way to build safe, trusting relationships.
- **Reading key documents** such as communication passports that are distributed by SENCOs which help staff get to know the young person and how to support them.
- **Being patient and flexible** and being aware that autistic girls may need information breaking down, time for additional processing of lots of instructions, a break or a different approach.
- Using a **calm voice** as shouting can trigger sensory sensitivities or exacerbate anxieties.
- Reflecting and not assuming autistic young people understand social cues e.g. what others perceive to be 'rude' or implied social messages through tone of voice, body language etc.
- Ensuring agreed supports and access arrangements e.g. exit passes, visuals, preferred seating
 positions, sensory fidgets and check in time are able to be used without challenge and are
 communicated to staff covering the class to avoid possible anxiety of not being able to use them.
- Providing consistency as much as possible in daily routines and giving warnings for changes in routine or reasons for missing lessons that may cause anxiety.
- Supporting young people to build resiliency around perfectionism as in some cases autistic girls can become very anxious about getting things right and need support to build resilience and acceptance in making mistakes.
- Recognising and supporting autistic girls to navigate their friendships (if needed!) Don't assume because they appear to have friends that they find it easy to navigate these friendships and don't assume if they are on their own that they don't want to be interacting socially. Providing informal check ins is often a better approach than 'intervention' which can cause more stress.
- **Being respectful of the language** the young person prefers to use around their diagnosis and the extent they wish others to know about their diagnosis. This is personal preference and can be stressful if the young person feels others will label or stigmatise or conversely not understand them.
- Being curious about, anticipating and planning for sensory sensitivities including smells, sounds, being outside, busy environments etc. by using agreed systems e.g. pre-warning or buddy for fire alarms, staff not to wear perfume, access to a quiet calm space when feeling overwhelmed etc.



Image Credit: Ellen Dixon: Ellen shares in this image their interpretation of the difficulties they may experience in being asked to make eye-contact or give a handshake when they do not want to.

How can we support autistic girls?

When supporting autistic girls in school this document should be used in conjunction with the Bolton SEND Handbook which contains examples of e.g. communication passports or other ideas for wider autism support. When considering what is a 'reasonable adjustment' the following document may be useful: Equality Act Document. Ideas gathered from our young people and their families in relation to autistic girls included the following:

SENCOs or Senior Leaders could:

- Work with services such as Speech and Language, Ladywood Outreach or Educational Psychology to develop and distribute pupil communication passports (see SEND Handbook for examples) and plan in time for these to be read for all staff working with the pupil and reviewed across the year.
- **Provide exit or toilet passes** that pupils can use within the school day or at key transitions that are stressful. These can allow pupils to avoid sensory overstimulation in busy corridors or toilets.
- Keep **regular communication (including positive communication)** between school and home to celebrate good days and share any difficulties that have come up during the day.
- Provide access to a safe 'base space' in school for lunch and break times.
- Support the young person to meet like-minded peers and consider how additional support (if wanted!) in extra curricular clubs or pastoral groups etc. may provide opportunities to make friends and develop social skills. Access to informal pastoral support in this manner can be supportive for girls who are anxious about friendships and may want help but may not want to appear different.
- Consider forming a smaller, nurture form group in secondary schools to provide additional support and access to key adults to check in more regularly.
- Discuss with the young person who they trust and allocate them as a key person. Plan in time for this staff member to check in with the young person to help them with forming positive relationships and navigating challenges in the day. A trusted staff member may be e.g. a librarian or PE teacher and asking the young person's view on who they feel safe with is important for this support to be successful.
- Ensure accommodations in tests and exams (such as extra time, additional space) are considered ahead of time and clearly communicated to and planned for by staff.
- Listen to and validate parent's experiences and difficulties as girls often present very differently at home to school. They also often know them best, including what works to help and what can be a trigger!
- **Discuss any possible interventions with the young person** and consider that being taken out of class could prove more stressful for them as it may provoke anxiety about missing work.
- Plan ahead for additional support around transitions (e.g. to secondary), which could include time to get to know the building, staff, routines and ask questions about any possible stressors.
- Reach out for guidance from services such as Educational Psychology, Speech and Language Therapy and Ladywood Outreach to support social communication needs. Given girls can present very differently to boys, it is important to gather wider contextual information when considering a referral for diagnosis and not to rely on screener questionnaires alone. Gathering information from home and accepting this may be different to school is also vital in understanding a young autistic girls' needs.

"Just because we look fine doesn't mean we are. We're masters of disguise and often our calm, puttogether demeanour is hiding low self-esteem and anxiety with a side helping of fear and rejection."

Pooky Knightsmith,

Director at Creative Education Limited and Pooky Knightsmith Associates, author, former chair of the Children and Young People's Mental Health Coalition and autistic woman and parent to autistic teenage girl

Considering Sensory Sensitivities

The Trees Are Too Loud

By Ellen Dixon

TES SEN Secondary Individual Poetry Competition Winner 2022



Ellen wrote this poem during their English GCSE exam. Even with the reasonable adjustments, the sensory overload was enough that the gentle breeze in the trees near the quiet room resulted in overload for them.

"The trees are too loud."

And no one will tell me why.

"The trees are too loud."

And no one else can hear it.

"The trees are too loud."

But it's ok.

The delicate dance of social interaction.

Tap tapity tap tap.

It seems to come naturally to everyone.

Tap tap tapity tap.

Everyone but me.

Tapity tap tap.

They're able to glide across the floor.

Tap tapity tap.

Posture, facial expression, form all perfect.

Tap tapity tap tap.

But I'm stuck backstage.

Tapity tappy tap tap.

An array of coloured, numbered, feet drawn out before me.

Tap tap tapity tap.

Listening for any cue, any clue.

Tap tapity tap tap.

But it's ok.

Representation Matters: Famous Autistic Women

We discovered through this project, that many autistic girls may not have peers who identify as autistic or be aware of any other females who have an autism diagnosis. We know representation matters and can impact self-esteem and support with difficulties around identity. Autistic women are all around us and have a wide range of jobs and lives. Some famous autistic women include:

- Greta Thunberg (Climate Activist)
- Temple Grandin (Academic and Animal Behaviourist)
- Summer Farrelly (Teen Animal Assisted Learning Creator and Facilitator)
- Chloe Hayden (Actress and Content Creator)
- Stefanie Preissner (Screen writer and actress)
- Holly Smale, Kate Foster, Katherine May & Libby Scott (Authors)
- Anne Haggarty ('Chaser' from TV Show the Chase)
- Elisabeth Wiklander (Cellist in London Philharmonic Orchestra
- Purple Ella (Autism/ADHD Content Creator)
- Christine McGuinness (Model)

Support from Bolton Services

Educational Psychology Services

Bolton EPS can support schools through observations, consultation, gathering evidence towards BSCIP referrals and autism training to enhance staff knowledge. Your link EP can also help to support you as a school to reflect on and develop your systemic ways of working when supporting autistic young people.

Ladywood Outreach Service

Ladywood Outreach Service offer support and guidance for staff through observations, 1:1 support and training and consultation for teaching staff. Ladywood's intervention can cover the following topics: understanding my diagnosis, stress, anxiety, emotional regulation, influence of the media, CBT/DBT and mindfulness, sexual relationships and behaviours and self-harming behaviours. Ladywood aims to empower autistic girls and to promote and develop their self-esteem and self-awareness.

Ladywood offer online and face to face training including: An introduction to Autism Spectrum Disorder (online), Autism Spectrum Disorder (face to face), ASD a deeper perspective (face to face), ASD girls (face to face) as well as running Teen Life and Early Bird National Autistic Society training for parents and carers.

Useful Resources

Useful Websites:

The National Autistic Society: www.autism.org.uk

The Autistic Girls Network: www.autisticgirlsnetwork.org

Spectrum Gaming: www.spectrumgaming.net

Useful Documents:

NASEN Autism and Girls: Under the Radar Guide

Autistic Girls Network: Keeping it All Inside

Autism and Trauma

Bolton SEND Handbook

Useful Videos/Video Channels:

National Autistic Society - YouTube

Too Much Information and Us | Sensory Overloads - YouTube

Limpsfield Grange Girls with Autism - YouTube

My Autism and Me - a Newsround Special - CBBC Newsround

Quiet Fidgets for the Classroom—Pooky and Lyra Knighsmith

Useful Bolton Services To Be Aware Of

Breaking Barriers

Autistic Society Greater
Manchester

Bolton Information Advisory
Service

Bolton Lads and Girls Club

Be Kind to My Mind

Bolton Parent Carers

Daytrippers

Family Fund

There are lots of fiction and non-fiction books you can read on autism and autistic girls experiences. You can find lots more on the <u>Autistic Girls Network Resource Page</u>.

Our team liked the following:

Suggested books for professionals:

- Education and Girls on the Autism Spectrum by Judith Hebron and Caroline Bond
- ASD Girls Wellbeing Toolbox by Tina Rae

Suggested books for young people and their families

- Spectrum Girls Survival Toolkit: Workbook for Autistic Girls by Siena Castellon
- Championing your Autistic Teen by Debby Elle and Gareth Morewood
- EYFS Fiction: Earmuffs to the Moon by Hafiza Issa
- Teen Fiction: Geek Girl by Holly Smale
- Teen Reading: My Fairy Jam Jar by Joley Colmer
- Adult Reading: Autism in Heels by Jennifer O'Toole

Training for professionals is available through Bolton EPS, Ladywood Outreach

Recommended online training from NAS: <u>NAS Women and Girls Training Module</u>

References:

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⁴Russell, G., Stapley, S., Newlove-Delgado, T., Salmon, A., White, R., Warren, F., Pearson, A. and Ford, T. (2021) Time trends in autism diagnosis over 20 years: a UK population-based cohort study Journal of Child Psychology and Psychiatry, August 2021.