autistic
girls network

Autistic Girls Network

Autism, Girls, & Keeping It All Inside

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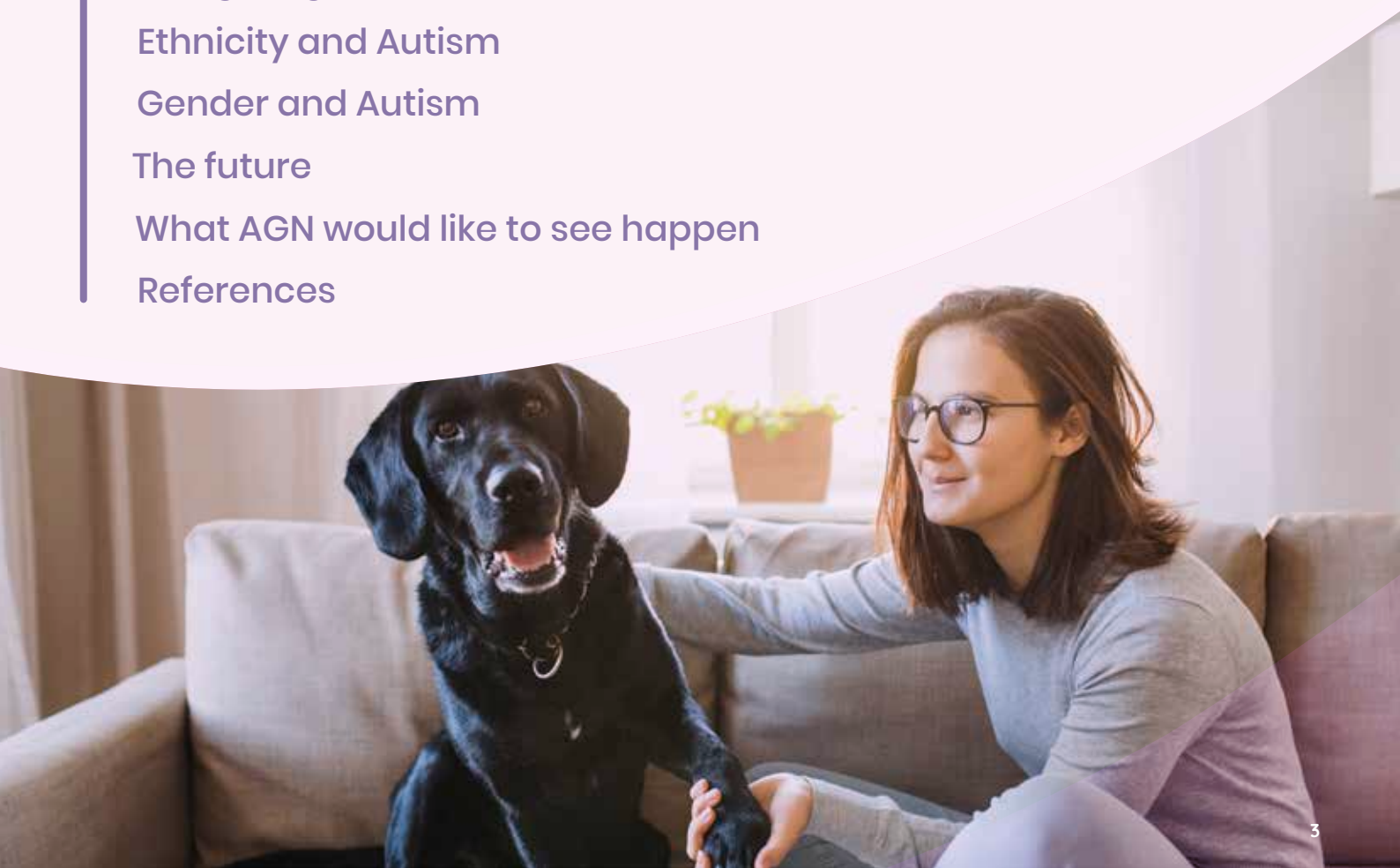


Autism, Girls & Keeping it All Inside

The topic of autism and girls has been much discussed in recent years, but while many are aware that girls may present differently, there is widespread misunderstanding about exactly how. This is a huge issue because autistic girls (and those who present in the same way) are being missed and outcomes for autistic females are particularly poor.

Official statistics still say that 1 in 100 people in the UK are autistic, but these figures are out of date. Official US figures from the Centers for Disease Control and Prevention (CDC - though autism is neither a disease nor should it be prevented) now say 1 in 44 but this is based on 8 year olds, and as we know all too well at Autistic Girls Network, many people are diagnosed as autistic after the age of 8. Official figures in Northern Ireland are 1 in 22. So all we can really say with certainty is that there are more than you think! This is not because autism has become more prevalent but because it has become better recognised. Girls in the UK are still being diagnosed autistic on average 2-3 years later than boys though (*Russell et al., 2021*). Given what we are coming to understand about the damage a late diagnosis and subsequent camouflaging of autistic traits can do to an autistic person's mental health, confidence and self-esteem, this is a statistic which needs to change fast. But girls aren't diagnosed later because there is a female phenotype of autism (there isn't), they are missed for complex reasons the largest of which are masking and presenting internally.

What do we mean by that?

When we talk about an external presentation of autism, we mean one that is probably more recognisable to the majority of people where the person behaves in a way which is visibly different to their non-autistic peers. They might stim (move, perform an action or make a noise in a repetitive way) by rocking or flapping their hands, they might be non- or minimally-speaking, they might exhibit distressed behaviour. As a generalisation, children brought up as girls don't tend to present that way as much (but some do and if they do, they are probably diagnosed earlier). Their autistic traits (and those of some boys and non-binary young people) are camouflaged and internalised to help them fit in with their peers, which can be a conscious or unconscious decision to avoid the stigma of being autistic. However, masking comes with a high cost in terms of mental health and keeping a strong sense of identity, and it's no coincidence that children and young people who present in an internal way are being diagnosed autistic at the time - and because - they have reached breaking point.

Diagnosis

Autism has to be diagnosed by behaviours, but unfortunately these behaviours often end up being those of traumatised and distressed autistic people, who only stop internalising them when they are at breaking point. Autistic children who present in an external way will be noticed and referred early, partially because they are causing disruption in school, and the school is invested in helping that disruption to stop or be more controlled. Autistic children who present in an internal way tend to behave much more passively and to be ignored. They are not causing a disruption so the added incentive is not there for them to be referred, and frequently the signs are not spotted until mental health has deteriorated to such a point that behaviour becomes more externalised and disruptive - albeit disruptive in a different way. But until we can start to recognise autistic children who present in an internalised way while they are still at primary school (or before), we won't break this cycle of lack of knowledge about internalised presentations, and these people not appearing in research because they are not yet diagnosed.

The diagnostic process is less likely to favour those brought up as girls (*Hull, Petrides and Mandy, 2020*) especially when there is no intellectual disability present - the ratio of girls:boys is 1:2 for autistic people with an intellectual disability, whereas it's 1:3 (*Loomes, Hull and Mandy, 2017*) in those without. The assessment tools used for diagnosis and research in the field of autism have almost always been developed from research using predominantly male samples. Girls and women need to be struggling more than male peers to get a diagnosis, and on average it takes 2-3 years longer (*Russell et al, 2021*). In the UK, there is a wide geographical difference in how likely girls are to be diagnosed. Some areas have a ratio of 1 girl to 30 boys, while others have a ratio of 1:2 (*Roman-Urrestarazu, 2021*). This is not just a statistical anomaly, rather a difference in how diagnostic teams recognise autistic girls. There is research suggesting that more women are referred for diagnosis as adults than men, which implies that more girls are being missed (*Happé et al, 2016*).

Bias

The history of autism diagnosis is also biased towards males. Neither Leo Kanner nor Hans Asperger, who might (controversially) be considered the founding fathers of autism diagnosis, paid much attention to girls. Kanner also considered autism a condition of childhood only, and dismissed those who did not conform to his rigid criteria - a subset who subsequently came to be diagnosed with Aspergers. Even now in autism research we are still dealing with some of the leftover unconscious bias from the 1950's, and when you consider that it generally takes 17 years for research to start changing things in real everyday life (*Morris, Wooding & Grant, 2011*) we still have a long way to go! Sadly, pioneer Lorna Wing identified in 1981 that there was a gap in diagnosis of autistic women, and this has still not been rectified (*Wing, 1981*).

What's really important in the diagnosis of any autistic person but especially tweens and teens who have already experienced years of knowing they were different to their peers, is that the diagnosis is presented in a positive way (in contrast to the medical model of deficiency) and is accompanied by experienced autistic voices and the formations of a positive autistic identity. The young people themselves need to be given agency to have some control over this process. Our diagnostic pathway in the UK is a long way from this ideal now.

Processing Differences

We couldn't complete this paper without touching on the subject of autistic inertia. You may already know about executive dysfunction, but we prefer not to use the 'dis' words like disorder, dysfunction and all the other pathologising language that surrounds autism. To understand autistic children, you really need to understand autistic inertia and monotropism.

By monotropism, we mean someone is funnelling (probably unconsciously) most of their attention into one thing, which can lead to what you might know as 'special interests'. But we'd like to open your mind to the idea that there's nothing weird or out of the ordinary about these interests. They are just strong interests, and it's no more odd to be interested in, for example, flags of the world, or K-POP stars, than it is to be interested in a game which involves some players being paid very large sums of money to kick a ball around a field of grass. Some football fans have very strong interests in their favourite teams. We don't call this a special interest. However, for an autistic person, their topic of passionate interest forms what Fergus Murray (2019) calls an 'attention tunnel'. The great part of cognitive processing is funnelled into barrelling your way along that attention tunnel. And this is where the inertia (having difficulty stopping and starting activities) comes in. Because if you're having a lovely time processing stuff about a topic you love, it's not a welcome intrusion to be pulled away from it.

Murray rather beautifully puts it:

> *"Thinking in terms of inertia also gives some insight into the discomfort of being interrupted, or plans changing. It's as if we've loaded a cart to the brim with thoughts and feelings, and then we suddenly have to steer it round a sharp corner."*

Other changes like transitions can also be deeply disconcerting for autistic people (and that includes all the ones you don't realise are autistic yet), and cause a feeling of control being lost. Demand avoidance and meltdowns are a reflection of a truly bewildering lack of control, of frustration at being misunderstood even at the same time as being accused of misunderstanding others. So autistic inertia makes transition difficult and also accounts for a delay in processing, because when the brain has allocated the bulk of processing load to your interest of choice, there's not much left to deal with interruptions. As Murray points out, a neurotypical (non-autistic in this case) brain is adept at dealing with lots of topics at the same time and filtering out lots of the information that comes in and the brain deems useless. An autistic brain hyperfocuses on one topic and doesn't filter in the same way (hence sensory overload). Both methods are useful for different tasks. Neurodiversity is a wonderful thing.

It's important for teachers to realise that it's much better to join a pupil in their 'attention tunnel' than to spend all day trying to drag them out of it. But it's important for parents to understand this too. Contrary to popular belief, relationships are very important to autistic children and young people, and joining them - genuinely - in their passionate interests is a great way to connect. If you can't join them,do your best to find other young people for them to share these interests with.

What may differ for girls

We've said that we're talking about internal presentations of autism rather than a specific female presentation. All of the items we mention below could also apply to the presentation of some boys and non-binary young people too, in which case they probably haven't been recognised as autistic until their mental health has started to break down. But it's impossible to deny the data that shows that it's largely those brought up as girls who have been missed. So why might this have happened?

Autistic traits in girls are frequently missed, overlooked, ignored, or their behaviour put down to "just being a girl". An autistic girl having a meltdown is said to be emotional and hysterical (a word historically only demeaning to women), because that's how girls are stereotyped to be. An example of this may be an autistic girl who struggles with dirt because of the texture and the idea of it, yet may be praised because historically girls were expected to be clean and tidy, and not messy. This is where societal expectations of women and girls (*North, 2021*) can create barriers to recognising, understanding and supporting autistic girls.

Autistic girls may have passionate interests which are viewed as more socially acceptable than the 'special interests' of their male counterparts. For example, animals and reading are common passionate interests amongst girls, alongside others. The common stereotypes of autistic people as liking trains or other more stereotypical male interests may not be true for many autistic girls. They may spend long hours drawing or reading, but because these are deemed acceptable interests, they are not picked up on as 'special interests' and an autistic trait. It's also important to realise that trying to fit in with non-autistic friends, and studying how to behave and what to say in order to fit in, can become a passionate interest on its own.

Autistic girls, much like other autistic people, may engage in different repetitive behaviours. This may not look like lining up objects or repeating words out loud (known as echolalia), although it could. It may instead look like re-reading the same book or re-watching the same film over and over again because it provides a sense of comfort and predictability. It may involve re-doing homework until it's 'perfect' (as it is common for autistic girls to be perfectionists), or repeating a certain behaviour which is comforting to them.

Autistic girls, and boys or non-binary young people, who present in an internal way may tend to internalise problems too, and this can cause damage to their mental health which is already in peril from camouflaging their autism. It can lead to increased anxiety and situational mutism (being unable to speak in situations which cause high anxiety or feel unsafe). Because this is an internal behaviour and is not a core feature of the diagnostic criteria of autism, despite being common in the cohort we're looking at, it can also cause these young people to be misdiagnosed if the assessor doesn't understand internal presentations (*Hull, Petrides and Mandy, 2020*).

Anxiety can be a major part of an autistic girl's everyday life, especially when they are masking and trying their best to fit in. This may mean that they keep it together all day at school, so to teachers there doesn't seem to be a 'problem'. This emotion and anxiety may all be released in meltdowns, shutdowns or anxiety attacks when they get home. This build-up of anxiety can cause anxiety-based school avoidance, (often called school 'refusal', but that implies a choice - there is no choice when you are so anxious). It could also cause situational mutism. Persistent absence from school and situational mutism might be put down to 'behaviour' in a child not yet recognised as autistic, but it may be a sign that needs to be understood in the context of anxiety and autism.

Friendships can be very important to autistic girls and also cause a great deal of anxiety, especially if there is conflict (Sedgewick, Hill and Pellicano, 2019). Autistic girls may be extremely sociable or chatty, or very shy and isolative. It is common for them to have one or two strong friendships, but struggle socialising in groups. This may not be obvious though, as they may have learned to mask their difficulties well. Unfortunately, feeling left out and being bullied is a very common experience for autistic people at school, and even in the workplace in adulthood. A 2016 paper found that although autistic girls identified less conflict in their friendships than non-autistic girls did, interviews by the researchers found more aggression in those friendships (Sedgewick et al, 2016). This indicates that the autistic girls may have found it difficult to identify the conflict. The 2016 study also found that autistic girls tended to have mostly non-autistic female friends, whereas autistic boys tended to have been shunned by their non-autistic peers. This suggests that as-yet unrecognised autistic girls are partially sheltered by their friendship group. Interviews with autistic women identified that a common theme was to not really feel as if they fitted into the friendship group, and for the friendships to easily drift away or peter out in conflict (Milner et al, 2019). Others felt that they had more difficulty keeping friendships than making them in the first place, but however lonely they sometimes felt or however difficult the friendships became to navigate, all respondents in the study wanted friendships above all.

We need to lose the idea that there is a 'right' way of playing, or socialising or communicating. Autistic people are often accused of being unable to do these in the 'right' way, but their way is just a different way. Damian Milton's Double Empathy theory suggests that we all need to consider both sides.

"Simply put, the theory of the double empathy problem suggests that when people with very different experiences of the world interact with one another, they will struggle to empathise with each other. This is likely to be exacerbated through differences in language use and comprehension."

- (*Milton, 2018*)

Autistic girls may feel an intense desire to fit in. This is why masking is so common. Although neurotypical social skills and behaviour don't come automatically to them in the way it does to their non-autistic peers, they may be experts at observing those around them and copying what they 'should' be doing, so that they don't stand out. Many have been doing this since a very young age. A 2016 paper found that autistic girls masked their unhappiness and anxiety in order to fit in with their peers and avoid disrupting friendship groups (*Tierney, Burns and Kilbey, 2016*). At the same time, autistic girls may also feel a desire to express their individuality, for example through piercings or brightly dyed hair. This may provide them with an emotional outlet. Girls and those who present internally may also use compensation to balance their strengths and weaknesses and to fit in with peers. Livingston and Happé (*2017*) talk about girls using different cognitive routes to reach the same skill level, for example in navigating a social situation or analysing facial expressions to identify emotion. Social interaction and the use of inference can also be problematic and autistic people can end up feeling like everyone else knows about a secret code and they don't. You can help at school and at home by really thinking about what you say and cutting down on the amount of inference needed to understand the conversation.

A particularly difficult time for those who grow up as autistic girls is puberty. At a time when they are struggling to understand and deal with their emotions, hormones can exacerbate their emotional dysregulation. The arrival of periods can also cause sensory issues which tend to be ignored due to periods still being taboo to talk about in many areas of society. It can be difficult for autistic people to manage periods, due to sensory issues created by period products, physical pain and nausea and hormones exacerbating existing sensory difficulties. It is important for this to be acknowledged and for autistic young people to be supported in managing at this time of the month. It can also be expensive for parents who may need to buy many different products before finding any that can be tolerated. These sensory needs, which can have the same financial implications, for those highly impacted, when buying clothes and food, should be considered in benefits applications.

What to look out for in an internal presentation of autism

Friendships

- May be on the edge of friendship groups or have intense friendships vulnerable to falling out.
- May be very uncomfortable with conflict.
- May prefer to play in their own way.

School

- May not raise a hand in class or be reluctant to speak when called on.
- May be unable to use strategies like Time Out cards because of situational mutism.
- May misunderstand pop culture or trends.
- May experience less difficulty and anxiety if seated with a friend, and if the seating doesn't change.
- May also vastly prefer pair or group work with a friend - it's difficult and anxiety-inducing to speak to someone they don't know well.
- May mask at school, explode at home.
- May be disinterested in sport.
- May use compensation techniques to disguise difficulties from teachers.
- May get by in primary school but transition to secondary is an explosion in sensory and cognitive input - a step too far.
- May have an ability to spot patterns and/or consider a subject without bias (if you can get them talking in the first place).
- May avoid or be uncomfortable with unstructured time at school and need support for these times more than lessons.
- May find aspects of school uniform (or other clothes) difficult or impossible - reasonable adjustment needed.
- May find transitions between classrooms very difficult.
- May be unable to eat in the dinner hall due to the sensory aspect of smell and so many people.
- May find assemblies difficult due to proximity of so many people.
- Will be startled and scared by teachers shouting at them or at the class.
- May find lessons like PE (or perhaps Food Tech and Design and Technology) difficult due to lack of structure or predictability and sensory reasons.
- Will need specific and adapted sex education.

What to look out for in an internal presentation of autism

Anxiety

- May have situational mutism.
- May be prone to extended absence from school.
- May have an eating disorder.
- May self harm.
- May have anxiety manifesting in physical symptoms eg. stomachache.
- May be more likely than peers to have mental health issues.

Emotional

- May experience intense empathy (including with animals or objects).
- May pretend to be a cat or other animal.
- May value soft toys and plushies for longer than their peers (or not stop).
- May seem emotionally and socially younger than their peers.
- May shutdown (freeze, stop processing what's going on and/or isolate themselves) as likely as meltdown.
- May exhibit a strong love of animals.
- May have Alexithymia (difficulty identifying and expressing emotions).
- May internalise problems and when unrecognised as autistic for too long may hear voices or develop an internalised presentation of OCD.

Sensory

- May have a strong sensory reaction to clothes, touch, noise or smell.
- May avoid baths and showers, hair brushing, tooth brushing for sensory reasons.
- May have poor Interoception (identifying physical sensations in the body which can be linked to identifying emotions).
- May self-soothe sensory overload by listening to music with headphones, pacing up and down or other favoured technique.

What to look out for in an internal presentation of autism

Social

- May try hard to understand and learn social codes.
- More likely than peers to be LGBTQIA+.
- May be more likely to be bullied than peers.
- May have a strong sense of social justice or moral compass - likely to stick up for the underdog in whatever way they are able to.
- May not play along with society's rules or recognise authority figures as anything other than equals.
- May laugh at inappropriate moments.
- May use echolalia (repeated, scripted speech) likely to be from TV shows etc.
- May have a tendency to people please and give the answers they think you want to hear (fawning).
- May be more likely to self-identify as Emo and/or Geek.
- May work extra hard to understand people.
- May have intense interests in common topics for their peers - eg. animals, fiction (especially Harry Potter) and also psychology and marginalised groups.
- May be less conforming to gender stereotypes eg shaving legs and armpits, long or straightened hair.
- May be more likely (when old enough) to have brightly coloured hair and multiple piercings.
- Masking or lots of 'peopling' will cause exhaustion.
- May need time alone to recover from the 'peopling'.

Autistic Inertia

- May have difficulty with organisation.
- May find it difficult to get started on a project or assignment.
- May find it difficult to build a plan without breaking it down into much smaller segments.
- Likely to have an intense focus on what is of interest.
- May find it difficult to be interrupted when 'in flow'.
- Likely to find transitions of all kinds difficult.

What to look out for in an internal presentation of autism

Other possibilities

- May have a vivid imagination.
- May enjoy collections - collecting IS the play, rather than doing something with the items collected.
- Can be perfectionists.
- Stimming (repetitive behaviours) less likely to be noticeable - small movements or internalised.
- Likely to have strong opinions when not masking in a safe space, and difficult to convince they are wrong.
- May have trouble with directions.
- May have a large or advanced vocabulary.
- May make strong use of routine or ritual.
- May have poor posture.
- May have restricted eating choices.
- As likely to be creative as into STEM.

What it's like to be undiagnosed for decades

Holly Smale is the best-selling author of the 'Geek Girl' series and was diagnosed autistic recently.

"I spent nearly four decades believing I was "broken", and being told that the different way I experienced the world was a result of something "wrong" inside me. It was only after my late autism diagnosis that I finally started making sense of not only my neurology, but of my past and who I actually am. It started me on the path to loving and understanding myself, in my entirety, and it has changed my life completely. I am proud of my beautiful, autistic brain, I no longer feel "broken", and I am passionate about not only the advocacy of autistic people but of the diagnosis - however late - that allows us to fully know and celebrate ourselves."

Problems with diagnosis

Autistic girls are let down repeatedly when it comes to accessing a diagnosis. On average, autistic girls are diagnosed 2-3 years later than boys. Stereotypes of autism and a lack of understanding of how autistic girls may present by professionals at all parts of the pathway can play a huge part in this.

Take a look at this image, showing all the reasons we've been told (in our Facebook group) why autistic girls have been refused an assessment or a diagnosis:

The referral process can be very challenging. Even when an autistic girl, boy or non-binary young person have very similar presentations, autistic girls tend to be overlooked by professionals. Speech delays have been known to have been put down to shyness and anxiety, and many still view autism as more of a "boy condition" so are more reluctant to refer girls for assessment. Where an autistic girl has more of an internalised presentation, they may not even pass the screening process to be referred. Many of the questions on the screening questionnaires do not reflect internal presentations, and frequently families are forced to choose a private assessment after not passing an NHS screening pre-assessment.

Even once a referral has gone through, the delay in waiting for assessment is significant. A questionnaire conducted by AGN pre-pandemic found that 43% of autistic girls waited up to two years for diagnosis, and 24% waited more than three years. This waiting time is, of course, worse now. There are Local Authorities in England where children have already been waiting for four years and have not yet had their assessment appointment date. The NICE guidelines say that the wait time between referral and assessment should be 13 weeks. This delay is failing autistic children and their families. It leads to the exacerbation of mental health difficulties and a lengthier time of not receiving adequate support for their needs.

What happens when not recognised

When autistic young people who present internally go unrecognised, they are likely to be struggling with anxiety, depression and other mental health problems, as well as poor self-esteem (*Livingston and Happé, 2017*). This can be due to feeling different from their peers, not receiving the right support for their needs, or feeling forced to mask their difficulties. Unrecognised autistic people who present internally may also have difficulty developing a sense of their own identity (*Mogensen and Mason, 2015*) and can develop unhelpful coping strategies such as self-harm, eating disorders or self-medicating with drugs or alcohol. They may be offered therapies such as CBT for their mental health without these being adapted for use with autistic people, meaning they are often ineffective.

There are higher rates of suicide attempts and completed suicide amongst autistic people (*Keating et al, 2021*). Autistic girls and women in particular are disproportionately represented in these statistics, with a four-times higher risk of suicide attempts than men (*Kõlves et al, 2021*) – and these figures don't account for the vast numbers of those who are undiagnosed. Mental health issues are common in autistic people. One study of autistic adolescents aged 10-14 found that 71% had co-occurring mental health disorders (*Simonoff et al, 2008*). Rates of anxiety and depression disorders are alarmingly high with one study indicating prevalence rates of 54% for anxiety conditions and 47% for depression. (*Hossain et al, 2020*)

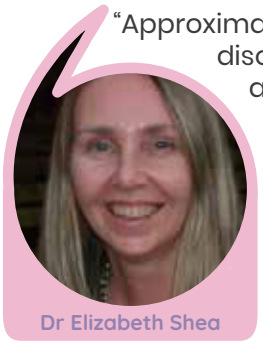
Autistic young people who present internally and go unrecognised may also find it harder to engage with their education to achieve their full potential. They may refuse to go to school because of high anxiety levels, or struggle to pay attention in a classroom, impacting on academic achievement. Furthermore, school exclusion is common amongst children with additional needs, and autistic young people who present internally who are not supported in the school environment may be excluded (*Sproston et al, 2017*), especially if it is not known that they are autistic. 45% of autistic pupils are excluded at some point (*Ambitious About Autism, 2016*), but this statistic is only counting those who have been diagnosed as autistic.

Ultimately, as well as a diagnosis hopefully opening doors to some support, autistic people also need it to have a chance to build their own identity and self-esteem. If you were unable to walk and in a wheelchair, you wouldn't blame yourself for that inability to walk. In the same way, if autistic people feel disabled (and the framework of disability has a place in the neurodiversity movement too), they need to be able to understand that there is a reason so that they aren't hard on themselves or believe they are 'broken'. There's a huge boost too in finding a group of people you can relate to when you've felt different for most of your life.

Autistic young people have a right to know that they are autistic. They deserve the chance to receive the right support and to understand themselves. They deserve the chance to thrive.

Co-Occurrence with Eating Disorders

Dr Elizabeth Shea, Consultant Clinical Psychologist says:


Dr Elizabeth Shea

"Approximately 1.25 million people in the UK are affected by an eating disorder (*Beat, 2018*) with impacts including poor quality of life and higher mortality rates (*Schmidt et al, 2016; Arcelus et al, 2011*). The prevalence of eating disorders in autism is not known, although it is estimated that 20-35% of females with anorexia nervosa may be autistic (*Westwood and Tchanturia, 2017*). It is now increasingly recognised that eating disorders frequently co-occur with autism and that autistic individuals are more vulnerable to developing problems with food and eating.

Clinical experience suggests these issues are primarily ones of restriction varying in severity and cause. For example, from sensory-based aversions to the look, smell, taste and feel of certain foods (which forms part of the new diagnostic label Avoidant and Restrictive Food Intake Disorder, ARFID) to significant calorie reduction and life-threatening weight loss which may lead to a diagnosis of Anorexia Nervosa (*DSM, 2013*). Many autistic women present with a complex combination of symptoms with potential causal factors including sensory sensitivities, social interaction differences, identity, cognitive style and a need for control and predictability (*Babb et al, 2020*). The social impacts of eating disorders, such as inability to eat with others, are likely to disproportionally affect autistic people.

When it comes to interventions there remains a significant gap in the knowledge base (*All Party Parliamentary Group on Eating Disorders, 2021*). The UK NICE guidelines (*NICE, 2017*) for eating disorders do not include ARFID nor how to treat eating disorders in autistic people. In particular, the lived experience of autistic women indicates barriers to effective treatment which include a poor understanding of autism, a lack of individualised care and difficulties accessing services (*Babb et al, 2021*). More research and professional knowledge are imperative. Not least to improve the understanding of how autism and eating disorders co-occur and to provide better and more effective interventions."

School

From **Andrew McDonald,** Head of Junior School:

"At the start of Key Stage 2 (ages 7 to 8) girls tend to be more socially advanced than boys of the same age. They tend to have more advanced communication skills, are more co-operative to instructions and can negotiate and collaborate with peers.

Whereas it becomes clear for boys at this age that they may be facing challenges of interpreting social cues and interacting, girls work much harder to be accepted socially and begin masking behaviour at this age. Crucially, difficulties are hidden from the professional (usually the class teacher) as girls are most motivated to build a good relationship with teachers at this age.

Early diagnosis of girls is therefore difficult and owing to coping strategies their emotional reservoir begins to fill. The emotional toll of masking and silently adapting begins to build and is often only detected at a tipping point.

Late diagnosed autistic girls may often have faced several years of struggling to respond in a challenging situation whilst not being able to communicate their confusion to the main education provider, usually a class teacher.

Anecdotally, I feel that there is a skills shortage in Key Stage 1 and Key Stage 2 of professionals trained to look closely at social behaviour of girls. Lots of educational literature tends to be focussed at Key Stage 3 and above."

School

By a **Specialist Assessor** on the British Psychological Society's Register of Qualified Educational Testers who wishes to stay anonymous.

"My background is in education, supporting Inclusion, mainly, but not exclusively in Secondary schools. In retrospect a number of the female students who were referred by school staff or parents, or self-referred, to be investigated with challenges to learning, would today, I think, be diagnosed as having autistic traits. I now feel quite uncomfortable to realise that with more experience, training and understanding, I could have met their needs better and pointed them in the right direction for a professional assessment. However, with cash-strapped CAMHS services, schools increasingly meet a different barrier.

Have I detected a difference in the way boys and girls present themselves? In general, most certainly, the girls have tended to mask their behaviour at Key Stage 3, using coping strategies to avoid notice, their often unpredictable ways almost invisible, hidden by clever phrases or anonymous action. Their characteristics appear to be more diverse to me. The boys, in my experience, will be more forthright. They do and say it as it is irrespective of the response this may evoke from their peers.

Currently, I only have a fleeting conversation, usually just 10 -15 minutes, with Key Stage 4 students who are referred to me as a specialist assessor, with a brief to gain evidence for schools' applications for exam access arrangements. One very recent anecdote immediately comes to mind which sadly demonstrates the difficulties some girls have faced over their entire school career. This is not unusual. I do acknowledge that it isn't easy for boys either and some characteristics are the same.

An able Year 11 student is running out of time in mock exams, unable to achieve to her ability level she struggles to say what she means, sometimes verbally, more often on paper. This difficulty with expressing herself and also the subtle misinterpretation of exam questions is not unusual. In exams this is exacerbated by her anxiety and what she described as 'zoning out' which she said was something beyond concentration. It leads to her having to re-read text to absorb and grasp an understanding. Her speed of processing, on the day I assessed her, scored as very slow. She wants to succeed but doesn't, as yet, have an equal opportunity. During exams she becomes increasingly frustrated and totally overwhelmed, then loses her temper.

I asked her how she has coped in school since Primary and she inferred that it has been easier to mask in the past by remaining quiet. However, with the increasing pressure at Key Stage 4 it has become very difficult. There have been sessions of confidential counselling. She talked about her anxiety, how this has impacted on her mental health and the irrational fears which haunt her. Her surname at the beginning of the alphabet involves her sitting at the front of the Main Hall for exams where she feels everyone is watching her. Similarly she rarely eats lunch because she dislikes what she perceives as being at the centre of attention in the school canteen. The school will now take discreet action for her.

Raising the possibility of exploring a diagnosis with parents and students is not always an easy conversation. Most are desperate for greater understanding and support because they have reached the end of the road. It is not easy for schools with limited budgets. I do believe that we are moving in the right direction, there is a much greater interest in neurodiversity and opportunities for professional development. It isn't yet enough though."

Why we'd like autism to be recognised before secondary school

Sarah Wild is Headteacher of Limpsfield Grange School in Surrey, the UK's only school for autistic girls.

"For too long the biggest misconception about autism has been that girls can't be autistic. "

Sarah Wild

Over recent years there's been an increased awareness across society that autistic girls can present very differently to autistic boys. However getting a diagnosis is still challenging for autistic girls, especially in their primary years. Many autistic girls at primary school can make conversation, want to have friends and are desperate to fit in and be "normal." The stereotype of an autistic child being locked into themselves and obsessive doesn't apply to autistic primary aged girls, who are reaching out and trying to socially engage with their peers. Autistic girls can be deceptively good at faking neurotypical behaviours from a very young age, and are experts at hiding in plain sight at school.

It is time for society to reimagine what autism looks like.

Masking or camouflaging

Masking or camouflaging is when an autistic person copies someone else's social behaviour and tries to make it their own – without fully understanding where that behaviour comes from. This can lead to serious problems. Masking or camouflaging is mentally exhausting and isolating. At primary school autistic girls are often surrounded by peers who really don't get them. They have to mask their difficulties all day, and pretend to be a different version of themselves. In many cases this leads to meltdowns at home as a result of an overwhelming and confusing day, with family life becoming very difficult.

This is why understanding, regulating and managing emotions is absolutely crucial to autistic girls' emotional and mental wellbeing. It is key to feeling well, happy and together and to accessing opportunities. It's the difference between autistic girls functioning and attending school each day or being stranded at home by their anxiety.

What can primary schools do?

Primary schools are lovely places populated by staff who are deeply committed to giving their all and ensuring great outcomes for children. Very often staff in primary schools will go the extra mile to make sure that children are well supported and are included in their school communities. Primary schools are usually smaller than secondary schools, and children at primary school experience a high level of staff continuity – so the adults who work with them know them very well. These protective factors can mask the problems that autistic girls face.

Over the past decade I have heard, many times, tales of parents talking to class teachers and SENCOs in primary schools about regular meltdowns at home at the end of the school day; only to be told that there is no problem in school so it must be about something else.

This is not strictly true. Autistic girls are professional maskers – the fact that they have meltdowns at home indicates that the school day isn't working, and is

causing them extreme distress and anxiety.

It is vitally important for primary SENCOs and class teachers to listen, really listen, to what a parent or carer tells them about how things are at home, and that parents, carers and school staff try to piece together the cause of the meltdowns as a team. It is useful to map meltdowns with parents and carers. Find out if they are happening on a certain day or every day. Can the young person identify what happened during the day to trigger a meltdown, or is it just an overwhelming sense that they can't cope or manage the day to day situation? Essentially primary school staff and parents and carers need to be partnered detectives trying to unravel the mystery of the day that went wrong.

Tips for educating autistic girls at primary school:

1. Build a relationship. Relationships are crucial to autistic girls – they need to feel accepted by you, and that you understand them.
2. Make learning concrete, contextual and visual.
3. Ask them how they would like to be supported in social situations – autistic girls will want to engage with others socially but may find this overwhelming or confusing.
4. Build in quiet space and time each day where the girls can process their thoughts and feelings without being socially "on show." Remember that masking all day is exhausting.
5. Create some bespoke sex and relationships opportunities. This cannot start too early as autistic girls have multiple vulnerabilities:
    - they want to please people.
    - they are sociable without understanding context.
    - they are concrete literal thinkers.
    - they can be very trusting.
    - they often have low self-esteem.

Sarah Wild

Headteacher – Limpsfield Grange School

You can find Sarah on Twitter: **@Head_Limpsfield**

Limpsfield Grange School **@LimpsfieldGrang**

Feedback about primary school from Limpsfield Grange Year 7 students

(December 2021)

We asked Year 7 students at **Limpsfield Grange**, the UK's only school specifically for autistic girls, to reflect on their experiences at primary school.

Great things about Limpsfield Grange:

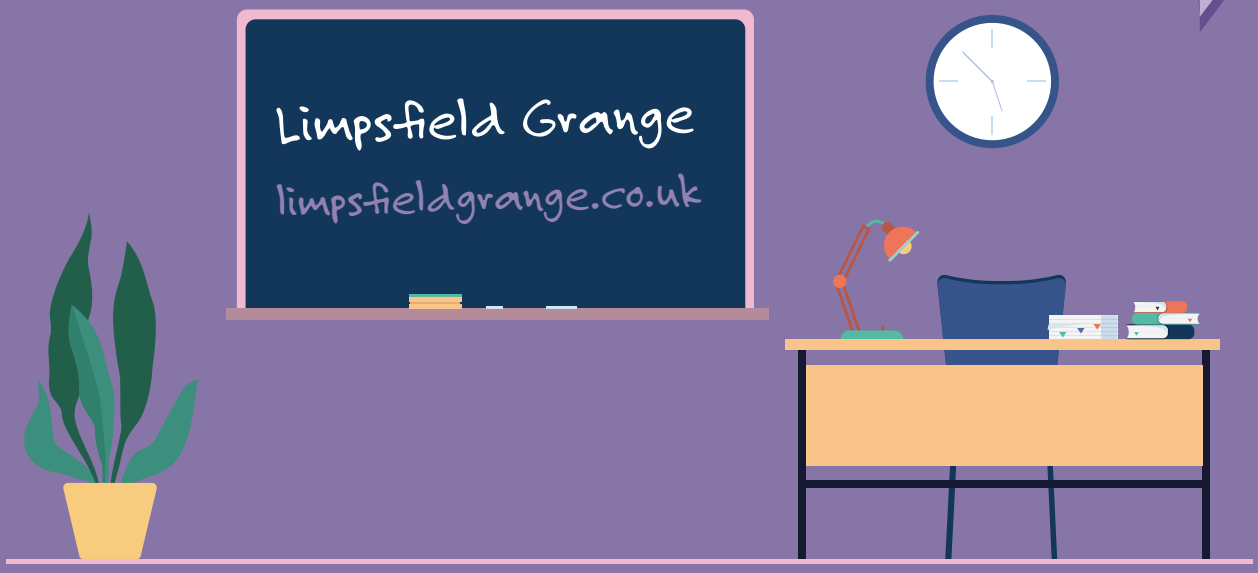
- There are people who can help with problems.
- I have friends.
- I can choose who I sit next to.
- It is calm.
- I get to work in class with everyone else.
- Animals!
- I am not judged.

I would have liked people at primary school to know:

- That everyone has different autism.
- That just ignoring bullies is really hard and you can't do it all of the time.
- Not everyone needs to know about my needs – it's up to me who knows about them.
- That sometimes I am sad for no reason.

Primary school would have been better if:

- I didn't feel left behind.
- Other students understood me.
- I didn't feel so pressurised and stressed.
- Staff knew how to help me.
- The work was explained so I could understand it.
- I didn't get bullied.



Current Research with School Staff

We asked **Dr Judith Hebron** about her ongoing research project looking at autistic girls in school through the eyes of school staff. This is her summary of the first part of the project, unpublished at the time of writing.

Perspectives, knowledge and understanding of autism in girls among school staff

Dr Judith Hebron

Dr Judith Hebron, Associate Professor, School of Education, Dr Paula Clarke, Associate Professor, School of Education and Miss Victoria Lynn, Laidlaw Scholar, School of Law, University of Leeds, UK.

Background

While knowledge of autism has developed significantly over the past few decades, attention has largely focused on boys and the male presentation, with the belief that girls (and women) were less likely to be affected. This assumption has now been widely challenged, and there is growing consensus that autism is far more prevalent in girls and women than previously thought. The stress and long-standing pressure to be seen as 'normal' is believed to result in unacceptably high levels of mental health problems. Indeed, many girls and women only receive a referral for an autism diagnosis following treatment for a mental health condition.

Our project

We administered a UK-wide questionnaire to gather the perspectives of all categories of teaching staff. We asked about staff knowledge, experience, training and confidence when working with autistic girls. In addition, we asked some open-ended questions about perceived challenges for autistic girls, useful strategies for supporting them, as well as barriers to effective support.

Findings

The questionnaire ran in early summer 2021, with 256 staff responding from across the UK. Respondents came from a wide range of roles, encompassing primary, secondary and further education, and with different levels of experience. Knowledge of autism was generally good, and most staff reported that they felt confident when working with a young autistic person, although nearly a quarter reported not having had any autism-specific training.

When asked to consider prevalence of autism, 40% of respondents felt that autism was as common in girls as it is in boys (50% felt it was more common in boys and 10% were unsure). Some worrying trends emerged when participants were asked about observed differences in the presentation of autism between boys and girls:

- Autistic girls were reported to be more likely to have friends than boys, and this may be because their interests are more similar to those of their peers than those of autistic boys. In addition, they tended to copy the behaviour of others more and try to hide their autistic traits compared to autistic boys.

- However, autistic boys were more likely to be bullied than girls (although the figures are worryingly high for both groups at 64.2% and 54.7% respectively) and were reported to have much higher levels of challenging behaviour. Both groups were observed to have difficulties coping with change and sensory over/under-sensitivity, with this being slightly higher for boys.

- Although reported prevalence of mental health difficulties was worryingly high for both groups, it was much higher for autistic girls (83% compared to 63.4% for autistic boys), and girls were reported to have more frequent absences from school than boys.

Most respondents felt that autistic girls are often misdiagnosed or diagnosed later than boys due to their ability to mask and camouflage their autistic traits. When asked about the perceived challenges autistic girls face at school, the most common responses were in terms of making friends and trying to fit in. It was frequently reported that other diagnoses had been given (e.g., anxiety) prior to recognition of autism. Mental health concerns were frequently mentioned by respondents in relation to masking, sensory overload, and difficulties arising from the school environment. There was consensus that a lack of awareness and understanding among teaching staff could be a challenge, with one respondent writing: "Just because girls mask so fantastically well, it shouldn't be deemed that they are fine in school. Wider education and understanding of autism in girls are required". Staff reported that receiving a diagnosis of autism was helpful, as difficulties could arise in providing adequate support without one.

Implications and directions for future research

Important themes are emerging regarding staff awareness and confidence, mental health concerns about autistic girls and masking. Respondents in this research project have shared a range of valuable strategies and highlighted priorities for staff training and development of a more inclusive school environment. The next stage of this study involves a more comprehensive and in-depth analysis of the data which will be used to inform a more detailed report and publications. It is hoped that the findings will contribute to further educational research and be used to inform school practice and staff training, and consequently the educational experiences of autistic girls.

Sex Education should be tailored for autistic young people

The reasons below highlight why we believe regular sex education in schools doesn't serve autistic young people well. Time needs to be found for this without creating a further feeling of segregation for autistic pupils.

- Euphemisms don't work - autistic young people need clear, explicit language with no need for inference, factual information, and support to put it in social context.
- Instruction needs to be adapted to the pupil's communication style eg. may be a visual learner.
- Autistic pupils may not have peer to peer conversations on sex so adults shouldn't assume they gain knowledge this way.
- It can be a neurotypical assumption that autistic people aren't sexual or shouldn't be sexually active. This is very unhelpful.
- Autistic pupils may not share neurotypical norms of what is public versus private, and need support to keep the most necessary aspects private.
- Autistic young people, particularly girls, can be highly vulnerable to sexual abuse. This is a safeguarding concern but education is needed to ensure that they understand consent, and that they are able to talk about body parts or sexual feelings.
- There is an increased likelihood that autistic pupils may be LGBTQIA+ and all sex education should reflect this and be inclusive.
- There is a possibility autistic young people will have sensory issues with sex, eg. touch and smells, and they may need support to find ways round this or communicate their clear boundaries to partners.
- The autistic community is a very sexually heterogenous and non-conformist population, and some may for example have strong interests in particular sexual activities, parts of the body or fetishes. While sex education doesn't need to cover this specifically, it should be inclusive and non-judgemental while still maintaining the young person and their partner's right to consent or not, always.
- Equally an autistic young person may be asexual and it's important to be inclusive and non-judgemental about this also.

Exploring autism with autistic girls and teenagers

From **Trudi Rainsberry**, Specialist Teacher in autism and SEND.

Trudi Rainsberry

Working in mainstream and special education, it is my privilege to support autistic girls and teenagers to explore autism and what this means to them. It is important not to project personal perspectives of an autistic identity, but to facilitate exploration and enquiry. With younger autistic children of primary age, it can be supportive to facilitate this through small groups, providing guidance to develop a shared understanding. When engaging individually with secondary age autistic girls and teenagers, enabling a supportive empathetic, non-judgmental environment is essential. This may be provided whilst engaging in preferred activities or interests, enabling the young person to feel empowered to be themselves.

Relating autistic young people's shared experiences can be beneficial, providing an opportunity to talk about autism in relation to particular talents, strengths, and interests, as well as areas in which they may have previous negative experiences, such as relationships, or people's attitudes towards 'stimming'. A focus on a young person identifying with their autism through strengths can be key to facilitating a positive experience and understanding of autism. In discovering what they like about themselves, the autistic young person can feel heard and begin to develop their autistic identity. It is also essential to enable autistic girls and teenagers to feel empowered to discuss their concerns and anxieties in a safe and genuinely empathetic environment.

In my experience in both mainstream and special school settings, exploring emotions can be problematic. 'Feeling' emotions in an atypical way, due to Alexithymia, can be compounded by communication differences and create anxiety that others interpret them as lacking empathy. This includes sharing and interpreting emotions through facial expressions. In my experience, autistic girls mask their emotions, sometimes appearing 'passive,' or 'shy.' Supporting autistic young people to focus on their 'likes' and 'dislikes' can be a more constructive alternative to discussing emotions, exploring 'strengths' and 'needs.' Empowering the young autistic person to identify their preferences and begin to express the accommodations they might find beneficial to improve their environment.

Being diagnosed in adulthood

In recent years, there has been a significant increase in the number of women being diagnosed with autism during adulthood. In the past 20 years, the number of people diagnosed with autism has risen by 787% across the United Kingdom, particularly amongst women (Russell et al, 2021). This is not because there is a rise in the number of autistic people, but that we have become better at recognising autism. Our understanding of what autism is and what it can look like has grown, and our diagnostic methods have improved. In adult diagnostic services the gender gap is much smaller than in child services, which leads to the conclusion that those who present as female are being missed at an early age (Leedham et al, 2020). This makes it even more important to research those late diagnosed people brought up as girls, so that we can discover what we're missing.

There remains a lack of research into autism and ageing, which raises concerns. For starters, many older autistic people remain undiagnosed. Others who have received a diagnosis later in life share feelings of shame, difficulty finding others to relate to and having to deal with stereotyped assumptions (Leedham et al, 2020). This lack of research is concerning when it comes to healthcare provision for elderly autistic people, as there are few guidelines for adjusting healthcare to meet the needs of autistic people, for example in dementia inpatient care. There has been a particular lack of research into older autistic women, because in the rare studies into older autistic people, women didn't greatly feature.

However, things are changing. There is an ever-growing group called Autistic Doctors International who are a group of - you guessed it - doctors who are autistic. They include GPs, consultants, psychiatrists, anaesthetists and others and are mainly women, with a keen interest in autism in the over 50's and in menopause. They are contributing to a growing body of research - by actually autistic researchers - in these areas.

If you're interested in reading more from Autistic Doctors International, you can see some of their ever-growing body of output here:

https://linktr.ee/autisticdoctors

Ethnicity and Autism

Estimates of the prevalence of autism in the population tend to be based on wealthy Western countries, and the statistics record less people as autistic in less developed or lower income countries, so the likelihood is that there are many autistic people as yet unrecognised in these countries (*Hull, Petrides and Mandy, 2020*). Black and, in the US, Hispanic families particularly struggle to get a diagnosis for their autistic children. There is potential bias all along the diagnostic pathway from recognising developmental concerns (which may present differently in different cultures), to referral (bias or lack of knowledge about presentation in different cultures may result in dismissal), to biased screening tools (for example, it is a Western notion that eye contact is necessary, in some countries making eye contact is rude or threatening), to bias in assessing what support is needed and how long it should continue (*Straiton and Sridhar, 2021*). All practitioners need to be conscious of their bias and endeavour to use tools which give a fairer result.

From **Warda Farah**, Speech and Language Therapist and Trustee of Autistic Girls Network:

"As an autistic Black woman, it was only when I turned 30 that I began to self-identify as being autistic. Throughout the years I had many challenges in education and the workplace.

Warda Farah

I remember when given a classroom task I would ask lots of questions, this was deemed by the teacher as being defiant, and that was the first time I was ever excluded from school. My teachers said that my behaviour was a choice and that I was attention-seeking.

On other occasions I was labelled as rude and disruptive. The school told my parents that I was emotionally disturbed and my parents, who had no knowledge of Autism or ADHD, did not question this.

Even in my 30's, medical professionals dismissed the possibility that I could be autistic because "I had friends, I had done well academically and I did not look autistic". I gave up on the idea of being officially diagnosed because of the trauma of not being believed by my GP.

Being diagnosed with Autism is hard enough for girls, but when you're a black girl it is even more difficult as there seems to be a lack of awareness on the topic.

There is a gap in the research looking into how Black girls experience autism. There needs to be open discussion and acknowledgement that girls from Black communities are also autistic.

Research is needed to tackle the inherent racism and bias in the diagnostic process for Black girls, which requires us to step away from the Western lens that autism is viewed in, to adequately address this group's needs."

There are other issues which need to be considered too, which take into account the intersection of autism and different cultural expectations or ideas regarding both disability and gender.

Why is autism less recognised in black and brown people and what can be done to change that?

- There have been studies showing that professionals can attribute communication issues to ethnic background, and therefore don't refer a child for an autism assessment (*Begeer et al, 2009; Wiggins et al, 2020*).
- It's true that there may be issues with English as a second language, and there may be social problems where families have difficulties getting access to health care, but if children are going to school, theoretically all should have an equal chance of being noticed and referred - that isn't happening.
- If there is a reason why some cultures don't want an autism diagnosis, we need to work with those communities to raise awareness about why it's important, both to secure support for the child and to help them understand their own identity.
- There may be less information about autism, diagnosis and support available in other languages - this can be a big barrier to some communities. We need better translation services and access to interpreters.
- There can be cultural issues around interacting with health/social care/ education professionals, and likewise these professionals may have little understanding of that culture, and may use inaccessible language.
- Some communities have a stigma surrounding disability in general, and autism included in that. Therefore some families don't like to be open about an autism diagnosis - sadly this will make the autistic person feel even more isolated and 'other'.
- Better awareness and understanding is needed on all sides, and all professionals should be aware that skin colour doesn't make a difference to neurotype.

Autism and South Asian Families

By **Reena Anand**, writer & speaker on Autism in BAME communities.

"Asia encompasses a multitude of cultures, from the Indian subcontinent to the vast plains of central Asia. And so, the term Asian doesn't really do justice to the broad richness of cultures and identities whom it is intended to envelop. This section focuses on the intersectional difficulties experienced by British citizens whose ethnicities derive from the Indian subcontinent.

Reena Anand

Research around the impact of cultural difference on the experience of families with an autistic child – whilst limited – has consistently identified that these children are further disadvantaged because of the layering effect from an intersectionality perspective of having multiple protected characteristics (Equality Act 2010) thereby compounding the victimisation they experience. Families often experience shame and judgement from their communities because of a lack of understanding of autism and misconceptions around its cause in addition to cultural expectations around how children should behave and what good parenting looks like. This is compounded by a general lack of representation and cultural competency in healthcare services resulting in families not accessing support for their child.

With regard to girls in particular, some parents have reported that they've rejected autism diagnoses for their daughters out of fear that other siblings' marriage prospects will be adversely impacted in the future. On the other hand, some professionals have reported that parents appear more willing to accept an autism diagnosis for a daughter than a son because of cultural expectations around continuing the family name and how they define what success looks like for their child, often rooted in academic prowess.

Moreover, girls can often present as more structured and ordered in their thinking and play, present with good language capability as well as being able to mask longer so their autism isn't identified as early as their male counterparts. Many of the qualities they exhibit are considered respectful in South Asian cultures which can further hamper identification such as, maintaining quietness, lack of eye contact or internalising emotions rather than freely expressing them.

It is therefore imperative that investment is made into generating greater awareness and acceptance of autism in girls within South Asian communities so that the myths which prevent parents accessing support can be addressed and these girls receive appropriate support and interventions so that they aren't impacted by resulting poor mental health as they progress through their teenage years."

Gender and Autism

Dr Wenn Lawson, Psychologist, autism researcher and author.

> *"The neurodiversity paradigm shift, encompassing all neuro types as being of equal benefit to society, raises questions that need further attention. What are we doing to prevent the need for masking? How are we protecting autistic girls and women from severe mental ill health?*

Dr Wenn Lawson

The gender and subsequent policy divide have only served to push the gap between us further apart. We must refocus on the bigger picture and broader dilemma, the intersectionality debate. This highlights issues of powerlessness, pathology, providence and other problems which are causing inner despair. Already females (however gender diverse) have struggled over centuries with such labels as hysterical, emotional, the fairer sex, and so on, then as practitioner eyes were opened to the reality of autism not being exclusively male, the issue for policy and appropriate resources for all, is hitting home.

Like autism, gender is also a spectrum of difference. Learning to be at home with difference, diversity and gender disparity while finding common ground can only profit the autistic individual, the family and society at large. Focussing upon quality of life in autism, uniting gender under the equality banner, remitting gender dysphoria and building mental fitness in the autistic and autism community create an intersection, not as a crossroad of indecision but more a roundabout that exits each in the direction of prosperity."

It would be hard to think of an area where society has taught us the 'right' way more than gender. Many of us have grown up thinking of gender as a binary concept - male and female. But we know now that gender identity is a spectrum, and also that autistic people are more likely to identify in a gender diverse way. In fact, according to a 2020 study, people who don't identify as the sex they were assigned to at birth are 3 to 6 times more likely to be autistic (*Dattaro, 2020*).

LGBTQIA+

Autistic young people are more likely to identify as LGBTQIA+ (a term used to encompass lots of different gender identities – see the link for a complete explanation) than their neurotypical peers, and this puts them into a double minority, with double the chance of 'minority stress'. Some of this stress can be alleviated by acceptance and support, whatever their gender identity or sexuality. How much you support and advocate for them needs to be led by them, but the importance of a simple acceptance of their identity can't be overestimated.

Follow the link below for a full definition of the meaning of LGBTQIA+:

LGBTQIA+ Acronym Explained

A Personal Perspective about Identity from **Claire Farmer**, Co-Chair of Trustees at Autistic Girls Network, local government SEND advisor and former Headteacher.

Claire Farmer

"There is an obvious possible correlation from my experience and it is one that simply comes down to: as an Autistic person, I am myself. This may sound oblique, but when one considers the social hoops and niceties we are all expected to learn, my world has been filled with stark contradictions that clearly make sense to many neurotypical friends and family members. For example, we are told from a young age to tell the truth, oh but not that truth as it's rude. Add a thousand more of those and it's no surprise that my internal truth, my sexuality, was just simple and was mine; was me.

My identity, initially as a young woman who was attracted to men and women, but more so women, was just who I was. I tried to put on that different skin that might make me more palatable to others but it just never worked. Instead, I held on to an internal acceptance within a world that was full of such nonsensical – to me – hate and bigotry. This presented a double bind in that not only was I clearly quite different to my peers, but I was also deemed a deviant by many, who made their mind up because of who I loved rather than who I was.
Add to this that I was called 'aggressive', because I spoke the truth or because I stood up to any injustice no matter what the consequences, you get a cocktail of truly feeling like you have been born on the wrong planet. Whilst it may be a generalisation, girls tend to internalise such things. It is not that the world is wrong for being so judgemental and appearing to have no ability to rationalise in the way you can, it is because you are wrong inherently. And herein can lie the beginning of a life of self-hate.

It can also form something that is so easy to feel is your safety net, even if it means you are far more open to bullying and others' hate or lack of understanding. It could also be that it feels like it is a 'more acceptable' way of being different. I appreciate that this seems to contradict what I've just said, but there are young people who can stick their stake in the ground in relation to their LGBTQIA+ identity more than being autistic, dependent on how they feel they may be received or indeed how comfortable they are internally with either. Whether this is or isn't the case, is almost irrelevant, the issue is that there is even an issue.

Honest and Open Communication

We need to therefore support honest and open communication (or not, as some young people may not wish to directly engage) when it's sought and not induce any form of shame. Have honest conversations with yourself about why certain things matter to you and actually – do they really matter? Try to not use cliches such as 'I just worry about how others will treat you,' or 'are you sure, we all go through phases.' Just have a think, do you really think that anyone would place themselves in such a vulnerable position (at least in the current climate) on a whim? And are you worried about how others will treat them or is it because you are uncomfortable or embarrassed? Do people go through phases? Of course, every single person does but you don't tell someone to not ever be in a relationship because they're likely to get hurt as how would any of us ever learn?

Support, genuine support and an ability to shift your own perspective and understanding if necessary, is key. Your relationships with these young people will be all the better for it in the long run, but more importantly you will be actively telling them that who they are, fundamentally, is just who they should be; themselves.

Both autistic and LGBTQIA+ pupils are at proven increased risk of bullying in schools, so that's something senior leadership teams should carefully monitor. Social relationships may already be difficult to navigate for autistic young people, and starting a new romantic relationship is always tricky - adding an additional layer of intersectionality makes it all harder to navigate without understanding support. "

How parents and/or schools can help

- Questioning your identity can be lonely - be there for them in a non-judgemental way.
- Let them know there's no rush. They don't have to get it right straight away, and they don't have to be like everyone else, including other LGBTQIA+ young people they know. But please don't imply that you don't believe them or that they don't know what they are talking about. It's likely they will have researched and thought long and hard about this before bringing it up with you.
- Try to find an online or face to face group for them if they are up for it - meeting other young people who understand will be important.
- If therapy is needed, make sure the therapist understands the intersectionality of autism and LGBTQIA+.
- Listen to the young person when they talk about finding their sexuality or gender identity with your full attention. At this moment, it's the most important thing in the world for them.
- Respect their wishes if they want to use new pronouns or a new name. Explain that you might sometimes make a mistake because your brain will naturally use the old pronouns/name for a while, but that you will try to get it right as quickly as possible. And ask friends and family to do the same if that's what the young person wishes.

What is gender dysphoria?

Some of the gender diverse group of people above will feel there is such a difference between the gender identity they were assigned at birth and their real gender identity that it causes much emotional pain and distress. This is gender dysphoria, and it's these group of people who may seek gender-related medical care (if they do, make sure their care is autism-adapted). The dysphoria can be physical (related to gender-specific parts of the body) or social (related to how people perceive their gender).

Risk of suicide or institutionalisation is worrying in the case of autistic trans people. Research by Murphy et al (*2020*) suggests not only that autistic people are more likely to be trans but that trans autistic people suffer higher levels of mental health issues such as anxiety and depression. It is vital, therefore, that access to diagnosis and to mental health support is improved for autistic trans people.

As for all the difficulties we mention in this paper, young people in care can be especially unsupported. Outcomes for autistic children and young people in care are "significantly poorer" (*Parsons et al, 2018*) than outcomes for autistic children and young people not in care, and poorer also than for other children with SEND in care. Statistics show that 3% of children and young people in care have an autism diagnosis but the actual figure is likely to be higher due to diagnosis delays and lack of referrals (*Parsons et al, 2018*), so the percentage of autistic children in care is higher than in the general population. Authorities responsible for these 'looked-after' children and young people have a responsibility to recognise and support both their autism and their gender identities when they have no families advocating for them.

How can you help?

It's very challenging for a child or young person to reveal that they don't feel they have been identified as the right gender. They will have struggled a lot internally before they got to the point where they decided to tell you. No matter your initial views, the best thing you can do for them at that time (and every other time) is to tell them that you support them, and (for parents) that you love them no matter what. If it's something that you have difficulty coming to terms with, make sure the young person knows that's no reflection on them. They need a rock - be that rock for them.

The future

Currently, the statistics for life outcomes for autistic people are very poor - severely lessened in educational and employment, more likely to have mental health issues, even a significantly lower life expectancy. But these statistics come from a period where we really didn't know or understand much about autistic people, and where we weren't even recognising most people as autistic. In the last 20 years, diagnosis rates have jumped by 787% (*Russell et al, 2021*), and all those people who had gone and still go unrecognised weren't included in any statistics. They got jobs, got married and carved out relatively stable lives (though not perhaps without a need for support and accommodations). Including them in statistics going forward is going to transform statistical outcomes just as much as understanding and accommodating autistic people better and decreasing the stigma of being autistic.

The foreword to the National Autism Strategy (*DfE and DHSC, 2021*) states "We've never had a greater public awareness of hidden disabilities like autism." But while there is increased awareness that autism exists, and increased diagnosis, there is still a worrying gap in understanding how autism should be accommodated and supported in mainstream schools, and an alarming rise in the referrals to mental health services. We've all had our lives turned upside down by the pandemic, but the rapidly rising trends in mental health referrals and in extended absence from school were there before COVID and remain after. NHS England funding is being poured into pilots like the Keyworker pilot, working with young people who are in danger of admittance to Tier 4 CAMHS inpatient units, the Mental Health Services and Schools pilot which established links between local mental health services for children and young people and schools, and the Autism in Schools pilot which has rolled out around England and aims to increase understanding around the needs of autistic pupils in order to decrease referrals to Tier 4 mental health units. The fact that the educational environment can affect mental health can't be denied, but if we continue to ignore the 72% of autistic pupils in mainstream schools (a figure which is going to be deceptively low given that we are still diagnosing people too late) we are incubating a bigger mental health disaster.

We believe that autistic pupils need to be diagnosed before the transition to secondary school, which is a huge transition for any pupil but even more so for autistic pupils. We talked about why this transition was so important, and so traumatic, as part of a study in 2021 (*AGN, 2021*), and our Facebook group is full of families whose young people were diagnosed after this and bear the mental scars to prove it. If the government really wants to meet the target set in the National Autism Strategy of 'Improving autistic children and young people's access to education and supporting positive transitions into adulthood' by 2026 then there is much work to be done in providing earlier diagnosis for ALL autistic people, whether they present internally or externally.

What AGN would like to see happen

- Systemic change is required to address the dire outcomes of autistic girls and expected increase in the number of people identified as autistic – we need more government funding, appropriate research into supporting autistic people, widespread cultural understanding and acceptance of autism, co-production with autistic people and radical changes to and improvements in autism-appropriate service delivery.

- Development of diagnostic criteria and diagnostic tools is needed which are appropriate to identify those with the more internal presentation of autism such as is common amongst autistic girls.

- There is urgent need to reduce waiting lists for diagnosis of autism (NICE guidelines specify 13 weeks between referral and assessment).

- In the internal presentation of autism, stereotyped characteristics of autistic behaviour such as lack of friends, flapping hands or a passion for train related trivia may not be apparent. Sensory or organisational issues may be as or more important than social issues. Look out for the quiet girl in the classroom, the one who has sensory issues with uniform, the one who cannot face the dinner hall or is overwhelmed when transitioning between lessons.

- Schools should be designed so they are universally accessible to autistic children with or without a diagnosis, including for example sensory calm environment, explicit instructions and presentation of materials in ways accessible to children with different communication and processing styles. Autistic children should be encouraged to be themselves at school and harmless activities such as stimming should be permitted. The need for masking at school traumatises autistic people.

- Autistic children are significantly more likely to be bullied at school. School staff need to proactively monitor and intervene. Do not tell a bullied autistic child to go and sort it out themselves. For this reason, and to remove the need to mask, we need to be working with a whole school approach to understanding and inclusion. Remove the bias and prejudice, and the stigma removes itself.

- There is a need for widespread awareness training about autism and the internal presentation of autism. In particular, training needs to be given to teaching staff at Key Stage 1 and Key Stage 2 to support earlier recognition of children with an internal presentation of autism.

- Transition to secondary school is a huge change for all children but especially so for autistic ones. It's vital that we can upskill to recognise pupils as autistic while they are at primary school so that nobody needs to make that traumatic leap unsupported. Once that happens, research within Autistic Girls Network Facebook group shows that breakdown (or what may be autistic burnout) generally happens by the February half term of Year 7, and anxiety-based absence from school is likely to follow.

- Neurotypical people's lack of understanding can seriously harm autistic children. If a parent tells you their autistic daughter has meltdowns in the evening, take it seriously and work with the parents, do not tell the parents she must be OK because she is OK at school. Similarly, if the autistic child tells you they cannot bear a sensory stimulus, believe them, you probably do not understand their sensory world.

What AGN would like to see happen (continued)

- A key tip for teachers is to use the autistic person's 'special interests' in teaching delivery – it is vital to work with rather than against the grain of an autistic child's attentional focus and processing style.

- Reasonable accommodations for autistic people in examinations must go much further than the current expectations of additional time and availability of a reader. For example, examination boards must write the questions in a way accessible to autistic people so that the questions are clear, unambiguous and without the need to make inferences. Exam boards should employ neurodivergent proof-readers to sense-check exam papers.

- Given the prevalence of co-occurring mental health conditions such as anxiety and depression, presence of these should trigger automatic investigation to see if autism is also present. Given the prevalence of eating disorders amongst autistic girls this should also be treated as a red flag. Diagnostic tools for anxiety and depression should be developed which have proven reliability for the way these conditions present in autistic girls. Holistic health services need to be developed and commissioned that can support people who are both autistic and have mental health issues.

- Tailored sex and relationship education is needed for autistic girls. In addition, professionals and carers need to be aware that autistic girls are highly vulnerable to sexual abuse and take appropriate safeguarding steps.

- More research – co-produced with autistic people – is needed on a wide range of topics including autism in girls, appropriate support packages, autistic wellbeing, ethnic diversity, aging, menstruation and menopause in autistic people, autism in non-binary children, interaction with doctors and other healthcare professionals and many other matters.

- It is important that the full heterogeneity of autistic people is understood and supported effectively and that misleading stereotypes such as the autistic person as young, white, male, computer nerd are challenged.

- We need to move from a pathological and deficit model to one that respects human diversity and autistic people's strengths and potential. Currently as a society we do not adequately understand what wellbeing and happiness look like for autistic people and it may well be different to what it is for non-autistic people. We need to go beyond fixing problems to actively help autistic people achieve wellbeing and happiness and fulfil their potential as autistic human beings.

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