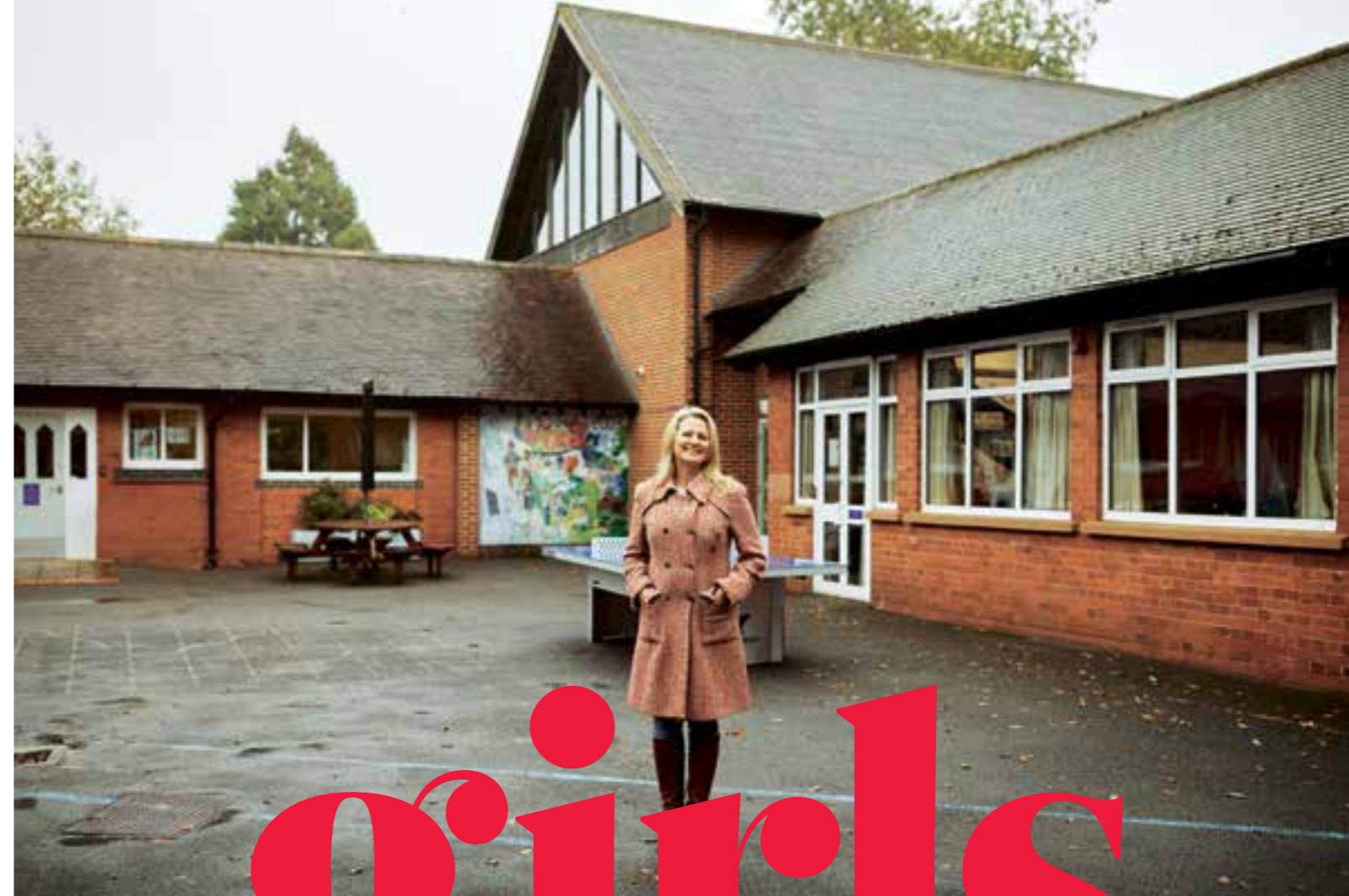




Greta Thunberg calls it her “superpower” — but autism is a male condition, right? Wrong, say researchers, who now believe that as many as a quarter of the people living with this complex disorder — diagnosed or not — may be female. *Sharon Hendry reports*

PHOTOGRAPHY BY JOHN ATTENBOROUGH

Super



girls

CHANGING THE CLIMATE
Top left: the environmental activist Greta Thunberg is proud that having Asperger syndrome makes her “different”

Above: Sarah Wild, head teacher at Limpsfield Grange School in Surrey, the only state boarding school for autistic girls in Europe

Left: Poppy, a student at the school, where many girls arrive from mainstream education feeling alienated and anxious

Right: Sophie, another student at Limpsfield. Staff encourage the girls to work on communication skills and prioritise their wellbeing and independence



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reta Thunberg may be best known for her work as an international eco-activist, but it's not the only issue on which the autistic 17-year-old is shining a much-needed spotlight. "I have Asperger's and that means I'm sometimes a bit different from the norm," she has said of the developmental disorder she describes as her "superpower".

Autism has long been seen as a male condition, but researchers now believe there could be thousands of undiagnosed cases of women and girls living with autism spectrum disorder (ASD) in the UK — overlooked because of how autism is taught in medical schools and perceived by doctors, teachers and society at large. As a result, diagnostic tests have largely been developed with a male population in mind.

"Scientists have often excluded autistic women and girls from research, such as brain imaging, because they expected maybe five or 10 males for every female," says Francesca Happé, professor of cognitive neuroscience at King's College London and a former president of the International Society for Autism Research. "So what we know about autism is largely about males — and part of the problem is that current diagnostic tools have developed largely from male-based research."

She continues: "We know from research that girls are on average diagnosed later than boys and typically have to show more obvious signs of autism to get a diagnosis." The reason for this, Happé suggests, is that the symptoms of autism in girls can be more subtle — with many learning "social camouflage" or "masking" to hide their unease when dealing with people.

While various studies, together with anecdotal evidence, have put the ratio of autistic males to females anywhere from 2:1 to 16:1, the National Autistic Society now believes that a quarter of the estimated 700,000 people living with autism in the UK, diagnosed or undiagnosed, may be female. Yet the society's research shows that only 20% of girls with Asperger syndrome — or so-called "high-functioning" autism — are diagnosed by the age of 11, compared with half of males.

Autism can cause difficulty with communication and social interaction, often accompanied by intense interest in certain subjects. Indeed, Thunberg's reluctance to smile sweetly through her impassioned speeches on climate disaster has led to some derision — with President Trump tweeting: "Greta must work on her



SPREADING THE WORD Female autism was unrecognised when Wild arrived at Limpsfield in 2012. She wants the "neurodiversity" of her pupils to be celebrated by the world at large

Anger management problem... chill Greta, chill!" While Thunberg has harnessed her traits to her advantage, lack of diagnosis can be devastating for others — ruining academic chances and preventing treatment for the crippling anxiety and depression that can accompany the condition. Happé fears for the "lost girls" suffering in silence without a diagnosis.

"I have met numerous women who had such a fight to get diagnosed, and the effect on their personal lives, relationships, work, self-esteem and mental health was phenomenal," she says. "Many are only diagnosed when they develop eating disorders or their mental health collapses. As many as 40% of those with anorexia are

"We've got to stop talking about autism as if it's some kind of disaster movie. Autism can be a really positive thing, with incredible strengths"

thought to be autistic. A diagnosis can prove a huge relief, helping people understand why they have experienced years of isolation and social difficulties."

Charl Davies, a tattoo artist from Blaenavon in Wales, wasn't diagnosed until she was 25. "I always felt growing up that I was different from other children, but it started having a real impact on me when I was about 10. I didn't understand why or how I differed from others, I just *felt* it and realised that being myself in front of other children meant they would think I was weird," says Davies, who is now 27.

"I began to copy and mimic other children in an attempt to fit in and be more accepted," she adds. "I would prepare phrases and topics, imitate eye contact and gestures, and even force facial expressions

like smiling. Nobody wants to be the odd one out and this was the beginning of a lifelong issue that I didn't identify or understand until after my diagnosis. It's called 'masking' and it is exhausting."

Davies says her parents raised questions about her behaviour, "but back then it was unheard of for little girls to be autistic". In many cases, autistic difficulties are often described in childhood and adult transitions as "terrible twos", "teenage tantrums", "prima donna behaviour" or being a "drama queen".

After her father died suddenly when Davies was 10, her autistic traits were passed off as grief.

"For more than a decade, I was in and

out of mental health services for severe depression, but nothing seemed to help. University was hard and I felt as though I had no real friends, no real purpose. At 19, I tried to commit suicide."

Davies was finally diagnosed while starring in an MTV reality series set in a tattoo parlour. She describes having a "complete breakdown" while out for dinner with colleagues after a day's filming.

"I started feeling an immense build-up of pressure and became consumed by my environment and the inability to process anything. I was overwhelmed by sensory overload. I ended up 'stimming' [making repetitive sounds or movements, such as rubbing hands together] and could feel my teeth biting down so hard my jaw was aching. I burst into tears and couldn't

continue anything I was doing. My teeth were chattering from the anxiety. I felt like I couldn't move."

Her employers helped to arrange a psychologist's appointment — and within weeks she was given a life-changing autism diagnosis. "It felt great. I finally had validation and understood why I felt this way. I also learnt that many women who live with undiagnosed autism can lead relatively normal lives and have successful careers, but at some point many will experience some kind of breakdown. All those years, I felt like I was floating through life, just existing, and now I finally feel like a somebody. It felt so good to know I wasn't just going crazy."

Davies believes that society hardwires girls to be better at masking their symptoms than boys. "I find that, being female, I am expected to behave in a certain way to fit in socially. Because of this pressure, females often develop the ability to mask. This could be why we are so often misdiagnosed or undiagnosed."

Within seconds of meeting her longed-for second child, Natasha Harding knew there were going to be challenges ahead. "As a yoga teacher, I'm quite good at popping my children out and Lexi appeared after a swift 51-minute delivery, weighing a healthy 9.2lb," she smiles. "There was just one problem. She was furious and let out a scream that had an intensity I had never heard before. My husband, Paul, looked at me and said half-jokingly, 'We've got trouble here.'"

The couple's instincts proved accurate, but it was another four years — a tumultuous journey that would rock the foundations of their family unit — before Lexi was diagnosed with ASD. Harding, who also has a 13-year-old son, Zak, recalls: "From that first scream onwards, things got harder and harder. She just cried and fussed all the time. I knew it wasn't normal because she was my second child, but at the same time there was nothing obviously wrong medically.

"She needed to be rocked really hard or patted really hard or tucked in really tight to achieve any sense of calm. When I tried to wean her at six months, she wouldn't take a thing. I worked out she didn't like the lumps in the food. Nor could she tolerate bright lights, TV, people — all these things would trigger huge meltdowns.

Lexi's differences became even more apparent when she went to a preschool nursery. By the age of four, she had been excluded from four different placements.

"As a family, we totally retreated into our own world. We felt so isolated, so alone, because Lexi's undiagnosed autism — and therefore high anxiety levels — meant she could be very aggressive. If we tried to socialise her, she was always the one biting, scratching or pushing over other children."

Harding took Lexi, then a two-year-old, to the GP seeking clarity, but was simply



Lauren Mittelmeier's parents fought for two years to secure her a place at the school

told: "Relax, you're telling me about a toddler." She adds: "Looking back, this makes me so angry. Lexi wasn't speaking at this stage, so there were pronounced delays, but this doctor clearly had no knowledge of autism."

Eventually an educational psychologist attending her yoga class suggested Harding pay for Lexi to be observed in her nursery. The resulting report was sent to a paediatrician, who carried out the standard autism diagnostic observation schedule (Ados) test. Even then, the results weren't clear.

"Even though all the classic signs of autism were there, Lexi did not score highly enough for a diagnosis, so the doctor suggested further assessments by a speech and language therapist and occupational therapist," Harding says. "Ados was originally developed with boys and men in mind at a time when the condition was not associated with girls, so diagnoses are often made on the basis of stereotypical 'male presentations' of ASD — things like poor engagement and minimal eye contact. But girls with ASD may use good eye contact and engage well with an adult in a clinic setting. They have more obvious difficulties with interaction with children of the same age. So they are often best assessed by a multidisciplinary approach, including a school observation by a skilled therapist, who can pick up subtle social impairments rather than just relying on approved diagnostic assessments."

Lexi was finally diagnosed just before her fourth birthday. "It was a huge relief for us all, even though we had used up our entire life savings," Harding says. "We had been forced to seek a private diagnosis because of a two-year NHS wait. The diagnosis, which has now been confirmed

by the NHS, has led to her gaining an education, health and care plan [EHCP — a legal document that guarantees support in school], and she has been accepted into a specialist ASD unit attached to a mainstream school."

Harding believes the diagnosis has been life-changing for her daughter. "Going through life feeling at odds with yourself and not knowing why can lead to severe mental health problems. People who say 'Why label?' are speaking from a place of ignorance."

Lexi is now six — but Harding has already researched a unique secondary school for her. Limpsfield Grange is Europe's only state boarding school for autistic girls, nestled in 11 leafy acres in Oxted, Surrey.

Limpsfield's head teacher, Sarah Wild, is passionate about her pupils' "neurodiversity" being celebrated by the mainstream world. "We've got to stop talking about autism as if it's some kind of disaster movie," she says. "Autism can be a really positive thing, with incredible strengths. We have to give autistic people space to be who they need to be, because that's where incredible things happen," she says, pointing to the example of Thunberg, whose single-minded interest in a particular subject and unnervingly direct way of communicating have helped her to become one of the most influential people in the world.

Many of Wild's 86 pupils, aged 11-16, have left mainstream systems feeling broken and misunderstood, but within weeks of arriving at Limpsfield they describe an immense feeling of relief and acceptance. Desperate parents from as far afield as Hong Kong and Nigeria attend open days, hoping to access a model of education woefully underrepresented globally.

A vivacious and dynamic woman who previously taught deaf children in inner London, Wild says female autism wasn't even heard of when she first arrived at Limpsfield in 2012. It was originally set up as a school for girls with "emotional and learning difficulties".

"I'd worked with autistic girls in London who do the incredible masking thing, and about 40% of the girls at the existing Limpsfield provision had autism traits," she says. "So I told the local authority we should change the designation of the school, but my suggestion was met with 'Girls don't have autism'. I replied, 'They absolutely do — and we need to think about how to meet their needs effectively.' There was no training available, so we had to make it up ourselves based on the knowledge of the girls we had."

Wild is determined to spread the word. "Girls and women *are* autistic and it looks quite different from the stereotypes we hold in our mind from movies like *Rain Man* and books like *The Curious Incident of the* ➤

PREVIOUS PAGES AND THESE PAGES: JOHN ATTENBOROUGH FOR THE SUNDAY TIMES MAGAZINE

Dog in the Night-Time. Girls can be much more sociable, empathetic, creative and quite emotionally intelligent — they desperately want to build relationships.”

It’s not only girls who suffer from missed diagnosis, she believes. “There are also a whole load of boys who present in this socially camouflaging way and they get missed in equal numbers. Children from black and minority ethnic groups too — if boys from African or Caribbean backgrounds have a meltdown at school, or display other autistic traits, it’s viewed as challenging behaviour and often people don’t ask what the underlying cause is.”

According to Wild, things usually begin to go awry for girls in the latter years of primary school. “It starts to get really rough at the end of year 4 because the social relationships with their peers change quite considerably. Boys will still be playing football in years 8 or 9 and their friendships are based around activities like sport, where the language is clear and there are rules. Girls’ socialisation is different. They stop playing games and their main way of spending time together involves talking about relationships and other people. At that point, the autistic girl thinks, ‘I don’t understand any of this. I can’t keep up’ — so the relationships start fracturing.

“Year 6 is horrific because by then they feel weird, coupled with the pressure of Sats and the uncertainty of moving [on to secondary school]. It’s the perfect storm.”

The result, she says, can leave them feeling “highly anxious” and “socially isolated” — emotions that translate into “self-harming, school refusal and massive meltdowns at home. They are exhausted trying to replenish their social energy.”

Having an intense interest in a specialist subject can be one way in which autism presents and is diagnosed in boys. Yet Wild believes this is another area in which girls are overlooked. “Their specialist interests are more socially acceptable. With lots of girls I come across, it’s animals or things like manga cartoons. On the surface it looks like a regular interest, but it’s longer lasting and all-consuming.”

Another area of confusion lies in food consumption. “Researchers have found that 40% of women in eating-disorder units meet the threshold for autism. Many girls — and boys — have a restricted food intake and some don’t want to eat at all. It’s not about what you want to look like — sometimes it’s about control as a way of dealing with anxiety, sometimes it’s about liking the numbers and patterns involved in calories. And there can also be a sensory element — some autistic women can feel food moving through their system, which is unpleasant, so it’s easier not to do it.”

While many Limpsfield students pass an impressive range of GCSEs, Wild says the school’s success is down to developing



STAR TURN Merry, one of the 86 students, benefits from a strong sense of acceptance

students’ ability to communicate, prioritise their wellbeing and develop their independence through following the school’s bespoke Wellbeing, Achievement, Communication and Independence (Waci) curriculum. “Anxiety and exhaustion are what hold autistic girls back.”

Lauren Mittelmeier, 15, a pupil from Betchingley, Surrey, agrees. Her parents were involved in a two-year fight to secure their daughter a place that involved moving from Dorset to Surrey and making a video that they sent to the local authority, pleading for help.

Lauren says: “I don’t know what I would have done if I’d been forced into secondary mainstream. I would have cracked. I was

“I was nervous about coming here, but it was such a relief because I’m not the odd one out any more. I don’t feel like I’m the only weird one”

nervous about coming here, but it was such a relief because I’m not the odd one out any more, I don’t feel like I’m the only weird one. Here, they don’t push, they encourage. Academically I’m good, but socially is the hard part. I get anxious easily and can’t keep eye contact for long periods. I have to mentally prepare what I’m going to say before I go up to someone. Sleeping is also really hard for me because my brain goes a mile a minute.”

Outside school, Lauren attends comic book conventions and loves My Little Pony and Steven Universe cartoons.

She says eloquently: “Society puts pressure on people to act a certain way and that’s why masking happens. One of the things people don’t really realise about autism is that it’s a spectrum. Two people

can have autism and one can be extrovert and the other introvert. It’s not one set of characteristics. We need to recognise what part of the spectrum people are on and find out what helps them best.”

Dr Sarah Lister Brook, clinical director of the National Autistic Society, agrees. “It’s a common misunderstanding that autism is a mental health condition. Autistic people are more at risk of developing mental health problems and often experience high levels of anxiety. However, their mental health, as for anyone, can be improved or made better. Autism is a different way of being in the world and therefore is something that is part of a person’s make-up, not something that needs to be made better.

“After years of research, we now know that it arises from a polygene effect — it is likely to be a result of the coming together of multiple genes and there is likely to be as much variation in the genetic profiles of autistic people as there are in the autistic behaviours we see across the spectrum. There is now a huge database mapping all the genes implicated and this continues to grow.”

Meanwhile, Lister Brook says terms such as “high-functioning” and “low-functioning” are being eradicated from the autistic lexicon, as they potentially mislead people into thinking in a binary way about the impact and challenges.

“The term ‘neurodiversity’ is becoming more widely used,” she explains. “After all, we are all unique genetically and this has an impact on our functioning in many different ways. Many of us have issues with social communication and rigid or repetitive behaviour at certain points in our lives.

“The term ‘high-functioning’ is often

used by professionals and parents to help us feel better about autism and rightly focus on strengths. However, people arrive in clinic with supposedly ‘high-functioning’ autism and what we discover is that even though they might be very verbal, their cognitive skills can be very mixed. In some areas they are functioning at a very low level, and their ability to process and manipulate information has been overestimated.”

Seeking diagnosis, she believes, is key to leading a fulfilling life. “Diagnosis can help people to develop a more positive self-identity. Suddenly, you are not just someone with problems — you have a condition you can have help with.” Or as Thunberg puts it: “Given the right circumstances, being different is a superpower.” ■