

Talk is central to all that goes on at Limpsfield Grange School. Here headteacher Sarah Wild holds a discussion with a group of students

The tipsy-turvy, wobbly world of female autism

Limpsfield Grange School is a special school for girls with communication and interaction difficulties and autism. Headteacher Sarah Wild shares their experiences with **Alison Thomas** and offers advice for mainstream teachers

'M. That's what I'd like you to call me please. M. I'll tell you why later.

'In fact, I'll be telling you lots about me and my tipsy-turvy, wobbly world. My beautiful, terrifying, difficult, anxious life. I mean, I'm just like any other teenage girl. I want to fit in, have friends and wear nice clothes. I want to be liked and I have ambitions, plans and hopes. I go to school and live with my mad family, but the difference is I deal with so many more shapes, sizes, noises, colours, textures and anxieties than you may ever know.'

M is for Autism

This is the introduction to a novel written by creative writing tutor Vicky Martin in collaboration with the students of Limpsfield Grange School, a Surrey County Council secondary school for girls with communication, interaction difficulties and autism. Ms Martin composed the text, but the words belong to the girls themselves – all 72 of them, the entire cohort of the school.

The first in a series, *M* is for Autism has sold worldwide and been translated into Danish and Spanish since its publication in 2015. *M* in the Middle came out a year

later and was longlisted for a children's literature award. The third title – as yet unnamed – is currently being developed and more will be created as new cohorts move through the school.

I deal with so many more shapes, sizes, noises, colours, textures and anxieties than you may ever know

It was a former student, Beth Warbouys, who first had the idea of capturing the female experience of autism in a novel. 'I went to the Autism Show in London in 2014 and, as I usually do, took some of the students with me,' says headteacher Sarah Wild. 'As she looked round the exhibition and saw how boy flavoured most of the literature was, Beth became quite cross and suggested we write a book of our own. When I replied that we might need to find someone who would help us to pay for it

first, she set off for the National Autistic Society stall and returned with the news that she had persuaded Robert Pritchett, NAS director of Autism Accreditation, to sponsor us.'

A collaborative venture

'If you've met one person with autism, you've met one person with autism' is a well-known truism, so it might seem an impossible task to capture 72 very different voices and combine them into a single character. Not so, according to Sarah Wild.

'It's the girls' interpretation of how M would behave in certain situations,' she says. 'They try to think: "What would M do here?" and their personal experiences feed into that.'

The girls settled on M as the name the central character would give herself because, as the middle letter of the alphabet, it is hemmed in by all the other letters, as well as being a name in its own right. 'They liked it because they felt it was squashed and pushed and constrained by all the things around it,' says Ms Wild, 'just as they are in the challenges they face every day.'

The novel evolves through a series of workshops, where Vicky Martin works with different groups of girls from across the school to explore their experiences through drama improvisations. 'They get an idea for a theme, like a visit to the cinema or going on a date, and act it out,' Ms Wild explains. 'The first group starts it off, then the second group works on what the first group has done, which is further developed by the third group, and so on, until a chapter begins to take shape. Ms Martin takes this away and writes it up, consulting the girls on her return to see if she has accurately captured how M would behave in the given situation and the language she would use. Sometimes the answer will be yes, while other parts will need to be revised. So the text goes back and forth quite a lot before the final version is agreed.'

Difference and loneliness

The books cover a host of issues that affect the students' lives, from identity, acceptance, and navigating the challenges of being a teenager, to making sense of social conventions and – the big one – anxiety. 'Anxiety is absolutely massive,' says Ms Wild.

But in what ways do girls on the spectrum differ from boys?

'I think the main difference is that they are really motivated by relationships and friendships,' she replies. 'They are very mindful of what other people think about them, and they care. It's not that boys don't want friends too, but in my

experience they seem less active in trying to find them, whereas girls start reaching out at an early age, trying to connect with people at school. But they don't understand how to start a friendship, how to build it, repair it and sustain it. When it doesn't work out, they start observing how their peers behave in social situations and try to replicate that, suppressing their natural instincts to effectively construct their social selves.'

The letter M is squashed, pushed and constrained by all the things around it, just as the girls are in their daily lives

Because it's not quite authentic, however, it still doesn't work out, and the girls end up being even more aware that they are different and feeling very isolated and alone. At the same time, the effort of double-thinking their every move, while simultaneously watching and analysing other people's reactions to them, leaves them mentally and emotionally drained.

'By the time they go home, having tried to please everyone and hold it together all day, they are done,' she says. 'That's when meltdowns or shutdowns occur because they have used up absolutely everything just getting through the day.'

Supporting autistic girls in mainstream

The girls at Limpsfield Grange benefit from being in an all-female environment where they no longer stand out from the crowd and can focus on exploring their true identity, learning to understand and manage their challenges, build on their strengths, and become comfortable with who they are. In this they are supported by highly trained staff, who give them lots of opportunities to talk through their issues, while the fact that their peers face some of the same challenges as they do leads to the development of some exceptional friendships which can last into adulthood.

That is very different from the typical experience of girls with autism in mainstream. So what can schools do to support them?

Building relationships is key, according to Ms Wild. 'They have got to have a really good relationship with a couple of people they trust, and that they feel OK to talk to about who they really are,' she says. 'I think that schools need to make a regular space for that, probably every day.

'I think they also need to talk to the young person about how they would like to be supported, because these girls are trying really hard to blend in. If you put in a whole lot of support, that can make them stand out even more, and they may not like it particularly.'

A daily check-in

Anxiety is ever present in the girls' lives and often makes it impossible for them



Concrete language and visual resources support the girls to explore their emotions and develop strategies to manage them



The school has several animals, which the girls help to look after. Working with an alpaca has a calming effect and can help people on the autistic spectrum in their social development

to function. One of the ways Limpsfield Grange School tries to address this is by having students check in with a member of staff at the start of the day to anticipate changes and challenges that might lie ahead, and again when lessons are over to review how things have gone. It's an approach Ms Wild believes could be replicated in a mainstream setting.

'If you do it every day, it will really help them,' she says. 'As the day goes by, all sorts of misconceptions are bound to arise, and this gives them the security of knowing that there is a place where they can take their anxiety and essentially fix it.'

She recommends restricting the scope of these conversations, however, not only because lengthy sessions would be unsustainable, but because they would actually be less productive.

Give it a rigid structure and set a strict time limit,' she advises, 'using visual reminders like sand timers or a smartphone app to make sure that you stick to it. We have 15-minute checkins here – five minutes to identify the problem, five to sort it out and five to move on positively - but even 10 minutes can make a big difference. If you let it run on too long, there is a danger that a student who doesn't have great relationships with their peers will take advantage of the opportunity to monopolise adult time, or they can start catastrophising. So you focus on the things that really need to be sorted out right now rather than trying to fix it all.'

Social and emotional difficulties

When girls are trying to interact socially, but don't understand how to communicate in the same way that

other people do, or how to read other people's intent, it makes them very vulnerable. To help them overcome this, Ms Wild recommends giving them lots of opportunities to talk about social situations, using a 'wondering out loud' sort of approach to deconstructing these, so they can understand how people have arrived at a given conclusion or why they behaved in the way they did.

They are so overwhelmed by anxiety that their language deserts them

She also points to the need to do some work around emotions, using concrete language to label how the girls are feeling and identifying what their triggers are for their peaks of anxiety.

'Quite often, they won't know how they are feeling, they will just know that things are getting out of hand,' she explains. 'So it's about helping them to work out what makes them anxious, how that feels physically and putting in some strategies so they can manage it before it takes them over.'

Language suitcases

Staff across Limpsfield Grange School use a common set of phrases to describe emotions and scaffold communication. The same terms reappear in language suitcases, designed to help the girls cope with their emotions during points of crisis.

'A lot of the girls find it quite hard to

self-regulate, especially when they are younger, as they have often had a very difficult time at primary school,' says Ms Wild. 'As a result, there are quite frequent meltdowns or shutdowns in school. The language suitcase is something we put together to support them when they become so upset, cross or shut down that they can't access any language, or they are so overwhelmed by anxiety that their language deserts them.'

The suitcases are a simple way for students to communicate to staff what it is they need to do. 'I need 10 minutes. I'm going to use something from the calm box to help me come down a bit.' 'I need to go for a walk', 'I need to go and see the goats' or 'I just need to sit here.' The next step is: 'I'll talk to an adult' or 'I'll write it down' or 'I'll deal with it myself.' And finally: 'I need another 10 minutes because I'm not ready' or 'I'm ready to go back and do some



Autism and girls

learning now' or 'I'm ready to go back and repair the situation'.

'When it all goes wrong, the girls get really worried about the fact it has gone wrong, and they don't know how to fix it,' says $\overline{\text{Ms}}$ Wild. "This provides a structure to take them through the steps that will lead to resolution.

Dealing with issues in real time

Dealing with problems in real time is another thing she believes is very important. She recognises that this can make delivering a lesson quite tricky, but the girls' levels of anxiety are so high, so utterly debilitating, anything that is upsetting them has to be dealt with then and there. 'If you try and save it for later, all they can think about is what has gone wrong, which makes them even more anxious, so absolutely nothing is going in. They can't learn anything at that point because they are consumed with worry,' she explains.

This is where a well-trained, experienced TA can prove invaluable. 'We are quite practised at it, so it's something we can just slip in,' she goes on. 'The TA will sidle up and quietly deconstruct the little incident that has just happened and help the student resolve it. The emphasis here is on: "We have got to get this sorted out because we are here to learn. At work, you can't let something destroy your whole morning. These are real life skills that you have got to develop.'

Advocacy

As the headteacher of a unique provision, Ms Wild is invited to lots of conferences to talk about female autism. She always tries to take some students with her to these events to represent their own experience.

'It's vital that people hear how different an autistic experience is from one person to another,' she explains, 'and also that they understand what that experience feels like from the individual's point of view. The girls speak very articulately and reflectively about what it is like to be them, and how they feel about autism in society. It is immensely powerful and quite often reduces people to tears.

For the girls themselves, these opportunities bring home to them that they have a voice and that people will listen. 'They have been marginalised all of their lives and probably will be once they have left us,' says Ms Wild. 'So it's really important that they understand that their experience counts and that they are building a picture of social understanding of autism in its widest sense. It is also a valuable skill for them to develop, because

Anxiety

'I looked up anxiety in the dictionary' writes M in M is for Autism, 'and this is what it says

Anxiety [noun]

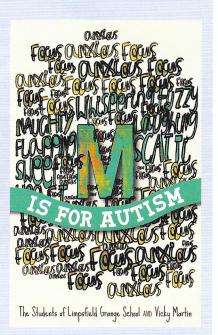
1. A feeling of worry, or nervousness, or unease about something with an uncertain outcome: "She felt a surge of anxiety".

But this is what I say.

Anxiety [noun]

1. An uncontrollable, wild, savage beast that prowls beside me taking me hostage at its will. Can make frenzied attacks which strangle the life out of me. Stops me walking, talking, or seeing or hearing. It shakes my brain, my inner core and rattles my nerves. Inflicts terror, causes chaos and prevents a normal existence.

'So I hope you can see it's not possible for me to just pull myself together, as I haven't worked out how to control this force, this frenzied, cruel beast. Sorry to interrupt you with anxiety but it interrupts me all day long...



Girls are very mindful of what other people think about them, and they care

their lives are going to be hard and they are going to need to self-advocate all the time. This is a way of giving them confidence and practice to do that.'

The importance of talk

The work that goes into developing the girls' powers of reflection and selfexpression is an ongoing process that is embedded in the very life of the school. We talk here all the time,' she says. 'Right from the day they first come to us, we are talking to them about themselves, about their autism, about society, about getting a job, about their future... everything. So we don't really do anything special for the conferences. In fact, for the last conference I went to, I didn't even know what they were going to say because they wouldn't tell me.

'They are incredibly self-aware by the time they leave us,' she adds. 'They are also hugely supportive of each other, and very conscious of each other's needs. That's something else we talk about constantly, because they have got to understand that the needs of other people are different, as well as being similar to their own.'

Transitioning to adulthood

Meanwhile, the original inspiration for the creation of the M series has lost none of the persuasive powers that convinced Robert Pritchett to sponsor the project. Now training as veterinary nurse and doing extremely well, Beth was in school just a few weeks ago supporting Vicky Martin with Year 7 on the third title. She also accompanied Ms Martin to the Spanish launch of M is for Autism last year and spoke at the NAS conference in Harrogate with Ms Wild in March this year.

'Beth has been involved in the series all the way through and is a very big advocate for the school,' says Ms Wild. 'For our current students, she is an invaluable asset as she can talk about the next step, transitioning into adulthood. She doesn't gloss over the difficulties and tells it like it is. Her experience is really powerful and she is a terrific role model.

All quotes from M is for Autism are printed with permission from Jessica Kingsley Publishers

FIND OUT MORE

- M is for Autism and M in the Middle:
- http://bit.ly/sc237-26 and http://bit.ly/sc237-27
- Learn more about autism and life at Limpsfield Grange School: www.limpsfieldgrange.co.uk
- Listen to Sarah Wild talk about her work: http://bit.ly/sc237-28

Teenage girls and autism

Julie Taylor of Surrey ASC Secondary Outreach Service reflects on the complexities of female autism and offers practical tips for parents and mainstream teachers

Statistics show that more men and boys than women and girls have a diagnosis of autism. Various studies, together with anecdotal evidence, have come up with men/ women ratios ranging from 2:1 to 16:1. National Autistic Society (NAS), March 2017.

'It's important to point out that every person on the autism spectrum is different,' notes Carol Povey, director of the NAS Centre of Autism. 'But, as a rule, girls are often better at developing ways to mask what we traditionally think of as the signs of autism, which can make it harder to diagnose. This "masking" can lead to a great deal of stress, and many women and girls go on to develop secondary problems such as anxiety, eating disorders or depression.'

The same point is made by Sarah Wild of Limpsfield Grange School on the preceding pages. Now, however, recent research sheds new light on the little-understood complexities of autism in girls and women.

According to a study led by William Mandy of University College London, while boys display stable, similar autistic characteristics throughout adolescence, girls are more likely to see characteristics ramp up during the teen and pre-teen years. While surprised by these findings, Dr Mandy believes they could explain why boys are diagnosed with autism earlier than girls and how guidelines for diagnosing autism in children could be biased against girls.

It remains unclear, however, whether the sudden increase in the severity of girls' autistic traits is caused by the social pressures of adolescence or stems from biological difference. Clearly, much more research needs to be done.

Supporting girls with ASC through puberty

My initial advice to families and schools is that any communication regarding puberty needs to be open, frank and unambiguous. ASC students are unlikely to be able to share information or concerns with their peers, so the onus is on us to address their

'Autism is more diverse than originally thought, with new ideas being put forward every day. In fact, it's a case of "the more we know, the less we know", particularly in how gender affects individuals with autism.'

Dr Judith Gould, Consultant Clinical Psychologist and Director, The Lorna Wing Centre for Autism

misconceptions and help them make sense of this period of transition.

Some students find the changes that are happening to their bodies very difficult to cope with and menstruation adds to this dilemma. Using a calendar and visual reminders about changing pads can help with this – plan and prepare is the key.

What's Happening to Ellie? and Things Ellie Likes by Kate Reynolds could be a useful read here. (http://bit.ly/sc237-29).

Sex and relationships

Make the implicit explicit when it comes to sex and relationships — students with ASC find non-verbal cues/communication difficult to read or to even to be aware of. There is also a lot of misunderstanding and misinterpretation of teenage social rules and these may need to be spelled out, with the help of scenarios or even stick figures with speech balloons.

Consent is also an issue – we find that girls at Limpsfield Grange will give their consent (even when they do not want to do something) because they believe that this is what neurotypical teenagers do.

- 'I thought to get a boyfriend you had to agree to have sex with them and so I told the first boyfriend I had that I knew about this and would have sex.'
- 'I wish I had learned to keep myself safe and what is meant if someone asks you to go for a walk and then they want to touch you – I did not understand.'

Make contextualised rules of conduct and reinforce these visually. You

can use a five-point scale to indicate things that are 'OK' and things that are 'not OK', or things that make the girl feel 'uncomfortable' and those that don't.

Preparing for the future

Families and schools need to be one step ahead, so that they can help to prepare teenagers for that 'next step'. Be ready to set the boundaries and social 'rules' for each context and then provide visual reminders, such as laminated cards.

Introducing girls to some of the literature by women on the spectrum may help them to avoid potential pitfalls as they approach adulthood.

- Two books we find useful at Limpsfield Grange are Women and Girls with Autism Spectrum Disorder: Understanding Life Experiences from Early Childhood to Old Age by Sarah Hendrickx and Aspergirls: Empowering Females with Asperger Syndrome by Rudy Simone (http://bit.ly/sc237-30 and http://bit.ly/sc237-31).
- We also use Robyn Steward for staff training, while her website offers detailed advice about life as an adult with Asperger syndrome, which students may be able to relate to: www.robynsteward.com
- Other valuable tools include:
 - The NAS web pages on sex education: http://bit.ly/sc237-32
 - The Australian Raising Children website http://bit.ly/sc237-33

See also Supporting pupils with autism through sex and relationships education, Special Children 230

The four challenges

In her article on pages 19-22, Sarah Wild highlights the importance of supporting students to recognise and understand their difficulties and develop strategies for managing them. Girls at Limpsfield Grange School are also encouraged to share

their experiences of autism with the wider world, not only to raise public awareness, but because 'their lives are going to be hard and they are going to need to self-advocate all the time.'

Psychologist and autism specialist Bill Nason makes the same point on LinkedIn (http://bit.ly/sc237-34), and identifies four challenges that most people on the spectrum share and need to address throughout their teenage years and into adulthood.

I have condensed and adapted some of his suggestions to create the following table.

Empowering teenagers with ASC to understand the four challenges

Sensory processing challenges

Light, noise, touch, taste, smell. Sensory overload is the primary reason for rising anxiety and a panic 'fight or flight' response. You cannot filter out or tone down these stimuli.

What you can do about it

Understand your sensitivities and how to avoid sensory overload or modify it. Appraise the school environment and know how much you can handle before needing a break. Use moulded earplugs if noise sensitive. Create a colour-coded timetable to show where sensitivities may erupt and interfere with learning.

As an adult you will...

...know what to disclose and ask for in terms of making modifications to your work environment. Your home will need to be a safe haven, a sensory-friendly escape to recharge.

Executive functioning challenges

You will have a hard time organising yourself to get things done: you may forget to do things or where you put things, have difficulty judging how much time you will take to do things, have problems doing several jobs at once and struggle with transitioning from one job to another. You will struggle to meet deadlines, to plan things and then organise what is needed. This is all due to weak neurological connections in the frontal lobes of the brain.

What you can do about it

Use lists, calendars and written instructions. Keep routines for everyday activities – 'To Do' lists. Use smartphones, iPads and wristwatch alarms to help keep track of time. Colour code files and information so that you can categorise and retrieve information when you need it. Preview and prepare for non-routine events – develop a script, social story or map to show how to do it. Have an exit plan if it does become overwhelming for you.

As an adult you will...

...have a few supportive people around you to help out. Tell people at work about your challenges and get help with timing and making plans.

Bill Nason shares these and many other insightful observations and strategies in his book *The Autism Discussion Page on Anxiety, Behavior, School and Parenting Strategies*. http://bit.ly/sc237-35



Information processing challenges

The world moves too fast and this creates too much information for you to process. Neurotypical people can filter out and process much of this information subconsciously but you find this difficult. You have to process information received simultaneously and consciously, which quickly drains your mental energy.

What you can do about it

Be conscious of how much mental energy you have. Learn what to avoid and when to ask for help. Eat a good diet, sleep well and exercise daily. Develop interests and hobbies to help you to relax. Don't wait until you feel yourself melting down – slow it down, tone it down and give yourself breaks. Realise that you will get things done, but it just might take you a bit longer. Use visual strategies to make sense of information and help you organise and learn it. Request extra time in exams if exam concessions apply.

As an adult you will...

...appraise things in your life to assess how draining they will be. You may need to take a break to recharge – a brisk walk or going to get a drink of water. Be honest with people about how much you can effectively handle. You may not be able to multitask but will need to be given the information sequentially and visually. Tell your colleagues to use clear language when explaining tasks to you, or get written instructions.

Social and communication challenges

You have a hard time reading social cues and reading the thoughts, feelings and emotions, perspectives and intentions of others. This can make you quite vulnerable, as you may not see the real motives behind people's actions. You are pragmatic, intellectual and factual. You may be good at interacting with one person at a time but may struggle in a group. You may find it difficult to keep up with non-verbal information, reading between the lines and understanding the many different invisible social cues and rules.

What you can do about it

You love and care for others in your own way and can be a committed friend and partner. You will be there and do things for others in a practical way, but may struggle at supporting people emotionally. Once you trust someone, you can be upfront about your strengths and weaknesses. They will have to spell out their thoughts and feelings to you, and you will both clarify and verify information with each other to stop any misunderstandings or upset.

As an adult you will...

...have to be upfront with your boss and co-workers. They need to know that although you may seem rude or overbearing, you don't mean to be. You may not realise that it is hurting their feelings. You may need key figures in your life to tell you when you are stepping out of line and what you need to do about it. These people need to be able to tell you to stop quickly, saying not only what you are doing wrong, but what you need to do to put it right. They can help you to interpret the many different invisible social rules.

Tips for mainstream teachers

Anxiety and behaviour

It is important to understand the student's behaviour. Outbursts and impulsive behaviours that can appear to be manipulative or intentionally rude are more likely to stem from heightened anxiety or lack of social understanding and awareness.

- Provide a visual timetable of the day, where students cross off each event as it occurs. This is also good for introducing unexpected changes that may take place. Highlight these so that the student can anticipate them without becoming upset.
- Apply consistent written rules. When the student breaks a rule, remind them to look at the list, rather than telling them what to do. By referring back to the rules, the direction seems less personal, as though the rules sheet is saying what to do, not the person.
- Prepare the student before they enter new situations. This might require having someone scout the situation ahead of time to anticipate possible problems and then write out rules that the student can keep with them when they enter that situation.
- If a student needs to communicate with you when they are upset, get them to write you a note or use a computer, as their ability to communicate verbally is reduced when they are anxious.
- In times of meltdown, give them a written note to go to a predetermined quiet area of the school. Don't speak to them at this point, as that is likely to escalate the situation. If more directions are needed, write them down. At first the student may crumple up the paper, but usually if you leave the paper by them and walk away, they will eventually read it.

${\it Classwork\ and\ homework}$

- Use visual symbols and cues to reinforce learning and attention.
- Present tasks in a way that visually highlights and organises important information. For example, highlight instructions for a test or sections of a book, or add a written reminder about the type of information to look for.



Students will need support to help them cope with less structured social situations

- Give the student explicit written instructions before they start an activity. What am I expected to do? How much am I expected to do? How will I know when I have finished? What will I do next? This will support them to be more successful and independent in completing activities. It will also decrease any anxiety they feel when they are unsure and unable to ask for clarification.
- Adapt worksheets to make them more accessible. For example, the class might have a homework assignment of 20 problems, presented on a single page. The student with ASC is more likely to be successful if these are spread over four pages. Accompany each problem with a large numbered box that corresponds to the number of the problem, so they can clearly see where the answer belongs. When all the boxes are filled in, they know they have finished that page.
- Supply more information for homework assignments than other students usually require, and a checklist of the materials that will be needed.

Organisation

- Provide checklists. These are particularly helpful when students have to complete a short series of related activities or when they need to organise a group of materials.
- Encourage them to use notebooks and planners to organise their work and materials.
- Encourage them to use proformas and flow charts to organise their thoughts, opinions and learning and

to present their answers in a logical, structured way.

Effective TA deployment

TAs should not serve as a shadow that steps in and helps whenever a problem arises. Instead, they can develop and implement the structures (e.g. schedules, modifying assignments, checklists) that will help to increase the student's independence, and ensure that these structures are implemented. They can also serve a very useful role by writing notes or jotting down key vocabulary from the teacher's verbal presentation.

For more advice on TA deployment see TA deployment in a primary setting and TAs who add value, Special Children 226.

Support for social situations

- Assign a peer or mentor to support the student in less structured social situations; this person also serves as a role model in behaviour.
- Support the student to participate in extracurricular activities related to their strengths and interests.

Some students will benefit from one-toone time using ASC-friendly strategies to help improve their understanding of social situations and give them specific behaviours to use when they are interacting with others. Useful strategies include:

- social stories (see Social stories for children with autism, Special Children 228)
- role play
- concrete problem solving, such as making a list of who to talk to when someone teases them, or helping them to write and check their own schedules
- creating scripts to help them learn what to say in a variety of situations.

Occasionally there are more emotional issues that need to be addressed, but every attempt should be made to relate these to concrete information that can be understood, and to keep these discussions from being too open ended. In some cases, communication may be more successful if the student and adult write back and forth to each other.