

Time for a rethink

We need to reassess what we know about autism and start again with a female perspective, says Sophie Walker

Ever heard the one about the man who wouldn't ask for directions, or the woman who couldn't read a map?

Society is full of jokes about the ways in which men and women are different. Many of them are nonsense, but most of them are based on an acceptance that men and women's brains work in different ways.

We know this because biologists and researchers tell us this. Studies have shown that women and men's brains are wired differently. Scientists have created tests to show that women score better at languages and men score better at spatial reasoning; that women can multitask and men prefer single subject learning.

**MEN AND
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These results are, of course, open to interpretation and conjecture. The conversation about the differences between men and women is an ongoing and very busy one. But one thing that everyone accepts is that the sexes think differently.

Why, then, do we assume that men and women with autism will think, and thus behave, in exactly the same ways?

The National Autistic Society, the UK's leading charity for people with autism and their

families, defines autism as a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.

Ask the person on the street to define autism and nine times out of ten the answer is likely to come back: 'Rainman'.

That Dustin Hoffman's character brought autism to a worldwide audience and shone a light on a diagnosis that many had previously never heard of is to be applauded. That it is still, nearly 30 years after the film's release, the benchmark for autistic behaviour, is a problem.

There are no women with autism in *Rainman*. But there are many women with autism in the real world, and their needs are going unmet because we are all still working to a male template, according to Liz Pellicano, a developmental cognitive scientist at University College London.

'Difficulties in detecting autism in girls by professionals (and parents) are unsurprising given that there has been so little research on gender differences,' she says. 'All of the research thus far has been conducted on girls versus boys who have already been diagnosed with autism under a biased male-centric diagnostic system.'

As a result, 'GPs don't really believe, even now, that girls can be autistic,' says Sarah Wild, Headteacher at Limpsfield Grange, a school for girls with autism. 'We have heard stories of doctors telling women on the spectrum that they can't be autistic because they can make conversation and have relatively good eye

contact. We need to unlearn what we think we know about autism and start again, this time with a girl bias.'

Disguising the difficulties

The ways in which women with autism differ from men with autism vary widely. After all, it is a spectrum condition, neatly summed up by a well-known saying in the community: 'When you've met one person with autism, you've met one person with autism.'

But talk to a room of parents of girls with autism and patterns very quickly start to emerge. One of the most common is that many girls with autism, unlike

the boys, will try to hide their difficulties in understanding the social conventions around them and will attempt to blend in, bowing to the expectation that girls behave more sociably than boys.

The stress and overload that this causes them often results in major meltdowns once they get home.

'My daughter hates getting up for school in the mornings because she can't bear the prospect of the day ahead of her. When she gets home in the afternoon she is pale from the strain of the noise and the faces and trying to follow the lessons and understand the jokes, while feeling permanently on the outside,'

NASEN'S NEW WORKING GROUP

Nasen believes that the needs of girls who may have an autism spectrum condition should be a priority. The association has set up a new working group, to be developed into a national forum, in order to promote awareness and increased support within schools and settings. It aims to:

- ▶ recognise and appreciate the unique identity of girls and women with autism and the positive contribution they make to society
- ▶ challenge the inequity of diagnostic experience and process which currently does not fully acknowledge the needs of girls and women
- ▶ positively change and influence perceptions and attitudes about girls and women with autism
- ▶ promote equal consideration of girls and women who have, or may not yet have, a diagnosis of autism
- ▶ provide pragmatic and practical information for schools, settings and colleges to better inform their response to providing appropriate support.

The working group will meet quarterly and invite attendance and contributions from ministers and top government officials leading on emotional well-being and mental health issues affecting pupils in schools, settings and colleges.

Jane Friswell, Chief Executive of nasen, comments 'Nasen is committed to galvanising the education sector to continue to raise awareness of the work of this group and to advocating for girls and women with autism spectrum conditions for improved services and support in both identifying their needs early and providing appropriate intervention to promote well-being, strengthen resilience and achieve independence in learning and life.'

Should you have a specific interest in the work of this group, contact nasen's Education Development Officer Alison Wilcox at AlisonW@nasen.org.uk.

WE ARE ALL STILL WORKING TO A MALE TEMPLATE

says one parent. 'She will often burst into tears as soon as she comes in the front door, or fly into an uncontrollable rage.'

Given these responses it does not come as a surprise, then, to hear from parents that many of their daughters have anxiety-related mental health illnesses. However, as these effects are often so closely linked to autism in girls, they may offer a way in for doctors seeking diagnosis guidelines.

'As autism is a medical diagnosis, the starting point needs to be to stress the importance of clinicians considering the possibility of autism being an underlying cause of, for example, anxiety, depression, self-harm, eating disorders and the like in girls and women,' says Rona Tutt, special educational needs lead for the National Association of Head Teachers.

The act of raising awareness is often cited as an essential part of improving understanding and thus improving support for women and girls on the spectrum. But what does 'raising awareness' in this context actually mean?

'Raising awareness is an important next step. But it is difficult to do so without knowing precisely what we need to raise awareness of,' says Liz Pellicano. 'We need much more research on girls and women across their lifespan, including their early behavioural features, their social experiences, their developmental trajectories,

their mental health and well-being, their engagement with education and healthcare services and the like, relative to boys and men. All of this is especially important for determining whether we need to develop specific ways of identifying and supporting girls and women on the spectrum.'

Joined-up services

It is also vital to have buy-in from health, social care and educational establishments from the NHS to children and young adult mental health services, social services and schools.

'There is a need to link closely with health professionals who are in a position to educate their colleagues in improving diagnosis,' says Rona Tutt.

Barry Carpenter, chair of a new working party to promote awareness about girls and women with autism, adds, 'The British Psychological Society and the Royal College of Psychiatrists are key institutions to co-opt if we want to improve the situation and give girls with autism spectrum conditions better education and better emotional support for their mental health.'

In the end, the benefit is not just for the girls, points out Carrie Grant, mother to three daughters on the spectrum. More girls with autism being able to live independently and take up employment and lead more fulfilling lives would reduce the nation's benefits bill and increase the happiness of all concerned. But a more profound result than that, Carrie points out, is the fact that societies flourish when they embrace those who think differently: 'High functioning girls with autism have a lot to offer. They are assets, not burdens. When they are fully understood, they can fly.'

Sophie Walker is a journalist and has a teenage daughter who has Asperger syndrome.

The go-to website for SEND!



The SEND Gateway's reputation is growing as *the* online SEND resource for all education professionals

The first year in the life of any website is a time of trial and development and after a demanding year that has seen the implementation of the SEND Code of Practice: 0–25 years, the SEND Gateway is going from strength to strength.

The SEND Gateway is an online platform promoting high-quality resources, events and news to dedicated special educational needs professionals, and is fast becoming the go-to website for SEND.

Developed by nasen, the SEND Gateway provides an opportunity for the education workforce to develop new skills and understanding, navigate recent and upcoming reforms to SEND and access resources and training materials from the UK's leading education resource providers.

In May, Nasen Live 2015 marked the first birthday of the SEND Gateway at a time when schools across England had been getting to grips with local offers, education, health and care plans and changes to SEN funding. The Gateway was originally designed to support the education workforce in their implementation of the SEND Code of Practice and at the launch it included resources that specifically fulfilled that aim. Today, the Gateway provides access to a wide range of resources supporting a spectrum of needs. In its first year, the site has had over 80,000 visitors and achieved a massive 326,773 page views – and it is growing!

New resource providers are required, meeting the

same high-quality standards of existing voluntary and community sector providers, to ensure that the standard of resources available from the Gateway is maintained.

One of the many great features of the SEND Gateway is the ability for registered visitors to provide feedback on resources used. Over the past year we have listened to feedback from both visitors and resource providers to improve the functionality and content of the website. New features developed as a result of this feedback include the ability to save searches each time you visit the Gateway, a new A–Z of publishers and the option to search for resources by price.

An aspect of development of the Gateway that we are really excited about is an effective practice area. Over the next 12 months a whole section of the website will be dedicated to providing support for effective practice in schools and other education settings and will include downloadable tools, videos, webinars and a link to online training.

To get the most from the SEND Gateway log on to www.sendgateway.org.uk and register to receive the latest updates on SEN resources, events and news and for the chance to provide feedback on resources, or just visit the website to see what's available and accessible for all school staff.

If you have a resource that you would like to share on the SEND Gateway email webadmin@nasen.org.uk or call 01827 311500.