

# Girls and Autism: Educational, Family and Personal Perspectives

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*Book review by Dr David Dossetor, Child Psychiatrist,  
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*The failure to recognise autism in girls has been a significant professional discourse, so I was attracted to this new book on the subject by well-known British authors. It provides a powerful overview with both scientific evidence along with accounts of personal experience. It is primarily targeted at appreciating the challenge in the UK educational system, and provides a strong advocacy for teachers and clinicians to sharpen their awareness of the differences in presentation of autism in girls. They often present with other problems and it takes a discerning clinician/teacher to pick up the autistic deficits behind these problems. I have tried to capture the main themes of the book- Dr David Dossetor*

**“For people with autism, trying to understand the rest of us is like travelling to a foreign country, which allows you access but not acceptance. For women and girls with autism it is more like sneaking in under cover of darkness, wearing a disguise, hoping no one will blow your cover.”** Autism has a male stereotype, shored up by Simon Baron Cohen's theory of an extreme male brain with systematising male brains vs empathising female brains, related to prenatal testosterone levels. Many females with autism mimic neurotypical behaviour, adopting social stereotypes of being quiet and biddable, creating an unbearable strain for themselves, often later being diagnosed with various mental illnesses, while their autism remains undiagnosed. The book aims to break the barriers to these stereotypes.

**A forum in 2016 provided a booklet ‘flying under the radar’ ([www.nasen.org.uk](http://www.nasen.org.uk)) to increase awareness.** Baroness Sheila Holland put girls with autism within the wider issue of the protection of minors and vulnerable adults to both on-line and off-line abuse (Child Dignity Alliance 2018). She hosted a forum in the House of Lords which enabled people to speak out, illustrating the struggles in school, problems of sensory overload, the unfathomable dynamics of friendships, feelings of isolation and the **anxiety of the fast paced classroom. This led to ‘the big shout 2016 conference’ and a call to action.**

It is the quality, intensity and co-occurrence of the behavioural-cognitive features that lead to a diagnosis of autism. However, the sex differential may not be 1:10 or 1:4 as has been reported in the past but nearer 1:2. In a

2012 study, 41% of girls with autism had experienced misdiagnosis compared to 30% males. They also experienced late diagnosis whereby only 8% were diagnosed by 5 years versus 25% of boys, rising to 20% vs 50% by the **age of 12. Many aren't diagnosed till their 20s and 30s.** Whereas boys with autism tend to externalise their stress, girls are more likely to have emotional disorders such as anxiety, self-harm, depression, personality problems, eating disorders and school refusal. These girls need early diagnosis, individualised needs assessment, and personalised interventions for education, social skills and relationships. Without scaffolding they are at risk of a lack of diagnosis, unemployment, lack of social contacts and dependency on their parents.

The book is presented in five parts; I the scientific evidence. II the lived experience. III education. IV adolescence and identity in relation to sex, gender, friendships and mental health. V looking to adulthood and the future.

**Chapter 2 Francesca Happe:** Although autism was always there, the awareness of autism has grown since **Kanner's description in 1940s, with increased recognition in those with high IQ, and a widening of diagnostic criteria with aspergers syndrome in the 90s.** It was thought if it occurred in girls, it was a more severe presentation.

There is evidence of a female protective effect. For example, looking for ASD in the siblings of ASD subjects, brothers are more likely to be affected than sisters. However, active surveillance with screening instruments finds a higher proportion of girls, compared to clinical cohort studies. As a consequence, females are under-represented or excluded in much research. Diagnostic overshadowing is where one diagnosis is overlooked by another: e.g. one study found 23% of women hospitalised for anorexia nervosa also had ASD on an ADOS. Additional features include: girls may present differently with lower levels of rigid and repetitive behaviours; narrow interests may appear neurotypical, such as horses or boy bands, art or literature and not trains, dinosaurs and **astronomy; social differences may be more ‘clingy’ rather than aloof and therefore they appear less isolated on the playground. Many girls describe ‘camouflaging’ behaviour through copying, although this is experienced as exhausting which leads to other mental health (MH) prob-**

lems. **Research is a circular problem: if girls aren't diagnosed, how can you research the features that would help with diagnosis?**

**Chapter 3. Katie Buckingham, 'The Advantages of autism: a personal journey'.** Diagnosed at 16, to her parents relief and her disbelief: she thought her life was over. She had already had MH intervention most of her life, but this diagnosis enabled her to start to see herself differently. Not fitting in had led to intense anxiety disorder, somatic anxiety and OCD. Challenged to participate in school outings etc, she started to find advantages, such as thinking independently, working out strategies before events and being able to focus. These helped her to write about coping with MH problems and become a MH advocate. It also helped her to be innovative in work and business. Despite these strengths it was still important for employers to understand autism. Too often autism is seen as a disability. Even though it can be **tough, it is better to be told that you have a 'condition that enables you to think differently, inspires specific interests and expertise, you have an eye for detail and a logical mind. Autism causes problems but you can be supported to face challenges and you can still succeed in life.** Her supportive father described it: some cars are petrol and others are diesel, but they can all get to where you want to be.

**Chapter 4. Carrie Grant, 'Raising the voice of the lost girls': "all behaviours, good or bad, are communication: so what are you trying to tell me?".** Most people find an earlier diagnosis helpful to understand who and how they are to themselves. Because her

autistic children were so different, each had to be parented differently. A parent group for girls with autism was **intensely helpful. She adapted 'non-violent resistance' as a form of parenting to help any two parties in conflict (derived from Haim Omer).** Schools only provide adjustments if a child is a problem to them. They only listened when her daughter started talking about suicide. Carrie *helped the school learn to support friendships.* Teachers need to consider: 1. The classroom from a sensory perspective. 2. The teacher-child relationship, so the child feels understood. 3. Adapting the subject to individual needs. 4. **Watching the child's friendships. This chapter indicates that parents may need to appeal the 'Education, Health and Care Plan' (or Statement of Special Educational Needs).** Schools are institutions that find it difficult to change and adapt and so often respond with rigidity and lack of empathy. Adjustments can take months or years to be implemented. Her daughter loved school, till threats of detention caused acute anxiety and school refusal. The lack of intervention for the bullying was devastating, re-evoking suicidal risk and the need for constant suicide watch. One daughter learned to **blend in and mask her problems, the other couldn't** mask her problems and blurted things out at school. How do we get schools to cater for children with such individual differences? Yet the cost of not educating them in terms of unemployment and mental health needs is infinitely greater. Investment, a change of mindset and policy are all needed to allow such girls be included and contribute to the community.

**Chapter 6. Vanessa Bobb, 'Black girls and autism: the spectre of diverse communities on autism'. Being black**





or part of any diverse community can add to the delay of diagnosis. They are more likely to be mislabeled as attachment disorder or low self-esteem and the parents are more likely to be blamed. Her intelligent daughter became very angry for professionals failing to understand her. **“Oh she looks normal!”** The black communities tend to reject labels of illness or disability because of the indication of shame or weakness which in turns isolates the family. As black people are diagnosed less often with autism, then professionals believe black people are less affected by autism. Even at autism conferences black families feel isolated from the white majority of autism families. We know autism affects all cultures similarly, but in minority groups there is more taboo, denial, concealment and distress. Diagnosis may be overshadowed by other stereotyped views: socio-economic difficulties, drugs, addictions, gangs, crime, teen mothers, **mental health and sexual abuse.** Her daughter's teen pregnancy redoubled these views, rather than appreciating the failure of sex and relationship education. Such prejudices influence schools' responsiveness to special need

considerations. Sometimes it leads to denial in professionals and sometimes in parents. It is also a worry that girls with autism are 3x more likely to be exposed to coercive sexual victimisation, including from partners. We **need specialised ‘staying safe’ programs and recovery programs** for the traumas. Think about how traumatic being stopped and searched by police is for someone with autism. We need autism champions amongst the police. Those with autism are often guilty by association with criminal friends and suffer major trauma in prison. Other institutions may be highly rejecting of autism. What if a Muslim women cannot wear her hijab because of sensory sensitivity? Some Christian churches attribute **autism to demonic spirits, or the parents’ lack of faith.** In all cultural settings people with autism and their families have to fight stigma and prejudice. Some organisations recognise the cultural challenges and they need to reach out to other institutions and cultures to help deepen the wider education of autism.

**Chapter 7. Sharonne Horlock** a special educator writes on a girls with autism support group and issues they face of identity.

### **Part III: ‘Girls, Autism and Education’.**

**Chapter 8. Rona Tutt ‘Leadership issues’.** Education providers need to listen to the individual girls and their parents better, as well as the professionals, in resolving special educational needs. This challenge conflicts with government focus on raising academic standards by set ages in keeping with the UK National Curriculum. Special educational needs and/or disabilities (SEND) reports often need a written statement of action, because of the weakness of implementation found on audit inspections. It is not just a question of whether the school can cope with the child, but also whether the child can cope with the school environment. Inclusion does not mean mainstream for everyone. It is a process rather than a place **tested by “where can this pupil be most fully included in the life of this school community?”; this needs a range of educational placements.** The mental health green paper: **‘transforming children and young people’s mental health provision’ (2017) expects schools to play a key role in prevention and early intervention and SENDs should nominate a designated senior lead for MH.** These changes need an inclusive ethos, coming from the principal.

**Chapter 9. Sarah Wild, ‘a specialist curriculum for autistic girls’.** The whole school culture should celebrate autistic girls with awareness and understanding. This can include: understanding the problems of masking, focus on the multiple contributors to anxiety and how to manage it, ensure safety especially while experimenting with relationships, clarifying communications and emotions, and reducing vulnerability by promoting independence.

**Chapter 10. Jane Friswell and Jo Egerton, ‘included or excluded?’** Exclusion from school encourages problems

to be solved by giving up and walking away. Rather, these kids need more support not less. In the UK, exclusion rates are going up slowly as is the permanently excluded number. Boys are excluded 3x more than girls. Exclusion rates for autism are increasing eg by 25% in the last year and 36% of the permanently excluded. Young people with Special Educational Needs account for about 50% of these.

The number of parents opting for home schooling has doubled in 5 years. 22% of teachers mistakenly recommend parents to **'informally withdraw' their children from school**. There is little research on exclusions. One study in the UK found 45% of families with a child with autism had **'illegally been put on a reduced timetable, sent home early or asked not to come to school on days of tests or outings'!** Exclusion law requires the school to comply with the Equality Act (2010). The principal has to investigate, taking account of special needs and be subject to an independent panel. Gill (2017) reported 50% of diagnosed conduct disorders and 33% of those with emotional disorders are recognised as having special needs. The proportion of excluded children with MH problems approaches 100%.

Research on girls with autism is scarce, but exclusion is **often due to 'self-exclusion', prompted by feeling isolation and distress in school**. In special education settings, 98% are boys, which recreates marginalisation for the girls. Girls with autism often present with anxiety which leads them to be sanctioned for bad behaviour. But fewer than half of teachers feel confident about supporting a **child with autism**. Honeybourne's study of girls with autism found they felt lonely, isolated, social misfits, and suffered related anxiety and depression. They wanted time alone and lacked the opportunity, struggled to meet like-minded people, had difficulty maintaining friendships, were teased and bullied, and struggled with group work. They needed structure brought to the unstructured, provision of a range of activities in breaks, clear guidelines for groups, specific roles and clear expectations, and make it normal to have a quiet space and time alone.

A study from the Institute of Public Policy Research found half of all pupils permanently out of school have a recognised MH problem; only 1/100 get 5 GCSEs, the majority end up in prison; exclusion is part of a downward spiral of underachievement. These figures are followed by some case histories of exclusion. Yet Kannadasan (2016) identifies that autistic girls are: non-judgmental, honest, rarely boring, special, logical, loyal, interesting, wonderful, diverse, imaginative and unique; and as Temple Grandin says **'different, not less'**.

*Chapter 11. Ruth Fidler provides a readable summary on Pathological Demand Avoidance in girls*. This controversial syndrome first proposed by Elizabeth Newsom in the 1980s, is used in some services and not in others. The

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chapter provides a helpful summary, and while some feel the diagnostic description helps describe some children, there remains a lack of research to help determine validity.

Part IV:

*Chapter 12. Meng-Chuan Lai, 'the neuroscience of autism in girls': doesn't replace other sorts of knowledge* such as cognitive styles and behaviour preferences and patterns. Sex refers to biology and gender to socially constructed characteristics which are affected by multiple factors but these are not distinct in maleness or femaleness. Generally, similar processes of brain development is seen in male and female autism, but females tend to have (or need) a greater degree of brain changes; both qualitative and quantitative. Restricted and repetitive behaviours involve motor regions of the brain (male autism) but camouflaging is associated with orbitofrontal cortical activation in women when thinking about **comparing themselves (but not found in men)**. The **'female protective effect'** may mean they need a stronger genetic load for autism, as illustrated by male siblings of an autistic child are more likely to show autism than female siblings. Conversely, infant girls siblings of an older autism child show enhanced attention to social scenes compared to infant boys, suggesting this social screening may have a protective effect.

*Chapter 13. Tina Rae and Grace Hershey, 'MH in girls with autism'*. Failure of diagnosis of autism in girls increases MH morbidity and prevents engagement in necessary learning, affecting future potential in cognitive skills, social skills and emotional wellbeing. The core features of autism affect the ability to gain emotional resilience which in turn affects health, longevity, education, and lifestyles such as smoking and drinking. On-line social connection can be positive but also stressful, abusive and addictive.

Despite limited research there appears to be increased self-harm in girls with autism. Impairment of social communication is associated with depression and substantially mediated by bullying associated with an increase in suicide attempts. Schools need to screen for risks and have good pastoral care. CBT can be adapted for autism,

but is limited by the delay in development of meta-cognitive skills. Work can be done to improve self-esteem, and reduce exposure to sexualised images. Teaching teens to play sexualised roles diminishes their academic success. Unrealistic attitudes to thinness contributes to sexism, sexual harassment and violence against women. They discuss a model of an adolescent social group intervention that they piloted, but it was important to be aware of the vulnerabilities of the participants with and without autism beforehand. Connection between young people, parents, teachers and clinicians depends on having a common language.

**Chapter 14. Felicity Sedgewick and Liz Pellicano, 'Friendships'.** Difficulties in social development is associated with maladaptive behaviours and poor adult outcomes. But how does this apply to girls with autism? Boys tend to share activities and focus on achieving social status, whereas girls have fewer closer friends based more on cooperative pretend play. Some autistic children are desperate for friends and some not so. Girls with autism 10-16 years rated friendships of higher quality, often with neurotypical girls, and showed higher social motivation than boys, which may be protective. Conversely boys were more likely to be rejected by peers. Autistic girls often have interests around people and animals, whereas boys are more focused on objects. Autistic girls rated friendships similarly to neurotypical girls, which was very different to autistic boys. Autistic girls are more interested in people, what they were doing and what they like. Autistic boys were more interested in activity than **affect. Autistic girls' friendships were closer and trusting**, even if it was limited to a few best friends. However, in conflict they would tend to see things as their fault, or entirely blame the other. In some ways they cope better with on-line relationships with type-written communication. However whether autistic or not, girls had high levels of insecurity in their friendships creating anxiety. Autistic girls tended to interpret neutral situations as negative or sarcastic. Autistic girls lack conflict resolution **skills and nuance, with an 'all or nothing approach'**. Often having friends becomes more important than having the right friends.

**Chapter 15. Gillian Loomes, 'approaches to adolescence and sexuality as a special educator and advocate'.** Autistic girls absorb adolescent discourses to construct their identity. Loomes describes the dialectical jigsaw for adolescent girls with autism. These discourses are often socially and politically charged but autistic adolescent girls deserve to be offered an autistic-feminist political identity in order to escape socially enforced conformity of silencing narratives that discredit our autistic experiences.

#### **Part V: 'Autistic girls for the future'**

**Chapter 16. Jo Egerton, Helen Ellis and Barry Carpenter, 'transitions and employment'.** Ellis presents a nice description of her experiences of transitions, but the world



of work is so unlike anything that school prepares you for. Offices have their management structures and unofficial social hierarchies which are challenging for someone with autism. Temple Grandin described the transition from school to college: to deal with such a change she needed a way to rehearse it, acting out each phase of her life by walking through an actual door. Employment is a predictor of social inclusion, economic independence and cognitive, physical and mental health and wellbeing and promoted by schools as a positive outcome. Only 32% of autistic adults are in some kind of paid work, and only 16% in full time work. 51% were over skilled for the job, and 40% were working fewer hours than they liked. 79% on out-of-work benefits wanted to work. Employers need to understand autism better. Girls with autism face a double discrimination with similar additional disadvantages to female neurotypicals. Autistic people need support throughout their lives to help the access and preparation for employment opportunities (National Autistic Society, 2017). Under identification of girls with autism leads to a lack of this support. Developing career aspirations is linked to forming a vocational career identity and gained from experiences and self-discovery. It in-

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*“Reversing her mental health and social trajectory is a slow complex process”*

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volves developing a vocational identity from interests and skills, and addressing the skills for workplace expectations.

### Final thoughts on the book

*This summary of science and experience pushes us to look more closely for autism in girls. Credit goes to the authors and other leadership figures who have evidently challenged the clinical, educational and therapist sectors in the UK to recognise the problems of autism in girls and act! Schools not only need to actively engage in the mental health of their pupils, but in doing so they may find the girls who not only need an autism diagnosis, but face a challenge of a complex combination of problems of mental health, social problems, self-esteem, stigma and exclusion. This fits my clinical experience. I recall one case of a 7 year old girl, sister of a patient, but who also needed help. Getting to know her was like a process of peeling off the layers of the onion of problems as I got to know her and she matured, trusted me and opened up, starting with a clinging maternal attachment, severe anxiety, non-compliance, lack of communication, school refusal and over few years going on to find the autism, the learning difficulties, deteriorating motor skills, problems of trauma and ADHD as well. Conversely, I also recently met a chronically depressed and recurrently suicidal 14 year old, who had not had her autism diagnosed by several mental health clinicians. Although diagnosing the autism brought new light to her problems, and may help understand why she was so difficult to treat, it was no immediate solution to her chronic mental health problems. Reversing her mental health and social trajectory is a slow complex process.*

*For the last 25 years, all schools have been challenged to look for and recognise the prevalence of autism mainly in boys and provide for their needs. The depth and complexity of the problems of girls with autism is a new frontier, needing awareness, advocacy and intervention for their autism and their comorbid issues. This book **increases one's awareness which is the first step to earlier recognition**, but needs progress towards establishing intervention and tackling the weight and complexity of their co-morbid problems. Do we have that leadership and skills to recognise these needs and make a difference in Australia?*

Further information:

Tony Attwood on **Autism in Females** lighthearted podcast <https://vimeo.com/122940958>

