



ROUTLEDGE

Girls and Autism

Educational, Family and Personal Perspectives

Edited by **Barry Carpenter**, **Francesca Happé** and **Jo Egerton**

Girls and Autism

Often thought of as a predominantly ‘male’ disorder, autism has long gone unidentified, unnoticed and unsupported in girls – sometimes with devastating consequences for their social and mental well-being. As current research reveals a much more balanced male-to-female ratio in autism, this book provides crucial insight into autistic girls’ experiences, helping professionals to recognize, understand, support and teach them effectively.

Drawing on the latest research findings, chapters consider why girls have historically been overlooked by traditional diagnostic approaches, identifying behaviours that may be particular to girls, and exploring the ‘camouflaging’ that can make the diagnosis of autistic girls more difficult. Chapters emphasize both the challenges and advantages of autism and take a multidisciplinary approach to encompass contributions from autistic girls and women, their family members, teachers, psychologists and other professionals. The result is an invaluable source of first-hand insights, knowledge and strategies, which will enable those living or working with girls on the autism spectrum to provide more informed and effective support.

Giving voice to the experiences, concerns, needs and hopes of girls on the autism spectrum, this much-needed text will provide parents, teachers and other professionals with essential information to help them support and teach autistic girls more effectively.

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Francesca Happé, FBA, FMedSci is professor of cognitive neuroscience at the Institute of Psychiatry, Psychology and Neuroscience, King’s College London, UK.

Jo Egerton is a schools research consultant, running school-based research courses for teaching school alliances and academies.

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We hope that this book is true to the ‘many voices’ we have tried to capture, all of whom share a common commitment to improving the lives of girls with autism.

Contributors

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Recently, he co-authored the book *Engaging Learners with Complex Learning Difficulties and Disabilities* (Routledge, 2015). Barry lectures nationally and internationally. In recent years this has included China, Japan, Abu Dhabi, Norway, Australia and New Zealand. He is co-founder of the National Forum for Neuroscience in Special Education. For the Mental Health Foundation, he chaired the National Inquiry into the Mental Health of Young People with Learning Disabilities, and is currently chairing, for the National Association of Head Teachers, a working group looking at the needs of girls on the autism spectrum.

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invisible disabilities and sensory needs. She has been involved in a variety of research and advocacy roles over the past 10 years, including the European Union's 'Autism in Pink' project. She is an active member of both the Westminster Autism Commission and the Advisory Group for the All Party Parliamentary Group on Autism (APPGA). Her current goals are focused on improving autistic people's experiences of work, celebrating and valuing the achievements of individuals and improving society's understanding of sensory needs.

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Carrie Grant is a well-known broadcaster and president of the Unite Union for Health Visitors and Community Practitioners. In 2018, Carrie received an honorary doctorate of arts from the University of Bedfordshire for her services to charity. She is mother to four children, three birth children and one adopted, all with special needs. Two of her girls are diagnosed with autism spectrum conditions, and Carrie, her husband David and daughter Talia are ambassadors for the National Autistic Society. Carrie sits on the largest Transforming Care Partnership Panel in the UK for Learning Disability and Autism, and has given keynote addresses at many health and education

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Francesca Happé is professor of cognitive neuroscience and director of the MRC Social, Genetic and Developmental Psychiatry Centre at the Institute of Psychiatry, Psychology and Neuroscience, King's College London. She completed her undergraduate degree in experimental psychology at Oxford University and her PhD at University College London, supervised by Professor Uta Frith at the MRC Cognitive Development Unit. Her research focuses on autism spectrum conditions. She has explored the nature of social understanding in typical development and 'mind-reading' difficulties in autism. She is also actively engaged in studies of abilities and assets in people with autism, and their relation to detail-focused cognitive style. As well as cognitive methods, her research has involved functional imaging studies, exploration of acquired brain lesions, and behaviour genetic methods. She is the author of more than 200 research papers and a book on autism for general readers, and was recently ranked in the top 10 most productive and highly cited authors in autism research worldwide from a bibliometric analysis of autism research published in 2005–2014. She was president of the International Society for Autism Research (INSAR) from 2013 to 2015 and on the board from 2012 to 2017. She has received the British Psychological Society Spearman Medal, the Experimental Psychology Society Prize and the Royal Society Rosalind Franklin Award. She was made a fellow of the British Academy in 2014, and was elected fellow of the Academy of Medical Sciences in 2017.

Grace Hershey graduated from Oxford Brookes University with first-class honours in occupational therapy. Since qualifying Grace has specialized in child and adolescent mental health. She has spent time working with young people with eating disorders and a range of other mental health needs in an inpatient setting. Latterly she has been involved in the delivery of CAMHS community based services where she works as both an occupational therapist and a key worker/care co-ordinator. Grace has a particular interest in girls with autism spectrum and co-morbid mental health needs.

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Wenn Lawson is an autistic lecturer, researcher, psychologist, advocate, writer, poet and trans-guy whose knowledge and understanding of autism is internationally renowned and respected. Wenn's insights and professional knowledge, ranging from first class honours in social work to a doctorate in psychology, inform all he does. Wenn lived for 61 years as a woman, raising a family, traveling, writing and joining the dots! He published his first book on autism, *Life Behind Glass*, in 1998. Since then, he has written and/or contributed to a further 20 books, as well as many journal articles. Wenn is passionate about the rights of those who so often cannot speak for themselves and aims to promote justice and equality for all. His work explores the influence of neurological development in autism as well as focusing on autism across the life span, learning, social demand and bridging the gaps so AS individuals can truly be involved with an inclusive society. Living with his wife in Australia, Wenn has autistic and non-autistic adult children and grandchildren.

Gillian Loomes has a degree in English law and European law, a PGCert in special education (autism), a PGDipEd (Advanced PGCE) in lifelong learning, and an MA in social research. Her MA dissertation examined disability advocates' perspectives on their everyday practice in the context of recent legislative developments within the sector, drawing on her prior professional experience as a specialist autism advocate within a UK charity. Gill's current PhD research focuses on the Mental Capacity Act 2005, and how its implementation in practice engages with, and impacts upon, the

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Carol Povey has worked with autistic people and their families for over 35 years in the voluntary and local authority sectors. Carol joined the National Autistic Society in 2001, and in 2010 she was appointed as the director of the Centre for Autism. The aim of the centre is to promote innovation, excellence and understanding across the autism sector and to provide a hub for greater collaboration, both UK-wide and internationally. Carol is responsible for the NAS's diagnostic services, research, training and quality assurance. She is also the chair of the editorial board of the NAS's professional conference. She has contributed to a number of publications, and has trained and presented at conferences nationally and internationally. She is the UK representative of Autism Europe and chaired the scientific committee of the XI Autism-Europe International Congress.

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Rachel Townson has grown up learning about autism and trying her best to advocate for her older brother. After completing her studies she left university with an honours degree in psychology and a Master's in autism studies. Continuing her quest for knowledge, Rachel joined the National Autistic Society's training and consultancy team and has now worked for the NAS for over six years. She currently oversees the development of online training modules for professionals and ensures that all modules and face-to-face training from the NAS has the autistic voice represented throughout. Rachel has been very privileged to be able to attend many conferences and hear from so many inspiring people on the autism spectrum. This enabled Rachel to self-identify as being autistic, and led to a formal diagnosis of Asperger syndrome in 2014 by Dr Judith Gould. Rachel continues to work within the training and consultancy team and enjoys her continued work with others on the autism spectrum.

Rona Tutt OBE is a past president of the National Association of Head Teachers (NAHT). She has an MA in linguistics and a PhD in the education of children with autism. In the 1990s, she opened the first provision for pupils with autism in her county. She has received an OBE for her services to special needs education and an outstanding reviewer award for her work on the *International Journal of Educational Management*. Rona represents the NAHT on a number of specialist groups including the Expert Reference Group of the Autism Education Trust (AET). She is one of the founder members of the National Forum for Neuroscience and Special Education (NFNSE). During 2015/2016, she was the interim chair tasked with establishing Hertfordshire's All-Age Autism Partnership Board. Rona has written and co-authored a number of books including: the DfE-funded *Making it Personal: A guide to personalisation, Personal Budgets and EHC Plans – for educational establishments and local authorities* (2016); *The SEND Code of Practice: 0–25 years – policy, provision and practice* (2015) and *Rona Tutt's Guide to SEND and Inclusion* (2016), both published by Sage. Rona is

much in demand as a speaker, writer, reviewer and judge. She remains actively involved in education through her books, articles and conference speeches, as well as being vice-chair of governors at two schools, one an all-age school for profoundly deaf pupils and the other a secondary school for pupils with autism, learning difficulties, and/or speech, language and communications needs. Rona is a Fellow of University College London's Centre for Inclusive Education (CIE).

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Sarah Wild and the students of Limpsfield Grange School. Sarah Wild is head teacher of Limpsfield Grange School for girls with communication and interaction difficulties including autism. Sarah has worked in education for 20 years, in a range of settings. She has had experience of leadership in a mainstream secondary school in the East End of London, and in special schools in London and Brighton. Sarah is a qualified teacher of the deaf and an English teacher. Since her appointment as head teacher Sarah has dedicated time to raising awareness of female autism nationally. Limpsfield Grange School was the subject of the ITV documentary *Girls with Autism*, and students of the school have written two novels with author Vicky Martin, both published by Jessica Kingsley: *M is for Autism* (2015) and *M in the Middle* (2016). Sarah and students from Limpsfield Grange speak nationally about female autism, and have spoken at the Autism Show London, National Association of Head Teachers and the National Union of Teachers special education conferences and the National Autistic Society professionals' conference. Sarah is a member of the NAHT's Autism and Girls Forum, and has recently participated in a House of Lords roundtable discussion about female autism.

Foreword

For people with autism, trying to understand the rest of us can feel like travelling to another country – learning another language and navigating a new landscape while brandishing a passport that allows you access, but not acceptance.

For women and girls with autism, it is more like sneaking into the same country under cover of darkness, wearing a disguise during the daytime and hoping every moment that no one blows your cover.

My daughter has autism. She was diagnosed when she was eight years old. It took five years to get the diagnosis. At the time I thought it was because our local systems were underfunded and overloaded, teachers and health professionals too busy, undertrained and defensive. Now I think that, while all that was the case, a good part of the delay was because my child was not a boy.

It is amazing that, thirty years after its release, the film *Rain Man* still sets the bar for what we understand as autism: boys and men who are extremely good at maths and do not understand other people. It is a picture based on the work of male scientists like Leo Kanner, who thought autism was mothers' fault for failing to love their children enough; of Hans Asperger, who thought no women and girls were affected by the syndrome he identified; and shored up by the work of Simon Baron-Cohen, who theorized that male and female brains are fundamentally different – men are better at systematizing, women at empathizing – and therefore autism is 'an extreme of the male brain'.

This template has not only trapped generations of men in cliché, but has also prevented thousands of women from getting the support and understanding they need because a male diagnostic gaze simply never sees them.

And while struggling to get by in a world that does not see them, many women and girls with autism will mimic the expected behaviour of 'neurotypical' women and girls, adopting social stereotypes to be quiet and biddable, which create an unbearable mental strain. Many are subsequently diagnosed with multiple mental illnesses while their autism remains unseen. Forty years ago it was believed that the ratio of men with autism to women with autism was 15 to 1. In 2015 data from the National Autistic Society suggested it could be 3 to 1.

As a woman who for years fought sexist attitudes and was dismissed as 'feisty' – who questioned lad culture and was called a prude – who objected to pink and diets and good behaviour, and was driven to distraction by being repeatedly shut down by aggressive condescension – it has been hard to watch my daughter experience a double discrimination: being female and autistic, defined and skewered twice over by patriarchal premise.

As Grace, now 16, puts it:

When I was little I said I liked pink and princesses because girls around me said they did and I felt I had to because they did. But I felt uncomfortable on two counts – because I didn't like it and I didn't understand why I was supposed to.

All girls are under immense pressure to fit in and be a certain way according to what they're told being a girl means. It's even worse for girls with autism because they're also trying to fit in with what being a human means.

Grace was lucky in one sense, in that, in the end, her frustration took the form of a 'typically male' reaction. She fought her way out of her predicament, literally swinging at the school bullies until her punches and kicks flagged a crisis to the authorities. I was also lucky that my employer agreed to my request to cut my hours at work, and I could take up a second job of cajoling my local education, healthcare and child support services to file reports on time and to the right people and agree a Statement of Special Educational Needs – now known as an Education Health Care Plan.

A diagnosis did not bring general acceptance from the outside world, nor did it bring sufficient support – but it brought just enough of each for Grace and me to function, while being aware daily of how thinly spun is the thread of our luck.

Grace still counters sexist ideas about autism every day:

When a boy with autism has a bad reaction, he gets immediate support from loads of teachers. When I get overwhelmed, I get told off about my attitude.

And as her mother I counter discrimination that will be familiar to many carers – we are whingers, incapable of discipline; feckless, self-centred, hysterical ... you name it. Because a society that does not value women does not value the care work that women do.

Female does not equal not-male. Autistic female does not equal not-autistic. The lived experiences of women and girls, wherever they are on the autism spectrum, are simply different. And while our society is terrible at understanding and embracing difference, it also relies on difference to progress. Every day Grace attempts to make her way in a world that does not understand her. Every day I work to build the kind of world that could.

This book sets out ways in which we can build bridges between our daughters, sisters, nieces, mothers, aunties and a world that does not see autism as female. It sets out the length of the journey ahead of us and the obstacles we must overcome. It questions assumptions, unpicks presumptions and answers questions to which we do not yet know the answer. And yet for all that, this is a work of huge optimism and encouragement. Because you cannot solve a problem until you identify that there is one. The biggest failing of our society has been to simply ignore the voices of women and girls. Thanks to this book, those voices can now be heard.

We should all embrace difference. We would all be better off.

Sophie Walker
Leader of the Women's Equality Party, UK
September 2018

Preface

This book is born of the commitment of a group of professionals from a range of disciplines – academics, policy-makers, parents, and importantly including young women with autism – to advocate for a vulnerable and often unrecognized group in our society – girls with autism. The National Autism and Girls Forum, originally brought together as a short-life working group by nasen (the National Association for Special Educational Needs), has been hosted and supported by the National Association of Head Teachers (NAHT) for the last two years.

The Forum, chaired by Professor Barry Carpenter CBE, OBE, has campaigned around the unmet needs of girls with autism, evocatively described in the Forum's 2016 introductory booklet as 'flying under the radar' (available from www.nasen.org.uk).

This booklet is still widely used in schools and has helped to create much greater awareness of the needs of autistic girls, showing why so many still go unrecognized and misdiagnosed. The Forum's key messages resonate for me with some of my recent work as a psychiatrist on global issues concerning the protection of minors and vulnerable adults from both online and offline abuse (Child Dignity Alliance 2018).

The Forum's messages also add emphasis to the pictorial narratives created by Books Beyond Words for anyone who finds pictures easier to understand than words. I was delighted to be asked to host a debate for the Forum at the House of Lords, which brought together interested politicians from both Houses of Parliament, representatives from government departments, national organizations in the field of Autism, family members, professionals, and some girls with autism themselves. The girls spoke eloquently of their struggles to cope, particularly in school settings. They described how sensory overload affects them, the unfathomable dynamics of friendships, the feelings of isolation when peers did not understand and their anxiety in the fast-paced classroom.

The vulnerability of girls with autism was a recurring theme, and in this respect I am eager to explore the contribution the pictorial narratives created by Books Beyond Words might make to reducing the potential dangers for the girls. This series (www.booksbeyondwords.co.uk) includes stories about the relationship difficulties experienced by young people, including girls on the autism spectrum, who may have an intellectual disability (Hollins et al. 1994; Hollins et al. 2005; Hollins et al. 2016).

The National Autism and Girls Forum, having created a wide support base, worked through the NAHT to organize a national conference, 'The Big Shout', in January 2016. This sell-out conference brought together delegates from every sector of the field, unexpectedly including international delegates. Girls and women with autism shared their lived experiences; families talked of their struggles and triumphs in getting

recognition of the needs of their daughters; members of the Forum shared their current research, evidence-based practice, training developments and critical insights. These presentations were the seeds of what you now see and read in this book, with its rich and diverse array of chapters.

A major output from the 2016 Conference was ‘A Call to Action’, co-constructed with delegates around key themes such as diagnosis, education and training, research, mental health, parents and carers, and post-school transition and employment.

The Big Shout became the ‘call to action’ that lived on beyond the conference and which enabled delegates to go back to their various settings, professional or personal, and share the conference’s key messages. ‘A Call to Action’ has acted as a script for focused conversation with politicians, government departments, local authorities and many other groups. It has even been used internationally to highlight the unmet needs of girls with autism.

The Big Shout conference spawned many informed voices who have campaigned tirelessly to bring about change and a greater understanding. In this respect I congratulate members of the National Autism and Girls Forum for their vision and determination, which has contributed to the many conversations I now hear in many quarters, showing that with increased understanding comes deeper compassion and action.

‘Many Voices’ is the title of the conference to be hosted by NAHT on World Autism Day, 2 April 2019, where this book will be launched. I hope that its content will inspire you, and that your voice will be added to the many who are now advocating for the needs of girls with autism.

I commend this book to you.

Professor Sheila the Baroness Hollins
Independent Crossbench Peer
The House of Lords
September 2018

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Part I

Introduction
