
THE LITTLE BOOK OF THE AUTISM SPECTRUM



Dr Samantha Todd 
Edited by Ian Gilbert

Praise for *The Little Book of the Autism Spectrum*

As head teacher of a specialist support primary school which has amongst its numbers over 50 pupils with autism I can see a place for this book on the shelves of our resource library. It would be a useful addition to support both parents and practitioners. Easy to read, with bite size nuggets of useful information, the book flows logically, touching on the key areas involved in supporting children with autism. The book provides a basic introduction to the subject of autism, an overview and some manageable strategies and tips to implement.

Dr Samantha Todd has set out in an easily accessible and undaunting way a useful guide book or check list for the teacher wishing to know they have 'got it right.' The book details the key areas that need to be in place to maximise the potential for pupils to make progress and goes on to tell you what you can do to support those learning areas.

**Andy Pitts M.Ed autism, Head Teacher,
The Birches Specialist Support Primary School, Manchester**

This is a very nice, concisely written work that will be especially helpful for parents trying to get 'up to speed' when their children are newly diagnosed. The book covers a wealth of material quickly without over simplifying. Highly recommended both for finding practical solutions and for better understanding the 'big picture' of what an individual on the spectrum may be experiencing.

**Lars Perner, PhD Assistant Professor of Clinical Marketing,
Marshall School of Business, University of Southern California**

This excellent little book, cogently written by Dr Samantha Todd fills a useful gap in the literature about autism spectrum disorder. The author, a clinical psychologist working in Manchester, has written a very accessible book which will be appreciated equally by parents and carers as well as by professionals working in children's services. The many themes covered in the book will be particularly relevant to those working in schools and early years settings responsible for autistic children, especially teachers and support staff.

The book is helpfully divided into three sections namely:

1. Understanding the autism spectrum
2. Developing skills and promoting well-being in children and young people with autism.
3. Working with behaviour

Beginning with the assessment process and covering the many questions facing anxious parents at the time of diagnosis, the author helpfully demystifies much of the jargon and the plethora of medical labels which cause confusion for families and also many professionals.

There follows a thoughtful account of the benefits to society of neurodiversity and the positive contribution made by people who are thought to be unusual or different.

For me, however, the key section is found in Chapter 4 where the author introduces the concept of 'the autism lens', a theme which involves the reader viewing aspects of home and school life specifically from the viewpoint of the youngster with autism. This metaphor is developed throughout the remainder of the book and enables the reader to appreciate the subtle differences which impact the lives of children and young people with autism.

The third section of the book focuses on working with aspects of behaviour and will be helpful to everyone attempting to understand, analyse and manage behaviour that is considered challenging in the home and the wider community including educational settings.

The Little Book also contains humorous illustrations of real-life situations and key learning points are provided as a helpful summary to each chapter. Furthermore, the glossary and references are useful aides for follow-up.

Personally I found *The Little Book of the Autistic Spectrum* a fascinating read and as a practitioner educational psychologist I will be recommending it to parents, school staff and colleagues as I believe it gives illuminating insight and plenty of sound practical advice which will be helpful to those who support children with ASD.

Eric Taylor, Educational Psychologist, Persona EPS Ltd

This book is a must-read for parents, professionals and young people with an interest in autism. It is a welcome addition to the existing literature on autism providing a clear, concise, and very readable overview of many of the key aspects to aid the reader in a broad understanding of autism. Through clear text, simple and effective illustrations, and regular key summaries this book guides the reader sensitively and thoughtfully through the facts, the impact, and solutions for working with young people with autism. The author places the young person at the centre of all the chapters focusing on the importance of parents and professionals trying to place themselves in the world of the young person. The later chapters on intervention illustrate this beautifully with multiple real-life examples to guide readers through many of the key issues faced by young people with ASD. There is a strong ethos of inclusion and acceptance throughout the book allowing the reader to place the young person at the centre of their thinking. This non-expert, non-judgemental approach is again a welcome break from the plethora of scientific writing on autism which may not always aid a broader audience in their understanding of autism. The book ends with a clear, practical glossary of terms, well-selected references, and helpful web-links, to guide readers towards further information and support.

**Dr Paul Wallis, Director of Psychological Services,
CAMHS Directorate, Central Manchester University Hospitals
NHS Foundation Trust**

This is a great book for people who want to know about autism. It is packed full of facts and information and signposts readers to other books, research, and organisations who can provide further help. The key point reiterated throughout this book is that people with autism are individuals with different personalities, likes and dislikes and that there is no 'one size fits all' approach that will magically work for every autistic person. The focus upon the different ways in which individuals with autism may think about and experience the world really encourages the reader to respond creatively. By using statements from autistic individuals to explain their perspective the author helps readers to gain insight into situations and behaviours which may appear baffling or unusual from the outside but make much more sense when viewed through an 'autism lens'.

The book contains information on most key areas that can be challenging for people with autism from communication difficulties, 'mindblindness', problems with eating, sleeping and tolerating situations due to sensory overload to self-injurious behaviour, psychiatric vulnerabilities, and repetitive behaviours. Each section gives good, sound, practical advice on ways of approaching or managing the difficulties and offers sources of further information and advice. This is no mean feat for such a comprehensive book and is to be applauded.

The book is written in simple language without jargon which makes it easy to read and the key points at the end of each chapter help to pull everything together. The tone is just right and is informative, factual, and interesting. The glossary is excellent and the references are extensive and wide ranging. My only surprises were the omission of Division TEACCH (although visual schedules are well covered) and that the National Autistic Society was not mentioned as a resource for training, publications, and parental support; notably their helpline and Early Bird/Early Bird Plus parent training schemes.

As a parent of a young man with Aspergers I would have welcomed this book wholeheartedly when he was younger and it probably would have helped me through many anxious times. As a teacher who has worked for many years with children and adolescents with autism I loved the warmth and empathy with which the author talks about the people with whom she works and her complete and utter dedication to these very special individuals.

**Pam Smith MBPsS, BMus(Hons), BSc(Hons), PGCE,
Postgraduate Certificate in Professional Studies in Education
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To J, S, and D, for the confidence

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Part One

Understanding the Autism Spectrum

Chapter 1

Introduction to the Autism Spectrum

The amount of information available about autism can be overwhelming and it can be hard to know where to begin. This section provides a brief overview of the condition.

- What is autism?
- What is the spectrum of autism?
- What causes autism?
- How many people have autism?
- What helps?

What is autism?

Autism is often described as a *developmental disability*. This means that it is usually first noticed during childhood. People with autism have a disability in terms of the way they understand and interact with other people, and this creates challenges when living in a very social world. However, some people do not think of autism as a disability, but simply as a different way of processing information and understanding the world.

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Autism is a lifelong condition. This means that someone with an autism diagnosis will always have the condition, but it doesn't mean they will always be the same. All children change, learn, and develop, so children with autism will also change – they won't be the same at 15 or 40 as they were at 3. However, it is important to keep in mind that they will experience ongoing challenges with their social interactions, communication, and behaviour.

What is the spectrum of autism?

Throughout this book I use the term 'autism' as shorthand for the whole autism spectrum. Autism spectrum diagnoses (also known as autistic spectrum disorders or autistic spectrum conditions) are given to a broad range of children who display significant difficulties in these two areas:

1. Social interaction and communication
2. Social imagination, along with restricted, repetitive behaviour and interests

Wing's triad of impairment

Dr Lorna Wing is a psychiatric consultant for the National Autistic Society, the parent of a child with autism, and high profile researcher and writer regarding the condition. In the 1970s she was instrumental in identifying the core difficulties of autism. She described three key 'impairments' shared by all children who have an autism spectrum condition: impairments in social interaction, social communication, and social imagination, including restricted and repetitive behaviours and interests. This is called the 'triad of impairment' or 'Wing's triad' (Wing and Gould, 1979).

The latest *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V; APA, 2013) reduces the triad to two.

The spectrum of autism has broadened considerably over time. Going back a half century, autism used to refer only to children who seemed to be 'in their own world'. These children show highly repetitive behaviours and routines, with very little interest in other people. This is sometimes referred to as 'childhood autism' or 'Kanner's autism', after the psychiatrist who first described the condition in 1943. These children often have severe delays in language and very unusual speech, or no speech at all.

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As the 20th century went on, the spectrum of autism started to widen. In 1944, the Viennese paediatrician Hans Asperger provided the first description of boys with a particular style of thinking and interacting. He described young people with average or above average intellectual ability, and no delay in language, but who showed specific difficulties in social interaction and imagination. The term 'Asperger syndrome' was coined to describe this condition.

So, whilst one person within the autism spectrum may have no spoken language and very little interest in other people, another person within the spectrum may have well-developed language and be keen to make friends, but struggles to do so effectively. What the two individuals share are significant difficulties in their social interaction, communication, and imagination. Both will also have restricted and repetitive interests and behaviour.

The number of terms used to describe children on the autism spectrum can cause confusion. It is important to remember that they are all part of the same 'family' of diagnoses, with the same essential difficulties but with differences in terms of intellectual ability and language development.

Diagnostic terms

DSM-V (APA, 2013) uses the term 'autism spectrum disorder' to include everyone on the autism spectrum. This sits alongside a description of how much the condition affects the individual and each person's individual profile of difficulties.

Children and young people who have already been diagnosed, or are diagnosed using different criteria, may receive one of these alternative diagnoses, all of which fall within the autism spectrum:

- *Childhood autism*: Language development is delayed. Difficulties are usually noticed early, often before the age of 3. There may be an additional learning disability but not necessarily.
- *Asperger syndrome*: Children and young people who receive this diagnosis typically have had no delay in their language development and should have at least average intellectual ability.
- *Atypical autism or pervasive developmental disorder – not otherwise specified*: This diagnosis may be given when children and young people show some or most of the features of autism but do not exactly meet the full criteria. It is important to remember that these are still autism spectrum diagnoses and difficulties may be severe.

- *High functioning autism*: This term is sometimes used for children and young people whose language development is delayed but who have at least average intellectual ability. There is an ongoing debate about whether Asperger syndrome and high functioning autism are two separate conditions or not. One argument is that high functioning autism is more likely to be picked up before the child starts school, whereas Asperger syndrome may not be noticed until school age. Does it make any difference in real life which diagnosis is made? Approaches to support the young person are broadly the same. However, responses by wider society to the two terms can be very different, with suggestions that Asperger syndrome carries less social stigma.

Is there such a thing as mild or severe autism?

There is a common misconception that people with childhood autism are at the 'severe' end of the spectrum and people with Asperger syndrome or high functioning autism are at the 'mild' end. Children with childhood autism who have limited language and an additional learning disability can certainly appear to have more severe difficulties in that their independence will be limited and their educational and social abilities greatly affected.

Introduction to the Autism Spectrum

However, children without language delay or learning disabilities can also experience severe difficulties as a result of their autism. These difficulties may relate directly to the core areas of social communication, interaction, and repetitive behaviours. They may experience challenges in the following related areas:

- Rigidity – strict rules about how things should be
- Anxiety, particularly social anxiety
- Awareness of difference between themselves and their peers

It is therefore vital not to underestimate the impact of Asperger syndrome or any autism spectrum condition on an individual's life.

What causes autism?

There is very strong evidence that autism has a biological rather than an environmental cause. There is also a strong indication that this is likely to be genetic: if one identical twin has autism, there is a 60–90% chance that their twin will also have the condition. Compare this to non-identical twins or siblings, where if one has autism the other sibling has a 5–10% chance of meeting the criteria for diagnosis. We also know that there are a number of biological differences associated with autism, including some genetic and neurological differences.

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We still don't know exactly how autism is caused – for most people there is not yet a clear answer for why *they* developed the condition. It seems likely to be a complex interaction between genes and some other factor(s) in brain development.

How many people have autism?

Current thinking is that about 1–1.5% of children have autism (Baron-Cohen et al., 2009). This number has risen steadily over the past few decades but this does not necessarily mean that autism itself is on the rise. Rather, it may be that the diagnostic criteria have broadened to include autistic spectrum conditions/disorders and Asperger syndrome, and professionals and parents are better educated about autism, so children are more likely to be given a diagnosis.

True or false?

- *Autism affects more boys than girls*

True. Most studies have found that more boys than girls meet the criteria for autism spectrum conditions, with boys at least three times as likely to have the condition as girls (Nicholas et al., 2008).

- *Autism is caused by poor parenting*

False. Early theories on the causes of autism included the hypothesis that it was caused by parental 'coldness', particularly on the part of the mother. This hypothesis has been rejected for many years, and the cause of autism is widely accepted as biological.

- *Autism is caused by the MMR vaccine*

False. There is no good evidence of a link between the MMR (measles, mumps and rubella) vaccination and autism following controversial claims made during the late 1990s.

- *People with autism have special talents, like in the film Rain Man*

Partly true. A very small percentage of people with autism show an extraordinary talent, such as being able to play complicated tunes after hearing it just once. This is sometimes known as 'savant

syndrome'. The vast majority of people with autism do not have one of these profound abilities but have strengths and difficulties just like the rest of the population.

■ *Children can grow out of autism*

False. Children with autism grow up to be adults with autism. With the appropriate support and education they can develop skills and progress, but they will still have the core features of autism as part of who they are.

Chapter 2

The Diagnosis of Autism

Diagnosis can be a necessary step towards children receiving the appropriate support. This chapter explains when and how autism is diagnosed.

- When to seek further assessment
- Who can diagnose autism
- How the diagnosis is made
- What happens next
- Weighing up whether to seek a diagnosis
- Alternative or additional diagnoses

When to seek further assessment

Concerns that a person may have autism can be raised at any stage in their development, from a few months old to adulthood.

The first five years

Sometimes parents or professionals notice potential difficulties very early on. This may be particularly true for children with childhood autism or those with delayed language development.

In the first year of life, some parents notice that their child is not babbling or reaching other expected milestones. This is not a reliable sign of autism but can raise concerns about development. As the baby becomes a toddler, parents may become aware that they do not seem very interested in other people. Communication is not developing as expected – for example, the child may not respond to their own name being called or may spend a lot of time playing in a repetitive way, perhaps lining toys up or flapping their hands repetitively. Some children initially seem to develop in a typical way but then regress, losing speech or other skills; this should always be assessed further.

Health visitors and family doctors can listen to early concerns and refer children on for more specialist assessment when this is appropriate. Even if a diagnosis of autism is not made at this early stage, interventions to help the child's communication and understanding can still help. Diagnosis can usually be reliably made from the age of 3, and sometimes clinicians are able to make a diagnosis before this. However, diagnosis sometimes comes much later for a variety of reasons.

The Diagnosis of Autism

Children from 5 to 10 years

For children with difficulties across the autism spectrum, differences may only become more apparent as the child starts and moves through primary school. They may show differences in the way they interact; perhaps they seem less interested in other kids or less likely to understand and join in with imaginary or group games. They may struggle with change, be very focussed on their own agenda, or seem unable to make or keep friends. Teachers and parents may also notice sensory sensitivities, such as a dislike of noisy playgrounds, assemblies, or the dinner hall, or a reluctance to wear certain fabrics or aspects of uniform.

Some children have quite subtle difficulties which only become clear as the gap with their classmates widens. For example, most young children have trouble sharing toys or taking turns and many can be shy and unwilling to join in. As children progress through school, however, most will develop their social skills and will have fewer problems in these areas. Children with autism may then start to stand out more as their social skills are not developing at the same rate.

Concerns in adolescence

Sometimes it is not until secondary school that difficulties in social interaction are fully recognised, and parents and young people themselves question whether to seek further assessment. The extra social demands of secondary education may highlight difficulties that were always 'managed' up till now.

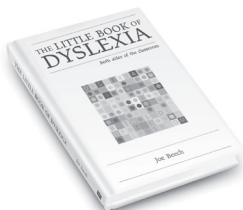
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In primary school, children have the same teacher all day and stay with the same classmates. This can help children to feel settled, and adults can get to know them and their needs. Secondary school usually means more movement around the school and interactions with many more teachers. The young person may struggle to cope with this transition. They may be getting into more trouble at school, refusing to go, or becoming more isolated socially. Their parents and teachers may be really worried about their ability to cope with exams and college if they don't get additional support.

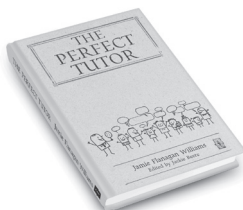
For a diagnosis of autism to be made, difficulties can't simply have started in the teenage years – differences in development must have been evident from the early years, even if these were not a cause for concern at the time.

Who can make a diagnosis of autism?

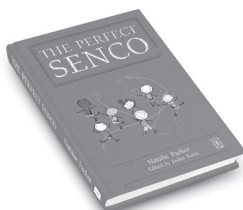
Anyone making an autism diagnosis should be specially trained to identify the condition. They also need to be able to rule out other diagnoses which can be confused with autism. A diagnosis may be made by a psychiatrist, paediatrician, psychologist, or speech and language therapist. These are specialists who have had additional training in the assessment and diagnosis of autism. Often this help is accessed by referral from the family doctor or another healthcare professional such as a school nurse.



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allows anyone who lives or works with children with autism to understand their world through an 'autism lens'.

The most positive step we can take with a child with autism is to understand the condition, and the world in general, from his or her point of view. This book develops the knowledge and delivers evidence-based strategies for communication, social interaction and the emotional, behavioral and sensory challenges faced by young people with autism.

"A concisely written work that will be especially helpful for parents trying to get 'up to speed' when their children are newly diagnosed, it covers a wealth of material quickly without over simplifying."

Lars Perner, PhD, Assistant Professor of Clinical Marketing, Marshall School of Business, University of Southern California

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"A great book, packed full of facts and information."

Pam Smith MBPsS, BMus(Hons), BSc(Hons), PGCE, Postgraduate Certificate in Professional Studies in Education (Autism). Special School Teacher, Surrey

"This excellent little book will be appreciated equally by parents and carers as well as by professionals."

Eric Taylor, Educational Psychologist, Persona EPS Ltd

Dr Samantha Todd is a clinical psychologist who works with children and adolescents with learning disabilities. She also provides regular training for teachers and children's services, and has co-developed a programme for behavioural difficulties, "Riding the Rapids: Living with Autism or Disability"[™].



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