

Explaining Autism Spectrum Disorder

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Note:

This book contains a number of examples of people with Autism Spectrum Disorder in various situations. In each example, although the situations are based on the experiences of a variety of people with ASD both observed and reported, the identities have been changed and details have been altered to make the example more universal. They are, therefore, designed to be illustrative, and should not be taken as direct case studies.

Foreword

Within the National Autistic Society we run a parent programme called help! Over 16,000 parents have undertaken the programme. Very few books have become such an instant hit in the way the author's first book *Finding Asperger syndrome in the family* did in 2007. Time after time we observe parents pick up her book in our lending library and not be able to put it down!

Clare Lawrence has written another refreshing, direct and engaging book particularly aimed at those who come with little prior knowledge. Her starting point is a reminder that autism is not uncommon – nearly everyone will know someone who has the diagnosis. The person with autism might be a child you work with in a school, someone you occasionally converse with as a work colleague or a next-door neighbour. Therefore we all need to be aware and have some practical ideas about how to understand and communicate.

Whilst explaining what autism is there is enough information to satisfy both the lay reader as well providing more in depth material for those with an interest in detail including some of the history of autism. In her explanations of autism the author manages to avoid presenting autism as a closed case - there are few absolutes in autism and she explains we are still learning about the differences in the brain that give rise to a diagnosis. She avoids clichés instead using

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interesting case examples to illustrate the variation in what autism looks like.

Acceptance of autism is the cornerstone of this book. Acceptance is not just a nice thing to do; acceptance is the lynchpin of self-esteem. And the author's message is that we can all play our part. If we have a generation of people with autism that grow up feeling OK about themselves then we can consider we are on the right track. Clare challenges the reader without preaching. She make us realize that acceptance is not simply thinking 'I will overlook your odd behaviour' it is about thinking of how to take it further - 'I will try to understand your odd behaviour... can you also understand mine?' because communication is two way. People with autism are in the minority but that does not mean their experience or ways of interacting are necessarily inferior. The ways those without autism interact are sometimes equally baffling and illogical. The reader is encouraged to see the 'communication ball is in the court of those without autism'. We should make the effort and take the time to understand and communicate with people who have autism.

She goes on to explain how we should always view behaviour in people with autism in the same way as behaviour in the rest of the population - sometimes confusing but always for a reason. And often the reason is an attempt to make contact – to communicate. We should respond to these attempts to make us comprehend their needs and not let our lack of understanding make us consider anything 'odd' as requiring 'treatment'. Her respect and understanding are evident throughout.

I enjoyed the numerous practical tips which make the book a rewarding reading. She gives useful insights for example using our own responses to help us in communication – 'It may well be that you feel slightly nervous about how to interact with a person with

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ASD ... hold onto that feeling! That feeling is how the person with autism probably feels most of the time'. Books like this help us all in our quest to understand and demonstrate true acceptance. If we can achieve this we are more likely to have a generation of people with autism who feel OK about their selves and take their place in society as equals.

Andrew Powell 2010

Introduction

This book sets about to try to give a brief and accessible introduction to – to 'explain' – Autism Spectrum Disorder (ASD). But why would most of us need Autism Spectrum Disorder explaining to us anyway? Surely very few of us are ever going to know someone with ASD, so why do we need to know?

According to Tian Zheng at the Department of Statistics, Columbia University [April 2009], we each of us know about 770 people at any one time. Conservative estimates of the prevalence of ASD in the general population [Baird et al, 2006] are about one in a hundred, so (although this is an unscientific way of doing it!), each of us may be likely to know around seven people with ASD at any one time in our lives. Of course, some of us will know more and many will know fewer, but the point is that ALL of us are going to know SOME people with ASD. We are going to meet them at work, as pupils in our child's class, as members of our golf club or choir or gym or book group. All of us could do with having a better understanding of what ASD is, of what it means, of how we can make communication easier with and for people with ASD and how we can help make the general environment more welcoming.

So who is this book for? It is for parents of a child with ASD, for grandparents, aunts and uncles, brothers and sisters. It is for friends,

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girlfriends and boyfriends, husbands and wives, for the person with ASD himself and his own children. It is for the teacher and employer, for the person in the library, the policeman, the security guard and the dentist. It is for the person who fits shoes and the person who cuts hair – for anyone who will come across people with ASD in their lives. In other words, it is for everyone.

Incidentally, I am referring to the person with ASD as 'he' throughout this book, but that is not really fair. Although men are more likely to have ASD than women (approximately four times as likely [Ehlers and Gillberg, 1993]), Autism Spectrum Disorder does occur in women, and it is important that this is recognised. "Asperger's and Girls" (Tony Attwood et al, Dec. 2006) is an excellent resource that explores how ASD may present in girls and women, and is well worth reading. For clarity in this book, however, unless I am using a particular example I will refer to the person with ASD as 'he', and parents, teachers, carers etc, in the main as 'she'. It just makes the grammar easier!

Autism or Asperger syndrome? Introducing the spectrum.

Although the term Autism Spectrum Disorder is becoming more commonly used it leaves many people confused. What is the 'Autism Spectrum'? Does it include autism and Asperger syndrome, and what's the difference between autism and Asperger syndrome anyway?

The term 'autism spectrum' was first used by Lorna Wing and Judith Gould in 1979. It was used when it became understood that autism did not present as a single, concrete condition but was something that manifested itself across a whole spectrum of presentation, from the individual who is considerably withdrawn and cut off from the rest of the world through to the person who may have a job, an education (often to a very high level), a family

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and all the usual trappings of an ordinary life, but who is known as slightly eccentric, different or unusual in his social interactions and relationships.

Since this spectrum has been recognised there has been a veritable flourish to identify and post-diagnose the famous throughout history with ASD. Mozart, Einstein, Newton, Andy Warhol, George Orwell, Napoleon... all have been put forward at some time as possibly having Autism Spectrum Disorder. The point of these speculations, I think, is the recognition that ASD is not new, nor has the 'type' – unusual thinkers, people who see things differently, those who find ordinary social relationships difficult to manage or maintain – sprung into being since given a name. There is an ongoing and vociferous debate about whether ASD is becoming more prevalent. Perhaps all that is happening is that we are getting more sophisticated in identifying the spectrum as more than a single, rather obvious condition.

Autism as a term was first used in 1911, and was adopted by Leo Kanner during his research in America in the 1940s. He described a condition called 'infantile autism' to describe a sub-group of his childhood schizophrenia study. At much the same time Hans Asperger in Austria was studying a group of children he described as having 'autistic psychopathy'. Kanner was writing in English and his work gained considerable attention in the English-speaking world, while Asperger's work remained confined to Europe and was not widely recognised until brought to attention by Lorna Wing. Perhaps because of this, Kanner's autism was widely known throughout the '50s and '60s where Hans Asperger's work has only really been acknowledged since the '80s. Were each familiar with each other's work? Asperger read and acknowledged Kanner's work on Infantile Autism but it is not clear whether Kanner was aware of Asperger's writings. What is least clear of all, and still the subject of

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much debate, is whether they were describing the same condition, or two different ones.

Kanner's (or Classic) Autism has traditionally been used to refer to the condition as it affects people who also have a learning disability. 'High Functioning Autism' has been used for people with an IQ in the 'normal' (70 – 130) range, or indeed above that. Autism, then, in itself is clearly not an intellectual impairment. Since the condition as described by Asperger did not include intellectual impairment, and indeed Asperger himself noted that many individuals with the condition had superior intellectual ability, 'Asperger syndrome' has traditionally been used to describe this subsection of the autism spectrum. However, since the two conditions share so much common ground, many argue that they are simply the same condition by another name, and indeed they are likely to be categorised as such in the new diagnostic criteria of DSM -5 (see p33*). Whatever term is used, ASD in all its manifestations is complicated, complex and varied. That is what makes it so fascinating!