



Introduction

Clare continues to be rather a loner and becomes noticeably upset if other children try to include her in their games or activities ... She is not very helpful in the classroom and can be very obstinate ... She finds it hard to follow general instructions and quickly panics. She is very self-centred ... inclined to daydream ... has difficulty working with others ... often sullen and determined not to co-operate. She dislikes being given a direct order ... Clare's difficulty to get on with people is impeding her learning as she cuts herself off and does not listen attentively ... tantrums ... After a determined start at the beginning of the term to play with the other children, she has now relapsed and is more alone than ever.

(extracts from my primary school reports)

Here is one of my most vivid memories of school: I am standing in a corner of the playground as usual, as far away as possible from people who might bump into me or shout, gazing into the sky and absorbed in my own thoughts. I am eight or nine years old and have begun to realize that I am different in some nameless but all-pervasive way.

I don't understand the children around me. They frighten and confuse me. They don't want to talk about things that are interesting. I used to think that they were silly, but now I am beginning to understand that I am the one who is all wrong. I try so hard to do what I am told, but just when I think I am being most helpful and good, the teachers tell me off and I don't know why. It's as if everybody is playing some complicated game and I am the only one who hasn't been told the rules. But no-one will admit that it's a game or that there are rules, let alone explain them to me. Maybe it's all a joke being played on me; I know about "jokes". I would be happy if they left me alone to think my thoughts, but they won't.

I think that I might be an alien who has been put on this planet by mistake; I hope that this is so, because this means that there might be other people out there in the universe like me. I dream that one day a spaceship will fall from the sky onto the tarmac in front of me, and the people who step out

of the spaceship will tell me, "It's all been a dreadful mistake. You were never meant to be here. We are your people and now we've come to take you home."

In the next few years, I would work out that the spaceship was never going to come and rescue me, but it wasn't until I was twenty that I finally found a name for my differences, when I was diagnosed with Asperger's syndrome, a mild form of autism. Five years later, looking back at my schooldays, I feel regret and anger for the needless pain I went through and for the energy that I and my teachers wasted pointlessly. If the right people had only been given the right information, more than a decade of my life might have gone very differently. Talking to other adults with Asperger's syndrome, I found that the same regret and anger were almost universal (in fact, my school experiences were far better than those of many others: I was academically able in many areas, had several good and sympathetic teachers, and the teasing and bullying that I experienced was comparatively mild).

It would be nice to think that things had changed since my school days, but, in discussions, teenagers still at school today described the same problems and issues as people in their thirties and forties (many of these school problems, incidentally, were described in Hans Asperger's original paper in 1944). In the '80s and '90s, awareness of and research into Asperger's syndrome increased dramatically, but it is still taking considerable time for this new knowledge to reach teachers and others "on the ground".

Consequently, people with Asperger's syndrome are often passionate about sharing our knowledge of and insights into Asperger's syndrome, in the hope that the next generation of children with Asperger's may not have to go through what we did. We don't need ramps or expensive equipment to make a difference for us; all we need is understanding. As one young man with Asperger's, Simon, commented, "I think the main problem with AS is simply a lack of awareness."

In recent years, several excellent guides to Asperger's syndrome by professionals have been published, including a couple aimed specifically at teachers (I've included a list of some of the best of these in the appendices). It would be redundant to duplicate this material, and in any case, I am neither a researcher (although I read as widely as I can in the research literature on Asperger's syndrome and autism), nor a teacher (although I work part-time at a school for children with autism and Asperger's syndrome, the particular children I work with are severely disabled, sometimes non-verbal, and so face very different educational challenges). My only qualifications for writing this book are that I have Asperger's syndrome and was once a schoolchild.

However, many teachers and other professionals who work with children and young people with Asperger's have said to me that, while the

practical advice and information provided by books written by professionals are indispensable, they still find it very hard to understand “what goes on in the head” of many of their students – what’s it’s actually like to be a schoolchild with Asperger’s syndrome. They report that autobiographical accounts by people with Asperger’s and other forms of autism have been uniquely helpful, and have enabled them to empathise with their students to a much greater degree, but obviously any autobiography can only describe the experiences of one individual, who may be more or less typical, and will cover many aspects of life other than school.

This book is not intended to replace but to complement those written by professionals and by other people with Asperger’s. I can’t advise on what teaching strategies are most effective with students with Asperger’s syndrome or provide practical tips. I can only describe what I and others experienced as children. I will try to communicate something of the subjective experience of school for children with Asperger’s syndrome, in the hope that this will equip teachers to approach such students with greater understanding. In keeping with this goal, I have generally avoided quoting from texts by professionals in favour of first-person quotes from people with Asperger’s syndrome. I have occasionally quoted from professionals either to back up the personal impressions of people with Asperger’s with research or when a comment has seemed particularly insightful. However, I have read extensively among accounts by professionals, parents and teachers in attempting to understand how they perceive us and why they sometimes react to us in the ways that they do.

In the following chapter, I have given a brief “beginner’s guide to Asperger’s syndrome”, summarizing basic information on the features of the syndrome, before going on to examine what this means “from the inside”, first in terms of overall perceptions of education and its goals, and then in practical terms, examining the experiences of schoolchildren with Asperger’s not only in the classroom but also in areas of school which are often ignored or not considered to be of educational interest, but which often loomed as large in people’s memories as anything that happened in the classroom. Inevitably, the division into chapters is somewhat arbitrary – many problems spill over from the classroom to the corridors or vice versa. I have devoted separate chapters to the topics of “challenging behaviour”, preparing for the world outside school, and finally to one issue rarely addressed by professional textbooks but of crucial importance to people with Asperger’s syndrome: sharing knowledge about Asperger’s syndrome with the pupil themselves.

In writing this book, I have drawn not only on my own memories but also on the accounts, experiences, and opinions volunteered by many other people with Asperger’s (including people from the UK, the USA, New Zealand, Sweden, Canada and the Netherlands), who generously granted their permission

for me to quote them and encouraged me to pursue this project. I hope that I have managed to convey something of the diversity of people with Asperger's syndrome, as well as the things we have in common.

For far too many people with Asperger's, as Jack commented, " ... *all* of school was either terrifying or totally boring ...". Hopefully this book may do a little to change things.

A note on terminology

Like many other people with autistic spectrum conditions (see Sinclair 1999), I object to the insistence on using "people-first" language by referring to "people with autism" instead of "autistic people". We are not people who "just happen to have" autism; it is not an appendage that can be separated from who we are as people, nor is it something shameful that has to be reduced to a subclause. As Sinclair notes, "It is only when someone has decided that the characteristic being referred to is negative that suddenly people want to separate it from the person."

A note on quotations

All quotations for which I have not cited a published source are from people with Asperger's syndrome. Some of the names given are real names, while others are pseudonyms; I have respected individual preferences about this wherever possible.