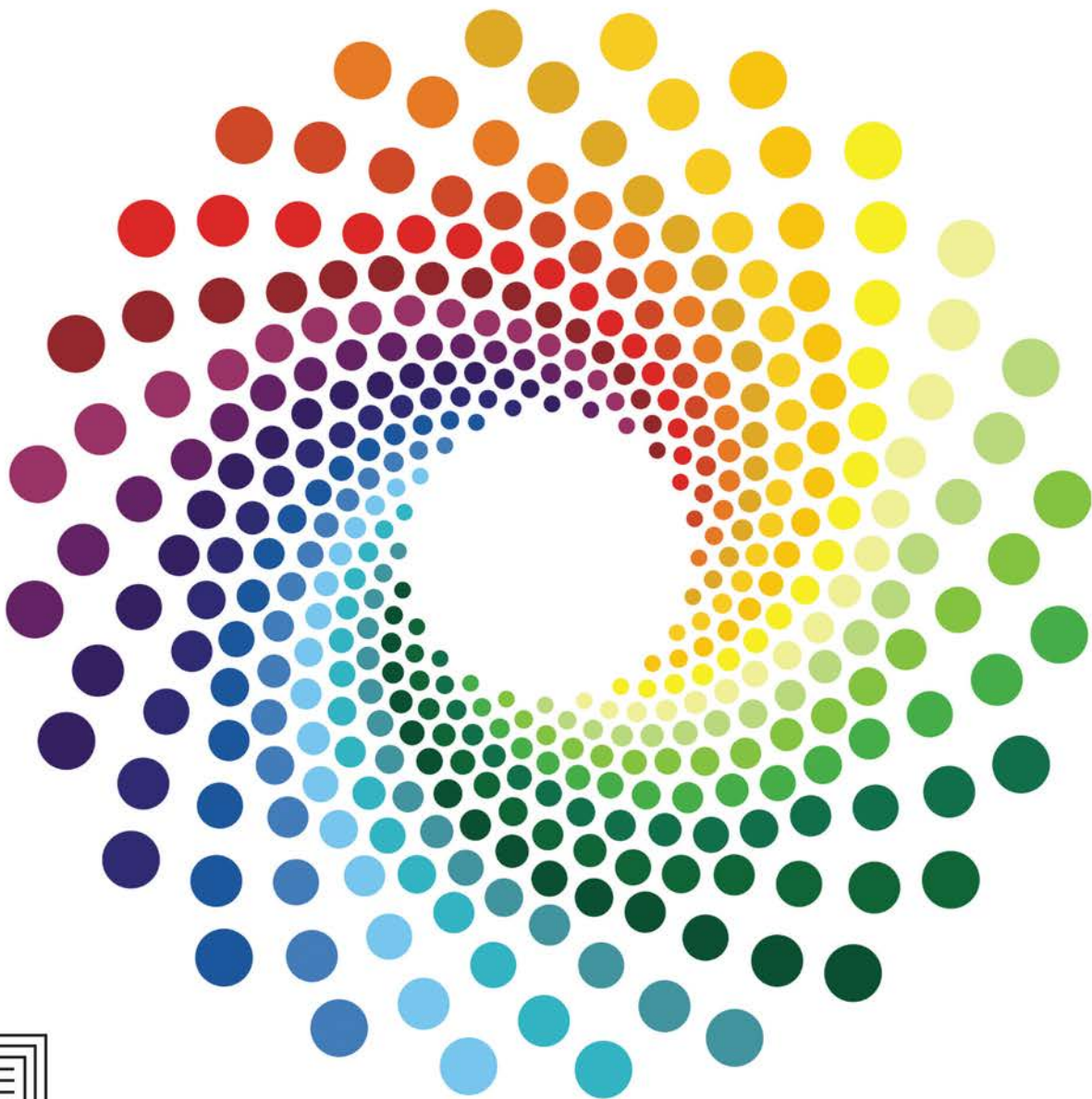


SUPPORTING PUPILS ON THE AUTISM SPECTRUM IN PRIMARY SCHOOLS

A Practical Guide
for Teaching Assistants



photocopiable

A **David Fulton** Book

Cary Canavan

Supporting Pupils on the Autism Spectrum in Primary Schools

Written to meet the needs of teaching assistants and learning support assistants, this book provides a practical toolkit for supporting students on the autism spectrum in mainstream primary schools.

The book offers a clear, jargon-free explanation of autism spectrum conditions and examines the difficulties arising from these conditions and how they can impact on students' learning. Addressing issues that arise on a daily basis, it is full of practical advice and strategies for supporting students socially and academically across all areas of the curriculum.

Features include:

- advice on supporting students through examinations;
- examples and case studies to illustrate how the strategies described work in practice;
- forms to help with information collection and evaluation; and
- templates to scaffold students' comprehension and learning in different subject areas.

Packed with photocopiable resources that can be adapted to suit individual students' needs, this book is essential reading for teaching assistants who want to help their students on the autism spectrum to reach their full potential.

Cary Canavan is a Consultant in Autism specialising in Asperger Syndrome. She offers training, advice and support for those teaching and employing young people with AS.

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Supporting Pupils on the Autism Spectrum in Primary Schools

A Practical Guide for Teaching Assistants

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Contents

<i>How to use this book</i>	vi
<i>Note on the terminology</i>	viii
Introduction	1
Part One	3
1 Strengths of individuals with Asperger Syndrome or High Functioning Autism	5
2 Important things to know about Autism Spectrum Conditions	6
3 Autism and Asperger Syndrome – a brief history	11
4 Girls with Asperger Syndrome	15
5 Parents are a valuable resource – use them	16
Part Two	19
6 Be prepared! Transition into primary school	21
7 Sensory overload – creating an autism-friendly environment	48
8 The real challenge – managing behaviour	71
9 Bullying and Asperger Syndrome	108
Part Three	123
10 Organization – practicalities	125
11 Autism is a communication difficulty	130
12 Handwriting difficulties, poor working memory and scribing for a pupil with AS	144
13 Written assignments	147
14 English Literature	181
15 Science, Technologies and PE	198
16 School trips	212
<i>Afterword</i>	215
<i>Glossary</i>	216
<i>Bibliography</i>	224
<i>Index</i>	229

How to use this book

The book is split into three parts:

Part One: Asperger Syndrome: the basic physiology, and how it can impact upon a person's life, together with a brief history of the condition.

Part Two: how the school's social and physical environment can impact upon the pupil's behaviour, and ways to manage it. It is critical to prepare for the pupil before they arrive. This section lays down the foundations for a smooth transition into primary school; explores the reason for a pupil's behaviour; and how to react in a crisis and avoid one altogether. The younger child with an ASC is less able to regulate their nervous system and control their emotions. This means that the behavioural challenges facing them on a daily basis are greater.

Part Three: subject areas; the difficulties they present and strategies, including photocopiable templates, to support your target pupils across the curriculum. In the primary school much of the learning is already supported by visual references and worksheets. Language modification and differentiation may help the pupil with AS to achieve beyond their years. The challenge for teachers and TAs is to send them to secondary school self-confident enough to continue to progress.

The book builds upon the need for consistency and clear instructions to support the pupil across the curriculum by reducing the number of different ways to do the same thing, and maintaining clarity of language so that the pupil understands exactly what is expected of them.

Most chapters contain an explanation of how autism, a neurological developmental disorder, affects the topic, be it behaviour or learning. This is followed by a discussion, practical advice, detailed description of strategies, and templates to enable you to support them effectively in lessons.

There is a comprehensive reading list of books and website addresses exploring the issues in greater depth at the end of each topic chapter. I have read all the books and chosen them for their usefulness and readability. The most insightful are written by people on the spectrum and these are italicised.

Autism is a heterogeneous condition: no two people with the condition are the same. A strategy or intervention that works with one child may not work with another. Therefore, you should learn about each individual and how you can support them effectively in school. Find out about their unique autistic operating system.

Autism is also largely a hidden condition. The pupil with a diagnosis of an ASC, regardless of having an Education Health and Care Plan (EHCP), has several basic needs and these are best met by putting together an Individual Education Plan that includes the following principles:

- 1 Maintain consistency at all times – avoid changes when possible.
- 2 Prepare for any changes – staff, room, timetable, groups – well in advance.
- 3 Have strategies in place from the start, which all staff dealing with the pupil apply without deviation.

- 4 Expectations of behaviour and working practices should be consistent from lesson to lesson, room to room, staff member to staff member.

If the pupils know what is expected of them, they can meet those needs and feel safe and competent. Change leads to confusion, fear having a profound effect upon the pupil's self-esteem. Knowledge of the impact of autism, understanding of the pupil's needs, tolerance and a genuine regard for the individual will enable you to support them to do the best they can. They will not disappoint you.

Accept ≈ Respect ≈ Protect

Note on the terms: Autistic Spectrum Conditions and Asperger Syndrome

According to the National Autistic Society (NAS): 'The term 'autism' is used to describe all diagnoses on the autism spectrum including classic autism, Asperger syndrome and high-functioning autism.'

However, in 2013 in the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders, (DSM 5) published by the American Psychiatric Association (APA), Asperger Syndrome (AS) has been absorbed into the term Autistic Spectrum Disorders (otherwise known as Autistic Spectrum Conditions – ASC). It continues to exist in the World Health Organisation's (WHO) International Classification of Diseases (ICD 10).

ASC is more popular as a term among academics than ASD because it is less stigmatising and acknowledges that, while individuals have been diagnosed as having disabilities, they also have areas of strengths in thinking, imagining, reasoning, learning, understanding and memory. Both individuals with High Functioning Autism (HFA) and AS have average to high IQs and people with AS have no delay in language although it may be stilted and idiosyncratic.

However, Asperger Syndrome is still classified as a separate term by the NAS, which is a primary resource here in the UK; so I use the term Asperger Syndrome (AS) and Autism Spectrum Conditions (ASC) interchangeably throughout the book.

Introduction

Staff supporting pupils on the autism spectrum in mainstream primary schools are often there at the start of the journey. You are invaluable to our children. You are interpreters, guardians and advocates. This book is for you. I hope the practical strategies and templates in this book will help you support your pupils and teachers across the curriculum.

I am an ex-English teacher with Special Educational Needs (SEN) teaching experience in primary and secondary schools. My son was diagnosed with Asperger Syndrome (AS) at the age of 13. When I realised he was autistic, two years before he was diagnosed, I resolved to learn as much as I could about the condition (a lifetime project). While studying for my masters degree in autism at the University of Birmingham, I took a job as a teaching assistant (TA) in a mainstream secondary school supporting pupils with AS.

However, while working as an SEN teacher in a primary school overseas, I had the privilege of working with a 9-year-old 'gifted child', who had Asperger Syndrome (undiagnosed). It was my job to challenge him. We learned Latin, French, studied Shakespeare and Chaucer. He was quite extraordinary. When he went to do the entrance exam for a scholarship to the top independent school in the country, he didn't do the English essay because the topics were 'boring'. Luckily, I told him to take the book he had written with him to show the principal.

At least 1 in 100 children are diagnosed with an Autistic Spectrum Condition (ASC) and 71 per cent of these are now educated in mainstream schools. Only 22 per cent of teachers have been trained specifically in ASCs, typically for 1 to 4 hours. Ideally, each school should have an autism base with specially trained staff to support the AS pupils and a continuous programme of training for all teachers in ASCs.

The reality is that the child with an ASC is simply another pupil on the SEN register and is supported, or not, by members of the SEN team, who may or may not have been trained or understand the condition and its impact on learning and behaviour. However, in my experience, TAs are going on the courses, and sometimes know more about ASCs than teachers.

Using the square peg (autistic) round peg (neuro-typical: NT) analogy: mainstream schools have lots of round holes; some may be different sizes to accommodate a range of round pegs but, basically, they are all round holes. Square pegs do not fit into round holes, unless you shave off the corners and knock them in. Doing this, you damage the square peg. It looks round but it isn't. If you have square pegs make square holes into which they can fit easily or, at the very least, make the round holes larger.

Many educators advocate the latter, believing that children with ASCs need to learn how to fit into the NT (non-autistic) world. Autistic children will become autistic adults. They may learn how to manage themselves but only in an autism friendly environment. They still suffer extreme stress and can meltdown or shutdown when overloaded. This doesn't change whether they are aged 4, 14 or 40.

The purpose of this book is to explain, in layman's terms, why pupils with an ASC have difficulties with learning and social skills and display idiosyncratic behaviours. Issues are

2 *Introduction*

discussed, followed by detailed advice, strategies and the tools to implement them. These are not exhaustive and I hope that you will read some of the recommended texts and develop your own strategies, tailoring them to the needs of the individual pupil you work with.

By the time you finish this book and are practised in using the strategies, I hope the support you give your ASC pupils will be underpinned by an understanding of why the child with AS behaves this way; the difficulties they face; and how you might support them with strategies and resources appropriate to the individual child.

Thank you for reading this book. I infer from this that you are interested in children like my son, and care enough to seek ways to help them achieve the best they can. Our children quite literally change the world, for all their difficulties.

Part One

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1 Strengths of individuals with Asperger Syndrome or High Functioning Autism

Before I talk about their difficulties, I would like to write about some of their strengths:

- The individual with AS/HFA is loyal and socially optimistic: they will persevere with a friendship, even if let down.
- They are free from prejudice and accept people at face value.
- Contrary to popular belief, they are very empathic and may surprise you with their insight. (They just don't know what to do about another person's feelings.)
- They will tell you what they really feel and think about something rather than what they think you want to hear.
- When they ask a question – they want the honest answer to it. There is no hidden motive behind it.
- They will tell the truth even if it means getting themselves in trouble.
- They rarely do something they know to be wrong, even when pressured.
- They have a strong sense of justice and neither fear nor favour.
- Their humour can be unique and unconventional.
- They love words, especially puns, and will make up their own jokes with them.
- They want to co-operate but often don't know how.
- If they enjoy a sport, they will train hard to be the best and are particularly good at individual sports.
- They have the ability to learn quickly and want to progress, especially if interested in the topic.
- When they start a task they want to do it perfectly.
- They have a good eye for detail and pick up mistakes.
- If it interests them, they can concentrate on a single task for a very long period of time.
- When they are interested or motivated in a task they will persevere with an extraordinary determination to finish.
- Their long-term memory is good, especially for childhood experiences, facts, figures, dates and film dialogue or audio recordings.
- They are creative, often insightful, and can provide an original solution to a problem.
- Their spatial awareness can be quite remarkable – they are visual thinkers.
- They often have an encyclopaedic knowledge of their special interest.
- Of average or above average intelligence, they have the potential to go on to university.
- They often have an interest or a talent for something: design, Japanese, quantum physics, art, music or computing – find out and nurture it.

2 Important things to know about Autism Spectrum Conditions

The Autism Spectrum covers a very broad range of Pervasive Developmental Disorders, which are life-long neuro-physiological conditions (see glossary for descriptions of each of these conditions):

- Classic Autism, also known as Kanner Syndrome or Low Functioning Autism;
- High Functioning Autism (HFA);
- Asperger Syndrome (AS);
- Semantic Pragmatic Disorder (SPD);
- Pathological Demand Avoidance Syndrome (PDA);
- Retts Syndrome;
- Tourette Syndrome;
- Pervasive Development Disorder Not Otherwise Specified (PDD-NOS) – this often develops into autism or AS later in life, or a child with autism may improve and be re-diagnosed with PDD-NOS.

Most ASCs are hidden disabilities caused by differences in the formation of the brain and the way it responds to stimuli. This is backed up by research using *functional Magnetic Resonance Imaging* (fMRI) scans, which detects blood flow through the brain in response to a variety of stimuli. Consequently, our expectations of individuals with an ASC can sometimes be compared to asking a blind person to 'look at this' or a deaf person to 'listen'; this is why it is so important that we understand the condition and appreciate the difficulties they are confronted with on a daily basis.

Research into autism is ongoing and new findings occur on a regular basis. The brains of individuals with Asperger Syndrome are bigger than average and they have more white and grey matter. Grey matter is responsible for extracting and processing information from sensory organs such as sight, sound and speech, and is involved in muscle control, memory and emotions. Various parts of the brain compare that information with what's in the memory and use the information to plan and execute behaviour. White matter carries information around the brain through electric and chemical activity, but this is also disordered.

More recent research suggests that the autistic brain has more neural pathways to carry information round the brain but that they are not co-ordinated, or that the white matter is too short so that the brain's neural pathways are under-connected. Or that more information comes into the brain than it is able to process, leading to overload. In order to function, people with autism use strategies to distract themselves from the stimuli that threaten to overwhelm them, leading to a display of idiosyncratic behaviours. Researchers concluded that this might explain the problems with attention: for example, if too much information comes in through the visual system, they become distracted and show less interest in social interaction. However, they also suggest that hyper-connectivity might explain the islets of ability in subjects and visual search or detailed focus processing.

Whatever the current theory, it is enough to know that autistic brains work differently.

Difficulties processing information

As a result of all these differences, people with an ASC have processing difficulties affecting:

- social interaction;
- emotional recognition and regulation;
- impulse suppression;
- language processing – input and output;
- fine and gross motor skills;
- planning and organization;
- attention, short term memory;
- the ability to be flexible;
- sensory regulation.

There may also be areas of profound ability in any subject area: not just science or maths and music or art.

To use a metaphor to illustrate the problem:

- 1 The typical brain is like a road network. Information coming in at A goes to B by travelling along the neural pathways. Like a car travelling along the motorways, the information gets to its destination without any fuss.
- 2 The autistic brain is different. Information coming in at A goes to B, but it takes longer, like a car going from A to B along detours. It may even get lost and end up at the seaside (C) for a holiday, turning up at its destination weeks or even months later.
- 3 With the uneven distribution of grey and white matter, and the low levels of chemical neurotransmitters to push inhibitory messages across the synapses (joints), it may even be a more arduous journey, with traffic jams and detours. The synapses may even be broken in some places so that processing is impaired and takes much longer.
- 4 The uneven distribution of white and grey matter may account for the exceptional abilities one can find in pupils with AS, such as calculating complex mathematical equations without the apparent need to process them, or a photographic memory by which large amounts of text can be quoted but with little comprehension. Like a shortcut, getting from A to B without really knowing how – it's just the way they have always done it.

Faulty connections may also account for sensory issues. Super-efficient neural pathways may cause hypersensitivity and a flood of information, so that the nervous system is constantly under pressure to process more than it can; and the lack of connectedness, together with thin white matter and patchy grey matter, can be the cause of hyposensitivity.

Processing tasks: planning and writing an essay has been described to me as like building a tower of cards – 'it's very hard'! An interruption by a well-meaning TA or teacher sends the tower tumbling down. They have to start all over again because of a poor working memory. How frustrating is that! You will see an upset and angry child.

The amygdala

The amygdala (there are two) are a small part of the brain that have a major influence on much of the behaviour of a child on the spectrum; they are responsible for recognizing and

co-ordinating information from different parts of the brain and processing an emotional response. It is one of the areas in the brain responsible for recognizing social cues such as facial expressions and body language: the emotional responses of other people. In the early years the amygdala are enlarged in people with an ASC, but they shrink to become smaller than normal in adolescence.

The amygdala trigger the flight or fight reflex. They are linked to the frontal cerebral cortex via the hypothalamus, which, depending on the information relayed, will suppress the reflex. For example, you see someone baring their teeth at you; your heart races, muscles tense, you feel hot and your hands sweat. These physical reactions are relayed via the hypothalamus to the pre-frontal cortex, which regulates the emotion on a subconscious level in nanoseconds.

At the same time, the cerebral cortex and hippocampus evaluate the information, based upon knowledge or memories of similar past experiences to make a judgement as whether or not there is a threat present. This information is relayed back to the amygdala through two inhibitory neurotransmitters called serotonin and glycine. The rational frontal lobe system overrides the basic instinct of the amygdala. If your brain reasons that the person is actually threatening you, you acknowledge that you are frightened and in danger and run in the opposite direction. If you recognize that he is smiling, your brain suppresses the desire to run away.

The 'faulty wiring' in the brain of children on the autism spectrum, connecting the amygdala to the frontal lobe, where impulses are controlled, may lead to a breakdown in communication. The autistic individual may be unaware of what is really happening. For example, after getting a fright from hearing a loud, unexpected noise, an adrenaline surge causes a racing heart and hyper-alertness to everything around about. The difference is that in a nanosecond NTs assess the danger and quickly realise that it's actually not going to hurt them. There is nothing to be alarmed about, the heart rate returns to normal and the child calms down quickly, although it takes 4 hours for adrenaline to clear the system. For the individual on the spectrum this may take far longer; the difficulties processing what has happened mean that instead of calming down, the panic rises as they try to work out what has happened. They want to understand; they can't; they become frustrated and angry and this feeling can last minutes, or hours, or the whole day. Adrenaline surges through the system throughout the day and its effects may last for days, leaving the person in a constant state of fear.

Another aspect of the high levels of fear that the child feels is that memories of that event will trigger the same reaction in the future, when placed in a similar situation or with the same group of people. All those intense emotions will come pouring back and send them into a blind panic. Try to imagine what it must be like trying to function while experiencing such an onslaught on the senses and emotions.

They will be unable to recognize that they are in a dangerous situation until they are actually in it. Or they may never see it... You will have to lay down a few rules, which they can use when they get older, to tell them that they must not do certain things and explain what might happen if they do.

Lack of inhibition

fMRI research has revealed that underconnectivity between various areas in the brains of people with autism (and ADHD) leads to a lack of inhibition and impulse control. This leads to:

- difficulties in Executive Function (organization skills);
- narrow interests;

- the need for rigid routine;
- language processing (literal interpretation);
- inappropriate behaviour.

It has also been linked to the lack of Theory of Mind (the ability to predict what another person is thinking or intends to do).

The effect of a disordered inhibitory system has implications for learning that are not immediately obvious. Research into language and metaphor comprehension in individuals with autism found that the reader must suppress knowledge of one object that is totally irrelevant to the analogy. The example was 'Lawyers are sharks'. The intended analogy was that they are aggressive and ferocious, not that they have fins and sharp teeth (Gernsbacher and Robertson, 1999).

NT children will have learned from experience and be able to act intuitively, but the child with autism has to consciously work through the complicated process involved in making the right choice:

- 1 Assess the situation: *which they have difficulty 'reading'.*
- 2 Choose what to do next: *which they may perceive as a totally new experience and have not a clue what to do, so do the first thing that pops into their mind.*
- 3 Assess their choice of action or words: *by this time they are likely to be stressed.*
- 4 Recognize that there might be a problem with what they are about to do or say: *not if they are now panicking.*
- 5 Make a decision based upon what they think might be the consequence of their actions: *unlikely they will be able to process this far.*
- 6 Choose what to do next to adapt their behaviour or language: *totally unable to do this.*
- 7 Then do it: *Too late!*

Pupils with AS often 'challenge' those people around them due to a lack of inhibition. These actions are due to poor neural connections, which fail to suppress 'inappropriate behaviour' until they are specifically taught the hidden social codes.

Children with AS have no natural respect for authority. If you are a teacher you are expected to know your subject. If you make an error they will tell you, reasoning that it's not logical to want to make a mistake or leave it uncorrected. If you ask a question, they will give you an honest answer. Be careful about what you ask and the way you word a question. Social situations can be tricky because the individual will not adhere to the unwritten rules and will say exactly what they think, regardless of the fact that they may be perceived as disrespectful, rude, or even offensive.

Never lie to a pupil with AS. They will not understand the motivation behind it, and may take it as an attempt to humiliate them and never forgive you. Remember, we are the adults and the pupil with AS has no intention of being rude or disrespectful, they are just saying it how it is.

Executive Function – organization skills

The ability to plan and carry out complex cognitive tasks – to organize oneself – is also governed by complex brain processes. Called Executive Function, in autism this ability is interfered with by dysfunction in the frontal lobes of the brain. EF deficit includes a poor working memory, inattention, and difficulties initiating, sustaining and inhibiting actions.

10 *Important things to know about Autism Spectrum Conditions*

It is important to understand that the neurobiological differences impact on the behaviour of the individual with AS. It is not a choice, and it should inform us as to how we manage the pupil in school.

Imagine:

- What it is like to be frightened every day of your life because your brain cannot predict what is going to happen next.
- Trying to concentrate while your body is being tortured.
- Living in a world surrounded by beings you cannot understand: it feels as if you have come from a different planet.

3 Autism and Asperger Syndrome – a brief history

No-one really knows what causes autism. It is not a modern phenomenon. There are the old tales of changeling children, stolen by the faeries and replaced with an identical child who screams and behaves 'badly'. Professor Uta Frith, a psychologist and world authority on ASCs, recounts in her book, *Autism: Explaining the Enigma*, a number of stories of people who display autistic behaviour. One example is Brother Juniper.

Brother Juniper, who lived in twelfth-century Italy, went to visit a sick brother in the hospital. When asked if there was anything he could do for him, the sick brother told Brother Juniper he'd love to have a pig's foot to eat. Brother Juniper went into the forest with a knife from the kitchens and cut off the foot of a live pig and carefully prepared a meal, which the sick brother enjoyed enormously. The owner of the maimed pig complained to the Franciscans but Brother Juniper could not comprehend what he had done wrong.

He was also in the habit of giving people anything they needed, including his clothes. He was told not to do that anymore. However, the next time he met a beggar Brother Juniper told him that he could not give him his clothes but if the beggar took his habit off him he would not stop him.

Frith also describes the Holy or Blessed Fools of Russia, whom she believes may have been autistic. They had no social awareness. Some roamed around naked, having a lack of sensitivity to pain, cold or hunger. They are reported as performing bizarre, ritualistic behaviour; Pelagija Serebrenikova, for example, collected stones and bricks and placed them beside a flooded pit. She threw them into the water. When they had all gone she waded into the pit and threw them out onto the side and repeated the exercise for years.

Some of these holy fools were mute; others ranted in the streets and talked gibberish, parroted people or spoke inappropriately. Treated with tolerance because of their isolation and physical hardship, they were considered touched by God and their bizarre behaviour was given significance in legends as lessons in life. They addressed Tsars and religious leaders without fear. Blessed Basil, fool for Christ, who robbed from the rich to feed the poor, is probably the most famous holy fool. He was canonized despite his criticism of Ivan the Terrible, whom he confronted about his brutality.

Today the most famous people with autism are: Dr Temple Grandin, professor of animal science, inventor, author and lecturer in autism education; Stephen Wiltshire, artist; and Carly Fleischmann, author, non-verbal autistic, who started her degree, age 18, at the University of Toronto in 2013.

Asperger Syndrome is different from classic autism (Kanner Syndrome) and is the most common form of autism found in mainstream schools. It is named after Hans Asperger (pronounced with a hard g), an Austrian psychiatrist who wrote a paper in 1944 about his observations of a group of children. While of average or high intelligence, they displayed untypical behaviour. They used formal and unconventional language; had poor social skills; lacked empathy for their peers; had an all-absorbing interest that dominated conversation;

displayed idiosyncratic behaviour; and were physically awkward. Lorna Wing, a British psychiatrist, coined the name in a 1981 paper in which she described Asperger's symptoms in a group of children she was studying.

In 1989 Christopher Gillberg, Professor of Child and Adolescent Psychiatry at Gothenburg University, Sweden, published the first set of criteria for Asperger Syndrome. It is considered to be the closest to Asperger's original description of the condition.

Little was known about Asperger's work in the English-speaking world until 1991, when Uta Frith translated Gillberg's paper into English from German.

In 1992 Asperger Syndrome was included in the World Health Organization's International Classification of Diseases (ICD-10) and in 1994 it was added to the American Psychiatric Association's (APA) *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV). These publications are the most popular references for a diagnosis.

Asperger Syndrome, as a separate condition, has been removed from DSM-5, published in May 2013. It has been replaced by the umbrella term Autistic Spectrum Disorder, with three levels of severity in order to provide a more precise diagnosis. However, recent fMRI (brain scan) research suggests that Asperger Syndrome is measurably different from autism.

It is generally agreed that AS is genetic and that the autistic brain begins to form mid-term during pregnancy, although brain damage caused by accidents, for example, can result in the person developing autistic characteristics. The greater prevalence of AS today can be explained by better diagnosis, larger populations and higher survival rates among children. The environment we live in today is not very autism friendly and their difficulties are more obvious. Education is a social activity because we expect children to work in pairs or groups and to discuss ideas and share opinions. A person with AS has social difficulties rooted in language impairment and rigid behaviour and will, therefore, stand out more in the modern classroom. Children with AS have fewer problems with speaking, although they can be quite literal in their interpretation of language, and are of average, or above average, intelligence.

Autism spectrum conditions cannot be 'cured' with medical intervention, although there are a number of therapies, including diet, which may lessen the effects of the conditions. It is a disorder of the brain, not a mental illness, although other illnesses, like depression, learning disorders such as dyslexia, motor difficulties such as hypermobility and dyspraxia, and Attention Deficit Hyperactivity Disorder (ADHD) may also co-exist.

The difference between autism and Asperger Syndrome is simply that in autism there is a developmental delay that is absent in AS. Indeed, children with AS may appear to be ahead of their peers in many areas such as language and reading. Children with AS can appear to be academically ahead of their peers in primary school; however, a word of caution, the difficulties experienced by a child with AS or HFA are very complex and very real. Unfortunately, it is largely a hidden disability and these children may need their support increased as they progress through school and their differences emerge, especially in those areas that require social interaction either in the learning environment or at play time.

Famous people diagnosed with Asperger Syndrome today include Paddy Considine, actor; Pip Brown aka Ladyhawke, singer songwriter; Daniel Tammet, savant, author, mathematician, multi-linguist; Gary McKinnon, computer hacker; and Clay Marzo, professional surfer.

The diagnosis journey

Children can be diagnosed with autism from the age of 18 months using ChAT (Checklist for Autism in Toddlers). If a parent or carer is concerned about the development of their child they will usually fill in a short questionnaire with their primary healthcare worker at the 18-month developmental check-up. It is the first step to obtaining a diagnosis. Its purpose is to identify children who are at risk of social-communication disorders.

Many children with HFA and Asperger Syndrome are diagnosed between the ages of 5 and 9. This is because there is no apparent developmental delay such as might have prompted an earlier diagnosis for other disorders. Others may only be recognized once they are in secondary school.

Some children may be missed altogether and grow up to be adults describing themselves as introverts or shy; indulging in life-long hobbies; becoming scientific researchers and leading lights in their careers. Others may suffer from loneliness, depression and isolation, unable to connect with their peers and regarded as odd and unsociable. Some develop strategies to be able to manage themselves and, while they may acknowledge that they have autistic traits, are never recognized as being on the spectrum.

Once the possibility of autism has been established, the parents can request their GP to refer them to be diagnosed for an ASC. One of the first things to be assessed is the child's hearing and sight, followed by an in-depth, multi-agency diagnostic process.

Initially a very detailed family history is taken by a medical professional trained in ASCs, usually in the form of an Autism Diagnostic Interview (ADI-R) or the Diagnostic Interview for Social and Communication Disorders (DISCO). This is followed by an Autism Diagnostic Observation Schedule (ADOS), where an educational psychologist observes the child over several hours in school or nursery; they will then go on to do a cognitive assessment (IQ test) appropriate to the child's age, such as the Wechsler Intelligence Scale (WISC). A speech and language therapist will do a communication assessment, because a communication deficit is one of the fundamental markers for a child with an ASC.

There are also other issues to be considered because other conditions often co-exist alongside autism. So the child will be assessed for ADHD, Sensory Processing Disorder and hypermobility or dyspraxia, and chromosomal analysis for Fragile X will also be investigated. Therefore there may be speech and language therapists assessing use of language; educational psychologists observing the child in school; physiotherapists conducting physical assessments; and neurological consultants doing EEGs and or MRIs. After which the professionals will get together to make a diagnosis – or not.

Contrary to popular belief, getting a diagnosis of autism is a complicated process. Some parents report that it can take anything up to seven years or longer.

The condition is very complex and may also co-exist with other conditions, for example, ADHD, Tourette's, Pathological Demand Avoidance (PDA), Irritable Bowel Syndrome, dyspraxia and hypermobility, which are all considered to be part of an ASC but not necessarily present in all children with an ASC. Autism is a heterogeneous condition in that there is not a single characteristic shared by everyone with an ASC. It is a complex brain disorder that can be affected by the environment because children with an ASC have to be taught everything – they do not naturally pick up social skills through intuition or observation.

Signs of Autism Spectrum Condition in young children

Very often it is teachers or teaching assistants in mainstream schools, who identify that there is a problem with the young child's development and a need to have a child assessed for ASCs. See below for a weblink to NICE's Quick Reference Guide to *Autism: Recognition, referral and diagnosis of children and young people on the autism spectrum*, to assess whether you should bring your concern regarding the child's behaviour to the attention of the SENCo and the child's parents.

Be aware of the delicacy of the situation. Although more people have heard of autism, some parents may be completely ignorant of the condition and require sensitive handling. Therefore, be prepared for a range of reactions and have helpful information to hand, such as may be found on the NAS website. You will need to justify your concerns and help them with the first step to diagnosis, should they wish to pursue it.

Further reading

Attwood, T. (2006). *The Complete Guide to Asperger Syndrome*. London: Jessica Kingsley Publishers.
Frith, U. (2003). *Autism: Explaining the Enigma*. 2nd edition. Malden, MA, and Oxford: Wiley-Blackwell.

Websites

<http://www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction.asp>

National Autistic Society (national charity), providing information, strategies and links to other useful sites.

'Autism – Recognition, referral and diagnosis of children and young people on the autism spectrum' at <http://guidance.nice.org.uk/CG128/QuickRefGuide/pdf/English>.

'Inclusion Development Programme: Supporting pupils on the autism spectrum – an interactive resource for headteachers, leadership teams, teachers, teaching assistants and the ITT audience.' <http://www.idponline.org.uk/psautism/launch.html>.

4 Girls with Asperger Syndrome

Statistically, only 1 in 4 people diagnosed with AS are female. There is growing concern that girls are being overlooked and that the figure is nearer 1 in 2. Females with AS seem to be better able to mask the condition by observing and copying their peers and, therefore, appear to be more socially adept, but often you will find that they have few friends and tend to focus on one person at a time.

Girls have better imaginations than boys and often have a 'fantasy' life and invisible friends. Interests may be cloaked in typical female behaviour, but they are more intensely involved or appear to be unconventional. They may be totally uninterested in their appearance and even prefer to dress like a tomboy, or they may be very interested in fashion and develop their own unique style. Most girls with AS choose not to draw attention to themselves; they have learned that this world doesn't operate the way they see it so they fall silent and observe. Pay attention to the girls who have difficulties and are very quiet in lessons. Are they copying their peers? How do they respond if you give them an ambiguous instruction? Are they often to be found by themselves in the playground or on the very outside of a group of their peers?

Currently, the female pupil diagnosed with AS may appear to be more extreme because she fits into the male model of an individual with AS. It has now been recognized that many females with AS do not fit into the diagnostic criteria of AS, which are heavily biased towards the behaviour of boys. There is a movement to develop a range of criteria appropriate to the diagnosis of girls with AS in the future.

There is a critical need in this area, not least to address the mental health issues associated with teenagers and women on the spectrum, particularly among those who are not yet diagnosed. A growing body of autobiographical literature written by women who were diagnosed later in life reveals that many suffer from depression, anxiety, eating disorders, self-harm and behavioural problems and show a lack of social skills especially in group situations, while able to sustain a close friendship with one other person at a time, and this person may change frequently.

Further reading

Marshall, T. A. (2014). *I am AspienGirl*. <http://www.aspiengirl.com/english>.

Riley-Hall, E. (2012). *Parenting Girls on the Autism Spectrum: overcoming the challenges and celebrating the gifts*. London: Jessica Kingsley Publishers.

Sainsbury, C. (2003). *Martian in the Playground: understanding the schoolchild with Asperger's syndrome*. London: Sage Publications Inc.

Simone, R. (2010). *Aspergirls: empowering females with Asperger syndrome*. London: Jessica Kingsley Publishers.

5 Parents are a valuable resource – use them

The mother knows the child better than anyone else. If the child is seven years old, that is the amount of time it takes to be awarded a PhD, so a mother of a seven-year-old child has an honorary PhD in the study of that child. I know to listen to mother's knowledge and advice. She will provide continuity and experience for the child's lifetime.

Tony Attwood

Writing this chapter, as a parent of a child with Asperger Syndrome, I would like to say that we really appreciate professionals who take the time to talk to us and learn about AS, to inform themselves as to the best way to support our children.

With all the challenges that face our children and the lack of understanding of autism in mainstream education, we have high levels of anxiety too. All we ask is that you remember Every Child Matters and our children need you to understand what it means to have autism and how that impacts on their daily lives.

Also consider how having a child on the spectrum affects our daily lives too, as we organize our days to support our children, helping them to feel safe and competent; wanting them to be valued and accepted for who they are. They are just children. Please, work with us to help our children.

Dear SENCo,

I would like to offer you the opportunity to engage with me regarding (my child), who has been diagnosed with an Autism Spectrum Condition (ASC). Autism is a heterogeneous condition and I am uniquely placed to offer you information pertinent to (my child) and how we might best enable him/her to thrive under your care and fulfil his/her academic potential.

Having a diagnosis of an ASC means that (my child) has a lifelong, pervasive developmental disorder that affects the physiology of the brain, resulting in cognitive processing difficulties and impairments in language, sensory processing and social communication. My child has certain rigid behaviours, a need for routine and is hyper or hypo sensitive to certain sensory input. His/her behaviour is not a choice but a direct result of different wiring in the brain.

A hidden disability, autism means that (my child) may appear, on the surface, to be high functioning when, in reality, surviving the school environment, decoding instructions, meeting the education demands and negotiating social interactions in myriad situations requires a huge effort. This places huge stresses upon (my child) as s/he attempts to meet the expectations of teachers, teaching assistants and peers in circumstances that are often confusing, due to a lack of understanding of what s/he is supposed to do. This can