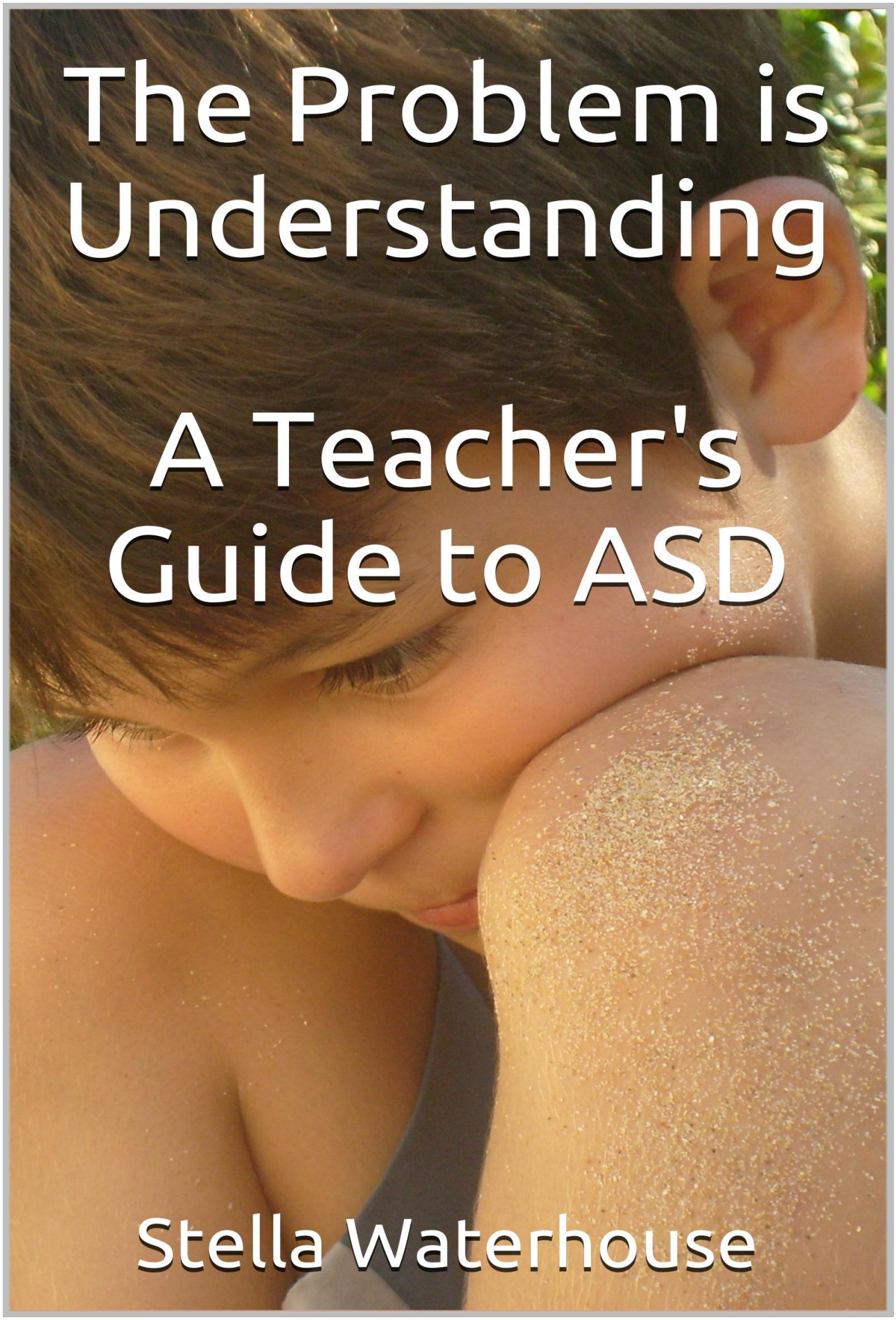
The Problem is Understanding
A Teacher's Guide to ASD
Stella Waterhouse

THE PROBLEM IS UNDERSTANDING

A Teacher's Guide to the Autistic Spectrum

Illustration by Kate Vargues

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INTRODUCTION

This book contains information both on the better known aspects of these conditions and on some of those lesser known but vitally important aspects which have great impact on the child's life.

Much of the information comes from the National Autistic Society and various books on the subject, but it also includes less well known ideas from other sources. These range from the writings of people with ASD to my own research as well as information from related areas such as dyspraxia, dyslexia and Attention Deficit Disorders which overlap in some ways.

This book aims to:
* give a clear picture of the problems such children face.
* detail the implications for learning.

A second book *A, B, C - A Positive Approach to Teaching Children with ASD* offers suggestions on teaching strategies as well as a variety of resources.

NB. While text refers to 'the child' or 'children' such differences affect adolescents too. However whilst the effects do not necessarily diminish in intensity as the child gets older it is true to say that many older children and teenagers find various ways of compensating for their differences.

The next book in this series will be *Accentuate The Positive – Teaching a Child with ASD.*

CHAPTER 1
A TEACHER'S GUIDE

What are Autistic Spectrum Disorders?

These complex developmental disorders cover a broad range of abilities, affecting the

child's social and communication skills and making the world seem extremely confusing and frightening.

More commonly found amongst boys than girls the symptoms begin in early childhood but are often not recognized until the child begins school - or sometimes even later especially when the difficulties are mild.

Criteria

In the mid-2013 the American Psychiatric Association published the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) in which the criteria for ASD were modified to exclude the previous separate diagnoses of *Asperger Syndrome (AS), Pervasive Developmental Disorder Not Otherwise Specified* or *Disintegrative Disorder*.

Confusingly though the latest research using brain scans seems to indicate some real differences between Autism and Asperger's syndrome. Meanwhile many of the people formerly diagnosed with Asperger's syndrome continue to think of themselves in that way.

The new criteria are based on functional impairment (currently or historically), in two main areas:

1) *Social communication/interaction.* Examples include:

* Problems reciprocating social or emotional interaction, including difficulty establishing or maintaining back-and-forth conversations and interactions, inability to initiate an interaction and problems with shared attention or sharing of emotions and interests with others.
* Severe problems maintaining relationships — ranges from lack of interest in other people to difficulties in pretend play and engaging in age-appropriate social activities, and problems adjusting to different social expectations.
* Non-verbal communication problems such as abnormal eye contact, posture, facial expressions, tone of voice and gestures, and an inability to understand these.

2) *Restricted and repetitive behaviours* (at least two of which need to be present). These include:

* Stereotyped or repetitive speech, motor movements or use of objects.
* Excessive adherence to routines, ritualized patters of verbal or non-verbal behaviour, or excessive resistance to change.

* Highly restricted interests that are abnormal in intensity or focus.
* Hyper/hypo reactivity to sensory input or unusual interest in sensory aspects of the environment.

Such children often have attention problems and/or may be hyperactive. Approximately a third tend to suffer from epilepsy as well.

Asperger's Syndrome

Prior to the change in the DMS those with Asperger's Syndrome were believed to share the problems of social interaction and have repetitive behaviours/obsessive traits. However they were thought to differ from children with autism because they had no significant delay in the development of language or in their cognitive and self-help skills or in their curiosity about the environment.

In the past AS was also linked to people of average (or above average) intelligence, many of whom cope relatively well with daily life. Even so it is important to note that some children with autism have similar abilities too.

Common Terms

The *autistic spectrum* describes the wide range of functioning and intellectual ability found amongst such children. At one end are those who have severe (and very obvious) learning difficulties, some of whom will remain dependent on others throughout their lives. Such children will often have been diagnosed at an early age and many will have been placed either in a special school or a special needs unit.

Others, with more moderate learning difficulties (some of whom were previously often diagnosed with Asperger's) may be educated in Speech and Language units although now, with the advent of inclusion, many 'higher functioning' and/or more verbal children are likely to be placed within a mainstream school.

At the far end of the spectrum are those children whose symptoms are much more subtle. They tend to cope relatively well in most situations and may escape diagnosis until much older - if it happens at all.

Many of them progress reasonably well at nursery or pre-school, although increasing

pressures and expectations can make life difficult as they get older. Indeed for some, regardless of intellect, their apparently odd behaviours prove so bewildering and problematic within the classroom setting that they can eventually lead to exclusion. Unfortunately in some cases the behavioural problems mask the social inabilities and lead to misdiagnosis or inappropriate treatment.

In adult life such people may hold down jobs and have families but will generally seem odd or eccentric.

A similarly broad spectrum is also found in other spheres:

* *Speech.* This may be non-existent, consist of echolalia (i.e. repeating whatever is said to them) or simple phrases or alternatively, be extremely clear (albeit often overly loud or repetitive in content).

* *Sociability.* A similar wide range is to be found here from those children who totally ignore their peers (although they may seek out adults if they need things), those who make limited contact with other children and yet others who, in contrast, may be overly sociable.

Other Problems

Many children with ASD have other problems too (often termed co-morbid conditions). These can include:

* *Attention Deficit/Hyperactivity* – some children have difficulty paying attention and listening to other people and often seems in a world of his own.

In contrast others also have problems concentrating but are also restless and distractible. Such a child may find it impossible to stay in his seat; will talk too much, interrupt other people's conversations; disrupting activities or even interfere with another child's things. He may also act impulsively – which can put him at risk of injury.

* Some children also have the type of tics associated with *Tourette syndrome*: a neurological disorder characterized by repetitive, stereotyped, involuntary movements and vocalizations.

* *Epilepsy* affects the brain and cause repeated seizures, also known as fits. During a seizure, the electrical impulses in the brain are disrupted, causing the brain and body to behave strangely.

The severity of the seizures is very individual so that some people simply experience a 'trance-like' state for a few seconds or minutes whilst others lose consciousness and have convulsions (uncontrollable shaking of the body).
Seizures fall into two groups:
** partial seizures – where only a small part of the brain is affected
** generalised seizures – where most or all of the brain is affected

Children with ASD are far more likely to suffer from epilepsy than their peers.

Other problems in this group include ***Obsessive-compulsive behaviours, co-ordination difficulties, anxiety and digestive problems*** - more details of which appear later.

From Child To Adolescent.
Each child's ability to cope with and adapt to his differences varies and may also be affected by other factors such as the situation he is in as well as his mood or health.

Although there will be some exceptions, as a general rule the younger child will be confused by his sensory and other differences and these may cause some bizarre or erratic reactions.

In contrast some older children will have developed various coping strategies which may make him less prone to behavioural problems; but can, unfortunately, often lead to greater withdrawal, thereby inhibiting his ability to learn.

A little later the natural turbulence of adolescence may be compounded by the lack of awareness and the continuing problems of literalness. It can give rise to some 'strange' confusions - as with the 14 year old who, being totally unaware that he was growing taller, became very distressed ' because the adults around him were shrinking'.

Generally people are much more tolerant of bizarre or difficulties behaviours in younger children than they are of the adolescent whose behaviour seems apparently 'infantile' or beyond control.

While it is extremely important for the child to learn that certain behaviours are

unacceptable in social situations, great care is needed. It is vital that you understand exactly why the child behaves as he does in certain situations, so that you do not develop unrealistic expectations or expect compliance (to the norm) when he is unable to understand what is being asked of him or in cases where the situation makes your demands unrealistic.

Always:

* assume he understands everything you're saying. Even though he may not necessarily respond at the time he may rerun and 'digest' your words later.
* assume that he hears what you say.
* treat him age appropriately - regardless of the fact that some of his behaviours make him seem younger than he actually is.

Related conditions

Fragile X syndrome

Linked to a defect in part of the X chromosome this is the most common inherited form of learning disabilities. One of the first signs tends to be in delayed speech and language development but it also causes a wide range of other difficulties with learning, as well as social, attentional, emotional as well as behavioural problems.

Rett Syndrome

This condition is similar to ASD but mainly affects females who develop normally until 6 to 18 months and then begin to regress significantly: some losing their speech, the ability to walk, and the loss of most basic motor functioning.

Learning difficulties, autism, seizures, disturbed sleep patterns and periods of irritability are common. Some children make spontaneous sounds or repetitive hand movements, hyperventilate and/or hold their breath and grimace or grind their teeth.

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CHAPTER 2
THE BIGGER PICTURE

While communication and social difficulties are generally obvious it is important to realise that - regardless of age, diagnosis, verbal ability or intelligence - all such children have immense difficulties in understanding other people and the world around them. Thus they:

* are unable to 'read' facial expressions or body language.
* have difficulties relating to other people and making friends.
* have a limited understanding of other people's feelings and their own.
* may not deal with their feelings in an age appropriate manner.
* find it difficult to cope with change.
* take things literally and can easily be confused or upset by words or phrases which have more than one meaning.
* have great difficulty understanding abstract concepts.
* cannot necessarily take something learnt in one context and use it in another situation.

However there are also several less obvious problems which affect the majority of such children. While these do not generally come within the teachers' remit it is useful to have some knowledge of them as they have a great impact on his behaviour and ability to learn.

Sensory Differences

Nowadays the sensory differences are actually included in the criteria. They generally affect all the senses - albeit to varying degrees - and, with the exception of vision, fall into three groups. Thus he may be hyper (over) sensitive or hypo (under) sensitive (although, confusingly, children in this group have a tendency to hyperactivity). There is also a third group of children who have sensations that Dr Carl Delacato (in his book *The Ultimate Stranger),* described as 'white noise'.

Let's take a brief look at each sense in turn along with some of the reactions they cause:

Visual Perceptual Problems.

Vision accounts for approximately 70% of the information we receive about the world around us; making it of great importance.

There is increasing evidence to suggest that children with ASD share the same type of visual perceptual problems found in children with dyslexia (albeit to a much greater degree). These are known under various guises from visual dyslexia/stress to

Meares/Irlen syndrome).

Unfortunately because these are not usually identified by an ordinary eye test they often remain undiagnosed whilst the child and those around him remain unaware that he sees in a different way from his peers.

Difficulties.

The symptoms include a range of focusing anomalies which can cause various problems including clumsiness.

Some children also have photophobia (making them hypersensitive to glare) which will be exacerbated under certain lighting conditions. This leads to several difficulties when the child learns to read and write. Thus he may:

* tire easily when reading; suffer eye-strain, headaches or migraine.
* see various visual distortions; skip lines & lose his place.
* be unable to see groups of words/figures at the same time.

Such problems may often be overcome, particularly in the early years when books have large print which is well spaced. Unfortunately though, as the child progresses through school, the print and the spaces between lines decrease in size. This, and some print types, can increase the strange visual effects shown below.

Please do not try reading the text below if you suffer from migraine.

THEY were standing under a tree, each with an arm round the other's neck, and Alice knew which was which in a moment, because one of them had "DUM" embroidered on his collar, and the other "DEE". 'I suppose they've each got "TWEEDLE" round at the back of the collar,' she said to herself. They stood so still that she quite forgot they were alive, and she was just going round to see if the word "TWEEDLE" was written at the back of each collar, when she was startled by a voice coming from the one marked "DUM". 'If you think we're wax-works,' he said, 'you ought to pay, you know. Wax-works weren't made to be looked at for nothing. Nohow!'.

When the differences are more severe (as they are in many children with ASD) they give rise to various focusing problems. The effects include:

* Difficulties following moving objects - e.g. when playing ball games. Some children may even be unaware of approaching cars until they get really close.
* Clumsiness - cannot judge differences in height or width – which is particularly noticeable when the child steps off a curb or over a threshold.
* Things seem ‘magnified’ (one girl saw a hair ‘as if it were a piece of spaghetti’). Thus she:

** is unable to focus on a whole face because one part (a hair, mouth, earring etc.) stands out.
** may be fascinated by the tiniest things.
** may be very good at intricate tasks.

Two particular symptoms give rise to some very 'bizarre' effects and may provide a clue as to why the child finds it so hard to 'read' body language. These are:
* Poor visual acuity (hypo-sensitivity) which fades the features on peoples' faces & surrounding details (like wearing sunglasses indoors on a dull day).
* Photophobia - this also causes features on peoples' faces fade so that the child does not get a coherent picture of that face. **Note** - this is NOT a phobia but rather a physical hypersensitivity to glare, brightness or fluorescent lights which exacerbates their difficulties. This is outside the child's control.

This means that many such children are only partially sighted, whilst some see in a fragmented way and others are – quite literally – faceblind.

Faceblindness
This is also known as prosopagnosia - from the Greek words prosopo – (face) and agnosia – (without knowledge).

Originally thought to be extremely rare it is now believed that around 2% of the population have some degree of prosopagnosia. In the past it was thought to be acquired as a result of a head injury or illness but it is now recognized that some people have 'developmental prosopagnosia' and were either born with it or developed it early in life.

Generally it is thought to arise from some type of malfunction in the part of the brain which stores faces. Even so accounts from some people with ASD make it seem likely that children with ASD fall into the developmental category. It is also possible that their 'face-blindness' actually stems from photophobia or poor visual acuity.

Certainly if you cannot see faces correctly the only 'picture memory' you could store would either be blank or extremely bizarre - which would make remembering and placing faces almost impossible. Imagine a postman/mailman trying to work out where to deliver letters if all he saw were blank envelopes?

The effects

Most of us have at some point been faced with a situation in which the person we met is 'out of context' so that we don't immediately 'place the face' and recognise them. For many people with severe face-blindness though the problem is far more distressing for they are unable to retain images of people. Thus they may not even be able to recognise members of their own families, whether they be parents, siblings or the people they see on a daily basis.

Seeing in a fragmented way or being face-blind causes several problems and means that the child will generally **not** be able to:

* identify people correctly by sight alone. Looking at people faces close up, as many children do, gives a clearer picture although many learn to rely on other clues that identify you like an earring; the way you walk or even your smell.
* read facial expressions or body language.
* find their way around an apparently familiar building very easily - which can prove particularly difficult in some situations e.g. if they need to use the toilet.

Can you imagine living in such a world? Where other children – and adults – are both bewildering and frightening?

To make matters worse his peers apparently cope well with the things that elude him: and that can leave him feeling frustrated and lacking in self esteem.

Auditory difficulties.

People generally associate hearing problems with an identifiable hearing loss but there are several other auditory difficulties which can have a devastating effect and may at times make many apparently ordinary situations almost intolerable. Common problems include:

* *Distorted hearing* - mishearing certain frequencies or hearing better with one ear than the other so that some letters or words are 'lost' or misheard.

This can lead to confusion and mean that his responses to questions are slower than his peers. It will also make it very hard for him to keep pace in a 'normal' conversation.

* *An inability to habituate* i.e. to shut out background noise – which can leave him struggling to hear in noisy situations.
* *Hyperacusis* - hypersensitivity to sound - particular everyday sounds are painful and

sound louder than they actually are. The sounds which cause problems are individual, ranging from quiet sounds - such a clock ticking, people eating or even a particular voice - to louder sounds like vacuum cleaners.

* *'Supersensitive hearing*' - so he hears things that other people may be unaware of – and may even hear the person on the other end of a phone. *ALWAYS assume that he hears (and understands) everything you're saying.*

* *Loudness intolerance* - cannot tolerate the same level of noise as his peers and may become very upset and distraught by loud noises e.g. fire alarms.

The Effects

Many children with ASD are tormented as everyday sounds, that most of us ignore or at least tolerate, constantly impinge and intrude upon them. Such auditory difficulties also:

* frequently underlie speech and/or language problems.
* interfere with his concentration and ability to learn.
* mean he needs to concentrate much harder than his peers in order to make sense of the spoken word: which is particularly difficult in noisy situations.
* make many places very difficult for him - e.g. at times the classroom and especially the dining area can be overwhelming.

The child with such problems may react to these noises in a variety of ways e.g. blocking his ears; withdrawing into himself; running away from the situation or having a panic attack (often perceived as a tantrum).

Such difficulties make learning exceptionally hard and some children seemingly give up and appear to be daydreaming instead of listening to the lesson. Even so some children do take the information in – although they often have to 'replay' it later before they can assimilate and understand it.

Smell, taste and touch.

The effects of these are often less evident than the auditory or visual problems but they can be quite distracting to the child causing a loss of concentration or even withdrawal.

Smell and taste.

Hypo-sensitivity in these areas can be dangerous. Not only will he be unaware of substances which are potentially harmful but he may also eat anything and everything:

whether edible or not.

In contrast those who are hypersensitive may have various food fads. When severe the child may find that some everyday smells (e.g. cooking, perfume etc.) disrupt their concentration. When extreme this lead the child to avoid close contact with others (as with the child who thought that '9 out of 10 people had halitosis').

Touch.
The child who is 'hypo' sensitive will actively seek – and enjoy - a 'rough and tumble'.

In contrast the 'hyper' child will generally dislike being touched - and may find a light touch more painful than a firm touch. He may also find some materials very irritating or 'scratchy'; hence the reason why some children wear a particular item of clothing ad nauseum or try to divest themselves of their clothing at every opportunity.

The Effects.
The jumbled or distorted information the child receives from his senses causes disorientation and confusion, leaving him in a nightmare world. This means that even things which other children consider pleasurable can be quite frightening e.g. playing in the playground or going out on a trip.

Worse still, unlike adults who have a wealth of inner experiences to help them survive, the young child simply does not have the resources to cope with such problems.

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CHAPTER 3
A WORLD OF DIFFERENCE

In addition to the sensory and other differences many children with ASD also have one or more of the differences detailed below.

Developmental differences

Simplistically, every aspect of development, from the emotional to the physical, is like a series of building blocks placed one upon the other. Each has to be placed in just the right position for the structure to be solid. Successful development is only achieved if each stage is completed correctly. If any stage is either missing or incomplete the child's progress can be damaged or slowed and that can have wide ranging and far reaching consequences. For some this will be physical problems such as migraines and travel sickness whilst others may have a variety of learning and behavioural differences.

Balance (is controlled by the vestibular system, located within the inner ear). It is vitally important in this developmental process because it:

* is the first of the sensory systems to mature.
* plays an essential part in the way the brain learns to interpret information from the other senses.
* is intimately connected to the development of coordination, stable eye movements and visual perception as well as how he sees, hears and feels the world around him.

Thus many such children may also any one or more problems with their balance, movement and/or vision. Interestingly it also plays an important part in helping the child develop the emotional stability that he needs in order to feel secure and develop self-control.

Speech, language and understanding

The speech of children with ASD is frequently described as ‘deviant' or ‘impaired.' The three main examples commonly quoted as deviant, consist of:

* echolalia – the repetition of things that have been said to the child by others.
* pronoun reversal
* extreme literalness.

However each of those things also happen naturally during a certain stage of child development.

1) Imitative learning occurs as part of normal development until about the age of three - for is only by imitation and repetition of both actions and words that children learn the various skills they will need in life.

2) Pronoun reversal too is simply the stage that naturally occurs before the child learns to refer to himself as ‘I’ or ‘me’; rather than copying other people who call him ‘you’.

Most children generally take this complicated process in their stride when they are about 3 years old, so perhaps, rather than a deviance from normal development, it is merely a halting of that perfectly normal process?

However many children do gradually become more fluent in time perhaps because they begin to adjust to their hearing differences.

3) Literalness is, once again, simply a natural part of growing up, although in ASD it will often continues into the teens or adulthood?

Such things often give rise to comments which become family treasures and are a godsend to a writer too, whilst also highlighting the many inbuilt confusions of the English language.

Award winning writer Jacqueline Wilson has included a young Aspie – Gus Carmichael aged 9 – in her popular children's series, Tracy Beaker. This character, played by Noah Marullo in the TV series of the same name, really helps foster an understanding of Aspies, through gentle comedy. Thus Tracy accompanies Gus to his music exam – a journey he has timed to the minute – and so when she leaves him in the taxi for a moment saying, '*I'll be right back*', he asks (quite logically), '*how many minutes is 'right*?'

Be aware that sometimes that literalness can cause great confusion for, like all youngsters, children worry about things adults find innocuous; like the little girl who stopped eating because she'd been told it would 'put hairs on her chest’.

Similarly unthinking comments can sometimes cause real worry or distress for Auties and Aspies, as with one young lad who had a tantrum because '*marble cake*' was on the menu; something he thought hard and inedible.

Conclusion

Clearly those so-called deviant aspects of language and understanding are all quite normal stages that every child goes through, supporting the idea that when, for whatever reason, ASD begins, it is inextricably linked with a slowing or halting of the 'normal' developmental process. That of course, leaves the child's development 'out of synch' with that of his peers.

Emotions

The child's ability to interact with other people – that vital process which helps each child learn to understand his feelings, deal with them appropriately and develop self-control and empathy – may also be halted or slowed. While he continues to grow physically, some of his behaviours remain like those of a younger child making him seem 'emotionally immature' and lacking in self awareness - and far less inhibited by the usual social expectations.

While this does not necessarily apply to all children those affected can have any one (or several) of the following problems:

* have little or no 'sense of self'.
* seem very aloof and independent; looks after himself and shuts other people out.

have difficulty understanding his feelings which may overwhelm him at times causing distress or acting out.

* be unable to cope with his feelings in an age appropriate manner - i.e.. his limited or poor self control means he continues to act like a 'terrible two' even when older.

not necessarily distinguish between your feelings and his own so he will be anxious, sad, happy, etc. whenever you are.

* have difficulty relating to parents and/or peers appropriately.
* lack empathy - has little or limited understanding of other people's feelings.

Even so it must be noted that many children do eventually develop some degree of self-awareness, self-control and empathy.

Dyspraxia

Praxis is the link between our brains and our behaviour that allows us to make choices, plan our lives and our actions. It enables us to dress ourselves, eat, play, write, work etc.

Unlike our reflexes, the movements involved in praxis are actually voluntary 'skilled' movements that are under our control. Although, as adults, we tend to take them for-granted the infant puts in many hours of practice as he crawls around and tries to pull himself upright or repeatedly reaches for and grasps an object that he wants to explore.

Some children with ASD also have dyspraxia which, while interrelated to the

developmental problems mentioned above, causes a number of specific problems.

The word comes from the Greek *dys* (bad) and *praxis* (the learned ability to plan, organize and carry out sequences of coordinated movements in order to achieve an objective).
In plain English it is simply 'the ability to get our bodies to do what we want when we want'.

Dyspraxia is also often associated with problems of perception, language and thought – although each child is affected differently. While the majority are generally of 'normal intelligence' for their age they may have difficulty both in the processing of information and in communicating what they know or understand.

The effect of these problems varies from child to child and also depends on age and character. Confusingly though the problems are often inconsistent: affecting the child very badly one day but seeming much milder on the next.

Major Problems arising from Dyspraxia.

This impairment or immaturity of the organization of movement can affect the child's ability to plan and/or carry out actions to varying degrees. Thus some children have problems in both planning and carrying out and co-ordinating the actions; others only in one area.
Such problems are demonstrated by:

* *Clumsiness; poor motor control; lack of coordination.* While this does not affect all children those who have difficulties with motor skills fall into two groups:

** *Gross motor skills* use the larger muscles in the body, those to run, jump and move about - so he bumps into things; trips/falls over; knocks into furniture or people.

** *Fine motor skills* require smaller, more delicate movements with an emphasis on coordination e.g. doing up buttons, getting dressed, doing jigsaws etc.

His tongue movements may also be clumsy – so he has difficulty swallowing and eating (something which will have an knock-on effect on the development of speech and language.

* *Praxis* - the ability to plan and/or carry out actions.
* *Sensory Integration* - the way he organizes and make sense of sensory information.

Apraxia

Some children also have Apraxia (i.e. verbal dyspraxia). This term encompasses a wide range of speech problems, which can make the child's speech unintelligible even to family

members. Included in this are problems when:

* Coordinating the movements of the mouth and tongue, which are needed to produce clear speech.
* Producing individual sounds or sequencing sounds together in words.
* Copying words - although can speak spontaneously
* Putting the words in the right order
* Producing the right word at the right time

Other Physical Differences

From their accounts it is also clear that some children also have strange physical sensations. Thus Carly Fleischmann said: *'It feels like my legs are on fire and a million ants are crawling up my arms',* whilst Gunilla Gerland had an almost constant shudder down her spine which periodically grew worse. As she said: '*I became slightly used to it, but it was a constant torture, most noticeable when it changed in intensity . . .'*

Just imagine how hard that must make life.

Clearly the child faces numerous obstacles in his daily life that his peers do not. These have no correlation to his intelligence but will hinder his ability to learn unless you help him achieve his full potential.

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CHAPTER
ANXIETY

Some people believe that anxiety is a co-morbid disorder (i.e. it occurs simultaneously) with autism whilst others think that it is part of the ASD itself. I incline to the latter view and believe that much of the child's anxiety actually stems from the sensory differences they live with.

Perhaps you'd like to try it for yourself?

The following passage (adapted from the work of the late Svea Gold who was both an author and therapist) demonstrates just how different and difficult life would be if you were unable to believe your senses.

> *Just imagine . . . '. . . walking your dog on a bright sunny day. While you're walking you prepare a shopping list, write a letter in your mind, and plan your day's work. Now imagine walking the same street, with the same dog, on a dark winter morning in a fog. You can't see more than about thirty feet ahead. The dog will protect you - but it's such a tiny dog . . . ! There is a strange noise, to your right. Tap, tap, tap . . . as you get closer, you realize it's just a drainpipe dripping . . . Every sound needs to be analysed as you go on your way. Suddenly the headlights of a car appear behind you, and as you step to the side, the car slows down and comes to a stop. All the kidnapping shows that you've ever seen on TV seem to turn into reality. The car starts off again, and the paper girl waves to you. . . You should have known her car, but in the dark all you could see were the lights. The adrenaline had gone to work, because in spite of the fact that it's quite cold . . . there is a hint of perspiration on your upper lip. . . you did not recognize the car! Eventually you get back home . . . But you haven't achieved anything. Your shopping list is not planned, the outline for your conference report is not in shape. You had been too busy protecting yourself to get anything else done'.*

Just a taster of how the child with ASD experiences the world. All day. Every day. Scary isn't it?

Quite naturally such sensory differences make life confusing, disorientating and frightening. Hardly surprising then that (although it is not always obvious) such children are extremely anxious.

That anxiety often inhibits their curiosity about the world. This can make them extremely apprehensive about trying any new experience, or simply direct their curiosity towards objects instead.

Possible effects

It is a given that fear can trigger a number of involuntary reflex actions. While most of us

rarely experience the type of stress that triggers such things children who live with anxiety on a daily basis often have a physical over-reaction to things most people think of as innocuous. This could include a visit to the supermarket, trip out, day at the fair and any number of other apparently exciting things – all of which tend to have one thing in common: they are generally filled with overwhelming sensory stimulation.

Such things can trigger any of the following reactions which will vary from child to child:

Freezing: This reaction is sometimes found amongst children with ASD who freeze in certain situations – even when they are seemingly pleasant. Thus, just like a rabbit caught in the headlights of a car, one girl I knew went mute when in a café and couldn't eat or drink anything at all.

Fight and flight: When this reaction is triggered extra adrenaline is pumped around the body to give us the extra energy needed to escape – or to stand our ground and fight. At the same time our heart rate increases, there is a change in blood pressure, respiration, and breathing and we may blink rapidly, go pale and tremble as our mouth dries, our stomach knots and we sweat with fear. Thus one child may simply run away; another become aggressive.

Freedom (Opposition) Reflex: This lesser known reaction (discovered by Nobel Prize winner, Ivan Pavlov) causes any animal to struggle when its movements are hampered. This explains why the child fights when restrained: behaviour which is often misinterpreted as defiant, resistant or even oppositional.

Anxiety also results in:

* *A dislike of change.* This makes routine of great importance throughout his life, providing some constants in a perplexing world. The child's reactions to change are very individual. Thus some will become distressed by apparently small things, such as an item which is out of a place but ignore larger changes whilst for others the converse is true.

* *A variety of stereotyped (repetitive) behaviours* which include:

** *Compulsions.* A variety of strange mannerisms e.g. flicking a bit of string repetitively or lining toys up in rows.

** *Obsessions* (thoughts) – so he may be preoccupied with a particular subject; talks about one topic repetitively; or collects particular toys/items like dinosaurs. The latter is similar

to a young child's' security blanket and - like the rituals - keeps anxiety at bay.

Unfortunately such things have a downside as changes in 'his' routine or interruptions to his preoccupation's can create even more stress. Generally though those behaviours will decrease when the child feels secure and knows exactly what is expected of him.

Exposure Anxiety

Many children with ASD also suffer from Exposure Anxiety (EA), a condition which was identified by Donna Williams in her book of the same name. This seems to be an extreme form of Social Anxiety (social phobia) in which the person feels acutely self-conscious in social situations.

Children with EA find any attention from other people potentially threatening. Thus they feel 'exposed' each time another person looks at them, talks to them or even compliments them. This has several different effects as the child may:

* feel unable to do things for himself if other people are around. Thus he: may use other people to carry out tasks for him - such as using another person's hand to turn a door handle, picking something up etc.
* only do things/help himself/talk or sing when he feels unobserved
* not use personal pronouns
* have various speech 'differences' which can mean that speech is: non existent; used only when he feels unobserved (selective mutism); limited to a few 'safe' words or phrases or very repetitive.
* 'hide himself' by copying the actions, speech and mannerisms of people he knows or of a character(s) that he has seen on television.

Mutism

Not speaking (now generally known Selective Mutism or SM) is generally recognized as an anxiety disorder over which the child has no control.

This is the child who literally can't talk. Each child is affected differently so that some:

* are unable to talk in social settings, such as school, but talk normally in places where they feel relaxed and secure.
* only speak to selected people or at home.
* speaks in a whisper.

* never talks at all (unless alone) – or perhaps when under stress – as with the child who shouted to his family when there was a fire.
* may also have difficulty smiling in social situations or looking others in the eye, and may look away when confronted or spoken to.

All too often the latter signs are misinterpreted so the child is mistakenly thought to be stubborn, disrespectful, wilful, attention seeking or controlling. **He is not. The reality is that such children are simply so anxious that they simply cannot speak.**

While SM can arise for a variety of reasons from trauma to depression in children with ASD it seems to be part of exposure anxiety.

In order to cope the child may attempt to 'block out' the things that tend to trigger his exposure anxiety. This can lead to some strange reactions as he:
* ignores the people he likes most.
* responds to direct praise by losing interest, disowning (or even destroying) his achievements.
* 'freezes' in certain situations (as discussed previously).

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CHAPTER 5
DIETARY ASPECTS

Another thing which can affect the child's performance at school is his physical health so although it is not within your remit as a teacher, I include some information on the more common digestive problems found amongst children with ASD.

Food Intolerances

Although still controversial area it is suggested that the majority of children with ASD are prone to be intolerant of casein (milk) and/or gluten (found in many cereals). It is thought that these effects build up gradually and impair the functioning of both the brain and the immune system. They can give rise to several wide ranging effects which include:

* poor concentration and memory
* a range of behavioural problems e.g. hyperactivity; aggression; self abuse
* sensory problems

This has led many parents to try exclusion diets. While the results vary those people with ASD who have tried the diet report a number of benefits. These include:

* increased concentration
* better memory
* clearer thoughts
* reduction in sleep issues
* reduction in stomach upsets
* improved mood and less anxiety

Other foods

There has long been parental concern over the effect of food additives and/or colourings on child behaviour; both of which seem to have a negative effect on many children with ASD, as indeed they do on those with attention deficit or hyperactivity.

It is also true to say that many children with ASD also react strongly to some 'proper foods' such as sugar, chocolate, carrots and oranges.

However rather than having a physical reaction (as to an allergy) the results tend to be behavioural. Thus one child may appear 'drunk' shortly after drinking a particular fruit juice (or even eating carrots) whilst another may be totally out of control until the effect of those delicious chocolate and orange biscuits wear off.

Reactive hypoglycaemia (low blood sugar level)

Many children with autism and Asperger's syndrome also suffer from 'reactive' hypoglycaemia. This is generally associated with a high intake of sugar and junk foods and leads to a drop in blood sugar levels as well as a rise in his adrenaline levels.

Attacks often happen either prior to a meal or some time after an excess of sugary foods and can give rise to a variety of symptoms which could include any of the following:

* hot and cold sweats
* a loss of concentration

* irritability
* dizziness, trembling, migraines/headaches, blurred vision, or general agitation
* vertigo and/or a loss of co-ordination
* fainting.

Sometimes it can be recognised as a hot sweat may cause the child to loosen or take off her clothes, and will then be followed by dizziness, trembling and, in severe cases, fainting.

Once he feels better the child may also suffer a 'memory blank' which - on rare occasions – can lead him to confabulate (so that he makes up a story to fill the blank).

Hypoglycemia can affect the child's ability to concentrate and learn. Specific effects can include:
* craving particular foods; eating non edible substances; excessive thirst.
* bouts of hyperactivity, self abuse or other disruptive behaviour - often within an hour or two of eating a food to which he is intolerant.
* physical problems - stomach aches; nausea; constipation/diarrhoea; headaches.
* agitation or hyperactivity either between or prior to meals or after eating sugary foods.

Bowel disease

A new bowel disease has also been discovered in some children with ASD in recent years. This can cause lumpy swellings in the intestine, recurring inflammation and constipation.

While controversy now rages in several countries about the possibility of links between this bowel disease, ‘regressive’ autism and/or the MMR vaccination it has to be noted that:
* this disease does actually exist (and can cause serious problems).
* treatment of the physical symptoms does cause the ‘autisms’ to diminish.

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CHAPTER 6

LEARNING DIFFERENCES

The problems already mentioned give rise to a whole range of effects (learning differences) which, once again, range from mild to severe. While those in the first section are commonly associated with general learning difficulties others are more specific to ASD.

Poor short term memory.

This can make it extremely hard for them to learn things or to retain that knowledge. Thus commonly such children will have periods when they forget personal memories, names, facts etc - even those they knew a little time before. Indeed one man described how he suddenly lost the ability to read – and having to relearn the whole process.

Children with the severest memory problems have great difficulty understanding everyday words and will interpret many of them in a narrow or idiosyncratic way - thereby compounding the problems and making it much harder for them to understand what other people say.

Short term memory problems can be associated with sleep deprivation which is quite common amongst children with ASD. Both the quantity and quality of sleep are important to our memories so getting too little sleep or waking frequently in the night can interferes with the ability to consolidate and retrieve information.

On the plus side though many such children have extremely good long-term memories and can retain a myriad scientific or other facts which are often linked to his particular interests.

Other problems can include:

* Limited understanding of directions and sequencing.
* Poor sense of time.
* Mixed dominance - i.e. uses either hand to write, eat etc.

Visual thinking.

Some children (like some of those with dyslexia) think in pictures rather than words.

This can have some positive aspects in art, computing etc. but unfortunately it adds to the problems when the child learns to read and write; leaving him unable to read and

comprehend abstract words such as ‘if’ ‘and’ or ‘that’ easily.

Imagine if all such words were deleted from this sentence. It would simply read *'imagine words deleted sentence'*. Which can make it reading extremely confusing!

Specific problems.

* *Information Processing.* Most people can process information from several senses simultaneously. In contrast the child with autism and Asperger’s syndrome is generally only able to process one piece of information at a time (mono- processing). This can lead to:

** *a slowed response* - causing a delay between being asked a question and reply. Some children respond so slowly that their reply seems meaningless.

** *‘shut down’* - when the ‘information overload’ becomes so overwhelming that his brain cannot, in the short term, cope with or respond to incoming stimuli.

‘Shutting down’ protects the child’s system but can make him extremely lethargic. When extreme it is sometimes mistaken for a form of epilepsy. In contrast other children will react to overload with a sudden ‘explosion’ of hyperactivity or bizarre behaviour.

* Some children process information too rapidly so that one word or sentence triggers numerous fast moving images which, when verbalized, may seem random and unconnected to the matter at hand.

In addition to the problems already mentioned the child may also have:

* *a lack of curiosity* – so that he is scared of trying new things.

* *poor speech modulation* - talks too loudly or have an expressionless voice.

* *poor awareness* of:

** *danger* - will not necessarily be as aware of danger as his peers. Thus he may not respond in the correct manner e.g. the noise of a fire alarm could cause him to freeze rather than to get out of a room.

** *bodily functions* - e.g. she may not realise that she needs the toilet until the need suddenly becomes urgent

** *pain* – one example being the child who jumped up and down despite a twisted ankle. NB. Even so other children may be overly sensitive.

** *other peoples’ motives* - his inability to ‘read’ faces and body language can make him seem naïve.

While some of his problems are obvious others will be more subtle. His lack of awareness may cause him to:

* seem offhand or withdrawn
* avoid eye contact.
* make direct personal comments which can seem quite rude.
* invade other peoples personal space: may stand too close to other people, stare at them or even touch items of their clothing.
* become agitated or aggressive when frustrated or confused.
* demonstrate age inappropriate behaviours e.g. laugh inappropriately, make odd noises.
* ask repetitive questions or argue repetitively – while often linked to his poor memory they frequently occur (or increase) when he is stressed.
* have difficulty understanding social rules.
* talk repetitively about one subject – often missing the 'cues' that indicate another person wants to speak.
* be unable to organise or limit his own behaviour in an appropriate way.
* seem very self-centred and aloof.
* regardless of intellect his comprehension will still be limited.

Please do not assume that he is being intentionally rude or negative or that the behaviour is specifically aimed at you. Such behaviours are merely part of the problems.

Many children on the autistic spectrum develop ways of compensating for their problems which are, in themselves, learning differences. These include:

* *using peripheral vision* - looking at things out of the corner of his eye or in quick short glances reduces the amount of stimulation bombarding his senses.
* *learning indirectly.* Although the child is unable to take in information in a 'normal' manner he will often be acutely aware of what is happening - even when he shows little apparent interest. He may then 'replay and digest' this information later when he is on his own.
* *intuition* - many of these children are highly intuitive and seem able to 'pick up' other peoples' emotions which they may then 'act out'.

Unfortunately that may include picking up on your weaknesses and foibles, which can sometimes make those who are inexperienced feel rather uncomfortable – and have even

led some people to think the child is a 'mind-reader' when clearly he is not.

Reading misbehaviour

There are times when the child may display behaviours which are seemingly random or uncontrollable, whether it be screaming, hitting out at others etc.

Sometimes this is simply due to his frustration at being unable to communicate his thoughts or feelings; whether it be *'I'm confused*'; *'I don't like that!'* or '*this is too hard*'; or '*he's teasing me'*.

Even so it does not mean that such children are always well behaved for, just like the rest us they can be mischievous. Thus one child frequently asked embarrassing questions when in public situations when he was sure to be overheard.

Lying.

It is clear that the majority of children with ASD generally take things too literally to lie but even so people need to be aware that it is possible to influence some of them into giving a particular answer for a variety of reasons..

* Those who are acutely aware of other people's feelings may offer the answer which they feel is wanted or which will please the other person.
* Alternatively, if two answers are offered when a question is asked some children will always choose the first answer while others repeatedly go for the latter.
* A hypoglycaemia attack may lead him to confabulate – as mentioned earlier.

Many people believe that such children lack imagination. However some children with ASD are actually highly imaginative and that alongside the fact that the child may be much younger in developmental terms than his peers can lead to some telling tall tales.

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CHAPTER 7
MORE VULNERABLE THAN MOST

Vulnerability.

His lack of awareness of others, visual problems and stereotyped behaviours often make the child stand out from his peers and, by drawing attention to his differences, can make him the butt of jokes or lead to bullying. This will make his life miserable and can cause a loss of self-esteem, depression or even mental health issues.

Signs Of Bullying.

Bullying can take many forms from name-calling to social isolation or even physical violence. Where the bully identifies that his victim is different his bullying may become more subtle so that he encourages the child with ASD to break the rules or 'winds him up' until he gets agitated or aggressive.

While physical signs such as torn clothes, cuts and bruises are easy to see those more subtle signs may be less easy to identify.

* Look out for changes in the child's behaviour such as a reluctance to go to school, increased anxiety, or an increase in problem behaviours whilst at school.
* Investigate any classroom incidents involving the child in-depth rather than simply putting it down to 'bad' behaviour on his part.
* liaise closely with his family in order to determine the cause/s of such things – especially because such children can be upset by changes and transitions.
* Take complaints from the child or his parents seriously, whether of physical, verbal or psychological bullying.

Cyberbullying

While historically, bullying has been a largely school-oriented phenomenon, cyber-bullying and text-bullying are now on the increase; allowing bullies to torment, threaten, humiliate or embarrass their classmates via e-mail, instant messaging and through online communities such as Myspace and Facebook.

Teachers need to be especially aware of this in relation to any child/teenager who uses a mobile or the Internet independently for they are obviously a possible prey to this awful form of bullying.

More details about bullying and children with special needs can be found in the forthcoming book Odd One Out?

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More details of the sensory and other differences
can be found on http://www.sensorydifferences.com

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THE AUTHOR

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THE AUTISM CODE

This four part series comprises:
The Cracks in the Code
The Ciphers
The Source Code
Decryption
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