Why Does He Do That?

A Positive Parent's Guide to Understanding the Autism Spectrum

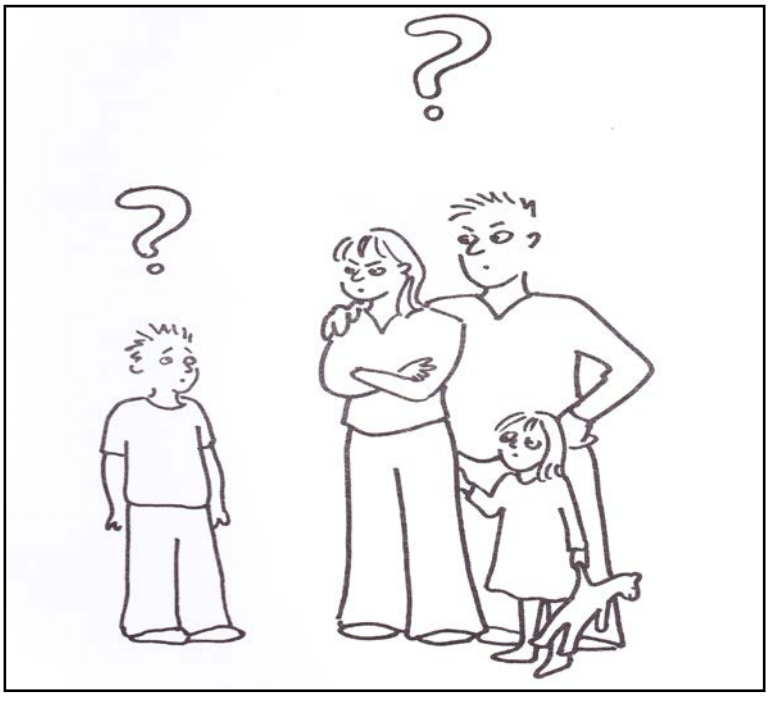

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Table of Contents

INTRODUCTION

People on the Autism Spectrum often feel they inhabit another planet, which is why some refer to themselves as aliens. Certainly, judging by their reactions, they find this world both impenetrable and frightening.

Such feelings are often thought to result from the difficulties they have in relating to those around them, and their inability – regardless of intellect – to empathize with or communicate their emotions to others, in the way that most people do.

That idea is constantly reinforced by the criteria used in diagnosing autism spectrum disorder (ASD). That focuses mainly upon the difficulties with social relationships and communication, but those are merely the tip of the iceberg.

Since autism and Asperger's syndrome were identified in the 1940s, many articles and books have been written by or featured people who have autism or Asperger's syndrome. Such accounts have come, over several decades, from people of various ages and abilities living in different parts of the globe, and yet despite this, they remain remarkably consistent.

Most noticeable is the fact that time and time again, one reads or hears the words 'fear, terror or confusion', as well as accounts of abnormal sensory experiences. These comments are supported by those people with ASD who are able to talk about their experiences.

The accounts of abnormal sensory experiences have been given further credence over the years by Dr Bernard Rimland and Dr Carl Delacato, and, since then, by the well-researched and documented work of those who study neuro-developmental delay.

Indeed, similar (but less severe) abnormal sensory perceptions exist amongst many other groups of people: from those with physical problems like migraine to those with learning disabilities such as dyslexia, dyspraxia and hyperactivity or attention problems.

This book gives a brief overview of the various problems experienced by children on a daily basis. Information on the better known aspects of these conditions has been kept relatively brief so that more space can be given to those lesser known but vitally important aspects: those of the sensory problems and anxiety, for, as you will see, many of the child's apparently odd mannerisms or bizarre behaviors can be explained by such things.

Please note that while, for the sake of ease the text mainly refers to 'the child' or 'children' and 'he', ASD obviously affects people of all ages and both sexes.

CHAPTER 1

A POSITIVE PARENT'S GUIDE

Criteria

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), published in 2014 by the American Psychiatric Association, modified the criteria for ASD by excluding the previous diagnoses of Asperger Syndrome, Pervasive Developmental Disorder Not Otherwise Specified, and Disintegrative Disorder, and simply using the umbrella term Autism Spectrum Disorder or ASD.

Even so, many people formerly diagnosed with Asperger's syndrome obviously continue to think of themselves in that way. That, along with the fact that a study done in 2013 used brain scans to identify some real differences between the two conditions, is why I have chosen to refer to it as a separate condition from autism.

Although the symptoms begin in early childhood, sometimes they are so mild that they may not be recognized until the child begins school – or even later.

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

1) *Social communication/interaction.* DSM-5 gives examples which 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 – from a 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 behaviors* (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 patterns of verbal or non-verbal behavior, or excessive resistance to change.
- Highly restricted interests that are abnormal in intensity or focus.
- Hyper or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment (such as an apparent indifference to pain/temperature, an adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Prior to the change in the criteria it was considered that those with Asperger's syndrome shared the problems of social interaction and had repetitive behaviors or obsessive traits. Even so, 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.

Asperger's syndrome was also generally 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.

Other problems commonly found amongst children on the autism spectrum include attention problems and/or hyperactivity and dyslexia, whilst epilepsy is also a major factor for many.

One final point that needs making is that while I welcome the inclusion of the sensory differences in DSM-5 placing them under the category of *Restricted, repetitive patterns of behavior….* is both wrong and misleading for it ignores the vital part that the senses play in learning about the world around us and – most importantly - in helping us interact with other people as you'll see in a later chapter.

The Autism Spectrum

The term 'autism 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 within either a special school or a special needs unit.

Others, with more moderate learning difficulties (who might previously have been diagnosed with Asperger's syndrome) may be educated in Speech and Language units, although since the advent of inclusion, many of the 'higher functioning' and more verbal children have tended to be placed within mainstream schools; some even being diagnosed with Semantic Pragmatic Disorder (SPD) rather than autism or Asperger's syndrome.

At the far end of the spectrum are the 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.

Even so some of those who progress reasonably well at nursery or preschool, will find that life gets increasing hard as they progress through school and the pressures and expectations become greater.

Indeed, for some, regardless of intellect, their apparently odd behaviors prove so bewildering and problematic within the classroom setting that they eventually lead to exclusion.

Unfortunately, such behavioral problems can mask their social inability and may sometimes lead to misdiagnosis or inappropriate treatment. In adult life such people may hold down jobs and have families but will generally be considered odd or eccentric.

A similarly wide spectrum is found in other spheres:

- Sociability: this ranges from 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.

- Speech may be non-existent, consist of echolalia (i.e. repeating whatever is said to them) or comprise simple phrases; but some children speak extremely clear even though they may not understand all the nuances of language.

Understanding

All such children (regardless of age, diagnosis, verbal ability or intelligence) have immense difficulties in understanding other people

and the world around them, the reasons for which will be discussed more fully in the following chapters.

Unsurprisingly, such problems make it extremely difficult for the child to relate to other people or make friends. Thus they:

- are unable to 'read' facial expressions or body language;
- have difficulties in relating to other people and making friends;
- have a limited understanding of other people's feelings and their own;
- may be unable to control their feelings in an age-appropriate manner;
- have difficulty coping with change.

From child to adolescent

Each child's ability to cope with and adapt to his problems will be different and may also vary according to other factors, such as the situation, his mood and – especially – his health.

Although there will be some exceptions, as a general rule the younger child will be confused by his problems, and that can give rise to some bizarre or erratic reactions.

In contrast the older child may have developed various coping strategies which make him less prone to behavioral problems, but unfortunately those can often lead to greater withdrawal, thereby inhibiting his ability to learn.

The natural turbulence of adolescence is often compounded by the lack of awareness and the continuing problems of literalness. That 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 he believed that *'the adults around him were shrinking*'.

Generally, people are much more tolerant of bizarre or difficulty behaviors in the younger child than they will be of the adolescent whose behavior seems apparently 'infantile' or beyond control, making it extremely important for the child to learn that certain behaviors are unacceptable in social situations.

However, you do need to take great care in doing this for it is pointless to expect compliance (to the norm) if the child is unable to understand what is being asked of him, or if the situation makes your demands totally unrealistic.

It is vital that, before developing unrealistic expectations or making demands on the child, both parents and professionals learn to understand exactly why the child behaves as he does in certain situations.

While the problems or their effects do not necessarily diminish in intensity as people get older, many people with ASD find ways to compensate for or cope with their sensory difficulties. Thus the focus shifts so that in adolescence and adulthood it tends to be on making friends or finding and keeping a job instead.

NOTES

CHAPTER 2

FOOD FOR THOUGHT

While signs of autism have been noted for centuries, it was not until 1943 that it was actually given a name. However, since the 1990s autism has increased, with many children seeming to develop normally before regressing: a point in time often associated with the onset of seizures.

Digestive/Gastrointestinal (GI) problems

Most of the research in this area has focused on children who, according to the Centers for Disease Control and Prevention (CDC), are over 3.5 times more likely to suffer from chronic diarrhea or constipation than other children.

Meanwhile other research shows that the pain and discomfort caused by GI symptoms is associated with a deterioration in behavior and may even trigger regression – particularly in those who are nonverbal.

Many people with ASD suffer from one or more of a range of problems, some of which are interrelated. These can affect the brain, the person's mood and, most importantly, his behavior. Despite that, on a more positive note, research now shows that alleviating such problems can often improve ASD-related behaviors.

The most common problems are:

- *Hypoglycemia* (low blood sugar level), which can lead to agitation either prior to meals or after eating sugary foods.
- *Leaky gut* – where the wall of the gut is damaged and lets food

particles through. This can cause abdominal pain, heartburn, insomnia, bloating, anxiety, gluten intolerance, malnutrition, muscle cramps and pains, and food allergies.

- *Candida (thrush)*, a fungal infection which can contribute to a leaky gut.
- *Irritable bowel syndrome (IBS)* – the symptoms of this can be quite variable and can include intermittent abdominal pain, bloating, wind or bouts of diarrhea and/or constipation. Other symptoms may include fatigue, nausea, headache, poor appetite, backache, muscle pains or heartburn after eating.
- *Coeliac disease* – a common digestive condition where an adverse reaction to gluten can trigger a range of symptoms, from particularly unpleasant smelling diarrhea, bloating and wind as well as stomach pain, weight loss and tiredness.
- *Gastroesophageal reflux (GER)* often affects babies (most of whom outgrow it by the time they are 12 months old) but is also relatively common amongst toddlers and children with ASD.

  GER occurs when the muscle at the entrance to the stomach fails to keep the stomach contents in the stomach – causing the excruciating pain that adults call heartburn (which may also account for at least some cases of unexplained, inconsolable crying). It can also cause other symptoms like coughing or wheezing as well as failure to gain adequate weight and bad breath.
- A *specific bowel disease* has also been discovered in some children. This can cause lumpy swellings in the intestine, recurring inflammation and constipation. While controversy surrounds 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 often diminishes the

'autisms'.

If you think that your child is suffering from any of those illnesses do consult your doctor or pediatrician as soon as you can.

You should also seek medical advice if your child has frequent bouts of diarrhea or is chronically constipated. These are serious issues and the causes need to be identified and remedied as soon as possible.

It is also important to note that runny diarrhea can sometimes be indicative of severe constipation and impaction (a blockage of feces).

Many children with ASD also suffer from:

- *Food intolerances* – especially to casein (milk) and/or gluten (wheat) – as well as other foods, such as chocolate or oranges. The effect tend to be behavioral – so that the person may become hyperactive or disruptive – often within one or two hours of eating.
- *Various other eating problems*, so that the person:
    - craves particular foods (often those to which he is intolerant);
    - eats non-edible substances (known as pica);
    - has an excessive thirst.

Genetic and/or metabolic problems

A number of genetic and/or metabolic problems have also been identified in some children. These include:

Genes and chromosomes. Generally, autism cannot be traced to a single-gene mutation or a single chromosome abnormality, although ongoing research shows that several different genes (like fragile X) and chromosomes like a duplication of Chromosome 15 or the 22q13 deletion syndrome may be implicated.

- *Mitochondrial diseases* – mitochondria are tiny parts of almost every cell in the body which turn sugar and oxygen into the energy needed for the cells to work.
- Poor *methylation* (the process by which the body gets rid of heavy metals). The body is unable to detoxify itself so that any heavy metals in the body accumulate, affecting both body and brain.
- Impaired *detoxification* – caused by a lack of the antioxidant glutathione (GSH). This can allow toxins like mercury, lead and arsenic to accumulate in the body.
- *Autoimmune problems* – where the body attacks harmless things and creates excessive inflammation. Such children often have a family history of inflammatory diseases, including allergies, asthma and eczema.

Epilepsy

Epilepsy is more prevalent among children with ASD than their peers. This results in seizures or periodic loss of consciousness caused by a disturbance in the electrical activity of the brain.

There are several different types of seizures commonly found in

children with autism. Some of them can be 'triggered' by certain situations from lack of sleep to stress, illness or flickering lights. They include:

- *Infantile spasms.* These usually begin within the first year of life, often between the ages of 3 to 8 months. Spasms often occur several times in a row and such clusters can occur several times per day. These spasms can disappear by the time the child is three or four years old but even so some children will continue to have neurological problems.
- *Atonic seizures – ('drop attacks')* in which the muscles suddenly relax making the child floppy – something that can be dangerous as he could fall and injure himself.
- *Absence epilepsy (also known as petit mal)* in which the child becomes unconscious for a short time. He may look blank and stare or flutter his eyelids and will not be able to respond to things happening around him.
- *Complex partial seizures* leave the child confused. He may make purposeless repetitive movements (called 'automatisms') and wander around or behave strangely. At such times the child is unaware of what is happening around him and will be unable to respond to your voice.
- *Generalised tonic-clonic seizures (also known as grand mal).* These are the seizures most people think of as epilepsy as the child becomes unconscious and then begins to convulse (jerking and shaking as their muscles relax and tighten rhythmically).

See the Appendices for information on two other types of epilepsy Landau Kleffner syndrome (LKS) and Dravet Syndrome.

NOTES

CHAPTER 3

GROWING UP

Development

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.

Many years ago Piaget, the well-known Swiss researcher, divided development into various stages, giving examples of the behaviors and general characteristics that would be seen during each stage, although today we know that the ability of many children is in advance of the stages he noted and that the transition from one stage to another is a more gradual, continuous process than the one he described.

These areas of development (also known as developmental domains) can be divided into four and include:

- *Motor skills*. During this first *sensori-motor* stage infants up to the age of two interact with adults by moving and will gradually develop both:
  - gross motor skills like sitting up or rolling over;
  - fine motor skills, for example picking up small objects.

- *Speech and language* – for most infants and children, acquiring speech is a natural process that goes through a number of stages so

that the child will babble before beginning to identify and imitate sounds.

Initially he needs both the physical ability to form speech and the ability to hear correctly but as he gets older he will also rely on his understanding and memory as he use words and gestures to make his ideas known. and also begin to imagine things that are not logical.

- *Cognitive skills* – during this third stage the child learns new things, processes information, begins to use logic, organize his thoughts and develops his working memory.

- *Social and emotional skills* - in this final stage, which happens broadly between the ages of 4 and 7, the child will begin to develop his reasoning skills and learning how to interact with others.

  During this period, he will also be learning to understand and deal with his own feelings and developing real empathy towards others.

Although children develop at different rates in relation to autism, it is important to note that:

- Self-awareness (the ability to recognize oneself as an individual separate from the environment and other individuals) begins at about 18 months of age, although it takes time to develop fully.
- Around the age of two, your child will begin to use pronouns she and he.

- Most children begin to refer to themselves as 'I' by the time they are three years old.

Time now to look at the hazards which can affect some children. The first two – Global Developmental Delay and Neuro-developmental Delay – have some similarities but are included because both can be found in children with autism and in children with other diagnoses too.

Global developmental delay (GDD)

This, as the name suggests, occurs during the child's early development and is generally identified when the child fails to meet the ordinary developmental goals in at least two areas of development, with many children also having significant communication difficulties.

Sometimes problems become obvious soon after birth as when the child has feeding difficulties or poor muscle-tone, while for others the difficulties pass unnoticed until the child goes to school when his learning or behavior difficulties becomes more obvious.

The most common signs of GDD are seen in the child who:

- is unable to roll over by 6 months;
- is unable to sit on the floor without support by 8 months;
- cannot crawl by 12 months;
- has fine/ gross motor difficulties;
- does things that are not age appropriate – so he may continue to use his mouth to explore new toys with;
- has communication problems;
- has poor social skills/ judgment;
- is sometimes aggressive.

GDD has many different causes which ultimately affect the functioning of the central nervous system. These could include:

- Genetic disorders.
- Metabolic disorders.
- Prematurity.
- Infections – such as Rubella or Meningitis.
- Fetal Alcohol Syndrome.
- Trauma to the central nervous system.

There are a number of diagnostic tests that can be done to identify the underlying cause of GDD. Sometimes these causes can be treated to cure the developmental delay, or at least to prevent it worsening. However, often the cause is never fully determined.

Physical development

Many such children have a variety of physical problems too, which can overlap. These could include difficulties with any or all of the following:

a) Proprioception (body awareness)

Proprioception is sometimes called the sixth sense and is so automatic that we are barely conscious of it. This is vital to our well being for it makes us feel safe and secure as we move around and do things

Situated in the muscles and joints, the proprioceptive system enables us to orientate ourselves in space; letting us know where our arms and legs begin and end and where they are in relation to one another – so that we can move around without crashing into things.

It also helps us perceive the outside world, telling us whether our bodies are moving or sitting still so that we can move around without having to look at our feet all the time. Without it we would need to watch our feet all the time just to make sure that we stayed upright while walking.

Another aspect is out ability to judge how much pressure to use when doing simple tasks from picking an object up to eating and writing. Without proprioception we can break things easily, send food flying in all directions or write so lightly that the marks on the page are almost invisible or so hard that they go right through the page.

This is the child who is always breaking toys or slamming doors; who strokes the dog or cat so forcefully that he hurts them unintentionally. A child who complains that some items - like a glass of milk - are too heavy or, alternatively picks them up so forcefully that the contents spill everywhere.

b) Vestibular dysfunction.

Anyone with a vestibular dysfunction will have difficulty integrating special awareness, gravity, balance, and movement. That will show in a number of different ways so that the child who is hypersensitive in this area may:

- Be afraid of crawling/walking.

- Wave their arms out to the side or hold them close to the body - to help maintain balance.
- Dislike physical exercise.
- Be uncoordinated, clumsy or awkward - often bumping into things.
    - Easily lose their balance or stumble/fall.
    - Dislike unstable surfaces and have difficulty learning how navigate stairs or to go up and down sloping surfaces.
    - May rock or swing gently - as this can help calm his overly-excited vestibular system.

In contrast children who are hyposensitive will generally:

- Seek vigorous activity - like twirling, spinning or swinging.
- Like jumping up and down.
- Have no fear of heights at all.
- Make exaggerated rocking movements - swaying from side to side - or forwards and backwards.
- Appear hyperactive - unable to sit still and constantly on the go.

Because the vestibular system is located in the ears sudden loud sounds can cause or increase the symptoms of vertigo, dizziness, or imbalance - and some people may even experience a sensation of fullness in the ears. Other indications could include:

- Staring at one point fixedly.
- Sticking the tongue out or making facial grimaces.

- Anxiety, panic and social isolation.
- Sensitivity to pressure/temperature changes and even the wind.
- Slurred speech.
- Pain, pressure, or other symptoms with certain dietary changes.

c) Movement/poor motor skills.

These fall broadly into two groups.

- Gross motor skills – problems with balance resulting in poor motor skills and control, as well as a lack of coordination and clumsiness. Confusingly, some children with such problems can be very good at fine delicate tasks.
- Fine motor skills – problems using the thumb and manipulating things – so that the child may hold a pencil in his fist. In contrast, some children have good gross motor skills – so that they climb walls, etc. – and often seem fearless.

d) Praxis

This refers to our ability to plan and/or carry out actions. Some children have a degree of dyspraxia and associated problems with perception, thought or speech.

Dyspraxia refers to children who have movement difficulties and means the poor performance of movement. The word is taken from the Greek 'dys' meaning bad and 'praxis' which is 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.'*

Generally recognized as an impairment or immaturity of the organization of movement it affects the child's ability to plan and/or carry out actions to varying degrees.

While there are those who have problems in both areas some children will only have problems in one area i.e. planning movements or the co-coordination of those movements.

Dyspraxia is often also 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 the problems are often inconsistent: affecting the child very badly one day but seeming much milder on the next.

Some children also have Apraxia (i.e. verbal dyspraxia). This 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, that 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.

Incontinence

This topic may be associated with physical development but may also have a number of causes as detailed.

Normally when the bladder is full it passes a signal to the brain and that should then signal to the sphincter muscles in the bladder that they need to open and contract.

The process of learning to control those muscles is a gradual one as every parent knows, and that, along many other bodily functions, can be hindered or halted by some of the problems mentioned in this chapter.

Other possible reasons for incontinence could include:

- Poor proprioception.
- Poor coordination between nerves and muscles this means that the bladder can sometimes fill up before his brain has registered the fact.
- Muscle weakness.
- A side effect of a medical condition or disability like cerebral palsy, spina bifida, brain injury or nerve damage.
- Problems with the transmission of signals in the brain.
- Urinary infections.
- An overactive bladder - so that the muscles used to prevent the passing of urine contract involuntarily and force urine out. This is more common in girls than boys and could result from an infection.

- A minor deformity in the urinary tract.
- It has also been suggested that anxiety can cause bladder weakness in children but there's little scientific evidence to support this.
- Infrequent voiding – which is when the child ignores the urge to go. Reasons for this could include:
    - a dislike of the school facilities;
    - not wanting to miss out on something;
    - a physical/movement problem that stops him getting there in time;
    - difficulty navigating their way to the toilet – see also visual problems.

Such problems can lead to an overfilling of the bladder and accidental urination or even infections.

Enuresis (bedwetting). Possible reasons include:

- An overfilled bladder. By the time the child is five the body should be producing vasopressin at night – a hormone that controls urine production. If not enough vasopressin is produced the urine production will continue as normal and may lead to bedwetting.
- An overactive bladder, that can only hold a small amount of urine.
- Deep sleep. Children usually sleep more deeply than adults) and that can mean it can take them longer to wake:
    - so that they don't have time to get to the toilet.
    - don't actually sense the signal that tells them their brain that their bladder is full

- Constipation is frequently associated with bedwetting, especially in children who don't wet themselves every night. Sometimes, treating constipation is all that's needed to treat bedwetting.
- Bedwetting can also be triggered by emotional distress, such as being bullied or moving to a new school.
- In rare cases, bedwetting may be the symptom of an underlying health condition, such as type 1 diabetes.

If you are worried about your child do consult your doctor although medical treatments aren't usually recommended for children under five (unless the child finds bedwetting particularly upsetting).

Encopresis

It is all too easy to assume that the child who soils his pants is simply misbehaving or that he's too lazy to use the bathroom and yet that is far from the truth. If the child is past the age of toilet teaching (over about 4 years) and still frequently soils his he may:

- Lack feeling in the bowel so that he doesn't have the normal urge to go to the bathroom.
- Lack control of the muscles involved.
- Have 'functional constipation' (which has no medical cause). In such cases the child may find it physically painful to go to the toilet.
- Have the type of digestive or bowel problems that are often found in children with ASD (as previously mentioned).

Neuro-developmental delay (NDD)

While Global Developmental Delay (GDD) indicates any of the delays mentioned above the term Neuro-Developmental Delay is somewhat different for it refers specifically to difficulties related to the primitive and postural reflexes.

Everyone is born with a set of primitive reflexes but as we develop they are gradually replaced by more sophisticated reflexes. If those early reflexes are not replaced at the correct time, they can remain 'active' in the body, leading to a variety of problems.

If any stage of development is either missing or incomplete the child's progress can be damaged or slowed, and that can have far-reaching consequences which are often not apparent until much later. Thus many children on the autism spectrum have a degree of NDD, leaving the whole system with a minor flaw; like a tiny crack in the foundations of a building.

Although the initial problems can easily be missed, if the problems begin in infancy the baby could be unusually irritable, difficult to feed and/or a poor sleeper. Alternatively, he may seem exceptionally placid or simply be slow to reach the 'normal' developmental milestones.

In contrast, others initially develop in an apparently 'normal' manner before problems begin to arise and the developmental process just seems to come to a halt at a particular point

For some children such problems arise because they already have a tiny flaw which begins to cause problems as they develop.

This often means that one stage of development is either shorter than it should be or is missed out completely, as with the child who shuffles on his bottom and then begins to walk without crawling or creeping in between.

That can make him seem more advanced than his peers, but it can also create future problems, for each of those developmental stages

plays a vital part in development such as hand–eye coordination.

The symptoms of NDD vary widely in severity so that when mild to moderate they are implicated in other learning differences like dyslexia or Attention Deficit, Hyperactivity or dyspraxia but when severe they are often associated with the symptoms of autism or Asperger's syndrome.

What though or the child on the autism spectrum whose problems develop in a slightly different way? The child whose development stalls, stops and then '*goes into reverse'*, so that he loses many or all of his previously acquired skills.

If this happens suddenly the child will be very confused and may withdraw into himself. He may also begin behaving in strange way – behaving obsessively so that he begins spinning plates/toys or lining his up in rows and getting very upset if anything is moved; having tantrums that seemingly happen 'out of the blue' and so on.

If it happens more gradually over a period of months, the child may initially be aware of it himself and can get very distressed by the changes: as we would if it happened to us.

Some of the children who regress in this way will already have had a tiny flaw as mentioned. Others however appear to have developed quite normally until that point.

In both cases it seems that the autism is, seemingly, being triggered by some external factor: although what that might be is the subject of much debate and controversy as a variety of studies have implicated different factors.

The effects of NDD

NDD can give rise to a wide range of problems, disrupting the way the senses receive and process information.

With the exception of the hearing and visual systems, which are

more complex, the sensory effects fall broadly into three groups, as the late Dr Carl Delacato discovered in the 1970s. Thus the child may be hyper (over) sensitive, hypo (under) sensitive or, alternatively, a mixture of both: something we'll look at in the next chapter.

Cognition and Understanding

The child's ability to socialize, explore and play will also be curtailed by the onset of the problems.

This, in turn, will affect the development of his cognitive skills* and understanding. All too often this can leave his level of understanding out of kilter with his intelligence. This can mean that he may:

- not understand apparently simple concepts. One example of this is the ability to know that a dining chair, an armchair and a picture of a chair all have something in common;
- not necessarily take something that has been learnt in one context and apply it in another situation;
- have difficulty understanding abstract concepts;
- take things literally. This can cause confusion and distress, and so he may get upset by words or phrases that have more than one meaning: like the child who had a tantrum when offered 'marble' cake.

Other things that he will find hard to understand can include: sarcasm; double meanings (as in many jokes); idioms such as *'on second thoughts*' as well as the increasing tendency to use verbs as nouns, e.g. *'that film was a good watch*' or *'the game is a must see.*'

Emotions

All too often the person with ASD appears 'emotionally immature'. This is because the onset of ASD, for whatever reason, disrupts the development of self-awareness too. It also curtails the child's ability to interact with other people – which is vitally important in helping him learn to understand his feelings, deal with them appropriately and develop self-control and empathy.

Although this does not necessarily apply to all children, those affected can display any one (or several) of the following:

- Little or no 'sense of self' (ego).
- Very aloof and independent; looks after himself and shuts other people out.
- Difficulty understanding his feelings – and may be overwhelmed by them.
- He 'hides himself' by copying the actions, speech and mannerisms of people he knows or of a character(s) that he has seen on television.
- Unable to cope with his feelings in an age-appropriate manner – so that his limited or poor self-control means he continues to act like a 'terrible two' even when older.
- Difficulty relating to parents and/or peers appropriately.
- Apparent lack of empathy and has little or limited understanding of other people's feelings.
- He cannot necessarily distinguish between your feelings and his own,

so he will be anxious, sad, happy, etc. whenever you are.

While some children go on to develop self-awareness, self-control and empathy, others retain the infant's ability to sense things and remain acutely attuned to other people's feelings, e.g. so that if another family member gets upset or annoyed, the child too may 'act out' those feelings.

Such behaviors can be confusing as they seemingly happen without cause so if you want to identify the causes it is worthwhile considering how the people around him are feeling.

Many children with ASD also feel the 'need' to please other people, and that can sometimes have unexpected consequences. Thus even though such children generally don't lie, some of them will give you the answer they 'feel' is wanted rather than the correct one.

Exposure anxiety

Some children with ASD also suffer from exposure anxiety (EA). EA is similar, but more severe than, social anxiety which makes a person feel acutely self-conscious. This condition, identified by Donna Williams in her book of the same name, can be quite crippling, as the child will find any attention from other people potentially threatening.

Thus the child feels 'exposed' each time another person looks at him, talks to him or even compliments him. 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;

- only do things/help himself when he feels unobserved;
- avoid using personal pronouns;
- have various speech ‘differences’, which can mean that speech is: non-existent; used only when he feels unobserved; limited to a few ‘safe’ words or phrases; or very repetitive. These are similar (but more severe) than the problems found in selective mutism: an anxiety disorder that prevents children speaking in certain social situations. It's important to understand that the child is not voluntarily refusing to speak but is literally unable to do so.

In order to cope with EA the child may attempt to ‘block out’ the triggers. This can lead to some strange reactions, as he may ignore the people he likes most or respond to direct praise by losing interest, disowning (or even destroying) his achievements.

Thought

While the pre-verbal infant thinks in pictures, most adults think in different ways in different situations: thinking in words when they are reading and in pictures if they are designing a garden or a house.

The majority of people think in words at the same speed as speech, and thus they ‘hear’ what they are reading in their minds. In contrast, many people with dyslexia think in pictures – something that also applies to some – *but not all* – people on the autism spectrum.

The work in this area was initiated by Ron Davis. As we learn from his book *The Gift of Dyslexia*, he had many problems throughout his childhood, but the one he found most daunting was his inability to learn to read.

Despite that, Mr Davis became an extremely successful engineer and eventually made a fortune. And, after finally managing to teach himself to read and write, he decided to try to help other people overcome this problem too – founding the Davis Dyslexia Association International (DDAI).

The DDAI believes that thinking in pictures is a major hindrance when people learn to read. This is because the person who thinks in pictures builds up a picture in his mind, adding to it as more concepts arise.

While that is far faster than thinking in words and can make the person very good at many subjects such as the arts or computing, unfortunately it places the child at a real disadvantage when he learns to read.

That is because while it is easy to visualize nouns, verbs and some other words, other words (particularly abstract concepts such as pronouns and adverbs) like 'I, you, it, with, if', or 'and' are much harder to visualize.

Thus the sentence' *His house is big and it has a chimney pot*' would seem to read'*… house… big … … … chimney pot.'* Confusing! Does the word big relate to the house or simply the chimney pot?

The effects of visual thinking in ASD

Some people with ASD are visual thinkers too. One of the most well-known is Dr Temple Grandin. Despite having Asperger's syndrome, she gained a doctorate in animal sciences and now designs equipment for handling cattle which is used across the world.

As her book *Thinking in Pictures* shows, this ability has been of great help to her in conceiving and developing her designs.

It is probable that visual thinking underlies some of the cognitive problems and speech difficulties that such children have. If you cannot easily conceive the meaning of such words, how can you possibly understand what people are saying to you?

Nor can you respond easily and fluently, for there will always be a time-lapse as you 'translate' the words into an informative picture and then 'translate' back into the words that you need to respond with. No wonder such children find it hard to 'keep up' with the conversation.

NOTES

CHAPTER 4

THROUGH THE LOOKING GLASS …

Growing up

Grow up anywhere in the world and, while the language and climate differ, much remains the same. From birth, the majority of us can see our parents and hear their voices. Our senses help us learn about the world. Initially we learn to associate pleasure and comfort with the touch, feel and smell of our mother, from the warmth of her body to the taste of her milk.

As we grow, we play with our food, enjoying its feel as much as its taste and texture. We have fun playing peek-a-boo and other games with our parents, 'exploring' our toys and the objects around us with all our senses. When we are hurt we get comfort from our mother's touch and find her voice soothing. In short, we use our senses to learn about relationships, the wider world and our place in it.

Imagine, though, growing up in a different way, where nothing is quite as it seems. You are not blind but you cannot see properly (although those around you assume you can). Your mother is just a large blob moving towards you; her outstretched arms may even look quite threatening …. although you can recognize her when she gets close.

However careful she is, it hurts when she brushes your hair. Things sparkle in the air. They distract and fascinate you. People frighten you, for their faces are disjointed and change when they move. Some of them smell overwhelmingly – of toothpaste, perfume, dogs, smoke.

Some noises sound really loud and are immensely frightening, like dragons breathing fire …. Background noises impinge on you all the time and stop you from hearing properly when people are talking. Your mother's voice is drowned out by the street noise.

This is the world inhabited by the child on the autism spectrum, who experiences the most bizarre sensations; a world in which the only constants are confusion, terror and fear.

Be quite clear.

This is not a world that the majority of us inhabit.

What though of the child who seemed to be developing normally until their development stalled, stopped and then *'went into reverse*'? It is a given that they lose previously acquired skills – but if their senses also 'unravel', they would find themselves in a nightmare world in which everything they previously knew had been erased. Hardly surprising then if their reactions to the things around them become strange and unpredictable, for they are no longer seeing, hearing or even feeling as they used to.

Time then to look at each aspect of these problems in turn as we step into a different world: the world inhabited by those with autism and Asperger's syndrome.

A visible difference

Vision accounts for over 70% of the information we receive about the world, which makes it extremely important to learning.

Unfortunately, there are a number of visual problems that can affect reading but that generally escape identification in an ordinary eye test.

Known by a variety of names including scotopic sensitivity, visual stress, visual dyslexia and Irlen syndrome, it simply means that the child, quite literally, does not see what other people see.

The signs of visual dyslexia include a range of focusing anomalies, so that the child often cannot use both eyes together, has a 'wandering' eye or a squint, whilst some children have poor visual acuity or even photo-phobia. Confusingly, photo-phobia is not a phobia at all but rather a physical 'over-reaction' to glare, brightness or fluorescence that is outside the control of the person concerned.

Such anomalies can cause a wide range of symptoms. These are individual but when mild include eye-strain, headaches/migraine and clumsiness.

Moderate problems are associated with reading and writing difficulties, although they can often be overcome, particularly in the early years when books have large, well-spaced print.

Unfortunately, though, as the child progresses through school, the print and the spaces between lines decrease in size, often causing strange visual distortions which make it harder and harder for the person to read clearly. Different fonts (the type of text) or a different colored text can cause additional problems.

Thus when reading some children with visual dyslexia may find that the letters move and jump off the page or suddenly appear as two texts next to each other.

Alternatively, the words may become distorted, while the spaces may form 'rivers' that cut through the text: problems that can make them lose their place or miss a line.

To get some idea of these problems try reading this book under different lighting conditions. If you normally wear glasses, try reading it

without them. Conversely, you could read it with sunglasses on in a darkened room or while shining a bright light on to the page. Difficult, isn't it?

Ongoing research indicates that many children on the autism spectrum share similar, but much more severe, visual difficulties. That, plus information from people with ASD themselves, indicates that they too experience a variety of effects that can include:

- Problems judging differences in height or width – particularly noticeable when he steps off a curb or over a threshold.
- Difficulty following moving objects – so he may not see an approaching car until it is very close.
- Seeing faces as if they are distorted or fragmented.
- Double vision – seeing two separate images at the same time.
- A confused perception of space and size – things may seem at times to change size or shape.
- Some things may even seem magnified – one child saw a hair as if it were a strand of spaghetti – which can lead to a fascination with tiny things and make him good at doing intricate tasks.

It is vital to note that any child who sees in this way is actually only partially sighted and also that his sight will vary in different lighting conditions.

That means that he lives in a world where nothing is quite as it seems, nothing is constant; where other people (and objects) can, at times, appear to be extremely frightening. And because he can only focus on one part of the face at a time, all that he sees clearly may be an eye, mouth, beard or earring. Just imagine how confusing that must be.

Faceblindness

For some children, things are even worse, as we learn from Swedish author Gunilla Gerland who has Asperger's Syndrome. In her book *A Real Person,* describes seeing people with blank faces. Nor is she alone, for others too describe seeing similar blank faces – perhaps framed by dark hair or with a hairy growth.

Frightening, isn't it?

Pictures of faces are stored in a special part of the brain. In some cases, 'face blindness' is caused by a malfunction in that part of the brain.

Even so, there is a possibility that, for some children with ASD, this 'face-blindness' actually stems from photo-phobia or poor visual

acuity. Although research has yet to determine the answers, it is clear that if you cannot see faces correctly the only pictures you could store would either be blank or extremely bizarre: which would make remembering and placing faces almost impossible.

Sadly, that can mean that the child may not always recognize the important people in his life even if he sees them every day – although as most children grow older they learn to use other clues such as smell, the way the person's clothes move, or an identifying feature like a mole, etc.

Perhaps such visual problems are at the root of emotional' blindness?' Certainly, most people communicate their emotions through their facial expressions or their tone of voice, as well as words.

As children, the majority of us naturally learn how facial expressions and gestures work by watching and interacting with our parents, but such visual problems will interfere with that 'learning process.' Hardly surprising then that the child finds it hard to decipher facial expressions or gestures – or use them himself.

Unsurprisingly this child will generally not be able to:

- Identify people correctly by sight alone. Looking at faces close up will give a clearer picture – although he may also use other clues like smell. This means that in some situations he may not even recognize you.

"I'm sorry Mrs Jones....Jason won't go home with you until you show him two forms of I.D."

- Read facial expressions or body language properly – making it impossible for him to communicate or interact with others in a 'normal' manner.
- Find his way around an apparently familiar building easily – which could be very difficult if he needs a toilet in a hurry.

Such visual problems cause great anxiety, but, unfortunately, they frequently remain undiagnosed.

All too often the child, his parents and even his teachers are unaware that he sees differently from his peers. That lack of knowledge can compound his problems and, combined with his inability to cope as others do, can lead to frustration and poor self-esteem.

The princess and the pea

In the fairy story of the princess and the pea, the princess was unable to sleep because the queen had hidden a dried pea underneath 20 mattresses. Unfortunately, such sensitivities are not confined to the realm of fantasy.

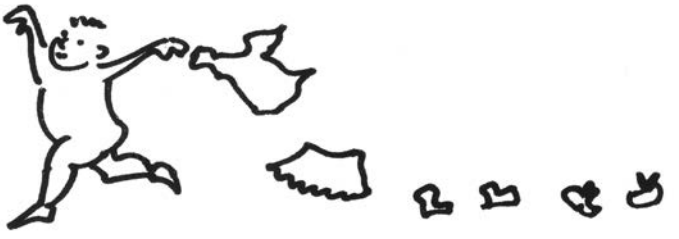
Sadly for the 'hyper' child, normally pleasant stimuli can often be painful and, to make matters worse, go on and on and on. Hardly surprising that the baby arches away from his mother when she tries to feed him, or the toddler moves away to avoid that hug.

This is the child who finds a soft, gentle touch more painful than a firm grip and dislikes the feel of the hairbrush, comb or toothbrush.

Some materials will feel irritating or 'scratchy' – which is why he may want to wear one particular item of clothing all the time or take his clothes off at every opportunity.

This is also a child who probably dislikes finger paints or getting sticky or gritty. One whose sensitivity may extend to the texture of food, which may be rejected because it is too lumpy, grainy, etc.

Confusingly though, real pain may either provoke a total overreaction or be ignored.



Such behaviors are not ‘autistic’ fads.

They arise because the child is hypersensitive.

In contrast, the hyposensitive child will usually enjoy vigorous sensations and physical contact and may even initiate a ’rough and tumble’ himself. However, the downside is that he may not always be aware when he hurts or cuts himself.

Nose pollution

Being ‘hyper’ to smell can have some far-reaching effects. Most of us might find it unpleasant to holiday near a farm where the farmer had been muck-spreading, but after a short time we would ‘shut the smell out’ so that it no longer troubled us.

Imagine though if that smell remained with us hour after hour. Hardly surprising that some everyday smells like disinfectant or perfume lead him to avoid places such as the kitchen or bathroom and even some foods. Or that such problems can limit social contact – as with the girl who said that *'9 out of 10 people have halitosis.'*

The relationship between smell and taste may also lead to some food fads and can put the 'hypo' (under-sensitive) child at risk, as his poor sense of smell and resulting lack of awareness may mean that he eats things indiscriminately – whether edible or not.

The torment of sound

People generally associate hearing problems with an identifiable hearing loss, but there are several other auditory difficulties that can have a devastating effect. These can, at times, make many apparently ordinary situations almost intolerable for the child.

The problems include:

- Poor auditory discrimination. He may mishear some letters or words or be unable to pin-point where sound is coming from. That can be quite confusing – and can even make it sound as if other people are talking nonsense. (Such problems are often associated with dyslexia.)
- Hyperacusis – hypersensitivity to sound – a condition that also affects some people with tinnitus. This means that he finds some specific everyday sounds painful. The sounds that cause problems are individual and can range from quiet sounds, such a clock ticking or people eating, to louder sounds, like vacuum cleaners and food mixers.
- Loudness intolerance, i.e. when the child cannot tolerate the same level of noise as his peers, so he will get very upset by loud noises, such as fire alarms.
- 'Supersensitive hearing'. He may also be able to hear noises (or conversations) that others are unaware of (something that can be worsened by vitamin and mineral deficiencies).
- The majority of children will also be unable to block out background sounds which constantly impinge on them.

Such auditory differences actually mean that many children with ASD are tormented by everyday sounds that constantly impinge and intrude upon them. Such auditory difficulties also:

- make many areas of the home very difficult for him;
- make shopping, the playground, classroom and even trips out potentially distressing and frightening;
- can underlie or aggravate speech and language problems;
- mean that he needs to concentrate much harder than his peers in order to make sense of the spoken word – something that can be particularly difficult in noisy situations.

Any 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.

Free Auditory

Checklists

Sensory integration

Sensory Processing Disorder (SPD), formerly known as 'sensory integration dysfunction,' effectively means that the child has difficulty organizing the incoming sensory and other information into the appropriate motor or behavioral responses that are needed in any given situation.

Because the ability to process that sensory information is so basic to all our actions, whether it be eating a burger, riding a bicycle or even reading a book, the child faces challenges in performing relatively ordinary everyday tasks.

Although many lists of symptoms include the unusual sensory differences that were mentioned earlier this inability to organize those incoming signals means that the child may have:

- motor clumsiness;
- behavioral problems;
- anxiety;
- depression;
- problems in class so that he cannot keep up with his peers.

NOTES

CHAPTER 5

PRIMARY EFFECTS

Disorientation and confusion

The different sensory experiences mentioned in the last chapter mean that the information the child receives from his senses is jumbled. And that, in turn causes disorientation and confusion, leaving him in a nightmare world.

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.

Try it 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 analyzed 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.

Scary, isn't it?

I hope this passage has given you some idea of just how distracting and disturbing such sensory distortions can be; how they can arouse great anxiety and also disrupt a person's ability to think or act in a 'normal' manner.

There are a number of different ways in which the child copes so let's look at each of them in turn.

a) Mono-processing

In contrast to most people, who automatically process information from several senses simultaneously, the child with ASD can generally only process one piece of information at a time –'mono processing'. Dealing with the sensory information he receives a little at a time is the only way in which he can make any sense of the world.

This is why he often uses peripheral vision

(looking out of the corner of his eye or in quick short glances rather than directly at a person or object), as it helps limit the amount of stimulation he receives.

Mono-processing also provides yet another reason for his slow responses. Taking in one piece of information at a time makes for a time lag between being asked a question and his reply – a delay that can make his answer apparently meaningless.

Even so, many children 'take in' everything that is going on around them – although they may not be able to 'process the information' until they are alone or in a quiet place.

It is also worth noting that delayed processing can also account for behaviors that seemingly happen 'out of the blue.' So if your child suddenly creases up with laughter or has an outburst of rage or fear that seemingly has no cause – remember that it could actually originate with something that happened earlier in the day but that has only just been processed.

b) Sensory and Information overload

In some situations, the child may suffer from an information overload. For one child this might only happen in a busy holiday town or at a party with lots of people moving around and talking. For another an 'apparently pleasurable' visit to the supermarket, with its lights, movement, smells and noise, might have a similar effect.

The reactions to such overload are varied. One child may suddenly 'explode' into hyperactivity, while another might become more obsessive or compulsive as he attempts to contain his anxiety within manageable levels.

The most severe reaction is when a child becomes extremely lethargic – because his brain 'shuts down' to protect him.

When this happens suddenly, it can sometimes be mistaken for a form of epilepsy.

c) Anxiety

A major 'side effect' of the sensory problems is anxiety. Although not always obvious, this is evident in:

- Withdrawal – as the child tries to protect himself by ignoring or excluding anything that might provoke anxiety.

  This is the child's way of protecting himself from a confusing and terrifying world. While some children will physically remove themselves from a situation, others simply 'disappear on the spot' – retreating into their own world and ignoring or excluding anything that might trigger their anxiety.

At such times they often appear deaf and blind to the things going on around them, and that in turn will severely limit their social interaction, the development of social skills and even speech.

- *A dislike of change* – which is why routine is extremely important to such children as it provides security. That routine provides some constants in a perplexing and confusing world.

  Reactions to change are very individual, with one child becoming distressed by apparently small things like an item that is out of a place whilst ignoring larger changes, and another doing exactly the reverse.

- *A lack of curiosity,* which along with the child's natural instinct to explore and play is often inhibited because new activities/places are perceived as frightening.

  Those children who do show curiosity often tend to direct it towards objects rather than people – perhaps because people seem more unpredictable.

- *Obsessions/compulsions* are integral to ASD (although not everyone shares that view).

  These are similar to a young child's security blanket, for by focusing his attention on them, they help keep his anxiety at bay so let's look at each factor in more detail.

  They begin as a way to help the child shut the world – and that anxiety – out. Eventually though the thoughts or behaviors 'take over' - so that they are in charge of the child rather than the other way around. Obsessive and compulsive behaviors may include:

- repetitive behaviors like spinning things, flicking a bit of string repetitively or lining toys up in rows, doing specific actions a particular number of times (and even 'having' to begin again if the

process is interrupted before it is complete);

- the compulsive collecting of particular items - toys/CDs, etc.;

- a preoccupation with a particular subject that he talks about repetitively.

Prolonged stress – as happens when you live with physical illness and sensory differences day in and day out – also has several other *physical* effects. Thus it:

- interferes with the digestive process and can cause severe stomach pains during or after meals;
- weakens the immune system;
- leads to vitamin and mineral deficiencies (which is why mega-doses of such things can sometimes be of benefit).

d) Other effects

Anxiety can also:

- limit his social interaction;
- affect the development of social skills and even his speech;
- affect his short-term memory (although his long-term memory may be brilliant);
- interfere with his ability to concentrate and learn.

e) Panic attacks

Many such children – regardless of age or ability – also suffer from 'panic attacks'. These often result from acute anxiety, although they can also be caused by sensory or emotional overload or simply by too much direct attention.

These panic attacks are instinctive and can result in any of the following reactions:

- He may become ‘frozen with fear’ and be totally unable to do anything (even something nice like eating a cake).
- Fight – so that he may suddenly ‘attack’ himself or another person.
- Flight – so that he suddenly up and runs away from a situation.

As adrenaline and other chemicals are released into the bloodstream you may spot some physical signs of this ‘high alert.’ These could include:

- dilated pupils;*
- an increase in heart rate and blood pressure;
- an increase in blood-glucose level;
- tensed muscles – particularly around the neck which can lead to long term aches and pains;
- the digestion and immune system shut down to allow more energy for emergency functions;
- difficulty focusing on small tasks (as the brain concentrates of determining where threat is coming from).

Those signs can sometimes be triggered by things that are seemingly innocuous but obviously have some emotional overlay – as with the boy went into panic mode at the mention of a particular word.

NOTES

CHAPTER 6

E-FFECTS NOT DE-FECTS

Learning differences

Unfortunately, the problems associated with abnormal sensory perceptions and anxiety also give rise to a whole range of cumulative effects that, once again, range from mild to severe and vary from person to person. These can have a great impact on the child's life, interfering with his ability to develop relationships and learn.

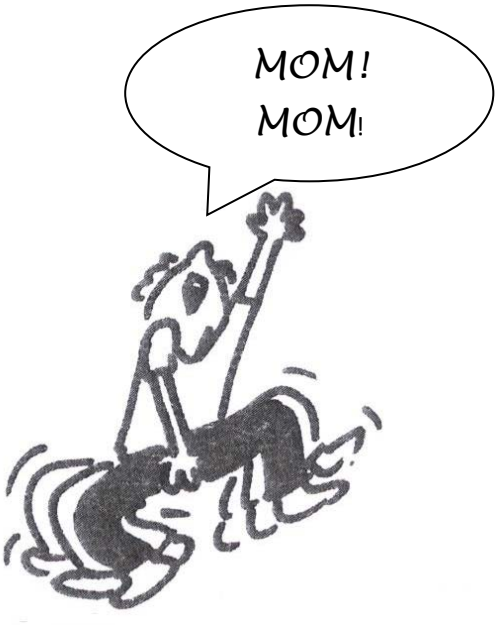
While the problems do not affect everyone with ASD, they can include:

- Poor short-term memory, which can make life and learning extremely difficult. Such problems often coexist with a good long-term memory (like that found in savants).
- Limited understanding of: directions, sequencing, sense of time.
- Mixed dominance. He may use either hand to write, eat, etc.
- Disorganization. He loses things, has difficulties organizing work, etc.

In addition to those problems already mentioned, the child may also:

- get easily irritated or frustrated;
- have poor self-esteem.
- have a poor or limited awareness of:

- *Danger.* He may also fail to respond in the correct manner to warning signs, e.g. the noise of a fire alarm could cause him to panic or freeze rather than to leave the room.
- *Bodily functions.* As mentioned previously he may not realize that he needs the toilet until the need suddenly becomes urgent or it is too late.



- *Pain.* His responses may be unusual. Some children are *very* aware of pain – complaining of toothache long before the dentist can identify the problem.

  Alternatively, other children may simply ignore pain like the boy who jumped up and down on a sprained ankle because he was upset at being taken to the casualty department!
- *Other people's motives.* His inability to 'read' faces and body language can make him seem naïve and can also make him very

vulnerable to bullying or exploitation.

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

- seem offhand, self-centered or aloof;
- make direct personal comments that can seem quite rude;
- invade other people's personal space, e.g. he 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;
- have difficulty understanding social rules;
- talk repetitively about one subject whilst missing the 'clues' that indicate another person wants to speak;
- have difficulties organizing or limiting his own behavior in an age-appropriate way;
- demonstrate age-inappropriate behaviors, e.g. laugh inappropriately, make odd noises, or have a panic attack (or even a tantrum).

Please do not assume that he is being intentionally rude or negative or that the behavior is specifically aimed at you. It is not!

Perseveration and Stimming

While stimming generally refers to repetitive physical movements, sounds, or repetitive movement of objects there is an overlap between these two things because both involve thought, words, or actions).

Professionals tend to be divided as to how to categorize stimming, some believing it is a form of perseveration and others suggesting it's a 'self-stimulatory behavior' with which the child either calms or stimulates himself.

Like most things in autism, however, things are not that clear-cut. In order to clarify things – both for myself and you - I've divided the varying behaviors into different groups alongside an explanation of the things that I think trigger them.

1) *Other signs of developmental delay*. This could include:

- hand flapping;
- a sudden outburst of sounds or repetitive speech which is often confined to just a few words or phrases.

  Both of the above are a sign of excitement or some other strong emotion.
- Echolalia – which is actually a natural stage of language development.
- Echopraxia (also known as echokinesis) – simply means an *involuntary* repetition or imitation of another person's actions.

2) *Repetitive thoughts and actions that happen in the here and now.* As previously mentioned these tend to be related to anxiety and are used to give the child some control over what is seeming a chaotic world. They could include:

- asking repetitive anxious questions even after he has been answered.
- sticking rigidly to a routine such as:

- lining toys up in rows;
- touching the same items in the same order every time he walks into a room or around the garden;
- crossing a room or walking around the garden or playground in a particular way - following the same route repeatedly.

- keeping everything in what he considers to be the 'right' place – examples being lining up things on the table, making sure all the handles on the cupboards are in a certain position or always placing the DVDs in a particular order etc.

  We are all familiar with the young child who won't step on the cracks on the sidewalk because they think that something bad will happen if they do.

  Gunilla Gerland links that type of 'concrete' thinking to her need to keep everything in its place. She explains that she made up her own theories as to how the world worked – so that if the living room had an ashtray on the table with the newspaper beside it and her sister then came back from school Gunilla thought everything had to look exactly the same the next day or else her sister might not come back.

And yet, as all successful athletes know, activities that are repeated time and again strengthen those particular pathways in the brain. That means that while such behaviors are initially under the child's control, they may gradually take over his life and become obsessive or compulsive.

This risks becoming a vicious circle as any interruption to his preoccupations or change in 'his' routine creates further stress. Even so such behaviors generally decrease once his stress has been reduced and he feels secure - and knows exactly what is expected of him.

Some obsessive interests can also be used to broaden his knowledge of a particular subject as they were for Temple Grandin, who

thanks to her mother's tenacity, some inspired teaching and her own skills, has gone on to achieve great things in her field.

3) *Calming techniques.* These are seen in children who, as in the section above, are suffering from overload – or trying to avoid it.

These calming techniques include:

- rocking backwards and forwards or swaying from side to side;
- playing on a swing;
- 'losing' himself in a cartoon on TV which he watches incessantly;
- humming/clicking his fingers.

Such repetitive actions can be very beneficial because they release stress chemicals into the nervous system, keeping the child calm and protecting him from overload and meltdown.

4) Sensorial behaviors. As Dr Delacato suggested these are often indicative of their sensory difficulties the child has.

They could include:

- feeling/touching/rubbing different textures;
- tapping or banging things repeatedly;
- watching the spin dryer go round and round;
- rubbing his eyes excessively.

4) Self-injurious behaviors could include:

- head-banging;
- biting himself;
- rubbing or scratching excessively.

There are several potential reasons for this:

- Physical problems such as a headache or an allergy (some of which may not be easily identifiable.) One example comes from Carly Fleishmann who told her parents that she felt as if her legs were on fire with ants walking up and down them.
- Delayed processing. Many children with autism learn by absorbing information during the day but cannot process it until later when they are in a quiet place without other distractions.

  That delayed processing can occasionally result in a sudden outburst of difficult behavior (as when the child suddenly remembers and considers a difficult or uncomfortable situation or happening) that is unrelated to the present situation.

- Occasionally such self-abusive behaviors are the result of abuse.

5) Perseverative behaviors are those that continue long after the appropriate end to them has passed.

These are not the same as hyperfocus i.e. the ability to concentrate single-mindedly on one question, problem or goal at a time, excluding all other diversions or distractions.

Examples of perseveration could include:

- Continuing to ask anxious questions about an event which has passed despite receiving an answer.

- Continuing to feel angry/sad/happy after the event that triggered that feeling is over - so that the emotion shown is out of kilter with the situation.
- Talking about the TV program that he watched earlier even though he has been watching a completely different one for some time.
- 'Ruminating' on a conversation/situation that is long gone.
- Banging an object even when it is clearly broken.
- Texting someone over and over even when they don't reply.

Because some children with ASD process incoming information tangentially a single word or sentence can sometimes trigger numerous fast-moving thoughts or images which, when verbalized, may seem random and unconnected to the matter at hand.

Thus an ordinary conversation about the holidays might begin with talk of a car journey and then move on to the destination and what happened after the person arrived.

The child who has such processing problems will be unable to follow this and, at the very beginning of the conversation, will get stuck on the word 'car' which triggers a chain of thought about all the cars the child has ever seen; their shapes, sizes and colors, and results in him thinking (and perhaps talking) about cars half an hour later, when the original conversation has long since moved on.

Perseveration is linked to a variety of problems that include:

- physical brain injury, trauma or damage
- dysfunction or dysregulation of the frontal lobes;
- aphasia;
- attention deficit hyperactivity disorder (ADHD) and Obsessive Compulsive disorder – one possible reason being that the child's ability to transition from one task to another is impaired in some way.

Challenging behaviors

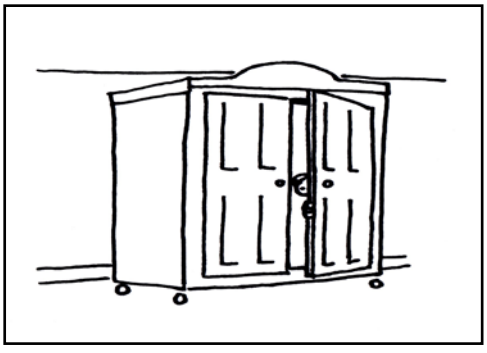
Challenging behaviors is a term that is often used to refer to 'difficult' or 'problem' behaviors, including aggression towards others, self-injury like head-banging, destruction of property, such as throwing or breaking objects, and even running away, some of which have already been mentioned.

Causes of such behaviors could include:

- *Pain.* Many children with ASD have a variety of physical problems too, although as previously mentioned the signs are not always obvious, especially in non-verbal children.

  To identify these you will need to watch out for any changes in behavior, as these may indicate a headache, stomach ache, ear infection, toothache or other pain. Such signs could include:

  - self-injury/abuse – like hitting himself or head-banging;
  - suddenly hitting out at others;
  - odd behavior like hiding in a cupboard.



- *The situation/environment*

An overload of noise or multiple stimuli can cause a panic attack or 'meltdown' or even cause the child to run away from the situation.

- *Lack of sleep*

Lack of sleep is associated with a variety of effects and can certainly make a person more irritable, short-tempered and vulnerable to stress.

- *Gaining a reward* (often thought to be attention-seeking)

  Sometimes the child will *learn* to react badly – because he is 'rewarded' by being excluded from (or allowed to escape from – or avoid) a particular situation that he finds difficult.

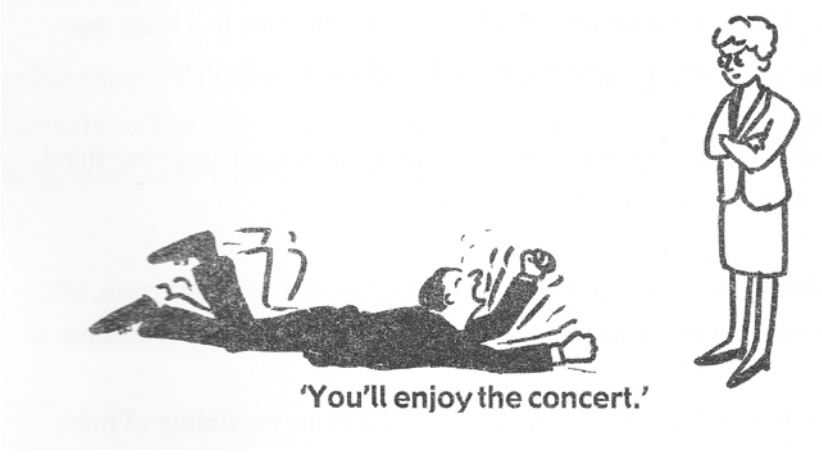
- *The behavior of those around him* (see bullying).

- *Exposure anxiety* (as already mentioned).

- *Abuse* - A thorny topic that will be covered in detail in the forthcoming book *Shadows on the Soul*.

- *An inability to control his emotions in an age-appropriate way.*

  That can lead to difficult behaviors which could range from having a 'tantrum' or destroying property to hitting out at other people or even hurting himself.



Please remember that:

- **difficult behaviors (like having a tantrum in a noisy supermarket) do not necessarily equal naughtiness – although that doesn't mean he's always an angel;**
- **an inability to speak DOES NOT mean he is unintelligent;**
- **he would if he could but all too often he simply can't.**

NOTES

CHAPTER 7

BULLYING

Vulnerability

Children with ASD, like those with other disabilities, are more vulnerable than their peers and this is often compounded by their lack of awareness of others, visual problems and stereotyped behaviors.

Any of those things will make the child stand out and, by drawing attention to his differences, can make him the butt of jokes or lead to bullying which can make his life miserable.

As with all children being bullied can also cause a loss of self-esteem, depression or other mental health issues.

Bullying

Bullying can take many forms, from name-calling to social isolation and, sadly, even physical violence – which is usually the most easy to identify. Sometimes though the bully will pick up on the specific difficulties that such vulnerable children have and use them when bullying him.

Examples could include:

- using his naivety to encourage him to break the rules;
- 'winding him up' or even causing a sensory overload - so that he becomes agitated/very anxious and:
  - acts in an apparently strange or inappropriate manner;
  - uses inappropriate language;
  - hits out/hurts another child;

- playing practical jokes that are intended to demean the person concerned – like one where a boy was asked to wear a silly costume to class on an ordinary school day.

Sadly this can sometimes mean that it is your child who gets into trouble with the teacher while the bully escapes unscathed.

Unfortunately bullying is not always confined to children, for adults can be bullies too as some of us know to our cost. Another problems is that occasionally a member of staff will misinterpret ASD behaviors as 'bad' behavior, and respond unhelpfully.

While those physical signs such as torn clothes, cuts and bruises are easy to see, the more subtle signs may be less easy to identify but could include changes in your child's behavior such as:

- a reluctance to go to school;
- increased anxiety; verbal outbursts;
- physical abuse towards others or himself;
- reverting to bed-wetting;
- sudden (or increased) incontinence during the day;
- an increase in problem behaviors whilst at school.

Even so it is worth noting that while such changes can result from bullying they could have other causes too – such as a change of teacher/classroom etc., so do liaise with the school so that you can determine the cause(s).

Cyberbullying

While, historically, bullying has been a largely school-oriented phenomenon, cyberbullying and text-bullying is now on the increase and may be sent via e-mail, instant messaging or online communities such as Myspace and Facebook.

This allows bullies to torment, threaten, humiliate or embarrass their classmates, as Jesse A. Saperstein clearly describes in his best-selling memoir *Atypical: Life with Asperger's in 20 $^{1}/_{3}$ Chapters*.

The older child/teenager who uses the Internet without support is obviously a possible prey to this awful form of bullying, so you may need to teach him how to protect himself – see the tips in the next book in this series, *Autism Launchpad*.

NOTES

CHAPTER 8

PARENT POWER

Donna Williams, the well-known Australian writer, artist, singer-songwriter, screenwriter and sculptor, refers to autism as being a fruit salad – with every child having their own individual mix of fruit.

Hopefully this book has given you an insight into the reasons behind particular aspects of your child's behavior, and helped you identify the aspects of autism that are most evident in (and important to) your child.

That puts you in the ideal position to make a real difference to your child's life by using the appropriate 'stress-busters' and other useful ideas that are to be found in the next book in this series. Autism Launchpad is your home. A place where you can offer the love, attention and help that your child needs to equip him for his 'launch' into the wider world. A place where, regardless of ability, you can lay the foundations so that he can be helped toward a happy and fulfilling life.

Meanwhile remember that:

- His difficulties make many apparently ordinary things extremely hard to do and he will have to make far more effort than his peers to complete tasks.
- Regardless of his difficulties, it is **vital** not to underestimate his intelligence or make your expectations too low as many children understand far more than those around them think.
- If you treat him in the same way as his peers, he will probably fail and that will diminish his self-esteem.

- It is highly likely that he knows he is not the same as his peers, even if he does not understand the reasons why.
- The child with ASD can be extremely sensitive to other people's feelings, so if you feel stressed or worried, he may get anxious.

As you have seen, ASD involves a wide range of differences which affect each individual to varying degrees.

Add to that the fact that some children are natural introverts, whilst others are more extroverted, and you can see that no two children are the same – each having their own very specific abilities and needs: something author Donna Williams likens to an 'autism fruit salad'.

Hopefully this book will have helped you to identify your child's abilities and needs, so that you are now in a position to understand where he requires adaptation and/or support, which treatments and/or therapies might be beneficial, and when he simply needs understanding, respect and acceptance.

In the past, a diagnosis of ASD (and most particularly of autism) was often linked to a doom and gloom prognosis. However, it is impossible to predict the future – or to accurately assess an individual's ability to progress – so such gloomy predictions should not be taken as fact.

They are not.

The next book in this series: *Autism Launchpad - A Toolkit for Positive Parents* contains a range of useful (and often relatively inexpensive) ideas that you can use to help maximize your child's potential as well as tips that can be used to help make life more comfortable for everyone else in the family too.

And that brings me neatly to the final two points.

Looking after yourself

Living with anyone who has special needs can be extremely difficult at times, both for you as a parent as well as for any other children in the family.

That is not simply because of the child's behavior, but also because, sadly, you may still have to fight for the health care and services that your child needs.

All too easy then to forget to look after yourself. But **vital not to**.

Don't forget that getting overtired and overstressed can lead to illness and even possible resentment towards the child so that it is vital that you find ways/times in which you can relax and make time to recharge your 'batteries.'

Siblings

Even though most siblings feel the need to protect and/or defend the child with special needs they will also need support too as they can often find it difficult to:

- Understand the problems their brother or sister has.
- Cope with the fact that his/her needs sometimes override theirs.
- Find their own identity.
- Bond with him/her.
- Have their toys or books taken - or even destroyed - by him/her.

- Cope if other children tease them about their sibling.

APPENDICES

These appendices offer a brief introduction to some of the problems that can also be found in some children with ASD.

Recognised chromosomal/genetic abnormalities

Down's syndrome

In the majority of cases, Down's syndrome usually occurs because of a chance happening at the time of conception which leaves the child with an extra chromosome 21.

The extra genetic material also affects all organs in the body and complications may rise at birth or may present later in life. That can leave them with a number of medical conditions, including:

- congenital heart disease (that affects 50%) and abnormalities of the gastrointestinal tract - gastroesophageal reflux and celiac disease being common;
- a number of eye problems - including near sightedness, astigmatism, and strabismus;
- recurrent ear infections, deafness;
- autoimmune diseases.

All children with Down's syndrome have some degree of developmental delay and often cognitive delays too. Those mean that they take longer

to learn to sit, crawl, walk, and talk than their peers and that learning can be more difficult for them than it is for their peers.

Many children find it easier to learn visually and learn to talk more easily if their main words are signed as well as spoken.

Fragile X syndrome

Fragile X syndrome (FXS) is caused by a "full mutation" of the FMR1 Gene and is the most common known genetic cause of autism or autism spectrum disorders.

Symptoms of FXS include a range from learning disabilities to more severe cognitive or intellectual disabilities.

Delays in speech and language development are common, as are a variety of physical and behavioral characteristics.

Rett's Syndrome

This is caused by mutations on the X chromosome on a gene called MECP2. Although it is occasionally found in boys it generally affects females, who are also often diagnosed as having autism.

The symptoms appear after a period of apparently normal or near normal development. That generally continues until the child is 6 to 18 months old at which point their development gradually slows down or stops.

That is followed by a period of regression in which the child loses her communication skills and also the purposeful use of her hands. Stereotyped hand movements such as hand-washing, gait disturbances, and slowing of the normal rate of head growth become apparent.

The child with Rett's disease may suffer from some of the numerous and often severe physical symptoms not normally associated with autism (excluding epilepsy which is common to both).

The signs of Rett's disease include:

- Slowing of head growth with age.
- Increased spasticity/decreased mobility with age.
- Loss of purposeful hand use.
- Muscle wasting.
- Poor circulation of lower limbs.
- Small feet.
- Unsteady stiff-legged gait (only half the sufferers achieve full mobility).
- Scoliosis – curvature of the spine.
- Epilepsy – 75 per cent may suffer with some form of seizure during their lives.
- Loss of previously acquired skills after normal development and/or regression of social development.
- Repetitive hand movements, which may include wringing, patting, clapping.
- Learning difficulties.
- Hyperventilation and/or holding breath and/or air swallowing.
- Grimacing, mouthing, grinding of teeth.
- Spontaneous vocalizations/laughter.

Rett's syndrome causes problems in brain function that are responsible for cognitive, sensory, emotional, motor and autonomic function.

These can include learning, speech, sensory sensations, mood, movement, breathing, cardiac function, and even chewing, swallowing, and digestion. Other problems could include seizures and disorganized breathing patterns while awake.

In the early years, there may be a period of isolation or withdrawal when she is irritable and cries inconsolably. Over time, motor problems may increase, but in general, irritability lessens and eye contact and communication improve.

Tuberous sclerosis (epiloia or Bourneville's disease)

This derives its name from tuber-like growths on the brain which harden and calcify with age. While it is thought to be mainly a hereditary disease, in some cases it seems to occur 'out of the blue.'

It can affect people in different ways and to varying degrees of severity. Over 50 per cent of people with it are intellectually normal and may even be totally unaffected by it, while others will have mild or even severe learning difficulties, although life expectancy is generally normal.

There are a number of different signs of this disease, although not all are necessary for diagnosis. If, however, your child has a combination of those shown do consult your doctor for further advice:

Symptoms can include:

- White (depigmented) patches on the skin – especially the limbs and body – which may be apparent at birth and also red or brown

'birthmarks' on the face (although both of these can also occur with other conditions.)

- Epilepsy, which often starts in childhood, although as the child grows older the seizures may change or even stop altogether.
- A facial rash across the nose and cheeks during adolescence, sometimes mistaken for acne. This starts as red pin-point spots but the redness may fade later and the spots will seem more like bumps.
- During adolescence, or even into adulthood, small nodules of skin may form around the finger or toe nails. This may occasionally be the only external sign of the condition.
- Teeth may be pitted in numerous places.
- Tuberous sclerosis can also affect some internal organs such as the heart or gut.

Other forms of Epilepsy not previously mentioned

Landau Kleffner syndrome (LKS)

This rare form of childhood epilepsy generally develops between the ages of 3 and 8. It may develop slowly over a period of months or suddenly appear overnight.

It results in severe language disorder which, when occurring in very young children who have not yet learnt to talk, may be mistaken for a developmental disorder, autism or deafness.

The symptoms can include:

- Abnormal electrical activity in one or both temporal lobes that are responsible for processing language amongst other functions. (This can be identified through a sleeping EEG as it does not always show up if the EEG is done while the person is awake.)
- Temporary neurological problems leading to:
    - Loss of bladder and bowel control.
    - Visual disturbances when the child cannot understand what he sees and might have difficulty in recognizing familiar objects such as people, clothes, etc.
    - Lack of comprehension – the child may become unable to recognize his own name.
    - Difficulty in recognizing environmental sounds, for example the telephone ringing. May appear deaf.
    - The ability to speak is often seriously affected and some children may completely lose their speech.
- Hyperactivity and/or lack of attention.
- Irritability and depression.
- 'Autistic'-like behaviors including:
    - avoidance of eye contact – very common;
    - avoidance of contact with others;
    - very disturbed sleep;
    - extreme fussiness over food;
- attacks of rage or aggression;
- insensitivity to pain;
- bizarre, inappropriate or repetitive play.

Dravet syndrome (Severe myoclonic epilepsy in infancy - SMEI)

This very rare form of childhood epilepsy affects around one or two children in every 500.

The epilepsy usually starts with seizures in the first year of life that are often associated with a high temperature (febrile convulsion).

Early development is usually normal but it tends to slow down towards the end of the second year. At this point the child may also lose previously acquired skills with speech and language being particularly affected.

By the second year of life the seizures may be more frequent and persistent - often involving one part of the body. These seizures can happen with or without a fever, and at any time of day and night. They can be:

- tonic-clonic seizures;
- myoclonic seizures ('myo' meaning muscle, and 'clonus' meaning jerk);
- focal (or partial) seizures that often involve just one side of the body, although both sides of the body may be involved.

These seizures can often be triggered by photosensitivity which leaves the child is hypersensitive to flashing or flickering lights or by hot environments/baths/showers.

Illness that may cause or contribute to ASD.

Rubella (German measles)

When contracted during pregnancy, rubella infects the fetus as well; the infection may continue for an extended period, sometimes even after birth. If it occurs during the first three months of pregnancy the risk of rubella associated defects is greatly increased and the eyes, ears, heart, central nervous system and the brain will be particularly susceptible to damage.

The rubella child may suffer from a combination of problems, one of which is multi-sensory deprivation. He may also suffer from:

- Unusual sleep patterns;
- Feeding difficulties – particularly in chewing and swallowing solids;
- Hyperactivity;
- Sensory damage which causes a low toleration of tactile sensations.

Meningitis and Encephalitis

Whether either of these can cause or contribute to ASD is a moot point. While pediatricians generally seem to believe there is no connection I have included them for two reasons. The first is that some parents do indeed think such illnesses might have been a factor in their child's autism, the second that both can potentially damage some parts of the sensory system.

Meningitis is a serious disease that causes inflammation of the lining around the brain and spinal cord – the meninges – and can develop very rapidly.

It can be caused either by bacteria or a virus. *Bacterial meningitis* is the most serious form, as it can be life-threatening. While most people do recover, it can cause serious complications and lead to deafness, brain damage, or learning disabilities.

In contrast *Viral meningitis* is the most common type of meningitis which can be relatively mild with flu-like symptoms. While It can be airborne or spread by poor hygiene bacterial meningitis can be passed on by close contact with an infected person and picked up by:

- being kissed or touched;
- people sneezing and coughing close by;
- sharing eating and drinking utensils and other personal items, such as toothbrushes.

The early symptoms of both types of meningitis can be very similar so it is very important to get medical help <u>as soon as</u> you notice any of the following warning signs.

- unusual, shrill cry or moaning;
- grunting or rapid breathing;
- being fretful or irritable when touched;
- vomiting;
- refusing food/poor feeding;
- pale or blotchy skin;

- being drowsy, floppy, listless, unresponsive or difficult to wake;
- having a fever with cold hands or feet (although this is less common in young babies);
- a bulging fontanelle (soft spot at the top of the baby's head);
- spots or a rash.

Bacterial meningitis can lead to *blood poisoning (septicemia)* if it's untreated, as bacteria can enter the bloodstream and multiply rapidly.

Septicemia

Septicemia can be very dangerous.

It causes a rash under the skin - a cluster of tiny spots that look like pinpricks and can start anywhere on the body.

If untreated, these spots will develop a bruise-like appearance, followed by purple skin damage and discoloration. If your baby has darker skin, the rash can be harder to see, so do check the paler areas too.

A meningitis rash doesn't fade so check by pressing a clear drinking glass on to the spots. The rash may fade at first so keep checking but if you have any doubt, get help immediately.

It's worth noting that the symptoms commonly associated with meningitis only appear when the disease is already advanced. Although some of them are similar to other childhood illnesses, like flu, if you are worried, don't wait - get medical help straight away.

Encephalitis

Encephalitis is a rare disease that is most common in children, the elderly, and people with weakened immune systems.

Encephalitis literally means an inflammation of the brain that, in most cases, is caused by a virus.

In milder cases the symptoms could include a fever, headache, poor appetite, lack of energy and a general sick feeling. In contrast in more severe cases, the child is likely to experience high fever and symptoms that relate to the central nervous system. These could include:

- severe headache/nausea and vomiting;
- stiff neck;
- confusion/disorientation;
- convulsions (seizures);
- problems with speech or hearing;
- hallucinations;
- memory loss;
- drowsiness/coma.

The symptoms are harder to detect in infants, but the important signs include:

- vomiting;
- a full or bulging soft spot (fontanel);

- crying that doesn't stop or that seems worse when an infant is picked up or handled;
- body stiffness.

Many people with encephalitis make a full recovery but in some cases, swelling of the brain can lead to permanent brain damage and lasting complications like learning disabilities, speech problems, memory loss, or lack of muscle control.

Other Related Problems

The term 'comorbid' is sometimes used if the child's has other conditions that are associated with an initial diagnosis. This could include things like sleep disorders, gastrointestinal complaints, epilepsy and more some of which have already been mentioned.

Even so there are a number of other conditions that are also frequently found in children with ASD so this section offers a brief overview of some of the most well known in both categories.

Attention Deficit/Hyperactivity Disorder (ADHD)

This common disorder has increased over the years and, as with autism, affects more boys than girls. While many people believe that it is behavioral it is often found in children who have a degree of neuro-developmental delay and so many such children share the sensory differences found in ASD – although generally to a lesser degree.

All young children have times when they have a burst of energy and tend to act or speak before they think, as when anxious or excited.

Unfortunately, studies suggest that in some schools it is the youngest children in a class who tend to be referred for assessment for ADHD – simply because such behaviors are more evident than in the older children in the class.

In contrast children with Attention Deficit/Hyperactivity Disorder have such symptoms all the time and in different settings: unless they are doing something that interests them when they may focus only too well (hyperfocus).

Even so, while the majority tend to be hyperactive, it is important to note that some children who are more 'hypo' (under) active and, although they share other problems they spend their time daydreaming and often seem listless and even depressed.

Such children have a range of problems that interfere with their ability to socialize and learn. These include:

- Lack of concentration/Inattention.
- 'Ants in the pants' – so that they find it impossible to sit still as they need constant movement.
- Impulsiveness.
- Disorganization.

Hyperlexia

The child reads precociously and may be fascinated with letters or numbers but still has significant problems with comprehension and a poor understanding of verbal language.

Similarly, his thinking may be concrete and literal, with other symptoms corresponding to ASD such as echolalia, pronoun reversal, a need for routine, sensory hypersensitivity, and strong auditory and visual

memory.

The 3 D's - dyslexia, dyscalculia and dysgraphia

People who are affected by any of these three problems often have difficulty with being organized and/ or have problems with following complex instructions.

This can make practical and academic aspects of life more challenging than normal, although the child may often develop strategies to help them overcome the most difficult aspects.

On the plus side some of them have great strengths that could include:

- a fantastic long term memory;
- an instinctive understanding of very complex things (that they can't always explain);
- artistic skills
- good kinesthetic (learning by doing or active movement) memory;
- creativity.

1) Dyslexia

The signs of visual dyslexia have already been discussed on the section on vision but others too have different theories about dyslexia.

Dr Harold Levinson is an American psychiatrist and author, who has been pursuing alternative theories and treatments for dyslexia since the 1960s. His research led him to conclude that dyslexia was a syndrome of multiple varied reading and non-reading symptoms

affecting over 40 million American children and adults that arises because of the interplay between dysfunctional mechanisms in the inner-ear and the way in which the child tries to adapt to and minimize those difficulties that causes: which is the reason that people with dyslexia have both balance and co-ordination problems in addition to their problems with reading.

The auditory differences also play a part as Dr Berard found when he identified various hearing distortions amongst his patients with dyslexia.

He determined that while a non-dyslexic person would generally use their right ear to interpret speech and their left for other sounds, some people with severe dyslexia interpret speech sounds only through their left ear or alternatively have no hemispheric preference at all: all or any of which can give rise to a number of problems in interpreting speech.

It is know that some children with dyslexia suffer from APD – or auditory processing disorders – to give them their full name. While the child's hearing is essentially normal he or she will struggle to understand speech in noisy situations: an ability which should normally improve with age and maturity. It has been suggested that in such cases the brain tries to use both hemispheres to interpret speech, which causes confusion as the connection between the two halves of the brain becomes overloaded.

2) Dyscalculia

Dyscalculia is a learning issue that causes serious math difficulties and is thought by some researchers to be almost as common as dyslexia. It is sometimes refered to as a learning disability or disorder or even 'number blindness' while many families just call it 'math dyslexia'.

Once again this condition origniates in the brain and varies in degree.

At one end of the spectrum are those who can't grasp basic number concepts however hard they work, because they cannot understand the logic behind them. And that will make a great deal of difference in the classroom as it provides the basis for all math.

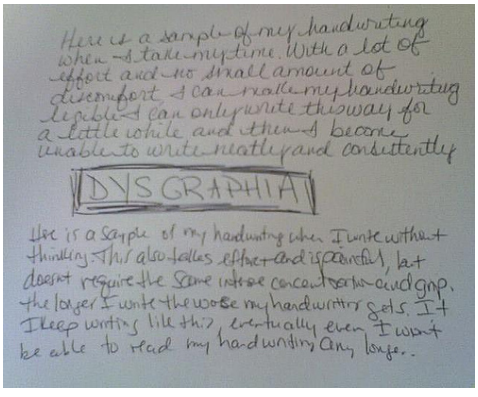
Meanwhile others understand the logic math but have difficulty knowing how and when to use that knowledge.

Regardless of the difficulties though that struggle with math can be confusing, and, even if the child is doing well in other subjects, it can lead to frustration, anxiety and low self-esteem.

3) Dysgraphia

The act of handwriting uses a complex set of fine motor skills which have to be coordinated with information processing. Dysgraphia is nothing to do with a child being lazy but is a neurological disorder which makes it hard for the child to form letters. Even those who can write need to concentrate far harder than their peers to produce clear and coherent writing.

That can result in a written product that's hard to read and filled with errors – and, most importantly, does not convey what the child knows and what he intended to write. One example comes from Asturnut on Wikipedia.



The text in that example reads:

> *Here is a sample of my handwriting when I take my time. With a lot of effort and no small amount of discomfort, I can make my handwriting legible. I can only write this way for a little while and then I become unable to write neatly and consistently.*
>
> *Here is a sample of my handwriting when I write without thinking. This also takes effort and is painful, but doesn't require the same intense concentration and grip. The longer I write the worse my handwriting gets. If I keep writing like this, eventually even I won't be able to read my handwriting any longer.*

Experts believe that dysgraphia arises because the child has difficulty with either one or both of the following:

1. Organizing information that is stored in memory
2. Getting words onto paper by handwriting or typing them

Written work may be:

- very poorly formed
- falling off the line or in an unusual position on the page
- a mixture of cursive and block letters in varying sizes
- difficult to read

When you have dyslexia, dysgraphia or dyscalculia, it is very common to have differences in the way that your central executive or working memory functions.

People with dysgraphia do not learn or think in exactly the same way as most of the population; they have a learning difference. They are often highly intelligent, as measured by standard, well recognized, tests.

Diagnosis of dysgraphia is often difficult to make as many people have handwriting difficulties and so needs to be done by

Dysgraphia can sometimes cause physical pain and may limit their ability to express their thoughts, making it difficult for the child to achieve his full potential. It will often worsen when the person is stressed or under time pressure as in an exam.

DAMP syndrome

This is not a well-known condition and there is still some controversy about its validity but the letters stand for:

D - Deficits/Disorder.

A - Attention (ADHD).

M - Motor Control (Dyslexia/Dyspraxia).

P - Perception.

Children with this syndrome are said to have a combination of problems with attention, motor control, and perception. This means that the problems can include:

- Attention-deficit/hyperactivity disorder.
  - limited attention span - easily distracted, flitting from one thing to another and struggling to stay 'on task';
  - forgetful, loses/misplaces things;
  - if hyperactive is restless and fidgety;
  - poor impulse-control – is impatient, interrupts others, grab items without permission, etc.
- Developmental coordination disorder (motor dyspraxia).
  - poor ability to plan and carry out motor tasks - is clumsy, messy, and struggles with daily life skills (e.g., buttoning, dressing, etc.);
  - Other motor challenges - muscle weakness, poor proprioception, so may step on other people's toes, bump into others or invade their personal space…
- Sensory processing challenges (e.g., sensitivity to touch or loud noises, food aversion, etc.)
- Average intellectual ability but often has learning challenges – mixing up letters and numbers while reading or writing.
- Speech and language difficulties e.g. articulation problems or stuttering.
- Behavioral difficulties – which may stem from frustration and/or low self esteem.

Speech and language difficulties

Receptive (passive) language means the ability to understand and comprehend language that is heard. In contrast *expressive language* (using words and language) means that you can convey your own thoughts and feelings to others with words, sentences and even gestures.

Receptive language relies on the child's ability to hear correctly, and understand what is being said but the skills needed to develop expressive language (either spoken or signed) are more varied and can include:

- Motivation.
- Attention and concentration.
- Pre-language skills including gestures, facial expressions, imitation, joint attention and eye contact.
- Pragmatics.
- Fine motor skills will also be needed if the child cannot speak for any reason.

Problems with expressive language vary from child to child according to age and stage of development but can be indicated if the child:

- Has difficulty naming items and objects.
- Lacks fluency.
- Has difficulty linking words together.
- Uses sentences shorter than other children of the same age.

- Uses sentences that sound immature for his age.
- Has difficulty finding the right words to use in conversation or when describing or explaining something.
- ***Produces sentences that are 'muddled' (i.e. words in wrong order, lots of stops and starts, a lack of flow).*
- ***Is not understood by unfamiliar people.*

The problems marked ** could also be indicative of possible hearing problems.

Semantic Pragmatic Disorder (SPD)

This term describes a set of abnormal language and communication developmental features.

Pragmatics refers to the way language is used in social situations. The child with pragmatic difficulties will struggle to use language socially so that:

- he doesn't know what to say or when and how to say it;
- he doesn't understand about taking turns when people talk - and may interrupt the other speaker;
- his conversation can often seem inappropriate or irrelevant and he may seem unaware of what the other person want/needs to know – saying too much or too little about a subject.

Semantic refers to the meanings of words and phrases.

This is the child who struggles to understand the meaning of more abstract sentences, finds it hard to work out the topic or key information in a sentence and can misinterpret and take phrases literally. A child who uses language in a restricted way – much as we would in a foreign country whose language is unfamiliar to us.

Oppositional Defiant Disorder (ODD)

It is a normal part of development that children argue, talk back, disobey, and defy parents, teachers, and other adults at times particularly between the ages of 2 – 3 and again in their teens. Such behavior is often worse when they are tired, hungry, stressed or upset.

For some children though such behavior is frequent and consistent interfering with life both at home and at school – which is when it might be considered a real problem.

Symptoms of ODD may include:

- Frequent temper tantrums.
- Excessive arguing.
- Questioning rules.
- Active defiance.
- Refusal to comply with requests/rules.
- Make deliberate attempts to annoy/upset others.
- Spiteful and revenge seeking.
- Blaming others for his or her mistakes or misbehavior.
- Being touchy/easily annoyed by others.

- Frequent anger and resentment.

Tourette's syndrome (TS)

Tourette syndrome is a neurological disorder characterized by repetitive, stereotyped, involuntary movements and vocalizations called tics – which can be either simple or complex.

- *Simple vocal tics* could include grunting, coughing, screaming, sniffing, squeaking, blowing, or shouting out words.
- *Simple physical tics* might include blinking, jerking the head, jumping up and down, twitching the nose, teeth grinding, rolling the eyes, twisting the neck or rotating the shoulders.
- *Complex vocal tics* could include: repeating other people's phrases (echolalia); repeating the same phrase over and over again (palilalia) or swearing loudly or shouting inappropriate words and phrases (coprolalia).

For the tics to be classified as Tourette's syndrome, they have to be present for at least a year* and include at least one vocal tic although most people diagnosed with Tourette's syndrome have a mix of physical and vocal tics: both simple and complex. It is worth noting that while people tend to associate swearing with Tourette's syndrome, that actually only affects a minority of people.

* Some children develop tics and then grow out of them after a few months. These are known as transient tics and are not classified as Tourette's.

Other potential problem areas.

Teeth grinding (Bruxism)

Many people grind or clench their teeth from time to time without harm but when it occurs on a regular basis the teeth can be damaged and other oral health complications can arise.

it often occurs whilst the child is asleep and has several potential reasons from stress and anxiety to an abnormal bite, missing or crooked teeth or a sleep disorder like sleep apnea (when the person literally stops breathing for a short time.)

While chronic grinding may wear teeth down to stumps when severe this can result in a fracturing, loosening, or loss of teeth and worse still can also affect the jaw. It can also cause or worsen temporomandibular disorder (TMD). This is a condition that affects the 'chewing' muscles and the joints between the lower jaw and the base of the skull and is sometimes referred to as 'myofascial pain disorder.' It can be very painful and may cause the jaw joint to click or pop as well as making it difficult to eat. Such symptoms can significantly lower quality of life.

Walking on tiptoe

Children often 'toe walk' as they are learning to walk especially when learning to walk (particularly on a bare floor.) Some get into the habit of doing this while others continue, off and on, just for fun: especially little girls who are pretending to be dancers.

Generally, until age 2, toe walking isn't something to be concerned about but do talk to your doctor if your child:

- Walks on tip-toe most of the time.
- Has stiff muscles, is uncoordinated, walks awkwardly, stumbles frequently or 'waddles.'
- Is slow to develop fine motor skills e.g. doing buttons.
- Can't seem to put his foot flat.
- Begins to lose motor skills.

Possible reasons for this could include:

- Short Achilles tendon, that actually prevents her from standing flat-footed and limits her range of motion in the ankle.
- motor disorder – e.g. a form of cerebral palsy like spasticity in which the affected muscles are stiff or which the Achilles tendons are so tight that the heel is pulled up and the toes point down.
- Damage to the part of the brain involved in movement.
- ASD.
- Idiopathic toe walking (a catchall diagnosis that means the cause is unknown, and habit is the most likely cause.)

Sitting in a W position

Some children tend to sit on their bottoms with their legs out beside them, forming a "W" shape - commonly called "W sitting."

While it may seem as if they are extremely flexible this can have several negative effects that can cause long term complications. By placing the hips at the extreme limits of internal rotation and it can give rise to potential problems that could include:

- Future orthopedic problems by causing pre-existing orthopedic conditions to worsen by tightening the major muscle groups – like the hamstrings, adductors and Achilles tendon.
- Hip dysplasia (developmental deformation or misalignment of the hip joint) - is often overlooked initially and can lead to hip dislocation.
- Poor balance development. That is because the child who frequently W-sits does not need to use his trunk muscles and that non-use can mean that trunk control and balance are slow to develop.
- Slow to develop midline orientation which is needed for the development of more advanced motor skills.

Tall tales and confabulation

While children with ASD rarely tell lies there are occasions when a few of them do.

Potential Causes:

1) *Developmental delay.* In some cases it happens because, regardless of age, the child in question is still at an earlier stage of development than his age suggests. Thus those tall tales are not lies – for they are simply used to help himself manage and cope with his fears.

2) *Confabulation.* This is a condition in which a person confuses fact with fiction (fabricating ideas that he actually believes). Some of these 'facts' are built around a real situation while others are totally made-up.

   This is not done by choice but can occasionally occur particularly if the child suffers from episodes of hypoglycemia, epilepsy or has

periods of ‘shut down.’ In such cases the fiction seems to come about because the brain hates vacuums and so tries to fill the gap in the child’s memory.

Gender Dysphoria

For most people their biological sex attributes and the gender a person "identifies" with/feels themselves to be coincide. However, there are some people who either feel they are the very opposite of their biological identify or that they don’t really fit into either the male or female categories.

That mismatch can lead to distressing and uncomfortable feelings that are termed gender dysphoria. This is a recognized medical condition, for which treatment is sometimes appropriate, and *not* a mental illness.

According to research it is clear that this tends to affect people on the autism spectrum more than in the general population. It is also known that transgender individuals with ASD need an extra level of treatment as they are at an increased risk of sexually unhealthy behavior.

The first signs can appear at a very young age when the child refuses to wear clothes typical for their sex or dislikes taking part in ‘typical’ games and activities. While, in most cases, such behaviors are just a normal part of growing up sometimes they underlie a deeper problem that persists throughout adolescence and long into adulthood.

In such cases those feelings leave the person feeling ‘trapped’ inside a body that does not match the way they perceive themselves. This can lead to great unhappiness as they may have a strong desire to change or get rid of physical signs of their biological sex, such as facial hair or breasts.

RESOURCES AND BOOKS

For more information on this series and ASD in general go to

http://www.autismdecoded.com

or join me at

https://www.facebook.com/theautismtipexchange

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The next book in this series is

Autism Launchpad - A Toolkit for Positive Parents

SAMPLE - CHAPTER 1

Your child's reactions will have helped you determine which of the many and various problems affect him and whether his sensory differences put in the hypersensitive, hyposensitive or mixed categories.

If your child suffers from any of the sensory differences, use whichever of ideas that follow are most appropriate to make his life more secure.

Give him a shield

- Encourage the use of earplugs or an iPod/MP3 player in certain situations, such as at mealtimes or during shopping trips, as this will relieve stress.
- Encourage the wearing of tinted lenses, sunglasses or a peaked cap to minimize the effect of bright sunlight, glare and fluorescent lights. Explain the reasons behind this to his teachers so that she/he will realize the benefits.
- Work out which clothes he finds most comfortable and buy more than one of each item.

- Wash new clothes, sheets, etc. before use to help soften them – or buy specially manufactured soft clothes.
- Ensure that all chemical or non-edible items are stored safely out of reach.

Interesting autobiographies

Atypical: Life with Asperger's in 20 1/3 Chapters Jesse A. Saperstein

A Real Person Gunilla Gerland

Nobody Nowhere, Like Color to the Blind Donna Williams

Thinking in Pictures Temple Grandin

Lucy's Story: Autism and Other Adventures Lucy Blackman

The Reason I Jump: One Boy's Voice from the Silence of Autism Naoki Higashida, David Mitchell and Keiko Yoshida

Carly's Voice – Arthur Fleischmann and Carly Fleischmann

How Can I Talk if My Lips Don't Move? Inside my Autistic Mind – Tito Rajarshi Mukhopadhyay

Do You Understand Me? – Sofie Koborg Brosen

Life Behind Glass – Wendy Lawson

Living Through the Haze – Michael Layton and Paul Isaacs

Look Me in the Eye – John Elder Robison

Women From Another Planet? – Jean Mille

A list of other books and resources can be found at:
www.autismdecoded.com

STELLA WATERHOUSE - AUTISM EXPERT & EDUCATOR

As a second generation educator and autism awareness expert I enjoy sharing my experience and understanding of the autism spectrum and the many challenges that people with autism and their families face in their daily lives.

My goal is to develop resources that will offer practical advice, insight and solutions to parents and teachers - so that the child's life is enriched and supported and family life is enhanced.

BRIEF BIO

I first came across autism in the late 1960s when I met three very different children, all of whom shared the same diagnosis. I went on to spend much of my career working with both children and adults with autism and Asperger's Syndrome as a teacher, caregiver and finally, as a Deputy Principal of a residential community for adults with ASD.

I began researching autism in 1990 and am a published author of several books including A Positive Approach to Autism which attracted good reviews from such well known autism experts as Donna Williams and Paul Shattock OBE.

I am currently completing my forthcoming series Autism Decoded.