



PATHOLOGICAL DEMAND AVOIDANCE SYNDROME

A MANUAL FOR PARENTS, TEACHERS, SOCIAL SERVICES
AND LOCAL EDUCATIONAL AUTHORITIES

Stress, anxiety, fear, helplessness, panic attacks, avoidance, severe and challenging behaviour, low self esteem, school failure often leading to exclusion.

All induced by trying to cope with the normal aspects of everyday living that you and I take for granted.





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PATHOLOGICAL DEMAND AVOIDANCE

This information sheet has been written in such a style as to try and make it accessible to children as well as adults in an attempt to inform as many people as possible about Pathological Demand Avoidance

'PDA, first described by Elizabeth Newson during the 1980's as a pervasive developmental disorder distinct from autism, is increasingly becoming recognised as part of the autism spectrum.'

Children with PDA may find it difficult to get on with other people. They can get bossy or play a little too rough. They may shout and scream if they do not get their own way or go from being happy to furious very quickly. They might seem to 'go over the top' sometimes. Children with PDA find it hard to 'tune in' to what other people feel and they often don't realise that other people's feelings matter as much as their own. They often interrupt because they don't understand that the social rules for conversation are important

Some children with PDA are 'obsessional'. Their biggest obsession is avoiding demands. They may ask the same question over and over again, talk about one topic of conversation a lot, get fascinated by certain toys, videos, games and other objects. They say things over and over again to avoid doing what they are asked to do, and they keep blaming others for things

Children with PDA may become easily upset or angered because they feel under pressure and this is hard to handle. They worry about things we don't even give a thought to and they feel anxious most of the time. Anxiety increases when they are asked to do something. Imagine how you feel when you have a test or exam to do - a child with PDA feels like that most of the time

Children with PDA find it difficult to take responsibility for the things they do. They appear not to care about what they should and shouldn't do. They often do not feel pleased with the good things they do and often do not feel proud or ashamed. Also, they don't seem to know when they've gone too far! They seem very rude or naughty at times because they don't understand which rules are important and get confused

Some children with PDA do not understand themselves very well - they do not understand what being a child really means for them personally. We know how to behave, we understand social rules and how to behave in school and home, we know what to believe and how we feel about ourselves - children with PDA find all of this very difficult to learn even though parents try very hard to teach them this sort of knowledge. They don't see anything as being their responsibility. They aren't very good at keeping secrets and they say things that are unkind without understanding the upset these words cause.

It is frightening and stressful to have PDA. You may have to handle a situation differently with a child with PDA as they often say the wrong thing, go too far or become agitated and argumentative without having any idea that they have been inappropriate.



PDA is quite rare. No one is really sure of the exact cause but it is believed the brain works in a slightly different way from other people's brains. Children with PDA may be quite intelligent yet there may be a huge discrepancy in what they achieve in school, due to their fear of failure and their inability to recognise that effort may be required.

Children with PDA may have difficulty telling the difference between real and pretend. Stories and games may be taken seriously. Children with PDA are often taken advantage of because they don't realise they are being tricked or lied to. They might seem as if they are showing off sometimes, but they don't realise what other people think. They try to take over situations because they don't understand that they can't be the adult!!

Children with PDA sometimes find being asked to do things difficult due to their anxiety led need to control, even easy things. They will have dozens of excuses why they cannot do something, will attempt to change the topic of conversation or talk and talk as avoidance strategies. Children with PDA can frequently become panicky or agitated and often become very angry.



Some children with PDA are a bit clumsy; you may notice it when they are running around or doing sports. They often find it hard to hold a pen or pencil and writing can be hard work.

There is no cure for PDA but with good teaching and encouragement they can improve all the time. There may have to be different rules for children with PDA as they do not always mean to do or say some things. If you understand why a child behaves in the way that they do you can help to make their lives a little bit easier which in the end will make yours a little bit easier too!

What is Pathological Demand Avoidance



If I get angry and violent it is because I am having a panic attack. I can't control it, it controls me. Please don't be mad with me I need you to help me.

Why is everyone always trying to control me? I don't understand. Please help me feel in control.

I'm so anxious about what others will expect from me that I try and control everyone. I don't want to be bossy, this is my coping mechanism.

Everyday is one demand after another. It isn't that I won't do it, I just can't. Please reduce your demands and expectations of me.

I just want to be free, why can't I be free, you decide everything and I have no choice at all. Please help me feel free and offer me more choices.

I'm only 5 and coping with so much anxiety and fear. Imagine I was your child, wouldn't you want someone to help and understand me?

Normal everyday demands send me into a state of panic and anxiety and so I try to avoid them. Please understand that I'm not being awkward or difficult on purpose.

PDA

WHAT IS PATHOLOGICAL DEMAND AVOIDANCE SYNDROME?

PDA, first described by Elizabeth Newson during the 1980s as a pervasive developmental disorder distinct from autism, is increasingly becoming recognised as part of the autism spectrum. It is a lifelong disability and, as with autism and Asperger syndrome, people with PDA will require different amounts of support depending on how their condition affects them.

The central difficulty for people with PDA is their avoidance of the everyday demands made by other people, due to their high anxiety levels when they feel that they are not in control. Hence the name of the syndrome: pathological demand avoidance.

People with PDA tend to have much better social communication and interaction skills than other people on the spectrum, and are consequently able to use this ability to their advantage. They still have real difficulties in these areas though, usually because they need to control the interaction. They often have highly developed social mimicry and role play, sometimes becoming different characters or personas.

Often in cases of PDA there will have been a passive early history, but this is not always the case. It is believed that there may be neurological involvement in some cases, with a higher than usual incidence of clumsiness and other soft neurological signs.

Other children on the autism spectrum can display one or more of these features but when many occur together it is helpful to use the diagnosis of PDA because things that help

people with autism or Asperger syndrome do not always help those with PDA.

People with PDA can be controlling and dominating, especially when they feel anxious and are not in charge. They can however be enigmatic and charming when they feel secure and in control. Many parents describe their PDA child as a 'Jekyll and Hyde'. It is important to recognise that these children have a hidden disability and often appear 'normal' to others. Many parents of children with PDA feel that they have been wrongly accused of poor parenting through lack of understanding about the condition. These parents will need a lot of support themselves, as their children can often present severe behavioural challenges.

People with PDA are likely to need a lot of support into their adult life. Limited evidence so far suggests that the earlier the diagnosis and the better support that they have, the more able and independent they are likely to become.

What are the characteristics of PDA?

The main characteristic of PDA is high anxiety when demands are made on the person. Demand avoidance can be seen in any child with an autism spectrum disorder but when the avoidance reaches pathological levels, major difficulties arise.

1. Resisting Demands Obsessively

This is the overriding criterion for diagnosis. People with PDA become experts at avoiding demands - they seem to feel an extraordinary amount of pressure from ordinary everyday expectations. It is often not the activity itself that is a pressure but the fact that another person is expecting them to do it. The person's threshold or tolerance can vary from day to day, or moment to moment. It is important to realise that the more anxious a person with PDA is, the less they will be able to tolerate demands. As a child, their avoidance of those making demands on them knows no boundaries and usually includes a level of social manipulation. Strategies range from simple refusal, distraction, giving excuses, delaying, arguing, suggesting alternatives and withdrawing into fantasy. They may also resist by becoming physically incapacitated (often accompanied by an explanation such as "my legs don't work" or "my hands are made of lava"). If pushed to comply, they may become verbally or physically aggressive, with severe behavioural outbursts, best described as a 'panic attack'.

One paediatrician, describing a child at five, wrote: "He has a wide variety of strategies to avoid obeying direct demands. He acts as if he has not heard, carrying on with what he's doing with a blank expression on his face. He distracts by starting to talk about something else and he will go on until his mother has forgotten what she wanted him to do. He makes excuses such as 'I've just got to' He says 'I can't' in a plaintive voice or falls to the floor and starts rolling around like a baby."

2. Appearing sociable but with difficulties recognised by parents

People with PDA are often very sociable and can display degrees of empathy previously not thought to be consistent with autism. Sometimes it seems that they are able to understand other people at an intellectual level but not at an emotional one. However, despite their use of social niceties, their social interaction is very often flawed by their inability to see the bigger picture, their lack of boundaries and their desire to be in control of the situation. They often understand rules but don't feel they apply to themselves. As children, this can lead to playground peer group difficulties. One parent described how "to other children he will happily act as if he was their mother - 'have you washed your hands' 'don't put your elbows on the table' - but he doesn't have a sense of needing to follow the same rules."

As adults, further education and employment difficulties may be apparent, but some adults with PDA enjoy success in both.

3. Excessive mood swings, often switching suddenly

People with PDA may switch from one state to another very quickly (eg from contented to aggressive), driven by the need to be in charge. This may be in response to perceived expectations. One parent described her 17-year-old son with PDA as "always imagining the worst case scenario" and this often being a trigger for outbursts.

4. Comfortable (sometimes to an extreme extent) in role playing and pretending

When they are younger, children with PDA often engage in a level of pretend play that would be unexpected from children with autism or Asperger syndrome. People with PDA are very good at taking on the roles and styles of others. The classic example is children who behave as if they were the teachers to other children. One mother described how her daughter would cope with a class of 30 or more imaginary children, commenting on them and talking to them; "She'll say, 'Oh, Callum's not here today, he's sick; Jason, you're not listening', then she will arrange pieces of paper for the class and move them from one room to another as a line of children." In extreme cases, children can become so engrossed in this role playing that they lose touch with reality.

5. Language delay, seemingly as a result of passivity

Although people with PDA may have some language delays at an early age, there is often a striking and sudden degree of catch-up. Certain elements of communication are not as disordered as in autism or Asperger syndrome, with more fluent use of eye contact (other than when avoiding demands) and better conversational timing. Some language difficulties remain, such as taking things literally and misunderstanding sarcasm and teasing. As an extreme form of avoidance, some children become selectively mute in many situations, yet their parents know they can speak when they want to.

6. Obsessive behaviour

The sort of avoidance that has been described is often linked to an obsession with a particular person (or less frequently, an object). Obsessions will vary from person to person but are often social in nature. Sometimes, obsessions with particular people can become problematic and overbearing for those who are on the receiving end.

Other related characteristics

Sensory sensitivities

Just as in autism and Asperger syndrome, people with PDA can often experience over- or under-sensitivity in any of their senses: sight, smell, taste, touch or hearing.

Other conditions and areas of overlap

PDA is often diagnosed alongside other conditions, such as ADHD, dyslexia, and dyspraxia. This may be a result of overlapping conditions but can also be due to confusion over the diagnosis. Before being diagnosed with PDA, some people will have already been diagnosed with autism, ASD, PDD-NOS (Pervasive Development Disorder Not Otherwise Specified) or Atypical autism. PDA can also be present alongside more generalised learning difficulties and, at times, the apparent verbal fluency of people with PDA can mask genuine difficulties in understanding.

Severe behavioural difficulties

A large proportion of, but not all, people with PDA can have real problems controlling their temper. As children, this can take the form of prolonged tantrums and violent outbursts, as well as less dramatic avoidance strategies like distraction, giving excuses etc. It is essential to see these outbursts as extreme anxiety or 'panic attacks' and to treat them as such, with reassurance, calming strategies and de-escalation techniques.

Sometimes a child with PDA can appear very anxious at home but remain relatively passive at school (a learnt coping strategy). In situations like this, parents are likely to feel very isolated and inadequate. In other cases, outbursts are far worse at school, where demands may be much greater, and this can lead to multiple exclusions at an early age. For some children, this anxiety can develop to such an extent that they become school refusers.

Who is affected by PDA?

Unlike autism and Asperger syndrome, both of which seem to affect more boys than girls, PDA affects boys and girls equally. There are no prevalence rates for PDA as yet. It seems likely that the genetic factors are similar to those in autism and that about 6% of children with PDA are known to have a sibling with an autism spectrum disorder. As more diagnoses of PDA are made, prevalence figures will become more apparent.

PDA affects people from all backgrounds and nationalities.

What causes PDA?

The exact cause of PDA is still being investigated. We do know that, as in autism and Asperger syndrome, it is linked to a hard-wiring problem in the brain. It is likely to be caused by a combination of factors, genetic and environmental, which may account for changes in brain development.

It is important to remember that PDA is not caused by a person's upbringing or their social circumstances and it is not the fault of the parents or the individual with the condition.

Is there a cure?

There is currently no cure for a person with PDA but our knowledge about appropriate interventions and educational approaches is growing. One of the most important reasons for distinguishing PDA from other conditions is to ensure that the child receives the correct educational approach. Best practice differs fundamentally between children with PDA and children with autism. The use of structured teaching methods, which are so successful for people with autism and Asperger syndrome, are usually much less helpful for people with PDA. One teacher, describing a pupil in a mainstream class, wrote: "we have found that the more routine there is, the worst he is you need to catch him unawares. We have tried using behavioural approaches with him but they have not worked. He doesn't seem to understand rewards he will snatch the reward and then not do the task. He has his set agenda and is always in control of the situation." People with PDA tend to respond much better to a more indirect and negotiative style that allows them to feel in control.

What is a diagnosis?

A diagnosis is the formal identification of PDA, usually by a professional such as a paediatrician, psychologist or psychiatrist. Recognition of PDA as a condition is fairly recent, and the apparent social abilities of many children with PDA may mask their problems. As a result, many children are not diagnosed until they are older. They may already have had a suggested diagnosis of autism or Asperger syndrome but parents may feel that something about that diagnosis didn't quite fit. It is usually the surface sociability and the often vivid imaginations of children with PDA which confuse professionals regarding the autism spectrum diagnosis.

Having a diagnosis of PDA is helpful for a number of reasons.

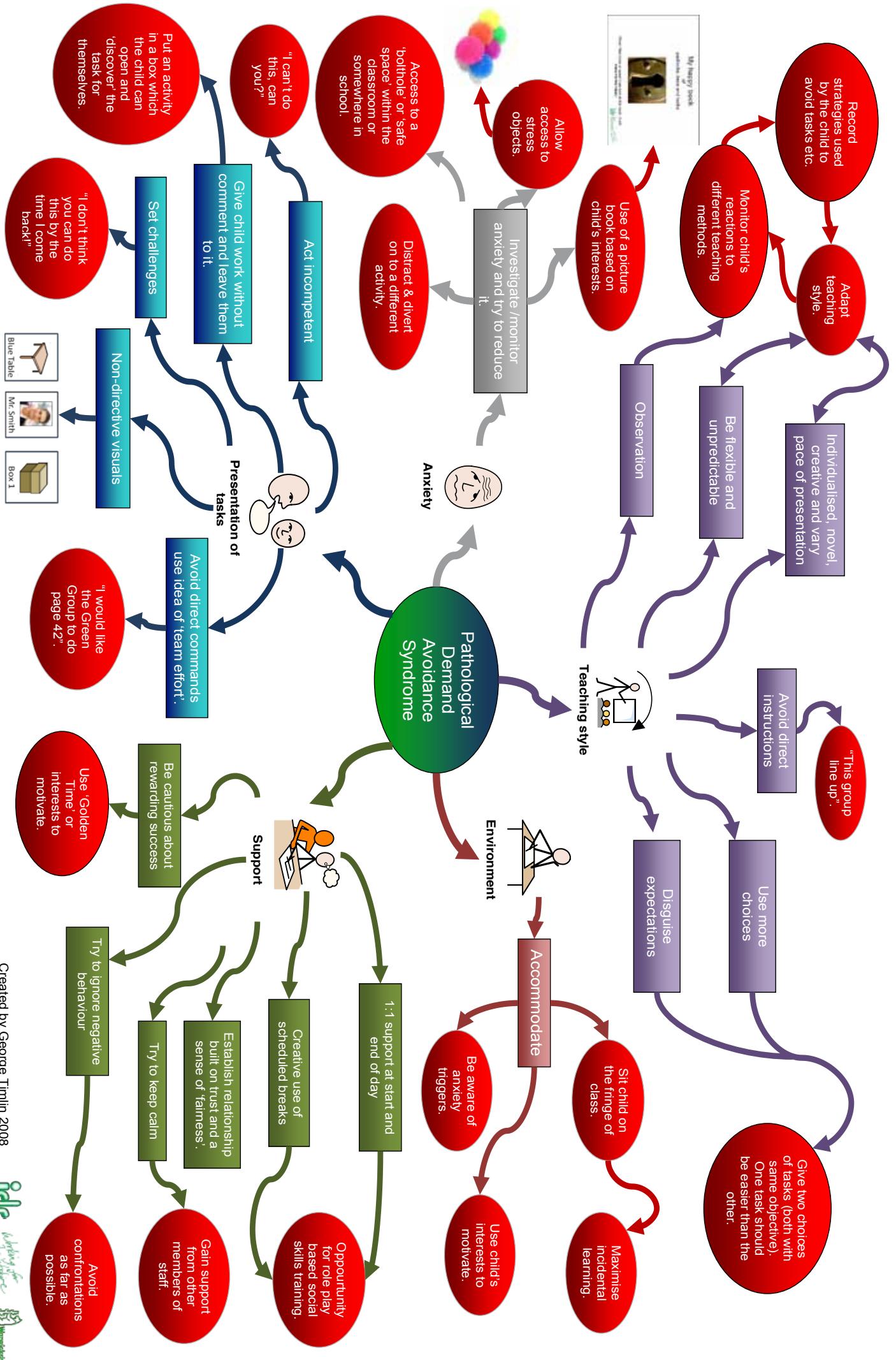
- It helps people with PDA (and their families) to understand why they experience certain difficulties and what they can do about them. It allows people to access services, support and appropriate advice about management strategies.
- It avoids other incorrect diagnoses (eg attachment anxiety disorder, ODD, emotional and behavioural problems or having a wilful and naughty child).
- It warns local authorities that this diagnosis can sometimes result in a high exclusion rate unless sufficient support is provided.

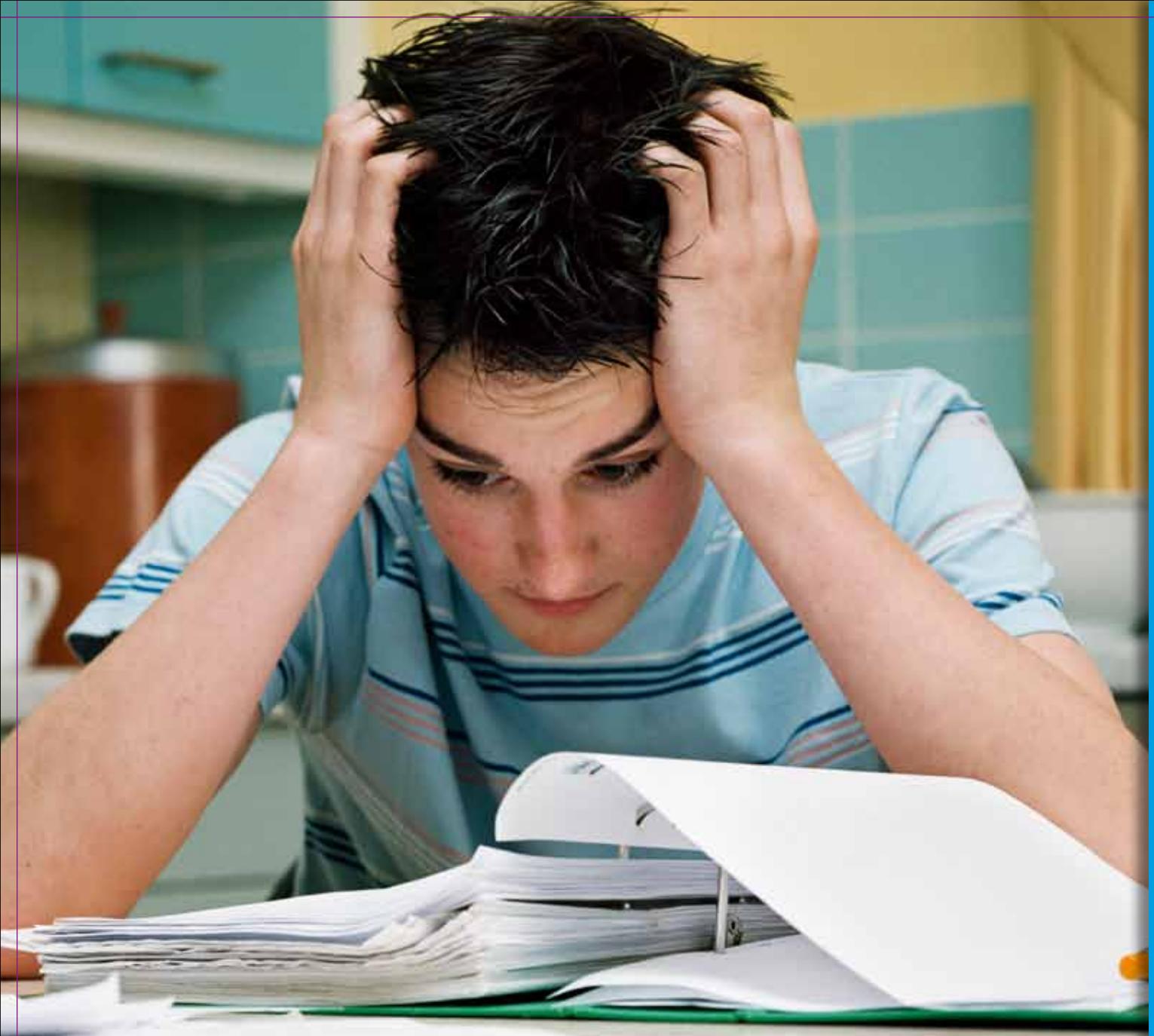
One parent described to us how "it was a huge consolation to find a set of characteristics and criteria that seemed to have been made for my child here was a tailor-made paper on my child."

To get a diagnosis, a GP referral to a local paediatrician who specialises in autism spectrum disorders may be sufficient. If local paediatricians are not yet familiar with diagnosing PDA, advice could be offered by the Elizabeth Newson Centre, part of Sutherland House Children's Services (see useful website page for details)

This section has been written by Phil Christie and Margaret Duncan.

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Handling at School and at Home...



some strategies to reduce anxiety for me.....and hopefully make life less stressful for you too!

I don't understand why rules matter (unless they are mine). Suggest I work out the possible reasons for a rule so I've agreed it but not been told it ... that way it's not a demand and I don't feel so anxious!

I have a form of ASD known as PDA - Pathological Demand Avoidance. My whole life is taken up with trying to avoid the demands you spend your whole life making! I can't help it... my brain just works that way!

Accept that sometimes I am so wound up I cannot function at all and please give me some space to sort myself out!

**THANK YOU FOR
LISTENING**

I am a linguistic master! ... I can interpret and manipulate what and how you say things to effectively avoid your demands! Be specific about rewards, answers to my questions or expected outcomes And don't give in to my nagging!

If you are new (like a supply teacher or new member of staff) I get really anxious because you might make loads of demands. Read the leaflet about PDA so you know I'm not just some naughty little boy - which could make life difficult for us both!

Direct demands cause me the most anxiety....

Phrase a demand as a choice. It's easier to cope with ... even if one choice is so undesirable there isn't really a choice! Sometimes you may even need to resort to a little bit of trickery!

I am brutally honest at times, more so when stressed - when I tactlessly tell you exactly what I feel!! ***Never take what I say personally –*** It's my emergency strategy to stop the anxiety.

I talk non stop so you can't get a word (or demand) in edge ways! Use a visual timetable or simple written instructions for a task so I ask you what I've got to do before you tell me... because telling me first spells disaster for my brain!!!

HANDLING AT SCHOOL AND AT HOME

The following guidelines have been prepared in consultation with school staff who have experience with PDA children as well as autistic children, and who have needed to re-think their methods and adapt them considerably in response to this condition.

It is useful to take a keyworker approach with children who have PDA, and this is because the individual relationship is more significant in making progress than simple consistency. Because the child is socially manipulative, the keyworker needs to know his personality very well, and to establish herself with the child as someone who has definite limits that are going to be respected. Having said that, the keyworker needs to be highly flexible and imaginative, capable of re-negotiating and re-earning the child's interest daily. It is helpful to know that what works today may not work tomorrow (because the child doesn't want to be caught out twice!), but that it may well work again in a week's time. Nothing will invariably work, and that is the price paid for social awareness coupled with demand avoidance.

This means that the keyworker needs to have a variety of strategies on hand, and not be too concerned if a particular one is unsuccessful on a particular day. The successful teacher of a PDA child will be someone who has liveliness, ingenuity, humour, wit and patience; this job is not for someone easily depressed, but for a person who enjoys a challenge, who can appreciate the sociable aspects of the child, and who can make use of any of his strengths, such as role-play. A degree of charisma is a bonus, since this will usually intrigue the child!

Teaching style

A highly individualised style is needed, based partly on the understanding of demand avoidance but partly on the individual child's personality and tolerances. Staff need to understand the nature of the condition, and that demand avoidance is not something that the child can overcome by an act of will, although he may manage a series of achievements by making a series of efforts. There is a real coping problem here which has

to be recognised; **the problem is an incapacity** rather than naughtiness. The child literally does not know what other children know by nature about how to behave, and is deeply confused; '**being told**' cannot solve the problem, and nor can sanctions.

Expect to be **indirect** in all demands made, rather than directive: eg not '**Now get on with this puzzle please**' but '**I wonder what's the best way of doing this puzzle - I can't quite see how to do it.....**'. Try tape-recording and listening to your requests critically, and practise re-wording them to be more indirect; you will become skilled at this. Don't be afraid to be intuitive, and don't abandon a strategy for good just because it didn't work first time. Use lots of humour: coax, cajole, and even challenge if you do it humorously, eg '**I bet you can't.....**'. Use variety in the pace of your presentation; variety in personal style; variety in learning environment. Disguise your expectations to the child. Make sure your colleagues understand why you are behaving in these ways! - you need their support, and also their co-operation in similar handling methods.

Introduce goals gradually, building on positive experiences - don't allow the child to feel he has failed, so make sure he gets some sort of acceptable achievement out of every encounter. You need to limit your expectations, even if you know the child has better ability, remembering that (as one mother put it) '**It's not so much that he can't or he won't, but more that he can't help won't**'. Try to empower him by allowing more choice in activities, direction etc. A very useful strategy is to offer a choice of two activities in which the one you really want him to do is the easier. But don't tell him not to do something in order that he'll do it through negativism - this may work a few times, but the message is not a good one.

Relationships

The child's progress at school hinges on his development of a strong, trusting relationship with the keyworker. Keep very calm and level in your emotions, including your facial expression - avoid showing the frustration that you will very likely feel, and never let him see it if you feel wary, scared or embarrassed. Give rather less eye contact than you would expect to. Be cautious about rewarding success: although praise can be motivating, often it makes the child decide not to give in so easily next time, and some children tear up work which has been praised. Ignore negative behaviours so far as you can. It can often be helpful to work beside or even slightly behind the child, rather than face to face.

Avoid actual confrontation so far as you possibly can; you will not win unless you are using unacceptable sanctions. Remember that the child has few boundaries and is driven to avoid demands by obsession. Your aim should be to help the child to discover that co-operation is no big deal after all, and can be very pleasant; confrontation won't teach him that. Take pride in your ability to negotiate and make acceptance more fun for the child, not in proving who's boss.

The teacher or keyworker, one hopes, will have a genuine liking for the child, and the ability to see and draw out his best potential. PDA children can be both frustrating and irritating, because they do their best to prevent teachers teaching. The most successful teachers of PDA children are those who appreciate the child's talents - even the talent for social avoidance - and find much to enjoy in the relationship.

Humour, pretending and role-play

Humour is extremely important, as otherwise the demands as perceived by the child become very oppressive for him. But novelty can be as useful as humour in oiling the wheels of the relationship. Remember that role-play and pretending are strengths, and use these: for instance, get the child to take a turn as teacher, teaching either the adult or perhaps a puppet (or even another child if appropriate). Puppets and toy animals can be useful as 'third person' to de-fuse the feel of confrontation in 1:1 work.

However, in some children role-play is very obsessional, taking up most of their time, and parents and teachers may want to try to reduce this, in an effort to keep the child in touch with reality. For instance, one 8-year-old, Nicola, was very resistant to 'being Nicola' except when being physically cared for. There was little point in trying to prevent this directly, but indirect methods could be tried. For instance, her parents could increase some of their nurturant care of Nicola, emphasising that it was Nicola who was being cared for. They could encourage her into helping with domestic activities that were particularly interesting, such as cooking or spring-cleaning, again making it clear that they were enlisting her help as Nicola to do things for the rest of the family: and the family would show their appreciation, eg clapping the cake or pudding she had made. This helped to show her that Nicola herself was a competent person, and didn't have to become a teacher (her favourite role) to exert this kind of control. One might also try saying to her 'I want Nicola to show me, not the teacher - I like Nicola best, please show me how to do this, Nicola'. Every opportunity was taken to present Nicola as helpful to others; usually by taking her seriously as a helper, rather than just telling her what to do or simply saying that she was not the teacher.

Home-school liaison

Teachers need considerable support from both colleagues and parents, and vice versa. Liaison and trust between home and school are absolutely vital. Schools and parents also need to understand that (as already discussed) the pressure of good behaviour is very difficult for the PDA child to sustain, and often better behaviour at school may be bought at the expense of worse behaviour at home - sometimes the other way round. This is a special reason for home and school being open, trusting and sympathetic to each other's difficulties. A daily home-school book is very helpful.

Overall, similar handling methods to those already mentioned will be found the most effective at home as well as at school; especially the use of indirect requests rather than direct demands. It can be easy to become extremely authoritarian and even threatening with a PDA child, because this often works briefly; but it does raise the stress for the family as a whole, especially brothers and sisters. Indirect methods, although they take longer, keep relationships happier. It can be helpful to think about priorities, and choose beforehand which issues to press through and which to let go; this makes it easier to be both reasonably consistent and kind. What often happens is that parents try to make a half-hearted stand about everything, and are then defeated: this is demoralising and depressing for parents, and teaches the child to resist still further. It is best to agree in advance those behaviours that the family will accept gracefully! On the whole, more latitude will actually be needed at home; this of course is true for most children, but is much more of a necessity for PDA children, who really cannot cope with being good all the time!

Some children show their reaction to the stresses of school by rocking for an hour or more when they get home. It can be difficult to break into this, but it may be helpful to say 'You can rock for twenty minutes, and then we'll.....', offering some interesting distraction. It seems that some children literally don't know how to stop rocking unless a limit is set for them; but the positive alternative needs to be offered. Again, cooking often distracts effectively.

Most parents find that it is necessary to be very truthful with a PDA child, who may obsessively 'go on' about any deviousness. We believe that truth is also important where a child is uncertain about the difference between truth and falsehood, as is often the case in PDA. Certainly we have found that, although it is sometimes tempting to stretch the truth for the sake of peace, it is seldom worth it; but it is worth a great deal, especially later on, to be able to say to the child with conviction 'Have I ever told you a lie? - no'. Trust is especially valuable with adolescent children with this condition, who do develop a respect for people they can trust, but often have quite suspicious attitudes towards people in general.

We can expect the child's social skills to improve gradually. Lashing out is likely to decrease as she gets more used to the expectations at school being more predictable for her, and as her outbursts are treated as panic attacks and she is offered increased reassurance and calming procedures. Some children are much helped by massage of hands and/or feet, and we have found that this can even be a preventative measure; one child who experienced a build-up of pressure during the morning, and was calmed by foot massage after a predictable outburst at midday, responded very well to having a foot massage on arrival at school instead, and often did not need any more during the day. This also gets over any suggestion that the child might feel rewarded for her outburst, though this in practice is not very relevant. The few minutes of 'counselling', recommended earlier, can also act as a calming procedure at the beginning and end of the day; and a similar quiet time on arrival home sometimes helps to reduce stress levels for the rest of the evening.

Finally

Perhaps it's worth reminding school staff of two things:

- However great the stresses of finding ways to teach a child with PDA effectively, they are nowhere near the stresses that families have to cope with; and one of the biggest stresses on families is the fear that the school will give up on their child. You can make an enormous difference, not just in helping the child to tolerate demands and to learn, but in enabling parents to meet the child's continuing needs at the same time as creating a happy family life for brothers and sisters.
- Whatever the difficulties, this is probably the most interesting and potentially rewarding child you will ever meet, who will challenge your ingenuity and flexibility every working day. This can be a growth experience for you and for your professional skills. One head teacher said 'We never realised how interesting she was until after she'd left us, and we missed her', reflecting perhaps the difficulties of having had to work without the support of guidelines.

We hope that this booklet will give staff a head start in understanding and enjoying working with a child who has PDA.

'This section was written by and originally published by the Elizabeth Newson Centre.'

You may wish to get support from other parents in your area. The PDA Contact Group can help with this.

The National Autistic Society can sometimes help you with a befriender and they have an information leaflet on PDA too. (www.nas.org.uk)

Schools find PDA very challenging sometimes. Training is available through the NORSACA website based in Nottingham.

Children have a difficult time understanding their PDA brother and sister. We have booklets on PDA for them for a small cost.

Social workers may be required to help you get respite if your child is very challenging.

You can claim DLA for most children with PDA.

Medication can sometimes be appropriate for children with PDA. Your paediatrician can help with this.

Children with PDA find being asked to do things (even simple everyday things) extremely difficult. They try to AVOID these DEMANDS. All children do this to some extent of course, but these children do this much more than is considered normal. This is why it is called PATHOLOGICAL.

In order to avoid these demands made of them, children with PDA will come up with all sorts of excuses:

"I'm too cold" "I'm too hot"

"I'm too poorly" "No..."

"My legs are made of lava"

"Just a minute..." "Look over there.."

"I can't right now."

"You do it..."

They may become very cross, agitated or aggressive and if the demands are pursued they may have a meltdown.

Has your child recently been diagnosed with or do you suspect your child may have PDA?

Are you at a loss how to manage your child?

Do you need support from other parents?

Do you need information for school as to how to manage your child?

Go straight to the PDA Contact Group website and forum for more help, support and information:



**PDA Contact Group Website
and forum**
www.pdacontact.org.uk

Margaret Duncan 0114 2589670
margoduncan@googlemail.com



A Parent's Guide to Understanding Pathological Demand Avoidance Syndrome (PDA)

Children with PDA may be very outwardly sociable but they have subtle problems with this which will cause real problems in the playground. Some examples of this may include that they:

Could be too bossy, and controlling.

Hug people too hard or get in their personal space too much.

Shout or scream if they don't get their own way, or are not first in the queue.

May be happy one minute and angry the next (Jekyll and Hyde personality).

May say something odd or strange in public.

May become so involved in a game that they believe it is real and that they are someone else.

Can be very good at telling other people what the rules are but don't often feel they apply to themselves.

Can become obsessional about certain activities to the exclusion of other things.

Managing children with PDA is not easy. The key to this is reducing demands and trying to allow them some control in a situation. For instance giving them choices of things. You may need to practice ways of 'asking' without asking eg:

"I wonder if you can help me do...."

"Lets see if there is a way to do..."

"You can't do this can you, I'm hopeless at it?"

"I bet you can't do this before I come back...."

Making a game out of doing things can help especially if it incorporates something they enjoy doing.

Realising the anxiety comes from the demands makes things a bit easier to understand although not necessarily easier to deal with as it challenges the traditional parenting methods which do NOT work for a child with PDA. But you will get better at this the more you practice.



A Teacher's Guide to Understanding Pathological Demand Avoidance Syndrome (PDA)

Some facts about PDA

PDA is a neurodevelopmental disorder which is increasingly being recognised as being part of the autism spectrum but requires very different management.

It is a lifelong disability characterised by an obsessively resisting the everyday demands of life. They often spend longer working to avoid the demand than they would have done by just accepting it!

Extreme mood swings are a common feature and they are often described as a Jekyll and Hyde character.

When they feel in control they are often enigmatic and charming, but when they feel they are not in control, they experience high anxiety levels which often leads to extreme and challenging behaviour.

PDA children often appear to have better social, interaction and communication skills than other autistics but lack depth in their understanding and are led by their need to control.

PDA children can have highly developed role play and social mimicry. They may adopt different personas and often use this as a strategy to avoid demands.

In order to gain a better understanding of PDA, a general information leaflet can be obtained from the National Autistic Society website:

www.nas.org.uk

More comprehensive education and handling guidelines are available, which can help you better understand and manage a PDA child in the classroom environment. Visit the PDA contact forum to download a copy:

<http://www.pdacontact.org.uk/>

The Elizabeth Newson centre (NORSACA) provides a range of conferences and events for both professionals and parents. It also has a publications list that has a number of papers on PDA. Details of these are available via their website:

www.sutherlandhouse.org.uk

The centre can also provide training for schools and other organisations across the UK.

Fiona Speirs is the former Assistant Head teacher of Rosehill School (a school which caters for Autism Spectrum Disorders in Nottingham) and is experienced in working with and handling children with PDA in the classroom environment. She offers a training package entitled: "Understanding and working with learners with PDA." More details can be found at her website:

www.fionaspeirs.co.uk

Is there a child in your class / school who has recently been diagnosed with PDA?

Do you need information and handling guidelines to help with managing a PDA child in the school environment?

The PDA Contact Group website and forum are a source of help, support and information.

There is an area of the PDA support group which is specifically for professionals and is not accessible to parents. We encourage all professionals to use this resource to share ideas, thoughts and tips about PDA.



PDA contact Group website and forum

www.pdacontact.org.uk

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Tips for Managing in Class

A classroom is filled with DEMANDS which often leads to high ANXIETY levels in the PDA child.

Instructions should be given in a NON CONFRONTATIONAL style and you may need to practice 'asking without asking' eg "I wonder if someone might be able to help me do this....."

Try to present CHOICES, so the child feels in control of the situation.

Use a neutral tone and body language, sometimes standing behind the child.

Have a SAFE space with nothing in it and have staff trained in proper restraint techniques if necessary to support the child there.

When a child 'melts down' use quiet tones, give lots of REASSURANCE even if they are swearing obscenities at you and lashing out. Try to think of it as a PANIC ATTACK.

PDA children will have poor spells when demands must be decreased accordingly and VICE VERSA.

Some PDA children avoid by using more subtle techniques and if not recognised will be an obstacle to their learning.

PDA children can show obsessive behaviour which may be focussed on a person eg another child or on objects.

Language delay is often another feature of the child with PDA but most children suddenly 'catch up'. They have more fluent use of eye contact and better conversational timing than other children on the spectrum.

Things to remember

These children are not naughty or overtly malicious although they are manipulative in the way they avoid demands. It is important to remember that underneath their robust exterior lies a very fragile and vulnerable ego.

Pushing a PDA child to obey demands will likely lead to high anxiety and 'meltdown' behaviour best seen as a panic attack. At this stage the child needs REASSURANCE and not blame or be made to feel ashamed as the child cannot help this behaviour.

PDA children may be compliant and tolerant at school then behave much worse at home. It is important for teachers and parents to realise that this is not due to less competent handling, but simply because they have reached their tolerance limits and need to 'let their hair down'.

It is important to communicate well with parents.

ASPERGER'S or PDA WHAT'S THE DIFFERENCE?

The Autism Umbrella is a term used for many Pervasive Developmental Disorders and sometimes referred to as the 'autism spectrum'. Many children with PDA may have previously been given a diagnosis of Atypical Autism, Pervasive Development Disorder Not Otherwise Specified (PDD NOS) or Asperger's Syndrome. What are the features that distinguish a child with PDA from a child with Asperger's?



Differences between PDA and Asperger's

People with PDA may remind others of autism/Asperger syndrome. However, because they do not fulfil those criteria precisely, or have other features that are unusual in autism and Asperger syndrome, they may have been described as having 'atypical' or 'non-typical' Asperger or autism, or 'Pervasive Developmental Disorder n.o.s' (not otherwise specified).

PDA CHILDREN

1. Passive Early History in first year

Often doesn't reach, drops toys, 'just watches'; often delayed milestones. As more is expected of him/her, child becomes 'actively passive', ie strongly objects to normal demands, resists. A few actively resist from the start, everything is on own terms. Parents tend to adapt so completely that they are unprepared for the extent of failure once child is subjected to ordinary group demands of nursery or school; they realise child needs 'velvet gloves' but don't perceive as abnormal. Professionals too see child as puzzling but normal at first.

2. Continues to resist and avoid ordinary demands of life

Seems to feel under intolerable pressure from normal expectations of young children; devotes self to actively avoiding these. Demand avoidance may seem the greatest social and cognitive skill, and most obsessional preoccupation. As language develops, **strategies of avoidance are essentially socially manipulative**, often adapted to adult involved; they may include:

- Distracting adult: 'Look out of the window!', 'I've got you a flower!', 'I love your necklace!', 'I'm going to be sick', 'Bollocks! - I said bollocks!'
- Acknowledging demand but excusing self: 'I'm sorry, but I can't', 'I'm afraid I've got to do this first', 'I'd rather do

AUTISTIC/ASPERGER CHILDREN

Seems much more abnormal much earlier; lack of social response and lack of empathy alert parents, together with poor body language and stereotypic behaviour.

Can be reluctant, but ignores or shuts out pressure in a non-social way, without acknowledging others' needs. Has very few conscious strategies for avoidance. Doesn't adapt particular strategy for particular person. Doesn't have enough empathy to make excuses, and usually not enough empathic language either. Direct, not devious.

this', 'I don't have to, you can't make me', 'you do it, and I'll', 'Mummy wouldn't like me to'.

- Physically incapacitating self: hides under table, curls up in corner, goes limp, dissolves in tears, drops everything, seems unable to look in direction of task (though retains eye contact), removes clothes or glasses, 'I'm too hot', 'I'm too tired', 'It's too late now', 'I'm handicapped', 'I'm going blind/deaf/spastic', 'my hands have gone flat'.
- Withdrawing into fantasy, doll play, animal play: talks only to doll or to inanimate objects; appeals to doll, 'My girls won't let me do that', 'My teddy doesn't like this game'; 'But I'm a tractor, tractors don't have hands'; growls, bites.
- Reducing meaningful conversation: bombards adult with speech (or other noises, eg humming) to drown out demands; mimics purposefully; refuses to speak.
- (As last resort) Outbursts, screaming, hitting, kicking; best construed as panic attack.

3. Surface sociability, but apparent lack of sense of social identity, pride or shame

At first sight normally sociable (has enough empathy to manipulate adults as shown in 2); but ambiguous (see 4) and without depth. No negotiation with other children, doesn't identify with children as a category: the question 'Does she know she's a child?' makes sense to parents, who recognise this as a major problem. Wants other children to admire, but usually shocks them by complete lack of boundaries. No sense of responsibility, not concerned with what is 'fitting to her age' (might pick fight with toddler).

Because of lack of social empathy, autistic children (even Asperger children) don't purposefully manipulate, though people around them may feel manipulated by the situation or by fate. They give no impression of sociability, except with questions or statements about their preoccupying interests from verbal children. They may become more sociable in time, but seldom develop real (natural) social empathy.

Despite social awareness, behaviour is uninhibited, eg unprovoked aggression, extreme giggling/inappropriate laughter or kicking/screaming in shop or classroom. Prefers adults but doesn't recognise their status. Seems very naughty, but parents say 'not naughty but confused' and 'it's not that she can't or won't, but she can't help won't' - parents at a loss, as are others. Praise, reward, reproof and punishment ineffective; behavioural approaches fail.

4. **Lability of Mood, impulsive, led by need to control**

Switches from cuddling to thumping for no obvious reason; or both at once ('I hate you' while hugging, nipping while handholding). Very impetuous, has to follow impulse. Switching of mood may be response to perceived pressure; goes 'over the top' in protest or in fear reaction, or even in affection; emotions may seem like an 'act'. Activity must be on child's terms; can change mind in an instant if suspects someone else is exerting control. May apologise but re-offend at once, or totally deny the obvious. Teachers need great variety of strategies, not rule-based: novelty helps.

5. **Comfortable in role play and pretending**

Some appear to lose touch with reality. May take over second-hand roles as a convenient 'way of being', ie coping strategy. Many behave to other children like the teacher (thus seem bossy); may mimic and extend styles to suit mood, or to control events or people. Parents often confused about 'who he really is'. May take charge of assessment in role of psychologist, or using puppets, which helps co-operation; may adopt style of baby, or of video character. Role play of 'good person' may help in school, but may divert attention from underachievement. Enjoys dolls/toy animals/domestic play. Copes with normal conventions of shared pretending. Indirect instruction helps.

Autistic children are seldom impulsive; they work to (their own) rules, and parents learn what will upset them. They do not put on an act for someone else until very much older, if then. Rules, routine and predictability help.

Inflexibility, lack of symbolic and imaginative play and lack of empathy all make it very difficult for autistic children to pretend (other than by arranging miniature objects), or to take roles more fully than by simple echoing - though Asperger children may learn 'scripted' roles, with difficulty and without fluency. Indirectness confuses.

6. Language delay, seems result of passivity

Good degree of catch-up, often sudden. Pragmatics not deeply disordered, good eye-contact (sometimes over-strong); social timing fair except when interrupted by avoidance; facial expression usually normal or over-vivacious. However, speech content usually odd or bizarre, even discounting demand-avoidant speech. Social mimicry more common than video mimicry; brief echoing in some. Repetitive questions used for distraction, but may signal panic.

7. Obsessive behaviour

Much or most of the behaviour described is carried out in an obsessive way, especially demand avoidance: as a result, most children show very low level achievement in school because motivation to avoid demands is so sustained, and because the child knows no boundaries to avoidance. Other obsessions tend to be social, ie to do with people and their characteristics; some obsessively blame or harass people they don't like, or are overpowering in their liking for certain people; children may target other individual children.

8. Neurological Involvement

Soft neurological signs are seen in the form of clumsiness and physical awkwardness; crawling late or absent in more than half. Some have absences, fits or episodic dyscontrol. Not enough hard evidence as yet.

Language is both delayed and deviant, non-existent in many. Even Asperger children show very disordered pragmatics of language, poor eye contact and social timing, little facial expression or gesture.

Autistic children are also obsessive, but less so with social topics. They are not obsessively focused on demand avoidance, and do not use obsessions for manipulative purposes. Order, arrangements and perceptual fascinations.

Some comparable involvement in autism; less in terms of crawling and episodic dyscontrol.

Any school will find that they have to make adaptations of one sort or another in order to meet the particular needs of a child with PDA. The first and obvious difficulty is that PDA children are 'active in being passive': they are obsessively concerned to avoid demands, and many parents describe their child as working harder to avoid the demand than she would have done by accepting it. Whatever the child's intellectual level, her PDA will cause her to function rather below that level for much of the time; thus educational support will need to be geared to helping the child to tolerate 'being educated' to the greatest degree possible, in order at least to approach her potential. We do not expect a 'cure', and it is typical that a PDA child's co-operation is maintained by continual effort on the part of staff and parents.

'This was first published in 1994 by The Elizabeth Newson Centre. Some of the terminology and language used may seem a little out of date.'

Sensory Processing Disorders



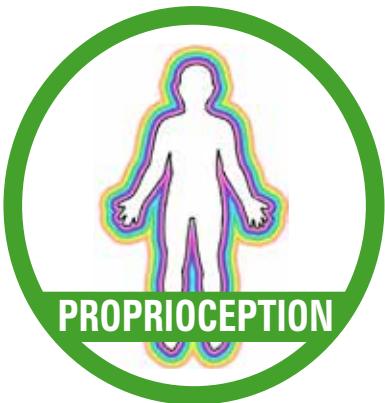
TACTILE

The sense of touch; input from the skin receptors about touch, pressure, temperature, pain and movement of the hairs on the skin.



VESTIBULAR

The sense movement; input from the inner ear about equilibrium, gravitational changes, movement experiences and position in space.



PROPRIOCEPTION

The sense of 'position', input from the muscles and joints about body position, weight, pressure, stretch, movement and changes in position.



AUDITORY

Input relating to sounds; one's ability to correctly perceive, discriminate, process and respond to sound.



OLFACtORY

Input relating to smell; one's ability to correctly perceive, discriminate, process and respond to different odours.



ORAL

Input relating to the mouth; one's ability to correctly perceive, discriminate, process and respond to input within the mouth.



VISUAL

Input relating to sight; one's ability to correctly perceive, discriminate, process and respond to what one sees.

Many if not all people on the autistic spectrum also suffer from sensory processing disorder to varying degrees.

Difficulty taking in or interpreting this input can lead to devastating consequences in, daily functioning, social and family relationships, behavioural challenges, regulating emotions, self-esteem and learning.

SENSORY PROCESSING DISORDER

We Receive And Perceive Sensory Input Through Sights, Sounds, Touch, Tastes, Smells And Movement.

If this neurological process becomes disrupted somewhere in the loop of intake, organization or output, then normal development and adaptive responses will not be achieved.

It is this disruption which yields a neurological dysfunction called Sensory Integration Dysfunction/ Sensory Processing Disorder.

Keep in mind, sensory processing functions on a continuum. Please understand that we all have difficulty processing certain sensory stimuli (a certain touch, smell, taste, sound, movement etc.) and we all have sensory preferences. **It only becomes a sensory processing disorder when we are on extreme ends of the continuum or experience “disruptive, unpredictable fluctuations which significantly impact our developmental skills or everyday functioning”.**

1. “The child with sensory dysfunction does not necessarily exhibit every characteristic. thus, the child with vestibular dysfunction may have poor balance but good muscle tone”.
2. “Sometimes the child will show characteristics of a dysfunction one day but not the next. For instance, the child with proprioceptive problems may trip over every bump in the pavement on Friday yet score every soccer goal on Saturday. Inconsistency is a hallmark of every neurological dysfunction.
3. “The child may exhibit characteristics of a particular dysfunction yet not have that dysfunction. For example, the child who typically withdraws from being touched may seem to be hypersensitive to tactile stimulation but may, instead, have an emotional problem”.
4. “The child may be both hypersensitive and hyposensitive. For instance, the child may be extremely sensitive to light touch, jerking away from a soft pat on the shoulder, while being rather indifferent to the deep pain of an inoculation.
5. “Everyone has some sensory integration problems now and then, because no one is well regulated all the time. All kinds of stimulation can temporarily disrupt normal functioning of the brain, either by overloading it with, or by depriving it of, sensory stimulation”.

It is important for us to break the sensory integration dysfunction symptoms down into categories based on each of the senses.

These categories are:

Signs Of Tactile Dysfunction:

Hypersensitive:

Refuses or resists messy play, resists cuddling and light touch, dislikes kisses, rough clothes or seams in socks, resists baths, showers, or going to the beach.

Hypo-sensitive:

Doesn't realize hands or face are dirty, touches everything and anything constantly, may be self-abusive, plays rough with peers, doesn't seem to feel pain (may even enjoy it!)

Signs Of Vestibular Dysfunction:

Hypersensitive:

Avoids playground and moving equipment, fearful of heights, dislikes being tipped upside down, often afraid of falling, walking on uneven surfaces, and avoids rapid, sudden or rotating movements.

Hypo-sensitive:

Craves any possible movement experience, especially fast or spinning, never seems to sit still, is a thrill seeker, shakes leg while sitting, loves being tossed in the air, never seems to get dizzy, full of excessive energy.

Signs Of Proprioceptive Dysfunction:

Under-responsive:

Constantly jumping, crashing, and stomping, loves to be squished and bear hugs, prefers tight clothing, loves rough-housing, and may be aggressive with other children.

Over-responsive:

Difficulty understanding where body is in relation to other objects, appears clumsy, bumps into things often, moves in a stiff and/or uncoordinated way.

Difficulty Regulating Input:

Doesn't know how hard to push on an object, misjudges the weight of an object, breaks objects often and rips paper when erasing pencil marks.

Signs Of Auditory Dysfunction:

Hypersensitive: Oversensitive

Covers ears and startled by loud sounds, distracted by sounds not noticed by others, fearful of toilets flushing, hairdryers and/or vacuums, resists going to loud public places (even cafeteria at school).

Hypo-sensitive: Undersensitive

May not respond to verbal cues, loves loud music and making noise, may appear confused about where a sound is coming from, may say "what?" frequently.

Signs Of Oral Dysfunction:

Hypersensitive: Oversensitive

Picky eater with extreme food preferences and limited repertoire, may gag on textured food, difficulty with sucking, chewing, and swallowing, extremely fearful of the dentist, dislikes toothpaste and brushing teeth.

Hyposensitive: Undersensitive

May lick, taste or chew on inedible objects, loves intensely flavoured foods, may drool excessively, frequently chews on pens, pencils, or shirt.

Signs Of Olfactory Dysfunction:

Hypersensitive: Oversensitive

Bothered or nauseated by cooking, bathroom and/or perfume smells, may refuse to go places because of the way it smells, chooses foods based on smell, notices smells not normally noticed by others.

Hyposensitive: Undersensitive

May not notice unpleasant or noxious odours, smells everything when first introduced to it, may not be able to identify smells from scratch 'n sniff stickers.

Signs Of Visual Dysfunction:

Hypersensitive: Oversensitive

Irritated by sunlight or bright lights, easily distracted by visual stimuli, avoids eye contact, may become over aroused in brightly coloured rooms.

Hyposensitive: Undersensitive

Difficulty controlling eye movements and tracking objects, mixes up similar letters, focuses on little details in a picture and misses the whole, loses his place frequently when reading or copying from the blackboard.

Sensory Integration Dysfunction symptoms must not be ignored! If you observe many of these signs in a child you know, please talk to a professional, such as an Occupational Therapist who can further evaluate and decide whether your child has a sensory processing disorder.

Stanley Greenspan, the author of "[The Challenging Child](#)" (1995) has an insightful analogy to help us understand what people experience when they can not effectively process, or interpret, sensory input.

He describes it this way:

"Imagine driving a car that isn't working well. When you step on the gas the car sometimes lurches forward and sometimes doesn't respond. When you blow the horn it sounds blaring. The brakes sometimes slow the car, but not always. The blinkers work occasionally, the steering is erratic, and the speedometer is inaccurate. You are engaged in a constant struggle to keep the car on the road, and it is difficult to concentrate on anything else."

It's no wonder children with sensory processing disorders feel out of control, exhibit a whole host of behaviours, and have difficulty concentrating and focusing at school!

Now, also imagine being a parent of one of these children. Many parents have expressed how exhausted, rejected, lost, incompetent and alone they feel in trying to live with, and understand, their child.

I challenge you to remember this beautifully painful quote the next time you encounter a child with sensory processing disorders and begin the process of awareness, understanding, and treatment to help them take control of their bodies, minds and self-esteem.

It is so very difficult for them. Let's acknowledge that and do our best to understand and help them!

Or to put it from an adult perspective - Imagine if:

- You could see obstacles in your way, but you could not make your body move the direction you wanted it to, to avoid them.
- You felt like someone had given you a shot of Novocain in your backside so you couldn't feel if you were sitting in the middle of your chair and you fell off 3 times during this training .
- Your clothes felt like they were made of fibreglass .
- You tried to drink a cup of water from a paper cup, only you couldn't tell how hard to squeeze it to hold onto it. So, you squeezed it too hard and the water spilled all over you. The next time you didn't squeeze it hard enough and it fell right through your hands and onto the floor .
- Every time you tried to write with your pencil, it broke because you pushed too hard .
- The different smells in this room made you utterly nauseous .
- The humming of the lights sounded louder than my voice .
- You couldn't focus your eyes on me because everything and everyone in the room catches your attention and your eyes just go there instead .
- The lights are so bright you have to squint, then you get a pounding headache half way through the presentation .
- Every time someone touches you, it feels like they are rubbing sandpaper on your skin .
- You could only sit here for 15 minutes and then you had to take a run around the building or do 20 jumping jacks so you could sit for another 10 minutes before your muscles felt like they were going to jump out of your skin .
- People's whispers sounded like they were yelling .
- The tag in the back of your shirt makes you feel as uncomfortable as you would if a spider was crawling on you and you couldn't get him off .
- You wanted to write something down but it took you at least 5 seconds to form each letter. You can see the letter in your head, but your hand will not go in the right direction to write it.
- You had to pull the car over 3 times on the ride here because the motion makes you sick.

These examples may sound extreme but for some with sensory processing disorders they are not.

At least as adults we have grown to understand ourselves and our bodies. We know what we can and can not tolerate, what does or does not feel good and most importantly, we have the coping skills and problem solving abilities to deal with it the best we know how. These children do not!

Unless we understand what is going on, help them understand their own bodies and minds, get them the right treatment and help them find the coping skills and insight, they will continue to suffer until adulthood.

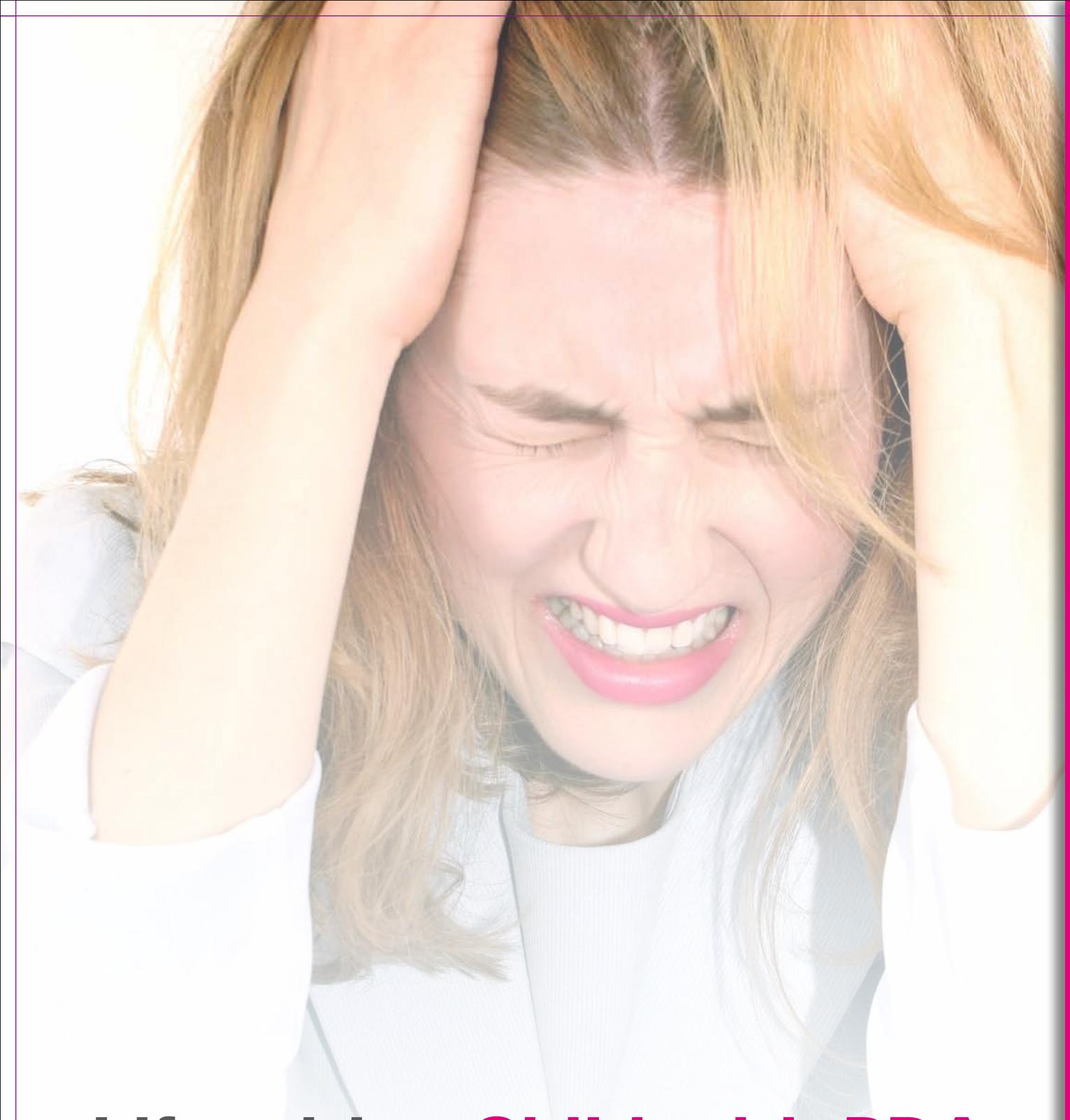
Sensory processing disorders are best treated if caught before the age of 7 when the nervous system is still malleable.

It is imperative we identify and treat these children as early as possible so we can make a positive difference and get to them before...

- Learning is too difficult
- Self-esteem has suffered too much
- Relationships never fully develop
- They begin to isolate themselves into their own little safe and protective world

The time is now!

'This information has been reproduced from www.sensory-processing-disorder.com'



Life with a Child with PDA and our journey to diagnosis from a parents perspective

This is my true account of living with a child with PDA. These are the facts and although it may seem hard to believe this is the reality of life with a child with PDA.

PDA is not the result of poor or inconsistent parenting and I along with hundreds of other parents are living proof of this fact.

Mollie's Story

Mollie aged 6 months to 3 years

- o A happy baby who cried very little (unlike my son who screamed and screamed until he was three years old).
- o Needed to be constantly entertained but was happy as long as this was facilitated (unlike my son who had screamed and screamed regardless of what I did). Caring for Mollie was like a walk in the park compared to those early years with my son.
- o Attended a private day nursery which she loved and they loved her especially her strong will and spirited nature. Nothing ever seemed to faze her.
- o At 18 months of age Mollie became very difficult which we put down to the terrible twos.
- o The behaviour was to the extreme and it was at this stage that life became very difficult with Mollie and I began to see worrying comparisons between her and her brother. Surely I wasn't going to have to go through all that again.
- o Mollie was very outgoing, confident, and full of fun and a real character which helped to balance the other and ever-growing more difficult side of her personality.
- o Getting dressed was a power battle that caused huge stress for all involved. There would be a stint on the naughty step between each layer of clothing. Very frustrating if you had to be somewhere for a certain time. The naughty step, despite my continual use of this method of control, did not cause or help Mollie to modify her behaviour in any way over this time period.
- o Following the battle of clothes would be the battle to get into the car. Mollie would refuse to get into the car regardless of where we were going. People would say "why don't you pick her up and force her in?" The answer to that is that a small child kicking, pulling and hitting is very difficult to manoeuvre and restrain in a car seat. The odd time that I did manage it she would simply unbuckle her belt and get out of the seat and hit me whilst I was driving the car.
- o Refusal to follow simple requests and if she was asked not to do something she would just blatantly ignore any family member who had asked this and continue with what she was doing. The naughty step would be the consequence but this became another battle of getting her to even stay out of the room let alone on a step and didn't prevent the repeat of such incidents.
- o Tantrums would last forever and my nerves were shredded. At this stage we were not experiencing any violent outbursts just absolute refusal to do anything and lots of the screaming ab-dabs.
- o At this stage in Mollie's life I wasn't too concerned. Her brother had been every bit as difficult as she had but because he internalized his feelings he always managed to suppress them at school and so he didn't give us any concerns there. He was 8 years old now and a child that needed a lot of careful handling but with that careful handling the violence had gone.

Mollie 3 – 4 years

With the start of school we were hopeful that Mollie would begin to mellow and that the terrible twos which had continued until now would begin to be nothing more than a distant memory. How wrong we were!!

School

- Within a few months Mollie was regularly kicking teachers and staff, other children, trashing the classroom and hurling missiles across the room.
- This was a huge shock because she had never behaved like this at her private nursery or at home, other than the car incidents, and we couldn't understand why she was behaving like this at school.
- During that first year at mainstream nursery school Mollie was suspended approximately four times.
- The school was very helpful but they were also at a loss with Mollie. They had not experienced anything like it before and none of the tactics successfully used on other children had any impact on her at all.
- The inclusion team and educational psychologist were summoned. Could they help Mollie?
- The educational psychologist was amazed to discover that Mollie had an IQ of 135 at 99 percentile placing her as very superior. Could Mollie be bored at school and need stretching?

Home

- Major tantrums if she can't get her own way. I can remember saying to my friend as we were walking home from school "I can't wait for the day when I can collect Mollie from school and reach the car without a major incident occurring". When she couldn't get her own way she would just lie in the middle of the walkway, leading to the main playground, screaming and refusing to move. I would ignore her and walk off and give her a consequence for her behaviour once I got home.
- Mollie is OK in public if there is plenty to do and few boundaries. Shopping is stressful because she will not stay by my side and runs off, so I keep shopping trips short. I would not attempt my weekly food shop with her at this moment. Any public situation where socially acceptable behaviour is required for a sustained amount of time rather than for a short spurt I avoid.
- Mollie has no sense of danger and runs off when we are out in public.
- Unbelievably jealous of others especially if it means that my attention is taken away from her. This trait has been obvious from a very young age. Mollie likes to have me all to herself.
- When I play with Mollie e.g. with dolls, she has to be in charge and instructs me on what my doll character should say. If we are colouring in she instructs me and what colours I can use. She likes to play games where she is the instructor and I or the family have to follow her orders. She wants to be a teacher when she grows up so that she can boss all the kids about. As Mollie's playtime is her special time with me I go along with what she wants to do.
- When Mollie wants something she wants is now and does not relent until it is done. If Mollie is upstairs and needs something she shouts me and I will usually reply "I'll be with you in a minute Mollie". Mollie cannot wait a minute she will shout repeatedly until I arrive; her voice gets angrier and more agitated with each shout.
- When Mollie gets exited she goes into what I can only describe as hypo-mode and when this happens she is uncontrollable and will follow no requests.
- It is worth noting that Mollie plays exceptionally well and without incident with older children and in turn older children like Mollie.
- The blind rages that escalate into violence and damage to property exhibited at school are now also exhibited at home.
- I go to the doctors, at the schools request, to see what help is available for Mollie. The only help available at that time was for my husband and I to attend a 'Triple P' parenting course. I knew that this would be a waste of our time and their's because I had already tried all of the traditional parenting techniques without any long-term success. We did however attend the course to show willing and to hopefully prove that whatever was going on with Mollie that it was not down to our parenting.

I have really dug my heels in with Mollie, determined to let no incident go without consequence, because as her parent it is my responsibility to turn this disruptive but at the same time funny and lovable little girl into a person that can integrate and be accepted by society. At times Mollie's behaviour and the constant battle of wills has made me feel stressed, tense, anxious, upset and angry to the point where I have sometimes felt totally churned up and helpless inside. If Mollie's behaviour has sometimes made me feel all of the emotions above because of her constantly forcing her will against mine, is this how Mollie feels, does she perceives the world in which she lives as constantly forcing its will against hers? I know that this is not the case and that we are trying to teach Mollie that there are rules and ways of correct behaviour for her own good and well-being. However in her little mind perhaps something is not wired correctly and in her eyes all she sees is a world full of people forcing her to do and behave in the ways that they want her to, taking away her control and causing the frustration to erupt into violent and aggressive tantrums because this is the only way that she knows how to deal with these emotions. We have tried using consequences with Mollie for her behaviour but she just doesn't seem to care they really do not modify her behaviour at all.

Mollie aged 4 – 6 years

School

Behaviours and problems at school continue to escalate and nothing that I or the school do reaps any long-term reward.

- Weeks of good behaviour are followed by weeks of bad behaviour and seem to alternate between school and home. E.G. good behaviour at school means that I get it in the neck as soon as I pick her up and bad behaviour at school usually means that there is a decrease in behaviours at home.
- No traditional methods of behaviour modification have any long-term effects.
- Mollie is again suspended on several occasions.
- Asperger's is suggested as a possible reason and even though I can see that she doesn't quite fit the profile I still grab it with both hands as a possible lifeline that is offering me an explanation so that I can help my daughter.
- Mollie is diagnosed with Asperger's but she still struggles at school and seems to be getting worse and worse.
- She has a statement for 20 hours of one to one a week and still things don't improve but steadily go downhill.
- Getting Mollie into school is proving more and more difficult and I am now dealing with school refusal

Home

Mollie is deteriorating and regressing before my very eyes. Where has my daughter gone and who is this impostor that has taken over her body? Family try to help out but no one can cope with the thought of looking after Mollie for more than a few hours and both of my parents work. As I explained to my dad a few hours of being Mollie free, which only occurs occasionally, is like being offered a sip of water in the middle of the Sahara, you just don't feel the benefit of it. Even the noise of her screaming or shouting or the feel of her clambering all over me sends me into a state of nervous, anxious panic. As a family my husband and I both feel very isolated and alone. There is no one to talk to who understands how stressful and draining life feels at the moment. Even family don't understand the impact that it has on your life because they don't live with it 24/7.

- Life is impossible and the tantrums are growing in their frequency and intensity. I have seen a documentary on TV called 'Young Autistic and Stage-struck' and there was a girl on the show with something called PDA. I have goggled this and the profile fits Mollie perfectly.
- I excitedly call the ASD assessment team to tell them of my discovery but disappointingly PDA is not fully recognized on the spectrum in Stoke-On-Trent and they are unable to assess for it at this moment in time.
- Mollie is diagnosed with Asperger's but none of these tried and tested behavioural techniques work for her.
- Mollie is also dyslexic and has sensory processing disorder affecting most of her senses which is one of the many reasons why school is so unbearable for her.
- Each day it is getting later and later before I manage to get Mollie into school only to have to collect her shortly after because she has kicked someone.
- In July 2010 I make the decision to withdraw her from mainstream school in the hope that a specialist school would be more suitable.
- Mollie is finding it more and more difficult interacting with her peers and is even more physically and verbally aggressive to everyone and anyone around her.
- Bedtime is a nightmare and she is still awake and wreaking havoc into the early hours.
- Mollie is always stealing other people's things and hiding them or throwing them away.
- She has started urinating on beds, towels and so on.
- Shops are becoming impossible due to the huge public meltdowns that she always has when I put a limit on how much money I am prepared to spend.

My resilience in dealing with the above combined with the years of dealing with my 12 year old son's demanding behaviour as an infant and his difficult emotional needs now combined

with a husband who has OCD is at an all time low. When Mollie was three I had my first taste of not being able to cope. I would pick myself up and start again, trying to think of new strategies to deal with and cope with her behaviour. The thought that this strategy would be the one that would work would give me light at the end of the tunnel and the desire to keep at it. These episodes of hopelessness, anxiety and questioning myself as a parent now occur on a more regular basis with shorter caps in-between. My optimism that I would eventually come across a method that would help me manage Mollie's behaviour successfully is all but gone. My fuse is shorter and I snap and shout more regularly. In short I feel trapped by her behaviour and physically and mentally exhausted. Following my dad's retirement and with the true extent of Mollie's difficulties now been fully recognised I have received excellent help and support from my all of my family without whom I would have gone under. I have consulted Mollie's educational psychologist as I am concerned that Mollie's behaviour is still deteriorating and the possibility that she may have a co-morbid disorder that is perpetuating the problem. He suggested PDA and I was amazed and relieved that he too, without me ever mentioning it to him, could also see the traits. I email the Elizabeth Newson Centre with Mollie's biography and the Ed Psych wrote a letter for me expressing his concern and that he too thinks that Mollie should be assessed. Phil Christie from the Elizabeth Newton Centre emailed me back and even spoke to me on the phone to say that these behaviours are common with PDA and that an assessment would be recommended.

MOLLIE IS NOW 7 YEARS OLD

- Mollie is more and more controlling of her environment and those around her.
- When she is in new situations Mollie regresses to that of a much younger child.
- When she is in new situations with children that she does not know she is very verbally and physically aggressive because she is unable to identify their intentions towards her.
- She is also the same with new adults in her life.
- Mollie hates unexpected visitors to the house she is either frightened of their intentions and she hates people speaking to me in-case they are trying to steal me from her.
- She will attempt to get unwanted visitors to leave and regain my attention and thus alleviate her anxiety by any means possible. Being rude, physically and verbally aggressive, trashing the house and so on.
- Mollie is manageable if interaction is one on one and her needs are being met i.e. she is in control.
- Mollie has a very short attention span and activities have to be chopped and changed to keep her engaged.
- Mollie has extremely high levels of energy and is unable to calm down and relax thus making sleep extremely difficult.
- Regardless of how many times I refuse demands and stand my ground the outbursts, when she does not get her own way, are actually increasing in intensity rather than decreasing.
- The smallest of demands are met with one avoidance technique after another and can swallow up huge amounts of time during the day and night.
- Mood can change rapidly from happy to aggressive as soon as a new need is not met.
- Mollie uses behaviour and avoidance to express her emotions and anxieties rather than speech.
- Everything in Mollie's day-to-day living has to be negotiated and goal posts are repeatedly moved.
- Mollie is at her most contented at home with one on one and does not want to go to parks or play areas any more.
- Mollie is happy and contented if the day's events are completely on her terms and are facilitated within her timescale. This makes normal day-to-day living impossible which of course results in outbursts.
- Mollie does not appear to have any concern for the feelings or emotions of other people and the world truly revolves around her.
- Almost impossible to encourage Mollie to do anything that she doesn't want to do even when there is a reward involved. Very often even this does not encourage the desired result and the reward that Mollie requests can be impossible to accommodate.
- Eventhough I have reduced the anxiety caused by sensory issues, mainstream school, unnecessary changes in routine, providing activities that don't require social interaction (unless Mollie chooses to do so). Mollie's outbursts and difficulties continue to escalate.

- Violent outbursts did not start at home and then transfer to school, they in fact started at school and then transferred to home.
- Mollie's usual way of communicating with me is by screaming and shouting at me. Even a simple question like 'is your film good' will be answered with 'get out you git'.
- Most days we have 2-3 meltdowns which involve screaming, shouting, trashing and damaging property, hitting, kicking and throwing objects at me. These objects can be phones, remote controls and even cups and plates. The rest of the day is spent trying to avoid, defuse or de-escalate any further outbursts.
- Going out is a no-no. Mollie refuses because she only wants to be in the house.
- Mollie is now on melatonin to help with her increasing sleep problem.
- I have given up work and I am now Mollie's full-time carer and virtually housebound.
- It is now January 2011 and Mollie is still at home but we have found a school willing to take on the challenge.
- My mum and dad have given me, and continue to do, so the most amazing support and unfortunately their lives have also been dramatically affected. They are both in their sixties and instead of enjoying retirement they are doing as much as they can to help me and they will not even book a holiday because they know how fragile my own mental health is.

I joined the PDA contact forum in December 2010 and following excellent advice and support that I received from other parents via the PDA contact forum I can now see a chink of light appearing at the end of the dark, lonely tunnel that I have been travelling down. I think I am starting to see the old Mollie return and the impostor that has taken her over during the last four years is fading. Below I have listed what I have had to do in order to reach this plateau.

- I care for Mollie full-time and we stay inside the safe place called home.
- I never ask or expect Mollie to do anything that may result in a meltdown. If I need a bottle of milk then a member of my family pick it up for me.
- Unexpected visitors are banned and visits are by appointment only.
- I leave everything under Mollie's control unless she is placing herself or someone else in danger.
- If I need her to do something like brush her teeth or hair I gently tempt her throughout the day and at some point she will happily give in but I never force an issue.
- I have asked people to email me when she is going through a phase of hating the phone rather than calling me.
- We have set days for respite with only one adult providing it, usually a family member, because with Mollie three's a crowd.
- The adult giving me respite is here to play with Mollie and not to talk with me.
- I tell Mollie that Grandma is coming to play because she wants special time with Mollie whilst mum does boring jobs. She is happy with this rather than thinking that someone is playing with her because mum has had enough.
- Mollie still enjoys going out to some places e.g. cinema and McDonalds and so if someone needs to talk to me we arrange for my husband to take Mollie out for a treat and make sure that the visitor arrives after she has left and leaves before she comes home. If she knew that someone was coming to the house she would want to stay at home so that she could control the visit.
- Mollie's new teacher is doing two home visits a week with Mollie and is following all of my advice on how to get the best from her. Mollie needs to see her as friend rather than an authority figure or it will never work.
- The school is going to build Mollie her own study room to lay out and organise to her own requirements.
- Mollie has her own unique curriculum which shall be mainly play and activity based with the main aim to be to keep her in school and most of all happy.

In the same way that a child who has an allergic reaction to the environment lives in a bubble I have adopted the same approach for Mollie and provided her with her own bubble to live in. When she is calm and has recovered from the assault on her system, that has been her life up to this point, I shall then gradually try to reintroduce one by one the more normal aspects of living. In time I am hoping that the bubble that sustains her emotional well-being can be gently taken away

November 2011

On May 13th 2011 Mollie was diagnosed with PDA at The Elizabeth Newson Centre. What a huge sense of relief to finally have the correct diagnosis and strategies to move forward with. No more trying to justify my parenting or my daughters behaviour to those around me. Here it all was in one clear and precise document. I felt vindicated for all of those years that I had tried to convince all of those around me that traditional behaviour approaches did not work, not because I wasn't consistent or firm enough, but because she simply did not respond to them in-fact they made her worse. It is vitally important to have an understanding of what drives the behaviour in order to fully understand and help any individual with PDA. A concrete diagnosis gives this understanding for parents and professionals alike. Understanding that Mollie's behaviour was her way of dealing with an anxiety driven need to avoid any perceived demands and to be in control at all times makes so much sense to me now.

Imagine the avoidance that you would see a sufferer of OCD elicit if you asked that person to put their hands in a bin. If you insisted and insisted and offered rewards or punishments or threats of physically making him, the anxiety within him would grow and grow. He may even feel so threatened that he may become verbally or physically aggressive in order to avoid the task. It isn't that he is refusing to put his hands in the bin but that the anxiety that this action provokes is preventing him from being able to comply regardless of what we offer as a reward or punishment. It isn't that he won't but that he can't, which is a different thing all together. The person with PDA will feel this terror and anxiety at the thought of complying with the most simplest of demands or even suggestions e.g. playing a game that isn't of their choosing. Is it any wonder that they try to stay in control and avoid all demands, real or perceived, at all costs when this is the only coping mechanism that they have in order to avoid the panic and anxiety that compliance will provoke.

September finally arrived and following some 14 months at home it was time for Mollie to really integrate back into school. Words cannot express what a huge difference that this has made for me and Mollie. I can now have time to do normal things and be a normal person for 6 hours a day. When I'm with Mollie I'm refreshed and ready to spend time with her and much more relaxed. Attending School has increased Mollie's self-esteem and helped her to feel like a normal little girl again. School and I are using the same PDA approaches in both settings and have regular meetings to discuss how things are going. Everything is left under Mollie's control and she chooses if she wants to go into the classroom or her own room. Sometimes she chooses the classroom or if her tolerance for demands is low she will spend the day in her own room. We have all agreed that the priority for Mollie's education is emotional well-being and to help her develop an understanding of her condition and how she can learn to control it instead of it controlling her. Everything is in place for a successful future for Mollie and we can start to hope for an easier ride ahead. Whilst she is in School I can catch my breath and wait for time to repair the impact that the past 5 years has had on my mental health. With the correct approaches and time hopefully Mollie will improve more and more and the huge meltdowns and explosions will become a distant memory. I don't know what the future holds or how Mollie will develop into a teenager and then an adult. All I can do is stay positive in the knowledge that I am doing everything that I can to give her the best chance of a promising future. Hopefully the early intervention that early diagnosis brings will make all of the difference for Mollie and for those that will follow her.

Mollie is funny, bright, bubbly, and full of mischief and if I could bottle her smile and sell it I would be a millionaire. This child disappeared and was taken away from me but slowly and surely I can see her creeping back. What better gift could any parent ask for? I have shared my story with you in order to spread awareness of PDA and the devastating effects that it does have on families. Without the correct diagnosis and intervention the future would be very bleak for these children and their families. The correct diagnosis and intervention can transform lives. We all need to be aware of PDA or these children will remain with either the wrong diagnosis and therefore wrong strategies or labelled as a willful naughty child in need of a sharp dose of behavioural management which just leads to more failure.

Since writing this Mollie's new school placement did breakdown. This was through no fault of the school but was due to Mollie's increasing self-awareness of her difficulties and differences. Her controlling nature had led to the breakdown of new friendships which lowered her self-esteem. Mollie's inability to tolerate the structure and boredom of a mainstream classroom and her difficulties with peers resulted in her becoming more and more isolated and spending more and more time in her own room with only her TA's for company. She began having regular outbursts at school which increased her anxiety about attending because she would be very embarrassed that school staff and pupils were witnessing her outbursts. She said to me "I don't fit in anymore, I don't fit in anywhere, I just want to go to a school where other kids have problems like me." We are now waiting for Mollie to attend a specialised ASD school that have experience of other pupils with PDA.

Visit my blog at
Shiggs55.wordpress.com

USEFUL WEBSITES

NAS Autism Helpline

Offers confidential information and advice on PDA and related issues.

Tel: 0845 070 4004 (open 10am-4pm, Monday-Friday)

Email: autismhelpline@nas.org.uk

National Autistic Society

www.autism.org.uk

The PDA Contact Group

A predominantly online support group for parents and professionals learning about PDA, it incorporates a website featuring information about PDA, its history and management guidelines for home and school, with a forum where parents and professionals can share ideas and strategies.

Web: <http://www.pdacontact.org.uk>

Support Forum: <http://ccgi.pdacontact.org.uk/forum/index.php>

Tel: 0114 2589 670 (Margaret Duncan, National Coordinator for the group)

Calls are preferred on Wednesdays or Thursdays but please leave an answer machine message if there is no-one to take your call.

The Elizabeth Newson Centre

Advice, support, training and a range of publications are available through the Elizabeth Newson Centre, part of NORSACAs Sutherland House Children's Services in Nottingham.

Web: <http://www.norsaca.org.uk> or <http://www.sutherlandhouse.org.uk>

The Maze Group

The Maze in Nottingham offers a drop-in centre providing support for and advice for parents, and training in Autism and PDA.

Web: <http://www.themazegroup.org>

CLEAR AND PRECISE INFO ON PDA

Written and Presented by a parent of a child with PDA and ideal for teaching staff.

www.youtube.com/user/bluemillicent

Sensory Processing Disorder

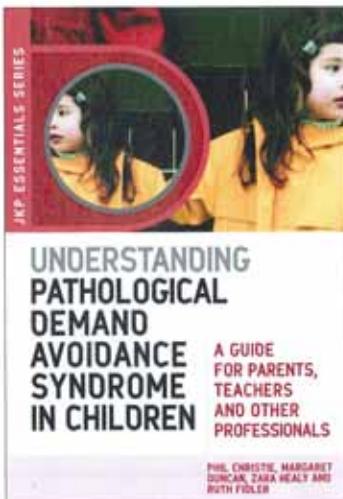
Everything you need to know about sensory processing disorder including a checklist of behaviours that can help you identify your own child's sensory issues.

<http://www.sensory-processing-disorder.com/>

Books

Understanding Pathological Demand Avoidance Syndrome in Children: A Guide for Parents, Teachers and Other Professionals

by Phil Christie, Margaret Duncan, Zara Healy and Ruth Fidler



The Explosive Child by Ross W Greene, PH.D.

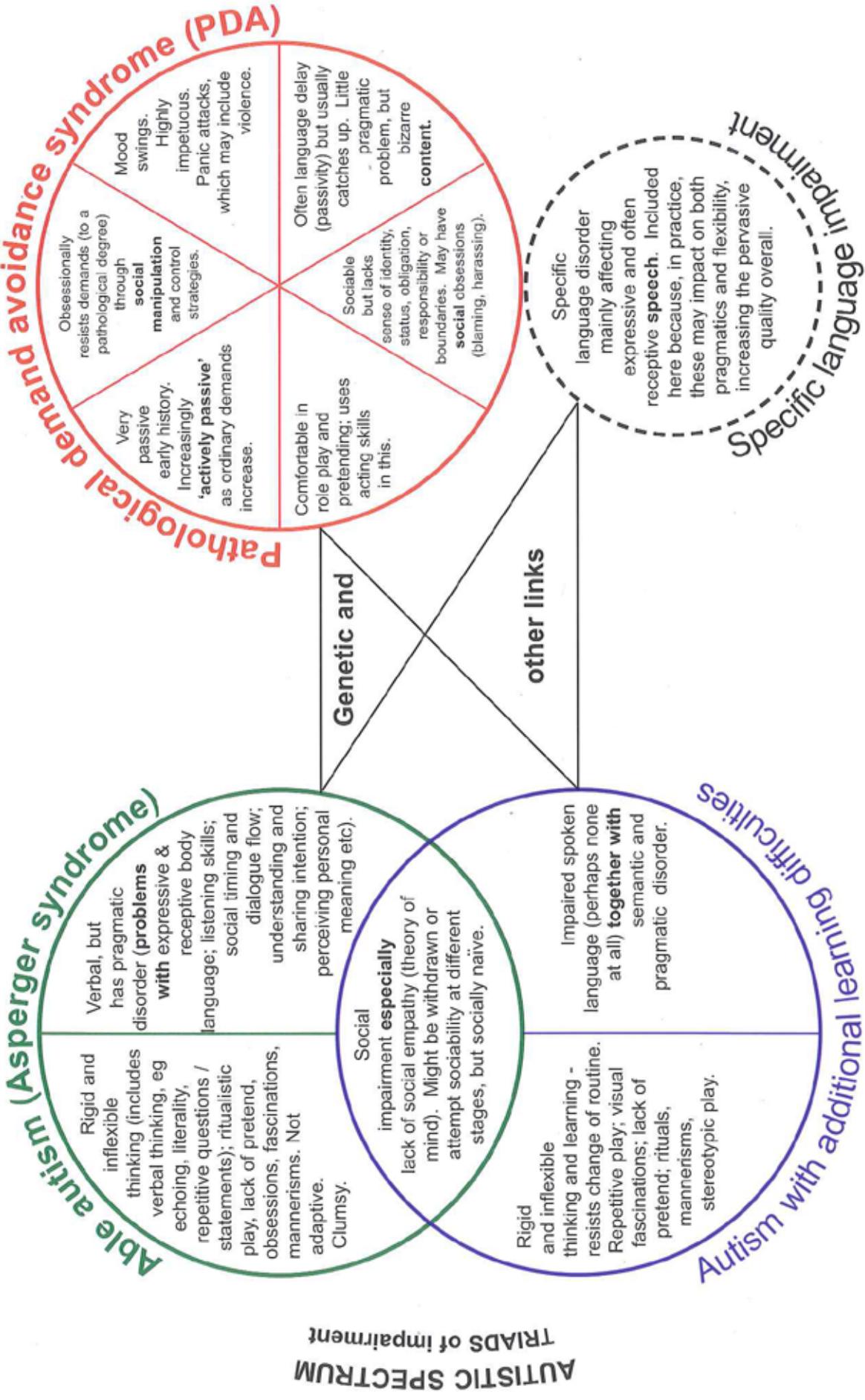
Managing Meltdowns by Deborah Lipsky and Will Richards

Raising a Sensory Smart Child by Lindsey Biel, M.A., OTR/L and Nancy Peske

All available from Amazon

THE 'FAMILY' OF PERVERSIVE DEVELOPMENTAL DISORDERS

(sometimes 'autistic spectrum' is loosely used to describe the whole family)



(The diagram shows clusters of symptoms making up specific disorders/syndromes)

Elizabeth Newson 1999