Pathological Demand Avoidance - A behavioural profile within the Autism Spectrum characterised by an avoidance of everyday demands and other specific features

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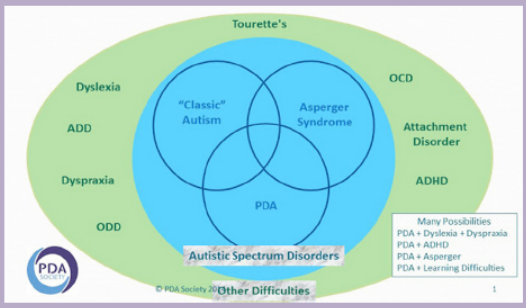
Introduction

The term 'Pathological Demand Avoidance' (PDA) was first used in the 1980's to describe a group of children who presented for assessment with a diagnosis of Autism/Asperger's syndrome but despite having some common features these conditions were not seen as typical of either of these diagnostic profiles. Whilst parents,'PDAers' (people living with PDA) and some professional groups continue to this day to lobby controversially for a distinct clinical diagnosis for this subgroup, it is still not established as to whether the features are part of the autism spectrum or a separate condition.

Diagram - www.pdasociety.org.uk



One thing, however, is very clear. The approach, behavioural and educational, that is required for this group is significantly different to that used with a child with autism and early recognition of this is paramount in the success or otherwise of the child's progress and adaptation to the demands of daily life.

The Identifying Key Features of PDA

Even when a child has a diagnosis of autism, parents will often immediately relate to this constellation of features which identifies their presentation as 'subtly different' to that of a child with classic autism:

- Passive early history in the first year,
- Continues to resist and avoid ordinary demands of life (strategies of avoidance are socially manipulative),
- Surface sociability but apparent lack of social identity, pride or shame,
- Lability of mood, impulsive and explosive, led by need to control,
- Comfortable in role play and pretending,

- Early language delay but rapid and atypical catch–up at around four years,
- Obsessive behaviour- strong fascinations and special interests,
- Neurological Involvement - clumsy and poor attention.

Is There a Link Between PDA and Oppositional Defiant Disorder (ODD)?

Some people feel that Pathological Demand Avoidance may be closely linked with Oppositional Defiant Disorder (ODD). In the literature, one is a pervasive development disorder and one is a mental health issue but in life this is not so easily defined. The demand avoidance in ODD may very often be anxiety-related, just as it is with PDA, however some children with ODD respond well to a behavioural reward/consequence system that would not work for a typical PDA child. One difference often quoted between those with ODD or PDA is that children with ODD are less keen on drawing attention to themselves in front of their peers; they want to fit in and can socialise in a typical way. Children with PDA on the other hand, are more likely to have unpredictable outbursts, even in front of their peers and they also tend to try and control all social interaction.

What is a Demand?

A demand can present itself in many ways during the course of a day; it is not always an instruction, timetable or worksheet. From the expectation that you will actually get up, get out of the car at school, make a choice at the hatch for dinner, obey social rules (queuing or not eating things before you've paid), answer strings of 'questions' in a short time frame (e.g. 1) How are you today? 2) What have you been up to? 3) Do you want to sit here? 4) Did you do your homework? 5) Is Kelly here today? 6) Can you just lean over and put the light on? 7) Are those new trainers? 8) Did you get them at Sports Direct?) and other people's agendas "I thought we'd start with literacy", can all trigger catastrophic and wholly disproportionate reactions. Signs around the environment, menus and rotas where implied demands are present can also cause an increase in anxiety. Always remember that when a child with PDA meets you, they may have already avoided or complied with many demands that day already. What you consider as a relatively small demand may just be the tipping point to an irrational response.

Strategies to Support

Living and working with a child with PDA requires a 'toolbox' of strategies which combine flexibility with the need to accomplish some simple demands to some degree in order to establish boundaries. Anticipating situations and planning for children with PDA who may appear to want no rules and boundaries at all, but will find having total control equally confusing and anxiety-provoking, is essential. It is helpful to understand that any one strategy will only have a very short shelf-life. Rewards and events which may on one occasion be the 'best thing ever' e.g. horse riding, computer time, a visit to a theme park etc. will be sacrificed in the blink of an eye in order to gain total control of a situation. Using their love of role-play and imagination is an excellent way of harnessing participation without the child realising that any demand is present e.g. making a maths lesson into a graph of children in school wearing 'Power Rangers' colours. However it is important to be aware that this approach can go too far as power and responsibility causes confusion and anxiety so pre-plan how far you will go **before** handing over control.

Top Tips

- Competition and daring will work well on occasions. Make everyday demands into a game.
- Give choices of where or how something will happen rather than whether it actually happens e.g. "Shall we go to grandma's by train or bus?" – hand over the balance of power to the child when the real issue is getting out of the house.
- Use your sense of humour and don't let the insults and threatening language get to you (take nothing personally).
- Use a network of support - don't be the one to field the meltdowns all the time.
- Every new day, afternoon, or lesson for example is a clean slate. The 'next face' breezes in as though nothing has happened.
- Present a choice, contract or demand and then allow time for processing without nagging or repetition. It may take a while for all the options to be internalised.
- Remember a BIG incident requires a LONG recovery period. Don't expect the child to return to task, to school or to regulate within a few hours.
- Language used to present tasks should also be carefully thought out; "I need help to do this. . .", "Would it be a good idea to . . .?", "Our next mission is to . . ." or "Let's investigate."
- When using rewards always have an optional 'get out clause' if they fail. "I know you haven't got any computer time today, what could we do to make this happen?" Be flexible.

- Refer the demand/conflict elsewhere and de-personalise it e.g. "we will have to ask the management/the Head/the electricity company whether we are allowed to plug one of these chargers in before we buy it, then we can come back for it", (instead of getting into a "No' we can't have it or "I haven't got enough money" situation).
- Be aware of the child's sensory profile. A calming space to retreat to with music or variable lighting can have a significant impact on their ability to cope with a bad day.
- Always pick your battles. Is it worth digging your heels in on this occasion or can you let this one slide to maintain regulation for another occasion? Don't see compromise as failure but as storing up points for the next situation. Learn how to navigate the child's triggers and be creative in ways to avoid setting them off. Learn the words "It's okay if. . . (we don't go, it doesn't happen, you can't do it).

What is a Good School Placement?

An early understanding of PDA, a willingness to make flexibility a way of life, a total re-think about what you can achieve in any lesson, depending on the child's presentation on the day and a whole school 'sea-change' in the tried and tested methods of engaging children, are non-negotiable factors in ensuring a successful school placement. Staff have to relinquish the mind set that "he will do it if I have to wait all morning" and exchange it for "if he does it that's great, but can we do something else that's productive until he does and if nothing is achieved today we'll try again tomorrow". A "he can't do it" rather than "he won't do it" attitude.

It is important both in mainstream and specialised placements to be flexible and creative with 101 different strategies in reserve to divert, motivate and engage the child; "don't finish that picture while I go to the cupboard because I want to colour that last bit", "I bet you can't get to the next lesson in less than three minutes", "A parcel has arrived in reception for Joe, would he be able to collect it", "I have to do a job in the hall can you come with me, I think you could be really useful".

The main focus of education should be to develop a consistent and mutually-trusting relationship which will build the child's self-esteem and self-worth alongside functional and academic skills which motivate and engage the child. Small successes in managing behaviour should be documented as being equally important to completing any exam or worksheet.

A child with PDA is not deliberately saying no. Once you see the diagnosis, the anxiety and the solutions, it is easier to see a way forward. Every day is a clean slate.

Here at Options Autism our staff have all undertaken training in order to understand PDA, how to anticipate and minimise challenges and how to support our young people using a range of strategies. We appreciate that some days and some demands will be difficult but we will always find something to celebrate about a child's achievements.

Useful Resources

- Understanding Pathological Demand Avoidance Syndrome in Children - A Guide for Parents, Teachers and Other Professionals (Christie.P, Duncan. M, Fidler.R and Healy.Z. 2012)
- PDA society - www.pdasociety.org.uk
- 'My Daughter Is Not Naughty', Sherwin J
- "Can I tell you about Pathologial Demand Avoidance Syndrome?", Fidler.R & Christie. P
- 'The Red Beast', Al-Ghani.K.I
- 'Starving the Anxiety Gremlin', Collins-Donnelly.K
- Bloggers - 'Dinky & Me', 'Steph's Two Girls', 'The Life of Duck', 'Understanding PDA', 'Dragonriko' and 'Me, Myself and PDA'.

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If you found this help sheet useful please feel free to share it with anyone who you feel may benefit.

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The complete series of help sheets can be found on our website www.optionsautism.co.uk/resources

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