

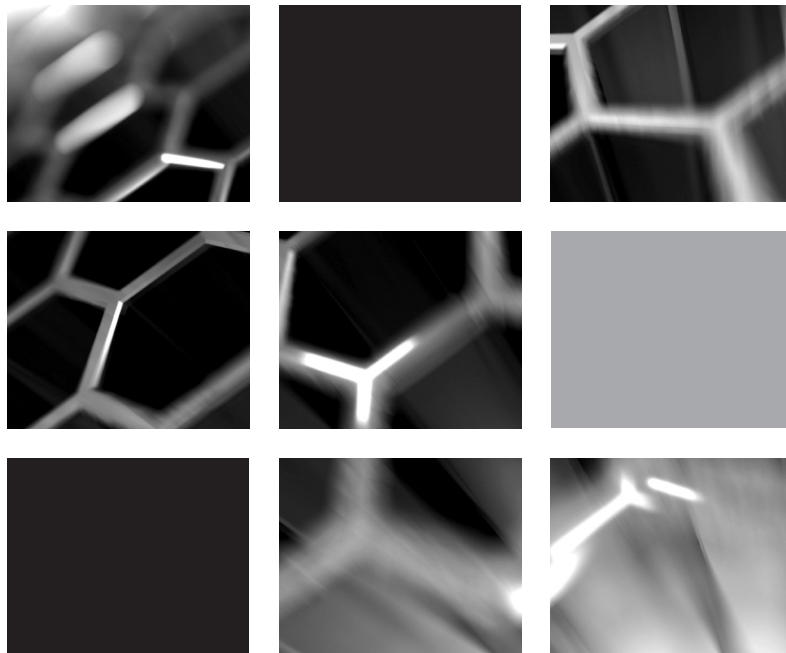


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Edited by Glenys Jones



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Sensory issues and Autism

Date: 14th December 2011

Venue: The Hub at Hazelwell

Time: 9.30am to 4.00pm

Price: £82 per standard delegate.

£65.60 for members of Autism West Midlands

We do not charge VAT

This seminar will include a general introduction to the importance of sensory issues in relation to autism and an explanation of associated concepts and terminology, including sensory processing, sensory modulation, sensory overload, hyper- and hyposensitivity. Also covered are the range of sensory issues that may be encountered in people with autism, with emphasis on the individuality of these issues for specific people. Ways of modifying the sensory environment and developing coping strategies for people with autism that will better enable them to function in a multi-sensory world will be discussed. Participants will also listen to a person with autism talk about their experiences of autism, in particular sensory issues.

Communication and Autism

Date: 11th January 2012

Venue: The Hub at Hazelwell

Time: 9.30am to 4.00pm

Price: £75 per standard delegate

£60 for members of Autism West Midlands

We do not charge VAT.

Participants will build on their basic understanding of communication difficulties and differences in autism and will have the opportunity to deepen their knowledge of the differing levels of competence of speech and other communication systems, in use and comprehension, found in individuals with autism. Participants will gain a better understanding of the need to adjust our own practice, to aid effective communication, and how to implement strategies that improve communication.

To book for either of these seminars, visit www.autismwestmidlands.org.uk/training or call us on 0121 450 7586.



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Helping your child with PDA to play: eight strategies for supporting a child with Pathological Demand Avoidance Syndrome at home

Josephine Carlile, Hertfordshire, UK

Editorial comment

This paper aims to add to the growing literature and interest in the group of children labelled as having PDA (Pathological Demand Avoidance syndrome). Discussion and debate continue as to whether this is a different condition from autism, whether it is perhaps the female presentation of autism (as more girls have been identified with the PDA profile than boys) or whether it shares some of the key features of autism and so should be recognised as a part of the autism spectrum. A book has recently been published on understanding PDA in children which provides details of their characteristics and discusses some of the main debates and strategies which are likely to be effective (Christie et al, 2011). What is true, is that children given this label are often very hard for parents and staff to work with, as they strongly resist the demands of others to engage in activities at home or at school. This paper describes the work done at home with a 7 year old boy thought to have PDA and suggests that these children need a rather different approach to that typically suggested for a child with autism.

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Acknowledgements:

Firstly, I would like to acknowledge Jack's family for giving me the opportunity to learn so much about PDA and family life. The last two years have been both challenging and hugely rewarding for me. I have seen first-hand how both Jack's mother and father continuously support each other. I want to take this opportunity to say how much I admire their never-ending strength and determination they show to ensure Jack's needs are met. Secondly, I would like to say thank you to Dr Natalie Roberts for her support and contribution during the writing of this paper. It has been her ongoing encouragement and time spent reading my drafts which has enabled this to be finished! Finally, I would like to thank Jack - a delightful and determined boy who faces challenges every day and whom I always get such pleasure being around.

Introduction

There is limited available research and literature on Pathological Demand Avoidance syndrome (PDA). It was first identified by Elizabeth Newson at the University of Nottingham (Newson, 2003) and was described as a pervasive developmental disorder, distinct from autism. However, it is now becoming increasingly recognised as part of the autism spectrum. Viewing it as a specific subgroup is important, as the strategies that have been found to be helpful for children with autism may not necessarily be helpful for a child with PDA. A core feature of PDA is the apparent need to resist normal, everyday demands made by parents, staff and others – hence the term 'demand avoidance'. This resistance appears to serve as a way of managing acute levels of anxiety, by trying to keep the environment and demands under their (the child's) control. Unlike other subgroups within the

autism spectrum, in PDA, theory of mind (ToM) and social skills can be deftly applied in order to manipulate others as a way of controlling the environment and resisting demands. However, the use of ToM and social skills appears to be at a functional and logical level, rather than at a deeper, emotional level.

By using a detailed case example, this paper aims to outline a number of strategies that were effective in supporting a child with PDA through the framework of play dates. Eight strategies are described that have been used effectively in supporting this child to learn some of the skills involved in playing with others and in building positive relationships. It also aims to expand the limited available literature informing and supporting families on practical strategies that can be implemented in the home.

Case study: Jack (fictitious name)

Jack is a seven year old boy diagnosed with PDA and Attention Deficit Hyperactivity Disorder (ADHD). He was diagnosed at the age of five and a half years after concerns around his resistance to every day demands and his difficult behaviour both at home and school. He presented as oppositional and impulsive. He often had anxiety attacks displaying swearing and hitting out at others in his environment. At school he had hurt teachers and other children. Within the home, Jack was physically and verbally challenging to his parents and his younger brother. When demands or requests were made of him, his high anxiety meant that his behaviour worsened, but then improved when demands were removed or, made in a way that he could tolerate. His anxiety attacks presented as extreme temper tantrums. Unexpected circumstances would produce a sudden incident. Confrontation or vying for control with him was futile and Jack required a great deal of support during these situations.

Lability of mood is a common feature of PDA and Jack can oscillate rapidly between moments of extreme happiness followed immediately by frustration and anger. He became highly anxious at school and had many negative experiences resulting in school refusal at the age of four. He now attends a specialist EBD school after almost a year out of school-based education. He is good at sports, but once he sees he is doing well, he seems to perceive this as compliance and a loss of control, and so he ends his participation.

Play dates

A play date is a scheduled time for supervised play where the fundamental aim is to support children who find it difficult to play with others by learning the rules of playing. Skills such as sharing, taking turns and speaking nicely to others are encouraged and practised. The play date is structured around 3 games during an hour's session, with a break in between. The games played depended on whether we were inside or outside. Inside games were either board games or practical games such as sleeping lions or Twister. Outside games include skipping and hide and seek. To secure motivation, the play date is reward based with the child working towards something they are keen to participate in at the end. During the session, tokens for engaging in the games are earned.

Play dates have rules. The ground rules are set during the first session by drawing up a list of expectations together

with the child, thus giving the child a sense of control. Because children with PDA seem to find demands or requests from others intolerable, depersonalising demands by using 'the system' or 'society' can reduce anxiety. For example, it is explained that there are universal expectations that everyone has to follow when they play. These are sharing, taking it in turns to choose which game to play, being patient whilst waiting for your turn and respecting the materials in the game. Expectations must be achievable and individually tailored to the child's level. It may take two or three play dates to determine if the expectations set are achievable. During the first few play dates with Jack, his anxiety around some expectations was so overwhelming they had to be removed. The play date rules were reduced to just one: 'No hurting others'. After a year of play dates, Jack began to tolerate many more rules, such as limiting his use of bad language, following directions to leave the room if he was becoming frustrated with his brother, and accepting my response if I said the game of his choice was not suitable. The guidelines for working with children with PDA suggest the need to synchronise the demand with the child's tolerance level (PDA Contact group). Flexibly adjusting expectations for each play date in accordance to Jack's tolerance levels on the day was an essential part of the intervention.

The following further eight strategies were found to be effective during play dates as a way of reducing his anxiety, and consequently his need for control and improved compliance:

- The use of humour
- Indirect praise
- Thinking aloud
- Flexibility and creativity
- Tone of voice
- Letting things go
- Treating anger as communication
- Positive relationships

Each strategy is outlined and supported with examples of how they were implemented.

Use of humour

Humour has worked well in the play date to diffuse tension and anxiety. Used appropriately, and selectively,

humour can be incorporated by talking in a funny voice, or making jokey comments. Children with PDA will often make requests which are impossible to meet. For example, Jack said that the only game that he wanted to play was tennis, when he knew that it was raining outside and we didn't have enough racquets for everyone. Responding with a joke about not getting wet hair in the rain was enough to reduce his need for control. Keeping things light-hearted and using laughter helped to lower Jack's anxiety. During one play date Jack was asked to stop hurting others. To enforce the request, the phrase, 'I am deadly serious' was used. He replied that he wished I was dead, so I laid on the floor and pretended I was. Jack laughed, became calmer immediately and stopped his challenging behaviour. This strategy enabled Jack to indirectly comply with what was being asked.

Indirect praise

Giving any child praise shows them that you are pleased with their behaviour. For a child with PDA, praise can be perceived as a signal of their compliance and of giving up of control. However, children with PDA want to be able to comply, but their anxious need for control gets in the way of this. Indirect praise is therefore more tolerable for them. After Jack had settled into the play date routine, his tolerance grew and he showed signs of increased compliance. However, if any form of direct praise was given (eg, well done; I am really pleased with that, or just a thank you), he would become oppositional. By removing all forms of direct praise, his behaviour dramatically improved. An example of indirect praise is talking to someone else about how well the child behaved when they are in earshot, or simply saying aloud '*Hasn't everyone been so well behaved today*' to no one in particular. Six months after working with Jack we were playing squash and he began to hit my head. It was playful but Jack was getting excited and it was starting to hurt. I told him it was hurting and so he stopped. I said '*thank you*' to him, and this led to another hit on the head.

Jack is very perceptive and knows immediately when people are pleased with him. As the relationship builds the tolerance levels to praise increase but it is still beneficial to try and indirectly praise whenever possible.

Thinking aloud

Thinking aloud is one of the most effective strategies to reduce anxiety and to enable the child to comply. During

one of the early play dates, Jack was anxious and was waving a stick in the air. It was not aimed at anyone but others were in proximity. Requests were often ignored. Without looking at Jack, I said, 'I think what Jack is doing is not appropriate; and he may hurt someone in a minute.' Jack responded by saying that he was not touching anyone with the stick. After suggesting that people can be hit accidentally, he waited and put it down a few seconds later and the play date moved on.

Thinking aloud can also help to diffuse an escalating situation when a child becomes anxious. Jack's anxiety is displayed through challenging behaviour. When Jack started to throw objects or become cross, thinking aloud was effective by saying, 'I think that Jack is feeling cross now, I wonder what the problem is?' As soon as the child becomes anxious, it helps to immediately voice your opinion. 'I think you might be feeling anxious and so shall we have a break?' This serves as a preventative measure, gives the child feedback on their emotional state and helps the child learn to identify their own anxiety. Gradually, Jack began to use words to inform us about his emotional state, rather than behaviour and objects, and he has not been physically challenging in a play date for over six months. Talking to a third person is an effective way to use the thinking aloud strategy. In addition, telling Jack's mother how great a play date was also seems to be a tolerable form of indirect praise.

Flexibility and creativity

Being flexible is vital for a successful play date. According to the tolerance versus demand balance it may be necessary to adapt and change expectations almost instantly. Strategies may work for a short while and then perhaps need to change. Novel experiences and unconventional approaches work the best. Being creative and imaginative in games can also increase participation on a day of lower tolerance. Some routines must be followed for the child to have safety and consistency, however it is also very important to be flexible to suit the child's changing needs. Unknown stressors may impact on the child's ability to cope on that particular day. Being flexibly prepared to change and saying, 'I think you are struggling with what I have asked you to do so perhaps we should change it,' is a way of responding helpfully to a child's distress signals. Being patient and being prepared to change the agenda is important. If you choose to 'fight' for control with the child, you are more likely to lose and the relationship will be negatively affected. Only the child's safety or the

safety of others are non-negotiables. Otherwise, be prepared to negotiate, compromise and be flexible during periods of high anxiety. This will give the child a much needed sense of control and enable them to feel less anxious.

Tone of voice

Tone of voice during a play date can inform a child when behaviour has become inappropriate. When Jack is behaving appropriately a soft, higher pitched, friendly tone was used and reinforced how enjoyable his company was. When Jack behaved in a way that was unacceptable, the tone changed immediately, to be lower and firmer. The aim was to inform Jack that his behaviour was beginning to become unacceptable. This was not always enough for Jack to stop the behaviour but the consistency meant that he knew exactly what behaviour was not tolerated. Clear facial expressions also gave a clearer message. During one session, Jack had refused to participate in a game which involved his brother. We told Jack that often he found playing difficult when he had had a bad day at school, so he did not have to join in if he chose not to. Jack sat and watched the game but made a rude remark about his brother. Immediately Jack was told, 'Rude remarks about people will not be tolerated. You may go inside if you are unable to watch appropriately.' The tone of voice was dramatically different; it was low and loud and facial expressions were exaggerated. Jack did not make another remark and immediately our tone changed back.

Letting things go

Once an incident has happened and been dealt with, however big or small, it is important not to dwell on it. As soon as Jack's behaviour improves, the tone of voice changes back. Nothing further needs to be said. It is important to let go of any residual, negative effects of an incident. The child's self-esteem and your relationship with them can then continue to develop. Jack is never reminded of how he has behaved in a previous play date. Every new game is a fresh start and When he lost at a board game, Jack suddenly became distressed and threw something which accidentally hit his brother. Jack was told 'ENOUGH' in a loud clear voice. Jack immediately stopped throwing and we suggested another game and the incident was not referred to again.

Anger as communication

Treating anger as a way of communicating underlying anxiety is an important strategy. Anxiety is a normal adaptive emotion to a situation in which there is a perceived threat. A child with PDA feels threatened by the demands of others or when they do not feel in control. Physically challenging responses are a way of controlling the situation and a way of communicating that they are not coping. When Jack began to show such behaviour, it was for two reasons. He was either becoming frustrated with a situation or becoming anxious. However, in both situations, his behaviour looked the same. Empathising with Jack when he was in distress helped to calm him. Thinking aloud by saying, "I can see this is really making you cross at the moment" encouraged Jack to say what was causing the distress. Listening to the content of verbal attacks and offering solutions taught Jack alternative ways to express his anger and anxiety. Once Jack was calm after a challenging incident, we found talking through the situation would sometimes enable him to think of alternative ways he could have expressed or discharged his feelings. Through the play dates, Jack has learnt that by exercising or playing an energetic game after he has had a difficult day at school, is helpful for him.

Positive relationships

The play date is an opportunity to create an environment where the child with PDA can have positive experiences within a relationship. Throughout the entire play date, the aim is to have fun. Negative incidents are not dwelled on. Given that throughout the play date Jack had to tolerate demands and to accept that he was not in control at times. We used the reward time as a "demand free zone", whilst adhering to safety rules. The reward and demand reduction enabled the relationship and a sense of trust to build. This time was also used, when appropriate, for exploring any worries that Jack wished to share. Children with PDA will often have many negative experiences. During the first few play dates, because of his anxiety, Jack displayed lots of oppositional behaviour, which meant that the play dates were punctuated with frequent negative episodes. This inevitably had an impact, but being consistent and genuinely positive meant that over time the number of positive and enjoyable experiences increased. Jack increasingly shared many laughs during the play dates and showed signs of looking forward to them each week. Play dates became a time when he could excel at

something and enjoy interacting in a positive relationship and a shared experience.

Concluding comments

Working with a child with PDA is not about removing all demands. It is about understanding the needs of the individual at any given time and adapting your approach accordingly. Through the use of a number of indirect strategies, everyday demands can be followed without increasing anxiety.

As the relationship grows, the demands placed can increase and so will understanding of the child. Sometimes Jack would become very distressed if he felt his distress signals had been ignored. There are times when Jack cannot handle the demands that he had managed the week before. This maybe because he has had a difficult week or day at school. It is up to the play date facilitator to ensure the demand/tolerance balance is in synchronicity.

All of the strategies mentioned are entwined with each other throughout the play date. The structure of the session allows rules and boundaries to be implemented in an indirect way. The focus on building a positive relationship through humour and thinking aloud strategies allows the child to learn to trust you. The relationship will be tested during periods of high anxiety such as the build up to school holidays and impending social occasions. This will result in elevated levels of resistance to demands. It's about understanding the child's needs and adapting the strategies used to accommodate them. During periods of lower anxiety is the time to really build the positives of your relationship and have lots of fun times.

Jack has given a valuable insight into PDA and what strategies are effective. It is important to remain firm and expect certain demands to be complied with, but adults need to play their part by being flexible and instantly forgiving. These same strategies can work in most situations at home or school and elsewhere. Playing can be beneficial to building a positive relationship with the child and gives the child experiences of fun, whilst learning how to interact with others, without raising their levels of anxiety. Jack once shouted, "*You do not understand. Everyday to me is like my worst day!*" Once you understand how challenging everyday demands are on the child, you empathise and move from imposing sanctions and showing anger at their apparent non-compliance and move to taking a positive approach which is more pleasurable and effective for all concerned and most importantly of greatest benefit to the child.

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