

Preventing school exclusion: a case study of a primary aged autistic child with ADHD and a PDA profile

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Editorial comment

Catrina Lyle is an advisory teacher within the Communication and Interaction team and Heather Leatherland is a mainstream primary school teacher. In this paper, they describe the work they did over a two year period with a 7 year old boy (Jack) who had had two fixed term exclusions from his mainstream primary school. He was initially diagnosed with autism and ADHD but did not respond to strategies often used with autistic children. Further assessment by the staff, his mother and the paediatrician suggested that he fitted the profile of a child with PDA or EDA (Extreme Demand Avoidant).

The staff received training on how to understand and support Jack and a detailed plan was drawn up which was regularly reviewed and modified, as needed. With a different view of his issues and the use of strategies recommended for children with PDA, Jack started to access the curriculum more readily and the challenges he presented to staff and peers reduced considerably. The paper illustrates just how important it is, irrespective of the diagnostic label(s), to understand the child's view of school and its demands, and to evaluate the approaches taken on a regular basis, in particular observing and respecting the child's response to these.

Introduction

Pathological Demand Avoidance (PDA) lacks recognition as a formal diagnosis in either the DSM5 or the ICD 10, which are the standard diagnostic manuals used in the United States and Europe yet the term has become widely discussed in both media and social media (Ayres 2015). PDA was first described by Professor Elizabeth Newson, a Consultant Clinical Psychologist, in 1983 and her seminal insights remain salient and relevant today (Newson et al, 2003).

She noticed there was a distinct group of individuals coming to her for diagnostic assessment, who exhibited features of autism, but did not quite fit the autistic profile. In addition to having some of characteristics of autism, they showed an extreme tendency to avoid simple every day demands. There has been a growing interest in this group, as shown by the well attended PDA conferences (held by the PDA Society annually) and specific training materials on PDA which have

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been developed, such as those by the National Autistic Society (NAS, 2013). In addition, there have been a number of publications on PDA (eg Christie and Duncan, 2010; Christie et al, 2007).

Teachers and support staff report that they find this group of pupils particularly hard to manage and educate owing to challenging and disruptive behaviour (Brede et al, 2017). Parent forums, such as the social media presence of the PDA Society and online parents support groups have led to heightened awareness among parents of children with autism. Some parents have therefore sought assessment for PDA.

More recently writers and researchers have suggested that the term be changed from 'Pathological' to 'Extreme' due to the former's negative connotations (Brede et al, 2017; Christie et al, 2012; O'Nions et al 2014). Indeed in Gloucestershire, where this study took place, the term Extreme Demand Avoidance has become an acceptable descriptor for autistic children and adults who display behaviours characterised by an obsessive, often anxiety driven need to avoid demands. The term 'Autism with Extreme Demand Avoidance' now appears on the Local Offer in many Health and Education Authorities in England (eg North Somerset, Avon and Somerset). However, anecdotal evidence and some small scale research suggests that this descriptor is often applied only if the child is close to, or has already experienced at least one exclusion (Gore-Langton et al, 2013a). Throughout the rest of this paper, the term Autistic Spectrum Condition with Extreme Demand Avoidance (ASC/EDA) will be used.

Approaches recommended for ASC/EDA

Phil Christie, a past colleague of Elizabeth Newson and a specialist in the field of ASC/EDA promotes the development of a positive and trusting relationship between staff and pupils both as a management strategy and as a means to reduce the anxiety caused by their obsessive need to avoid demands. If ASC/EDA is not understood, staff can perceive demand avoidance as a moral choice and resort to punishment and sanctions rather than support and positive intervention (Gill et al, 2017). Similarly, school staff might view school exclusion as the ultimate deterrent for what they deem

to be unacceptable behaviour, although there is little evidence that this is effective (Ravet, 2011) and adds to the already high demands made on parents.

Exclusion and the cost to society

Exclusion can either be permanent, where a pupil is removed from the school's roll, or fixed term where a pupil is excluded from the school for a fixed period of time (eg for a day, a week or longer). A report by the Institute for Public Policy Research in England (Gill et al, 2017) lists the reasons given for exclusion in England during the academic year, 2015–2016, with persistent disruptive behaviour being the most common. Alarming, the data showed that 77 per cent of the children excluded had recognised Special Educational Needs (SEN) and that SEN children were seven times more likely to be excluded than their typically developing peers. Autistic pupils aged 5 to 18 years in England, accounted for over 9 per cent of the exclusions. Although there is no current data on the exact number of autistic pupils with features of Extreme Demand Avoidance (EDA) being excluded from school, a survey by Gore–Langton (2013) suggests that 75 per cent of the 57 children with a diagnosis of ASC/EDA had experienced exclusion from school.

Aim of this paper

In writing this, we hope to provide useful information and insights for staff and parents in other educational settings who might be struggling with challenging, disruptive or extreme behaviour. As stated, Jack had already had two temporary exclusions from school and our aim was to prevent further exclusions by changing the way his behaviour was perceived and developing strategies to support him.

The case study: Jack (fictitious name)

Jack was 7 years old when this work started. The names of family members and friends are not mentioned and no reference is made to the name of his school, nor its precise geographical location. All other descriptions which may have identified him have been removed.

Jack was educated in a small, rural, mainstream Primary School in the South West England. He was initially diagnosed with autism and ADHD and was

supported using an Education Health and Care Plan (SEN Code of Practice 2014). Funding was provided for a Teaching Assistant (TA) with experience of working with a child with autism.

He is a boy of average to above-average intelligence, with an uneven academic profile including strengths in mathematics, science and spelling but difficulties with handwriting, grammar and creative writing, other than in stories of his choosing. His work was mainly written out by a Teaching Assistant as Jack often struggled to write. He spent a large proportion of his time outside the classroom. Unstructured times, such as break and lunch times could trigger his most challenging behaviour, making his relationships with peers difficult.

Jack began Year 2 in a mixed ability class with a new teacher. Initially, he was quite calm and he accessed some of the curriculum as he enjoyed the novelty of his surroundings. After a few weeks, however, his behaviour rapidly deteriorated and he became violent towards adults and children with the occasional use of weapons, turning over and throwing furniture and explosive verbal outbursts. As a result he received two fixed term exclusions.

Jack failed to respond to tried and tested interventions, indicated for autistic learners such as visual timetables, structured learning and other TEACCH strategies (Treatment and Education of Autistic and Communication Handicapped Children, Schopler, 1966). He especially struggled with completing activities within a specified time frame. He found every day demands stressful and would display bizarre, disruptive and sometimes challenging and dangerous behaviour, which could range from 'pretending to be a tiger' to avoid written work to turning over furniture in a rage or using a stick or other sharp object as a weapon. The school then sought the support of the local advisory teacher for autism (CL).

Extreme Demand Avoidance assessment

The school contacted the advisory teacher who observed Jack's behaviours and, with input from his parents and the class teacher, completed the Extreme Demand Avoidance Questionnaire (EDAQ) (O'Nions,

Christie, Gould, Viding and Happé, 2013) as there was a feeling that interventions typically indicated for a child with autism and ADHD were unsuccessful. Although never designed as a diagnostic tool, the EDAQ is often used by educational professionals to indicate the presence of EDA in individuals with an autism diagnosis (O'Nions et al 2014). The questionnaire is simple to administer with most questions scoring between 0-3. The level indicating the presence of EDA for children of Primary School age is 50. Jack scored 57, putting him well above the cut off point. We sent the results along with notes we had made during observations to a paediatrician who subsequently diagnosed Jack with Autism Spectrum Condition (ASC). The descriptor 'Extreme Demand Avoidant (EDA) behaviours' was also added.

We were mindful of the fact that as yet EDA is not a recognised diagnosis. EDA (PDA as described in 2002 when the interview was developed) is however, included in the Diagnostic Interview for Social and Communication Disorder (DISCO, Wing et al, 2002). Clinicians who have had training within the last 5 years are aware of the condition and may include reference to either PDA or 'Extreme Demand Avoidance' within written behavioural descriptors, although this varies from area to area (O'Nions et al 2013). The paediatrician who added the EDA descriptor to Jack's diagnosis had this knowledge and worked closely with the advisory teacher and other professionals in line with the NICE Guidelines: 'Quality statement for a diagnostic assessment by an autism team' (NICE, 2014), to gain a full picture of his profile. Medical professionals widely acknowledge that children with ASC/ EDA require quite different management to those with more typical forms of autism so may be receptive to adding this behavioural descriptor (Gore-Langton et al, 2016).

Agencies involved in supporting Jack and the staff

During the work with Jack, we used the 'Assess, Plan, Do, Review' cycle, familiar to many special needs practitioners within education. We used our own notes made while working with Jack and had access to both educational and medical records, including his Education Health and Care Plan and the annual review documents. The advisory teacher had monthly

or termly contact over a 2 year period with Jack or his parents, teachers and support staff. The second author was Jack's class teacher and she had daily contact with Jack during term time for 2 academic years. They both also worked closely with Jack's parents and other family members and educational professionals such as teachers, teaching assistants and other support staff including behavioural support workers and the Special Needs Co-ordinator (SENCo). There was also contact with outside agencies such as Educational Psychologists, Speech and Language Therapists and Occupational Therapists. Behavioural data was recorded using Antecedent Behaviour Consequence (ABC) charts (Maag 1999) and written observations recorded by the TA and class teacher. This then fed in to the Consistent Behaviour Support Plan (CBSP).

Adjustments made to support Jack

Jack was provided with a quiet safe space and staff used EDA focused teaching styles, including the use of fantasy, humour and choice. Importantly, both school staff and parents fed into the CBSP (see *Appendix 1*) and participated in the meetings where details of its implementation were discussed. The plan has been regularly reviewed and as Jack is becoming older and more aware of his own need for self regulation, he is beginning to feed in to these meetings. All those involved understand the need for this 'consistently inconsistent approach', whereby the teaching style and the desired outcome can vary depending on Jack's stress levels. He is aware that all staff are working towards supporting his needs. His current success is due to the level of trust he has in the adults who work with him day to day.

The advisory teacher delivered Level 1 Autism Awareness Training, developed by the Autism Education Trust, to all staff. This training explained how autism can affect social communication and sensory processing. More focused training provided staff with a variety of strategies to overcome potential barriers to learning. The class teacher attended a specific Extreme Demand Avoidance course, which was written and delivered by the advisory teacher and an Educational Psychologist. During this course, the teacher developed a greater understanding of the

defining characteristics of EDA and the findings from research regarding the condition. Most importantly, the teacher learnt different strategies to support a child with EDA including, flexibility of approach, adjusting expectations and personalising the learning (Hylton, 2010). Humour, entering into his imaginary world and choice, seemed particularly effective for Jack.

Through working with the advisory teacher, the teacher began using Antecedent, Behaviour and Consequence charts (ABC, Maag 1999) to identify patterns in his behaviour. The most frequent situations which resulted in challenging behaviour were writing activities, changing between uniform and PE kit and working in groups without his particular friends. Using this information, and notes gathered from Jack's parents, a Consistent Behavioural Support Plan (CBSP – see *Appendix 1*) was developed to ensure a flexible, yet consistent, approach that would be used by all adults to support Jack in staying safe within school. The teacher then held a student clinic session with all members of staff in school, to introduce them to the CBSP. The CBSP provided clear and specific instructions, sentence starters and alternative strategies for adults when dealing with Jack, dependent on the arousal zone he was experiencing. Alongside the CBSP, a risk assessment was undertaken to ensure the safety of Jack, his peers and staff within the school environment.

In response to Jack's needs, the teacher introduced a number of strategies that would support him in staying safe in school and accessing the curriculum. A flexible approach was central to controlling the level of anxiety that Jack experiences. This includes adjusting the expectations upon him dependent on how he was feeling. Adults working with Jack completed continuous risk assessments which determined the expectations they have of him during each learning experience. The teacher and teaching assistant adapted the task, environment and content to support Jack in accessing the curriculum. He also needed to be close to his teacher to feel safe and closely involved in the day-to-day goings on in the classroom. Adults provided him with small choices throughout the day that gave him an element of control and helped to regulate his own anxiety. A consistent routine supported Jack in feeling

secure in school and jobs and responsibilities within the classroom provided a sense of achievement and control. When Jack began to feel anxious or frustrated, adults supported him by using non direct language that avoided placing a demand on him or offered a distraction to alleviate his anxiety. There was also a safe space where Jack could take himself and using different resources, toys and books, begin to calm down.

After any significant event, a restorative justice approach was used in the classroom that supported Jack in understanding the consequences of his behaviours, for which he often displayed remorse. In these circumstances, adults offered a choice of activities which allowed Jack to calm down before further conversation about the event could take place.

Restorative approaches involve reconciling students with the person they have hurt (eg a member of staff or another pupil) through the use of empathy and strong personal relationships, rather than through blame or shame (Hopkins, 2003) This approach was found to be effective with Jack because, like many individuals with EDA traits, he had a strong sense of moral justice and more developed social skills than children with other forms of autism. The strategies in place were reviewed every six to eight weeks, following the 'assess, plan, do, review' format. During these reviews, adults discussed Jack's behaviours, latest interests and the success of the strategies in place. This allowed all adults to be informed and up-to-date with best practice to ensure a consistent approach across Jack's school and home life.

Concluding comments

During the last year, Jack has been accessing the curriculum alongside his peers and has made great academic progress. He has not been excluded at all due to significantly reduced incidences of challenging behaviour. Jack was also voted pupil council representative by his peers, an important position with responsibilities that include the demands of attending meetings and feeding back information to his classmates. He was given the narrator role in his latest Christmas play, a part he desperately wanted the previous year but was unable to undertake due to his challenging behaviour.

Jack has secure friendships within his class and is now better able to cope during unstructured times, where previously he struggled. This is a real turn around and borne out of a real team effort with constant and regular reviews and conversations between teaching staff, Jack, his parents and other professionals. As is often said, it is the setting and the demands made that pose the greatest challenge to a child and if these are adjusted to address their individual needs and preferences, then the child is enabled to relax and learn and progress.

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Appendix 1: Behaviour Support Plan – Jack

To be read by all staff, the advisory teacher and parents.

Jack has an Education Health and Care Plan (EHCP) and a diagnosis Autism Spectrum Condition with Extreme Demand Avoidant Behaviours.

Communicate clearly, calmly and concisely.

Always use behaviour strategies that reflect Jack’s learning needs and refer to the risk assessment to reduce risk and ensure health and safety for both staff and student.

Green: Proactive: If Jack is in a positive mood and seems calm/ alert employ these tactics.	
Behaviour	Support
Jack may become excitable and joke with his friends.	Acknowledge his actions indirectly eg ‘You three seem to be having fun together.’
Jack is calmer outdoors than indoors eg Forest School.	Encourage fresh air at lunch and break time. Allow opportunities for outdoor learning where appropriate.
Jack requires regular movement in order to remain in a calm/alert state.	Encourage physical activity, such as walking, at least once a day.
Jack may wish to sit near to or assist the teacher during group/ whole class activities.	Give Jack a choice of two places near to the teacher. Give him a job to do like handing out the white boards and pens.
Jack may wish to work with one of his close friends during group/ pair work.	Allow Jack to have one close friend in his group.

Reactive: Amber – Active: If Jack is beginning to become distressed or agitated or overexcited use these tactics.	
Behaviour	Support
Jack may look at items (cards, comic, books) on his desk and become disengaged and drift off into his fantasy world.	Calmly suggest that he puts his cards/ comic or book away and try and re-engage him in the lesson using aspects of his fantasy play. Do not remove his items as this may escalate his behaviour. If appropriate, give him a small quiet sorting task such as tidying books or coloured pencils.
Jack may put his head down on the desk or put his coat on and pull his hood up over his face.	Allow him some time to rest and remain still. Use a continuous risk assessment to decide how long you give Jack in his space, before approaching him (estimate 5-10 minutes). Do not tell Jack how much time he has in his space as this may escalate his behaviour. Then approach him calmly and encourage him to re-engage in the lesson.
Jack may use fantasy as a reason why he cannot participate in required activity eg: "I can't get changed for PE as I'm a tiger and paws can't do buttons."	<p>Do not insist that Jack does as he is told as this will escalate his behaviour. Either: enter Jack's fantasy world "We are doing high jump today. I bet tigers are good at jumping"; use negotiation "Maybe today the tiger could just wear his trainers?"; or humour "Why did the tiger loose at monopoly? Because he was playing a cheetah!"</p> <p>Aim for Jack to participate in the activity at his own level given the situation and his level of arousal.</p>
Jack may ask to go to his safe space/ leave the classroom and go to sit there by choice.	Communicate to other staff in the classroom that Jack is in his safe space. Use a continuous risk assessment to decide how long you give Jack in his space before approaching him (estimate 5-10 minutes). Do not tell Jack how much time he has in his space as this may escalate his behaviour. Once this period has elapsed stand outside the safe space and say "I'm here Jack". Do not repeat yourself as this will escalate Jack's behaviour. Allow Jack to come out of his safe space and return to his desk. Do not talk to him until he speaks to you. Re-engage him in his work when he indicates that he is ready.
Jack may pretend to be angry but can't control moving into real anger.	Staff need to observe Jack closely and assess his behaviour. The sign that he is not angry is that Jack looks at TA's eyebrows and gives a half smile with the left hand corner of his mouth if he is not angry. Use de-escalation techniques including tactical ignoring, distraction or giving him a larger social space if you are not certain how he will react. He can then be brought into a calm state of mind by using humour. He is fond of knock-knock jokes. If he does not smile and uses his peripheral vision to look at the staff member, then he may be continuing into an angry frame of mind.
Jack may ask for food, eg crackers or a drink.	Allow him to go outside of the classroom or to a quiet area of the room away from other students and finish his crackers or drink.
Jack may make inappropriate comment or call out, eg "I don't give a **** about clouds."	Communicate calmly and clearly. Selectively ignore the language. Staff to walk away for 5–10 minutes. Give him time to calm and then ask another member of staff to swop in.
Jack may growl. He may put his head down and start flapping arms.	Ask Jack to take a message to another class or find another good reason for him to go for a walk. Use a continuous risk assessment to establish whether it is safe for Jack to go alone or whether he needs support from another pupil or a member of staff.

Red: Reactive – If Jack becomes highly excited or distressed and his behaviour becomes a danger to himself or others, use these tactics.	
Behaviour	Support
Jack may shout inappropriate or aggressive things. Jack may switch quickly between pretend anger and real anger (see Amber section).	Check whether anger is real or pretend (see Amber section). If anger is real communicate calmly, clearly and concisely . Ask him firmly to stop shouting. Do not enter into discussion. If he persists, encourage him to use his safe space within the class or go to the SEN room.
Jack may aim a pencil or other sharp object at an adult when aroused. Or Jack may swing wooden objects such as sticks or pieces of wood (see risk assessment to reduce risk).	Ask Jack calmly to put the object down. Move other students or staff away from him. If he continues and you judge it safe to do so, approach him and ask him to stop. Do not attempt to remove the object from his hands unless you have the appropriate positive handling training proscribed and licensed by the school. If you are trained and perceive that there is a risk to Jack use appropriate hand over hand guidance to remove the object and dispose of it. When you have done this encourage him to use his chill out card and go to his safe space or the SEN room.
Jack may throw or push over tables or chairs	Ask Jack to stop. Move other students or staff away from him. Observe Jack at a safe distance. When the incident is finished and you perceive it to be safe to do so, ask Jack to use his chill out card and go to his safe space or the SEN room
Jack may run away. (See risk assessment to reduce risk).	Allow him to leave. Do not chase him or stand in his way as this may escalate Jack's behaviour and cause danger. Report him missing to a member of the Senior Leadership Team. If you are able to follow him and it is safe and appropriate to do so, walk behind him at a safe distance. Remain silent and allow him time to calm down. Observe Jack at a safe distance. Call for a member of SLT
Jack may hit or kick wall, doors and glass windows. Jack may hit himself in the head.	Tell Jack calmly to 'stop' and wait until he does so. Do not intervene physically unless you have appropriate positive handling training and have assessed that there is a severe risk to the health and safety. Remain silent and allow him time to calm down. Observe Jack at a safe distance. Call for a member of SLT. Ask Jack to move to his safe space, or the SEN room.
Jack may find a large or dangerous unsafe object, eg a stick and bang it against a tree (see Risk Assessment) or may harm another student.	Tell Jack calmly, once to 'stop' and wait until he does so. Ask him calmly and concisely to put the object down. Remove the other child/ children to safety. Do not intervene physically unless you have appropriate positive handling training and have assessed that there is a severe risk to health and safety. Remain silent and allow him time to calm down. Observe Jack at a safe distance. Call for a member of SLT. Ask Jack to move to his safe space, or the SEN room.

Blue Post: Reactive – Use these tactics when Jack is calming down after a serious incident: This may take over one hour.

Behaviour (use student's name here in each statement)	Support
Jack may go into his safe space.	Allow to go into/remain in his safe space.
Jack may ask for food or a drink.	Allow two crackers and one glass of water.
Jack may ask to watch a calm video such as waterfalls, play Lego	Allow to play with Lego or watch the waterfall clips on his iPad.
Jack may ask to go for a walk. Jack may ask for time outside.	Allow to go for a walk. Ensure supervision at all times.
Jack may fall asleep.	Allow a short nap on the bean bag in his safe space. After 20 minutes say 'Jack I'm here'. Do not speak to him unless he speaks to you as this may escalate his behaviour.