

Extreme/‘pathological’ demand avoidance: an overview

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Abstract

Pathological demand avoidance (PDA) was coined in the 1980s to describe children on the spectrum of pervasive developmental disorders who show an obsessive resistance to everyday demands, an extreme need for control, and an apparently poor sense of social identity, pride, or shame. The term PDA has since attracted considerable interest and controversy. Here, we provide an overview of PDA, discuss the clinical presentation of individuals with a PDA profile, and differences compared to children with documented attachment difficulties. We then discuss empirical work describing how anxiety-driven avoidance of routine demands can emerge in children with ASD. We provide recommendations for strategies that aim to avoid strengthening habitual avoidance behaviours, and instead, allow new mutually rewarding routines to develop, which may provide opportunities to gradually increase the child’s tolerance of demands. We argue that using the PDA profile, or describing relevant behaviours, as part of a clinical formulation can be helpful in alerting caregivers and educational professionals to particular challenges surrounding compliance with everyday requests in some children with ASD.

Keywords autism spectrum disorder; child development disorders; neurodevelopmental disorder; pervasive developmental disorder

Background

Pathological demand avoidance (PDA) is the subject of increasing interest and debate in the UK. It was first coined by Elizabeth Newson in the 1980s to describe children on the spectrum of pervasive developmental disorders, who came to clinical attention because of their obsessive avoidance of

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everyday demands and requests. They used apparently ‘manipulative’ behaviour to avoid demands, resorting to acts that others would find shocking or outrageous. They also showed sudden changes in mood driven by a need for control; a lack of sense of social identity, pride, or shame; and a tendency to be comfortable in role play and pretend (e.g., adopting others’ styles as a coping strategy). Obsessions were also common, particularly obsessions with avoiding demands, and pre-occupations with other people. Other features were language delays and ‘neurological soft signs’, such as delays in reaching motor milestones. Strikingly, those described as having PDA were as often girls as boys.¹

Newson’s descriptions¹ reveal that children with this profile often experience severe challenges at home and school, meaning that families are desperate for help. If routine requests are pursued, the child’s anxiety may increase, leading to verbal or physical aggression, or threats to harm oneself or others. For many families, all activities revolve around accommodating the child’s requirements. Attempts to proactively manage situations to reduce meltdowns or aggressive outbursts, and thus ensure that the child can remain safely in the home, place an enormous burden on families.

In the UK, interest in PDA has increased rapidly over the last ten years, substantially outpacing research on the topic. Adults who identify as having PDA, parents of children with PDA, and young people, have been the driving force behind increasing awareness. These groups have authored books and articles based on their lived experience, which have much to offer. However, the lack of research on PDA presents challenges for clinicians, who have a limited evidence base to draw on. Here, we summarise existing research and draw on clinical experience in an attempt to address this gap.

PDA as a subgroup vs. PDA as a dimension

In her seminal work, Newson argued that PDA be considered a ‘subgroup’ within the spectrum of pervasive developmental disorders, also described as the autism spectrum. This was influenced in part by the narrow diagnostic criteria for autism in the 1980s. It also drew on Newson’s observations of differences in the profiles of children with PDA compared to more ‘prototypical’ autism; and her observation that recommended management for autism, such as routine and repetition, was unhelpful in those with PDA. Instead, strategies that were not rule-based, but instead used novelty to engage the child and distract from demands, were more successful.¹

Despite increasing acceptance that the PDA profile Newson described does exist in some children on the autism spectrum, the data that led to the proposal of PDA as a sub-group may have been influenced by the type of referrals that Newson’s specialist centre received, leading to a “collider bias”. Given the high threshold of severity required for assessment at the time, Newson likely assessed the most severe cases, both of ‘prototypical’ autism, and of PDA. This pattern means that milder presentations of ASD and PDA were unlikely to be present in her sample. Therefore, her data may over-estimate the degree to which PDA separates as a sub-group within the autism spectrum as we now know it. This does not imply that the profile Newson described does not exist, but rather there is likely a broader range of profiles: varying in severity of both ASD and PDA features.

Therefore, whilst some children may benefit from novelty and flexibility, others who present with demand avoidance may require routine-based approaches, with adaptations to reduce emotional reactivity.

At present, PDA is not included in the International Classification of Diseases (ICD-11), or the Diagnostic and Statistical Manual (DSM– 5). There is no agreed diagnostic algorithm to determine who should meet criteria, and no consensus about whether PDA is a good candidate for inclusion as a sub-category within ASD in the future. Recent research suggests that PDA features are on a continuum, and vary across individuals with ASD. Thinking about PDA or 'EDA' (Extreme Demand Avoidance) dimensionally is useful in drawing parallels with the wider international research literature on demand avoidance in ASD.

Despite continued debate surrounding PDA, there is increasing consensus that description of a PDA or EDA profile, or of relevant behaviours, as part of clinical formulation, can be helpful in alerting caregivers and educational professionals to these particular challenges. As we discuss below, the presence of PDA characteristics has implications for management. Unless avoidance of everyday demands, emotional reactivity, and their impact on day-to-day functioning are assessed, it is impossible to monitor the degree to which interventions are effective in managing them.

Understanding the nature of demand avoidance

Many (indeed most) children will display some behaviour that challenges and will attempt to avoid parental requests at some point during childhood. Children with autism, by the nature of their difficulties with social communication, tendency for rigid thinking and difficulty adapting to change, may be temperamentally pre-disposed to episodes of behaviour that challenges. However, there is often a clearly identifiable reason for their resistance to certain tasks. Difficulties with executive functions, working memory, and processing speed can present challenges in the classroom. Uncertainty about the outcome of a change of plan can cause anxiety and resistance. Likewise, children who have experienced developmental trauma in their early years can display behaviour that appears to be challenging as a result of a hyper-aroused sensory system.

For children with the PDA profile, there is often no clear reason for their distress in response to apparently innocuous requests. There is typically no history of trauma, at least not in the accepted sense of poor attachment/separation from a caregiver. The nature of demand avoidance in those with the PDA profile often appears illogical or counter-productive to an outsider: completing a simple task would require less effort than the distress and upset caused by avoiding it warrants. This avoidance has been described as 'pathological' because it does not appear to make logical sense, and it leads to severe disruption to the individual's everyday functioning.

Prevalence of PDA characteristics

Only one study so far has investigated the prevalence of PDA characteristics. This study, using population cohort data from the Faroe Islands, suggested that one in five children with ASD showed some indications of PDA, whilst one in 25 showed a profile very consistent with Newson's account of PDA.² Those

with indications of PDA spanned the full range of intellectual ability. Only one out of nine with indications of PDA in childhood would still have met criteria in late adolescence/early adulthood, although the study did not investigate whether other difficulties (e.g., internalising problems) became more prevalent.

These findings suggest that the PDA profile as Newson described it is relatively rare, but having some PDA features is relatively common in children with ASD. Evidence that, for many, these features remit with age is consistent with evidence from population studies of other profiles (e.g. ADHD), which suggest relatively low stability from childhood to adulthood. However, since only 4% of the ASD sample showed close resemblance to accounts of PDA, more work is needed to investigate stability in severe profiles.

PDA and its relationship to ASD

Gillberg and colleagues² note that, based on clinical experience, the PDA profile is much less common in the general population than in ASD, although it may occur in a few % of certain non-ASD populations, e.g., those with language disorder, selective mutism, or epilepsy. Indeed, certain behaviours characteristic of PDA increase the likelihood of meeting ASD criteria. Children with a PDA profile often present with social interaction difficulties, e.g., behaviour that peers find embarrassing or age-inappropriate, and also show considerable rigidity in their thinking, exemplified by their resistance to everyday demands and need for control.

In the international literature, there are many accounts of profiles resembling PDA, often described as ASD with co-occurring oppositional defiant disorder (ODD) or disruptive behaviour. We found that children reportedly identified by clinicians as having PDA were rated in the most affected 1% of their age group for peer problems, anxiety, and anti-social traits. However, we have argued that diagnosis of these difficulties as co-occurring ODD may be unhelpful, since demand avoidance in children with ASD is not necessarily defiance. Labelling it as such is potentially counter-productive in terms of how behaviours are understood and managed.

Clinical presentation

One of the study authors (JE) runs a clinic known for its awareness of the PDA profile, which receives a significant number of referrals of young people with these difficulties. The following criteria are used to identify a PDA profile in children with ASD:

- (1) Demand avoidance that has been present since early infancy and presented across contexts and time, often beginning with the child demonstrating reluctance to comply with daily tasks such as nappy (diaper) changes, being placed in a car seat, or being fed by someone else. Once the child is mobile, there is often extreme resistance to walking with parents as requested when outdoors or to following basic requests, such as to tidy up or take a bath;
- (2) Features of demand avoidance are noted in the child during the assessment process;
- (3) Avoidance is pervasive and often seems illogical or perverse (e.g. the child may be unable to eat when hungry, if requested to do so) and causes significant disruption to daily activities,

which leads to parents/caregivers needing to go to great lengths to manage any demand;

- (4) Avoidance is not limited to a specific activity (or activities) in a specific context (e.g., reluctance to attend school or complete homework, for example).

A key point to note when beginning any assessment is that many children with a PDA profile ‘mask’ or camouflage their social difficulties, at least in the initial part of the appointment. The ‘surface sociability’ described by Newson is a genuine phenomenon and can distract from the true extent of their difficulties. Many children adopt ‘socially manipulative’ approaches, which might be better described as ‘socially strategic’, and may include the child asking if the assessor has had a nice day, or beginning to talk about something that has happened to them. ‘Socially strategic’ approaches often lack subtlety (e.g. breaking one’s glasses to avoid homework), contrasting markedly with sophisticated and successful manipulation for personal gain characteristic of individuals with callous-unemotional traits. It is important to appreciate that these social approaches are often quite superficial, and frequently scripted. They lack depth and cannot be maintained in the longer term.

This can present a significant challenge to clinicians who only have a short period of time in which to assess a child. More oppositional behaviour only tends to become apparent when the child is pushed, even gently, to comply with demands. Children then often begin to make excuses, which increase in intensity as time goes on. These can range from simple excuses such as ‘I feel sick’ or ‘my legs don’t work’, to more imaginative ones such as ‘I can’t possibly; I’m Mr Platypus and platypus’ don’t talk’ or ‘I can’t do that because the Government has raised the terror threat to critical’. Some may use more subtle avoidance tactics such as talking excessively to leave no space for further questions, suggesting that the clinician carries out the task instead of them, or attempting to distract by pointing out something in the room. If the demand is not removed, the child can quickly escalate to more extreme avoidance, such as prostrating themselves on the floor, deliberately urinating or making themselves vomit, running out of the room, or throwing (or threatening to throw) items in the room.

Clinical assessment and necessary adaptations

For clinicians using structured tools such as the ADOS-2, it is often necessary to adapt the assessment considerably. Children presenting with the PDA profile often attempt to direct the clinician where to sit, how to administer the assessment, and even what they should say. Attempts to counter this, impose boundaries, or insist upon a hierarchical adult-led approach frequently lead to a rapid deterioration in co-operation and behaviour. Instead, clinicians need to use humour, offer choices, or express a need for help, thus shifting the perceived power balance and allowing the assessment to continue.

Even with adaptations, behaviour typically deteriorates over the course of an assessment. In a recent study³ this difference in interaction style resulted in significantly different scores on the ADOS-2. For example, the item entitled ‘Quality of Social Response’ gives the following description of the type of interaction warranting a score of 2: ‘Odd, stereotyped responses, or responses that are restricted in range or inappropriate to the

context’. For a score of 3, the description is: ‘Minimal or no response to the examiners’ attempts to engage the participant’. Children deemed to have the PDA profile received significantly more scores of 3 on this, and similar, items, compared to ASD children without a PDA profile.

Differential diagnosis

Challenging and dysregulated behaviour, including difficulties with self-regulation, is frequently seen in children who have experienced a traumatic or disrupted early history. This can lead to challenges for clinicians in determining whether the child’s behaviour fits the PDA profile or whether their difficulties can be better formulated using an attachment framework. The Eaton and Weaver study³ found that characteristics described in **Box 1** were observed and reported significantly more frequently in children with ASD with a PDA profile vs. children with documented early attachment difficulties typically associated with abuse, neglect, or trauma, who did not have ASD.

A formulation for demand avoidance in ASD

In her seminal work, Newson argued that avoidance was driven by the child’s need to reduce anxiety and distress triggered by real or anticipated demands. The wider research literature on ASD suggests that anxiety is indeed often a driver of avoidance in ASD. Work by Lucyshyn and colleagues⁴, in which they video-recorded problematic home routines, revealed heightened emotional arousal and distress when the child tried to avoid or escape demands, leading the authors to conclude that everyday demands trigger anxiety in some children with ASD.

Numerous factors may underpin anxiety or distress triggered by demands and expectations in children with a PDA profile. Parents describe that, for some children, a strong need for control was evident from infancy. Many children with the PDA profile also experience significant sensory processing difficulties, impacting their ability to self-regulate. Other factors include fears and phobias, intolerance of uncertainty, and poor understanding and acceptance of social hierarchy, which may make demands seem unfair and thus more aversive.

Work by Lucyshyn and colleagues also provides a framework to understand why habitual patterns of avoidance develop that become very resistant to change. Avoidance behaviour that leads

Characteristics observed and reported more frequently in children ASD plus PDA profile vs. children with attachment difficulties without ASD³

- Obsessively resists/avoids ordinary demands
- Superficial/surface sociability
- Seemingly manipulative behaviour
- Elaborate excuses
- Sabotaging (the child apparently deliberately spoiling an event that s/he had been looking forward to)
- Dominating or bossy towards peers
- Rapid, inexplicable changes in mood
- Comfortable in role play
- Ineffectiveness of traditional reward and consequence-based parenting strategies

Box 1

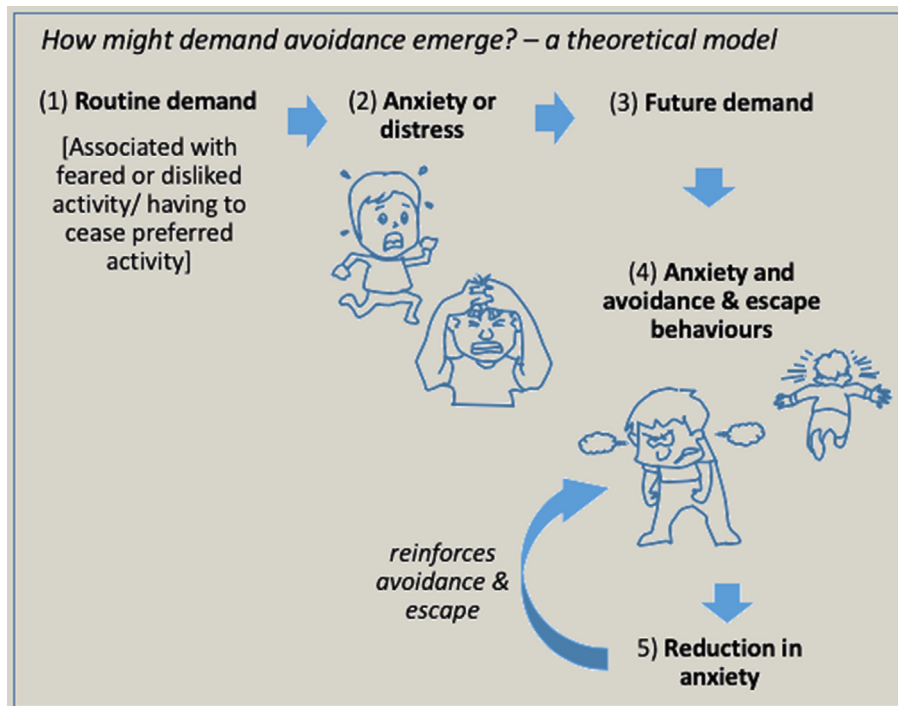


Figure 1 Theoretical model of the development of habitual avoidance. Reproduced from O’Nions, E, Child behaviour and parenting strategies - a research update (<https://lizonions.files.wordpress.com/2019/09/1909childbehaviourparentingstrategiessummary.pdf>).

to delay or withdrawal of demands is reinforced by the reduction in anxiety that the child then experiences.⁴ This increases the likelihood of avoidance in response to future demands. Over many repetitions, avoidance can become a habit (see Figure 1), which may be triggered by any external request. Research has shown that once established, habits are not easily changed by altering the outcomes associated with the behaviour that has already become habitual (e.g., by offering rewards or threatening punishments).

Work by Lucyshyn and colleagues⁴ sheds light on why punishments are reportedly counterproductive in children with a PDA profile. Punishment, or threat of punishment in the context of a distressing demand is likely to increase the anxiety and distress associated with it, and increase the child’s motivation to escape. Contingent rewards evoke distress in some children by emphasising adult authority, and provoking conflicting feelings between wanting the reward and needing to avoid the demand. By increasing the aversiveness of the situation, these approaches can increase the strength of the reinforcement that the child receives when delaying or escaping a demand, and thus increase, rather than decrease, the likelihood of future avoidance.

Blocking attempts to escape an anxiety-inducing demand by threat of punishment may also have negative effects on the child’s mental health, since this leaves the child with no means to escape the aversive situation and reduce their anxiety. This may lead to escalation or shut-down, which over repeated episodes may induce ‘learned helplessness’. It might also lead the child to fear and resist any interactions where they expect demands, leading to chronic irritability and social withdrawal.

Family experiences

The experience of raising a child with the PDA profile varies depending on the family make-up and family dynamics. Families

with only one child typically adapt their parenting to meet the needs of their child. The clinical picture is often of an infant described as ‘difficult’ or less socially motivated than a typically-developing child, resulting in gradual withdrawal from social activities and the child becoming increasingly socially isolated, with many refusing school or nursery, as well as apparently pleasurable social activities. Early on, the child may begin to display extreme dysregulation and ‘meltdowns’ lasting for many hours, which frequently involve destructive behaviour or aggression towards the caregiver when faced with any demands. This quickly leads to compromise and adaptations to the parenting style. Parents are often shocked when they realise how much their everyday behaviour is shaped to and determined by their child’s demands.

In families where there is more than one child, this is much harder to accommodate. Frequently, these are experienced parents who have successfully raised other children. All strategies they have previously used are tried, and quickly fail. Ultimately, parents may approach their GP and request a referral to their community paediatrician or local CAMHS team. Once they receive an appointment, many experience criticism of their parenting and an often immediate assumption that the child has attachment difficulties. This leaves parents feeling confused, blamed, and ultimately let down. They are frequently sent on multiple parenting courses and offered no targeted support. In some cases, this can lead to family breakdown and mental health difficulties for parents who find it impossible to live a normal life and provide their other children with the social and leisure opportunities they want and deserve.

Although anxiety plays a role in avoidance, observations by Lucyshyn and colleagues⁴ suggest that problem behaviour in children with ASD can also be motivated and reinforced by need

for attention or provision of desired activities. In a few cases, parents find themselves going to enormous lengths to meet their child's every requirement, finding that opposing the child results in an escalation of the child's attempts to exert control. It is easy to criticize parents for giving in to the child in this situation, however, those who are trying to work, raise other children, and live in close proximity to neighbours, often find no alternative.

Support strategies for parents

Parental reports³ suggest that traditional parenting strategies involving clear, unequivocal boundaries and contingency-based reward systems imposed on the child often do not work. Some parents reported that following advice given during parenting courses had actually made their child's difficulties worse. What appears more effective is a low demand, low arousal approach, which tries to avoid strengthening habitual patterns of avoidance and escalating emotional reactivity. This allows new mutually rewarding routines to develop, presenting opportunities to gradually increase the child's tolerance for demands and things not being on their terms.

Management strategies that many parents report finding helpful include establishing some non-negotiable boundaries, but granting the child a certain degree of autonomy, placing less importance on absolute compliance with demands, and 'picking battles' carefully. Strategies to reduce the likelihood of triggering avoidance include minimising direct instructions by using indirect language or non-verbal cues, framing demands as a challenge, or inviting the child to choose which activities they will complete from a list. Adjusting expectations proactively based on the child's anxiety levels can also reduce the likelihood of confrontation. Other approaches include reducing the aversiveness of demands or non-preferred activities with humour, or by developing positive rapport, embedding playful interaction, or including activities that the child enjoys. Some children reportedly benefit from visual schedules to enhance predictability, and mutually agreed-upon rewards.

These approaches can be difficult for families with more than one child, as they require considerable effort, and render a consistent family-wide approach almost impossible. However, if demand avoidance is seen in the context of anxiety, any approach that allows the child to self-regulate has to be more beneficial than forced compliance, meltdown, and loss of self-esteem. Work by experts in parenting interventions suggests that supporting parents to consider their own and their child's behaviour non-judgementally, to recognize and distance themselves from their own negative emotions, and to develop parenting goals accompanied by action plans, can help parents to identify effective strategies.

It is helpful to remember that children with a PDA profile are not deliberately difficult. If the socially strategic behaviour is seen for what it is – a scripted and limited strategy for ensuring predictability and control, rather than labelled as 'manipulative', the child's behaviour can be reframed in a more compassionate way. More research is needed to examine what works best to support these young people and their families in achieving greater wellbeing and quality of life. ◆

REFERENCES

- 1 Newson E, Le Maréchal K, David C. Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders. *Arch Dis Child* 2003; **88**: 595–600.
- 2 Gillberg C, Gillberg IC, Thompson L, Biskupsto R, Billstedt E. Extreme ("pathological") demand avoidance in autism: a general population study in the Faroe Islands. *Eur Child Adolesc Psychiatr* 2015; **24**: 979–84.
- 3 J. Eaton, K. Weaver, An exploration of the Pathological (or Extreme) Demand Avoidant profile in children referred for an autism diagnostic assessment using data from ADOS-2 assessments and from their developmental histories. *Good Autism Pract.* in press.
- 4 Lucyshyn JM, Irvin LK, Blumberg ER, Laverty R, Horner RH, Sprague J R. Validating the Construct of Coercion in Family Routines: Expanding the Unit of Analysis in Behavioral Assessment with Families of Children with Developmental Disabilities. *Res Pract Persons Severe Disabl.* 2004; **29**: 104–21.

FURTHER READING

- Christie P, Duncan M, Healy Z, Fidler R. Understanding pathological demand avoidance syndrome in children. London: Jessica Kingsley Publishers, 2012.
- Lucyshyn JM, Fossett B, Bakeman R, et al. Transforming parent-child interaction in family routines: longitudinal analysis with families of children with developmental disabilities. *J Child Fam Stud* 2015; **24**(12): 3526–41.
- Dumas JE. Mindfulness-based parent training: strategies to lessen the grip of automaticity in families with disruptive children. *J Clin Child Adolesc Psychol* 2005; **34**: 779–91.
- Eaton J. A guide to mental health issues in girls and young women on the autism spectrum: diagnosis, intervention and family support. London: Jessica Kingsley Publishers, 2017.
- O'Nions E, Viding E, Floyd C, et al. Dimensions of difficulty in children reported to have an autism spectrum diagnosis and features of extreme/'pathological' demand avoidance. *Child Adolesc Ment Health* 2018; **23**: 220–7.

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Practice points

- Some children with ASD show characteristics of PDA, including obsessive avoidance of everyday demands, and an extreme need for control
- Families often adjust by altering their routines to accommodate their child's difficulties
- Parents often report that rewards and punishments do not work
- Low demand, low arousal approaches that avoid strengthening habitual avoidance can be helpful in developing new more positive routines