Here, we would like to give you an update on preliminary findings from the Child Behaviour and Parenting Strategies study, led by Dr Liz O’Nions, Prof. Ilse Noens (KU Leuven, Belgium) and Prof. Francesca Happé (King’s College London, UK). More findings will be available in due course, once the research papers have been submitted to academic journals.

The Child Behaviour and Parenting Strategies study was designed to investigate links between child behaviour and parenting strategies, as well as many other factors, with a particular focus on children with developmental disabilities such as autism spectrum disorder (ASD).

We invited parents/carers of any child aged 6 – 16 to take part in the study, by completing electronic questionnaires on a range of topics. The vast majority of parents who took part were living in the UK (97%) with children with ASD or significant traits of ASD.

Many parents also reported that their child also had difficulties complying with demands and requests, and became distressed or irritable very easily. This summary will focus on these profiles, and in particular, the concept of extreme/’pathological’ demand avoidance.

We first became interested in ‘demand avoidant’ children when Lorna Wing and Judith Gould told Francesca Happé about young people they were seeing who, in their view, were the hardest to help or teach.

These children were often excluded even from expert autism settings, enjoyed role play and fantasy, and were as likely to be girls as boys. What appeared to be different about them was that the usual ASD approaches were said to fail.

When our research began, there was only one paper on these ‘demand avoidant’ children published in a clinical/research journal, despite huge parental concern in the UK:

“These kids are just astonishing. The combination of difficulties is very hard for people to understand and the lack of support, once all the usual behavioural approaches are tried and have failed, is really soul-destroying.”

- parent of boy aged 6.
Extreme/ ‘pathological’ demand avoidance (PDA) was initially described in the 1980s by Elizabeth Newson (University of Nottingham). Key features included an obsessive avoidance of routine demands, manipulative or outrageous behaviour if demands were pursued, sudden changes in mood (attributed to need for control), and outbursts, meltdowns, aggression and dangerous behaviour. Newson’s descriptions and our previous study findings reveal just how problematic these behaviours can be. Everyday requests initially elicit a range of mild avoidance strategies (e.g. excuses, attempts to negotiate, arguing, ignoring). If they are pursued, behaviour became more extreme:

- “Having to get ready for school, she would hit, bite or shout, or use more passive behaviour such as complaining that her legs ached" - parent of girl aged 9.

- “He didn’t want to do the work so he pushed out the lens of his glasses so he couldn’t wear them any longer”. - parent of boy aged 13

- “If she gets a group of people together in a room, she acts like a very strict teacher, telling people off and to be quiet” - parent of girl aged 16

Some children also seemed to lack an awareness of their place in the social hierarchy, and had a sense that they were ‘on a par’ with teachers and other adults:

- “Although we explained to her that children were not allowed to sit there [emergency seat on aircraft], she still believed that she should be exempt from this as she wasn’t a child”. - parent of girl aged 10.

Parents’ concerns about their child’s behaviour are evident in their responses to questionnaires measuring levels of problem behaviour relative to children of the same age. In one study, those who had been identified by clinicians as showing PDA were in the most affected 1% of their age group for peer problems, symptoms, anxiety, and anti-social behaviour or “conduct problems”.

Preliminary work with observations of children with ASD and PDA features suggests that low-level avoidance (e.g. delaying, ignoring, making excuses) was relatively common during semi-structured interactions that formed part of our research protocol. More severe problem behaviour was less common.

This suggests that other methods may be needed to measure severe behaviour for clinical purposes. Indeed, in research or clinical settings, it would be unethical to push a child to comply with something to the point where they become acutely resistant or resort to serious problem behaviour.

When Newson came up with the concept of PDA in the 1980s, she considered it a separate ‘subgroup’ from autism, though still part of the spectrum of pervasive developmental disorders.

When Newson’s work on PDA began, the criteria for autism were very narrow, and only a fraction of those who now have a diagnosis of ASD would have qualified. Since those who Newson considered to show PDA wouldn’t have met criteria for autism, Newson...
proposed PDA as a separate diagnosis.

Since then, the criteria for autism have widened a great deal. Increasingly, the term ‘ASD’ is used, reflecting awareness that many different presentations form part of the autism spectrum.

Nowadays, clinicians would often diagnose ASD in children who display PDA features alongside problems in social interaction and communication, and rigid and repetitive behaviours and interests.

In our current study, around 92% of children whose diagnosis mentioned PDA or who had PDA features also had a diagnosis of ASD, or traits indicative of an ASD according to their parents. However, since our sample was recruited from particular sources (parent networks and support groups with a focus on ASD, developmental disabilities or PDA), ours is not a ‘random sample’. This means that it is unlikely to reflect the real degree of overlap of these traits in the general population.

**SUB-GROUP OR CONTINUUM?**

Whilst Newson thought of PDA as a ‘sub-group’, recent research suggests that PDA features are in fact on a continuum, meaning that relevant traits and behaviours vary across individuals with ASD, and also occur in those who don’t meet the threshold for an ASD diagnosis. The data also suggest that there is no natural cut-point that designates who should and shouldn’t meet criteria for PDA. Therefore, we are increasingly thinking of PDA as a continuum instead of a sub-category. With more sensitive measures capable of capturing specific developmental profiles, it may be possible to identify sub-groups within a broader dimension of extreme demand avoidance.7

Some critics of PDA have argued that PDA features are simply part and parcel of ASD. This implies that they have the same underlying cause as ASD symptoms. However, data from children with ASD and problem behaviour in the United States suggests that the severity of resistance to demands and irritability are more strongly related to each other than to the severity of the child’s ASD symptoms8.

This implies that behaviours central to the concept of PDA – resistance to demands, and sudden changes in mood – are more than simply a reflection of how severe the child’s ASD is. Instead, it seems likely that other factors interact with ASD characteristics to influence the development of these behaviours.

**PARENT POWER**

In the UK, PDA adults, parents, and more recently, young people identifying as PDA have been the driving force behind increasing awareness of PDA. This shift has happened very rapidly in the last ten years, and, as we will describe later, has been enormously helpful for many parents whose children display this profile.

However, at present, PDA is not included in the International Classification of Diseases (ICD-11), or the Diagnostic and Statistical Manual (DSM-5). These are the official diagnostic manuals that list clinical diagnoses and the criteria required to make them, based on international agreement.

This means that, at present, there is no diagnostic algorithm to determine who should and shouldn’t meet criteria for PDA, and no consensus about whether PDA would be a good candidate for inclusion at some point.

In order to be considered for diagnostic manuals, it is important that a concept has been thoroughly researched. However, at present, PDA has an extremely small research base.

Most of the research to date has been with volunteer samples: parents and families who are extremely dedicated to helping their child. Therefore, the current research on PDA also doesn’t represent everyone who is referred for clinical assessment.
Given its lack of official status, clinical professionals are often hesitant to use PDA during diagnosis. However, some are willing to acknowledge ‘PDA features’ or a ‘PDA profile’ when they come across children with this presentation, recognising that this can help families to understand their child and inform others about their difficulties.

Clinicians who are not comfortable with the term PDA may be willing to describe ‘demand avoidance behaviours’ or simply mention behaviours that form part of the profile in diagnostic reports. This can also be helpful as a signpost to those involved in the child’s care.

We think that increasing acknowledgement of behaviours described in PDA is an encouraging development, since it reflects research showing that some children with ASD really do show these characteristics, and as a result, experience considerable distress.

Much of this work comes from researchers who may not even have heard of the term PDA. Indeed, both historically and currently, many different descriptions have been used for children with these difficulties. In the next section, we will move on to thinking about what might be the drivers of these patterns of behaviour, and how they might develop.

In psychology, the term ‘formulation’ broadly means a ‘working theory’ of what is happening or has happened at a psychological level to impact an individual’s thoughts or behaviours, taking into account interactions between the individual and their experiences.

Elizabeth Newson, who came up with the concept of PDA, believed that avoidance behaviours were driven by the child’s need to reduce the anxiety triggered by real or anticipated demands. Indeed, other research suggests that challenging behaviour and avoidance/escape are perceived by parents as the most common presentations of anxiety in ASD. Sometimes, this may not be obvious to those who don’t know the child well:

“[His] distress does not stop when he had the desired result. Also destroying property seems deliberate but at that point he has lost control and is acting on impulse.”
- parent of boy aged 8.

Evidence that avoidance of demands in ASD can reflect anxiety is not only based on parents’ opinions. Work by Lucyshyn and colleagues from the University of British Columbia and the University of Oregon involved videoing problematic home routines in children with ASD who had difficulty during everyday tasks. They observed heightened emotional arousal and signs of distress when trying to avoid or escape parental demands.

Other clinical studies using behavioural analysis approaches mention desire to escape and avoid demands as a driver of various forms of problem behaviour (e.g. self-injury) in children with ASD and other developmental disabilities.
Sample characteristics – Child Behaviour and Parenting Strategies Study

Child characteristics (N = 363)

- ASD + PDA/EDA features
- ASD only
- EDA only

Child gender

- Male
- Female
- Other/complex gender identity

Note: ASD refers to reported diagnosis or traits above threshold

School type

- Mainstream
- Special school/alternative provision
- Unit in mainstream
- Home-educated
- Not currently enrolled
- Other

Estimated ability level

- Similar to mainstream peers
- Similar to mainstream + specific difficulties
- Slightly behind
- Markedly behind
- Very far behind

Independence in daily living activities

- Similar to or ahead of peers
- Needs a bit more help
- Needs a lot more help
- Completely dependent on caregivers for daily living tasks
Lots of things can make complying with demands difficult for children with ASD. Possible factors (some of which have been mentioned by a range of authors, e.g. 9, 15, 18–20), include the following:

1. **Intolerance of uncertainty/need for predictability:** Problem behaviour may occur if there is an unexpected change, something is different from how it should be, or the child needs to enter a chaotic or unpredictable environment.

2. **Difficulty reading intentions:** The child may not infer that demands are motivated by a desire to help them, or are considered by parents to be in their best interest. Instead they may assume that parents are trying to upset them by encouraging them to do something they dislike, provoking distress.

3. **Sensory sensitivities:** Part of a demand, e.g. having to eat certain foods or washing, may be severely unpleasant or distressing for the child.

4. **Fears and phobias:** Certain activities e.g. leaving the house can be a source of anxiety, if this increases the chance of encountering feared stimuli.

5. **Problems regulating emotional response:** If the child has greater emotional instability, there is more chance that mildly unpleasant events will be very upsetting, and the child will have more difficulty tolerating ‘normal’ frustrations e.g. transitions from preferred to disliked activities.

6. **Problems learning from experience:** This can cause the child to make the same mistake repeatedly, resulting in high levels of frustration.

7. **Reduced internalisation of social norms or expectations:** If the child does not internalize social norms, there is less intrinsic motivation to comply with rules or expectations.

8. **Feeling that they are adults too/sense of fairness and equality:** If the child perceives themselves as ‘on a par’ with adults and people in authority, they may see the imposition of rules and restrictions that they disagree with as unfair, provoking anger or distress. This mechanism has been particularly mentioned in the context of accounts of PDA.

Many everyday demands are mildly unpleasant for any child (e.g. moving from a self-chosen activity to a routine task). However, young children quickly learn that complying leads to praise and positive attention, whereas refusing to comply or breaking rules results in negative attention (e.g. being told off) or parental disappointment.

In neurotypical children, interactions with caregivers surrounding demands are thought to foster the self-concept of being a ‘good child’; the child naturally picks up and values how others view them. Maintaining reputation and self-concept by attracting positive attention/avoiding negative attention, is a motivating factor to comply with requests, even when they are not being supervised.

However, if the child has a delay in developing awareness of others’ perspectives (often the case for children with ASD), this process may fail. As a result, the child may appear wilfully defiant, when in fact, their brain is processing situations involving demands or expectations differently.

In line with this idea, there is evidence that parents of children with ASD use concrete rewards at a younger age than is the case for typically developing children. Parents also continue to use positive strategies when the child is older than in typical development. These more direct forms of reinforcement may be helpful in getting children and young people with ASD to comply and conform.

Intriguingly, these are precisely the strategies that we are told work less reliably for children with a PDA profile compared to others on the spectrum. In the next section, we will...
consider what factors might explain this.

**Emergence of Avoidance**

To try to understand how avoidance of demands might become more frequent and severe in some children resulting in a profile resembling accounts of PDA, we have come up with a theoretical model informed by work on the development of phobias, and other work on anxiety-driven non-compliance in ASD\(^6\) (see next page).

Before explaining our model, we should highlight that it is only one possible account, which attempts to describe behaviour where avoidance is driven by anxiety. It is possible that other factors, such as failing to accept the demand, may also lead to avoidance without anxiety.

Based on our model, we predict that, once anxiety has been triggered by a demand or perceived pressure to conform, attempts to persuade the child to comply by being strict, threatening consequences or offering rewards contingent on complying run the risk of increasing distress.

This is because increasing pressure to comply may increase the child’s anxiety, and as a result, increase their motivation to escape demands. This could both intensify avoidance behaviours and make it more likely that demands provoke avoidance in the future.

Over time, avoidance may become a habit - an automatic response cued by any demands that elicit anxiety, or even anticipated or self-imposed demands\(^23\). Over repeated episodes, this may get triggered by a wider range of stimuli, such as parental comments, or contextual cues signaling imminent demands. In extreme cases, this could lead to chronic anxiety or irritability.

**Consequences**

Traditional approaches to reducing problem behaviour often suggest use of consequences as a disincetive. However, consequences may be problematic in the context of high anxiety. This is mentioned in the research literature on behavioural management approaches in children with developmental disabilities\(^26\):

> “consequence-based manipulations [...] can reduce problem behaviors maintained by escape and avoidance but do not reduce the aversive properties of the environment. Thus, the individual is left in an aversive environment with no functional response.”\(^26\) (Brewer et al. 2014, p. 118).

This suggests that, if the child is in a state of distress, imposing consequences for problem behaviour may leave them with no means to escape or reduce their anxiety.

As a result, they may escalate (e.g. engage in more extreme behavior), or shut down and become passive (e.g. refuse to leave their bedroom, refuse to get up from the floor all day at school). Over repeated episodes, this may lead to a state of profound distress and ‘learned helplessness’.

**Feedback on Our Model**

We asked parents for feedback on our model. Whilst some parents found the model to be helpful and accurate, others felt that their child had displayed a strong need for control that was evident from infancy.

We agree that it is possible that demand avoidance could emerge through a different route than what we have described. Indeed, it is likely that different developmental processes might operate for different children, meaning that there may be no one explanation for how a profile resembling PDA could emerge.
**How might demand avoidance emerge? – a theoretical model**

1. **Routine demand**
   [Associated with feared or disliked activity/ having to cease preferred activity]

2. **Anxiety or distress**

3. **Future demand**

4. **Anxiety and avoidance & escape behaviours**

5. **Reduction in anxiety**

**Habit formation in the development of demand avoidance:**

- **Cue** → **Activity** → **Reinforcement**

- **Demand** → **Avoidance/escape** → **Reduced anxiety**
**DIFFICULT EXPERIENCES**

So far, we have considered how everyday experiences might have a part to play in the development of avoidance behaviours. Much of what we have considered describes possible responses to very typical parenting strategies, which could be counterproductive in certain contexts (i.e. if the child’s anxiety is extremely high). In addition, we should recognise that parents are constrained by their wider environments (e.g. work demands, other caring responsibilities), so it is very much to be expected that some conflicts would be unavoidable.

As part of our research questionnaire, we also asked parents about their child’s difficult or traumatic experiences, which may also have impacted their anxiety.

Approximately one quarter of parents reported that their child had experienced a serious/traumatic event or experience, unrelated to their difficulties, with a lasting impact (e.g. bereavement, house moves, accidents). Forty-one percent of parents reported a traumatic event that was secondary to or related to their child’s difficulties.

Approximately 17% of parents felt that their child’s school experiences had been traumatic - including victimisation, lack of support, bullying by peers, and inappropriate strategies employed by the school to manage anxiety or non-compliance⁵:

“He was fine in reception and year one at mainstream school [...] In year 2 he had a teacher who said "I am going to break him of this" - meaning his demand avoidance (we had not heard of PDA then). She punished our son and was generally very strict with him and by the end of the year he was having meltdowns/panic attacks, throwing furniture, assaulting teachers, running out and had gone from needing no support at school to needing round the clock 1:1 support and a Statement.”
- parent of boy aged 12.

In particular, parents also reported that imposing more control in response to challenging behaviour had backfired:

“My son had many traumatic experiences in school settings from the outset. The strategies recommended in mainstream [...] exacerbated his anxiety levels further by imposing more and more control, isolation from peers, insistence on completing repetitive activities beneath his abilities that he could not tolerate. This led to regular meltdowns in which he would damage property and buildings and attack teachers or assistants. [...] His current school is very different but he still really struggles to attend as a result of his early experiences.”
- parent of boy aged 14.

Restraint or physical interventions used when the child is attempting to flee a threatening stimulus (e.g. a highly aversive demand) may be particularly problematic. Around 5% of parents felt that restraint, confinement or physical intervention when their child was experiencing severe distress had made their problems worse. This was most often reported in school settings, but also in the context of medical procedures⁶:

“I believe that her early years at school were processed as traumatic. She has a fear of teachers and suffered flashbacks and panic attacks following an incident that resulted in her being physically restrained. Attempting to transition back into school, following a three year period of home ed, has resulted in a major and long lasting set back re her mental health including self-harm with blades.”
- parent of girl aged 14.

These examples highlight the pressing need for staff in schools (in particular, in mainstream settings) to receive more training on managing behaviours that reflect anxiety and distress in children with ASD. In addition, increased access to educational settings that are equipped to manage difficulties pre-emptively are vital to reduce acute episodes, where restraint may be unavoidable for safety reasons.
Notably, difficult experiences weren’t confined to school. Victimisation, bullying, assault or abuse in the community in general (including by peers, or members of the public) were reported by approximately 9% of parents. Around 6% reported experiences such as neglect, abuse or witnessing domestic abuse, and a further 2% of children had been fostered/adopted.

Other traumatic experiences included distress surrounding medical conditions or their treatment, and excessive reactivity to apparently minor events. Some parents reported that the child experienced their own reactions as traumatic:

“She has been in a number of public situations where she has frozen and has been unable to move due to anxiety - she is fearful that this will happen again which has had a dramatic impact.”
- parent of girl aged 6.

A few parents also reported that their child limited their difficult behaviour to one context:

“A lot of the questions [in the research questionnaire] would merit a very different scaled score dependant on the location. e.g. in home or at school. He will suppress and contain his anxiety and emotional state until home, whereupon he will vent his anger mainly on his mother. He will even whisper to her, “I am going to fight you when we get home mummy”, and appear fine, until home.”
- parent of boy aged 8.

More research is needed on masking and context-specific presentations, where internalisation of distress may provoke a build-up of anxiety over time.

**ADAPTED PARENTING**

 Whilst overt signs of distress that were common in our sample are easy to spot, some parents noted that their children were much less expressive. This made it difficult to determine their emotional state and the possible impact of stressors:

“Our daughter has always been highly anxious, we believe this is due to her PDA (which is described in her ASC diagnosis), so what might seem minor events to us can be traumatic to her, but she also masks, so this [is] hard to assess.”
- parent of girl aged 6.

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Parents often reported using ‘natural consequences’. This type of consequence follows logically from the child’s action, e.g. an argument leading to a delay in leaving the house leading to missing an activity. Rather than a punishment, parents conceptualized these more as a learning opportunity. Since they follow logically, they do not represent an imposed parental agenda, as is typically the case with other types of consequence.

“Traditional behaviour management strategies do work sometimes however my son will seek to manipulate and control and negotiate which makes things difficult and mean that it takes superhuman effort on the part of the adult to manage the situation.”
– parent of boy aged 9.

**MASKING**

In our study, parents gave detailed accounts of how they had altered their approach to managing their child to reduce meltdowns and boost wellbeing. Many parents reported managing anxiety pre-emptively by avoiding use of consequences, recognising that extreme reactions were a reflection of anxiety:

“We do not use consequences [...] we used to [e.g.] naughty step, taking things away, go to your room etc.) but they just caused meltdowns and made the problem worse and worse until we realised all our sons behaviour was a result of anxiety and that punishment made anxiety worse and so we stopped all consequences except natural ones.”
- parent of boy aged 12.

When the child’s anxiety levels were low, some parents did use consequences, though these could be difficult to implement:

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The importance of de-escalation rather than discipline in the context of distress was evident in how parents reported managing acute episodes. Parents' descriptions often resembled accounts of 'low arousal techniques'27:

“We have learned by experience not to put demands on him if he is exhibiting challenging behaviour as the behaviour is communicating to us he can't cope and more demands (including stop) are not what he needs - we may talk to him afterwards about his behaviour and make plans with him of what he can do differently next time and what we can do differently next time.” - parent of boy aged 12.

Remaining calm and 'stepping back' was also seen as helpful during acute episodes:

"I now understand how vital it is that I keep absolutely calm, keep stimulation to a minimum. If she thinks I'm angry, she gets angry etc. etc. So I have to 'poker face' constantly even under extreme duress....that is extremely tiring and takes huge effort all the time. But the results are worth it." - parent of girl aged 15.

Parents often noted that following guidelines on managing PDA had been helpful in reducing the frequency of problematic encounters:

"Many of the more extreme effects that our child [used] to experience are now mainly avoided and have been reduced to almost nil due to the specific handling that we have with our child, which is based on the handling guidelines for PDA." - parent of girl aged 15 years

This included minimizing demands and letting go of expectations:

"We place very few demands on him outside of school to enable him to cope with the demands of attending (he previously had almost 12 months out of school). This means we have a lot less meltdowns/stress at home but is not the way we would have chosen to parent.” - parent of boy aged 15.

Flexibility and adaptation to accommodate anxiety levels was also an important theme:

"I and other professionals have tried every parenting strategy in the book! What we have found is that sometimes a strategy will work and sometimes it won't. It depends on the child's underlying anxiety at the time.” - parent of boy aged 9.
In the final part of our study, we asked parents “If you were to choose one moment that really was a turning-point in how you were able to manage your child’s behaviour and/or help him/her, what would that moment be?” Some key themes are described below.

**TURNING POINTS**

A major theme in parents’ responses was developing a new understanding that the difficult behaviour was a reflection of anxiety and, as a result, developing a more accepting view of it:

“Accepting that demand avoidance is not a deliberate act to annoy or control anyone but is an innate need to be able to control what she could control in a scary world where most things are not in her control. She at that moment is no more able to listen to reason and stop the behaviour than an epileptic is to stop themselves from having seizures.”
- parent of girl aged 14.

Sometimes, insights gained from books or online resources had been pivotal in triggering this shift in understanding:  

“The turning point for me was after I read “The Explosive Child” by [Ross] Green and I learned to manage my son’s meltdowns in the same way that I may manage a panic attack. As soon as you accept that these behaviours are that of a vulnerable child who is using them as the only way they know how to communicate, you look at things and handle things, entirely differently.”
- parent of boy aged 9.

“It would be when I became aware of PDA strategies and read understanding PDA Phil Christie and Ruth Fidler and The Explosive Child by Ross Green. I understood the anxiety and potential triggers much better when I was using autism strategies alone. […] Also working collaboratively with my son meant I recognised his difficulty with certain things and we were able to reach solutions together. I was then able to closely support my son to implement these. His aggression began to reduce significantly and over a relatively short time scale.”
- parent of boy aged 11.

Many parents explicitly mentioned finding out about PDA as the turning point:

“When I read about PDA, the light bulb moment and realised it was sheer panic causing him to ‘meltdown’. I knew something was wrong rather than he was naughty but not anything I could put my finger on… that moment changed everything, how I parented, how I talked to him, where I took him (no more supermarket shopping). I explained everything we would be doing when leaving the home and still do…”
- parent of boy aged 15.

“For us it was when the Psychologist evaluating for ASD asked if we had heard of PDA - We hadn’t. I went out and started researching immediately and realised our son just was “that child” - it fit and gave us something to work with, to understand and to help. The minute we could start to realise why he did the things he does and that anxiety was the tremendous key to underpinning behaviours we started to adapt ourselves to his needs and deal with situations hundred fold better.”
- parent of boy aged 12.

For other parents, a shift towards a more accepting attitude emerged due to intrinsic factors:

“My son had had a dreadful day at school. He had been in the head teachers office all day because his behaviour was awful. I had had a bad report from the head teacher. We climbed in the car and my son flinched. He was frightened of what I was going to say when I told him off. This was after months of me telling him off and reprimanding him for his behaviour at school.

I realised in that second that it was destroying our relationship. I took a deep breath and said I don’t like your behaviour, but I’m your mummy and I love you. You only get one relationship with your mum. I was letting headteachers, teachers, sencos opinions affect the way I saw my child.

From that moment on I said to [son] that headteachers
will come and go, but you only get one mum. I probably won’t like what you’ve done if you have got into trouble at school but I’m no longer going to discipline you for it. I’m going to support you and try to figure out why you behaved in the way you did. I am here to guide and protect you. I never want you to fear my reaction. Since then, he knows I believe in him and I honestly believe this was a turning point” - parent of boy aged 9.

Several parents saw diagnosis as the key turning point towards developing a more accepting view of their child’s difficulties. Some parents cited examples of receiving an ASD diagnoses, and others specifically mentioned the PDA label:

“Receiving a diagnosis of autism [...] helped me to accept that there were underlying reasons for the behaviour (other than just being naughty) and that I needed to accept and understand these if I wanted to help my son.” - parent of boy aged 9.

Parents also reported that diagnosis ended a period of confusion and uncertainty in their minds.

“I gained confidence after diagnosis. It was the single point where the confusion of what was going on ended. There was an acceptance that things weren’t going to change unless I did something to change it. It allowed me to say, no he’s not naughty, he’s autistic and I’m doing my best to help him.” - parent of boy aged 15.

Receiving a diagnosis also addressed a challenge that parents often encountered - perceived judgement from others:

“Life was incredibly difficult up to this point [before diagnosis] as we constantly had to fight to get recognition from friends, family and school that there was something different about our son and that he wasn’t just another naughty child.” - parent of boy aged 10.

Diagnosis also altered parents’ beliefs about themselves in relation to their child’s difficulties. In particular, it allowed them to let go of feelings of guilt:

“I finally had real, tangible proof that my son’s behaviour was caused by something other than bad parenting.” - parent of boy aged 15.

Parents also reported that interactions with clinical professionals could also help to build parents’ confidence by focusing on their strengths:

“[X]’s first appointment was a triage with a specialist Neuro CAMHS worker. It was [...] in this appointment when she said, ‘there’s a lot of love in this family’. Just that acknowledgment made us even more determined to be the best and most understanding parents we could be.” - parent of girl aged 8.

Interactions with specialists gave parents implicit ‘permission’ to adapt their parenting approach to meet their child’s needs:

“My child had no diagnosis and increasingly challenging behaviour, which was not responding to any of the usual parenting strategies or advice. [...] Attending [a course run by the PDA Society] made me realise that it was OK to parent in a different way.” - parent of boy aged 8.
Finally, participation in courses and attendance of support groups were helpful in introducing parents to others who had children with similar difficulties, reducing their sense of loneliness and disconnection:

“Finding a local support group made me realise I was not alone and others were having similar issues. They gave me the confidence back I had lost which had made me depressed and left me feeling worthless and hopeless”
- parent of boy aged 11.

**PDA – Resolving Debates**

The previous examples demonstrate how new understandings and acknowledgement of the child’s difficulties from clinicians and the wider community can help parents to move forward and develop a better relationship with their child.

Many (but not all) of the examples provided reference the concept of PDA. It is clear that learning about PDA has helped many families to better understand their child by realising that problem behaviour can reflect anxiety and overwhelm. It has also helped parents move forward using recommended strategies designed to address avoidance in the context of anxiety.

However, the concept of PDA has also triggered disagreements, particularly between parents and clinicians⁸, who can have conflicting goals when it comes to clinical diagnoses. In some cases, these have undermined parents’ confidence and fostered their sense of isolation.

Much of the disagreement has centred on whether PDA represents a separate subgroup and should be seen as a diagnosis in its own right. However, if we make a slight shift in our focus from the issue of diagnosis towards focusing on behaviours that are described in PDA and the mechanisms behind them, much conflict is avoided and more attention given to the critical issue: what can be done to help the child?

Even if we think about PDA more loosely as a continuum of behaviours that can occur in ASD, the concept can still be very helpful. In particular, there are many similarities between behaviours described in PDA and other avoidance patterns that sometimes occur in ASD, such as avoidance of foods (avoidant restrictive food intake disorder), where the child will only eat certain foods considered ‘safe’³⁸, or avoidance of speaking (selective mutism). In all three, the factors mentioned earlier (particularly anxiety and sensitivity to environmental triggers) are thought to play an important role, and as such, management strategies are likely to overlap.

A recent article published by Prof. Jonathan Green in the Lancet Child and Adolescent Health⁹, a leading medical journal, concluded the following (p. 460):

“The DSM-5 revisions include […] the recognition of associated features that support an autism spectrum disorder diagnosis, and the identification of concurrent problems and disorders. […] This recognition should mean that problematic behaviours, such as extreme demand avoidance and emotional dysregulation, will be included in diagnostic formulations and inform the development of comprehensive child and family intervention programmes”.

An encouraging outcome of our study was that many parents told us that they had successfully reduced their child’s distress and extreme behaviour with a better understanding of the child and figuring out the right approaches¹. These reports highlight the need for collaborative efforts to figure out what factors exacerbate the child’s avoidance and extreme behaviour, and what can be done to help reduce it.

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References & notes:


4. Preliminary observations collected as part of Liz O’Nions’ PhD.


7. Some adults who self-identify as PDA, and parents/carers of children with PDA contest this view, and instead feel that PDA represents a sub-type of ASD associated with a distinct cluster of traits, including imagination, fantasy/role play, and charm. Indeed, as described in Newson’s accounts, some individuals do show all of these features. Further analysis is needed to explore co-occurrence in random samples.


Child behaviour and parenting strategies – a research update


25. Desirable activities can also reportedly trigger avoidance.

