



# PATHOLOGICAL DEMAND AVOIDANCE: *supporting pupils*

All references, along with other useful resources, can be found through the PDA Society ([www.pdasociety.org.uk](http://www.pdasociety.org.uk)) and Autism Associates ([www.autismassociates.co.uk](http://www.autismassociates.co.uk))

## BACKGROUND

Pathological Demand Avoidance (PDA) is a term that was first used in the 1980s by Professor Elizabeth Newson. Initial descriptions outlined an evolving understanding of a group that reminded people of children with autism but were often 'atypical'.

The central characteristic was 'an obsessional avoidance of the ordinary demands of everyday life' (Newson et al, 2003) combined with sufficient social understanding to enable the child to be 'socially manipulative' in their avoidance. Newson proposed that PDA should be seen as a separate syndrome within Pervasive Developmental Disorders, which was the recognised category used within the psychiatric classification systems of the time.

Since then, and especially over the past five years, further research has continued to explore the nature of this profile, how best to describe it and the type of adjustments needed in educational provision.

## PDA IS PART OF THE AUTISM SPECTRUM

Despite continuing debate among clinicians and researchers, PDA is now widely understood to be part of the autism spectrum. At the time of writing this article, the government announced a review of services and support for autistic people that will inform the new autism strategy to be published in autumn 2019. One of the four key areas identified was 'improving understanding of autism and all its profiles, including recently identified forms such as Pathological Demand Avoidance (PDA)'.

You can read about the review at <https://bit.ly/2rnFwWc>.



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starting-point for making the adaptations needed to improve the educational experience and outcomes for all learners on the autism spectrum.

While some controversy may continue to surround the classification of the PDA profile, there is wide agreement about the need to recognise the particular education and support needs of these children. This was forcibly advocated in an article about PDA published by the British Psychological Society in 2016 which concluded that “it is essential that this help is provided to these very vulnerable individuals and their families”.

Guidelines have evolved that promote an approach based on a less directive and more flexible style than the more structured methods often advocated for children with a more ‘straightforward’ presentation of autism. Such guidelines have now been adopted into the National Autism Standards published by the Autism Education Trust, which can be downloaded at <https://bit.ly/2Rc6hFF>. The limited research on educational approaches that support the efficacy of this approach, and parents responding to an online survey carried out by the PDA Society, have endorsed their effectiveness.

In other publications about PDA (Christie et al, 2011 and Fidler and Christie, 2018) this methodology has been detailed and given the title of ‘Collaborative Approaches to Learning’. Underpinning the approach is the understanding that the child with PDA doesn’t make a ‘deliberate choice’ not to comply and can’t overcome the situation by ‘an act of will’. He or she may, however, make a series of achievements towards this end as trust and confidence builds. It is the role of supporting adults to enable tolerance and confidence to grow so that expectations can be progressively increased.

Individuals who present with this profile are driven to avoid everyday demands and expectations; this is rooted in an anxiety-based need to be in control. Demand avoidance can be seen in the development of many children but it is the extent and extreme nature of the avoidance that causes difficulties. The features of PDA are ‘dimensional’ which means that they affect individuals to varying degrees.

The main features of PDA include:

- ▶ **resistance to and avoidance of the ordinary demands of life (e.g. getting up, joining a family activity and other day-to-day suggestions)**
- ▶ **using social strategies as part of the avoidance (e.g. distracting, giving excuses)**
- ▶ **appearing sociable on the surface but lacking depth of understanding**
- ▶ **excessive mood swings and impulsivity**

- ▶ **being comfortable in role play and pretend, sometimes to an extreme extent**
- ▶ **‘obsessive’ behaviour, often focused on others.**

### GUIDELINES FOR EDUCATIONAL PROVISION AND SUPPORT

Recent reports, including that by the All-Party Parliamentary Group on Autism (2017), have concluded that many children with autism are being let down by the education system; exclusions are rising significantly and fewer than half of the children surveyed said that they were happy at school. This is especially true for those with more complex presentations of autism such as a PDA profile.

These reports highlight how assessment, which leads to a greater understanding of an individual’s profile and needs, is the



## → TEACHING &amp; LEARNING



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### KEY PRINCIPLES

The key principles behind this approach are about observing the child and listening to everyone's perspective and working together to find negotiated solutions. The teaching style needs to be modified including adjusting expectations and adopting a less directive style of working.

Regardless of the setting or level of support, flexibility and potentially considerable adaptations will also be needed at an organisational level.

The timetable may need adjustment, e.g. the amount of time spent on particular subjects or where learning takes place. Another issue might be the extent of the 'adjustment' to whole-school practice or policy that is needed to include a particular pupil, e.g. think about the uniform

policy, arrangements for assembly, break times, etc.

Classroom staff need to be supported to ensure that they can provide enough differentiation and personalisation to both the curriculum and the way in which it is delivered. The degree of adaptation and personalisation needed for many children with PDA doesn't sit easily alongside inflexible whole-school policies.

### PRINCIPLES INTO PRACTICE

Putting these principles into practice requires a range of strategies, a few of which are below, to maintain the pupil's engagement:

- ▶ **Choosing priorities: What is important now and what can we come back to? Use of a simple priority rating scale completed by staff and parents together can be a useful starting-point.**
- ▶ **Being indirect and avoiding unnecessary confrontations: priorities will need to be put in place but with a child with PDA there is the potential for 'flashpoints' regarding a host of everyday expectations. Using indirect, invitational language and giving more choice can help to avoid unnecessary confrontation, e.g. "It would be great if we could get this done today; shall we do it in the hall or the library?" "Oh this**

looks a bit tricky...perhaps you might be able to help?"

- ▶ **Adapting visual strategies: using visual strategies is very helpful for most children with autism, clarifying information in a way that gives more time to process. Schedules and systems can come across as being too prescribed though and seem to represent a 'to-do list'. They can be adapted to be more flexible to enable a pupil to better see choices and possibilities.**
- ▶ **Providing extra processing time: this is important for all children with autism who are likely to need more time to fully process some of the information they are given. This may be the case for the child with a PDA profile too and they may also need additional time to process whether they can co-operate at that particular moment (this is likely to be linked to their level of anxiety).**

### CONCLUSION

Understanding of PDA is still at an early stage but there are exciting developments happening and greater emphasis being given to the need for flexibility and personalisation in educational provision. These developments provide an opportunity for wider recognition and better understanding and support for individuals with PDA and their families.

Using invitational language and embedding choices into requests can help avoid confrontation.



#### BIO

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