

East Sussex Position Statement regarding Pathological Demand Avoidance (PDA) - December 2023

Purpose of this document

The following position statement has been co-produced between:

- Education East Sussex
- East Sussex Community Paediatrics
- Child and Adolescent Mental Health Services (CAMHS), and
- East Sussex Parent Carer Forum

It aims to ensure a shared understanding of Pathological Demand Avoidance (PDA)¹ to inform how best to support children with this profile and their families. We work together to ensure every parent/carer in East Sussex feels that their voice, their views and their experiences matter. It also allows them to contribute towards developing and improving services to positively impact upon the lives of children and young people with SEND.

Our hope is that this document will empower parent/carers, children and schools to:

- Explore the demand avoidance a child is demonstrating, and
- Implement approaches to meet the child's needs.

Much of the information in this statement comes from the PDA Society and we have included several links to their website. Linking so closely to the PDA Society ensures that any information is research-based, up-to-date and informed by those with lived experience.

What is PDA?

PDA is widely regarded as a profile of Autism. It does not currently appear in diagnostic manuals (DSM-V, ICD-10/11). For this reason, NHS professionals in East Sussex do not make this separate diagnosis or carry out separate assessments for a PDA profile. However, when a child is being assessed for autism and presents with recognisable or reported elements of a PDA profile, we will describe this within the child's assessment report.

We guide readers to the PDA Society's '[Identifying & Assessing a PDA profile - Practice Guidance](#)' document. This is currently the best way for parent/carers, schools, health and other practitioners to identify whether a child has a PDA profile.

Types of Demand Avoidance

Demand avoidance - This is a natural human trait, which involves not being able to do certain things at certain times, either for yourself or others, and also refers to the things we do in different degrees and for different reasons.

Autistic demand avoidance - Autistic people may avoid demands or situations that trigger anxiety or sensory overload, disrupt routines, involve transitioning from one activity to another, and activities/events that they don't see the point of or have any interest in. They may refuse, withdraw, 'shutdown' or escape in order to avoid these things.

Demand avoidance in PDA - pathological demand avoidance is all-encompassing and has some unique aspects:

- many everyday demands are avoided simply because they are demands. Some people explain that it's the expectation (from someone else or yourself) which leads to a feeling of lack of control, then anxiety increases, and panic can set in;
- this avoidance can also apply to pleasurable or preferred activities that the individual is highly motivated to do, which can be confusing to those around them;
- there can be an 'irrational quality' to the avoidance - for instance, a seemingly dramatic reaction to a tiny request, or the feeling of hunger inexplicably stopping someone from being able to eat;
- the avoidance can vary, depending on an individual's capacity for demands at the time, their level of anxiety, their overall health/well-being or the environment (people, places and things).

What might a PDA profile look like?

A PDA profile is also a spectrum and presents differently in different people. Some individuals may have a more **externalised** or active presentation - where demand avoidance may be overt, physical, aggressive or controlling. Others have more **internalised** or passive presentations - where demands may be resisted more quietly, anxiety is internalised and difficulties are masked. Many have a **variable** presentation, depending on other factors like how well they are managing at the time, the environment, the setting, their age and so on. It can be helpful to think of a 'window of tolerance' that expands and contracts according to these factors. Further information can be found online:

- [Window of Tolerance | office.com](https://www.office.com)

With PDA, people may also simply refuse, withdraw, 'shutdown' or escape in order to avoid things, though more often other 'social' approaches are tried first. Initial avoidance approaches might include distraction (changing the subject, engaging in interesting conversation), procrastination, excusing yourself (giving explanations as to why you can't comply), incapacitating yourself (saying 'my legs don't work') or withdrawing into role play or fantasy (pretending to be an animal/character) or reducing meaningful conversations.

If these approaches don't enable the demand to be avoided - or aren't noticed or acted on by others - there may be a rapid escalation as panic sets in and options run out. This

isn't a deliberate choice, it's an instinctive flight/fight/freeze response triggered within the nervous system. Meltdowns in PDA are best understood as being like panic attacks.

It is important to be aware of those children who might go into freeze mode or fawn mode (pretending to be or saying they are ok). They may not appear obviously distressed but may be experiencing toxic stress on the inside.

How do we support children and young people with PDA?

Traditional behavioural approaches are not usually effective with individuals with PDA, as rewards, praise and consequences can be perceived as demands. Low arousal approaches, which keep anxiety to a minimum and provide a sense of control, are good starting points when thinking about what works for PDA. It is important to consider the environment and make accommodations which support agency and autonomy. A partnership based on trust, flexibility, collaboration, careful use of language and balancing of demands works best. One possible model is PANDA. This stands for:

- Pick battles
- Anxiety management
- Negotiation and Collaboration
- Disguise and manage demands
- Adaptation

PDA Society have created a [PDF called 'Helpful approaches for parents and carers \(pdasociety.org.uk\)](https://pdasociety.org.uk). This outlines the PANDA model.

Any PDA strategies will only work when used within a 'PDA approach', that is to first prioritise safety, trust, relationships and authenticity. It is important that those supporting make sure that they themselves are regulated and able to be with the child at that time (known as "Co-regulation"). It is also important for those supporting to know that it's OK to ask for help if they are not able to co-regulate. This relates to Dan Siegel's model of interpersonal neurobiology, "my brain waves affect your brain waves", that we can sense stress from another person, so the child might sense an adult's stress and be impacted by it, but also the adult might sense the child's distress and be impacted by it.

Our aim is that all children and young people in East Sussex are educated in an appropriate environment which looks to meet their individual needs. Schools and settings can gain further information and support from the Communication, Learning and Autism Support Service (CLASS), and the Educational Psychology Service (EPS), both part of Education East Sussex. Parent/carers can access information and support from CLASS+.

Useful links

- [Pathological Demand Avoidance | PDA Society](#)
- [Communication, Learning and Autism Support Service \(CLASS\) on 1Space](#)
- [Educational Psychology Service \(EPS\) on 1Space](#)
- [CLASS+ on Facebook](#)
- [Demand avoidance | National Autistic Society](#)
- [East Sussex Parent Carer Forum website](#)
- [Demand Avoidance vs Pathological Demand Avoidance PDF | East Sussex Healthcare Trust](#)
- [Resources menu | PDA Society](#)

This position statement will be reviewed in December 2024.

¹ This term is disliked by some in the Autistic community, and we would prefer to use the wording 'Persistent Drive for Autonomy' to support the shifting narrative to become more neuro-affirmative and identify support needs.