





Dorset Position Statement regarding Pathological Demand Avoidance (PDA)



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The following position statement has been co-produced between Parent Carer Forums (Dorset Parent Carer Council and Parent Carers Together), Health and Education representatives to inform this statement. Our aim is to ensure a shared understanding of Pathological Demand Avoidance (PDA) and to provide a clear and consistent message across Dorset so that children and their families can be supported in the best way possible

What is Pathological Demand Avoidance (PDA)?

PDA is considered to be a profile of need under the wider diagnostic framework of Autism Spectrum (so a PDA profile cannot be considered without a diagnosis of ASD).

It can be helpful to think of PDA as a way of describing a range of anxiety-driven behaviours, where the child or young person often seeks to avoid everyday seemingly reasonable requests because they trigger anxiety. The child or young person often attempts to talk their way out of or avoid the requests to an extreme extent. This set of behaviours may be termed PDA and in some areas of the country, young people may receive a separate diagnosis. PDA can be understood as part of the anxiety response that has a significant impact on daily functioning and should be viewed as a spectrum of difficulty rather than a categorical profile.

PDA does not appear as a separate diagnostic condition in nationally and internationally recognised diagnostic manuals (such as DSM-V or ICD-11). For this reason, NHS professionals in Dorset do not make this separate diagnosis and are not able to offer additional assessments to consider this need. However, for a child who has been assessed as being on the autistic spectrum but also presents with a demand avoidant profile this may be recognised and described within the child's assessment report and diagnosis.

Pathological ...means that this demand avoidant behaviour is extremely debilitating for the young person. "Actions are completely out of the control of the individual; they are not being wilful or rude. Nor can it be regarded as a power game or being naughty. For the person concerned a request (demand) is likely to produce a level of anxiety that is beyond anything the rest of us can even begin to imagine."

Demand ...means any demand: direct, indirect, implied or consequence. Even internal demands such as 'I ought to' are included.

Avoidance ...means that the individual will not be able to do what is asked of them. It is not that they do not want to; they cannot. *Tigger Pritchard (2017)*

What might PDA profile look like?

Children and young people with a PDA profile may use a number of strategies in response to demands. Behaviours that are typically but not always seen are:

- Resistance to / avoidance of everyday demands
- Using social strategies, such as negotiating as part of avoidance
- Appearing sociable, yet lacking depth of understanding
- Experiencing intense emotions and mood swings
- Comfortable in fantasy / imaginative play
- Displaying obsessive behaviours, often focused on other people,
- Controlling behaviours
- Use of distractions
- Shouting, or becoming aggressive.
- Falling to the ground or saying body parts don't work,
- Difficult or sometimes dangerous behaviours.

With a PDA profile, these behaviours may be a form of a 'panic attack', often referred to as 'fight, flight or freeze' responses.

Why is it important to recognise PDA?

PDA isn't a choice, but with understanding, helpful approaches from others and finding individual coping strategies, it can become more manageable.

Individuals who meet the profile of PDA can be mis-understood as behaving in a defiant and resistant manner out of choice, which is inaccurate. Adopting a compassionate approach when working with and supporting children is really important. It is also helpful to clarify what may be negotiable and non-negotiable rules and expectations for children to provide them with a sense of autonomy, and to avoid presenting children with a high number of demands that they may be unable to follow.

Unfortunately, it can be common for parents and carers to feel blamed for their children's behaviour. Individuals with PDA may often wrongfully be perceived as being 'naughty' or 'manipulative' and can struggle in their educational settings. This raises long term concerns about mental health, higher educational, social and employment opportunities.

It is important that PDA is recognised and understood so that appropriate support strategies can be put into place in both the home and school environment and that parents and professionals are working together from a joined-up perspective and a shared understanding.

How can we support children and young people with PDA?

Children and young people with this profile usually respond better to personalised, non-confrontational approaches and also tend not to respond to conventional (e.g. rewards and penalties) parenting, teaching or support approaches. The most important thing is to gain a strong understanding of the presentation of the individual and to use approaches which are going to be most effective for them.

When PDA strategies are found to be helpful for the child or young person then we would suggest they are employed by parents/carers/school, even when a demand avoidant profile has not been identified. It is ultimately the interventions and support, based on the needs of the child or young person that are essential, working with the idea of "What helps now" rather than focusing on further assessment and diagnosis

Autism Statement

We are committed to supporting all autistic children and young people. We recognise that each individual has a unique set of needs and strengths, which we will endeavour to support with a co-ordinated partnership approach across the voluntary and community sector, education, social care and health.

Being unable to follow through on demands is a common response to anxiety in children with and without Autistic Spectrum conditions. For children with a diagnosis of Autism, Pathological demand avoidance (PDA) is a term used to describe a continued and pervasive extreme/intense resistance to everyday demands through socially motivated strategies that originate from an anxiety-driven need to be in control or avoid completing tasks due to the uncertainty of how to complete the task, and fear of failure. The PDA profile of Autism can sometimes be difficult to identify and it's not uncommon for it to be missed, misunderstood, or misdiagnosed, which may lead to poor outcomes for children and young people.

This statement will be reviewed periodically in line with emerging research

Links and Resources

Schools can request further information and support from the Education Psychology Services, as part of BCP Council and Dorset Council SEND Services and via the resources available on the PDA Society website.

Parents, carers and young people can access additional information and support from both Local Authorities, Dorset and BCP SEND Local Offers and the PDA Society. The PDA Society also offers training and downloadable resources for parents and professionals.

The resources below have been suggested by families in Dorset as well as practitioners and we hope you find them helpful:

PDA society www.pdasociety.org.uk/ provides many resources and information including helpful approaches

National Autistic Society www.autism.org.uk/about/what-is/pda.aspx

BCP SEND Local Offer – <u>The Bournemouth, Christchurch and Poole SEND Local Offer -</u> BCP Council

Dorset SEND Local Offer Dorset's Local Offer - Dorset Council

Produced by:

NHS Dorset

Dorset Council

BCP Council

Parent Carers Together

Dorset Parent-Carer Council

If you have feedback on our Pathological Demand Avoidance Statement, please scan the QR code below to be taken to our feedback form or click on the link:

https://forms.office.com/e/WmaThRiHrP

