

East Sussex Position Statement regarding Pathological Demand Avoidance (PDA) **September 2020**

The following position statement has been co-produced between Education and Health professionals and the East Sussex Parent Carer Forum to ensure a shared understanding of Pathological Demand Avoidance (PDA) and 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 and contribute towards developing and improving services to positively impact upon the lives of children and young people with SEND.

What is Pathological Demand Avoidance (PDA)?

Perhaps the best way of thinking about PDA is 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.

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)

This set of behaviours may be termed Pathological Demand Avoidance and, in some areas of the country, young people may even receive a separate diagnosis of PDA.

PDA does not appear as a separate diagnostic condition in nationally and internationally recognised diagnostic manuals such as DSM-V or ICD-10. For this reason, NHS professionals in East Sussex do not make this separate diagnosis. However, for a child who has been assessed as being on the autism spectrum and presents with a PDA profile, this will be recognised and described within the child's assessment report and diagnosis.

What might a PDA profile look like?

Children and young people with a PDA profile may use a number of strategies in response to demands, for example delay tactics, distraction, shouting, falling to the ground, saying body parts don't work, negotiating, escape, difficult, aggressive or dangerous behaviour.

Behaviours that are typically (but not always) seen are:

- Resistance to / avoidance of everyday demands
- Uses social strategies as part of avoidance
- Sociable, yet lacking depth of understanding
- Excessive mood swings
- Comfortable in fantasy / imaginative play
- Displays obsessive behaviour, often focused on other people

These behaviours are a form of 'panic attack', often referred to as 'fight, flight or freeze' responses.

How do we support children and young people with PDA?

Children and young people with this profile do not generally respond to the traditional approaches recommended for autism. Often the children and young people respond better to a more flexible and non-confrontational set of personalised 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.

Schools can gain further information and support from the Communication, Learning and Autism Support Service (CLASS), and the Educational Psychology Service (EPS), both part of East Sussex County Council's ISEND service. Parents can access information and support from CLASS+.

Autism statement

We are committed to supporting all children and young people with autism. Autism is an umbrella term that describes a range of conditions, some of which you may have heard described as Asperger's syndrome, Autism Spectrum Disorder / Condition (ASD, ASC), high functioning autism, social communication disorder, pervasive development disorder or pathological demand avoidance. We recognise that each individual has a unique set of needs and strengths which we will support with a coordinated partnership approach across the voluntary and community sector, education, social care and health.

Links

Communication, Learning and Autism Support Service ([CLASS](#))

Educational Psychology Service ([EPS](#))

CLASS+ (<https://www.facebook.com/CLASSPlusEastSussex/>)

National Autistic Society (<https://www.autism.org.uk/about/what-is/pda.aspx>)

PDA society (<https://www.pdasociety.org.uk/>)

East Sussex Parent Carer Forum (<https://www.espcf.org.uk/>)

Children's Integrated Therapy & Equipment Service (CITES)

(<https://www.kentcht.nhs.uk/service/east-sussex-childrens-integrated-therapy-and-equipment-service/>)