



## PDA Statement

The following position statement has been co-produced between Alder Hey Children's NHS Foundation Trust, Education (Liverpool and Sefton) and Parent Carer Forums (Liverpool & Sefton) to ensure a shared understanding of Pathological Demand Avoidance (PDA) and how best to support children and young people with this profile and their families. We work together to ensure every parent/carer in Liverpool and Sefton 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)?

Demand avoidance is a common response to anxiety in children with and without Autism Spectrum conditions. In contrast, Pathological demand avoidance (PDA) is not common and is characterised by a continued and pervasive extreme resistance to everyday demands through strategies of social manipulation that originate from an anxiety-driven need to be in control.

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.

PDA was first described as a separate clinical entity by Elizabeth Newson and colleagues in Nottingham and almost all published research regarding PDA comes from this group. There is ongoing debate but most professionals believe that children described as having PDA fall within the autistic spectrum (ASD). Children and young people with ASD and a demand avoidant profile may respond to different strategies particularly in educational settings.

PDA does not appear as a separate diagnostic condition in nationally and internationally recognised diagnostic manuals such as DSM-5 or ICD-10. As there are no formal 'diagnostic criteria' for identifying a PDA profile of autism, Alder Hey does not make this a separate diagnosis. However, for a child or young person who has been assessed as being on the autism spectrum and presents with a demand avoidant profile, this will be recognised and described within the child or young person's assessment report as "ASD with a PDA profile".

Alder Hey will only consider recognising PDA as a profile within a diagnosis of ASD, therefore the assessments and information gathered as part of the diagnostic process must result in a diagnosis of ASD before PDA can be considered and recognised. Where there is no diagnosis of ASD, PDA will not be considered.

However, if 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 diagnosis has not been reached, as ultimately it is the interventions and support based on the needs of the child or young person that are essential rather than focusing on further assessments 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, including delay tactics, distraction, shouting, falling to the ground, saying body parts don't work, negotiating, escape, manipulation, aggressive or dangerous behaviour.

Behaviours that may be typical (but are not always) seen are:

- Resistance to / avoidance of everyday demands e.g. getting up, getting dressed, eating a meal or washing.
- Using 'social' strategies as part of the avoidance e.g. not just saying no, withdrawing, shutting down or running away, distraction, making excuses, physical incapacitation, withdrawing into fantasy, procrastination, controlling, reducing meaningful conversation or masking.
- Sociable, yet lacking depth of understanding
- Excessive mood swings e.g. difficulties with emotional regulation, rapid mood swings, impulsiveness and unpredictability.
- Comfortable in fantasy/imaginative play e.g. this can sometimes be to an extreme extent with other personas being adopted for a prolonged period of time.
- Displays of obsessive behaviour, often focused on other people

Some of 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 and also tend not to respond to conventional parenting, teaching or support approaches

Often the child or young person responds 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 [Here](#)

### **Resources:**

<https://www.pdasociety.org.uk/>

<https://www.autism.org.uk/>

<http://www.seftonpcf.org/>

[www.livpac.org.uk](http://www.livpac.org.uk)

<https://www.theisabellatrust.org/>

<https://www.liverpoolcamhs.com/>

[Liverpool SEND Local Offer](#)

[Sefton SEND Local Offer](#)

[Education support](#)

[Sefton CVS](#)