



## Summary

This document aims to improve the understanding of 'Pathological Demand Avoidance' (PDA), to ensure everyone in Norfolk, Suffolk and Waveney is clear about what is meant by PDA and to signpost to resources available through the national [PDA Society](#). This includes resources on how to identify and assess PDA and how to support someone with a PDA profile.

This Position Statement has been co-designed with people with lived experience. People with lived experience, health (Norfolk and Waveney Integrated Care Board), social care and education (Norfolk County Council), and the Norfolk All Age Autism Partnership Board (NAPB) worked together to ensure a shared understanding of what we mean by 'Pathological Demand Avoidance' (PDA) and most importantly how we commit to support children, young people and adults who may have this profile.

We have worked together to ensure that children, young people, adults and their families in Norfolk, Suffolk and Waveney have been listened to and their views and experiences genuinely matter and contribute to developing and improving services. The best outcomes are achieved when children, young people, adults, their families, and carers are included, respected and valued as equal partners alongside other agencies and systems. We hope that this Position Statement reflects this value within Norfolk, Suffolk, and Waveney.

We recognise, understand, accept, and value that there are a group of autistic children, young people and adults who present with a PDA profile. We recognise this as part of understanding autism.

## What do we mean by PDA?

'Demands' means lots of different things but overall means something that someone is expected or asked to do. It could be a request, an instruction, a rule, or an expectation. Avoiding demands can be a common response to anxiety in all people at times and this includes autistic people.

In contrast PDA is not common and is very different to someone feeling anxious and avoiding a demand. It is characterised by a continued and pervasive and extreme resistance or 'avoidance' to demands of any kind. It is driven by anxiety and the need to be in control. The presence of a demand makes the person feel so anxious that they are strongly compelled to get away from it; they have usually found many different ways to do this. The 'demand' could be something challenging but equally it could be something enjoyable, familiar, or part of everyday routines, but the presence



or anticipation of a demand causes a level of anxiety that is unbearable. The impact of this can be debilitating for a person.

Many people in the autism community would term PDA as a Persistent and Pervasive Drive for Autonomy. This is used interchangeably with Pathological Demand Avoidance.

## Recognition and Assessment of a PDA profile

The PDA profile of autism can sometimes be difficult to identify and understand and it's not uncommon for it to be missed, misunderstood, or misdiagnosed, which may lead to poor outcomes for autistic children, young people, and adults.

There is on-going debate, but we know that some autistic children, young people, and adults can be described as having a PDA profile. PDA does not appear as a separate diagnostic condition in nationally and internationally recognised diagnostic manuals such as the DSM-5 or ICD-11. **This means that you cannot get a diagnosis of "PDA" alone.**

As there are no formal 'diagnostic criteria' for identifying a PDA profile of autism, Norfolk, Suffolk & Waveney does not make this a separate diagnosis either. However, for a person who has been assessed as being autistic and presents with a demand avoidant profile, this will be recognised and described within their formulation and their written diagnosis will be 'Autistic and presents with a PDA profile'.

Norfolk, Suffolk & Waveney will only consider recognising PDA as a profile within an autistic diagnosis. This means that the quality of the assessment must be compliant with good quality evidence-based assessments for autism. PDA cannot be diagnosed without this and without a diagnosis of autism. This must always include a multi-disciplinary assessment.

We agree to use the language "Autistic with a PDA profile". We agree that this will be valued, accepted and the child, young person or adult who is autistic with a PDA profile will be supported appropriately.

We commit to continuing to work together to ensure that autistic children, young people and adults with a PDA profile are valued, accepted, understood and supported appropriately.



## What might a PDA profile look like?

Children, young people, and adults 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', or behaviour. **It is understood as 'can't' rather than 'won't'.**

Below is a list of behaviours, styles, and ways of interacting that may be typically (but are not always) seen:

- Resistance to/avoidance of everyday demands such as getting up, getting dressed, eating a meal, or washing.
- Using 'social' strategies as part of the avoidance such as not just saying no, but instead withdrawing, shutting down or running away, using distraction, making excuses, physical incapacitation, withdrawing into fantasy, procrastination, controlling, reducing meaningful conversation, or masking. Some of these behaviours are a form of 'panic attack', often referred to as 'fight, flight or freeze' responses.
- May be described as "sociable" and can mask differences or difficulties with social interaction.
- May have significant mood swings such as difficulties with emotional regulation, rapid mood swings, impulsiveness, and unpredictability.
- Comfortable in fantasy/imaginative play; 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.
- Seems unable to do things which the person may previously have enjoyed, chosen, or asked to do.

We commit to continuing to work together to ensure good quality and valid assessment for all autistic children, young people and adults including those with a PDA profile.

We commit to continuing to work together to build understanding, knowledge and acceptance of Autism with a PDA profile.



## How do we support autistic people with a PDA profile?

Autistic children, young people and adults with a PDA profile do not typically find the approaches that are often helpful for autistic people useful. This is also applies to traditional or typical teaching and parenting styles.

'Behavioural or reward-based interventions' are unlikely to be helpful. People are likely to need support that understands autism with a PDA profile and are "PDA friendly".

We also know that if ways of supporting someone or helping someone works, that they do not need a diagnosis for this to happen. If a child, young person or adult seems to feel less anxious with a PDA friendly world then we should not insist on a diagnosis for this to happen.

An autistic child, young person or adult with a PDA profile needs a flexible, creative non-confrontational personalised approach. The most important thing is that the person is understood and the world around them understands them. It is vital that we understand their need to feel in control and that we do not approach this in a way that seeks to take that control away.

We commit to continue to work together to understand the best ways to support each autistic child, young person and adult with a PDA profile and to ensure this includes awareness, training and specialist support.

## Further Information and links?

Information for education professionals:

<https://www.pdasociety.org.uk/working-with-pda-menu/info-for-education-professionals/>

Additional resources:

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

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

