PAULA WEBB • CHAIR AND ADULT ENQUIRY LINE LEAD • **PDA SOCIETY**

STRAIGHT **TALK**

Paula Webb asks if people with Pathological Demand Avoidance are misunderstood or whether it's a lack of awareness of the condition.

Pathological Demand Avoidance (PDA) is a profile on the autism spectrum. Whilst individuals with a PDA profile share similar difficulties to others with Autism spectrum disorder (ASD) – social communications and interaction difficulties, sensory challenges and some restrictive/repetitive behaviours – their central difficulty is an anxiety-driven need to be in control and avoid everyday demands and expectations to an extreme extent.

The National Autistic Society describes the distinctive features of a demand avoidant profile as:

- Resisting and avoiding the ordinary demands of life.
- Using social strategies as part of avoidance (eg. distracting/giving excuses).
- Appearing sociable, but lacking understanding.
- Experiencing excessive mood swings and impulsivity.
- Displaying obsessive behaviour that is often focused on other people.

People with a PDA profile are at particular risk of being misunderstood, as a recent survey by the PDA Society highlighted:

- 70% of the nearly 1,500 people surveyed said that lack of understanding or acceptance of PDA was a barrier to getting support.
- 70% of respondents felt they would benefit from support from social care but only 8% considered they had enough support to meet their needs.
- 78% reported difficulties with daily tasks.

We're hoping that this report will prompt everyone providing services and support to ask themselves 'might PDA be the answer to this person whose behaviour is perplexing?'

Adults with a PDA profile may be in social care placements because they have been diagnosed with autism and identified as needing support or because they have developed mental health difficulties.

The PDA Society speaks daily with PDA adults and their families, carers or partners. Time and time again we hear that, due to PDA behaviours being misunderstood or misdiagnosed, their needs are not being met, placements are breaking down and they are being moved on again and again without anyone recognising the true nature of their difficulties.

Securing a diagnosis of 'ASD with a PDA profile' is difficult at any age, but especially as an adult. The extreme demand avoidant behaviours may be dismissed, or they may be mislabelled as anti-social personality or conduct disorders. Alternatively, years of being undiagnosed and misunderstood can lead to an array of mental health issues which are then thought to be the cause of issues.

There are also adults with a PDA profile who are not getting any support or services from adult social care providers, either because they have no diagnosis or may be deemed too intelligent or articulate to meet the necessary criteria.

The key point about the PDA profile is that the recommended support strategies are very specific and very different to those for people with other autism profiles. Using inappropriate support strategies with an individual with PDA, including conventional ASD approaches, can be ineffective, counter-productive and even damaging.

A key starting point when supporting someone with PDA is to understand the anxiety and intolerance of uncertainty that underlies many of the presenting behaviours, and that angry or aggressive outbursts are actually panic attacks.

Careful management of an individual's anxiety and the amount of demands being placed on them (which can take many forms, not just direct requests but also expectations, desires and praise), using indirect language and humour and an approach based on negotiation, collaboration and flexibility are all effective strategies.

To improve outcomes for adults receiving social care services, with or without a diagnosis, PDA needs to be on everyone's radar.

Clearly, staff training in PDA is also key. Local authorities' adult social care and health teams may offer training; Autism East Midlands runs a one-day course on PDA specifically for support workers; other training organisations may also be able to help.

We hope that with greater understanding, needs-based and outcomes-focused care services will become the norm for this most misunderstood group of autistic people, and not the exception as it so often is today. **CMM**

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Further information on PDA is available at **www.pdasociety.org.uk**.