

PDA IN OUR WORDS

ABOUT PDA SOCIETY

The PDA Society is the only specialist PDA charity in the UK. We provide information, training and support to PDA people and their families, as well as professionals working with PDA-autistic people.

Our strong commitment to research underpins every step we take towards improving understanding, support and outcomes for PDA people in the future.

WHAT IS PDA?

PDA, or Pathological Demand Avoidance, is currently understood as a profile on the autism spectrum which is characterised by a fear response to demands. PDA isn't an independent diagnosis, but it can be identified as part of an autism assessment to indicate the most helpful support approaches.

PDA IN OUR WORDS

This booklet contains headline findings from new research conducted by PDA Society, PDA in Our Words. The full report and research methodology will be available on our website.

The research highlights the voices of PDA people and their families sharing the profound difficulties they face when their needs aren't recognised, and the life changing difference it can make when they receive the right support.

THE EDUCATION SYSTEM ISN'T MEETING THE NEEDS OF PDA CHILDREN

Key facts:

More than 70% of PDA children and young people struggle to attend school regularly.

More than 90% of PDA children and young people have experienced extreme anxiety, and more than 50% have experienced depression.

Only 52% of PDA children in school have received any emotional or practical support from a member of staff.

PDA children are facing significant challenges in accessing assessment, diagnosis and support services. Many PDA children don't have any access to professionals and are solely reliant on their families to support their needs.

Crucially, schools are struggling to adapt their support around PDA children. This results in the majority of PDA children struggling to attend school, which is having a long-term impact of children and young people's wellbeing.

WHAT HAPPENS WHEN WE MEET NEEDS IN EDUCATION...

"In Year 10 I stopped going to school. There was no communication, you weren't valued as a human. It's a sickening environment to be in for anyone, but with PDA, I hated it. The craziest rules that didn't make any sense, but were all about power and authority and control.

But things got so much better when I started at the college I'm at now. They encourage students, and they don't look down on them or lash out and get angry with them for behavioural things. They recognise that students don't misbehave for no reason.

I've found that this low demand environment works really well and my attendance has improved a lot. Being accepted like that is a really nice feeling. I don't want to take it for granted because often the rest of the world is not like this."



PDA ADULTS STRUGGLE TO HAVE THEIR NEEDS MET IN WORK

PDA adults experience a high rate of financial hardship because of a lack of access to higher education, training or employment. Many PDA adults told us that the main barrier was a lack of access to support.

More than half of PDA adults are reliant on friends, partners and family members for practical support on daily basis, rather than professional services, and it's very common for PDA adults to experience mental health challenges, loneliness and isolation because of difficulties with everyday tasks.

Key facts:

More than 75% of PDA adults have experienced financial hardship.

More than 40% of PDA adults are not in higher education, training and employment.

More than a 25% of PDA adults said they had no access to support at all.

WHAT HAPPENS WHEN WE MEET NEEDS AT WORK...

"I work part-time with disabled kids. The policies and general atmosphere are positive: inclusion, all behaviour is communication, prioritising choice in whatever form works, just generally treating the kids as 'equals'.

My boss is also very respectful – she often works directly alongside the rest of us, and she doesn't try to demonstrate "power over us" or anything. I haven't told her about my PDA but she knows I am autistic and gives me breaks if I ever get overwhelmed.

I'm lucky, because I just stumbled into my job but it's been really good for me, and really PDA-friendly despite not specifically trying to be. It's given me confidence and independence, and a sense of purpose – I actually feel like I'm doing something useful in the world."

PARENTS OF PDA CHILDREN DON'T FEEL HEARD OR SUPPORTED

Key facts:

More than 60% of parent carers have experienced disputes over their child's education and 16% have gone to an educational tribunal.

Almost a quarter of parent carers have experienced a social services investigation.

13% of parent carers have experienced an allegation of fabricated and induced illness, and 13% have been accused of parental alienation.

Parents and carers of PDA people are carrying a heavy load of unpaid caring responsibilities, with high social, physical, economic and emotional consequences.

Parents often report positive differences in their children when they implement person-centred approaches, but progress can be stalled or reversed when this isn't understood or reflected by professionals.

A lack of awareness of PDA means that parent carers are much more likely to be subjected to judgement, scepticism and blame, particularly single parents and those from minoritised ethnicities.

WHAT HAPPENS WHEN WE MEET THE NEEDS OF PARENTS...

"When our daughter started school, we were told by teaching staff that she was "absolutely fine" at school, there were no problems at all. It was so confusing, seeing how difficult everything was for her, but having professionals say there was nothing wrong.

We were very lucky in that we had some savings and could pay for a private assessment with a paediatrician who recognised the PDA profile of autism. She changed everything for our family. As soon as we met her, we felt believed, understood and not blamed. She wrote an extremely detailed diagnosis report with recommendations, which has been such a useful tool in getting our child the support she needs.

We also changed schools and found education professionals who understood about PDA and were willing to think outside of the box and allow our daughter the flexibility, understanding and compassion that she needs. They don't always get it right, but they are open to feedback, and we now feel confident enough to give it."

FOCUSING ON NEEDS AND STRENGTHS

Everyone deserves to get timely support that meets their needs when they are struggling, especially when this is having a long-term and detrimental impact on their daily lives.

There is no legal requirement to have any diagnosis to be able to access appropriate support in the UK; in the Families Act, the Health and Social Care Act and the Equalities Act, access to support is based on identified needs alone

With services stretched to capacity however, diagnosis is being used unlawfully to gatekeep vital support in education, work and healthcare, and waiting lists for assessments are longer than they have ever been.

We believe that a renewed focus on individual strengths and needs would be life-changing for PDA people and the autistic community as a whole. This would allow everyone to get help quicker, wherever they are on their diagnosis pathway, and would encourage more flexible and varied provision to respond to the diverse experiences of autistic people.

To achieve this, we need to support collaborative partnerships between PDA adults, parents and professionals, which reflect the value of lived experiences, and have the flexibility to adapt when the current approach isn't working. When we get this balance right, the impact can be truly transformational.

IF YOU SUPPORT PDA PEOPLE

FREE RESOURCES

Many professionals supporting autistic people have not received training about PDA. We have a range of free introductory resources on our website, including:

- [PANDA approaches](#)
- [PDA and autistic demand avoidance](#)
- [Practice guidance](#)

FREE ENQUIRY LINE


Our free enquiry line supports PDA adults, parent carers and professionals who work with or support PDA adults and children. To receive tailored information and guidance, you can get in touch [through our website](#).


TRAINING

If you want to find out more about supporting PDA children and adults, we run [online training](#) for a variety of professionals, and in-person on request. You can reach us at: training@pdasociety.org.uk.

MAKE A DONATION

We are reliant on donations to continue raising awareness about PDA. By [making a donation](#) you are ensuring we can continue fighting for brighter futures for PDA people and their families.

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