



PDA Society 5th Anniversary Survey Report

Thank you to everyone who answered our survey in Oct/Nov 2020 – this enabled us to review the PDA Society's impact to date and will help shape our services and projects for the future. These are the main findings ...

Our information & resources are highly regarded

- 87% respondents had benefitted from our written information
- 81% valued having information about PDA to share with others
- 77% benefitted from information about helpful approaches

“ *Each adult that has an interaction with my child, teachers, tutors, sports coaches, friends, family members, dentist... EVERYONE gets a printout from the PDA Society.*

Your website is my bible, I'd be lost without it.

I have found a wealth of advice, support, ideas, practical help and information which is helping me to thrive as a parent and helping my child as a result.

Because of the PDA Society I have a recognised source of information to send to professionals about our son's neurology, and have been better able to articulate and advocate for his needs.

Professionally presented resources have really helped to get others on board e.g. schools. ”

The information & support we offer is unique and not being provided elsewhere

“ *I am especially grateful for the times we have had individual support through the PDA Society helpline - often when we have been at crisis point and completely without other forms of support. We won't forget that - the value of a person who truly understands, who doesn't judge and knows their way through the utter shambles of statutory support service was huge.*

Because of the PDA Society, and only the PDA Society, as a family we have been able to learn, to breathe, to open our hearts and minds to view a different world. A beautiful world, a world that needs time, support, patience, encouragement, understanding, nurturing, love and laughter.

The PDA Society website is the ONLY place I can go to read other people's experiences, strategies, support and encouragement.

Information from your website prevented breakdown in long term foster care placement.

The PDA Society makes sense and provides validity, hope and avenues for progression that are not easily ascertained in the health and care services in the UK. ”

Our work has had a positive impact in terms of improving understanding of an otherwise perplexing presentation ...

for individuals ...

Of the PDA adults and young people who answered this question, the following percentage either 'strongly agreed' or 'agreed' that the services or support they've had from the PDA Society had had a positive impact on the following outcomes:

- 88% understanding myself
- 75% positive PDA identity
- 73% knowing what approaches help me
- 65% improved quality of life
- 62% feeling part of a community
- 67% being understood by others



It's very hard not having the information and support that people with different disorders have and for most my life I have been depressed and suicidal thinking there was something wrong with me, but when I first read about PDA I was reading about myself and it was the first time I'd been able to put my struggles into words.

I found why I behave and feel the way I do.

Without the PDA Society I would likely be in an ATU at this rate.

Without the PDA Society I would still feel very alone with my struggles, because of the case studies and information I was able to relate to other people for what felt like the first time in my life.

for professionals ...

Of the professionals working with PDA who answered this question, the following percentage either 'strongly agreed' or 'agreed' that the services or support they've had from the PDA Society had had a positive impact on the following outcomes:

- 96% my own personal understanding of PDA
- 96% knowing what approaches are helpful for PDA
- 87% improved quality of life for the PDA person I work with
- 96% ability to support the PDA person I work with appropriately
- 87% improved awareness/recognition of PDA amongst colleagues
- 93% personal development



As an educational psychologist I have found your information to be invaluable for parents, especially those who have no access to a diagnosis through the medical route.

Because of the PDA Society my staff have a much better understanding of the needs of many of the young people who come to our specialist college.

for parents/carers/family members ...

Of those who answered this question, the following percentage either 'strongly agreed' or 'agreed' that the services or support they've had from the PDA Society had had a positive impact on the following outcomes:

- 97% my own personal understanding of PDA
- 96% knowing what approaches are helpful for PDA
- 87% improved quality of life for the PDA person I know
- 85% improved quality of life for my myself/my family
- 70% feeling part of a community
- 78% others understanding PDA
- 68% the PDA person in my life receiving the right support



The information from the PDA Society allowed us to 'find' our child, to help understand how to support her and to lead educators on her care.

Without the PDA Society, I would have never understood my little man as I do now. I welcomed him into this world, but you welcomed me to his world!!!

Thanks to the PDA Society, I'm learning how to be the parent that my daughter needs and deserves.

I feel I am a more patient, tolerant and compassionate parent because of the information provided by the PDA Society and this has significantly strengthened the relationship I have with my son.

... and that this has been transformational in terms of outcomes

It is extremely valuable realising that we are not alone. That is literally life-saving.

Without the PDA Society I would never have considered that my daughter was on the autistic spectrum. I would've continued to feel that she was just 'naughty' and that I was a bad mum.

Without the PDA Society, I would have continued to parent my child in the way the professionals (who did not recognise PDA and kept saying ODD) were telling me. I am now better able to advocate for my child and parent him in a way which supports him rather than punishes.

It was the start of the journey from difficulty and chaos, to happy and settled.

I'm truly grateful that I've been able to turn things around with my son and he's genuinely got a chance of a normal life with my support. This would never have happened without the PDA Society.

The information from the PDA Society literally changed our lives as a family - we suspected our daughter was autistic but finding the info on PDA was transformational. I can now parent according to PDA needs - I wouldn't have had the confidence at all to do that, or to challenge school when things were going wrong. Totally life-saving for me.

Without the PDA Society my family would still be at breaking point.

Just having someone understanding what we are going through as no one else seems to care.

The PDA Society saved my family and helped me to point others in the right direction.

The PDA Society is viewed as trusted and professional



- 94% of respondents said they were 'very likely' or 'likely' to recommend the PDA Society to others living and working with PDA.

There's a strong call for the PDA Society to

- **raise awareness of PDA with the general public**
80% respondents said this was the challenge they'd most like our help with
- **further understanding and acceptance amongst professionals**
78% respondents said awareness and support in education settings was a top priority and around 50% of the additional comments made related to lack of recognition, understanding and consistency in health, education, social care and local authorities

"I find the lack of understanding and refusing to acknowledge the condition very stressful in all sorts of situations. I often feel powerless and avoid using the term PDA for fear of losing any kind of support.

Even with getting an ASD/PDA diagnosis for my daughter, we are met with disapproval, disbelief, refusal of services, etc.

Social workers assume parents of autistic kids with a PDA profile are in need of parenting courses rather than their kids having difficulties. Too often mothers are accused of having FII just because they've investigated their child's difficulties.

It would help if educators and health professionals had more training and stopped focusing on the behaviour and started focusing on the meeting needs.

I have sourced lots of information - regardless of my knowledge and experience, the LA and NHS dismiss my views as "Mum says ..." - without them sharing this understanding this leads to continued animosity and mistrust.

Clinicians and schools need to have a better understanding of the unique profile of PDA in relation to other types of autism. Also for them to recognise how girls and women present and the differences in home and school settings, and the challenges of masking.

Proper recognition of PDA would help: the get-out clause at the moment is "it's not in the diagnostic handbook".

Most autism courses are focused solely on 'typical' autism diagnoses, so parents of children with a PDA profile are left in the lurch and given little to no support on how to best support their child's unique circumstances. Schools also consistently apply traditional autism management techniques and are quick to assume ADHD, ODD and attachment disorders are at play, forcing the child to conform and exacerbating their anxiety. Techniques for managing PDA should be a first port of call before making sweeping judgements about personality and behavioural issues. CAMHS also need to recognise that support for a PDAer's anxiety should be given as a priority.

It's also clear that access to an accurate diagnosis and appropriate support is still not forthcoming

It was very noticeable that whilst the PDA Society's information and services has led to many positive outcomes as explained above, the figures relating to accessing an appropriate diagnosis or the right support were considerably lower (only 38% of PDA individuals and 57% of parents/carers/partners said that we'd been able to help with access to an appropriate diagnosis; and 43% said we'd be able to help with access to the right support).

Conclusions & next steps

Thank you again to everyone who took the time to complete our survey. We'd also like to thank the PDA Society team, the vast majority of whom are volunteers, for all their expertise, experience and commitment, and for spending so much time and energy helping others.

This survey shows that we've had a very positive impact in our first 5 years as a registered charity.

The charity's reach and remit had grown considerably during this time, and it has successfully transitioned from its origins as a parent/carer forum to a rounded and respected organisation which has kept focus on its primary aim of improving outcomes for PDA individuals and their families.

Our model to date has been volunteer-based, with all volunteers directly connected to PDA. This model has been low-cost and flexible, however, the combination of the charity's growing remit and our volunteers' often complex home lives (along with the additional challenges that Covid has brought) means it may not be sustainable in the longer term.

Over the last 12-18 months the PDA Society has contracted some help in administration and communications, and the charity has always paid a nominal fee to its training facilitators. The trustees intend to gradually evolve the charity's operational model to include more contracted support for both ongoing operations and project management. This will also necessitate a more proactive and formalised fundraising programme.

Looking ahead to the next 5 years, the PDA Society's primary aims are:

- to increase acceptance and understanding of the PDA profile within the concept of 'dimensionality' in autism
- to improve outcomes for individuals and families by focusing everyone involved on 'what helps'

“ We are trapped between a medical services saying a diagnosis isn't needed to get support, and support services that deny our needs without a diagnosis

I work with social workers every day and most do not even know anything about PDA and will place people into supported living with low-level support because they look physically able and do not recognise their deeper issues.

My son, and one other child I know of, cannot get a diagnosis of anything because their behaviours don't fit the traits of any currently recognised conditions, such as ASD.

I've been told my daughter doesn't fit criteria, i.e. no hand flapping, good eye contact and can hold a conversation.

I work in CAMHS. No real support base for PDA amongst colleagues due to diagnostic schedules/resourcing. Constant battle for me to show PDA still valid. ”

Responding specifically to the key points raised in the survey, this table gives a flavour of what the PDA Society is doing and planning ...

You told us

Some of the things we're doing & planning

We're making a difference

- Keep doing what we're doing and whilst we grow/evolve don't stray too far from our roots

Wider public understanding of PDA is your biggest challenge

- Create new, easily shareable content – starting with a new "What is PDA" video
- Continue to develop resources which inform & explain
- Continue with our active social media presence & to pursue opportunities for media coverage
- Work with advocates, charities and professionals to increase awareness of dimensionality in autism and understanding of PDA & helpful approaches within this

Awareness and support in education settings is your second biggest challenge

- Offer further training and support for education professionals and schools/colleges
- Continue to offer support for families navigating the education system (liaising and signposting to other specialist organisations as appropriate)
- Continue to provide education-focused resources
- Encourage an education champions network to share best practice

More consistency/recognition is needed in all our public services (healthcare, education and social care)

- Undertake a project to support a more consistent approach to identifying the PDA profile – sharing the results of this as widely as possible with professionals involved in recognising, assessing and diagnosing autism
- Undertake a project to document best practice in post-identification support – sharing the results of this as widely as possible with professionals supporting autistic people
- Advocate for integrated needs and strengths-based assessments
- Input into professional education as well as continuing professional development
- Explore opportunities for 'masterclasses' in identifying and supporting the PDA profile
- Continue to develop helpful resources
- Encourage a champions network to share best practice
- Encourage more research
- Encourage wider understanding of the dimensionality of autism across all relevant professions
- Share information about what services are available that may be helpful and how to access them

Accessing appropriate diagnosis and support is difficult

Mental health difficulties and ADHD seem to co-occur with PDA

- Encourage research to explore these overlaps further
- Signpost and work with other organisations which specialise in mental health and ADHD

Families are unable to get appropriate support from CAMHS

- Continue to address concerns about CAMHS with relevant authorities
- Continue to provide timely and helpful information, support and training for individuals and families

There were some things we do that respondents weren't aware of ...

- Regularly share information via social media and our monthly newsletter about our different services & resources – e.g. online discussion forum, info/support for siblings, training & webinars, resources for adults, local support groups, info on how to set up a support group, regular giving facility (and many other ways to donate/fundraise), discussion forums for educators, international groups, monthly newsletters ...

You'd like to see similar organisations in other countries

- We've supported organisations in other countries by allowing info from our website to be used, and have given permission for materials to be translated into many other languages

You'd like us to lobby for greater recognition of the PDA profile

- As a small organisation with limited resources, we aim to achieve this by working collaboratively with relevant organisations and individuals and through the activities and services listed above