PDA lives worth living

Autistic people with a PDA profile are experiencing a mental health crisis.

This isn't inevitable.

This report outlines the scale of the problem and what we can all do to make a difference.

PDA Society

The charity for PDA people and everyone in their lives.

Registered Charity Number : 1165038
www.pdasociety.org.uk

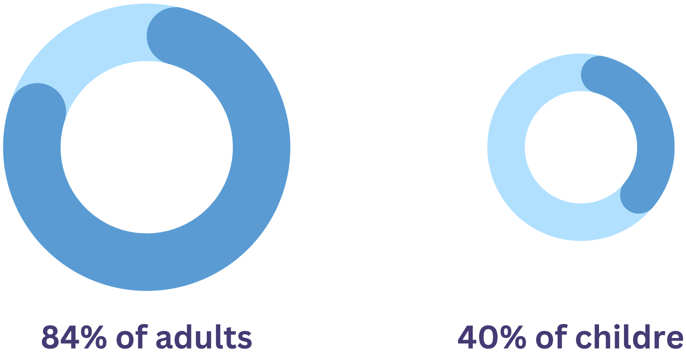
About autistic people with PDA

PDA[1] is most commonly described as a profile on the autism spectrum. This means that people with PDA are autistic, and may have differences in social interaction, communication and sensory processing, and some restrictive or repetitive behaviours. In addition PDA people[2] will have a fear response to demands, and use social strategies to avoid them. The cluster of traits common to autistic people with PDA is known as a **PDA profile**.

Demand avoidance is not uncommon in autistic people; however, most demand avoidant autistic people do not fit a PDA profile. Whilst their behaviours might seem similar on the surface, the approaches needed for PDA autistic people and other demand avoidant autistic people can be different. Conventional strategies, such as consistent routine and structure, boundaries, literal language, or rewards, are not only ineffective, but can actually make things worse.

We believe that all autistic people have a right to access professionals who are focused on meeting their individual needs, whether they have a formal diagnosis or not. For this to happen, it is essential to have an understanding of what works for people with less common presentations of autism, such as PDA.

The percentage of PDA people who have ever considered taking their own lives



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[1] PDA stands for Pathological Demand Avoidance, a term coined by Elizabeth Newson in 1983.

[2] A note on language. The PDA profile is part of the autism spectrum. In this document we refer to people with PDA as: autistic-PDA people, autistic people with PDA, autistic people with a PDA profile, and because it is a term the PDA community use, PDA people. Our use of the term PDA people does not infer that we consider PDA to be separate diagnosis to autism.

About us

The PDA Society is the **only specialist PDA charity in the UK.**

We care about PDA people and believe that happy autonomous lives are possible – everything we do is about trying to make life better for PDA people and the people who care about them.

We do this by:

- Raising awareness of PDA and providing high quality, trustworthy information.
- Providing training to parents and professionals to help them understand how to support PDA people, and to build safe, supportive connections.
- Offering tailored support to PDA people and their families through our enquiry line service. This is entirely staffed by trained people who ‘get it’, either because they are PDA themselves, or are a parent carer of a PDA person.
- Supporting the PDA community to build connections and act collectively to influence positive change for PDA people.

Underpinning all of this is our commitment to research and using evidence to influence better understanding, better support and better outcomes for autistic-PDA people.

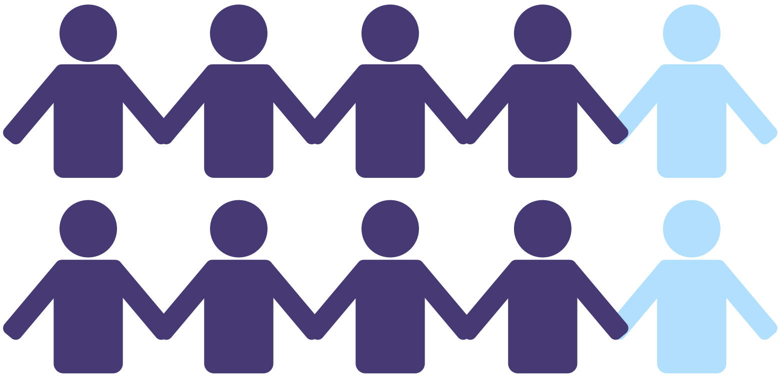
Overview

In May 2023, PDA Society ran a survey of PDA adults and their families, as well as parents of PDA children. We had 921 responses and the results were clear; autistic-PDA people are experiencing a mental health crisis. Here are some of our key findings:

- **87% of children & 82% of PDA adults have experienced severe anxiety in the last year.**[3]
- **84% of PDA adults and 40% of PDA children have considered taking their own lives.**[4]

Despite the fact that 66% of PDA children and 82% of PDA adults felt they needed professional support for their mental health in the last year, one in four autistic-PDA adults couldn't identify anyone, either personally or professionally, who could give them the support that they needed. Those who could identify sources of help mostly named friends or family members, as opposed to professionals.

More than 80% of PDA adults and children have experienced severe anxiety in the last year.



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[3] All statistics for PDA children are reported by their parents.
[4] These statistics refer to the number of people who have ever considered taking their own lives.

PDA Society conducted a similar survey in 2019 which suggests a worrying trend. In 2019, 19% of parent carers reported that their[5] PDA child had experienced depression. In 2023, 45% of children and 80% of PDA adults told us they have been depressed within the last year.

We have since worked collectively with PDA adults, parent carers and professionals to identify key areas which could improve this situation for PDA autistic people, which would likely also benefit other autistic people.

We believe that autistic-PDA people would have better health outcomes if:

- Receiving a formal diagnosis was no longer a barrier to accessing support, with a focus instead on assessing and meeting the needs of all disabled people, even when the cause of their disability is not fully understood.
- Professionals embraced the complexity and diversity within autistic communities, sharing widely different approaches that are helpful for people with different profiles, rather than assuming one size fits all.
- Barriers in asking for help were reduced, by offering choice and flexibility in how that help is asked for and received.
- Signposting and specialist support was available to professionals, so they could offer effective help to PDA people in crisis.

[5] Part of this difference may be due to question wording. In 2018 we used the term ‘severe depression’, whereas in 2023 we used ‘depression’. However, this is not likely to explain all of the increase.

Having a stress response to demands means that autistic people with a PDA profile are likely to experience daily challenges to their mental health.

Sadly, the ongoing debate around how PDA people are labelled has overshadowed the reality that PDA people and their families are being failed by a system that isn't meeting their needs. This contributes to further devastating and avoidable damage to the mental health of PDA people.

The good news is that this is not inevitable. It is possible to provide help and support to PDA people which makes life bearable and opens up the possibility of safer and happier futures.

Together we can make things better.

The following pages contain the personal accounts of PDA people and their carers. If you are affected by any of these stories and need support with your own situation, you are welcome to contact our **free enquiry line.**

Key findings

1. PDA adults and the parents of PDA children told us that a diagnosis is being unlawfully used as a barrier to accessing services.

The latest NHS statistics show there are currently 143,119 people on the waiting list for an autism assessment.[6] If access to support is dependent on a diagnosis, this increases pressure on diagnostic services and leaves vulnerable people without support, negatively impacting their physical and mental health.

If all professionals focused on meeting individual needs where a diagnosis is not in place, then fewer PDA people would find themselves in crisis.

> “I can't get on the waiting list (for diagnosis) and I can't afford the assessment. I have been refused DLA. They stated the reason was that he is not diagnosed so can't get it, so I'm left without that help also. GPs don't understand and won't help. CAHMS refuse to help because they are not in mainstream school. The NHS paediatrician in my area has refused to see both children who were referred from different professionals. Access to professionals without having to fight for years for a simple appointment would be nice.”
>
> **- Sandra -**

> “Since diagnosis we’ve had more support in general and professionals understand him. They have been able to take training courses in PDA and PACE, and the approaches are then used to support him correctly. This has meant that he’s more regulated, the pressure is lower and he is happy again. His mental health is in a much better place.”
>
> **- Mike -**

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[6]NHS autism statistics July 2022-June 2023

Many people told us they were (wrongly) advised that they couldn't have an EHCP assessment, a child in need assessment, social care assessment or carers assessment until they had a formal diagnosis. We were also told that mental health services have refused to begin working with people who are on a waiting list for an assessment. PDA people are being refused reasonable adjustments at school, at work and in the health service without a diagnosis. Being unable to access the right support can have a negative effect on mental health outcomes.

Others reported that, after receiving a diagnosis, they experienced more willingness from professionals to take additional training or try different approaches. While this is excellent news for people who have reached the top of the waiting list, or can pay for a private diagnosis, it increases inequalities for people who are less able to ask for help and who cannot afford to pay privately.

“After I got my diagnosis a lot of people understood me a bit better, especially teachers, so they tried to phrase things in different ways and tried to give me as much time as I needed to complete demands.”

- Asim -

We believe it would improve mental health outcomes for PDA people if support was made available in response to presenting needs rather than after diagnosis.

“(If) the world understood everyone has the right to accommodations regardless of being neurotypical or neurodiverse. If everyone was inclusive then we wouldn't need diagnosis to give us the correct provisions.”

- Bwale -

Key findings

2. We were told that professionals often insist on using what they consider traditional autism approaches with PDA people.

We heard from parents of PDA children who had only been given information about one support approach which involved setting rigid boundaries (often not suitable for any autistic person), which they worried had caused their child unnecessary distress. Many people told us that so-called traditional support approaches for autism were unhelpful resulting in both a worsening of their presenting behaviour and of their mental health.

> “Don’t just assume he needs autistic strategies! He needs quite the opposite and it confuses professionals when they knows he’s autistic but the typical ASD strategies don’t work and they don’t understand why. PDA needs to be recognised and accepted by ALL professionals - CAMHS told me that PDA is ‘controversial’ and weren’t willing to accept that he wasn’t a typical autistic child and he needed someone to be patient with him.”
>
> **- Rachel -**

> “Home life was brutal, with violent explosions, threats, and general unhappiness. This turned into anxiety, depression and suicidal ideations, which eventually led to hospitalisation. We had physical and emotional violence in our home and damage to our property. Over time, we encountered school refusal. After hospitalisation, we decided to stop following “expert” advice and things began to turn around. This made so much more sense when I learnt about PDA.”
>
> **- Eve -**

One mother told us that the approaches used by school caused such distress that he was self harming daily. Despite this neither CAHMS nor school were prepared to try lower demand approaches with him.

“I had to take him out from the school for his safety. He is 10 years old. He acted completely different at home and in the community from at school. At home I use PDA approaches and he’s fine, not an angel but he doesn’t hurt anybody. He's so violent at school. At eight years old, he started really harming others, pulling hair and biting on a daily basis. And in the meetings they would ask me how I dealt with that. And I told them I managed behaviour differently at home and it worked but they just didn’t listen.

He started to be not himself. The severity of harming others and himself was just unbelievable. And because he had severe speech and language delay a lot of time, people don't understand what he's saying, and of course he gets frustrated and extra anxiety on top of his PDA. Every morning for 6 months he was screaming with distress about going into school. I went to CAMHS. They tried medications on him.

Meanwhile I felt my son was unsafe at school, he had bruises, really heavy bruises on his back, it turned out that school had started restraining him. I can’t understand how this was an easier choice for them to make than trying the flexible approaches that worked at home. I took him out of school more than six months now, he's at home with me. In that time, I’ve not had one incident with him.

He’s been released from CAHMS – I said to them so you’ve had my little boy on your list for three years, you’ve tried to medicate him and it turns out all I had to do was take him out of a school who won’t treat him the way he needs to be treated. It’s ridiculous – all his distress, the self-harm – that wasn’t about his PDA. It was about his teachers not being prepared to try a different approach with him.”

Parents also talked about feeling pressure from other parents and from their families:

> “Normal parenting didn’t work, discipline didn’t work, everyone thought I was just a bad parent and that I needed to be firmer, yet my child was just getting worse whenever I tried to be firmer, at 5 years old he talked of wanting to die because life was just hell for him, and people still wanted me to be firmer with him.”

- Rosie -

We believe it would improve mental health outcomes for PDA people if everyone had access to information about different approaches that can work for the variety of presentations of autism.

> “Using a different approach has totally changed things (for the better) - not always, but a lot of the time a low demand approach has made a world of difference. It’s also made me feel better about how I parent, and made me feel more confident in my approach to parenting - especially when it goes against the norm.”

- Charlotte -

Key findings

3. We heard repeatedly that asking for help around mental health was too hard.

We found that 66% of children and 82% of adults needed mental health support in the last year. Respondents told us that the restrictive options for contacting GPs created additional stress-inducing demands for PDA people, that made it hard to even book appointments to ask for support.

We also heard that the lack of flexibility in setting appointments around people's needs, and the lack of understanding from medical professionals about what's helpful for PDA people, makes it nearly impossible to access support. Part of the problem was professionals not understanding the number of demands involved in navigating their administrative systems.

> “Beginning all the various tasks I need to do, including leaving the house, beginning tasks which are not repetitive, and contacting people. Anything which is outside the normal routine could be almost impossible to do, but I've developed a successful strategy to accomplish these things. But sometimes I still need to rest in bed for a day or two when my brain crashes.”
>
> **- Noah -**

> “He has now got an appointment with a psychiatrist in December, but I've got to get him there, in a different town and it's at half past 9 in the morning. How the hell am I going to get him out of the house anyway and then at that time? He has only left the house on his terms once in 3.5 months. And asking for a different time? Oh, it'll be January. Hardly anybody understands PDA and it is too mentally exhausting for me to continually fight to get him the help he needs.”
>
> **- Ash -**

“It’s never easy to get help - call the GP 8 o'clock in the morning and they reject all the calls and so I don't really get to go to the GP or get any real care coordination. The GP’s don’t know what they are dealing with - they think it's something different. I feel so angry I have to keep fighting for everything. I have to really overcome so many demands just to get an appointment with the GP. When all I'm asking for is for them to write a letter or, you know, just to come to my house and to take some blood sign or something like that, it's not even a very complicating thing for them to do.

And there’s enough to navigate just to get the care that you actually need from the NHS when you need it. It can be an absolute nightmare, it really can, because especially if you've got a lot of stuff on your medical file, like a background or lots of different opinions and things.

It all becomes so complex and often the people treating you don't even have a relationship with you, it’s just like a kind of roller coaster ride, and you know whoever turns up is treating you that moment, they'll make a report or an assessment from the session of what's going on, but they won't always join it up or have the information and the wider issues. They don't always treat you properly as a result and that's really stressful.

It should be that there's a kind of care coordinated nurse really, that's assigned to everyone who has a PDA diagnosis. If they don't have that support and they don't have that ongoing relationship and contact, they just sort of push you from pillar to post. That's what my experience has been and it's very stressful. It's very, very hard to cope with. I'm sure no one really wants it to be that way but everyone seems to have better things to do than help. ”

- Jonathon -

We believe it would improve mental health outcomes for PDA people if people who self identify as PDA, or have a diagnosis, could receive reasonable adjustments around booking appointments and how and where they get support from primary care.

“It would be great if in each GP surgery, in each area of primary care, in each school, in each LA Send Team there was a specialist who understands and is trained in PDA. My son’s life would be vastly improved if he could have a GP who is PDA trained or a PDA Care Coordinator for example, who could review his medication, who could perhaps on his terms talk to him, build up a relationship and have regular appointments with him, the same as if someone had a consultant/specialist.

My son after being discharged from Cahms at 17 because of his age, has just been left and neglected and his mental health has declined even further. We have been passed between different adult services who don't know enough to help. My son at 19 is not functioning, he is just existing, he is just on his computer, has no friends, he is not taking part in any education nor work. Why isn’t he automatically receiving regular appointments with a consultant/specialist trained in PDA?”

- Violet -

Key findings

4. Ten percent of PDA children and thirty-two percent of PDA adults had received in patient care at some point in their lives. However, respondents told us when PDA people reach crisis point professionals don't have the knowledge about PDA profiles to be able to support them effectively.

> “My son had a mental health crisis for over two years - self harming, suicidal ideations and an attempt. No support was given because professionals didn't know how to engage him and their language and approaches only made things harder. CAMHS weren't willing to accept PDA.”
>
> **- Hanifa -**

> “The level of care my young person has is negligent/dangerous. I am left trying to single-handedly support their mental health and I am not an expert.”
>
> **- Janet -**

Families told us about the difference it made once clinical staff understood PDA

> “I could not keep the siblings safe whilst also thwarting my daughters' suicidal attempts - following her when she absconded and restraining her when she stood in four lanes of traffic and we waited for police/ambulance. So we went into a voluntary arrangement with child protective services and she spent some nights outside of the home each week. It was after this time that her psychiatrist learned about PDA and I changed my approach. She has been home full time for five or six years now.”
>
> **- Angus -**

James’ Story

“There was one incident in my life where the police were called, and I was taken to mental hospital. They diagnosed me with paranoid schizophrenia. Which was the worst wrong diagnosis you can get when you have PDA because once you've got that diagnosis, it's almost impossible to convince people that you are struggling with anything else. It's probably on the hardest label to get rid of.

So I had to meet with other psychiatry networks to come up with a proper treatment plan for myself. Because I wasn't getting the support that I should have been getting to help with my PDA, it became very, very complex and I think, you know, sometimes we have behaviours when frustrated can seem, like one condition when actually there's something completely different. And then, you know, if you get on the wrong medication regime, your whole life can fall apart and there's not much.

You can really do about that because the side effects of some of these antipsychotic medications when you're on them are like torture. You know, they really are absolutely awful medications to go on. I couldn't think straight, I couldn't function properly, I would forget everything. And I think, you know, a lot of people who are autistic, do go on these antipsychotics at one for another because they get misdiagnosed.

I do wonder, you know, how many people are there who are PDA and have been misdiagnosed in a mental hospital? And are not getting proper treatment in the community. Because from the time I've spent in mental hospitals, you know, it does seem like that that does happen a bit.”

We believe it would improve mental health outcomes for PDA people if mental health crisis professionals had access to PDA resources, including a linked professional with deep knowledge of PDA and PDA support approaches.

> “There was mental health support for our child from someone who actually understands PDA. Most have not either heard of it or learned anything about it. And their approaches tend to be typically behaviourist approaches which just don't help.”
>
> **- Andrea -**

What next?

It is not acceptable that so many PDA autistic people are struggling with their mental health so acutely that they feel their life is not worth living. We believe that, if PDA people could access the right support at the right time in all aspects of their lives, this would reduce the number of people going into crisis.

We are working towards a future where this is a reality. That’s why we are:

- Working with PDA adults, parent carers and professionals to build guidance on finding services that are appropriate for PDA people’s needs.
- Putting together specific training, support and resources for all professionals who work with PDA people.
- Continuing to invest in our enquiry line so that anyone who needs support and information about PDA can get timely and personalised help.

We can’t do this alone...

PDA people would have better outcomes if:

- All Local Authorities and Health Agencies committed to needs-based routes to access support, which aren’t blocked if a formal diagnosis isn’t in place.
- All Local Authorities and Health Agencies provided basic information to their teams about dimensionality within autism, and the different approaches that work for autistic people with different profiles, including PDA.
- All Health providers provide clear information on how to request and receive reasonable adjustments in care.
- All Mental Health Crisis teams had access to a named person with specialist knowledge about PDA and appropriate approaches to use with PDA people.

We are putting out an open call to anyone with the ability to influence these changes in their role. Whether it’s national, local, or one GP practice or school at a time – if you’re committing to making the necessary changes to tackle this mental health crisis then we want to hear from you. We’ll help in any way we can.

PDA people can live happy, fulfilling lives. Let’s help make this possible – together.

How this report was produced

The statistics in this report are from a survey PDA Society undertook in Spring 2023. The research findings on Mental Health can be found in full here.

Quotes from this report have been anonymised, and came from survey responses, facilitated sessions with community members and written submissions from PDA people and family members.

Should this profile be called PDA?

Research on PDA is in its infancy, and there is ongoing debate about how to categorise or label the experiences of PDA people. The focus of PDA Society is less on the terminology used and more on ensuring that individual needs are understood.

We do not know how many PDA people there are in the UK. There has only been one study of prevalence, which was small and therefore not definitive.

However, this study suggests that 1 in 5 autistic people could have a PDA profile, which could mean there are as many as 140,000 children and adults across the UK who are not receiving the support they need to thrive.

We believe all autistic people should have access to professionals who are focused on meeting their individual needs whether they have a formal diagnosis or not, and that for this an understanding of what works for people with less common presentations of autism such as PDA is key.

If you have further questions, or think you can support us to improve outcomes for PDA people, you can reach us at: comms@pdasociety.org.uk

PDA SOCIETY