People with misunderstood autism profile facing mental health crisis say national charity.

Tuesday 14 November, 2023

In a report released today PDA Society revealed that more than 80% of autistic adults with a PDA profile have considered taking their own lives.

The report's findings come from a survey conducted by the PDA Society in May 2023, and suggest that **80% of adults and 40% of children with a PDA profile of autism have considered taking their own lives.** The data also shows that more than 80% of PDA people have experienced severe anxiety in the past year.

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

PDA (which stands for Pathological Demand Avoidance) is 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 will have a fear response to demands, and use social strategies to avoid them. It isn't known how many PDA people there are in the UK. The only study of prevalence, which was small and not definitive suggested that as many as 1 in 5 autistic people could have a PDA profile. If this was the case it would equate to 140,000 people across the UK.

Conventional strategies suggested to support autistic people, such as consistent routine and structure, firm boundaries, or rewards and consequences, are not only ineffective with PDA people, but can make things worse. PDA Society's report suggests that this is key to understanding the mental health crisis that PDA people are experiencing. They believe it is essential professionals understand what works for people with less common presentations of autism, such as PDA.

PDA Society's CEO, Elizabeth Archer says "It's devastating that so many PDA people are considering taking their own lives. **We found that 82% of PDA adults felt they needed professional support for their mental health last year, but a quarter couldn't name a single person or service that had offered them that help**. And where people had received support, they overwhelmingly talked about getting that from family and friends not professionals.

PDA people struggling with their mental health deserve access to help from professionals who recognise the challenges they face and ensure that help is accessible to them. Our report outlines four changes in approach that could transform PDA people's experiences, both of stressors that contribute to this crisis and of seeking help. This situation is not inevitable, with fair access to help and support PDA people can live happy lives"

Evidence from the report suggests that, even with a diagnosis in place, there are very few health professionals who have access to adequate training, resources or specialists to advise on support approaches that are safe for PDA people.

One parent of a PDA child said, **"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 [with] him and their language and approaches only made things harder. "**

PDA Society are calling for wider recognition of less common presentations of autism, including PDA, and for all healthcare providers to follow a needs-based support approach with autistic adults and children.

PDA Society is the only specialist PDA charity in the UK. You can read the report in full on their website or get in touch at comms@pdasociety.org.uk.

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CASE STUDY

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Scan Me:

Agnes (pseudonymised)

Agnes' son had two very difficult years with his mental health and behaviour. Professionals wouldn't use PDA approaches with him. Instead he was medicated and restrained. Agnes has now taken him out of school.

"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."

About PDA

PDA 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 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, firm boundaries, or rewards and consequences, are not only ineffective with PDA, but can actually make things worse.

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.

About PDA Society

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.

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