



# Being Misunderstood in Education

Experiences of the  
Pathological Demand Avoidance  
profile of ASD

March 2019

## Introduction

There is a group of autistic people for whom highly structured approaches are not only unhelpful but can lead to increased and debilitating stress. Instead, collaborative approaches to learning and daily living tasks are significantly more effective. This need for a tailored approach makes it essential for this group to be identified, even though research into causation and relationship to other conditions is in its infancy.

The PDA Society conducted an online survey for two weeks in March last year, 2018, through the PDA Society website and social media. 1,445 parents, professionals, adults with PDA and their partners or family members contributing and provides a snapshot of the current situation with the usual limitations of a self-selecting sample. The main survey report entitled 'Being Misunderstood' was published in May 2018 and is available from the PDA Society website. The results demonstrated that, in practice, the constellation of traits **is** being identified by some who diagnose ASD, and that this is most often done through use of terminology which reflects the idea of a '**Pathological Demand Avoidance profile of autism**'.

This report describes the *education findings* in more detail. Overall 70% of 969 young people were not able to tolerate their school environment or were home educated. It was found that staff in special schools were more likely to be knowledgeable about the PDA profile, but that they still struggled to provide an environment that these young people could access easily.

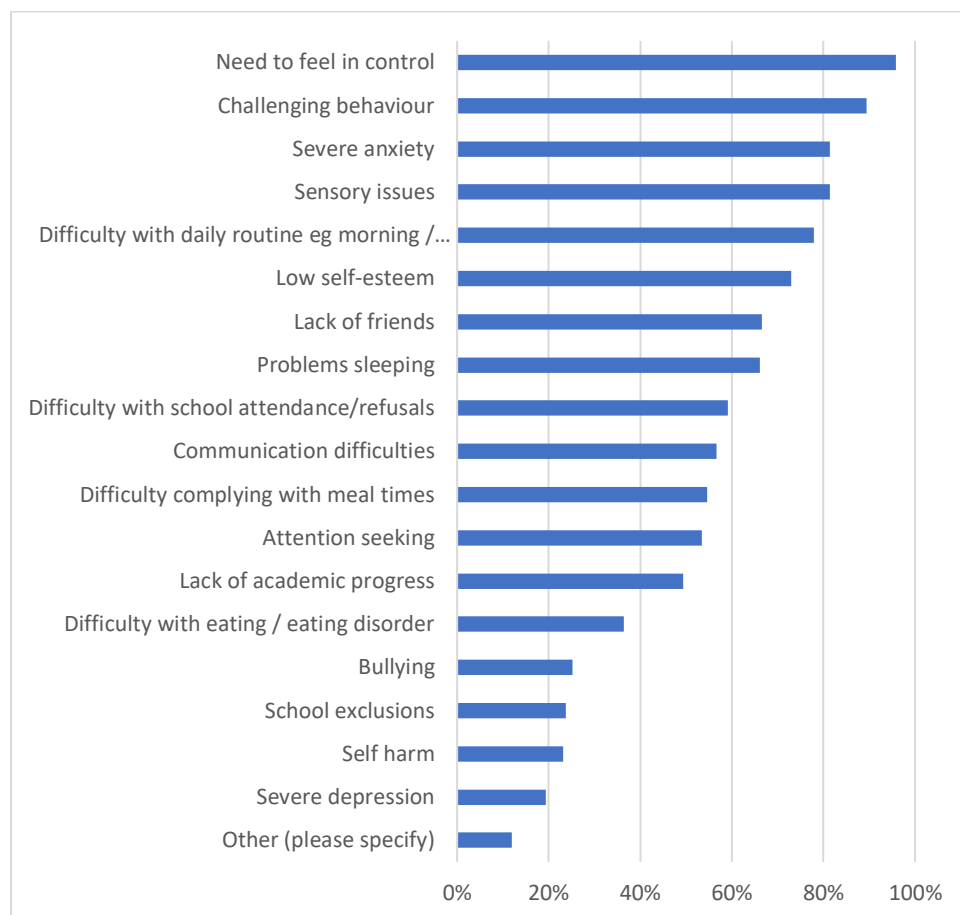
For outcomes to improve, understanding of the PDA profile is needed to ensure appropriate accommodations are made. For this to happen local leaders of education and children's services must frame the way in which this autism can be managed. They must also invest in suitable provision and support to be available if school-based services are unmanageable for the child and become damaging.

This report provides data and comments from relevant parts of the survey and concludes with the education-related conclusions and recommendations first highlighted in 'Being Misunderstood'.

## Experience of living with a PDA profile or demand avoidance traits

### Are any of the following significant issues?

Parents were asked about the significant difficulties that their child or young person experiences



The proportions of young people experiencing multiple difficulties is striking, with a need to feel in control being identified by 96% of respondents. Severe anxiety and sensory issues were significant for 8 out of 10 young people.

Given that severe depression was identified by 2 out of 10, this could suggest that the anxiety is associated with the ASD condition rather than being a symptom of a mental health disorder per se (although it could still be described by clinicians as a 'co-morbid psychiatric disorder').

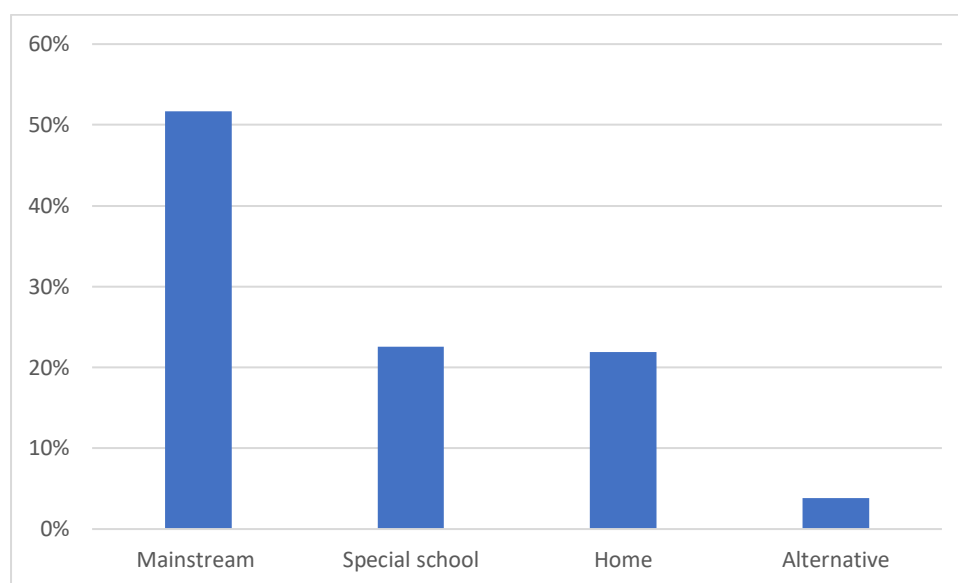
The difficulties are ones you would expect to see in a group of autistic people. Nevertheless, it is notable that almost 80% identified difficulties with daily routines such as morning and bedtime routines, around 60% had trouble with school attendance, and more than a third (36%) had difficulties with eating or an eating disorder.

## Education outcomes

### What type of school / college does your child attend?

Mainstream state funded	44.7%	433
Mainstream independent	7.0%	68
Specialist state funded	14.1%	137
Specialist independent	8.5%	82
Home ed - by choice	6.0%	58
Home ed - no choice/tutored at home	11.2%	109
Alternative provision	8.4%	82

The question gave a number of choices and also allowed an explanation of 'alternative provision'. The comments showed that 45 (55%) of this group explained that their child was not able to get into either school or alternative provision (school refusing). The remaining 37 in the 'alternative provision' category were attending specialist settings of different types, including pupil referral units or hospital education units. A few were waiting to transition between placements.

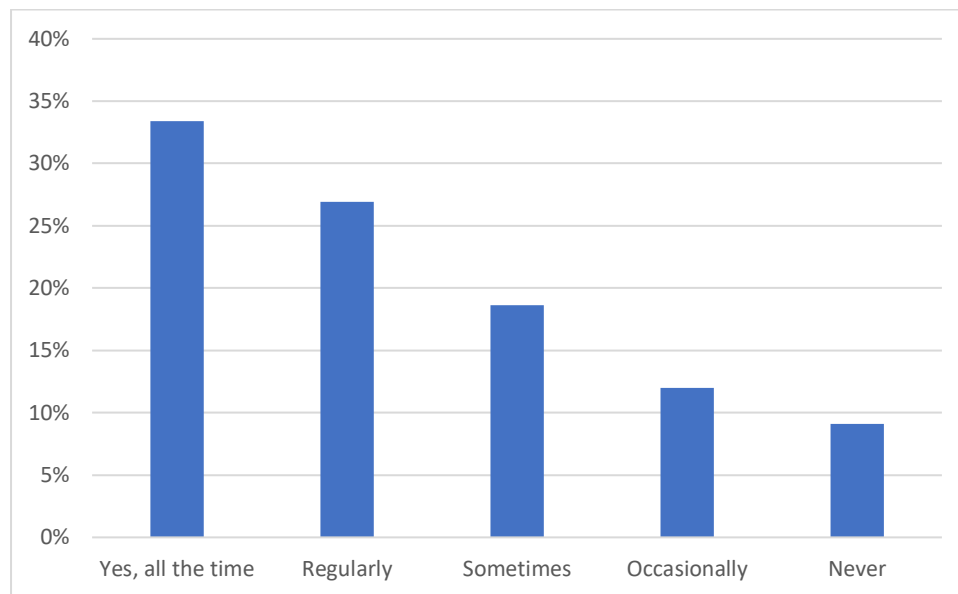


Just over half were enrolled in mainstream settings, with about a quarter enrolled in special schools or specialist settings.

That left over 20% who were at home, either because they were being home-educated (often by choice) or because the stress involved in going to school was so great that they could not access the school environment.

## Does your child struggle to get into school?

Analysis of this question allowed filtering of the answers so the graph applies to only those enrolled in schools.



Of the 720 children on a school roll, only 1 in 5 (21%) never or occasionally have problems getting into school. In contrast, parents said that 34% struggled 'all the time' and a further 27% 'regularly'.

Notably, special schools were unsuccessful at finding ways to enable these young people to access education, with two thirds (67%) of those enrolled finding they regularly had problems attending or had problems 'all of the time'.

## Has your child ever been excluded from school?

Of those surveyed who were enrolled in a school, 40% had experienced temporary exclusion from school and 7% had been permanently excluded at some stage.

## Adult experience of school

Adults were asked to comment on their experience of school and 82 did so. Many comments would be expected of anyone with autism, though again the level of school refusal was again notable.

Most common phrase was used 17 people who said they 'hated it', two described the experience as torture, others saying it was the worst experience of their lives. Some described bullying, many talked of loneliness and isolation, and some also talked positively about their enjoyment of the academic aspects.

*“Utterly alienated, confused, mostly the work was boring as I took things in much quicker than other kids. Definitely spaced out with sensory overload. Injustice. Never sure why I was in the corner or whatever again. Always loved the work.”*

*“School wasn't easy for me. I preferred to go off into my fantasy world. I also felt that i didn't fit in, and i often challenged my teachers. I was often told that i was lazy, stubborn etc.”*

*“Primary - it was manageable but as I got older became very anxious although hid it Grammar - avoided school at all costs”*

*“Loved the learning aspect but hated being told what I could learn. Struggled with demand of timetables, routines and interactions with others, including teachers”*

*“I hated school, I wanted to kill myself rather than continue to go. I was homeschooled/unschooled for 3 years then went to secondary school, where I still wanted to kill myself and left at 16 and went to college for 2 years, which was no better.”*

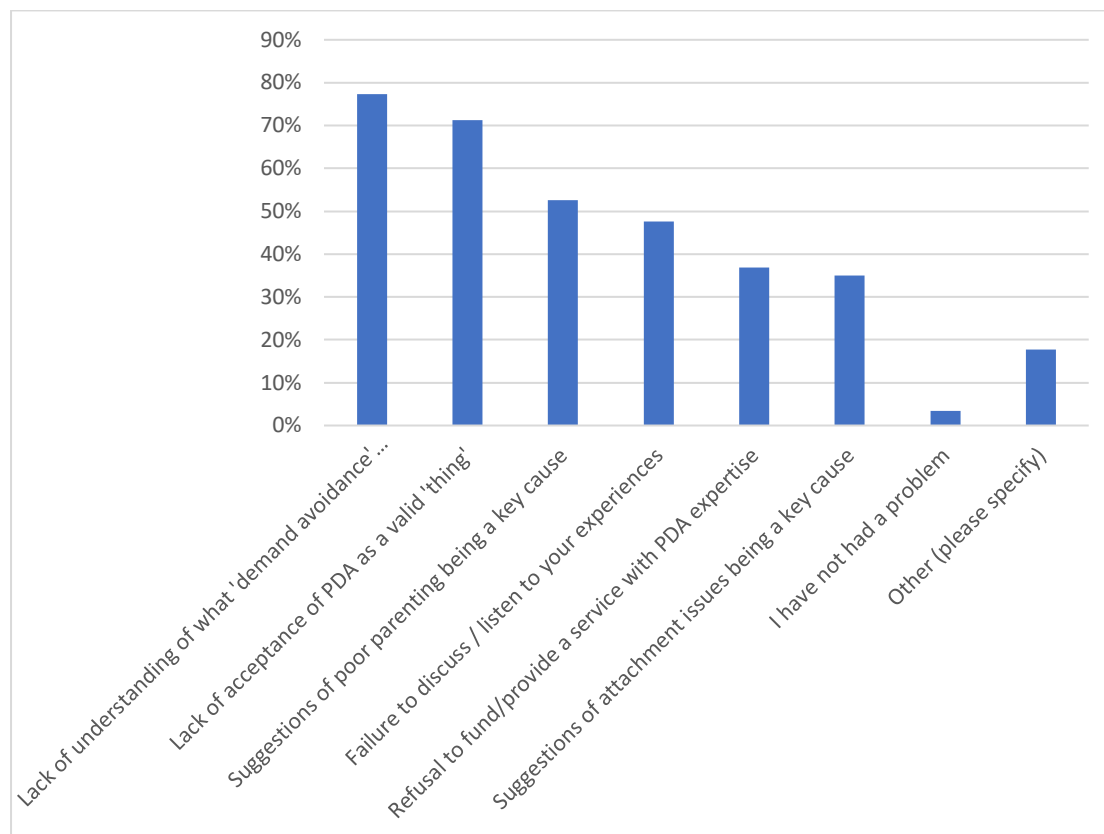
*“Bullying by teachers and peers. Spend most of time withdrawn, nose in book, daydreaming, trying to escape. Lots of playground fights with bullies. Less fighting in teenage years as it was more in my power to just leave the premises.”*

### **Did you get qualifications?**

Despite the difficulties, 39% of the adult respondents had a tertiary-level qualification, a number gained in later years.

## Barriers to support and quality of services

Parents were asked: Have you found that any of the following have been a barrier to getting relevant support?



The main problem people felt was a barrier was the understanding of what 'avoidance' means in practice. This was cited by more than three-quarters of respondents and it is understandable, as the underlying causes of behaviour can be difficult to tease out and demand avoidance is a phenomenon that is very difficult to describe. In addition, health workers in particular only see young people for a very short period of time. It is likely that the lack of familiarity and training means very many professionals are unable to grasp the complexities and difficulties of this type of behaviour.

The lack of acceptance of 'PDA' as a valid 'thing' was identified by 7 out of 10 as being a barrier. When you have to start by persuading someone of the very existence of what is essentially a constellation of behaviours within autism, it is clear you are unlikely to get a knowledgeable, insightful response.

More than half had the experience of feeling that they were taking the blame for the problems their child faced. It is common for some professional groups to start with the assumption that difficulties in a child are caused by problematic parenting, which is not a basis for collaborative working.

Almost half felt there was a failure to listen to what they were saying. There has to be more understanding that it is the parents who are the experts on their children and successful professional working involves extracting the solutions from parents and supporting them to achieve.

Out of over 1000 responses, only 36 people said they hadn't faced barriers.

187 people described other reasons that they had not had support, and a small number described more positive caveats:

#### **Examples of responses:**

*"Initially the above were an issue until we saw a paediatrician who understood PDA."*

#### **General lack of services or funding**

*"No funding for ASD full stop!"*

*"It is such a huge battle to get any support in XXXXX. Lack of resources means that waiting lists are long, skills/expertise are limited and staff are demotivated. We couldn't watch while our daughter's mental health declined any more so we use all her DLA money (and more!) to pay for private help."*

*"General lack of funding in education, social care and health led to my son's mental health declining. I believe if he'd had support at the start instead of waiting 6 years, he wouldn't be in a residential school now."*

#### **Lack of written diagnosis**

*"Before this wording in diagnosis we had no support, 5 school exclusions and very part time school timetable and LA refused an EHCP assessment but with the wording they changed their minds and assessed and now in specialist school with support - nothing changed just words"*

*"Refusal to put on waiting list for ASD assessment as can show empathy"*

#### **Lack of understanding and training**

*"I have not had a problem due to the listed barriers but lots of problems due to other barriers. I have also had all the specialist residential colleges for ASD we've contacted express concern that he may not meet their entrance criteria because he has a PDA diagnosis which isn't an ASD diagnosis. This is in the last six months. I've also had concerns raised from the assumption that PDA=inevitable challenging behaviour. Generally more problems from within the autism industry than outside."*

*"Inability to recognise that typical ASD interventions are not helpful with PDA"*

*"Teaching staff who think they know better (but lacking ASD and PDA training) and insist on inappropriate strategies, to the detriment of my child. Parenting specialist"*



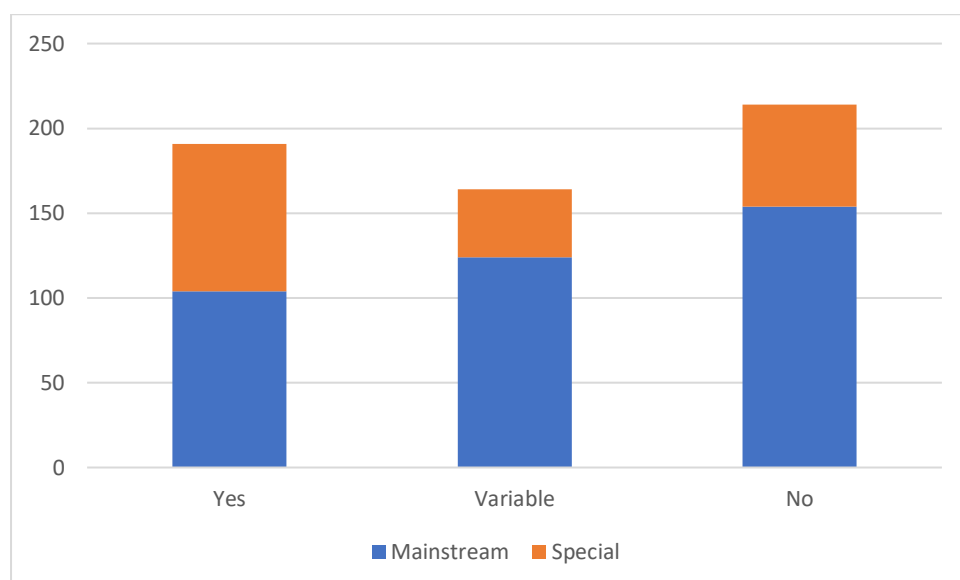
*who ‘doesn’t believe in PDA’ and then dismissed lots of PDA strategies we were using and that WORK (we didn’t go back)”*

Adults were also asked about the barriers that they have faced. While 63% said a lack of understanding and awareness was a barrier, 75% said it was also down to their inability to explain or ask for help.

### **Have education professionals you have met accepted the PDA profile of ASD as a useful descriptor and implemented appropriate strategies?**

For this question, respondents were invited to *describe* their experiences of working with education professionals.

Analysis of the individual responses allowed categorisation, which can be summarised as follows:



A third (34%) of those with a child on a school roll said that their current school was accepting and helpful and 38% said they were not. Special schools were more likely to be accepting and helpful with 47% of parents engaged in this type of school reporting positive responses.

### **Examples of the comments received:**

#### **Mainstream schools**

*“Yes at the current school. My daughter is in her second term without incident. Prior to that she has refused school and had multiple suspensions for attacks on staff and absconding and self harm.”*

*“In primary school the senco was adamant my child had ODD, it was hard to make progress, and he was challenged constantly. A new SENCO arrived for his last year who had personal experience of PDA and from here on in, things have improved for him. In senior schools, his teachers need to be chosen with care and generally are the more educative, non combative types, things are going very well this year.”*

*“Yes - my daughter's school is amazing. They allowed me to bring the person who diagnosed my daughter in to train all the teachers. Her teacher is always trying new strategies with her. Couldn't praise them enough.”*

*“Yes the autism champion is brilliant and fully supports our daughters needs with PDA strategies. The school staff are well informed and brilliant.”*

*The ed psychologist and specialist teacher understand it... the school don't have a clue that's why he keeps being put in situations he can't cope with and ends up with behaviour that gets him excluded.*

*“I usually share with professionals after they've started running out of ideas to help my PDAer. They will say they think the profile matches my PDAer, usually amazed at how closely it matches, but they are resistant in giving the nuanced support called for. I may end up getting a lecture about how it's not a recognized diagnosis, or that the point is not to label my son but give him the help he needs (though I never start the process with "here's a label", but always with "I know this may seem out there, but in the UK they have this profile that very much matches my son, and you may find some of these strategies interesting or useful"”*

*“Not in the LA, the school have been fine with it as they are not influenced by the LA or local NHS policy on PDA not existing! They have been open to receiving information explaining her masking a lot of her PDA in school and female presentation of ASD and ADHD.”*

*“No. We bang our heads against a brick wall on a regular basis. The school ignores our advice and prefers to listen to the area autism outreach team who have never met our son! Strategies for classic asd make his behaviour worse...”*

*“Not always ...threatened with prosecution for school refusal.”*

*“No unfortunately, but the educational psychologist recognised my son had traits after an hour of sitting with him at school, but other professionals won't except as a diagnosis as not recognised here in Wales.”*

## **Special schools**

*“Class teachers at my request looked at PDA website and found it a really good description of my son. They now use PDA strategies that have had a significant impact on improving his behaviours. And also employ them with other very challenging pupils and say they help with them too!”*

*“Yes. The school have been very willing to work with the correct strategies which have enabled him to attend school full time.”*

*“Yes - briefly at an excellent Secondary until we got the EHCP, and we were directed to state specialist School (that failed)”*

*“Yes they accept it but they don't know how to get the best out of a child with PDA. ASD strategies do not work.”*

*“They recognise it but still think the onus is on him to adapt/ conform. I anticipate he'll be permanently out of education soon, even an independent specialist autism placement is breaking down.”*

*“No they use ASD but it says in her EHCP to use PDA strategies but most have no awareness”*

*“No, they said they wouldn't discuss it as can't be diagnosed.”*

*“Never. And I'm intelligent and her teachers are fully qualified. But they refuse to acknowledge PDA at all.”*

*“No as it's not recognised by Brighton and hov , so there is no strategy for it in place at school, as the strategies are so different from ASC”*

*“Home educated ten years but now in school but was unbelievably suggested that maybe my daughter was so intelligent, she could of looked up PDA on the internet and is acting it out.”*

*“I think they humour me with support. I don't think they fully embrace it as they would other diagnosis”*

*“Most don't understand it. See ASD and just apply everything they know about that.”*

### **Home-education**

Of those who recorded that they were ‘home-educating but not by choice’, many had previously been enrolled at school. These responses help to illustrate why families are forced into home-educating.

*“Yes but I didn't feel anyone was interested without a diagnosis’*

*“Yes but not school because the local authority autism specialist came in and took everything out because apparently every child with asd needs exactly the same things, structure, planning and constant demands made on their time so they don't have chance to get anxious. About 1 week after this was implemented my son gave an adult in school a concussion and started self harming and actively trying to die.”*

*"Yes, after I provided information and research they accepted my daughter had PDA but initially stated no issues as my daughter masked."*

*"Yes, but badly"*

*"Yes, her third School recognised and did everything they could but having had two previous placements go wrong it was really too late and she needed time off."*

*"Family support worker agrees he fits profile but she is non medical and has yet to come up with helpful strategies. I find everything out myself."*

*"I was told children that have pda are the most difficult to teach, because if they are not happy about something you can not do anything with them (that was from the senco at the pru my daughter was then attending) I don't think she believed my daughter had pda."*

*"Last school accepted but struggled to implement."*

*"N/A Diagnosed after he left school. EHCP specifies Autism base but when we looked around we realised it was totally unsuitable (being EXPECTED to attend 60% of mainstream lessons within a year, etc)"*

*"No - have teacher all info from pda website - did not implement any strategies to help my child - so Home educate now"*

*"No knowledge of PDA which led to high levels of anxiety and self injury behaviours removed my child from school and he's in a much better place"*

*"No until I threatened court, schools are ill equipped, under funded and are too busy ticking boxes to warrant pda training"*

*"No, it has never been mentioned to me. I discovered your website by chance and it was incredible as it described exactly what we're going through."*

*"No, they tried to prevent us getting a diagnosis of autism and is one of the reasons we left to home educate"*

*"No. I've felt like an over anxious parent. People, generally, just thought that my husband and I were ineffective parents. They would not listen to our daily struggles because my son masks his difficulties brilliantly."*

*"No. I was told not to mention it by the asd team and when I pushed for greater support at school or alternative provision sighting PDA I was reported to social services for 'medicalising' my child and attempting to keep him from the world by the interventions team despite a diagnoses of asd"*

*"None. Stuck out of school for over two years now :( "*

*"Not at all, leading to deregistering her & home educating"*

*“Not yet. So we're educating otherwise”*

*“One head teacher did and it made a massive difference. My son then moved to secondary school and the school would not recognise PDA strategies and tried to punish PDA out of him”*

*“Only our school Social Worker has even remotely accepted the concept of PDA.”*

*“Our pastoral care teacher was great but has now been made redundant. have now left school ourselves.”*

*“They could not meet my child’s needs that is why we removed from school to unschool.”*

*“They have struggled initially to accept it... the longer they dealt with us the more they started to get it. Two staff then attended a PDA conference and really got it!!”*

*“they only wanted to use visual & expected my son to comply 100% with visual information”*

*“While they have had to accept it as a diagnosis the school have no real understanding of what it means in practice and do not use appropriate strategies. Tutors that I have got in and have instructed have listened and implemented the correct strategies and it has helped.”*

## In conclusion

The data from parents is irrefutable; the school environment clearly doesn't suit the majority of these young people.

Of almost a thousand young people in education or of education age, half weren't in school and a further 20% were 'regularly' unable to access it. The nature of the level of 'demand avoidance' experienced means it is difficult (though not impossible) for schools to be able to provide a suitable educational environment.

The causes of poor outcomes are identified in the full report as:

- 1) **The nature of the profile**; some level of challenge is inevitable given this profile is so difficult for individuals to manage daily living tasks.

However, this is exacerbated by:

- 2) **Failure to explore the profile**; lack of knowledge and experience are sometimes coupled with professional scepticism.
- 3) **Failure to understand**; even when impairments are identified, support offered can be misdirected and ineffective.
- 4) **Lack of agency**; diagnosis or appropriate assessments are sometimes refused leaving parents with nowhere to go.

Nevertheless, there are examples where schools and alternative education provision do successfully engage these young people, including the case studies described in the full report: the *NAS Robert Ogden School* and *Spectrum Space*.

**Education services and schools** must increase their awareness of the needs of individuals with a PDA profile of ASD, and how to make reasonable accommodations.

- Educational psychologists and SEN co-ordinators should have **training available in the PDA** profile of ASD and feel confident to support staff to work in appropriate ways with individuals.
- **Ways of engaging** that are very different from the norm may be needed, such as allowing part-time attendance and student-led learning. Special schools should consider the development of new educational environments where existing ones fail.
- Staff should be **encouraged to work together** with parents of those with a PDA profile to truly understand the condition.
- Schools, including special schools, should **review cases** of young people they are currently excluding or who are unable to attend to see whether a PDA profile of ASD may be an explanation.
- Local authorities and attendance officers should **identify those with a PDA profile** and offer suitable tailored support.
- **PDA-friendly education schemes**, with a focus on how best to support learning, should be developed for those who cannot thrive in schools.