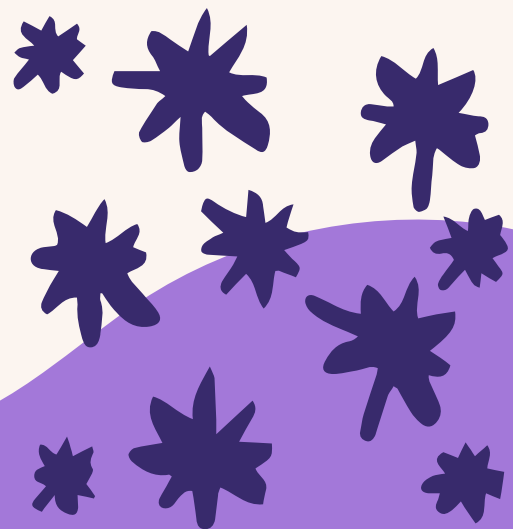
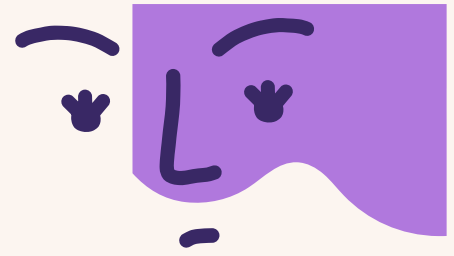




Leila's reflections:

# The story for PDA children and young people





## Leila, PDA young person

**Hi, I am Leila, a 21-year-old with PDA. I will take you through this section of the report, adding context to the statistics in the survey using my own lived experience.**

Not everyone in my life knows I'm PDA because I don't want assumptions about that to shape how they think about me, or the opportunities I'm offered. For that reason, I've used a pseudonym in this report.

Growing up for me was extremely challenging due to the difficulties PDA presents. Children and young people with PDA face significant barriers to diagnosis, assessment, and support services. They often feel misunderstood and neglected, placing immense strain on the young people as well as their families, and forcing them to cope without professional support.

This report is crucial because PDA children are suffering, as I once did. The lack of understanding and support affects their wellbeing, confidence, and ability to cope with school. Let alone enjoy it. Many PDA kids love learning, and offer a unique perspective on life, with a strong sense of justice and self-belief. Unfortunately, growing up within the education system, especially with inadequate or incorrect support, can completely shatter this.

## Knowing ourselves

Knowing about PDA has been life-transforming for me, and I have heard many other families of PDA children say it was for them too. Early diagnosis and support could have spared me much emotional pain and turmoil, improving my social and academic life, confidence, and overall health. Now I know and I am in university. Whilst I still face significant challenges, I have found ways to cope. Embracing my PDA has improved my life immensely, allowing me to regain my love of learning and find my own path.





## Leila

The survey asked participants what difference it made to them when they learned about PDA. The following three stories are examples I've picked, which illustrate that it does make a difference - but it's not everything. The experiences of Reuban, Denise and Jude underscore the fact that knowing about PDA does not remove the stigma and lack of understanding PDAers can face. It can help you internally but does not change the outside world.

### Reuban's story

**“Before I knew about PDA: My daughter’s secondary school education was so traumatic at times I find it difficult to describe. The misunderstanding and false promises made by professionals caused another layer of school-based trauma. Family and friends’ lack of understanding and refusal to educate themselves led to a reduction in contact with them and our safe circle being reduced.**

**Now I know: We constantly come up against people who do not understand PDA and do not want to understand it. Schools, doctors, professionals, family and friends cause constant hurt and I try to protect my daughter from it all. I have huge concerns about how my daughter will do at college and in her future - I worry what more trauma she will experience and the lasting impact of it. She is intelligent, articulate and a wonderful human being. She hopes to raise awareness of PDA and change the future for young PDAers.”**

### Denise's story

**“Before I knew about PDA: School was challenging for my son, he was misunderstood, and he wasn't given the correct support for his PDA. The school involved autism outreach once my son had a diagnosis of autism but all the strategies they suggested weren't working. PDA was never mentioned by school, autism outreach or the paediatrician.**

**Now I know: Since learning about PDA and getting informed professionals involved such as SaLT, OT and educational psychologist, things have got better. We now use PDA strategies and have a good understanding of our son's needs. However, I still feel PDA is generally misunderstood by professionals and school especially.”**



### Jude's story

“Before I knew about PDA: Things were chaotic and emotional and my son was truly not getting his needs met. Everything came to a head almost a year ago and although my son was able to go to school the majority of the time, he was not able to leave his room/bed the rest of the time. We had a ‘no-demand’ household for him, but feel like we lost him since he was unable to participate in anything outside of gaming. We missed him.

Now I know: Life is calmer, and my son has slowly been able to re-engage. Once we decided to home school and the demand of school has been removed, he is slowly engaging. This last week he went to dinner with the family, played chess with his dad and went on walks with me and the dog. He was able to brush his teeth twice on his own. He is thankful he is being heard and I am sure we are doing the right thing to protect his mental health.”

A PDA profile of autism is usually identified during an autism assessment. Because there is still academic and clinical debate about the terminology and classification of PDA, recognition of PDA is currently inconsistent. Identifying PDA can also be difficult because it may present in a way that is different to how some people, including clinicians, currently think about autism, and there are overlaps in presenting characteristics between a PDA profile of autism and other conditions.

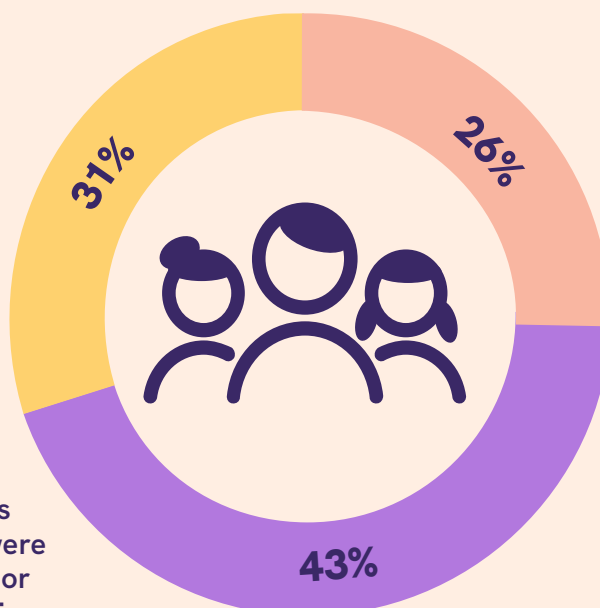
### Of the children in our survey:

**31%**

have a formal diagnosis that explicitly refers to PDA

**43%**

didn't have a diagnosis which referred to PDA, were waiting for a diagnosis, or had a different diagnosis.



**26%**

have a diagnosis that alludes to or implies PDA\*

\* The most common examples include autism or ASD with a demand avoidant profile, demand avoidant behaviours, or demand avoidant traits.



# Daily challenges and mental health

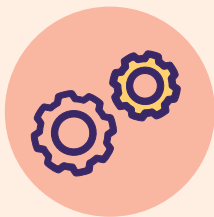


## Leila

It is imperative to grasp that children and young people with PDA face a heightened risk of mental health challenges. From personal experience, the isolation is particularly harmful, as others often downplay PDA struggles as ordinary. Comments like ‘everyone goes through school stress’ or ‘everyone gets anxious’ undermine the unique difficulties faced by PDA people. Recognising these issues through the PDA lens is essential.

The emotional turbulence and mental health hurdles I encountered, coupled with a lack of understanding, has left enduring problems. The continuous dismissal has eroded my confidence and contributed to long-term mental strain. My experience is not unique, which is why it is so important that we take these difficulties seriously.

### Of the children whose parents responded to the survey



**99%**  
need to be in control



**99%**  
experienced mood swings



**98%**  
have sensory differences



**99%**  
have difficulty with daily tasks



**93%**  
have challenges with sleep



**91%**  
have difficulty getting out and about



**91%**  
have severe anxiety



**83%**  
have low self-esteem



**79%**  
have challenges with eating



**70%**  
experience isolation and loneliness



### The data suggested that race impacts experiences of PDA:



**84%**

of PDA children from ethnically minoritised backgrounds needed access to mental health services

**75%**

of PDA children from white backgrounds needed access to mental health services

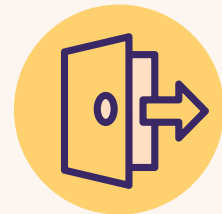
“I was anxious and stressed as a child, and I couldn’t understand why, or why I was different from everyone else. As I got older, I started to just shut myself in my room; meltdowns became less frequent, but I was isolated and completely avoided all social interaction because any demand was too much. I rarely went to school, and so didn’t get to see my friends, and missed out on a lot. I became depressed and struggled a lot with my mental health.”

- Rashpal



**70%**

children experience isolation and loneliness



**91%**

children have difficulty getting out and about

“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.”

- Diane



**91%**

children have severe anxiety



## Getting support

Throughout the survey, a strong theme was how hard it is for PDAers to access a formal diagnosis, and how without a diagnosis it was almost impossible to get the right support.

“Eventually we realised he was autistic, but the NHS ADOS did not score him highly enough to get a diagnosis. He was 15 by then and ever since it has been impossible to get his needs appropriately met by professionals.”

- Brian



**90%**

parents and carers said the child they care for relies on family for day-to-day support needs

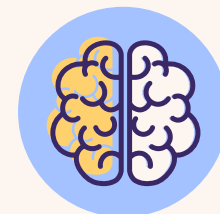
“Still can’t access much from services to help her, still not on any pathway for assessments. So any and all support for her is still just from myself.”

- Jo



**84%**

parents and carers said the child they care for relies on family for support when they’re in crisis.



**76%**

children needed mental health services at some point





Even when there was a formal autism diagnosis in place, there were still many barriers preventing PDA children from accessing appropriate support.

**“We always knew that there was something but just not what that was. Since the age of two we had been seeking professional help to work this out but experienced significant pushback from professionals that kept directing us to positive parenting courses and then anxiety support.”**

**- Martha**

**“My daughter was diagnosed with autism at age 11. I attended a CAMHS parent support group following diagnosis and was taught classic autism strategies including the importance of boundaries. Over the next couple of years, my daughter’s attendance at mainstream high school declined, then stopped. Distressed behaviour at home started, then escalated. I realised the strategies I’d been advised to use - the imposition of boundaries and the expectations associated with them - were actually the triggers.”**

**- Daniel**

Parents and carers also described the profound challenges they faced when trying to get PDA identified as part of their child’s autism assessment.

**“My child has been assessed as having autism with ‘PDA like’ tendencies recently (the local authority doesn’t recognise PDA officially).”**

**- Mike**

**“Whilst the ASD assessment from the psychologist mentions a PDA profile, our paediatrician is not someone that accepts the concept/presentation and our psychiatrist had not even heard of it.”**

**- Pauline**

**“We struggled for a long time to get support and an ASD diagnosis for our child because PDA doesn’t display in the way people expect autistic children to be. Our PCT doesn’t diagnose PDA, just ASD with demand avoidance mentioned in the diagnostic report.”**

**- Asha**





## Leila

My diagnosis was life-changing for me; it validated my experiences. I realised my autism had been missed by countless doctors and mental health professionals because it was expressed entirely differently.

However, once the initial relief wore off, I realised that this was simply not enough. Despite being lucky enough to have a formal diagnosis, like one parent points out above, there is so little recognition and understanding. When I explain my condition to doctors, mental health professionals, education staff, friends, and family, they continuously do not take it seriously and I feel almost embarrassed.

Similarly to how autism in women is frequently overlooked due to differences in socialisation, it is also important to recognise the intersectionality of PDA with gender and other marginalised identities, and how that may change your experience of diagnosis and support. For instance, women and girls often face additional pressure to conform and act as 'people pleasers'. This societal expectation can lead us to internalise the pressure to meet demands, so it is harder to spot.



PDA when recognised is often dismissed as merely a profile or a cluster of traits, which I believe is not sufficient for people to recognise its seriousness. I find this dismissal invalidating, as my experience of being autistic is entirely characterised by PDA. In my opinion, there needs to be a standardised diagnostic definition for PDA, and serious efforts must be made to ensure it is recognised as legitimate. To truly recognise something, and increase awareness it **MUST** be defined, this should be of utmost priority.



# Education

**“School was extremely demanding. I masked what I know now was my demand avoidance and hid it extremely well, but the demands of homework, schoolwork, talking to different people and GCSE exams wore me down.**

**I would come home every day either stimming for hours or falling asleep because I was too exhausted.”**

**- Matthew**

## Leila

Matthew’s story really resonated with me. As well as the experience of going to school, after school was a nightmare. I couldn’t engage with my family or talk to them without lashing out because I was so exhausted. I was often too tired to even manage my homework, which was a struggle in itself. The experience of school was so debilitating that I lacked the mental and physical capacity to do anything other than rest, but I would feel guilty for resting. For me, the word ‘struggle’ when talking about attendance is an understatement. I experienced an inherent resistance to demands that felt insurmountable and manifested as both physical and emotional pain.

I’d also like to highlight that PDA children can come from families whose financial circumstances may prevent them from home-schooling their children. This places an enormous strain on parents and potentially causes children to feel guilty, knowing their parents are forced to go above and beyond to support them. As someone who went to state school, I know how easily students fall through the net, particularly in terms of support and their mental health generally, but this is often even more extreme with PDA. As undiagnosed PDA, teachers would frequently disregard me as being badly behaved when I was really struggling and needed more individual support and a relationship with the teachers.



## PDA Society

The majority of children whose parents completed our survey (**42%**) were enrolled in a mainstream, state funded school, and **11%** were being home educated because it was the only option available to them. **19%** of parents and carers chose the 'other' option when describing the type of education their child was receiving. Free-text answers showed that these children's situations often involved a mixed approach, for example, they were still enrolled at a mainstream school but were unable to attend so were largely at home. Others were at home whilst they were trying to access EOTAS.

In the survey, many parents and carers described the length of time it was taking to find the right education setting for their child, and the time it takes for children's mental health to recover from being out of school or in an inappropriate environment. A lack of support and understanding from school, including from specialist staff such as SENCOs (special educational needs and disabilities coordinators), was a common experience.

**"She is no longer in school due to anxiety around unmet needs and attends an alternative provision for 1.5 hours per week which is gradually increasing to one day. After lots of fighting, time and money, we have just received an EHCP. She still has school trauma and runs and hides if she sees a teacher or adult from her primary or secondary school."**

**- Gemma**



**44%**

said their children struggle to get into school all the time, and 16% said they struggle fairly regularly

**"She does not attend any educational setting, has no GCSEs (having been on track to achieve nine top grade GCSEs in year 9). Her high school SENCO didn't believe how much she was struggling (she loves performing arts so her masking is professional). She is now enrolled at the perfect setting but hasn't yet managed to sustain attendance, even though they have earned her trust. That's how much damage her mainstream school did."**

**- Richard**



**51%**

of parents and carers with a child enrolled in an education setting said their child received emotional or practical support from a SENCO, teacher or teaching assistant



**“It’s incredibly difficult to get the local authority or school to implement support, which is only escalating his panic attacks. A few weeks ago I picked him up from school. On arrival I found him in the foetal position under a table (where he had been for over 20 minutes).”**

**- Lorna**

**“My son is so depressed now that he has no qualifications through no fault of his own. He tried so hard to get GCSEs at college but just couldn’t make up seven years’ missed education in 24 weeks.”**

**- Robbie**



**85%**

said their child had experienced emotionally based school avoidance/anxiety (EBSA) at some point in their lives, and 74% had experienced it in the last year

When PDA children received well-informed support and understanding at school it made a huge difference, for example when all staff members in a school receive training on PDA, or when schools created bespoke timetables which involve learning in creative ways outside of the classroom. Families also told us about children and young people who, despite having a really tough time during their school years, achieved things that didn’t seem possible at the time.

**“It’s taken five months of her building trust with her new teacher but it’s helping her get to school and stay at school. A good teacher is EVERYTHING, and she has an amazing one this year.”**

**- Jodie**



“Against all the odds my son who is now 18 has recently passed his driving test, attended college to become an electrician, has an apprenticeship with a large engineering company and is doing exceptionally well despite all the challenges and him being out of school from the age of eight for three years.

I’m so incredibly proud of him and how much he’s taught me – not only about PDA and autism but about myself and the resilience I had to draw on to get through some very difficult times.”

- Lucas

Sadly, many parents and carers experience a long and bureaucratic process when trying to access an education for their child, which is illustrated by Alison’s story below.

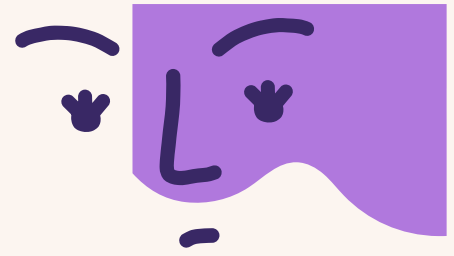
“Things are still difficult due to a lack of support and provision. He has been out of school for 18 months with very limited provision in this time. His anxieties have continuously increased to the point that he is unable to leave the house on most days. His mental health is not great, he is teetering on having depression and he has a very negative view of himself.

Fifteen specialist schools that have been consulted all stated they cannot meet his needs. The local authority is now offering a place at an SEMH secondary school that is quite big and busy, an environment that he won’t be able to cope in. He attends an alternative provision where he is doing really well because he can do computer gaming there, which currently is his main interest. He wants to spend more time at the provision but he only gets funding for two hours a week and we have been chasing to get his funding increased for the last five months.

There is such a lack of mental health support for young people with ASD/PDA and very limited educational provisions for children who cannot cope in mainstream schools and most specialist settings. Considering how short childhood is in a whole lifetime there is way too much time being wasted to get any appropriate support put in place. My son started to really struggle over four years ago and he is still not getting the support he needs.”

- Alison





## Leila

This section was particularly difficult for me to read because it echoes several struggles I faced: the difficulty getting out of bed, the inability to recharge each day, and the constant battle to catch up on rest. Mornings were excruciating at times. Mustering enough energy just to leave the house felt like a huge ordeal. The anxiety was so consuming that eating became nearly impossible. As I grew older, I'd intentionally delay leaving to the point it would not be worth trying to make the timing. In college, my anxiety peaked to the extent that I had to abandon in-person classes altogether.

It's crucial to understand that while many children feel anxious about going to school, the anxiety triggered by PDA is a different level - it renders you physically unable to cope. This level of anxiety is truly traumatic, as it left me both physically and mentally debilitated. The pressure from school's demands would make me unwell, rendering me unable to eat, sleep, or function. I love learning, but the school experience nearly destroyed this passion and pushed me to breaking point. The demands, socialising, and rigid schedule overshadowed everything I enjoyed. For children like me, particularly if they are undiagnosed, it can even ruin a significant portion of their childhood and adolescence.

To any children currently in school: it is possible to get through this. I was diagnosed with PDA before attending university, and although I still struggle with demands, the learning style has improved. I can now self-initiate my studies, have more choice with what to attend, and preserve my love of learning in the process.





## What I hope you've gained from reading this section



### Leila

To all readers, I urge you to take this report seriously. Support and recognition can change a young person's life. I hope this report sheds light on our experiences and offers solidarity to others facing similar difficulties. Being misunderstood or unsupported is isolating and emotionally painful. We owe it to young people to listen to their experiences and advocate for them.

Having person centred support is very important. This is particularly true in times of crisis or extreme stress. The parent trying to support their child who found it had the reverse effect stood out to me; PDA children or young people can feel broken because traditional support, particularly using structure or inflexibility, e.g. 'you must do this to improve your mood', may send them into a state of panic, leading to a feeling of their difficulties being 'unfixable'. If I had received the right support earlier, I would not have struggled in relationships or school as much. More research is needed into effective support strategies that do not negatively impact on PDA children.

I also really agree with the parent's comment in the report about the importance of building trusted relationships. Any teacher or family member who showed compassion, flexibility, and provided the right kind of support for me personally was completely transformative and truly stood out.

I hope that one day, PDA children can grow up without such extreme difficulties. To achieve this, we must provide understanding, open-mindedness, attentive listening, and suitable support. No one should endure a painful childhood simply because their brain works differently.





## Case study:

# When we get it right for children



School life was incredibly hard because, before he was diagnosed, my son was misunderstood and labelled a naughty challenging child, and he reached burnout resulting in EBSA. He ended up being signed off by CAMHS and was out of full-time school for around 18 months.

After some time to put together a plan, the school started to send his favourite TA to meet us, and she would play with him in the park. After a while he started going into school to play games with her. The school built a sensory room; we would go in there together with his TA and they would spend time playing together. Once my son had his PDA diagnosis, the school brought in an outreach teacher who specialised in PDA and she gave training to school staff.

However, my son still didn't feel able to go into the classroom or engage with his class teacher. At this point we didn't yet have an EHCP. The school and the local authority inclusion team decided to arrange alternative provision for him. He did a dual placement, going into school for an hour, half an hour, fifteen minutes – depending on the day and how well he could tolerate it, and then the mentor from the alternative provision would come and pick him up and take him out. They'd do swimming, rock climbing, hiking, treasure hunts, go to the forest or the beach. They had a building where they could meet with other children and do things like baking or games.

It was this that positively impacted on my son's mental health and wellbeing the most. It was all "let's work on you as a person", rather than "let's do work".

Once the EHCP was granted, the school allocated a full time 1:1 to my son as requested. He was ready to go back then, so it was a natural progression for him. His 1:1 did PDA training and PACE training whilst she worked with him, and she has turned his life around! She's put in so much effort to learn about PDA and understand him as a person.

He has a very bespoke timetable. He doesn't have to be in the classroom, he can dip in and out. I know this is a very rare set up – we've been so lucky with the school. When I see the statistics about the number of PDA children out of school it makes me so sad, because it's not impossible to accommodate these kids. It's just making the effort, and his school – his 1:1 especially – have made so much effort. If his 1:1 hadn't made the effort he wouldn't be in education now. 18 months ago we were under CAMHS for suicidal attempts, but now he's so much happier and he doesn't have those thoughts as frequently anymore.

**Our son is so much better in himself because he feels understood and validated. That's what all these kids want – they just want someone to 'get' them.**