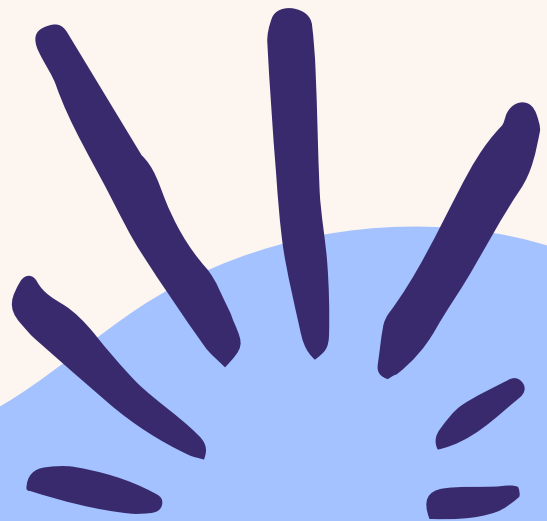
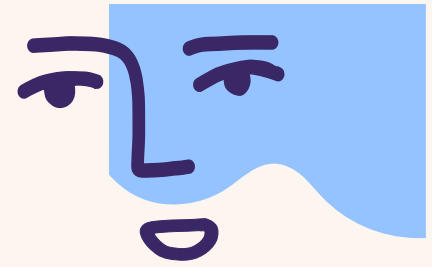




Jennifer's reflections:

The story for parents and carers of PDA children and young people



**Content warning:**

The sections below discuss topics that might be upsetting for some readers, including parental blame and child removal.

Jennifer, PDA adult and parent carer

I'm Jennifer and I'm a PDA adult and parent carer to my youngest child who has PDA. I also run a support group for parents of autistic, ADHD & PDA children. There were no surprises reading the survey findings.

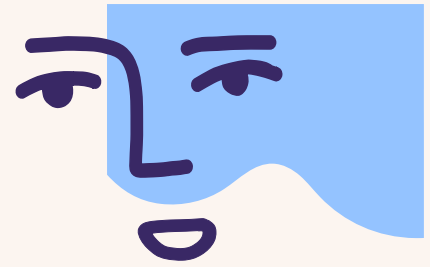
I hope the report helps you understand that it can feel like we are swimming upstream - it's really hard to ignore that everyone else's family is gently floating along in the opposite direction. There are so many unknowns attached to the way that we are parenting. We have a child whose nervous system is so sensitive, who is so anxious, whose behaviour is so externalised and so challenging that we're coming out of it with bruises and damage to our property and we're managing it in the only way we know how, which is to hold a space for him with gentleness and compassion and to support him to get back to a point where he is able to regulate. And then we do this over and over again on repeat. It's the only thing that works, and sometimes we get it wrong, and sometimes we try more 'traditional' approaches and we're very quickly reminded that they don't work.

I hope reading this section helps people to understand what it is like caring for a PDA person, and what an important job that is. When we accommodate PDA kids, actually we get brilliant adults. We get adults who are compassionate, kind, gentle, who will have such a positive impact on the world. So we have to trust in that process. And trust in the families going through it.





Knowing our children



Jennifer

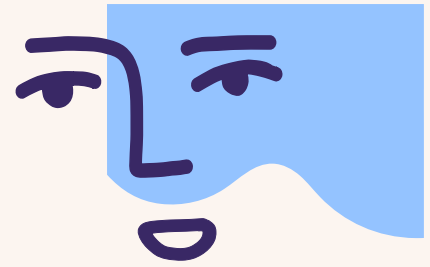
One of the most striking and relatable parts of the report is parents talking about the difference learning about PDA made. This quote describes it really well.

“I stumbled across an article on PDA late one night and realised that I’d been holding my breath whilst I read. This was it. I finally knew. I cautiously followed links to further articles, half afraid that I would read something that wouldn’t fit and would cast doubt that this might not be it after all. But everything I read was describing my child. I felt huge relief that we knew

what was going on, coupled with the grief of knowing that this wasn’t just a ‘difficult phase’. We knew from that moment on that our lives were permanently on a different trajectory and that took some getting used to.”

- Josie





Jennifer

People who responded to the survey identified as parent carers of PDAers. Some people were parents or carers of children – others of adults. The survey asked parents what life was like before they knew about PDA and then once they did. I've chosen two families' descriptions below.

Stuart's family

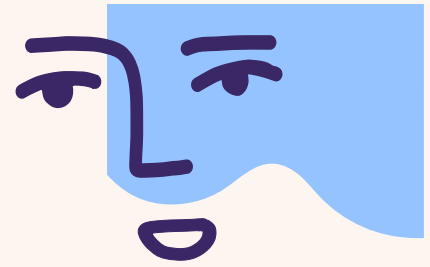
“Before I knew about PDA: I felt like a total failure, as a person and as a parent. We were burnt out, mentally exhausted and in crisis. I'd followed all the regular parenting and nothing changed, or even sometimes made worse.

Now I know: It's so much better than it was. Following advice on the PDA society website, listening to other PDA folks, being able to make changes to implement support that helped us both and our family as a whole. We no longer exist in shame and blame and we have closer, stronger relationships as a result.”

Katie's family

“Before I knew about PDA: As parents, we felt that we were failing at every step and education, the medical world and society as a whole was only too happy to let us feel that way. Every interaction with 'professionals' of any kind left us feeling like we just needed to try harder, be better and to just manage what others were apparently achieving with such ease. For our child, he must have been so frightened trying to cope in a world where not even his parents could understand him.

Now I know: Life now is completely different. Life is happier and calmer. Connection and trust is being restored. But there are long-term wounds, inflicted by the system of education and medicine, that are still healing in us all as a family. Our son has left formal schooling due to sheer lack of knowledge, training and quite frankly, any willingness within educational staff to know better and do better.”



Jennifer

While for other families hearing about PDA suddenly brought things into focus, for us, it was more a slow drip, drip, drip.

It took lots of exploration and conversations with a family friend and we started to gain this understanding of what PDA looks like. As a parent it has given me two things:

- With the benefit of hindsight I can now look back on why my older (PDA) children's childhood was so hard and give myself grace and compassion about that.
- For my younger PDA child who is at home, what it gives me is certainty and confidence. I now understand that drive for safety, for autonomy, that constant battle with self-regulation, and understand that there's no straightforward answers but we must protect his experience of safety at all costs.

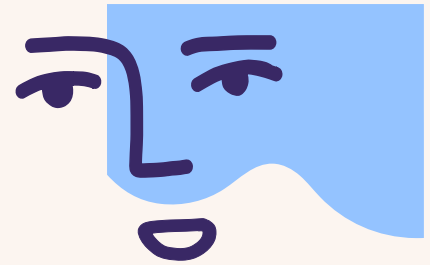
I really liked the 'after' quote from a parent highlighted here. It really outlines how many approaches are needed to start to rebuild a happier home.

"We now understand PDA as a nervous system disability and a profile of the autism spectrum. We try to provide our daughter with accommodations and support, including giving her more autonomy, reducing demands using declarative language, providing lots of co-regulation, recognising and supporting her sensory needs, and letting go of ableism and traditional parenting models."

- Luna



Pressures on family Life



Jennifer

Nearly a quarter (23%) of parent carers said their family had experienced family breakdown. As a parent carer and someone who spends most of my life with other families of PDA kids this came as no surprise. People talk to me about three really big reasons why keeping a family together is so hard:

- Families disagree about what will work for their child. Maybe a partner isn't getting on board as quickly or is directly in opposition to the parenting strategies that are helpful, or there is generational interference with grandparents, aunts, uncles, being critical of what's happening within the home. That can really lead to really massive disagreements and chronic stress.
- The safety of siblings is a consideration when PDA children are potentially harming their siblings, or the needs of siblings are not being met because of one child's needs dominating. So, what I'm seeing is parents having to make extraordinary decisions, like having siblings living in different houses, or going on separate holidays in different places, having to try and accommodate their children separately if they can and if there's enough adults to support this.
- When we as parent carers cannot meet our own individual needs because a child or children need all our support all the time. There is nothing left, no time when one of us is not caring. And it is more than just being a carer for a disabled child - we are continuously lending our own central nervous system to our child to regulate them and that leads to burnout and fatigue. We cannot meet the needs of a relationship or a partner, and the only way to have any kind of life outside of caring roles is to not be in relationships with each other.

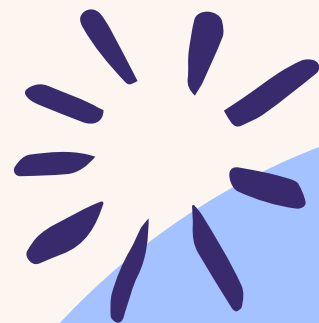
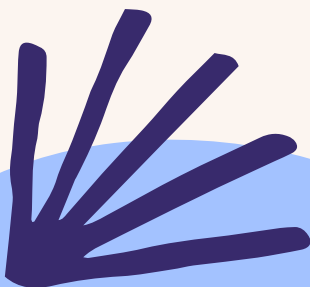


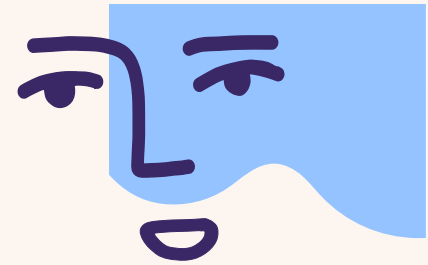
“(I feel I’m) holding family relationships together by a thread a lot of the time. Overwhelming and exhausting not just as parents but for siblings and my son too. Neighbours and friends, even some extended family members would sometimes think they could give their opinions, and these were always that everything looked fine, they were lovely children and then later young people.”

- Dominika

“There was often a lot of conflict between me and my husband as well, because he favoured more “traditional,” do-this-because-I-said-so disciplinary techniques, and he often criticised me for not disciplining our son enough and forcing him to comply with typical standards of behaviour. We argued a lot about how rigid he (my husband) was in his approaches to our son compared to how flexible I was, and I tried to persuade him that his rigid methods weren’t working and explain why I was taking more creative approaches. It created a lot of conflict and discord.”

- Erica





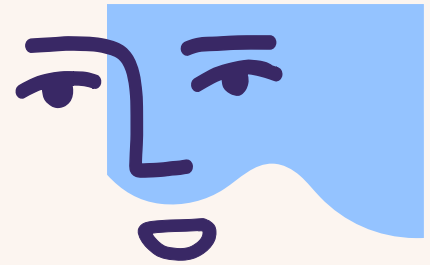
Jennifer

Lots of parent carers talked about money worries. We experience this too. We both have degrees, are married and in our forties, yet we are renting which is incredibly expensive. We are on Universal Credit, we have to apply for discretionary housing payment from our local authority to bridge the gap, which then means that how we spend money is under scrutiny. How we spend money as a PDA family isn't really accepted by the system.

It sounds extravagant when we are buying branded foods and takeaways because that is all our child can eat, or paying for multiple TV subscriptions because we never leave the house and it helps our child to regulate. Or we buy clothes and shoes that never get worn because of sensory issues, and we pay for clubs and days out we can't attend. We spend money replacing expensive devices like iPads and phones that have been broken again, and we cannot manage without them because they are an essential accommodation. Meanwhile, we are both underemployed, working a few hours a week from home to accommodate our son's needs. We haven't been able to follow career pathways, we can't have savings, we have a really poor credit rating, we can't get a mortgage, we can't access the shared ownership scheme, and we can't access social housing, so we are really stuck.

Most of the families I'm in touch with, at least one of the parents is not working and is a full-time unpaid carer. A large percentage of families have a child out of school or on the verge of school breakdown. It has a huge economic impact, but also a huge cost to their own mental and physical health. Parents have a lot of secondary chronic health conditions, and lots of our families are really stuck because they can't afford to live. This increases poverty and a downward spiral of poverty leading to stress leading to poor health leading to poverty.

These parents have to support their children, usually without appropriate provision and support from education and social care, and so people are giving up their jobs and giving up their careers. Those who are able to work are really vulnerable because they are getting calls from the school multiple times a day. Their kids are being excluded multiple times a day and multiple times a week. They take their kids to school in the morning, and they've got no idea if their kids are going to go in on that day, if it's going to take five minutes, an hour, three hours. There's just so much uncertainty and unpredictability, it is impossible to stay working for most of those families, no matter what point they are in their child's education journey.



Jennifer

It's no wonder families are struggling – not just financially but emotionally too.

“I’ve had to halve my working hours and significantly reduce the size of my job. My career is over and I’m just surviving in my job to pay the bills.”

- Jess

“I had to give up my career and become a full-time carer and my husband became self-employed so that he could manage his work hours and be more flexible, but financially it was difficult to manage.”

- Kobie

“I suppose the best way to describe it would be that as a parent I felt not only like every day was like balancing on the edge of a cliff not knowing what we were going to endure, but I felt like a failure as a parent. Not only was I portrayed as a failure by certain professionals at points throughout our journey, but hearing from your child some harrowing reasons why he no longer wants to live was devastating and took a massive toll on my mental health.”

- Logan

“It’s dealing with the outside world (especially my son’s mainstream school) which is making me physically unwell. I am fighting injustice on a daily basis and am ‘battered away’ and made to feel like a fussing parent because it feels as though everyone has a one-dimensional view of what autism looks like.”

- Miranda



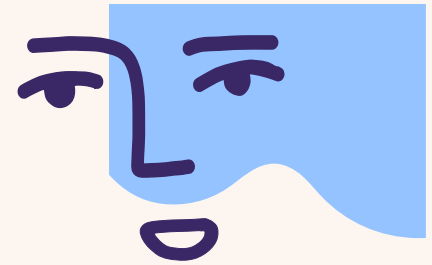


Being believed and getting help

Jennifer

So much of the advice and recommendations put in place for parents is thought to be evidence based, but we haven't thought critically about whether this evidence base is suitable for this population. And how can we get better evidence about parenting interventions when the professionals say that PDA doesn't exist.

We are told by society that to be good parents our children need to eat five portions of vegetables, brush their teeth twice a day, should be in bed at 7.30pm, and that good families eat at the table and only have an hour of screen time a day. This is just not a reality for our family and the absence of these things is seen as a cause to raise safeguarding concerns.



Whilst this optimum model of parenting is evidence based, it doesn't consider the needs of disabled children and it overlooks that we are just about surviving. It is not appropriate to give parents the extra guilt of being measured against an ableist optimum, that most non-disabled families are struggling to meet. There is no measure that looks at the impact of prioritising a child's dental care over their consent, autonomy and mental health.

“School was a nightmare. One problem was people believing my child had attachment disorder, thereby implying that my parenting had been damaging or neglectful, when the opposite was true - this was incredibly hurtful. I was already suffering because my child never, ever did what he was told or what was expected of him etc. I had very low esteem because I seemed to be a rubbish parent in spite of doing my best. Looking back over 8 years I can see that I was actually incredible - and so is my child!”

- Primrose



“I felt disapproval from other parents and teachers, who said I should be more disciplined with him, set hard boundaries and equally rigid consequences to ‘teach him to obey’. I felt pressured to comply with their advice, even though I knew it wouldn’t work, and would make things worse. I felt like I was failing him, because I could see his pain and distress, but I didn’t know what to do to help him, or how to connect with him in a way that he could cope with.”

- Greg

“When I spoke to doctors about it, I was told that it was a parenting issue and that I needed to set more boundaries. They didn’t understand that the boundaries themselves were the problem, as my son’s meltdowns appeared to be centred around his need for control.”

- Ruby

“The difficulties my child faced were labelled as being our fault, because of poor parenting and parental mental health struggles. We were sent on lots of parenting courses and professionals tried to shame us into changing our child’s behaviour and presentation.”

- Leon



61%

have experienced disputes over their child’s education/schooling at some point



16%

have experienced an education tribunal



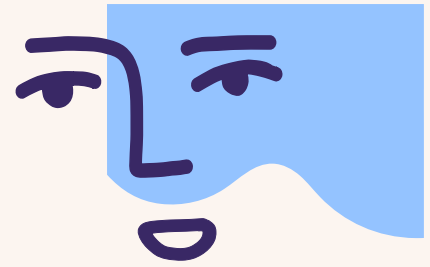
24%

have experienced a social services investigation



13%

have experienced allegations of fabricated or induced illness (FII), 13% have experienced allegations of parental alienation.



Jennifer

Parents and carers also explained how the disbelief and blame could lead to untrue accusations that they are harming their child when they seek support. Many families were accused of fabricating illness in their child because professionals didn't understand what their child was experiencing.

I can see how this could happen - our child has sustained serious injuries during meltdowns, as have we, and it is only our privilege that has protected us from suspicion. When I talk about privilege, I mean that we have protective factors that have allowed us to be believed when advocating for our child - we are white, we are in a heteronormative relationship and live together, we have housing (private tenancy) and have been able to get support with benefits to keep our home. We are both neurodivergent but are able to mask and people-please. I have had to learn more about PDA than any professional involved in my child's care, positioning myself as an expert so that I can fight his corner with absolute certainty. Even then, the doubt constantly creeps in.

What parents said in survey responses, and what we've experienced ourselves, is that when we tell you what is happening in our homes, we need you to believe us. In our particular case we are believed, but there is no actionable support in response to that because the system simply isn't equipped to help us.

"Mainstream primary was hell on earth for both my son and me. As is becoming more and more common, I devastatingly got falsely accused of FII. It was easier for the head teacher to blame me. Our doctors were fantastic and there was no case to answer BUT I will take it to my grave!"

- Laura

"Two social workers sat with the NHS diagnosis in hand insinuating I had Munchausen Syndrome and was putting it all on my child."

- Adele

"My world has shrunk dramatically. I am unable to work due to my son's needs. I left my professional career but I am adjusting. I rarely go out socially at all and spend most of my time in the home environment as a result. We have not been able to go on holiday now for several years as the demand level is too high for my son and it's expensive to book and repetitively cancel."

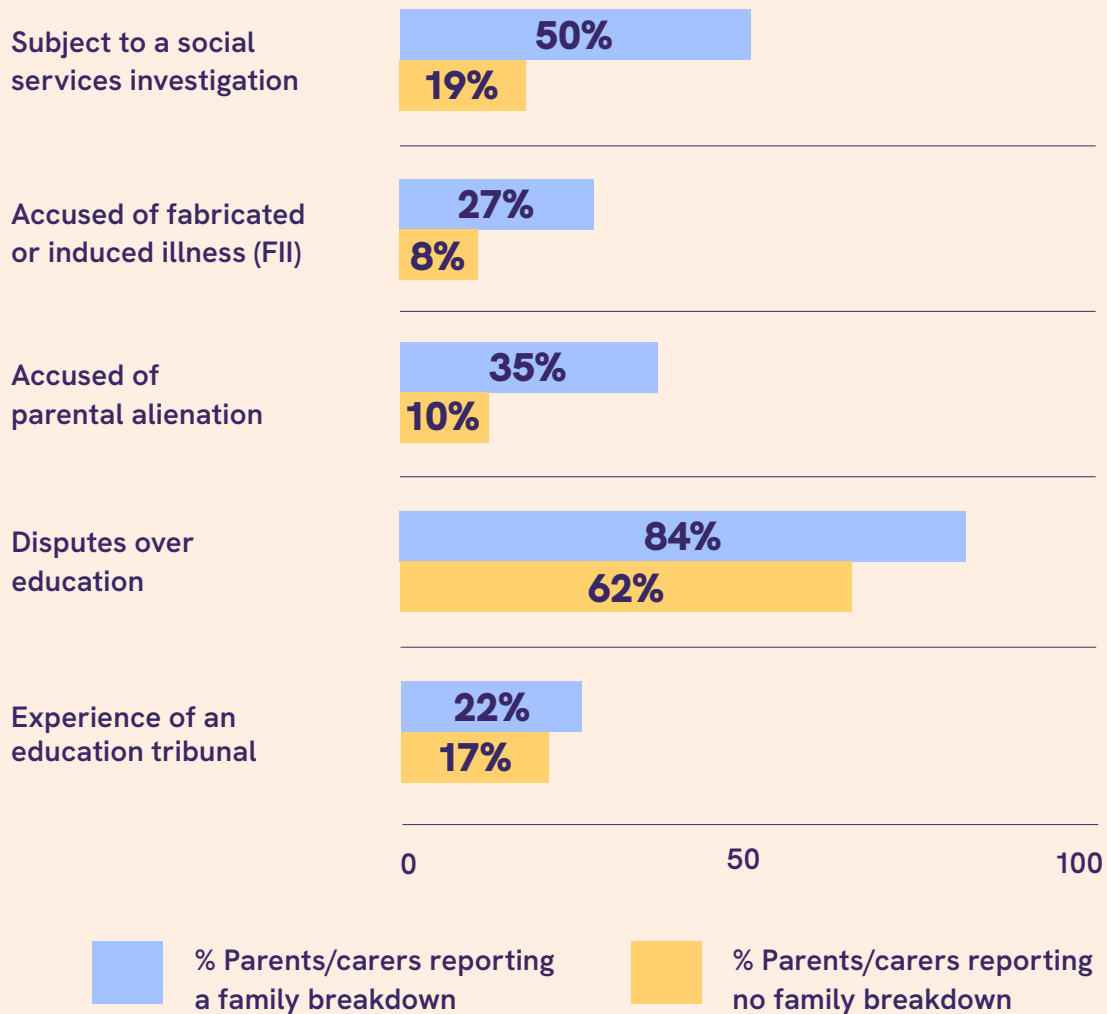
- Charlie

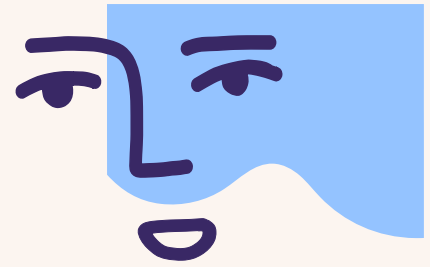


Inequality

Some parents and carers are particularly vulnerable to parent blame. Parents and carers of PDA children from ethnically minoritised backgrounds were more likely to report being subject to a social services investigation (36% compared to 21% of parents of children from white backgrounds). The data also showed marked differences between parents who had experienced family breakdown and those who had not.

Parents and carers who had experienced family breakdown



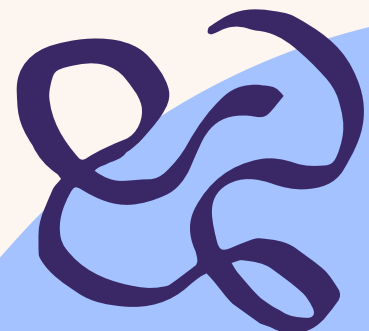


Jennifer

Reading this, it is important to state that I have a considerable amount of privilege. I'm white, educated, middle class, married to the father of my child - this gives me all kinds of unearned protections. It is safe for me to be openly and proudly autistic. I am constantly aware that if somebody with my level of privilege is being so thoroughly let down by the people who are meant to be helping us, then how bad is it for people who are marginalised in ways that I am not?

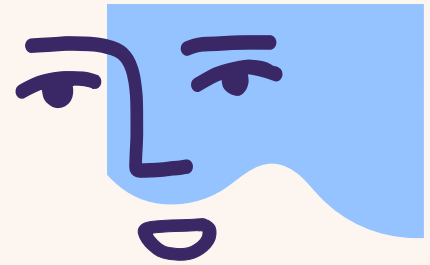
It's really noticeable that single women are more likely to be accused of fabricating illness in their children, and I did experience this before I met my husband. It is horrifying but not surprising that people from minoritised communities are more likely to have to face a social services investigation. Misogyny and racism are so baked into our society, and we sometimes don't notice ourselves when we are acting to reinforce this. Professionals need to act on the findings of this report to tackle systemic inequality and injustice, and we need to be proactive in building communities that are inclusive and welcoming. We need to create more safe spaces for communities to access support.

Advocating for your child is hard enough. It's not just about knowing about PDA, it's also about knowing the law, knowing how systems work locally and who to talk to. Parents are already dealing with more than they can cope with and we shouldn't give them more work to do. I think it's really important that we push that back on to the professionals to do the research, to check they are being fair, and to take discrimination out of the system.





What I hope you've gained from reading this section



Jennifer

When I read this report, it reminded me that so many families are not going through just one or two of these issues but are experiencing alienation, isolation, poor mental health, missing education, family breakdown, poverty and parent blame all at the same time. Many families are supporting more than one child. We are not seen. We are not believed. We do not exist in the research or diagnostic manuals. We are discredited, disbelieved and even accused of harming our children. We are so, so alone. And we are not okay.

Families have so much knowledge, and if you listen, we are all saying the same thing. We are the evidence base. PDA kids have the potential to be leaders, trailblazers & changemakers. They are your best teachers. Be curious and open to what they have to tell you, and I truly believe that you will be glad you listened.

“Having a professional who understands PDA, and agrees that my son has it, has been so validating. It has made it easier for me to get support for him at school and elsewhere. Having a professional on side means that I don't feel crazy, there are less people gaslighting me into thinking it's all in my head and that my parenting is wrong. We need more professionals to understand and recognise PDA – especially in schools and childcare settings.”

- Rushali

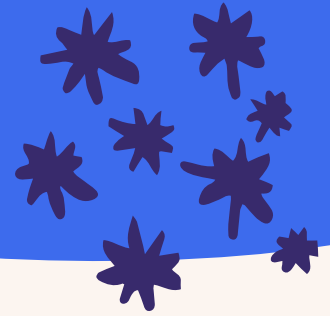
“I had been constantly knocking on professionals' doors, saying that my son reminded me of the children I knew who were autistic but at the same time, he seemed to have a completely different set of needs. I was constantly dismissed. Until one kind and understanding professional did take notice. My GP agreed to refer me out of the area to a different CAMHS. There we worked with a brilliant child clinical psychologist, who agreed that my son fitted the PDA profile and wrote a report hinting at PDA. Following this, other services began to take me more seriously.”

- Jonah



Case study:

When we get it right for families



We spent quite a few years trying to engage in 'normal' family life, to be like other people who sat down at family meals, followed rules and traditions, went on holidays, welcomed surprises and generally did what was expected. During this time, we were asked by family members things like: 'when is she going to start listening to you?' or 'why are you giving in to her all the time?' We didn't know the answer to these questions, and they made us feel like we were failing.

When our daughter started school, we were told by teaching staff that she was 'absolutely fine' at school, there were no problems at all. So we couldn't understand why she had such huge meltdowns as soon as she came out of the school gate. It was so confusing, seeing how difficult everything was for her, but having professionals say there was nothing wrong.

I don't know what would have happened if my partner hadn't started doing her own research at that stage, and actively seeking out professionals who understood PDA. As is the case for many families, we found out about PDA through the internet! We were very lucky in that we had some savings and could pay for a private assessment with a paediatrician who recognised the PDA profile of autism. She changed everything for our family. As soon as we met her, we felt believed, understood and not blamed.

Our daughter also seemed to know that this person understood and would help, and she opened up to her. The paediatrician spoke to us all for hours, I'm sure for longer than we had paid for, and explained everything to us and our daughter in a child-friendly way. She wrote an extremely detailed diagnosis report with recommendations, which has been such a useful tool in getting our child the support she needs.

We changed schools and found education professionals who understood about PDA and were willing to think outside of the box and allow our daughter the flexibility, understanding and compassion that she needs. They don't always get it right but they are open to feedback and we now feel confident enough to give it.

Having access to understanding and knowledgeable professionals has been a game changer. Our confidence in advocating for our daughter is now so much higher, not only because we know our instincts are right, but also because we feel we have the backup of these wonderful people who have believed and helped us.