



## **PDA best practice - what the PDA community would like professionals to know**

This is one of two videos that share best practice about PDA for professionals from all sectors – including healthcare, education, social care, the law, therapists, counsellors, advocates and policy makers.

These videos have been created to help empower you with knowledge about PDA and information about helpful approaches.

This video shares the PDA community's voice, following a survey asking about experience of professionals who've made a positive difference and inviting comment on what they'd like others to know about PDA and what helps.

The second video features professionals from a range of sectors who explain why they feel it's important to identify the PDA profile and share their own best practice tips.

It's important to mention quickly that many people have sadly only had poor experiences with professionals on their PDA journey to date – this is documented in our [Being Misunderstood report](#).

However, our aim here is to highlight examples of best practice and share key pointers so that you feel more knowledgeable and empowered, and in turn can help improve outcomes.

There were lots of common threads in the comments we received and we've grouped a representative sample of responses under these 5 themes:

- Listen to us
- Focus on relationships
- Accept PDA and advocate for us
- Think outside the box
- Treat us as individuals

**Starting with the first theme: listening.** Listen was the word mentioned most frequently in our survey. The message here is: please listen to us, believe us and validate our lived experience. Read, research and learn.

*"My consultant paediatrician listened to me and my parents and then altered her approach to be PDA friendly."*

*"Listen to adult PDAers and read regularly about PDA so that you know how best to support the individual you're working with."*

*"Our educational psychologist had 35 years' experience. She was wonderful with us as a family and probably the only professional ever to have treated me as a good mother. If someone with that much experience can listen to the parent's voice and work with the family, then everyone should be able to."*

***“Go out and do your homework, research it so that you can understand more about what is required and what is needed. Listen to the children, listen to the parents if they're young children because parents know their children best and they'll be your biggest help in working with their child.”*** – Kirsty, parent to a PDA child

***“Be curious. Listen. Start with the assumption that oppositional behaviour is a sign that a child is struggling, and that families are consulting you because they are seeking support and assistance, and that parents love their children.”***

***“Involve parents even if the young person is over 18.”***

***“My son's SLT listened, listened, listened. She then got other professionals on board.”***

***“Remember the child at the centre. Focus on needs. Listen to parents about what works - they know their child best. If you feel the parent is a ‘problem parent’ due to the number of emails or phone calls, please see this as a parent who's trying to communicate the struggle and needs help.”*** – Parent to a young person with PDA

***“A family support practitioner knew about PDA and recognised it in my son. She stepped in to mediate when his former school were badly failing him. Her major contribution was simply being a professional who believed me and backed me up.”***

### **The second theme is relationships**

Please make us feel safe. Connect with us. Build relationships and trust. Respect us and treat us as equals. Work as a team with us and those around us.

***“Start by being kind, warm, relational, making them tea or a soft drink, offer snacks that are on the side for them to take if they wish, making them relaxed. Not rushing through an assessment. Leave windows before and after the assessment, or even expect the assessment to be shorter than usual. Be flexible, think outside the box and don't show ANY signs of impatience, stress or frustration!”***

***“Work with us not against us. You're not in control of me and the sooner you realise that control isn't necessary the sooner we'll get along.”***

***“Demand avoidant children aren't trying to manipulate you or push your buttons; their nervous system is telling them to be afraid and they are responding accordingly. Make them feel safe. If you try and control them, you do the very thing that creates fear.”***

***“Time and patience is everything. Our OT is flexible and intuitive, changing activities as soon as she senses our daughter's reluctance. She has taken time over many months to build trust.”***

***“Trust what the individual is communicating whether that's verbally, behaviourally or emotionally and for that matter trust the people around the individual, especially the caregivers, the parents, the mums. Trust what we're saying, believe us. It's dreadful to not be believed. And trust the experts, the real experts on PDA who are the PDAers themselves.”*** – Lindsey, parent to a PDA child

*"A secondary school teacher has a kind and gentle way. He stays calm and is flexible, he's constant and level in his mood. When other teachers have 'lost it' my son has lost trust."*

*"A counsellor took time with my daughter. She found out about her, listened to her and used her interests to help her explore ideas to help her get out of the house. She cared enough to go away and find out about PDA. It takes time to earn the trust of a PDAer, as so many people will have already let them down or pushed them into things they can't cope with. Listen and let the person's interests act as the catalyst for forming a relationship."*

*"My son had severe school-based trauma and trusted no adults outside the family. His new school came to the home and interacted with me for weeks until my son started to come down and say hi, then over the days and weeks went into the garden with tutors and eventually started to leave the home with them. This has built up to around 60-70% attendance out of my son's own choice, and he will leave healed of his trauma with dreams of studying psychology at university. All down to the staff who focussed on the relationship with him and didn't try to control him."*

### **The third theme is acceptance**

Please understand and talk about PDA so it can be recognised and supported more helpfully at an earlier stage, avoiding problems downstream and improving outcomes. Advocate for us with other professionals.

*"Our paediatrician is awesome and worked closely with us for my daughter's whole life. But she had never even heard of PDA – and so, neither had we. This is too bad, as we could have started supporting her in appropriate ways much earlier."*

*"Please, please, please don't get hung up on semantics. NICE Clinical Guidance identifies demand avoidance as part of the possible signs of autism. Focus on needs!"*

*"Capture the young person and family's lived experience in a way that others involved in their care can understand and best support them."*

*"Recognise PDA and PDA helpful approaches. There's so much great advice available and when applied it can be transformative."*

*"Our paediatrician was open minded and willing to entertain PDA. The previous one had dismissed my son due to his ability to make eye contact and thinking he couldn't be autistic."*

*"A youth offending worker took on board PDA and researched it in order to help my son. Through this she built a very rare trusting relationship with him and supported him."*

*"Having such an amazing neurodevelopmental team in our area makes all the difference, they all have such a great insight into PDA. Because they have*

*collaborated together they've been able to drive the message and understanding forward. I think if other areas had this approach and developed a guide, it would make things clearer for all."*

*"A specialist support assistant is working 1:1 with my son in a mainstream primary. She really understands PDA. She's flexible, creative and fun. She understands the negative experiences he's had at school previously and is very proactive, working collaboratively with him and me. It really has completely changed what had become a very difficult situation. I hope that this has opened school leaders' eyes (who had reached the point of thinking it was impossible to meet PDA needs in mainstream) that this 'radical' approach of reducing demands and allowing him autonomy is not only possible but successful."*

### **The fourth theme is all about thinking outside the box**

Please be open, humble, honest, calm, humorous and flexible, and throw away the rulebook.

*"As a child, my psychiatrist would talk to me normally in the room as I sat crouched under a chair. My speech and language therapist would talk to me through my cuddly toys which were my interest at the time."*

*"I recently had a telephone consultation with a psychiatrist. It was light-hearted and he made jokes which put me at ease straightaway. He didn't question my diagnosis or my medication – two big triggers for me. He had read my notes, read up on PDA and had a quick chat with my partner beforehand."*

*"There are no staff prizes for getting them to do it your way. Be flexible in your approach and pick your battles and a little humour can go a long way."*

*"I want all professionals to realise that everyone needs to understand my needs. Take receptionists for instance, it's really helpful if they know that I can't wait in a waiting room and instead I need to wait outside the building or in a side room." – Julia, adult PDAer*

*"Forget all you've been taught in how to 'manage' behaviour. PDA individuals need a range of strategies to feel safe and secure. These often feel uncomfortable at first but these reasonable adjustments support a child's holistic development and ultimately will mean more PDA children will be able to be educated in a school setting."*

*"Humour, genuine positivity and a relaxed atmosphere are more enabling than rules and hierarchy of authority and 'consequences'."*

*"Remember that in-school education is not the only way to learn and that wellbeing needs to be prioritised over attendance."*

*"A speech and language therapist and child psychologist saw my son as a human being first. They understood his struggles and didn't get offended by his anxiety or refusal, his walking away or his inability to engage. They went with the flow, put no*

*pressure on him to conform and because of it they got him to the place they needed him to be and got the information they needed for the assessment. It was like magic."*

*"My child's piano teacher rolls with dynamics that aren't the norm – lessons with no practice at home, accepting that my child will skip every third or so lesson. She doesn't make our family feel weird."*

**And the fifth and final theme is about treating each person as an individual**

Please meet us where we are, there's no one size fits all. And please embrace the neurodiversity paradigm.

*"Use the language preferred by the person you are helping and avoid medical mumbo jumbo like 'disorder.'"*

*"Understand that understanding of autism and neurodiversity is evolving and changing rapidly: quit clinging to outdated paradigms."*

*"Stop trying to teach a fish how to fly and then judging it on that basis. Autistic people are not and never will be neurotypical, stop thinking you will ever help us to be and instead help us to reach our potential."*

*"Meet each child exactly where they are, with no preconceived notions about what will 'work' or not. No amount of textbook reading is going to help you in the trickiest times, it comes down to remembering that there is a human being there with you, and interacting on a human level."*

*"I find it particularly beneficial to have a telephone or email chat with the professionals before her appointments so that I can brief them on PDA, her current mood and anything else that might help the appointment run smoothly including her triggers and what not to discuss." – Paul, Julia's partner*

*"ASK the PDAer what works for them."*

*"Our play therapist just tried to convey safety and love to our son when she didn't quite know what was going on with him."*

*"Whatever you're faced with remember you're dealing with a human being and a family who are doing their best. Be kind above all else."*

*"PDA is being different and should be more recognised in adults and is more commonly being diagnosed in adults and each and every one of us is different. So yeah I live with PDA and autism and ADHD, but PDA ... all we need is more awareness and stuff and people to have training such as carers, mental health teams and stuff like that. So, I have PDA and I'm happy and I'm proud to say I have PDA." - Anna*

Thank you to everyone who completed our survey and shared their experiences and comments. We hope this video has been helpful.

You may also be interested in listening to the other video in this series, where professionals share their thoughts on the importance of recognising the PDA profile and their key pointers for fellow professionals.

For this and further information, please see our website – [www.pdasociety.org.uk](http://www.pdasociety.org.uk)