



## **PDA best practice - what the professionals would like you 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 professional voice - 24 professionals from a range of backgrounds explain why they feel it's important to identify PDA and share their tips for best practice.

The second video in the series shares the PDA community's voice letting us know about professionals who've made a positive difference and highlighting what they'd like you to know about PDA and what helps.

It's great to see how many common threads there are between these two videos which can be broadly summarised under these five key themes:

- Listen
- Focus on relationships
- Accept and advocate for PDA
- Think outside the box
- Focus on each person as an individual

We'll now hand over to the professionals...

### **Dr Gloria Dura-Vila, Consultant Child & Adolescent Psychiatrist and Medical Lead for Autism in Surrey and Borders NHS Foundation Trust**

Let me explain to you why I am so passionate about identifying PDA across all ages using a very simple idea. One size does not fit all. I sometimes use the metaphor of having a shoe completely tailor-made and designed that fits perfectly in every way that captures a young person's own style of autism. Providing an off-the-peg or one size-fits-all shoe is not going to give an autistic person the best chance to walk tall, it may even make walking more tricky for them if the recommendations don't fit their own style of autism. So how about getting rid of this impersonal shoe? We professionals should aim to give the autistic person a shoe that fits them perfectly. Identifying PDA is part of this personalization of autism and it is essential that we get the right strategies. When the shoe fits perfectly they will be able not only to walk, but to run and jump and to climb mountains.

### **Julian Norman, Barrister, Drystone Chambers**

The law is improving when it comes to autism awareness but to make it work well lawyers need to be proactive. Here are four brief ways in which we can do that:

1. **Understanding.** Recognising different profiles within the autism spectrum and particularly that not everyone is an obsessive rule follower of the stereotype. Knowing that challenging behaviour may be anxiety driven or that avoiding a

question isn't necessarily evasive is crucial and needs to be communicated to the rest of the court.

2. **Empathy.** We're all used to courts but they are a high demand situation at a time when anxiety is already running high. We need to see if we can reduce demands where possible.
3. **Support.** Get that intermediary. If we can't do that, listen to what our client needs and to their parents where relevant. Ask for sensory adjustments to the court. Make sure that the court really understands what this client needs to give their best evidence.
4. **Collaborate.** Many neurotypical clients just want their lawyer to tell them what to do. We need to be prepared to take a much more collaborative approach with PDA clients.

### **Karen Baker, Special Education Adviser and Trainer**

I think it's important to recognise the PDA profile and to acknowledge that it's not something that's a choice for those young people, it's driven by a need for control and high levels of anxiety. I think you need to invest time in developing an open and honest relationship and getting to know the individual. Listen to what the young person's saying and more importantly hear what's not being said. I think you also need the humility to recognise when we may have set that individual up to fail by not putting in place the things that we've recognised and acknowledged need to be there.

### **Lisa Cooper, Director of Community & Mental Health Services, Alder Hey Children's NHS Foundation Trust**

I think it's really important for health professionals to recognise PDA as part of a diagnosis within autism spectrum disorder. It's really important that health professionals are trained to be able to support children, young people and their families, and at Alder Hey we've worked to ensure our staff know how to recognise PDA and also to be able to offer advice and support to children, young people and their families so that they can access all of the resources that they need.

### **Pete Sandford, Carer, Sheffield Health and Social Care NHS Foundation Trust**

I've found awareness of both autism and PDA to be very important in building an understanding of the unique experiences of each person and retaining a compassionate perspective on the individual who may become distressed when things don't work out as planned. Being PDA aware for me means being really clear in my communication, being careful to watch for the level of demand or expectation I might be communicating, being sensitive to push-back from the other person and curious about why that might be. I'd always want to work towards a win-win outcome and make sure that even when there are differences, I'd want to keep the dynamic adult to adult and I'm okay, you're okay.

### **Laura Kerbey, Founder of Positive Autism Support and Training & Director of Kite Therapeutic Learning Service**

I am really passionate about raising awareness of PDA in schools and colleges. I see that the current system is failing them and I also know that given the right support these are amazing individuals that can just thrive. Remember that the opposite of

anxiety is trust so the most important thing you can do if you work with someone who has PDA is to build up a trust and build up a relationship. Once you have that you can do amazing work together. Also just take off your teacher hat and just become a learning facilitator, go with the flow and I promise you if you do those things, you work together, share the demands, amazing things can happen.

**Cathy May, CBT Coach and Neurodiversity Specialist, Side by Side Coaching**

PDA is a particular interest of mine and I've just been accepted by Oxford University to study my ideas about interventions for parents of children with PDA profiles. Parents are our greatest asset, and they need to be believed. They need to be an active part of any process of recovery for their children - they know them best and I believe that if we're going to reach the child then we really need to help the parent too and as an integral part of that process.

**Hannah Morris, Independent Educational Psychologist, Ed Psych 4 Kids**

We need to understand a child's strengths and areas for development in order to be able to help them be happy and thrive in education. This is particularly important for children with PDA because misunderstanding increases a child's anxieties and the resulting behaviours often mask not only their learning potential but the positive aspects of their character and who they are as a person. Take time to build a trusting relationship with the child and find out how they experience the world around them. Once we understand a child's perspective and trust is established then support that is put in place will be more effective and meaningful to the child.

**Jude Seaward, Learning Disability Nurse and Behaviour Therapist, Simply Misunderstood**

I first learnt about PDA in 2001 and it was a condition I didn't know anything about so I did a lot of research. What I did learn was actually the diagnosis was really important because if we handle the situation wrong we can actually exacerbate someone's health and wellbeing. People with PDA learn best through experience. When you're working with someone trust the fact that you have the skills to deal with the situation, so you don't need to plan. The more I planned to do something the worse it has worked, so, what I found worked best was actually to allow the person to bring forward what they wanted to discuss and know that I had the skills and I had the awareness to help rather than having a set plan session.

**Cathie Long, Independent Social Worker, Vivacity**

I work with many families where a child or young person presents a PDA profile and sometimes children are inappropriately placed on a child protection plan and there are occasions when parents are wrongly accused of exaggerating or making up their child's difficulties. Therefore my message is to other professionals to listen to the parents, to work with them and to really try and gain an understanding of the difficulties that are experienced within the family rather than coming from a place of blame because if we can work together with families then we can agender difference and we can make life much more okay for that child and young person.

**Ange Heyes, Headteacher - Independent Special School, Kedleston Group**

I'm a headteacher at an independent special school for children with autistic spectrum condition or social emotional mental health and I've found that our strategies and ethos work very well for all these children. However, on occasions these tried and tested methods don't seem to work. Why? There has to be a reason. I've found that this reason is often undiagnosed PDA. Because I'm aware of PDA, I can introduce strategies and they do work, so it's important that local authorities and those people writing EHCPs, understand that PDA is different and needs diagnosis so that the children thrive, flourish, learn and enjoy school.

**Raelene Dundon, Autistic Psychologist and Director, Okey Dokey Childhood Therapy**

I am really passionate about getting the word out about PDA to help the professionals like myself to understand the needs of PDAers and to really recognise that those needs are different to other neurodivergent children and adults and that we really need to work with them in a particular way in order to best support them. They need a really indirect, trauma-informed and person-centred approach so any therapy really needs to be relationship focused and absolutely child-led.

**Clare Truman, Teacher & Education Consultant, Spectrum Space**

I believe that everyone deserves to have their needs met in education and throughout their lives. I've worked with many PDA individuals whose needs haven't been met in education and I want to change that. When supporting PDA individuals I find it's helpful to allow them to take the lead, acting as a facilitator rather than an instructor. So, when teaching, I work collaboratively with my pupils. Following their passions and interests we work together, solve problems together and learn new things together.

**Vicki Dawson, CEO and Founder of The Sleep Charity**

My first tip is to find out as much as you can about PDA if it's something that you don't already know about. My second tip is to work in partnership with the family - they're the experts on the child. Ask lots of questions, really get to the heart of what the young person enjoys and how best to approach them so that you're not putting them under any pressure.

**Sara Heath, Independent Autism Practitioner, Shropshire Autonomy Self-Help Group**

I'd like to mention that those with PDA will often be challenging but they are the ones that are reacting to being challenged. My strategy is to be kind and supportive to them because I know that their anxiety is related to their own difficulties and that adding to their stress only makes things worse.

**Lynn McCann, Independent Autism Specialist Teacher, Reachout ASC**

In our years of supporting individual autistic children we've come across those who don't respond to the usual autism strategies and in fact become more stressed with the additional demands that these put on them. It's so important to identify those children with a PDA profile because we need to understand what challenges they are facing each day and to use the helpful approaches to help reduce the stress and

make school more successful for the child. We always start by working with the child, their parents and the teachers to identify all the demands we're putting on the child. Then by using the priorities approach we can develop a plan that matches the demands of each day with the tolerance levels of the child. It's so important to help teachers understand that the child is having panic attacks and that its 'can't not won't' when it comes to them avoiding or refusing demands.

**Alison Hart, Occupational Therapist, Children's Choice Therapy Service**

PDA is another barrier to function, to be able to explore independent skills, purposeful activity and creates a sense of avoidance and not achieving full potential. Sensory processing is that first point in that learning of understanding how our body works and how we work within that environment and we all need that understanding as a platform to be able to build our independent lives and to be able to build functional skills and that's why as an occupational therapist I feel that we have an important role to play in understanding the child with PDA.

**Dr Jo Jones, Consultant Paediatrician, Healthcare 4 Kids**

I've been working with PDA children for about 15 years. I still remember the first child who told me her story and I began to understand what it's like for these children. Why am I passionate about PDA children? Because people don't understand them. Typically, they're seen as naughty, wilful and spoilt and they're really not. I think the amount of anxiety that they carry around is extraordinary. I see many query PDA children and I still find that about 50% of them aren't. They're typical type autism but carry huge amounts of anxiety because of certain things like transitions, the fact that they have to see the point of doing things - if they see the point they'll happily do it. Whereas for a PDA child, just the expectation of them being asked to do something causes huge distress. In my clinics I try to keep things as low-key as possible and I simply go with them. I think the take-home message that I would like to give is that these children are brave, extraordinarily brave. I wouldn't be able to cope with one day with the amount of anxiety that they carry.

**Ken Upton, SEND Advocate, Talking SENSE!**

It is vitally important for PDA to be identified to ensure the right support or special education provision is in place and importantly is enforceable. I know of many families whose local authority don't or won't recognise PDA, which often leads to unmet needs leading to the child or young person experiencing isolation, exclusion and in some cases denied an education in a school. Please identify PDA amongst our children and young people and please ensure they receive the right support and special educational provision.

**Deborah Wortman, Psychotherapist, Brighthouse Counselling & Psychotherapy**

I'm really passionate about PDA as I think it's really important to understand the challenges that this client group face on a daily basis due to high levels of anxiety and sensory sensitivity. One of my top tips is get to know your client, develop the therapeutic relationship, find out who they are, find out their hobbies, their interests and really enjoy being with them in the room.

**Emma Mander & Meg Walls, Founders - Great Minds Together & NHS – Health Education England Autism Peer Education Programme**

We're passionate about increasing understanding of PDA because what a lot of professionals that aren't aware of PDA don't realise is that certain strategies that they may use to manage behaviour can actually be harmful for people with a demand avoidant profile. Our society is built with demands and schools are full of them and what a lot of school staff may not realise is that their own behaviour policies can be a trigger in itself for children and young people. It's important to take the time to understand the need behind the behaviour, this way you will be able to build a relationship with that person and they will feel listened to and understood as a result. PDA is driven by high levels of anxiety and once people understand this rather than issuing sanctions for behaviours that some young people simply cannot help, the closer we will be to an inclusive society.

**Pip Buckley, Managing Director, bibic**

I'm here today to talk to you about PDA. This is an issue we feel there's not enough knowledge about out there and we're passionate about increasing the knowledge about the strategies that you would use for a child who displays PDA. These would not be your normal strategies that you'd use with other behavioural conditions like boundaries, we're actually looking at low arousal strategies, strategies where you're supporting negotiation with that child and giving them control over the outcome. We find that if you use a softer, low arousal approach, that supports those children to better reach their full potential.

**Natalie Menagh, Headteacher, Specialist Secondary and Post 16 Centre**

I believe it's essential to raise awareness of PDA and the challenges that individuals and their families face in managing the everyday demands of life. It is only through correctly identifying needs that we can even begin to help. Most of us are in education to get the best outcomes for children and young people and it's important to realise that we don't have all the answers. The best educators continually reflect on their own practice and the learning environment they provide and adapt for the child's needs. This is a very complex and ongoing process when working with a PDA child and it's always best achieved as part of a team which includes parents and carers. There will be no quick fix or unfailing strategy, the demand made of you both personally and professionally will be great but the outcomes will make it all worthwhile.

**Libby Hill, Speech & Language Therapist, Small Talk Speech and Language Therapy**

I work with lots of children and young people with PDA and I have met and listened to lots of adults with PDA and that's taught me a great deal. I'm learning all the time but that's taught me a great deal and I'm always slightly embarrassed when I think back to the early days of working with PDA and how little I knew. So, I need fellow professionals to know that PDA is completely different to traditional autism. It needs a completely different approach to support them and we, the professionals, need to make the right accommodations. So, we need to make sure that we use a low arousal approach, go with the flow, have a plan b and a plan c and maybe even a d, be led by the child or the young person, see what they do as a neural response not

deliberate defiance. In actual fact they are the most marvellous group of young people and it's actually a pleasure to work with them.

Thank you to everyone for sharing your experience, expertise and passion. We hope this video will help empower other professionals with the information to recognise and support PDA more effectively.

You may also be interested in listening to the other video in this series where the PDA community shares examples of best practice and what they'd like professionals to know about PDA and what helps.

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