SEND Reforms & PDA – your guide to getting involved

Introduction

Hello,

This pack is designed to help you use your experiences to build an understanding of PDA in decision makers, and to develop trusting relationships so you can help them ensure that any new legislation around SEND considers and makes best efforts to meet the needs of our children.

We are really grateful that you want to be part of this change. PDAers deserve for their school years to be happy – to have the option of schools which meet their needs if that is something they can manage, and if they can't, to have other options available so they can continue to learn and thrive. The PDA Society are a very small charity, and we can't secure this change without your help.

But together with parents, grandparents, and young PDAers who are in or who have just left education and anyone else who cares – we can ensure that everyone involved in making decisions knows a little more about PDA and how they can help.

Over the coming months we'll share information with you as we hear it, provide tips and training on getting voices heard and work with the community to respond to policy suggestions, so decision makers know how changes in policy could impact our families. Some of these updates will be in our regular newsletter, but if you want to be the first to hear about opportunities to get involved – you can sign up for updates here Expressing an interest in influencing – Fill in form

Thank you for caring. We don't yet know what the SEND reforms will be, but I am sure that they will be better for all children if they are designed with PDAers in mind. Thank you for being part of ensuring that happens,

Looking forward to working with you,
Ed Archer
CEO – The PDA Society

The Briefing

Why must any new education legislation consider PDAers?

Because PDAers are autistic people for whom “business as usual” in education simply doesn’t work. There are likely to be 18,000 PDAers of school age in England. These children are experiencing extreme, fear-based responses to everyday demands, and are currently underserved by an education system that neither understands nor meets their needs. This results in anxiety, declining mental health and children being unable to attend school.

Education is not working for these children or their families. It’s not ok that our school system leaves so many children so deeply unhappy and too frightened and overwhelmed to engage in learning. In our 2023 survey 40% of parents of PDA children told us their child had considered taking their own life – we must do something to change this.

Schools and teachers tell us it’s rare to have the training, experience or resources needed to support PDAers in school. As a result, school can be such a source of anxiety for PDAers that it affects every aspect of their lives. Without support being available in school many parents are stuck being forced to make impossible choices; do they force their child to attend school knowing the impact it is having on their wellbeing, or allow them time to recover at home and face judgement, blame, financial penalties and in some case legal action for doing so. These are impossible choices to make.

In some cases, parents end up home schooling their child to prevent them becoming increasingly mentally unwell. For many families, this means one parent has to step back from work—losing both income and the enjoyment it brings—because the alternative is sending their child into a system that doesn’t understand their needs and is pushing them into burnout.

Children are not getting the chance to learn. Their wellbeing is being destroyed, and their families sliding into poverty. All because their needs aren't being recognised or met.

This isn’t okay. But thankfully it also isn’t inevitable. Every day the PDA Society works with schools and teachers who are going above and beyond to get it right for PDA children. We are seeing some children thrive at school, or with fractional timetables and EOTAS packages for children for whom full time school is simply too much.

PDA children, their teachers and parents are doing their best, they need change urgently so that a generation of PDAers education isn’t wasted.

The Statistics

Prevalence research suggests that 1 in 5 autistic people could struggle with PDA, that equates to at least 18,000 children of school age right now.

PDA Society's 2023 survey (with nearly 1000 responses) found parents of PDAers reporting:

- 91% of PDA children have severe anxiety.
- 40% of PDA children have considered taking their own lives.
- 98% have sensory differences.
- 91% have difficulty leaving their homes.
- 85% have experienced emotionally based school avoidance at some point in their school lives.
- 44% of PDA parents say it's a daily struggle to get their child into school, a further 16% say it is a regular occurrence.
- 49% of parents with child in school said their child was getting no emotional or practical support with their school anxiety.

Why are things so difficult?

Distracting debate about how to categorise PDA instead of what helps

Much of the public and professional conversation remains stuck on whether PDA is a distinct diagnostic category - children and families cannot wait for academic consensus. We can't be distracted from the fact these children exist and are struggling right now. Policymakers must prioritise understanding what works for these children – and then making that happen.

A one size fits all approach to supporting autistic people

Mainstream autism strategies assume consistency, predictability, and routine are helpful for all autistic children — but these can be intolerable for PDA children. Rigid timetables, behavioural sanctions, and inflexible attendance expectations often escalate distress and breakdown. Schools and teachers need access to better tools and training. They also need flexibility within regulatory frameworks to be able to make adjustments for these children.

The assumption that this is new or Covid related

There needs to be clarity that PDA’s identification predates Covid by decades; these challenges are not pandemic-driven. What Covid did was reveal what happens when children are not forced into masking, compliance, or overload.

Parents are now more likely to know what their child is like without school stressors and so likely to intervene earlier when their child is heading for burn out. Parents aren’t choosing non-attendance. In fact many parents report having to lose household income, and negative impact on their own wellbeing and that of the wider family as a result of having to withdraw their child from school (either by taking time off or by off rolling) or witness the further deterioration of their mental health. Families frequently report being disbelieved, blamed, or accused of enabling avoidance. This erodes trust and prevents collaborative solutions.

Punitive approaches to mental health related school absences

Approaching attendance as an outcome in itself, without nuance, is creating harm for families. Regular absences of SEND pupils should signify that needs aren't being met, and prompt supportive action to identify and meet needs. Sadly, this is not parents experience. Instead, they face fines, pressure, and rigid targets which ignore SEND realities and can be re-traumatising.

Commitments that would make a difference:

1. A funded research programme around PDA and school avoidance which focuses on:

- Developing a screening program to identify children who have PDA traits and for whom classic autism approaches are unhelpful. Ideally making this screening available before school age and linking to specialised parent mediated interventions. (similar in methodology to Jonathan Green's PACT work in Manchester)
- Identifying approaches that work for children in school.
- Suggesting what support is most effective for children educated outside schools (including fractional timetables and supporting self-led learning).
- Understanding how to effectively transition children back into Education after burnout.
- Building evidence around how we skill up parents and professionals early in children's lives – to minimise any disadvantage experienced because of PDA.

2. **To reframe absence as an alert that extra support might be needed.** Building practice around understanding of how school attendance and behavioural concerns can be symptoms of unmet need or of inappropriate support in school, and ways to fix this.

3. **Freedom for schools and teachers** to take decisions around flexing curriculum, offering fractional learning, or supporting a home/school hybrid model as children need, that is resourced and able to be implemented when concerns first arise.

4. **Training** for all school staff, everyone involved in assessment and placements and for parents about PDA and approaches that work, so there is a shared language and shared expectations for children. And for this training model to be robustly evaluated in order that practice can be established quickly.

5. **Facilitated practice supervision** for school staff where they are struggling to meet a child's needs to help them consider changes and adaptations they can make.

6. **Investment in EOTAS packages** that are flexible and quality assured for children, as soon as need is identified.

Making sure your experiences inform the new legislation.

Why should I get involved now?

The Government will shortly be developing new reforms to the SEND system. For these reforms to work in the real world, ministers and policymakers need to hear from families who have lived through the system — especially where it has failed, and what would have made a difference.

Your personal experience is evidence.

This section is about using your experience to influence national SEND policy, using your story to illustrate what changes your family, or families like yours need.

Who might need to hear my story?

Your story is important. Many people involved in the process might benefit from hearing it.

You might want to start by sharing your experiences and needs in the governments space for “The Send Conversation” SEND reform national conversation - Page 1 of 15 - Department for Education - Citizen Space
There are lots of questions in this form. If you want to think about them and plan your answers, we’ve copied all the questions here.

If you choose to respond to this it would be great if you could let us know both that you did and what you said, we’ll anonymously combine responses into case study reports to share with decision makers. Please send copies of your responses to comms@pdasociety.org.uk with “My SEND response” as the subject line for the email.

It’s always really useful to respond to written enquiries like the one above – however the most impactful way to make a change is to build a relationship with a human being. Here are 3 places you might want to start:

- Your local MP, who can raise issues directly with ministers, speak in debates, ask parliamentary questions, and influence departmental policy.
- Senior leaders in your local authority, if they are already trying to help families like yours and want evidence to support what they are feeding into national consultation processes.
- Your parent carer forum who may be consulted.

Your MP is usually the simplest and most effective first step. They are elected to represent you, and Parliament is where national SEND policy is made. Once you know who your MP is, you can check whether they hold roles that give them additional influence (committee member, ministerial role, shadow minister, etc.).

Finding your MP and their roles

You can identify your MP by searching with your postcode on the Parliament website.Once you've found them you might find it useful to:

- Check their parliamentary roles.
- Note whether they sit on relevant committees (e.g. Education, Health).
- See whether they hold a Government or Shadow brief linked to children's policy, equality, or public services.

This helps you understand whether their interest in in you as a constituent primarily, or whether what you have to say can be used in their other roles too.

How to write to your MP

MPs receive thousands of campaign emails. Many offices do not individually reply to template messages.

A personal, respectful, concise letter is far more effective. You might find it helpful to use the following structure

1. At the top:
   Your name, full address and postcode.
2. First lines:
   "I am one of your constituents, living in [area]. I am writing to share my/ my child's/ my grandchild's experience in education, in the hope it helps you contribute to the debate around/ shape the new SEND legislation in development"
3. Then:
   "I would appreciate the chance to talk you through my family's experiences – and let you know what would make a difference for us and families like ours."
4. Next (the context section):
   Use a couple of short paragraphs to describe your experiences. It is helpful to focus on: how the system failed to meet your child's needs, what adjustments would have helped, the impact on your child and your family.

Meetings — using your minutes wisely

Any meeting you have is likely to be time bound – so it's helpful to prepare beforehand. Most MPs offer short "surgery" appointments — often 10–15 minutes.

You might want to think about it beforehand and decide how to briefly describe to them key moments that show:

- Where your family's needs weren't met
- What you needed
- Why you were told that wasn't possible
- What needs to change to make it better for you and other families
- What difference that would make for families like yours

In the first section we've said what the PDA Society think the changes that would make the biggest difference are. You may wish to talk about those or suggest something different that is important to you.

The person you speak to might have questions about PDA or have already decided what they think is needed. There are some frequently asked questions at the end of this document and how the team at the PDA Society would answer them, it could be helpful to either bring them with you for reference or read them in advance.

You might also choose to leave something behind to help them to remember your story, and what you are asking for. Leaving something behind helps you stay in their mind long after the appointment is over. We'd recommend – something about what the issues are for PDAers generally (you can find a download of the summary briefing here) with a note clipped on the front reminding them of your story, and something personal – perhaps a drawing or craft made by you or your child. It needs to be small, ideally useful or decorative and of very minimal value (otherwise they can't accept it).

Here is a video talking about how these types of kindnesses can help people remember and appreciate your experiences. https://youtu.be/vP7S_oVbI4A?si=nj52qCHwto2VwLav

After the meeting it is helpful to send a short thank-you email summarising: what you discussed, the key issues you hope they will raise, any commitment they made (e.g., writing to the Minister, raising a question, sharing your evidence).

If you do not hear back within a few weeks, a polite follow-up is appropriate. MPs often juggle large caseloads, so gentle persistence isn’t rude in fact it's often considered helpful.

Working collaboratively with other people who care

Local authorities and the Government often hold consultation events — sometimes by inviting your Parent Carer Forum, sometimes by asking individual parents to join small meetings or online focus groups. These spaces are a powerful opportunity to shape the reforms, and collaborating well with other parents makes your collective voice stronger.

In these meetings it is helpful to be succinct and clear about what helps rather than retelling every detail of what went wrong. Think about the system changes you want to see and why they would have made a difference. It can be helpful to use the chat or messaging functions (if online) to share key links, documents or examples that support your point, instead of talking for a long time.

A good way to work together is to “yes-and” other parents — acknowledge where you agree, add briefly to their points, and avoid dominating the discussion. Being brave enough to share your perspective, and concise enough that others have space to speak too allows you to be very effective in this kind of meeting.

Consultation organisers often announce these opportunities through Parent Carer Forums, local SEND newsletters, council engagement teams, school SENCO networks, or national charities, so keeping an eye on these channels can help you hear about chances to contribute.

Responding to surveys and written calls for evidence

Sometimes you'll be invited to share your views through an online survey or a written call for evidence. These can be just as influential as meetings, especially when policymakers are gathering real-world experiences to inform national SEND reforms. Before you begin, you might find it useful to take a moment to read the questions carefully, so you understand exactly what feedback is being requested, many consultations ask for views on specific proposals, problem areas or priorities.

Try to answer each point directly, succinctly and in plain language. Focussing on what changes would have made a difference for your child and what would help families more broadly, rather than describing every detail of your journey. Where examples from your own experience help illustrate why a particular change is needed, including one or two short, relevant moments can make a real impact.

Working with others to influence change

If you want your experiences to be heard in as many decision-making spaces as possible, it's worth thinking about how you might connect with other parents or carers who share your goals.

The PDA Society will be asking for parents help sharing messages during the send reforms – and there are other groups and organisations you might want to work with too.

Groups such as PDA support networks, autism support groups or your local Parent Carer Forum can be brilliant places to start. During periods of reform, these groups may invite MPs or officials from the Department for Education to meet with them, giving families more time and space to share experiences collectively. If you want to find your local Parent Carer Forum, you can do so here :Find your local parent carer forum . If you want to find local PDA support groups, you can do so here Organisation Directory - PDA Society

Working as a group can also help everyone feel prepared and confident. Some groups choose to meet beforehand to talk through what they want to say and to coach one another — making sure the key messages are clear and consistent. Others decide to nominate one or two people to speak on behalf of the group, supported by a short survey capturing the experiences of many families. This allows someone to say, "I'm here as a parent, but I'm bringing the voices of 50 others in our area who told us these same issues are affecting their children."

A simple survey can also produce a helpful leave behind. If you take this approach, think carefully about what information will genuinely help the person you're trying to influence: a mix of simple, closed-choice questions (numbers, yes/no, frequency) and a small number of free-text responses works best. Free-text takes much longer to analyse, so aim for no more than 5–10 total questions to keep things manageable while still capturing meaningful insights.

Frequently asked questions

This section is designed to help you answer questions you might be asked in conversation with decision makers in a way that this clear, compelling and lands. If you are asked for detail on research or clinical practice, we recommend referring them to us at comms@pdasociety.org.uk.

What is PDA?

PDA (or Pathological Demand Avoidance) is a term coined in the 1980's by developmental psychologist Professor Elizabeth Newson OBE. The term is used to describe autistic people who show "an obsessive avoidance of the ordinary demands of everyday life".

There are a number of traits that help identify PDAers' additional challenges to other autistic people, but the most easily identifiable trait continues to be a fear response to demands that makes daily life incredibly difficult.

There is an emerging body of research around PDA (which you can find information about here). In the only prevalence study on PDA it was suggested that 1-5 autistic people is a PDAer – if that estimate is correct that would mean there are 18,000 PDAers of school age in England today.

Is PDA a real thing? I heard there is some debate?

PDA isn't a stand-alone diagnosis if that's what you mean by real. It is not in the DSM where PDA would sit within Autism.

There is some debate about whether PDA should be classified as a stand-alone condition, part of autism or as part of ADHD. Current research supports it being a profile of autism. However, this debate is a distraction – what no one is debating is that there are a group of children and adults for whom their fear response to demands in so fundamental that it can impact on every element of their life.

What does this mean for PDAers in school?

It depends – like all autistic people PDAers experiences are contextual – this means that different people will have different experiences, and that one person will be able to manage different things in different environments, and on different days depending on what is going on for and around them.

However, lots of PDAers find school really hard and this can show up as:

- Zoning out and placid non engagement and non-compliance with the curriculum, followed by exhaustion/ distress at home.
- Disruptive, and defiant classroom behaviour.
- Physical attempts to leave the classroom.
- Masking and fawning as a coping mechanism to disguise distress, followed by meltdowns once in a safe place (home).
- Refusal/ inability to go to school at all.

Unfortunately, what this means is that where PDAers are in school their needs are either unseen (because they are using coping mechanisms to cope despite being under often severe distress) or experiencing disciplinary responses to showing their distress.

What is means is that many parents struggle to be believed or to get the right support for their children in school., As a result, families find themselves with a child who is on roll at a school but can’t attend or attends very rarely, or they off roll and homeschool their child – not because they want to but because this feels like the safest option for their child’s mental health.

Some PDAers do successfully remain in school, but periods of burn out are common, as are other equalising behaviours to regain some of the autonomy that is lost in the school environment, for example extremely controlled eating, self-harm, or complete self-isolation when out of school. Families talk about their children not leaving their rooms, being unable to speak, or to eat in a room with others because of how overwhelming school is.

What does this mean for parents?

For many families this means losing at least one income in order that a parent can look after a child at home or be available to facilitate a partial timetable. This can be made worse by attendance fines, feelings of being distrusted and checked up on with daily phone calls, home visits welfare checks, and letters perceived to be threatening and unsupportive. Parents report strains on finances, on their own mental health and family breakdown as a result of this.

All of these things add to the PDAers experience of school as a demanding place and ironically makes it even harder for them to attend.

So, are PDAers just not able to cope with anything then – or is it just school?

PDAers by their nature find demands difficult. However, in many environments they can make adaptations to their lives to sidestep unnecessary demands in order to continue to thrive in their lives. The PDA Society knows many happy adult PDAers.
School is a particularly difficult place for PDAers because there are so many non-negotiables in the school day that demands get stacked on top of each other making it harder for PDAers to cope in this environment than almost any other.

Things children are expected to manage without any comprise available include: what time they arrive, eat, drink, and leave, who and how many people they are with, whether they should be quiet or talk, stand or sit, on the chair or on the carpet, go to the toilet, what subjects they do when, and what work they do, in what colour, with what pen, what they wear, the temperature, set up, noise and light levels of the rooms they are in, what they eat, drink, and even what they can bring in their bags. As a child that experiences extreme stress in response to any loss of autonomy it is no wonder school is a place that for many PDAers becomes completely unbearable.

There are however some schools that are supporting PDAers effectively in their education, as well as EOTAS providers showing ways PDA children can meet their potential outside of a school environment. While school is likely to always be challenging for PDAers there are changes that could make it more manageable for many.