

YEAR PLAN 2022-2027



Welcome



I'm excited to be sharing this 5-year plan (our strategy), which was written with the help of PDA individuals. It's the first plan we've published and has 6 goals that explain what we hope to achieve from 2022 to 2027.

This plan was produced using feedback from the PDA community* (with surveys run in 2018 and 2021), feedback from professionals and our own experience. From our surveys we heard that PDA individuals are still struggling to:

- Access a diagnosis identifying a PDA profile, with lack of research given as a reason for this.
- Have their individual needs as PDA individuals understood.
- Access the personalised strategies needed to help.

Our 5-year plan aims to tackle these challenges and improve the quality of life for PDA individuals and those who support them. Our 6 goals focus on:

1. Research
2. Information/training for professionals
3. Information/training for the PDA community
4. Support
5. Inclusivity
6. Sustainability and compliance

This is an ambitious plan. Behind it we'll have an operational plan to put this into action, a fundraising strategy, budget, people plan and more. I look forward to reporting back in 2023 on how the first year of our plan has gone.

Sally Russell

OBE, Chair of Trustees

What's in this booklet

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About PDA

PDA stands for 'Pathological Demand Avoidance'. Professor Elizabeth Newson first used this term in the 1980s. She was a psychologist working with autistic children and first wrote about PDA in 2003.

Since 2003 there's been more research and PDA is now widely thought to be a profile of autism. However, not everyone agrees, and more research is needed. A statement on alternative views can be found on the PDA Society website.

The PDA Society's focus is on what helps. PDA individuals avoid every day demands. This includes avoiding things they like. PDA individuals don't choose to avoid these demands, it's a matter of can't not won't. There is more to PDA than avoiding demands including PDA individuals:

- Having active imaginations, liking fantasy, role-play and pretence.
- Experiencing high anxiety and a strong need to control their own worlds.
- Being sociable and using social ways to avoid demands.
- Feeling things intensely, with feelings that can change quickly.
- Being very focused, often on other people.

Knowledge of PDA helps PDA individuals to understand themselves. It also helps others to understand and support them. Getting the right help can make a big difference. For example, autistic people without a PDA profile may find doing the same thing the same way and being direct helps. Whereas for PDA individuals, being more flexible, indirect and negotiating can be more helpful.

There are mixed views on the term 'Pathological Demand Avoidance' within the PDA community. Some use this term as they feel it explains how they experience demand avoidance. Others don't use the term for a range of reasons and may use alternative terms such as 'Pervasive Drive for Autonomy' or 'extreme demand avoidance'. In this plan we use the term 'PDA'.



About the PDA Society

In 1997 parents of PDA children started the PDA Contact Group. Over time the group changed its name to the PDA Society and in 2016 registered as a charity.

The PDA Society is run by five Trustees who are all volunteers and have a direct connection to PDA. In 2021 they appointed a CEO to help them run the charity. The charity's CEO is autistic and has a direct connection to PDA.

The charity supports all PDA individuals, the people who support them (e.g. parents/carers) and professionals. This includes PDA individuals without a diagnosis or who do not identify as autistic.

Each year, the PDA Society answers 2,300 enquiries from people seeking support, delivers training to 2,400 parents, carers and professionals, and provides information resources read by over 500,000 people through our website and social media.¹ All services are run by the PDA community and include:

- Enquiry line
- Online forum
- Information resources
- Training (online and in person)
- Conference every other year
- Volunteering and contract opportunities

The enquiry line, online forum and information resources are all free. Any income from training, conferences or the PDA Society's shop is used to cover the charity's running costs including paying members of the PDA community for their time on the enquiry line or as trainers. Most PDA Society funding comes from the PDA community.

Our two aims as a charity are:

- Increasing awareness and understanding of a PDA profile.
- Improving outcomes for PDA individuals by focusing everyone involved on 'what helps'.



Our 6 goals

1. RESEARCH

Promote high quality multi-disciplinary research to extend understanding of PDA and the approaches needed, informing policy and practice, with improved outcomes for PDA individuals.



2. INFORMATION/ TRAINING FOR PROFESSIONALS

Embed awareness and understanding of PDA with health, social care, education and other professionals, focusing on personalised approaches and improved outcomes not terminology.



3. INFORMATION/ TRAINING FOR THE PDA COMMUNITY

Equip the PDA community with the resources and training needed to help themselves and, should they wish, to self-advocate impactfully as experts by their own experience.



4. SUPPORT

Provide specialist support delivered by the PDA community and for the PDA community that is unavailable elsewhere and meets the needs of PDA individuals, transforming their quality of life.



5. INCLUSIVITY

Be inclusive of all PDA individuals and the people who support them, working closely with the PDA community and other organisations to ensure PDA Society services are accessible and accountable.



6. SUSTAINABILITY AND COMPLIANCE

Be a resilient organisation adapting to a rapidly changing external context, with a diverse income portfolio, high professional standards and culture of monitoring, evaluation and learning.



Goal 1. Research

Promote high quality multi-disciplinary research to extend understanding of PDA and the approaches needed, informing policy and practice, with improved outcomes for PDA individuals.



The situation now

Understanding of PDA is in its early stages. The first research paper was published in 2003. Since then, more research has been published, but there is still much to learn. Some clinics identify PDA as a profile of autism, whilst others don't recognise PDA because it's not listed in the diagnostic manuals.

More research is needed before everyone can agree on what PDA is, what helps and its inclusion in the diagnostic manuals. Research needs to involve PDA individuals and the people who support them because PDA can't be properly understood without listening to the PDA community's lived experiences.

What we'll do

Stimulate and shape research

We'll invite researchers, other professionals and the PDA community to suggest the top research questions for PDA. With them we'll define the top 10 questions and encourage researchers to find the answers, hosting an annual PDA research meeting to share ideas/information.

Promote co-production with PDA individuals

PDA individuals are the most important people in all of this. All these questions and answers must involve them. If PDA individuals aren't listened to, the answers may not be right. "Nothing about us without us" will guide our approach on research.

Put research into practice

We will take new research to policy makers to inform their decisions. We will also use these findings to shape our information resources and training.

If we get this right, we'll have:

- More high quality PDA research.
- An evidence base, for identifying a PDA profile and knowing what helps.
- More professionals accurately identifying PDA and supporting people in ways that help.

Goal 2. Information/Training for Professionals

Embed awareness and understanding of PDA with health, social care, education and other professionals, focusing on personalised approaches and improved outcomes not terminology.



The situation now

The PDA Society has been working with professionals since 1997. These include doctors, social workers and teachers. We want these professionals to know what PDA is and what helps. We provide information for professionals on our website and social media. We also offer training to professionals online and in person. Some professionals are unsure about PDA, saying more research is needed. We agree that more research is needed, but what PDA individuals tell us is also important. Our focus is on what helps, not what we call things.

What we'll do

Update our information resources/training

We hope to learn new things about PDA from research. We'll add this to the information we give professionals. If someone doesn't agree, we'll publish the alternative perspective so people can decide for themselves. We'll aim to give greater balance to adults and children in our resources/training.

Train where professionals work/learn

We'll extend our delivery model for training professionals. We'll place greater focus on taking training to professionals, alongside them coming to us, with training delivered in partnership with their workplaces or places of study. We'll get our training accredited so professionals trust it.

Bring professionals together to improve practice

We want to facilitate professionals learning from each other to support PDA individuals in better ways. We'll support an Autism and Complex Need Special Interest Group for professionals to share what they are doing. We'll explore setting up sector specific networks for professionals interested in PDA to share and develop best practice. We'll also set up a professional advisory group to the PDA Society.

Undertake a listening project

There may be other ways we can help professionals that we've not yet thought of. We'll ask other organisations what they think about PDA and what could be helpful to inform our thinking on this.

If we get this right more professionals will:

- Understand what PDA is and what helps.
- Accurately identify PDA in assessments.
- Support PDA individuals in ways that make a positive difference.

And the PDA community will have:

- Opportunities for paid work as trainers for the PDA Society.

Goal 3. Information/Training for the PDA Community

Equip the PDA community with the resources and training needed help themselves and, should they wish, to self-advocate impactfully as experts by their own experience.



The situation now

We provide PDA individuals and the people who support them with information and resources about PDA through our website and social media. On average we train 200 people a month and over 500,000 people access our resources online each year. This increases awareness and understanding of PDA amongst the PDA community, complementing the support we offer (see Goal 4). We also run PDA training for parents and carers. All our information is written with the help of PDA individuals. Our training is delivered by the PDA community.

What we'll do

Update our information resources/training

We hope to learn new things about PDA from research. We'll add this to the information we give the PDA community. If someone doesn't agree, we'll publish alternative perspectives so people can decide for themselves. We'll always shape new content with input from PDA individuals.

Make resources more inclusive/accessible

We'll ask PDA individuals and the people who support them how our resources can be more inclusive and accessible to everyone in the PDA community. We'll work with PDA individuals to produce these new resources and will form a PDA Youth Panel to hear the voice of young people.

Telling people about PDA in other ways

Sometimes information and training are not enough. We'll talk to the PDA community and look at new ways to help them to be heard. We'll offer training to PDA support groups. We'll resume our biennial conference and offer the option of virtual attendance. We'll campaign publicly around PDA Day (15th May).

If we get this right, the PDA community will have:

- Up-to-date, inclusive and accessible information/training about PDA.
- Confidence to ask people for the support they need.
- Improved awareness of PDA amongst the general public.
- Opportunities for paid and voluntary work with the PDA Society.

Goal 4. Support

Provide specialist support delivered by the PDA community and for the PDA community that is unavailable elsewhere and meets the needs of PDA individuals, transforming their quality of life.



The situation now

We run a free and confidential enquiry line so people can contact us with questions about PDA. Our enquiry line is run by people with a direct connection to PDA who are specially trained and are either paid or volunteer. The most common questions we're asked on the enquiry line are about PDA diagnosis, education and co-occurring conditions (like eating disorders). More and more people are using our enquiry line with 196 enquiries on average each month. We think this is because more people are now aware of PDA. It could also be in part due to the closure of an advice line run by a national autism charity and because of the additional pressures caused by the Covid pandemic.

What we'll do

Extend our enquiry line

We plan to increase our enquiry line team, so it's there for everyone who needs it. We'll fundraise to get the money to pay for this.

Launch an 'Enquiry Line Plus' service

Sometimes email/telephone support for the person contacting us is not enough, and people need our help when they're in crisis and/or with professionals who may not understand PDA and what is needed. Our plan is to provide extra help by making an 'Enquiry Line Plus' to support cases like these.

Establish new partnerships

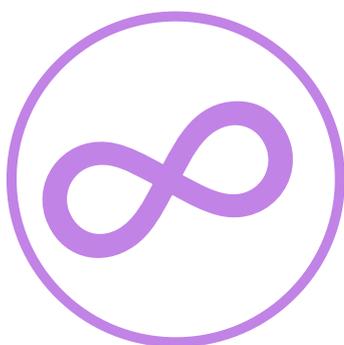
As a smaller charity, we can't provide all the support that's needed on our own, so we'll look for other organisations who can help and share our values. The PDA community will be involved in deciding what help new providers give.

If we get this right, the PDA community will have:

- Better support that's easier to access.
- Greater access to specialist emotional and practical support.
- Impactful crisis-support that is unavailable elsewhere for PDA individuals.
- Opportunities for paid and voluntary work with the PDA Society.

Goal 5. Inclusivity

Be inclusive of all PDA individuals and the people who support them, working closely with the PDA community and other organisations to ensure PDA Society services are accessible and accountable.



The situation now

The PDA Society is run by the PDA community for the PDA community. Everyone involved has a direct connection to PDA and our CEO is autistic. We offer support to all PDA individuals and the people who support them. This includes people without a diagnosis and those who do not identify as autistic. We want everyone to feel welcomed whatever their age, gender, ethnicity, sexuality, religious beliefs and disabilities. We're mindful that the people running the PDA Society are all white women. This means some people may feel the charity is not for them and feel excluded. We want to do more to address this.

What we'll do

Review current practice

We'll ask people what we could do to improve inclusivity. We'll ask everyone, not just friends of the PDA Society as friends may tell us what we want to hear. We can't improve unless we listen and act on what people tell us.

Design/deliver an inclusivity action plan

We'll use what people tell us to design and deliver a plan to make our services more inclusive. We'll deliver this plan with other organisations, who can help us reach new groups of PDA people and the people who support them.

Ongoing monitoring

We will extend demographic monitoring to include the people we support, not just the PDA Society team. We will use this monitoring to track how we are doing against our inclusivity action plan, making changes as needed.

Immediate actions

We will seek to extend the Board of Trustees, so Trustees are more representative of the whole PDA community. We will establish a PDA youth panel, to complement our PDA adult panel, and review the way we engage with PDA adults to bring in new voices including those who are detained as in-patients or in the criminal justice system. We will also review the way we present information online to make it more accessible.

If we get this right:

- PDA people and those who support them will feel more included and able to access our services whatever their age, gender, ethnicity, sexuality, religious beliefs and disabilities.
- Our team and the people we support will be more reflective of the UK population in respect of age, gender, ethnicity, sexuality, religious beliefs and disabilities.

Goal 6. Sustainability and compliance

Be a resilient organisation adapting to a rapidly changing external context, with a diverse income portfolio, high professional standards and culture of monitoring, evaluation and learning.



The situation now

We're a small charity with big ambitions. We want to help more PDA individuals and the people who support them. We also want to increase the amount of support we offer that isn't available to the PDA community elsewhere. We need to find more money so we can do this. This year we appointed our first CEO. Her job is to help PDA Society's Board of Trustees, contractors and volunteers achieve the goals in our 5-year plan.

What we'll do

Fundraising plan

We'll produce and deliver a fundraising plan, so we have the income needed to deliver our goals. This will include new things like applying for grants from trusts. It will also include more of what we do already, like regular giving. If we don't get this money, we'll need to change our plans.

People plan

We'll produce and deliver a people plan, so we have the people with the skills and experience needed to deliver our goals. We will invest in our existing team, and as we bring onboard new people, we will strive to ensure they reflect the diversity of the PDA community.

Monitoring, evaluation, and learning

For us to know if we are making a difference, we will need to ask people how we are doing, reflect on what they tell us and then make any changes needed. We will ask the PDA community at the start of our plan, mid-way through and at the end of the plan how we are doing and what impact that is making. We will also ask people as they use our services and ask our team annually.

Improved systems, structures, policies

We'll invest in a new database and update our website and policies. We'll do things in a professional way to a high standard. Safeguarding will be key. We'll put together back-up plans for unexpected events. We'll continue listening to the PDA community and be willing to learn and change.

If we get this right:

- We'll have the money to deliver our 5-year plan.
- Our team will be happy and effective in their roles.
- We'll be strong enough to keep going whatever happens.
- The PDA community will have confidence in us and feel heard by us.

Contact us

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The PDA Society is a charity registered in England and Wales
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