

5 YEAR PLAN 2022-2027

Full Version



Contents

Welcome	2
About Pathological Demand Avoidance (PDA)	3
About the PDA Society	4
Strategic Objectives	5
Objective 1 - Research	6 - 7
Objective 2 - Information/Training: Professionals	8 - 9
Objective 3 - Information/Training: PDA community	10 - 11
Objective 4 - Support	12 - 13
Objective 5 - Inclusivity	14 - 15
Objective 6 - Sustainability and Compliance	16 - 17

Welcome

As Chair of the PDA Society, I am delighted to introduce our first published strategy.

This is an ambitious strategy, co-produced with PDA individuals to meet their needs. If successful, this strategy will see increased acceptance and understanding of a PDA profile and improved outcomes for individuals and families, focusing everyone involved on 'what helps'.

In this strategy we outline our goals for the next 5 years. These goals have been shaped through conversations with PDA individuals and the people who support them, including feedback from our 5th Anniversary Survey (2021) and Being Misunderstood Survey (2018). We have also reached out to a range of sectors for their input including health, social care, education, voluntary and community.

Throughout these conversations we heard the same themes. PDA individuals struggling to have their needs identified by professionals, who recommend more 'typical' approaches for supporting autistic people that do not help or make things worse. We also heard the transformational difference made when a PDA profile was identified, and personalised approaches that took this profile into consideration were applied.

Despite demand avoidance being included in the National Institute for Health and Care Excellence (NICE) Guidelines, we know that more high quality multi-disciplinary research is the key to moving us forward. Without this, a PDA profile will not be universally accepted and recognised in the diagnostic manuals or guidelines used by clinicians, and access to a formal diagnosis and the approaches that help will remain a postcode lottery. Research will take time and alongside this we know so much more is still needed to raise awareness and understanding of a PDA profile amongst professionals.

We also know we need to extend and deepen our support for the PDA community. Demand for our enquiry line has doubled in the past few years. Our training courses for parents/carers are regularly sold out with waiting lists. Each month 38,000¹ people visit our website to access our online resources. Our team is routinely being asked for specialist support that goes beyond the practical advice and emotional support we currently offer.

In this strategy we set ourselves 6 strategic objectives which we hope will tackle these challenges being faced by the PDA community. These objectives focus on research, information, training and support. They also prioritise inclusivity, sustainability and compliance. Underpinning this strategy will be an operational work plan, fundraising strategy, budget, people plan, impact monitoring survey and safeguarding policy, amongst other things. We will review our plans annually to ensure we are achieving our goals and, if not, we will update as needed.



Sally Russell

OBE, Chair of the PDA Society

About Pathological Demand Avoidance (PDA)

In the 1980s Professor Elizabeth Newson first began using the term 'Pathological Demand Avoidance' (PDA) to describe the profile of a group of children she had seen for assessment.

In 2003, Newson published a journal article making the case to recognise PDA as a separate syndrome,² with further research published since then by other academics and clinicians.³

PDA is now widely, but not universally, understood to be a profile on the autism spectrum characterised by the traits listed below. Alternative perspectives on PDA can be found on the PDA Society's website in a statement on diagnostic terminology.

- Resists and avoids the ordinary demands of life, this may be the case even when the person seems to want to do what has been suggested.
- Uses social strategies as part of the avoidance (e.g. distracting, giving excuses).
- Appears sociable on the surface, but lacking depth in their understanding.
- Experiences excessive mood swings and impulsivity.
- 'Obsessive' behaviour that is often focused on other people.
- Comfortable in role play and pretend, sometimes to an extreme extent.

Identification of a PDA profile is important as it helps us to understand a person's needs and signpost them to helpful approaches. Autistic people who are demand avoidant but don't have a PDA profile may benefit from more consistent, structured and concise approaches, whereas a PDA profile generally requires greater flexibility, negotiation and indirectness. This understanding can be transformative and significantly improves outcomes.

Four decades on, our understanding of PDA is still at an early stage and more research is needed. Whilst diagnostic manuals do not currently recognise PDA as a profile of autism, NICE guidance does include 'demand avoidance' as a symptom of autism and allows clinicians to use clarifying terminology such as 'Autism with a PDA profile'. The PDA Society's primary focus is less on terminology and more on individual needs being understood, leading to clear signposting of helpful approaches.

Use of the term 'Pathological Demand Avoidance' is not without controversy. Within the PDA community some people feel the term is accurate and appropriate, as their experience of demand avoidance is innate and all-consuming. Other people feel the term misrepresents their experiences and prefer alternative terms, such as 'Pervasive Drive for Autonomy' or 'extreme demand avoidance' amongst other alternatives put forward. In this strategy we use the term 'PDA' or a 'PDA profile of autism'.

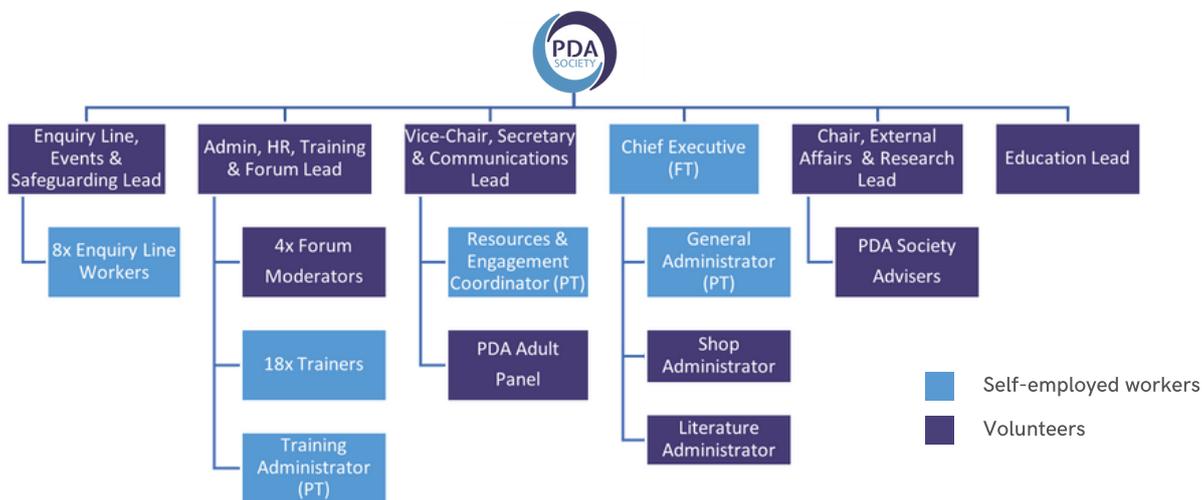


About the PDA Society

The PDA Society started out as the PDA Contact Group, set up in 1997 by parents of children with a PDA profile of autism, and became a registered charity in January 2016.

We provide information, support and training about PDA for individuals, families and professionals. We aim to increase acceptance and understanding of a PDA profile within the concept of dimensionality in autism, and to improve outcomes for individuals and families by focusing everyone involved on what helps.

The PDA Society is led and run by a small team, all of whom have a direct connection with PDA and many of whom are volunteers. In 2021, the charity appointed its first CEO to help further the charity's mission and reach. We receive no statutory funding and are reliant on donations, income from our training courses and the sale of merchandise from our shop.



Each year, the PDA Society responds to 2,300 enquiries from people seeking practical and emotional support, delivers training to 2,400 parents, carers and professionals, and provides information resources to over half a million people with 455k people visiting our website and 61k people following us on social media.⁴ We provide a holistic package of support for individuals, families and professionals including:

- 1:1 emotional and practical support delivered by phone/email via our enquiry line
- Online peer-to-peer forum hosted through our website
- Signposting to in-person support groups, Covid restrictions permitting
- Training for parents/carers and professionals, with a biennial conference
- Extensive information resources through our website and social media channels
- Volunteering/contracting opportunities for the PDA community, who may otherwise be unable to access the workplace

Our aims for the next 5 years are to:

- Increase acceptance and understanding of a PDA profile
- Improve outcomes for PDA individuals by focusing everyone involved on 'what helps'

Strategic Objectives

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: PROFESSIONALS

Embed awareness and understanding of PDA with health, social care, education and other professionals, focusing on personalised approaches and improved outcomes rather than terminology.



3. INFORMATION/ TRAINING: 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.



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.



Context

Understanding of PDA is at an early stage, with the first research paper published in 2003.⁵ As such there is a range of academic and clinical perspectives about PDA with much more research needed. Until this research is undertaken, PDA will not feature in the diagnostic manuals for neurodevelopmental conditions, and it will be at a clinician's discretion to use clarifying terminology such as 'ASD with a demand avoidance profile'. This makes getting a PDA assessment/diagnosis and accessing the best support approaches a postcode lottery.

Whilst academic and clinical perspectives are important, we believe the large and growing body of lived experience from PDA individuals and the people who support them is equally valid. However, we recognise that this lived experience, and any associated campaigns, will not influence those who produce the clinical guidelines for diagnosing and managing neurodevelopmental conditions to include PDA. This can only be achieved by high quality research. For this reason, research is critical if we are to improve access to a PDA assessment/diagnosis and the practical approaches that help, and in turn improve outcomes for PDA individuals of all ages.

Next Steps

- Promote high quality research informed by the views of PDA individuals and with due consideration of alternative explanations for behaviours.
- Lead a research priority setting exercise, bringing together professionals and the PDA community to identify and prioritise the top 10 unanswered questions in respect of PDA.
- In defining these priorities, stimulate new research interest, focus existing research efforts on the most pressing questions and provide an evidence base for research funding.
- Host an annual research meeting starting in 2022, bringing together researchers from across the spectrum of viewpoints on PDA with the aim of moving discussions forward.
- To value both academic and action research,⁶ with professionals identifying and acting on learning as it emerges in practice, alongside qualitative case study research.
- As new research is undertaken and findings published, take this evidence to policy makers to inform policy and in turn practice, engaging proactively in consultations.
- Use these findings to inform our work, adapting our understanding and approaches as needed, and disseminating them with the PDA community and professionals.
- Consider research findings in the context of the PDA community's lived experiences and, if differences arise, to engage constructively and collaboratively with researchers.



Outcomes

- High quality research published that improves understanding of PDA and the approaches that help.
- Clinicians and other professionals have more confidence to use clarifying terminology to identify a PDA profile when undertaking autism assessments.
- Improved prospects of the diagnostic manuals and guidelines on supporting and managing recognising a PDA profile.
- Research meets the needs of PDA individuals and the people who support them as it is co-produced with them and undertaken in a collaborative way.

Measures of success

- Number of high quality research projects in respect of PDA.
- Number of diagnostic centres listed on the PDA Society website who are able and willing to identify a PDA profile.
- Percentage of PDA individuals and the people who support them who, when asked through our biennial impact monitoring survey, feel PDA research is relevant to them.
- Prospects of:
 - Diagnostic manuals recognising a PDA profile in future versions.
 - Autism guidance recommending clinicians consider a PDA profile.

2. Information/Training: Professionals



Embed awareness and understanding of PDA with health, social care, education and other professionals, focusing on personalised approaches and improved outcomes rather than terminology.

Context

Since 1997 the PDA Society has been working with multi-disciplinary professionals to raise awareness and improve understanding of PDA. Our professional information resources are produced with input from these professionals and PDA individuals and we offer training co-led by PDA adults with PDA supporters. This is something we are proud of as we value our “experts by experience”. Our trainers have the option to be paid, providing opportunities for the PDA community to receive payment for meaningful work when many face barriers to accessing work elsewhere.

When engaging with professionals we take a needs-based approach, focusing on the personalised approaches needed to support PDA individuals to achieve the best outcomes, rather than the terminology. Whilst professionals may not always agree on PDA terminology most recognise the “cluster of traits” described in a PDA profile and that different approaches are needed to those commonly used to support autistic people. By raising awareness and improving understanding of PDA amongst professionals, we hope to improve outcomes for PDA individuals and their families as they access professional support.

Next Steps

- Review, update and extend our professional resources and training:
 - Incorporate the latest information as research progresses (see Objective 1) and we gain new insights from people’s lived experiences (see Objective 4).
 - Give greater acknowledgement to different viewpoints so professionals can make an informed decision about their practice.
 - Give greater balance to professionals supporting both PDA adults and children, recognising that to date the charity’s resources have been focused more on children and young people.
- Extend and deepen our engagement with professionals:
 - Identify national providers of professional information resources, which share our values, to co-produce PDA information resources and help us to reach new audiences.
 - Extend our delivery model for training professionals, so we 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.
 - Give professionals enhanced confidence in our training offer by investing in formal accreditation of our PDA Society training courses and identifying more PDA individuals and supporters with professional backgrounds to become trainers.
 - Undertake a “Perspectives Project” with UK autism organisations to better understand their perspectives and then use this learning to inform the development of new resources and explore opportunities for new initiatives.
 - Support the establishment and running of an independent multi-disciplinary Autism and Complex Need Special Interest Group (ACNSIG) providing a space for professionals to share practice and develop awareness and understanding.
 - Explore the establishment of sector-specific PDA networks for professionals to share best practice and develop awareness and understanding.
 - Establish a professional advisory group to the PDA Society building on the existing model of individual advisers, creating a space for like-minded professionals to share their experience, expertise and perspectives.
 - Utilise PDA Day (15th May) as an opportunity to increase general awareness and understanding amongst professionals through public campaigning.



Outcomes

- Health, social care, education and other professionals have the information and training needed to have:
 - Greater understanding of PDA and the approaches that can help, informed by the latest academic and practical research.
 - More confidence and capability to accurately assess and identify a PDA profile and to signpost to the approaches that can help.
- PDA individuals are better supported by professionals who have an improved awareness and understanding of their needs and can apply individualised approaches that help.
- The PDA community has meaningful voluntary and paid work delivering information resources and training to professionals on behalf of the PDA Society.

Measures of success

- Number of professionals who:
 - Attend PDA Society training.
 - Access PDA Society information resources.
- Number of diagnostic centres listed on the PDA Society website who are able and willing to identify a PDA profile.
- Percentage of professionals who attend PDA Society training and as an outcome report the following:
 - Better understanding of PDA and increased confidence to accurately identify a PDA profile.
 - Better understanding of helpful approaches for PDA and increased confidence to sign-post or apply these approaches.
- Percentage of PDA individuals and the people who support them who, when asked through our biennial impact monitoring survey, report that professionals are:
 - Considering a PDA profile when undertaking autism assessments.
 - Taking their PDA profile into account when supporting them.
 - Signposting them to approaches that are helpful.
- Percentage of PDA Society volunteers and workers who, when asked through our annual internal feedback survey, report the following outcomes:
 - Gained new life skills.
 - Feel valued and appreciated.
 - Improved self-esteem.

3. Information/Training: 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.

Context

The PDA Society currently provides PDA individuals and the people who support them with a range of information resources through its website and social media platforms. The charity also runs online and in-person training for parents/carers. This training is delivered by the PDA community and provides opportunities for the PDA community to receive payment for meaningful work. Our resources aim to increase awareness and understanding of PDA, giving people the information needed to help themselves and the people they support. These resources are well used with 455k people visiting our website each year, 61k people following us on social media and on average 200 delegates trained per month and 2,400 per annum.⁷ Our information and training are consistently described as being “transformative” to the lives of PDA individuals.

Listening to our panel of PDA adults we know there is more we could be doing to offer resources and training for PDA individuals. Whilst we have made improvements, we are mindful that there is more we could be doing to ensure we’re inclusive of all ages not just children and young people. Reflecting on our website and information resources we know some people find a lot of text difficult to read. Our resources need to be fully inclusive of gender, ethnicity, sexuality, religious beliefs and all disabilities (see Objective 5). We also hear from people that having the awareness and knowledge only takes you so far, if you do not then have the confidence to self-advocate.

Next Steps

- Review, update and extend our resources and training for the PDA community:
 - Incorporating the latest information as research progresses (see Objective 1) and we gain new insights from people’s lived experiences (see Objective 4).
 - Giving due acknowledgement to different viewpoints so PDA individuals and the people who support them can make an informed decision about PDA.
 - Ensuring our resources/training are fully inclusive and accessible to every PDA individual and the people who support them with no one excluded (see Objective 5).
 - Ensuring our resources/training are relevant to both PDA adults and children.
 - Working closely with our PDA adult panel to co-produce new resources/training that meets their needs, and exploring the establishment of a PDA youth panel.
 - Exploring new ways of presenting resources and training that are accessible to everyone (e.g. on-demand training) and updating the charity’s website with quick read options.
- Explore opportunities to offer a programme of activity that empowers PDA individuals and the people who support them to self-advocate impactfully as experts by experience.
- Engage support groups being run for PDA individuals and parents/carers, sharing the latest information resources and offering training as required to group facilitators.
- Resume our PDA Society conferences for the PDA community, starting early 2023 with a hybrid model that is accessible to people in person and virtually.
- Identify new and innovative ways to publicly campaign on PDA Day (15th May) raising general awareness and understanding of PDA amongst the general public.



Outcomes

- PDA individuals and the people who support them will have:
 - Training and information, informed by the latest academic and practical research that equips them with clear understanding of PDA and the most appropriate approaches that can help them thrive.
 - Confidence to self-advocate with clear strategies that will assist them when engaging with the professionals involved in their care and support.
 - Access to voluntary and paid work as they deliver the PDA Society's support services, leading to an improved sense of value and mental wellbeing.

And they will feel:

- Valued and included with no barriers to accessing PDA Society support services.
- A broader cross section of the public, when asked, will have a better general awareness and understanding of PDA as a profile of autism.

Measures of success

- Number of PDA individuals and the people who support them:
 - Attending PDA Society training.
 - Accessing PDA Society information resources.
- Percentage of PDA individuals and the people who support them, who attend PDA Society training and as an outcome report the following:
 - Better understanding of PDA and the approaches that help.
 - Greater confidence to support themselves or to support PDA individuals.
 - Improved quality of life as these approaches are applied
- Percentage of PDA individuals and the people who support them, who use our information resources and, when asked through our biennial impact monitoring survey, report the following:
 - Better understanding of PDA and the approaches that help.
 - Greater confidence to support themselves or to support PDA individuals.
 - Improved quality of life as these approaches are applied
- Percentage of PDA Society volunteers and workers who, when asked through our annual internal feedback survey, report the following outcomes:
 - Gained new life skills.
 - Feel valued and appreciated.
 - Improved self-esteem.
- Levels of inclusion, as measured by demographic monitoring surveys, in respect of those accessing PDA Society training and resources.

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.



Context

Since 2014, the PDA Society has provided PDA individuals and the people who support them with emotional and practical 1:1 support through an enquiry line via telephone or email. This service is run by trained members of the PDA community and is free, confidential and non-judgmental. It is available to anyone who identifies as PDA and the people who support them, whether or not they have a formal diagnosis or identify as autistic. This service is the front-door to the PDA Society's support services from which people are signposted to the online forum, support groups, information resources, training and our biennial conference. Enquiry line workers are paid, providing opportunities for the PDA community to receive payment for meaningful work when many facing barriers to accessing work elsewhere.

In recent years there has been a consistent increase in the number of people contacting the enquiry line and the complexity of the queries being raised. On average our enquiry line receives 196 enquiries each month with diagnosis, education and co-occurring conditions (e.g. eating disorders) being the main reasons for people making contact.⁸ Reasons for this are thought to include greater awareness of PDA, the closure of the National Autistic Society Helpline and increased need associated with the pressures of the COVID pandemic. As the number of enquiries has increased, so too has the complexity of the support required. In some cases, this has exceeded what the Enquiry Line has been able to help with, without any suitable alternative support service to sign-post people on too.

Next Steps

- Grow the existing capacity of the Enquiry Line to meet increased need and demand.
- Extend the Enquiry Line to include an "Enquiry Line Plus" service, providing intensive 1:1 support when there is a high level of unmet need with a risk of serious harm; an imminent key decision; involvement of multiple agencies with poor knowledge/understanding of PDA; and/or an inability of support services to move things forward. If this service is successful, to explore opportunities for commissioned work.
- Remain vigilant and responsive to the unmet support needs of PDA individuals, especially those from marginalised groups, considering the development of other new support services as and when these arise. Any new services will be designed with PDA individuals and delivered by the PDA community, with opportunities for meaningful paid work and volunteering.
- Proactively explore opportunities to build new partnerships with other organisations, including formalised referral pathways and jointly delivered projects. Partnership working can enable the charity to reach new people, build the capabilities of other organisations to support PDA individuals and in turn acquire new skills and experience from partners.



Outcomes

- PDA individuals and the people who support them will have:
 - A single point of access to the latest PDA information that assists them to apply, or ask others to apply, practical approaches that help to improve their quality of life.
 - Access to emotional and practical support from the PDA community, leaving them feeling more connected and less isolated, leading to improved mental and physical well-being.
 - Transformational, life changing support that moves people out of crisis when at high risk of serious harm and/or facing a life changing decision involving multiple agencies.
 - Access to voluntary and paid work as they deliver the PDA Society's support services, leading to an improved sense of value and mental wellbeing.

And they will feel:

- Valued and included by the PDA Society with no barriers to accessing support services.

Measures of success

- Number of people supported through the Enquiry Line and Enquiry Line Plus service.
- Percentage of PDA individuals supported by the PDA Society who, when asked annually as part of our impact monitoring, report improved:
 - Understanding of themselves and the approaches that help.
 - Quality of life as they apply this understanding and approaches.
 - Mental wellbeing, with reduced feelings of isolation.
- Percentage of people supporting PDA individuals who access PDA Society support and, when asked annually as part of our impact monitoring, report improved:
 - Understanding of PDA and the approaches that help.
 - Confidence and capability to support PDA individuals.
 - Mental wellbeing, with reduced feelings of isolation.
- Percentage of PDA individuals supported by the Enquiry Line Plus service reporting a transformational positive life change as an outcome of the PDA Society's support.
- Percentage of PDA Society volunteers and workers who, when asked through our annual internal feedback survey, report the following outcomes:
 - Gained new life skills.
 - Feel valued and appreciated.
 - Improved self-esteem.
- Levels of inclusion, as measured by demographic monitoring surveys, in respect of those accessing PDA Society support services.

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.



Context

The PDA Society is a charity run by the PDA community for the PDA community with an openly autistic CEO. Everyone involved is a PDA individual, PDA supporter (e.g. parent to a PDA individual) or someone with a direct connection to PDA; from the people who run our enquiry line to those delivering our training. We have a PDA adult panel that we consult when producing new resources and we proactively promote initiatives being led by the wider PDA community through our social media platforms. Our support services are open to anyone who identifies as PDA, whether diagnosed or autistic, recognising the barriers to getting a formal diagnosis and the different viewpoints on PDA being a profile of autism.

It could be easy for us to say we are an inherently inclusive organisation. However, that only looks at inclusivity through one lens. We know that we have more PDA parents than PDA individuals running our services; that we have an over-representation of white women involved at both a governance and operational level; that we do not know enough about how representative the people we support are of the general population; and that we could be reaching a wider and more diverse group of PDA individuals through partnership working with other organisations. Over the years the PDA Society has sought to improve inclusivity, but there is more we could be doing. This objective will give greater priority to the PDA Society's approach to inclusivity.

Next Steps

- We will critically review our starting position. We will ask people to tell us what barriers they face to inclusion and how we could be doing better. We will actively listen and act on what we hear, putting in place a plan that is regularly monitored and updated.
- We will extend demographic monitoring to the people who use the PDA Society's services, not just the PDA Society's team, with voluntary anonymised questionnaires. We will use this data to inform our inclusivity planning and ongoing monitoring.
- We will proactively identify new partnerships with other organisations which share the values of the PDA Society and are well placed to support our inclusivity work, recognising the skills, experience and networks they will bring as subject matter experts.
- We will strive to extend the Board of Trustees to improve inclusion given the current demographic make-up of the Board.
- Reflecting on the voice of PDA individuals within the PDA Society, we will:
 - Establish a PDA Youth panel to complement our existing PDA Adult panel.
 - Review the way our PDA adult panel works and bring in new voices.
 - Review the way we present information to be more inclusive of all PDA individuals.
 - Reflect on what more we could be doing to include PDA individuals detained in in-patient units or within the criminal justice system or where there is another reason that makes it particularly challenging for them to engage with our support services (e.g. engaging providers of Independent Mental Health Advocacy services).



Outcomes

- The PDA Society team, including Trustees, volunteers, workers and advisers, is more reflective of the demographic composition of the UK.
- People supported by the PDA Society's services are more reflective of the demographic composition of the UK.
- PDA individuals and the people who support them will feel more included and better able to access the PDA Society's services whatever their age, gender, ethnicity, sexuality, religious beliefs and disabilities.

Measures of success

- Demographic monitoring data shows the PDA Society team and the people supported by the PDA Society's services are more representative of the UK general population.
- Impact monitoring data shows an increased percentage of people using the PDA Society's services who feel the charity is inclusive and accessible to all in need of support.

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.



Context

Since the PDA Society registered as a charity in 2016, we have undergone a period of growth with annual income increasing from £30k to £82k with thanks to several generous individual donations. These donations have meant the charity could respond to a sharp increase in requests for support, each month on average responding to 196 enquiries to our enquiry line and training 200 people.⁹ In 2021, the Board of Trustees appointed their first CEO tasked with supporting the charity to define and meet the needs of the PDA community over the next 5 years.

Looking ahead, the Board of Trustees anticipates that demand for the PDA Society's existing support, information resources and training will continue to grow, as awareness of PDA increases. We have identified a need to be doing more to promote high quality research and to improve access to a PDA diagnosis and in turn the approaches that help. We have also identified a need for new services for PDA individuals when these needs are not being met elsewhere. To deliver on this the PDA Society will need to more than double income to around £200k per annum over the next 5 years and put in the place the systems and structures required to do this well.

Next Steps

- Develop and deliver a 5-year fundraising plan, informed by our 5-year budget, including:
 - Taking a more proactive/diversified approach to fundraising/income generation.
 - Starting to apply for grants from trusts, foundations and lottery programmes.
 - Exploring opportunities to increase earned income via consultancy services and statutory commissions, as well as identifying corporate sponsors.
- Develop and deliver a 5-year people plan, including:
 - Investing in our existing team ensuring they have the support and training needed to deliver the new strategy. If someone is feeling over-stretched, we will take action.
 - Acting on the recommendations of our inclusivity review (see Objective 5).
- Extend our monitoring, evaluation and learning framework including:
 - Biennial impact monitoring for all services with baseline monitoring (Year 1), mid-year monitoring (Year 3) and final year monitoring (Year 5).
 - Annual impact monitoring for the Enquiry Line and Enquiry Line Plus service.
 - Annual internal feedback gathered from the PDA Society team.
 - Demographic monitoring across all services.
- Identify opportunities for partnerships with organisations that value PDA individuals, thereby enhancing our resilience and sustainability through collaborative working.
- Invest in our systems and structures, to deliver the best possible service for the PDA community. In particular:
 - Put in place a new database, to hold contact and HR information, automate processes wherever possible and update policies/procedures with best practice.
 - Review and update our policies, procedures and working practices in keeping with legal requirements and best practice, with assurance that we are getting things right from the Trusted Charity Mark.¹⁰



Outcomes

- The PDA Society will have fully costed and resilience-tested organisational design, systems, process and people plans in place to deliver its 5-year strategy.
- Services standards will be established and measured to ensure that services are delivered to high a standard, meeting the needs of the PDA community and keeping every person and their information safe.
- The PDA Society will have scenario plans in place to ensure resilience to overcome unexpected events, always ensuring the continued provision of core services.
- The PDA Society will act with integrity and be accountable to the PDA community through its panels, surveys and other feedback mechanisms, with a willingness to learn and change.

Measures of success

- Actual income/expenditure is in keeping with budgeted income/expenditure and if unexpected events occur, the delivery of support services is prioritised and sustained at planned levels with savings made elsewhere in the budget.
- Low turnover within the PDA Society team and a high percentage expressing satisfaction with their involvement, when asked through our annual internal feedback survey.
- PDA Society is awarded the Trusted Charity Mark in recognition that the organisation is well run, conforms to legal requirements, is accountable and transparent.
- Percentage of the PDA community who, when asked through our biennial impact monitoring survey, express confidence in the charity's integrity and accountability.

Contact us

www.pdasociety.org.uk

info@pdasociety.org.uk



The PDA Society is a charity registered in England and Wales
Charity number: 1165038
www.pdasociety.org.uk