PDA in our words: Why we need to listen to PDA people and their families

The findings of the PDA Society's 2023 community survey

We would like to sincerely thank the 921 members of the PDA community who took the time to complete our survey and tell us about their experiences. It is this lived experience that has informed this report and our recommendations for change.

We would also like to thank the PDA Society team – including staff members and volunteers – who helped to design and pilot the survey, and to analyse the data collected.

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Contents

Executive summary

In May 2023, the PDA Society launched its community survey, to which 921 people responded.[1] This report presents the survey findings, focusing on the experiences of three groups of survey respondents – PDA children and young people, PDA adults, and parents and carers. We wanted to find out more about what life is like for the PDA community, to listen to and learn from lived experience, and to use this knowledge to advocate for change.

What is the picture for PDA children and young people?

> *School was extremely demanding. I masked what I know now as my demand avoidance and hid it extremely well, but the demands of homework, schoolwork, talking to different people and GCSE exams wore me down. I would come home every day either stimming for hours or falling asleep because I was too exhausted.* (PDA adult)

621 parents/carers of under 18s responded to the survey. The findings from this group are presented in section 3. They told us that:

- The education system is failing PDA children and this is impacting on their health and wellbeing. 60% of parents and carers said their children struggle to get into school either all the time or regularly. 85% said their child had experienced EBSA[2] at some point in their lives (74% had experienced it in the last year). 76% of parents/carers said that their child had needed mental health services at some point, and 91% said their child had experienced severe anxiety.
- Children face significant challenges to accessing assessment, diagnosis and support services. Parents and carers described multi-year waiting lists - both for assessment and support.
- Children with a PDA profile of autism are overwhelmingly supported by their families, rather than support services or professionals. Unsurprisingly, 90% of parents and carers said the child they care for relies on family for day to day support needs and 84% for support when they're in crisis. However, only 51% of parents/carers with a child enrolled in an education setting said their child received emotional or practical support from a SENCO, teacher or teaching assistant.

What is the picture for PDA adults?

> *I found life incredibly challenging, even the easiest tasks seemed so impossible, and I treated myself so badly, telling myself I was useless when I couldn't manage to do certain things, or when I had meltdowns because I couldn't cope with getting somewhere with the demand of getting there by a certain time. So full of stress, high levels of anxiety and depression.* (PDA adult)

170 PDA adults and 105 parents/carers of over 18s responded to the survey. The findings from these groups are presented in section 4. They told us that:

- On reaching adulthood, many PDA people are unsupported in higher education, training and employment, and as a result experience financial hardship. 36% of self-reporting PDA adults were not in further/higher education or employment at the time of the survey. Of those adults who were in education or employment, 40% said they always or regularly struggled to

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[1] Section 1 of the report outlines the survey methodology, and Appendix 3 contains the survey questions.

[2] Emotionally based school avoidance/anxiety

attend. 77% of self-reporting PDA adults said they had experienced financial hardship at some point (39% in the last year).[3]
- PDA adults experience mental health challenges, loneliness and isolation, and difficulties with everyday tasks. 84% of self-reporting adults said they had experienced suicidal thoughts and 65% had self-harmed at some point in their lives.
- Most often PDA adults' main source of support is friends, partners and family, rather than professional services. 26% of self-reporting PDA adults said they had no support at all, despite being in need of it.

What is the picture for parents and carers?

> *I suppose the best way to describe it would be that as a parent I felt not only like every day was like balancing on the edge of cliff not knowing what we were going to endure, but I felt like a failure as a parent. Not only was I portrayed as a failure by certain professionals at points through our journey, but hearing from your child some harrowing reasons why he no longer wants to live was devastating and took a massive toll on my mental health.* (Parent of under 18)

Altogether, 727 parents and carers of PDA people responded to the survey.[4] The findings from this group are presented in section 5. Parents and carers told us that:

- Parents and carers of PDA people are carrying out heavy loads of unpaid care responsibilities, with high social, physical, economic and emotional consequences.
- Parents see clear and positive differences in their children when they implement collaborative and person-centred approaches, but find that progress is stalled or reversed when these approaches are not understood or followed by professionals.
- Parents and carers are vulnerable to parent blame when professionals do not have adequate knowledge about neurodiversity broadly, and PDA specifically. 61% of those responding to the survey as parents or carers have experienced disputes over their child's education/schooling at some point, and 16% have experienced an education tribunal. 24% have experienced a social services investigation, 13% have experienced allegations of fabricated or induced illness (FII),[5] and 13% have experienced allegations of parental alienation.[6]

What are the commonalities across the three groups?

We have presented the findings from each of the three groups separately, as each reported different challenges, difficulties and positive experiences. However, there were some clear commonalities. These include:

- *Education and employment*
  Our data show that PDA people of all ages are not having their needs met in education and employment. They experience high levels of anxiety around the 'demand' to participate in education institutions and in workplaces designed by and for neurotypical people, and they

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[3] This is higher than statistics representing the general adult population in the UK. The Financial Conduct Authority states that 24% of all UK adults have low financial resilience.

[4] Parents/carers of PDA people both under and over 18 years old (727 respondents in total).

[5] Discussion of the term "FII" is included in section 5.

[6] Discussion of the term "parental alienation" is included in section 5.

do not feel understood or supported. For many PDAers, this anxiety is a constant pattern throughout the lifecycle as they are expected, and try, to 'fit in' to different settings.

- *Health and wellbeing*
  PDA people of all ages told us how struggling and being misunderstood in education and employment settings impacts negatively on their health and wellbeing. Mental health challenges were a commonly cited issue. We heard about children as young as five with such high anxiety levels that they began to self-harm or have suicidal thoughts. As PDAers grow older, mental distress can become more ingrained – we heard from adults who had felt suicidal for decades.

- *Diagnosis, services and support*
  Another common theme across the age groups was the challenges faced by PDA people and their parents/carers in accessing timely and appropriate assessment, diagnosis and support. Children and young people face long waiting lists for diagnosis, and are not always assessed by clinicians with knowledge of the PDA profile of autism. Adults gave examples of their PDA not being recognised; instead many had received misdiagnoses of mental health conditions. The main source of support for the vast majority of PDA people is family and friends, rather than professional support.

- *'Getting it right' can be transformational*
  Survey respondents of all ages told us about times when a person or institution had 'got it right' for them – in education, employment, health services or family life. These examples, which we discuss in sections 3, 4 and 5, as well as in Appendix 2, demonstrate what can happen when we understand PDA, listen to and act on lived experience, and think outside of the box.

Intersectionality

As we are aware that minoritised groups in our society experience structural discrimination and disadvantage, we wanted to ensure that we were able to analyse our data from an intersectional perspective. While we are limited in what we can say due to the small number of respondents from ethnic backgrounds other than white,[7] our data indicate that PDA people from ethnically minoritised groups may be experiencing exacerbated difficulties and inequalities. The data also illustrate the particular vulnerability of some groups of parents – in particular single mothers and parents from ethnically minoritised groups – to experiences of parent blame. In addition, our data show some gender differences among adult PDAers. We have integrated our findings on intersectionality into sections 3, 4 and 5 of the report.

What needs to change?

Everyone deserves to get timely support that meets their needs when they are struggling, especially when this is having a long-term and detrimental impact on their daily lives.

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[7] 86% of our sample were from a white ethnic background. Survey respondents whom we have categorised as from ethnically minoritised communities or backgrounds include the 1% of our sample who chose the category 'Asian/Asian British'; the 0.5% of our sample who chose Black/African/Carribbean/Black British; and the 7% who chose 'mixed or multiple ethnic background'.

There is no legal requirement to have any diagnosis to be able to access appropriate support in the UK; in the Families Act, the Health and Social Care Act and the Equalities Act, access to support is based on identified needs alone.

With services stretched to capacity however, diagnosis is being used unlawfully to gatekeep vital support in education, work and healthcare, and waiting lists for assessments are longer than they have ever been.

We believe that a renewed focus on individual strengths and needs would be life-changing for PDA people and the autistic community as a whole. This would allow everyone to get help quicker, wherever they are on their diagnosis pathway, and would encourage more flexible and varied provision to respond to the diverse experiences of autistic people.

To achieve this, we need to support collaborative partnerships between PDA adults, parents and professionals, which reflect the value of lived experiences, and have the flexibility to adapt when the current approach isn’t working. When we get this balance right, the impact can be truly transformational.

1. About this report

The PDA Society

The PDA Society provides information, support and training about PDA for individuals, families and professionals. We aim to increase acceptance and understanding of a PDA profile and to improve outcomes for individuals and families by focusing everyone involved on 'what helps'. Promoting high quality research, informed by what matters most to the PDA community, is one of our 5-year goals. In 2022-23 we conducted a research priorities consultation exercise, which culminated in the development of nine overarching research questions that are important to the PDA community. We hope that the survey data we have collected and the analysis presented in this report will help to continue the research journey towards better understanding of PDA.

Terminology and language

We recognise that there are different opinions and preferences within the PDA community about language and terminology, and we respect the different perspectives on this. In this report, we have used the terms 'PDA adult' and 'PDA child or young person' to differentiate between different groups of respondents. We also use the terms 'PDA people' and 'PDAer'. When referring to PDA we have referred to the PDA profile of autism, recognising that PDA is widely, but not universally, understood to be a profile on the autism spectrum.[8]

Methodology

Our community survey ran for three weeks in May 2023. The survey was collaboratively designed and tested by PDA Society staff and volunteers, all of whom have lived experience of PDA. It contained a mixture of multiple choice and open-ended questions, designed to gather both quantitative and qualitative information.[9]

921 people responded to the survey. It was open both to respondents with a formal diagnosis of the PDA profile of autism, and those who do not have a diagnosis but identify as PDA.

The survey began with four open-ended questions for all participants, after which participants were routed to a set of tailored questions according to which of the following groups they identified with:[10]

- PDA people age 17 or over
- Parent or carer of a PDA person age 18 or over
- Parent or carer of a PDA child under age 18
- Partner of a PDA person age 17 or over

The survey was disseminated via the PDA Society's communications and media networks. This means that our sample is made up of self-selecting respondents. However, we believe that what the data tell us presents an accurate picture of the experiences of many in the PDA community. It also

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[8] More information on language, terminology and diagnosis can be found on the PDA Society website: https://www.pdasociety.org.uk/resources/pda-society-statement-about-diagnostic-terminology/

[9] The survey questions can be found in Appendix 3.

[10] If participants felt they belonged to more than one of the groups, they were invited to complete the survey more than once if they wished to.

aligns with the stories we regularly hear through our enquiry line, training work and liaison with professionals.

The survey was hosted online and data were encrypted and stored securely. Data analysis was carried out using Survey Monkey analysis tools. All participants were required to read about the purpose of the study, confidentiality and anonymity, and how their data would be used, and to indicate that they understood this before proceeding with the survey.

2. The overall picture

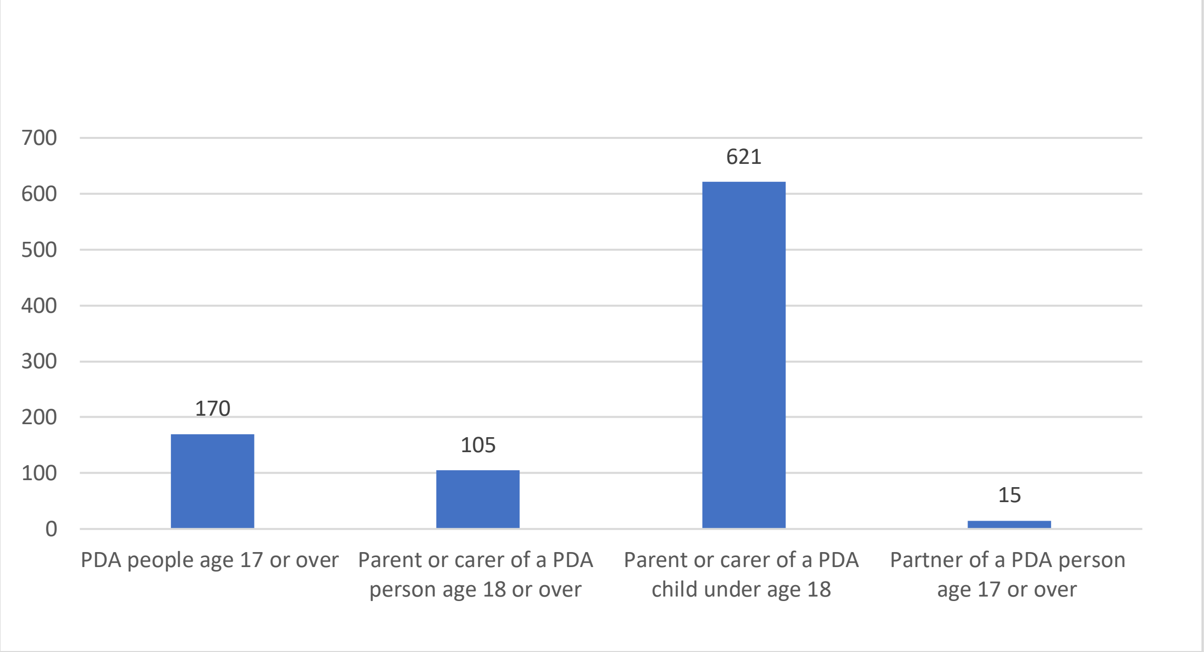
Whose experiences have we captured?

Below we set out information about the people who responded to the survey. We then go on to outline some of the key characteristics of those whose experiences were being discussed in survey responses: PDA adults, children and young people. We did not collect demographic information about the parents, carers and partners who were completing the survey on behalf of their children or partners.

Category of survey respondent

Survey respondents were asked to let us know which of four categories they identified with.[11] As figure 1 illustrates, the majority of responses were from parents or carers of under 18s (621 responses). This was followed by 170 PDA people age 17 or over, 105 parents or carers of over 18 PDAers, and 15 partners of PDA people.[12][13]

Figure 1: Category of survey respondent



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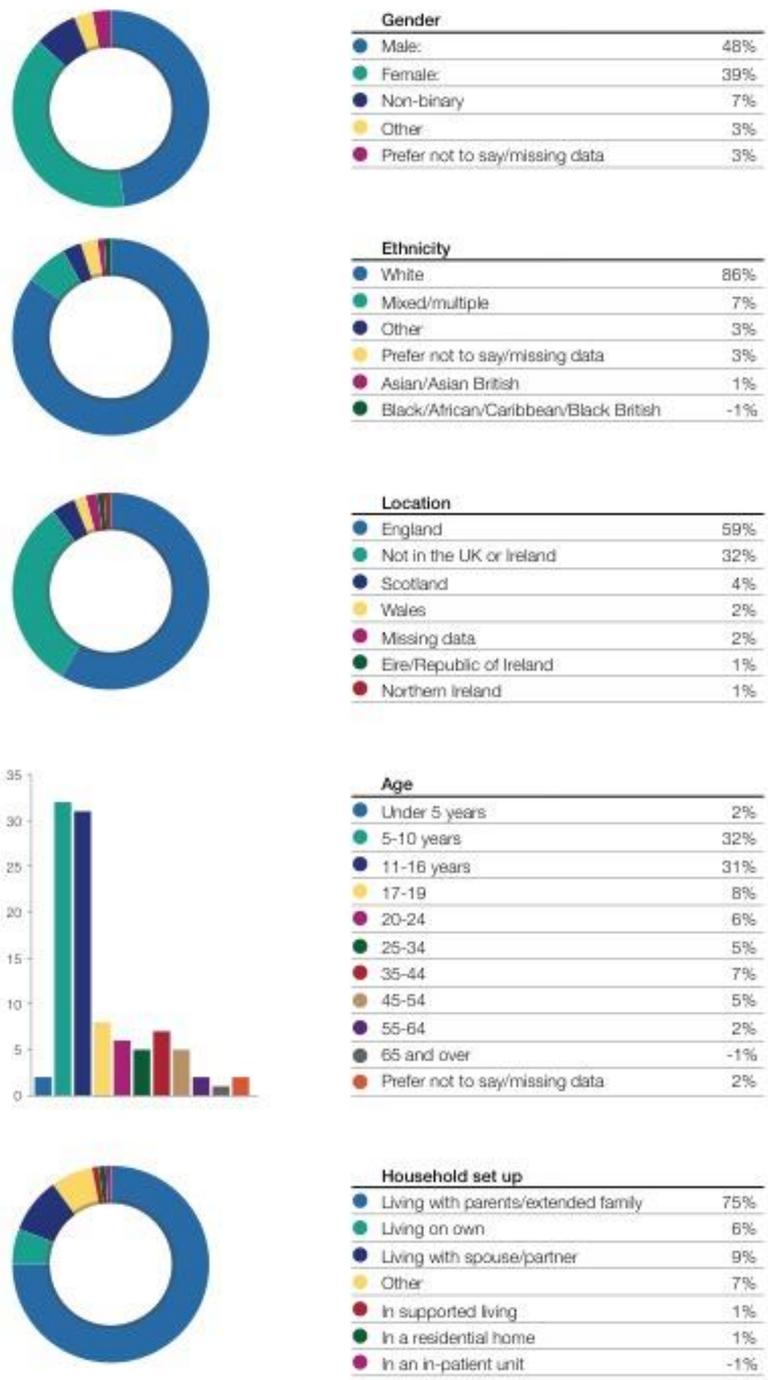
[11] If participants felt they belonged to more than one of the groups, they were invited to complete the survey more than once if they wished to.

[12] Data from partners of PDA people have been excluded from the analysis presented in sections 3-5 of this report due to the small size of this group.

[13] In total, these four groups add up to 911. Another ten participants filled in the initial open-ended questions but did not complete the question asking which group they identified with, and therefore were routed to the end of survey.

Figure 2: Gender, ethnicity, location, age and household set up of survey sample



	Gender	
●	Male:	48%
●	Female:	39%
●	Non-binary	7%
●	Other	3%
●	Prefer not to say/missing data	3%

	Ethnicity	
●	White	86%
●	Mixed/multiple	7%
●	Other	3%
●	Prefer not to say/missing data	3%
●	Asian/Asian British	1%
●	Black/African/Caribbean/Black British	-1%

	Location	
●	England	59%
●	Not in the UK or Ireland	32%
●	Scotland	4%
●	Wales	2%
●	Missing data	2%
●	Eire/Republic of Ireland	1%
●	Northern Ireland	1%

	Age	
●	Under 5 years	2%
●	5-10 years	32%
●	11-16 years	31%
●	17-19	8%
●	20-24	6%
●	25-34	5%
●	35-44	7%
●	45-54	5%
●	55-64	2%
●	65 and over	-1%
●	Prefer not to say/missing data	2%

	Household set up	
●	Living with parents/extended family	75%
●	Living on own	6%
●	Living with spouse/partner	9%
●	Other	7%
●	In supported living	1%
●	In a residential home	1%
●	In an in-patient unit	-1%

Gender

As figure 2 shows, 48% of our overall sample was made up of PDA people who identify as male. 39% identified as female, and 7% as non-binary. However, when the data were broken down by group, we found that the majority of PDA adults completing the survey on their own behalf identified as female (59%), followed by 22% who identified as non-binary and 15% who identified as male.

Meanwhile, the majority of parents/carers were completing the survey on behalf of PDA children and young people who identified as male (54% of parents/carers of over 18s and 57% of parents/carers of under 18s). 29% of parents/carers of over 18s and 37% of parents/carers of under 18s were responding to the survey on behalf of PDA children or young people who identified as female. For non-binary children and young people, the figures were 9% (over 18s) and 3% (under 18s).

Ethnicity

Figure 2 illustrates the ethnic background of survey respondents. The vast majority (86%) of respondents reported that they, or the PDA person they were completing the survey about, were from a white ethnic background. 7% of respondents chose the mixed/multiple heritage option, 3% chose ‘other’, 1% chose Asian/Asian British, and less than 1% chose Black African/Caribbean/British.

Location

The locations our respondents were based in is displayed in figure 2. 59% were located in England, and 32% were based outside of the UK. Among this category the most common locations were the United States, Australia and Canada, as well as New Zealand and European countries such as Germany and the Netherlands. 4% of our sample were based in Scotland, 2% in Wales, and 1% in the Republic of Ireland.

Age

As figure 2 shows, under 18s made up the majority of PDA people in our sample, with 32% of the sample being 5-10 years old and 31% being 11-16 years old. PDA adults were spread across age categories, with a decline in numbers after age 45.

Household set up

We asked respondents about their living arrangements, and as figure 2 demonstrates, 75% were living with their parents or extended family. This is not surprising given that the majority of our sample were under 18 years of age.

When the data on household set up were broken down by group, we found that 41% of PDA adults completing the survey on their own behalf were living with a spouse or partner, and 24% of this group were living on their own. These figures differed from those reported by parents/carers of over 18s, 72% of whom said the PDA adults they cared for were living with parents or extended family.

What did survey respondents tell us?

Findings common across respondent groups

We present the survey data for three groups of respondents – children and young people, adults, and parents and carers, in sections 3, 4 and 5. It is important to consider each of these groups separately as each reported different challenges, difficulties and positive experiences. However, there were some clear commonalities. These include:

- *Education and employment*
  Our data show that PDA people of all ages are not having their needs met in education and employment. They experience high levels of anxiety around the 'demand' to participate in education institutions and in workplaces designed by and for neurotypical people, and they do not feel understood or supported. For many PDAers, this anxiety is a constant pattern throughout the lifecycle as they are expected, and try, to 'fit in' to different settings.
- *Health and wellbeing*
  PDA people of all ages told us how struggling and being misunderstood in education and employment settings impacts negatively on their health and wellbeing. Mental health challenges were a commonly cited issue. We heard about children as young as five with such high anxiety levels that they began to self-harm or have suicidal thoughts. As PDAers grow older, mental distress can become more ingrained – we heard from adults who had felt suicidal for decades.
- *Diagnosis, services and support*
  Another common theme across the age groups was the challenges faced by PDA people and their parents/carers in accessing timely and appropriate assessment, diagnosis and support. Children and young people face multiple-year waiting lists for diagnosis, and are not always assessed by clinicians with knowledge of the PDA profile of autism. Adults gave examples of their PDA not being recognised; instead many had received misdiagnoses of mental health conditions. The main source of support for the vast majority of PDA people is family and friends, rather than professional support.
- *'Getting it right' can be transformational*
  Survey respondents of all ages told us about times when a person or institution had 'got it right' for them – in education, employment, health services or family life. These examples, which we discuss in sections 3, 4 and 5, as well as in Appendix 2, demonstrate what can happen when we understand PDA, listen to and act on lived experience, and think outside of the box.

Before and after stories

We began our survey with open-ended questions asking respondents to tell us what their lives were like before they found out about PDA, and what their lives were like after finding out. The majority of respondents told us that finding out about PDA has helped them to better understand themselves or the PDA person they care about. But they also said that knowing about PDA wasn't enough on its own – if PDA lives are to be made better, the wider world also needs to find out about and understand PDA.

In sections 3, 4 and 5 we include some 'before and after' stories of PDA children, adults and parents/carers. Below are three examples of before and after stories that describe experiences across whole families.

Before we knew about PDA	**After we knew about PDA**
Our family lived in utter turmoil. We found no support. Even from calling child mental health crisis lines. We were judged by family, we were hanging on by a thread. Our marriage almost ended several times. I had been researching for a few years, trying to figure out what was going on. We saw three different paediatricians and they just shrugged their shoulders. Then I stumbled across PDA. I cried as I read the	Life is still a rollercoaster. But we have learnt how to lower demands, meet our child where they are at. We are brave enough to face judgement from others about our parenting and way if being. Our child has begun to emerge from a long period of burnout. We see their sparks of self again. We still face obstacles with schooling. Obstacles of finding allied health professionals who understand and care.

diagnostic criteria. Everything made sense. 114315941472	Hearing lived experiences of older PDA individuals has been a window of hope and reassurance that we are doing a better job of being parents and companions on my child's journey in life. That I can be that co-regulating, trusted person for my child.
Stress, trauma, meltdowns, autistic burnout, anxiety, depression, violence, property destruction, aggression, panic attacks, school avoidance - for us as parents and our children. Our family was falling apart. Financial and marital stress. Confusion, disappointment, anger, guilt. Constant searching, trying to "fix" everything, endless appointments, professionals, diagnosis, parenting courses, books. From the outside it might have looked like we were holding it all together but we weren't! 114316639014	Very different now. Acceptance, understanding, a whole new way of living. Home schooling our PDA child. Giving up a career. Making financial and living changes for our family. More peace, happiness, calm. Letting go of unrealistic expectations. Listening to the voices of PDAers and finding PDA affirming professionals for guidance and support. Truly seeing our son for who he is. Understanding his needs. Supporting in a PDA friendly way. Eager to keep learning more.
Life was confusing. So many things did not make sense. Simple tasks were increasingly becoming difficult, and for reasons without any explanation. Suddenly we found our entire family walking on eggshells, trying to accommodate someone we didn't understand. 114330479274	Loads different. We have learned from PDA adults - so many wonderful things. We have reduced demands, we allow for autonomy, and we trust. We have also learned to be really great listeners.

What has changed since our last survey?

In 2019 we published our Being Misunderstood report, which outlined the findings of our 2018 community survey. This survey captured the experiences of 1,445 parents, professionals, PDA adults and their partners or family members. While the 2018 survey was not identical to our 2023 survey, meaning that we can't make like for like comparisons, it is clear that since 2018, things have not improved for PDA people.[14]

- In 2018, 70% of children and young people were not able to tolerate their school environment or were home educated.[15] In 2023, the corresponding percentage was 72%.
- In 2018, 19% of parents/carers reported severe depression in their PDA child or young person, and in 2023 52% said their child or young person had experienced depression at some point.[16]
- In 2018, 81% of parents/carers reported that their PDA child had experienced severe anxiety, and in 2023 the figure for experiencing severe anxiety at some point was 91%.
- In 2018, 73% of parents/carers reported their child had low self-esteem, and in 2023 this had risen to 84%.

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[14] We are not able to make comparisons around the situation for PDA adults in 2018 and 2023, as there were too many differences between the questions for adults in the two surveys.

[15] This statistic encompasses children who were not enrolled in a school (excluding those home educated by choice) or were struggling 'all the time' or 'regularly' to get in school.

[16] Part of this difference may be due to question wording. In 2018 we used the term 'severe depression', whereas in 2023 we used 'depression'. However, this is not likely to explain all of the increase.

- In 2018, levels of reported self-harm among PDA children was 23%, and in 2023 this had risen to 41%.

Research has demonstrated the impact of societal events on the mental health of the population during the five years since our last survey; events including the COVID-19 pandemic, the cost of living crisis, and continuing cuts to the funding of health and support services.[17] The post-pandemic landscape has also brought increasing recognition of the underfunding of our education system, and the failure of this system to provide children with SEND the education that they deserve and are entitled to.[18] Recent government education policy has focused on improving attendance rather than tackling the root causes of school avoidance and anxiety.[19] The data presented in this report shines a light on the reasons why this needs to change.

Intersectionality

As we are aware that minoritised groups in our society experience structural discrimination and disadvantage, we wanted to ensure that we were able to analyse our data from an intersectional perspective. While we are limited in what we can say due to the small number of respondents from ethnic backgrounds other than white,[20] our data indicate that PDA people from ethnically minoritised groups may be experiencing exacerbated difficulties and inequalities. The data also illustrate the particular vulnerability of some groups of parents – in particular single mothers and parents from ethnically minoritised groups – to experiences of parent blame. In addition, our data show some gender differences among adult PDAers. We have integrated our findings on intersectionality into sections 3, 4 and 5 below.

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[17] National Autistic Society (2020) Left stranded: The impact of coronavirus on autistic people and their families in the UK; The Health Foundation (2021) The unequal mental health toll of the pandemic; World Health Organisation (2022) Mental health and COVID-19: Early evidence of the pandemic's impact. Scientific brief; MIND (2023) Mental health of half of adults in England and Wales negatively affected by cost-of-living crisis

[18] https://www.theguardian.com/education/2023/sep/03/special-educational-needs-provision-crisis-england-record-complaints; https://www.childrenscommissioner.gov.uk/news/commissioner-calls-for-radical-rehaul-of-the-send-system/

[19] https://notfineinschool.co.uk/attendance

[20] 86% of our sample were from a white ethnic background. Survey respondents whom we have categorised as from ethnically minoritised communities or backgrounds include the 1% of our sample who chose the category 'Asian/Asian British'; the 0.5% of our sample who chose Black/African/Carribbean/Black British; and the 7% who chose 'mixed or multiple ethnic background'.

3. The picture for PDA children

Key points:

- The education system is failing PDA children and this is impacting on their health and wellbeing.
- Children face significant challenges to accessing assessment, diagnosis and support services.
- PDA children are overwhelmingly supported by their families, rather than support services or professionals.

Content warning: The sections below discuss topics that might be upsetting for some readers, including self-harm and suicidal thoughts.

Before and after: What changes?

Parents and carers of PDA children and young people described what life was like for these children and young people before, and after, they and their families found out about PDA. The examples below demonstrate what a profound and positive impact knowing about PDA and implementing the right strategies can have on a PDA child. They also show, however, that this impact can be restricted to the child's life at home if professionals outside of the home do not also understand PDA. There are more examples of before and after stories in Appendix 1.

Before we knew about PDA	After we knew about PDA
Chaotic, emotional and my son was truly not getting his needs met. Everything came to a 0head almost a year ago and although my son was able to go to school the majority of the time, he was not able to leave his room/bed the rest of the time. We had a no demand household for him but feel like we lost him since he was unable to participate in anything outside of gaming. We missed him. (Parent of under 18)	Life is calmer and my son has slowly been able to re-engage. Once we decided to home school and the demand of school has been removed, he is slowly engaging. This last week he went to dinner with the family, played chess with his dad, went on walks with me and the dog. He was able to brush his teeth twice in his own. He is thankful he is being heard and I am sure we are doing the right thing to protect his mental health.
School was challenging for my son, he was misunderstood and he wasn't given the correct support for his PDA. School involved autism outreach once my son had a diagnosis of autism but all the strategies they suggested weren't working. PDA was never mentioned by school, autism outreach or the paediatrician. (Parent of over 18)	Since learning about PDA and getting informed professionals involved such as SaLT, OT and educational psychologist, things have got better. We now use PDA strategies and have a good understanding of our son's needs. However, I still feel PDA is generally misunderstood by professionals and school especially.
My daughter's secondary school education was so traumatic at times I find it difficult to describe the words to describe it all. The misunderstanding and false promises made by professionals caused another layer of school based trauma. Family and friends' lack of understanding and refusal to educate themselves led to a reduction in contact with them and our safe circle being reduced.	We constantly come up against people who do not understand PDA and do not want to understand it. Schools, doctors, professionals, family and friends cause constant hurt and I try to protect my daughter from it all. I have huge concerns of how my daughter will do at college and in her future - I worry what more trauma she will experience and the lasting impact of it. She is intelligent, articulate and a wonderful

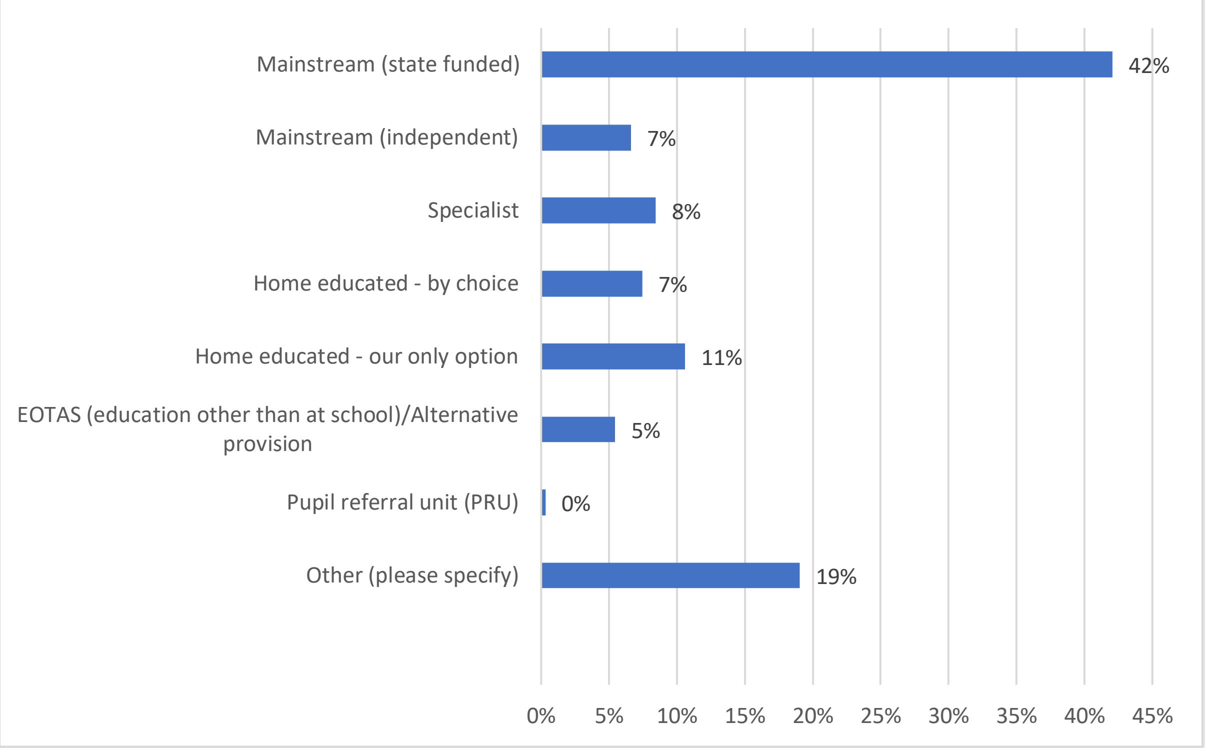
(Parent of under 18)	human being. She hopes to raise awareness of PDA and change the future for young PDAers.

Education

> *School was extremely demanding. I masked what I know now as my demand avoidance and hid it extremely well, but the demands of homework, schoolwork, talking to different people and GCSE exams wore me down. I would come home every day either stimming for hours or falling asleep because I was too exhausted.* (PDA adult)

This section presents survey data on the education experiences of PDA children and young people. Figure 3 shows the type of education that the children and young people covered by our survey were in. The majority (42%) were enrolled in a mainstream, state funded school. 11% of children were being home educated – not through choice but because it was the only option available to them.

Figure 3: What type of education is the child/young person you care for in?



Sample size: 604

19% of parents/carers chose the 'other' option around type of education. Free-text answers showed that these children's situations often involved a mixture of the options given. For example, they were still on roll at a mainstream school but were unable to attend so were largely at home. Others were at home awaiting, or trying to access EOTAS.[21]

Figure 4 shows the data on PDA children's struggles with school attendance. 44% of parents and carers said their children struggle to get into school all of the time, and 16% said they struggle fairly regularly. This is linked to the data in figure 7, below, which shows that 85% of parents/carers said

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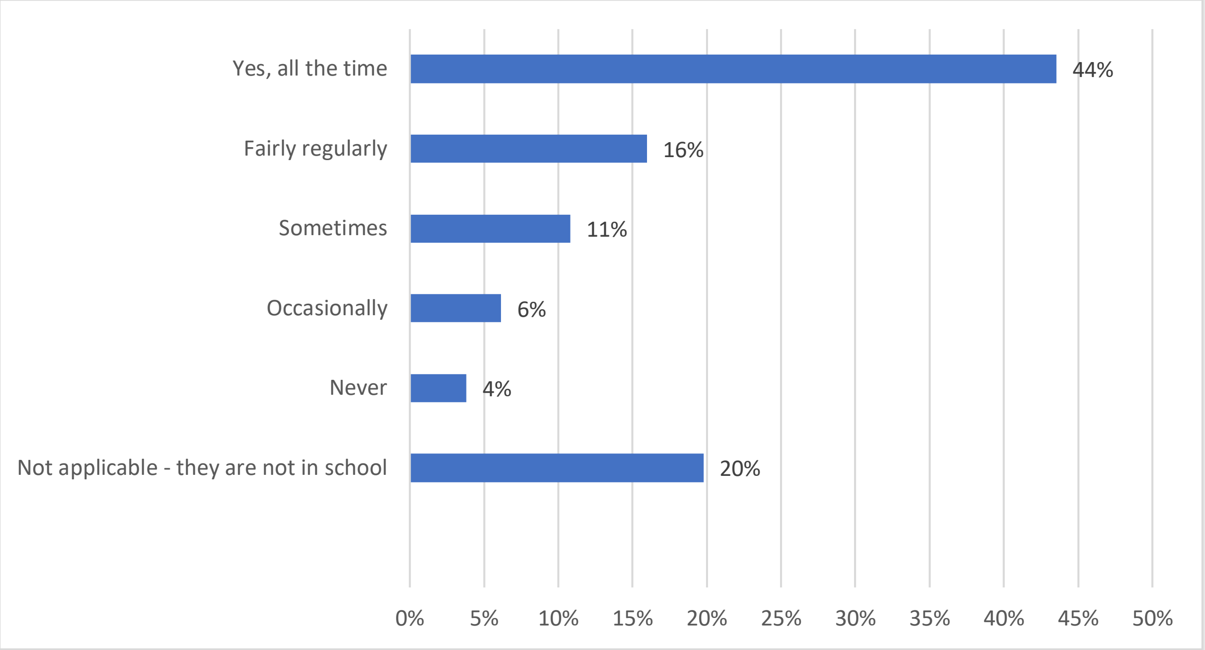
[21] Education other than at school

their child had experienced emotionally based school avoidance/anxiety (EBSA) at some point in their lives (and 74% had experienced it in the last year).

Figure 4: Does the child/young person you care for ever struggle to get into school?



Sample size: 602

As figure 5 illustrates, 46% of children living in England in our sample have an education, health and care plan (EHCP), and 16% are in the process of applying.[22] Our analysis also showed that 62% of children with an EHCP in England struggle to get into school either all the time or regularly.

Figure 5: Does the child or young person you care for have an education, health and care plan (EHCP)?

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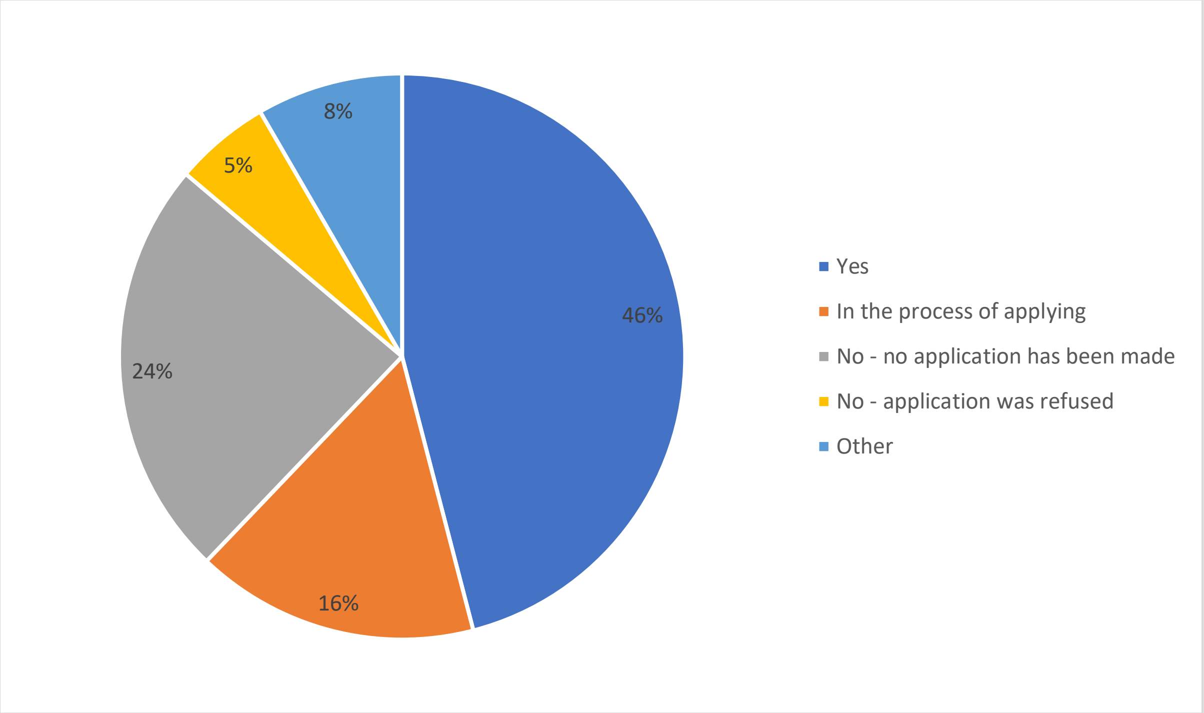
[22] There are different processes in place in other countries of the United Kingdom - more information on this can be found here for Wales; here for Scotland; and here for Northern Ireland



Sample size: 383. Data on EHCPs refers to children under the age of 18 living in England only, as the processes differ in other countries

Many parents and carers described the negative impacts that being at school had on their child, as well as the length of time that it was taking to find the right education setting, and to repair the child's mental health:

> *She is no longer in school due to anxiety around unmet needs and attends an alternative provision for 1.5 hours per week which is gradually increasing to one day. After lots of fighting, time and money, we have just received an EHCP. She still has school trauma and runs and hides if she sees a teacher or adult from her primary or secondary school.* (Parent of under 18)

> *It's incredibly difficult to get the local authority or school to implement support. Which is only escalating his panic attacks. A few weeks ago I picked him up from school, on arrival I found him in the foetal position under a table (where he had been for over 20 minutes).* (Parent of under 18)

> *She does not attend any educational setting, has no GCSEs (having been on track to achieve nine top grade GCSEs in year 9). Her high school SENCO didn't believe how much she was struggling (she loves performing arts so her masking is professional). She is now enrolled at the perfect setting but hasn't yet managed to sustain attendance, even though they have earned her trust. That's how much damage her mainstream school did.* (Parent of under 18)

A lack of support and/or understanding from school, including from specialist staff such as SENCOs (special educational needs and disabilities coordinators), was a common theme in parents and carers' responses. Worryingly, as figure 9 below shows, only 30% of all parents/carers of under 18s (and only 51% of parents/carers with a child enrolled in an education setting) said their child received emotional or practical support from a SENCO, teacher or teaching assistant.

Some parents and carers with older children described the long-term effects of being out of school, or being in the wrong setting, for their children:

> *My son is so depressed now that he has no qualifications through no fault of his own. He tried so hard to get GCSEs at college but just couldn't make up seven years' missed education in 24 weeks.* (Parent of over 18)

The example below illustrates the long and bureaucratic process that many parents and carers told us they had been through to try and access an education for their child.

> *Things are still difficult due to a lack of support and provisions. He has been out of school for 18 months with very limited provision in this time. His anxieties have continuously increased to the point that he is unable to leave the house on most days. His mental health is not great, he is teetering on having depression and he has a very negative view of himself.*
>
> *15 specialist schools that have been consulted all stated they cannot meet his needs. The local authority is now offering a place at an SEMH[23] secondary school that is quite big and busy, an environment that he won't be able to cope in. He attends an alternative provision where he is doing really well because he can do computer gaming there, which currently is his main interest. He wants to spend more time at the provision but he only gets funding for two hours a week and we have been chasing to get his funding increased for the last five months.*
>
> *There is such a lack of mental health support for young people with ASD/PDA and very limited educational provisions for children who cannot cope in mainstream schools and most specialist settings. Considering how short childhood is in a whole lifetime there is way too much time being wasted to get any appropriate support put in place. My son started to really struggle over four years ago and he is still not getting the support he needs.* (Parent of under 18)

Health and wellbeing

> *I was anxious and stressed as a child, and I couldn't understand why, or why I was different from everyone else. As I got older, I started to just shut myself in my room; meltdowns became less frequent, but I was isolated and completely avoided all social interaction because any demand was too much. I rarely went to school, and so didn't get to see my friends, and missed out on a lot. I became depressed and struggled a lot with my mental health.* (PDA adult)
>
> *My son had a mental health crisis for over two years- self harming, suicidal ideations and an attempt. No support was given because professionals didn't know how to engage him and their language and approaches only made things harder. CAMHS weren't willing to accept PDA.* (Parent of under 18)

This section presents survey data around the health and wellbeing of PDA children and young people. Figure 6 shows that the vast majority of parents/carers said that their child has experienced a need to feel in control (99%), mood swings (99%), sensory differences (98%), difficulty with daily tasks (99%), challenges with sleep (93%), difficulty getting out and about (91%), severe anxiety (91%), low self-esteem (83%), challenges with eating (79%), and isolation and loneliness (70%) at some point.

Figure 6: Has the child/young person you care for experienced any of the following?

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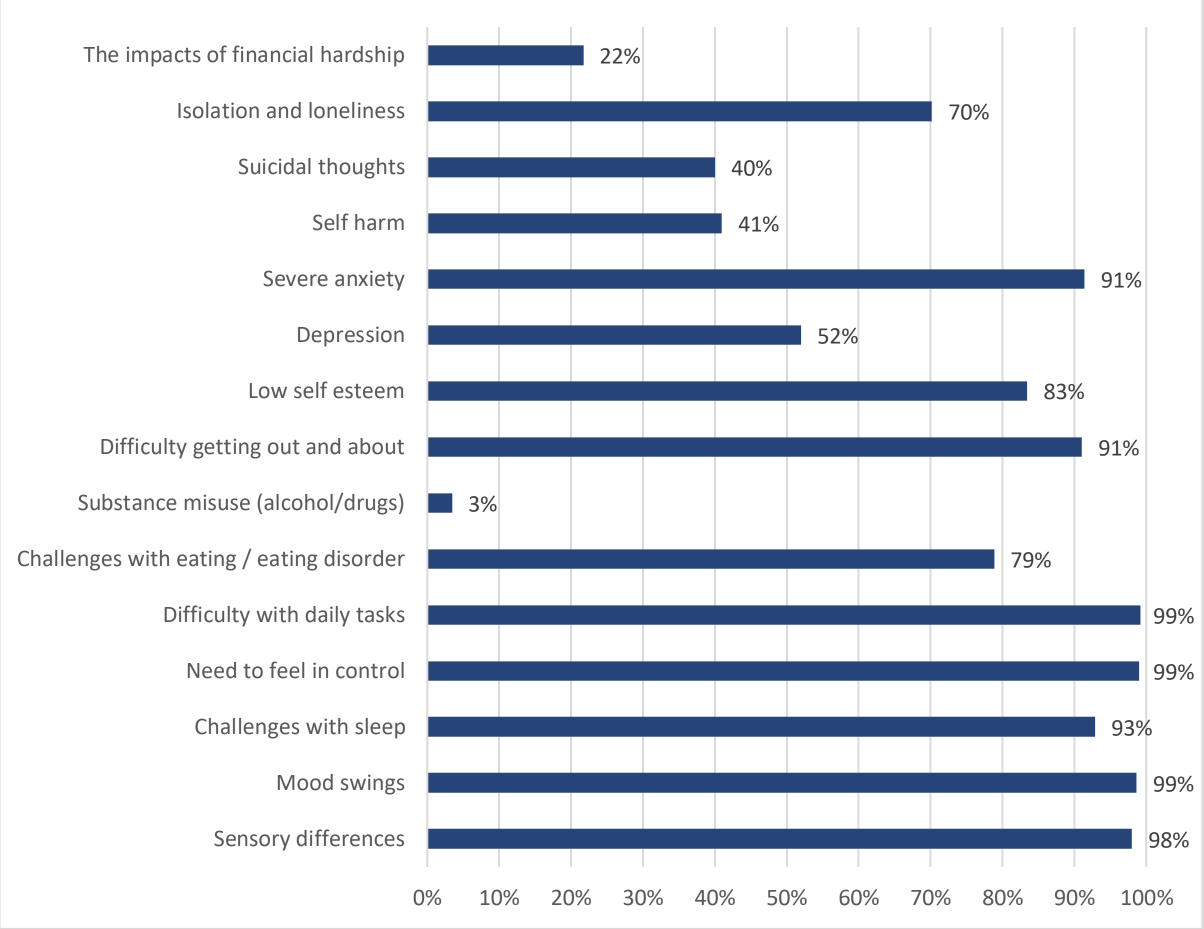
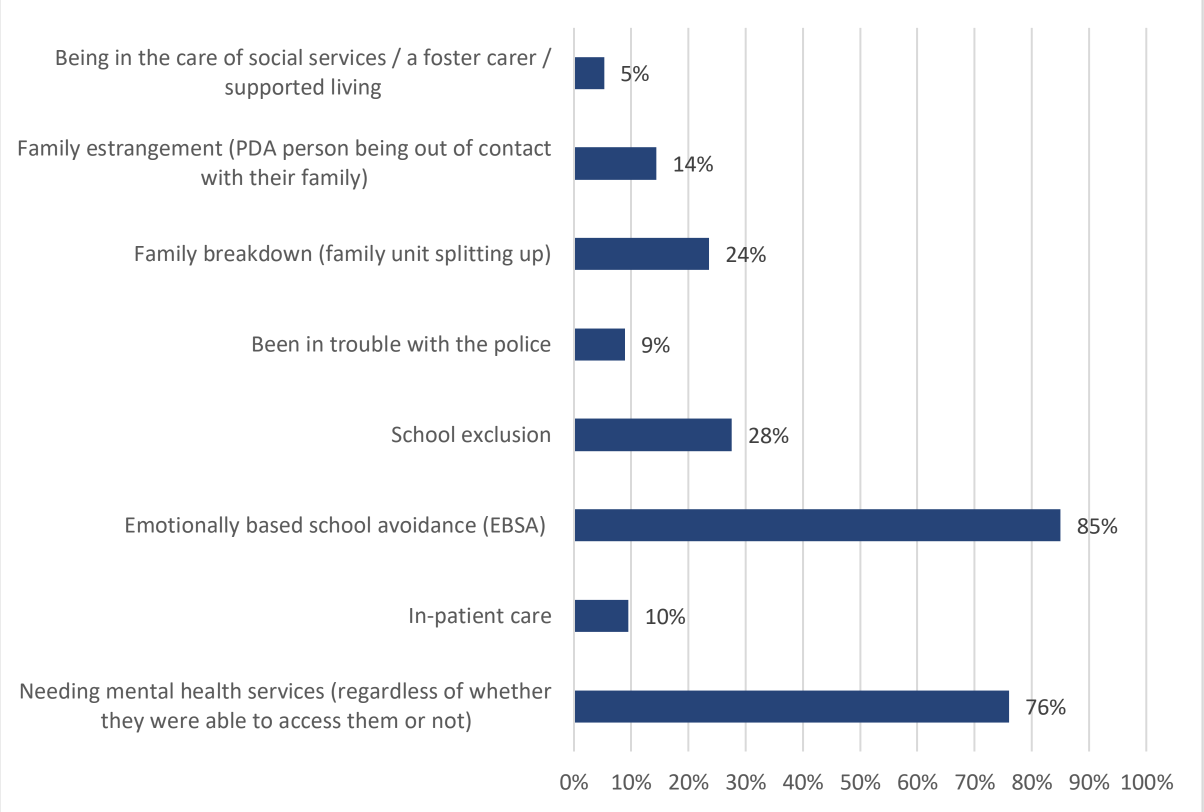
[23] Social, emotional and mental health



Sample size: 605. Data refers to those who answered either 'yes – in the last year' or 'yes – but not in the last year'.

Similarly, figure 7 highlights that 85% of PDA children and young people have experienced emotionally based school avoidance/anxiety (EBSA) at some point. 73% of parents and carers said their under-18 had experienced EBSA in the last year alone. In addition, 76% said that their child had needed mental health services at some point.

Figure 7: Has the child/young person you care for experienced any of the following?



Sample size: 605. Data refers to those who answered either 'yes – in the last year' or 'yes – but not in the last year'.

Intersectionality
Parents and carers of PDA children from ethnically minoritised backgrounds were more likely to report that their child needs, or has needed mental health services (84% compared to 75% of parents of PDA children from white backgrounds).[24]

Diagnosis, services and support

> *The problem is that PDA is so little understood and is unrecognised by many local authorities and professionals but this is really damaging because the strategies used by many to help young autistic people do not work for those with a PDA profile and this has a negative effect on the individual causing their problems to amplify.* (Parent of under 18)

This section contains our survey data on diagnosis, services and support. A PDA profile of autism is usually identified during an autism assessment. Because there is still academic and clinical debate about the terminology and classification of PDA, recognition of PDA is currently inconsistent. Identifying PDA can also be difficult because it may present in forms that may be different to the

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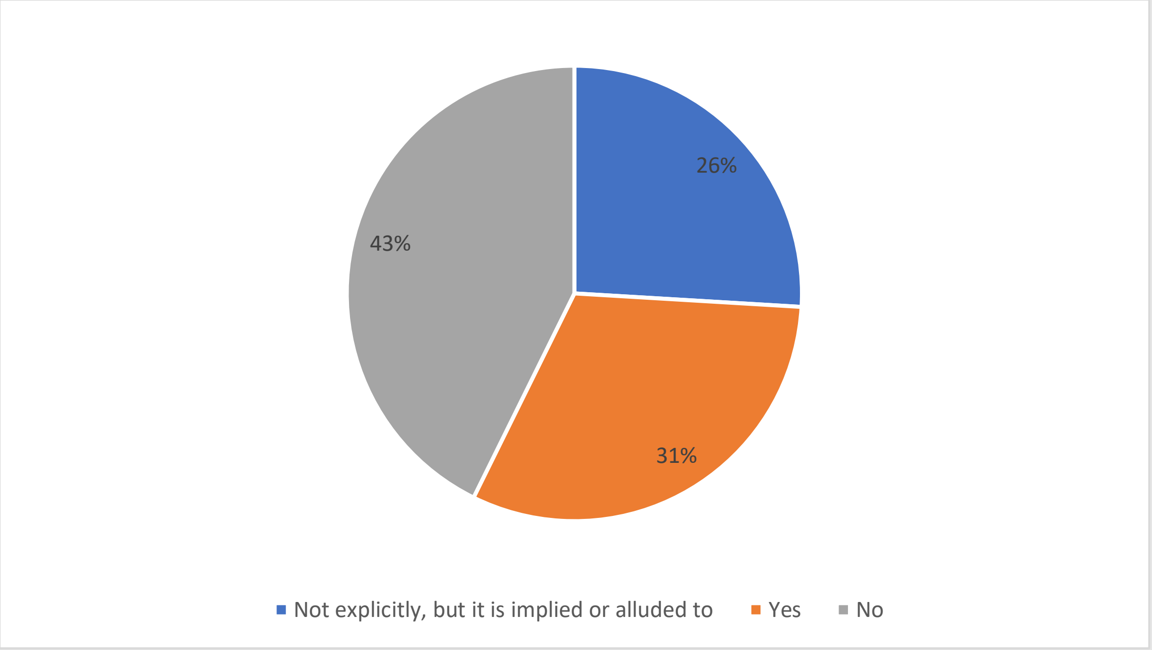
[24] It is important to note the small sample size of survey respondents from ethnically minoritised backgrounds. 86% of our sample were from a white ethnic background. Survey respondents whom we have categorised as from ethnically minoritised communities or backgrounds include the 1% of our sample who chose the category 'Asian/Asian British'; the 0.5% of our sample who chose Black/African/Carribbean/Black British; and the 7% who chose 'mixed or multiple ethnic background'.

way some people, including clinicians, currently think of autism and there are overlaps in presenting characteristics between a PDA profile of autism and other conditions.[25]

Figure 8 shows that 31% of the children in our sample have a formal diagnosis that explicitly refers to PDA, and 26% have a diagnosis that alludes to or implies PDA. The most common examples given of the types of diagnoses in this latter category were autism/ASD with: a demand avoidant profile; demand avoidant behaviours; or demand avoidant traits.

Figure 8: Does the child/young person you care for have a formal diagnosis that includes or refers to PDA?



Sample size: 609

In their free text responses, parents and carers described the challenges around trying to get PDA identified as part of an assessment:

> *My child has been assessed as having autism with "PDA like" tendencies recently (the local authority doesn't recognise PDA officially).* (Parent of under 18)
>
> *We struggled for a long time to get support and an ASD diagnosis for our child because PDA doesn't display in the way people expect autistic children to be. Our PCT[26] doesn't diagnose PDA, just ASD with demand avoidance mentioned in the diagnostic report.* (Parent of under 18)

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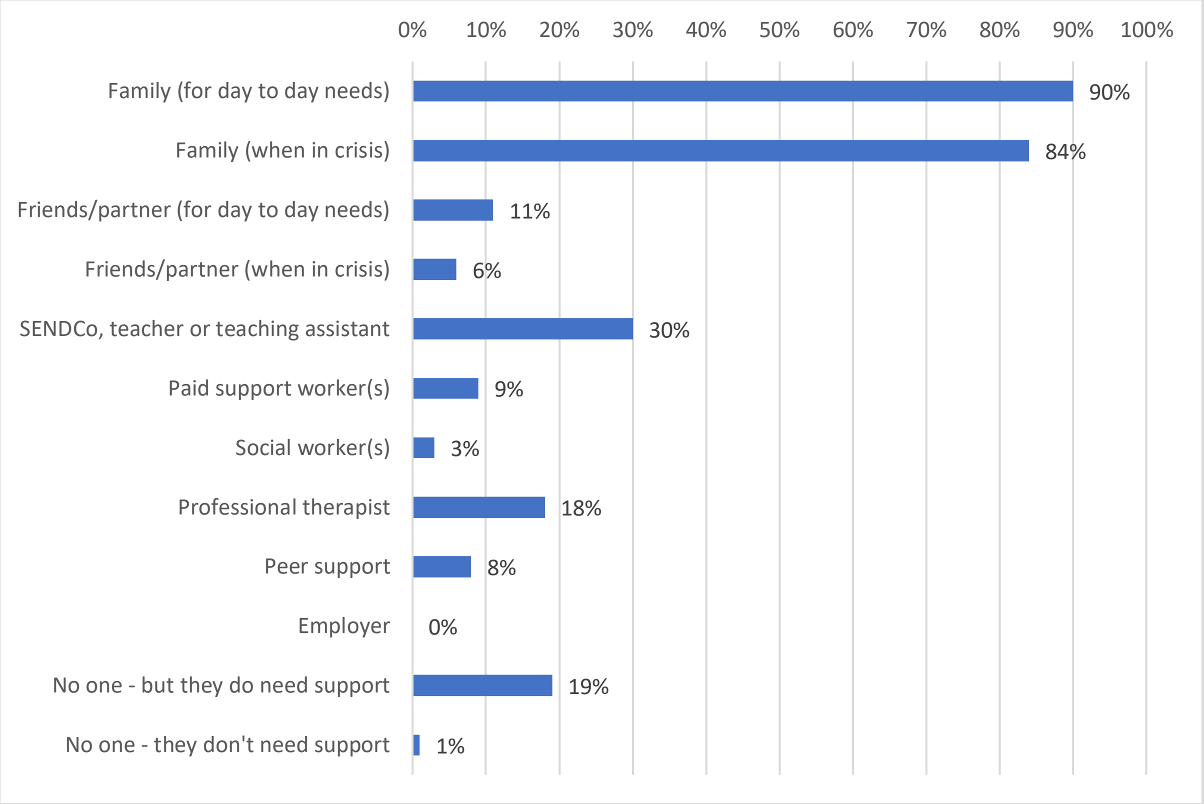
[25] Despite these difficulties, a PDA profile can, and should, be taken into consideration when undertaking autism assessments. This is in accordance with NICE Guidelines, which list demand avoidance as a 'feature of possible autism'. Autism assessments should consider all the presenting strengths and challenges, including demand avoidance. The extent of, and reasons for, demand avoidance should be determined in collaboration with the individual and, in children's services, their parents. Demand avoidance can occur for different reasons, so it is important to understand that a PDA profile may not always be the best explanation. More information is available on the PDA Society website, and in the practice guidance for clinicians on identifying and assessing a PDA profile.

[26] NHS Primary Care Trust

> *Whilst the ASD assessment from the psychologist mentions a PDA profile, our paediatrician is not someone that accepts the concept/presentation and our psychiatrist had not even heard of it.* (Parent of under 18)

We asked parents and carers about the support that their child receives. Respondents could choose more than one option. As figure 9 illustrates, the vast majority of parents and carers said the child they care for relies on family for day to day support needs (90%) and for support when they're in crisis (84%). As mentioned in the education section above, it is concerning that only 30% of parents and carers (and only 51% of parents/carers with a child enrolled in an education setting) said their child received emotional or practical support from a SENCO, teacher or teaching assistant.[27]

Figure 9: Who supports your child/young person?



Sample size: 592

In their open-ended responses, parents told us how difficult it could be to find the right support for their child, both before and after diagnosis:

> *We always knew that there was something but just not what that was. Since the age of two we had been seeking professional help to work this out but experienced significant pushback from professionals that kept directing us to positive parenting courses and then anxiety support.* (Parent of under 18)

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[27] There is an issue with the data in figure 9, in that 90% of respondents said their child was supported by family, yet 19% said their child received no support. It is likely that some respondents chose both 'family' and 'no one' in their response to this question, perhaps thinking of 'no one' outside of the family who provided support to their child.

> *My daughter was diagnosed with autism age 11. I attended a CAMHS parent support group following diagnosis and was taught classic autism strategies including the importance of boundaries. Over the next couple of years, my daughter's attendance at mainstream high school declined, then stopped. Distressed behaviour at home started, then escalated. I realised the strategies I'd been advised to use - the imposition of boundaries and the expectations associated with them - were actually the triggers. 114322134862*

Some parents and carers were keen to stress that their child had still not been diagnosed, meaning that all support had to come from family:

> *Eventually we realised he was autistic, but the NHS ADOS did not score him highly enough to get a diagnosis […] He was 15 by then and ever since it has been impossible to get his needs appropriately met by professionals.* (Parent of under 18)
>
> *Still can't access much from services to help her, still not on any pathway for assessments. So any and all support for her is still just from myself.* (Parent of under 18)

What happens when we get it right for PDA children?

As the 'before and after' excerpts included at the beginning of this section illustrate so well, when parents and carers learn about PDA and 'get it right' for PDA children, the results can be life changing. What seems to be more difficult however, is 'getting it right' for PDA children outside of the home - in assessment, diagnosis and support, and at school. While our survey respondents reported many challenges in these areas, we did hear some positive stories. We heard about all staff members in a school receiving training on PDA, about schools creating bespoke timetables for PDA children - often involving learning in creative ways outside of the classroom. We also heard about the positive impact that well-informed, understanding teachers can have, with one parent noting that:

> *It's taken five months of her building trust with her new teacher but it's helping her get to school and stay at school. A good teacher is EVERYTHING, and she has an amazing one this year."* (Parent of under 18)

We also heard about children and young people who, despite having a really tough time during their school years, had, with support from their families, achieved things that didn't seem possible during those tough times:

> *Against all the odds my son who is now 18 has recently passed his driving test, attended college to become an electrician, has an apprenticeship with a large engineering company and is doing exceptionally well despite all the challenges and him being out of school from the age of eight for three years. I'm so incredibly proud of him and how much he's taught me – not only about PDA and autism but about myself and the resilience I had to draw on to get through some very difficult times.* (Parent of over 18)

The examples below demonstrate what can happen when we get it right for PDA children and education. What 'getting it right' means will differ for each individual child and their family, so we have included four very different 'success stories', in settings ranging from home education to mainstream school. These, and other examples, are presented in more detail in Appendix 2.

Example 1: Provisions put in place by a mainstream primary school

School life was incredibly hard because before he was diagnosed, my son was misunderstood and labelled a naughty challenging child. He reached burnout resulting in EBSA.[28] He ended up being signed off by CAMHS and was out of full time school for around 18 months.

After some time to put together a plan, the school started to send his favourite TA to meet us, and she would play with him in the park. After a while he started going into school to play games with her. The school built a sensory room; we would go in there together with his TA, and they would spend time playing together. Once my son had his PDA diagnosis, the school brought in an outreach teacher who specialised in PDA and she gave training to school staff.

However, my son still didn't feel able to go into the classroom or to engage with his class teacher. At this point we didn't yet have an EHCP. The school and the local authority inclusion team decided to arrange alternative provision for him. He did a dual placement, going into school for an hour, half an hour, 15 minutes – depending on the day and how well he could tolerate it, and then the mentor from the alternative provision would come and pick him up and take him out. They'd do swimming, rock climbing, hiking, treasure hunts, go to the forest or the beach. They had a building where they could meet with other children and do things like baking or games. It was this that positively impacted on my son's mental health and wellbeing the most – it was all: "Let's work on you as a person" rather than: "Let's do work".

Once the EHCP was granted, the school allocated a full time 1:1 to my son as requested. He was ready to go back then, so it was a natural progression for him. His 1:1 did PDA training and PACE training whilst she worked with him, and she has turned his life around! She's put in so much effort to learn about PDA and understand it/him as a person, and to acknowledge that he doesn't need traditional autism strategies like visual timetables and now and next boards. That just doesn't work for him.

He has a very bespoke timetable. He doesn't have to be in the classroom, he can dip in and out. His 1:1 is really good at gauging his tolerance levels and thinking about how to accommodate him and keep his focus. If she can see that he's having a really bad day she'll remove the demand and they'll go and build dens instead, or do baking or junk modelling. He loves teddy bears, so his 1:1 frames learning around this – for example they'll make a den for the teddy and then do some work inside the den. We don't do homework, and for activities he finds hard he has a lot of scaffolding. The class teacher has had PDA training too, but she is clear that my son's 1:1 is the person whose lead she follows, as the 1:1 knows him best and he trusts her.

I know this is a very rare set up – we've been so lucky with the school. Although I had to argue every step of the way for this kind of support during the EHCP process! When I see the statistics about the number of PDA children out of school it makes me so sad, because it's not impossible to accommodate these kids. It's just making the effort, and his school – his 1:1 especially – have made so much effort. If his 1:1 hadn't made the effort he wouldn't be in education now. 18 months ago we were under CAMHS for suicidal attempts, but now he's so much happier and he doesn't have those thoughts as frequently anymore. He's so much better in himself because he feels understood and validated. That's what all these kids want – they just want someone to 'get' them.

(Parent of under 18)

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[28] Emotionally based school avoidance/anxiety

***Example 2: EOTAS*[29]**

It was quite a journey to get to this point, because we didn't really know what we needed at first. School definitely wasn't working for my son, but no one else understood, and it really made me doubt myself because everyone was saying "he has to go to school". I even had a head teacher telling me that not forcing him in could be counted as child abuse. But I knew that no matter how much we lowered demands at home, it was never going to work while school was still there. And as I was the one making him go, he lost trust in me completely. By the time we stopped sending him in, he already had a lot of trauma from school.

Then the COVID lockdowns came, which were very difficult for so many people, but for us it provided an opportunity. I'd discovered PDA, and I knew what we needed to do, but we both worked and we needed both incomes. The lockdowns gave us that opportunity – I didn't have to be at work, so I thought: "Right, we're going to do it". At first there was a lot of regression. My son wanted to spend time completely by himself in his room with the curtains shut. We had to enter very carefully. He was down to only two safe foods. But slowly he came back – he started coming out of his room, wanting to come on walks with us. This gave me more trust in my own instincts, because I could see that yes, this was what he needed. When the schools re-opened he didn't return. We got him diagnosed privately and did a parental application for an EHCP. I carried on researching and found out about EOTAS. I visited local alternative provisions and decided what we needed to ask for.

It took 60 weeks to get the EHCP agreed, and then another six months to get the EOTAS package in place. This sounds very long, but I now know I was quite lucky compared to others, and I didn't have to go to tribunal. We're now in our second year of EOTAS, and the difference is amazing. My son has built a lovely relationship with his learning support assistant at the alternative provision. The first year at his alternative provision was all about relationship building. He was in nature a lot – climbing trees, stick collecting. His learning support assistant completely understood about masking and how to approach it. My son started to feel able to say when something was too much for him, so she could start to offer more unstructured learning-based tasks – just a couple of minutes here and there. Now he is able to do things like crosswords and worksheets when he's with her. He also now feels able to spend time at a 'base' with other children, and he enjoys this. He knows that he has choice and that if it's too much for him he can leave. The slow build-up really worked.

I can't describe the difference in our home life. Obviously having my son at home with me comes with its logistical challenges, but it's worth it ten times over because he is ten times happier. While previously he was in constant fight or flight mode, now his anxiety levels are so much lower – his distressed behaviours have reduced dramatically. The way I'd describe it is, it's difficult but we're all really happy. There's no more constant worry. As a family we're just happy.

(Parent of under 18)

Example 3: Home education

Once I started reading about PDA everything made sense. I read as much as I could – I found PDAers online, support groups, professionals, books, organisations. Listening to voices of PDAers and learning about ableism was the most life changing part though. It was the part that made me

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[29] Education other than at school

‘radically accept’ and make the major life changes that needed to happen. Up until that point I was trying to ‘fix everything’. I learnt no one needed ‘fixing’. We just needed to accept and embrace a new lifestyle. And letting go of mainstream schooling was the big one.

I have found that home schooling in an “unschooling”, child-led, self-directed style suits my child, as they can have the autonomy they need to feel safe. In my experience as a teacher, I will sadly admit that I don’t think there is much about schools that suit most PDAers. The schooling system has a very long way to go to be right for them.

Since beginning home schooling, my child is more relaxed, calm and settled. They have been able to better regulate their emotions, are able to understand their sensory likes/dislikes, and can advocate for themself. They are far less irritable and angry. Violent outbursts are now very infrequent. They no longer talk of hating themself or their life. They no longer say they are ‘stupid.’

Their attitude towards learning is similar in that they still dislike ‘school work’ and resist maths, reading or writing. However, by giving them control and letting go and not making them do ‘work,’ they have actually developed a great attitude towards learning, in their own way, on their own terms. My child will pour themself into projects of interest in which they web-research, read, watch videos, plan, draw, write, budget.

They are now able to better engage with friends and family and with the community. It was like they were so exhausted just getting through a school day they had nothing left for anything else. Now they do.

I had been reluctant to give up my job to home school. I wanted my child to have the chance to try and make it work at school. We were concerned about the shift to home schooling being too demanding on me as a mum. That it would be too difficult to spend so much time one on one. But that hasn’t been a problem as the child I spend so much time with is a much happier, calmer, connected person so it has worked out better for everyone.

We no longer feel like we are trying to force a life that didn’t fit. We’ve accepted who we are and what suits our family. I’ve let go of controlling how it ‘should be.’ We’ve leant into what works for us. We’ve simplified our lives. We’re trying to not compare, or wish or want. We’re not all the way there and I know there will be ups and downs and we’ve still got troubles but compared to how things were, it’s a huge positive change.

(Parent of under 18)

Example 4: A young person’s view on education and the college ‘getting it right’ for them

In Year 10 I stopped going to school. I was really unwell. I was diagnosed with anorexia – I wasn’t eating at all, and on top of that I wasn’t sleeping either. My secondary school was very mainstream – massive classes and they didn’t want anyone whose attendance was bumpy as they just wanted the best grades. They saw us as either ‘good’ students or ‘bad’ students. The ‘bad’ students were always being told off, got low grades, were always in detention. Lots of the teachers seemed power hungry, and seemed to hate children which is really weird. They would get angry at the most random things – one time because I had the wrong colour hair clip! The craziest rules that didn’t make any sense, but were all about power and authority and control. There was so much underlying tension and hierarchy.

It’s a sickening environment to be in for anyone, but with PDA, I hated it. I despised the whole hierarchy thing. There was no trust, you couldn’t question anything, it was all built on a bunch of rules that didn’t make sense. There was no communication, you weren’t valued as a human. The system is very factory-esque, very prison-esque. Kids leaving the house at 8am and coming back at 4pm, and having that all day, from the age of five – it’s crazy to expect kids to do that and be fine! You don’t matter when you’re in a system like that.

But things got so much better when I started at the college I’m at now. It’s amazing. It’s private so it’s very small, and most of the kids there have struggled with education in some way. It’s not specifically for neurodivergent students, but lots of them are, and many are funded by EHCPs. They’re very catering towards the individual, and it’s a really beautiful, close-knit environment. There are no authority figures. The classes are small and the teachers are called by their first names and don’t have many rules. Some of the kids there were kicked out of their old schools for misbehaviour, but the teachers are very smart – they know that punishments don’t work. They encourage students, and they don’t look down on them or lash out and get angry with them for behavioural things. They recognise that students don’t misbehave for no reason. There are no students who are disliked by the teachers or are picked on by the teachers. Students know they won’t be rejected and so their behaviour improves. It’s very accepting. Being accepted like that is a really nice feeling. I don’t want to take it for granted because often the rest of the world is not like this.

I’ve found that this low demand environment works really well and my attendance has improved a lot. I know that the problems I have around eating and sleeping aren’t going to just go away, but sometimes you just need to feel happy and fulfilled in your life, then you won’t need to seek fulfilment in other ways. And that’s what I’ve found – things have got so much better, when before they were really bad. I can’t imagine any other school being able to help me in the way the college has.

(PDA young person)

4. The picture for PDA adults[30]

Key points:

- On reaching adulthood, many PDA people are unsupported in higher education, training and employment, and as a result experience financial hardship.
- They experience mental health challenges, loneliness and isolation and difficulties with everyday tasks.
- Most often their main source of support is friends, partners and family, rather than professional services.

Content warning: The sections below discuss topics that might be upsetting for some readers, including self-harm and suicidal thoughts.

Before and after: What changes?

PDA adults described what life was like before, and after, they found out about PDA. The examples below demonstrate just how challenging living with PDA can be throughout the lifecycle. Many respondents described the learning journey they had been on once they identified as a PDAer. They show that while understanding oneself better can bringer greater self-acceptance and peace, life remains difficult for adult PDAers. There are more examples of before and after stories in Appendix 1.

Before I knew about PDA	After I knew about PDA
I found life incredibly challenging, even the easiest tasks seemed so impossible, and I treated myself so badly, telling myself I was useless when I couldn't manage to do certain things, or when I had meltdowns because I couldn't cope with getting somewhere with the demand of getting there by a certain time. So full of stress, high levels of anxiety and depression. (PDA adult)	Life in general feels like I can cope a lot better, that I don't have to force myself to fit into a neurotypical way of living because I know I am neurodivergent and there is nothing 'wrong' with me, my neurobiology just means I need to live in a way that enables my nervous system to feel safe.
I struggled more with the anxiety, impatience, anger, fear that I believed were personality flaws that I needed to mend. Most of my attempts to 'fix' myself ended up nowhere. (PDA adult)	I realise I'm not broken. I have these reactions for a reason. I no longer feel broken, repulsive, or like an ugly duckling. I feel grateful for my gift, love for the 10-year-old child that struggled with social situations, school, bullying, abuse, projects, assignments, reading, homework, and my family. I want to help all PDAers get the inputs and skills they need to succeed.
I did not understand any emotions I was feeling. I could not understand how anxious I felt majority of my life. So many people who	The hard parts are still professionals not understanding PDA. The good parts are when others do understand and use the right

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[30] The data in this section focuses on responses from PDA adults (self-reported) and where useful/relevant, also includes responses from parents/carers of over 18s.

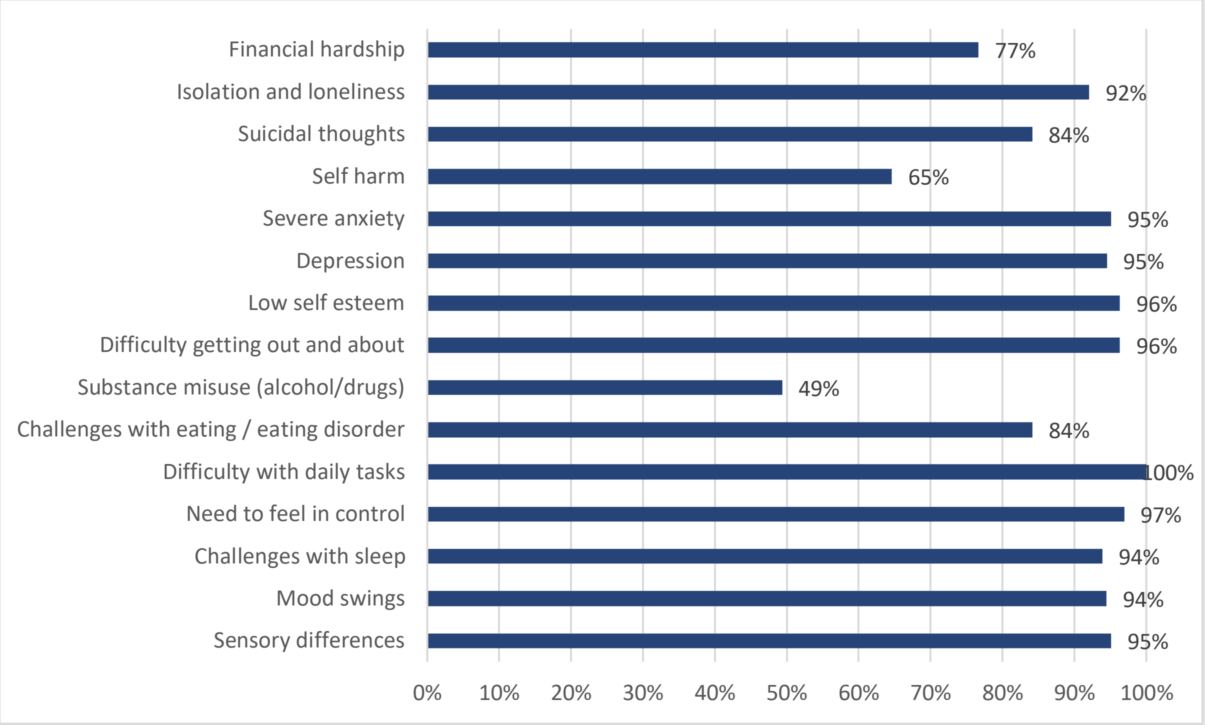
worked with me blamed me for my behaviour. They could not understand my profile of autism as the strategies did not work. (PDA adult)	strategies. I feel I am really starting to understand myself properly now.
Unrelenting judgemental. I would be told that not showering every day or brushing my teeth was disgusting and offensive. I knew all of these things were unacceptable, and I wanted to be a person who did those things, but that always felt like an unattainable goal, like I wanted to be someone I never could. It propagated through my entire life: struggles with law enforcement, with parents, with friends and partners. The more expectations there were for me, the less I was able to meet even basic ones. (PDA adult)	I still struggle with all of those things, and in some ways struggle even more now that I'm aware of my masking. The world isn't structured for people like us, and the everyday demands of getting up to go to work and look a certain way, act a certain way, do meaningless things over and over. It's exhausting and terrifying and it feels like the entire world is a prison.
Full of guilt and shame, wondering why I couldn't function on the same level everyone else did. Wondering why I had not the slightest desire to work; why I actively avoided everyday demands. Why life felt like spinning plates, utterly exhausting and totally unrewarding. The overwhelming certainty that I was definitely not like everyone else, but the reason why remaining a stubborn mystery. Finally finding I was skilled and talented, but that there still wasn't really a place in the world for me. (PDA adult)	I can be kinder to myself and better advocate for myself, although in a world without any concept of PDA this is still exceptionally difficult. I feel as though I am in persistent burnout - any day of greater activity causes such exhaustion, the days of recovery that follow seem wasted with inactivity and consumed with guilt. The inability to bounce back and get on with everyday life becomes harder.

Health and wellbeing

> *I had mental health difficulties including depression and anxiety. I had numerous instances of autistic burnout, but didn't have the knowledge or understanding that that was what I was experiencing. I had chronic low self-esteem and couldn't understand why everything was difficult for me, while everyone else had their lives together. I used alcohol and drugs to help me cope with life and to "perform" socially.* (PDA adult)

This section presents survey data around the health and wellbeing of PDA adults. Figure 10 shows that all of the PDA adults in our sample have experienced difficulty with daily tasks. The vast majority have experienced a need to feel in control (97%), difficulty getting out and about (96%), low self-esteem (96%), sensory differences (95%), mood swings (94%), challenges with sleep (94%), and isolation/loneliness (92%). 84% of PDA adults said they had experienced suicidal thoughts and 65% had self-harmed at some point in their lives.

Figure 10: Have you experienced any of the following? (PDA adults – self-reported)



Sample size: 164. Data refers to those who answered either 'yes – in the last year' or 'yes – but not in the last year'.

As figure 11 highlights, parents and carers of over 18s also reported very high levels of difficulties with daily tasks (99%), the need to feel in control (99%), challenges with sleep (99%), mood swings (98%), severe anxiety (96%), sensory differences (95%), and isolation and loneliness (90%) among the PDA people they care for. 66% of parents/carers of over 18s said their PDAer had experienced suicidal thoughts at some point in their lives, and 60% said their PDAer had self-harmed.[31]

Figure 11: Has the PDA person you care for experienced any of the following? (Parents/carers of over 18s)

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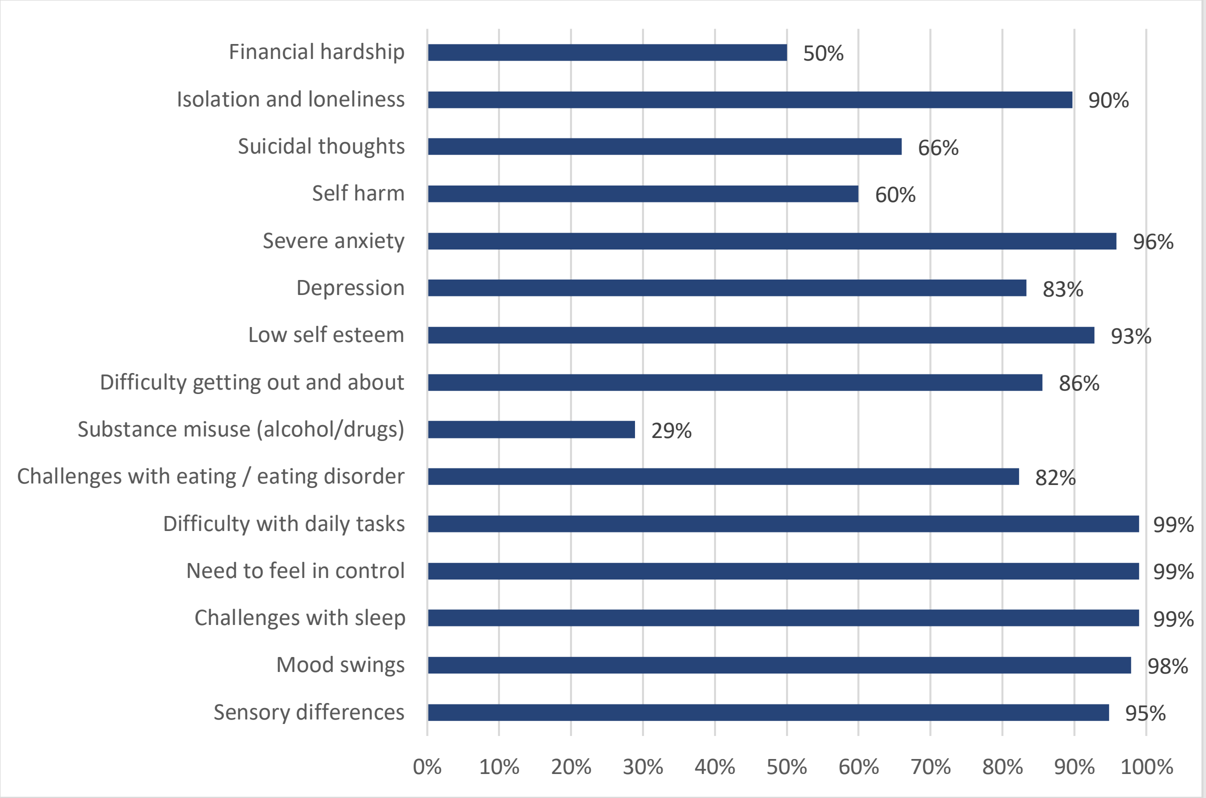
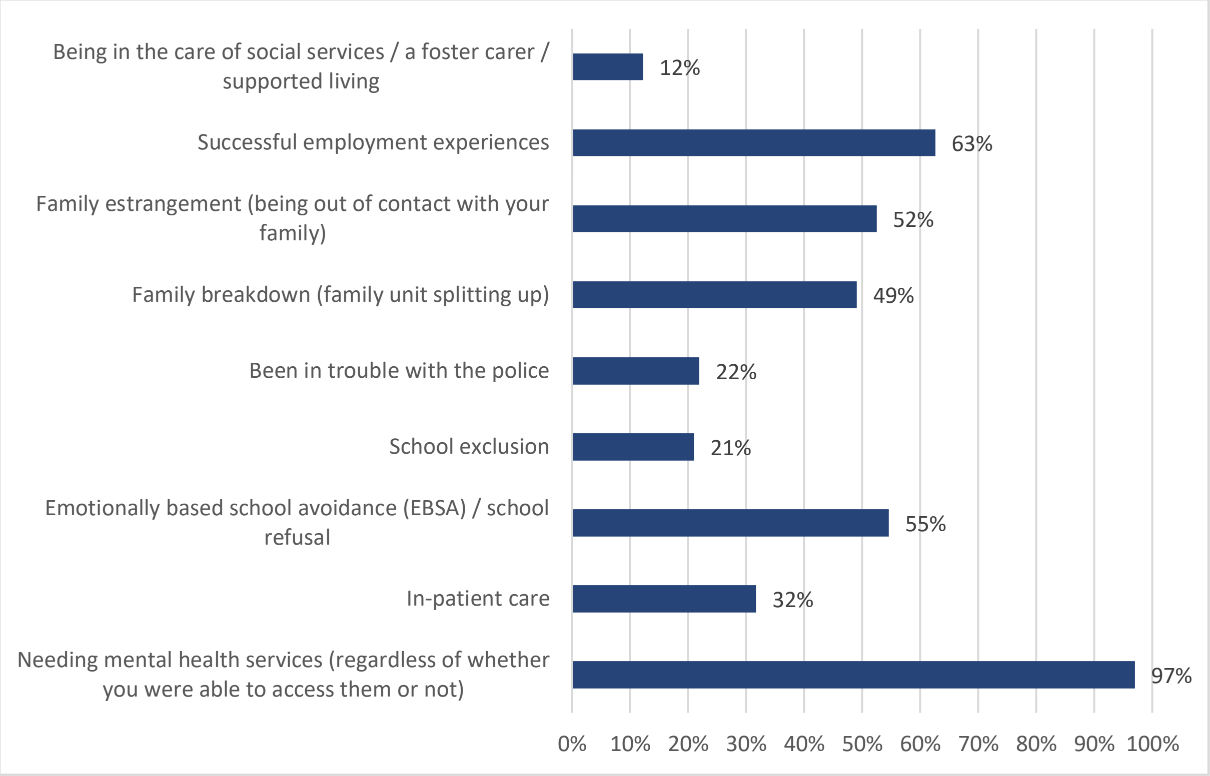
[31] Some of the differences between the experiences of PDA adults (self-reported) and those of over 18 year olds as reported by parents and carers may be explained by the fact that the age of the PDAers in the latter group was, on average, younger than the average age of the self-reporting PDA adults. They were more likely to be living with their parents/carers and receive more support. Differences may also be partly explained by the fact that self-reporting PDA adults are talking about their own experiences, whereas parents and carers may not know as much about the lives or feelings of the PDA young adults they care for, unless that young adult has shared everything with them.



Sample size: 97. Data refers to those who answered either ‘yes – in the last year’ or ‘yes – but not in the last year’.

Figure 12 shows that 97% of PDA adults have needed mental health services at some point, and that 55% experienced EBSA when in education. Just over half (52%) had experienced family estrangement (being out of contact with their family) and just under half (49%) had experienced family breakdown (the family unit splitting up). More positively, 63% had had successful employment experiences at some point (employment is explored in greater detail later in this section).

Figure 12: Have you experienced any of the following? (PDA adults – self-reported)



Sample size: 165. Data refers to those who answered either 'yes – in the last year' or 'yes – but not in the last year'.

A similarly high demand for mental health services was reported by parents and carers of over 18s (94%), as figure 13 illustrates. 83% of parents and carers said their PDAer had experienced EBSA, and only 25% of this sample reported positive employment experiences.[32]

Figure 13: Has the PDA person you care for experienced any of the following? (Parents/carers of over 18s)

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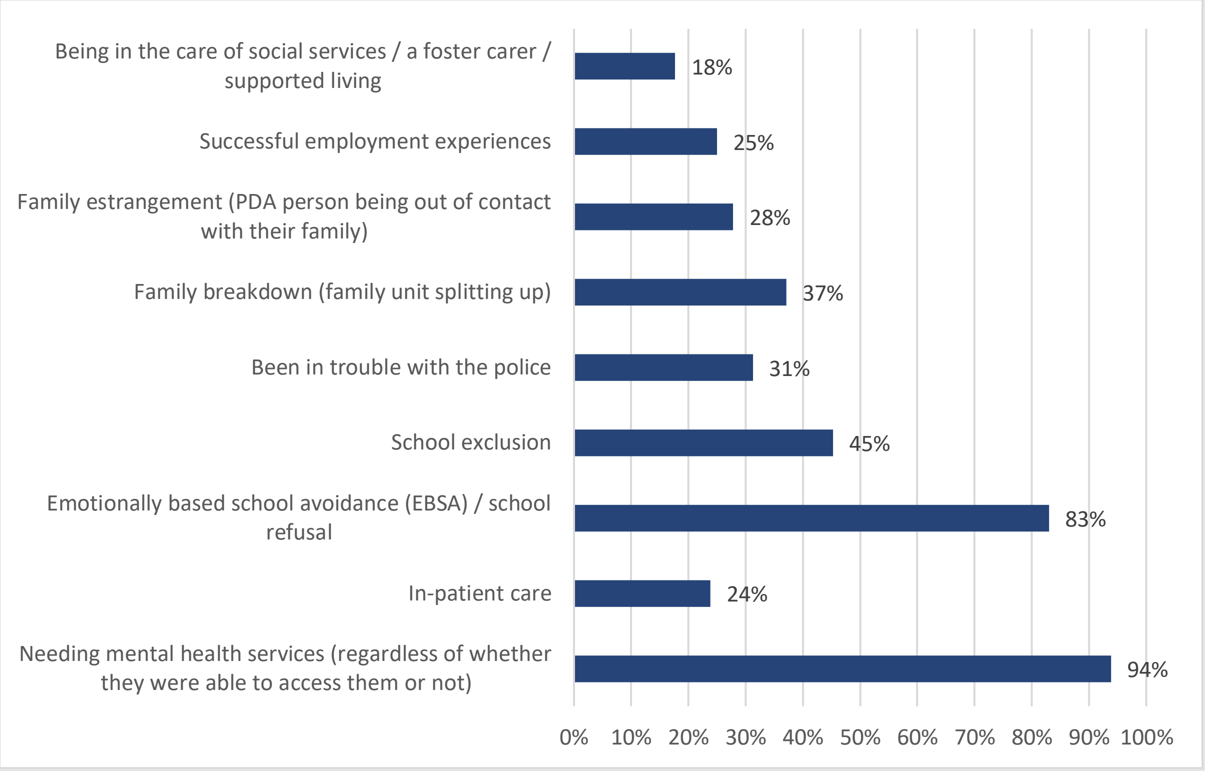
[32] Again, the differences between self-reporting PDA adults and over 18s as reported by parents and carers may be explained by the younger average age of the PDAers in the latter group.



Sample size: 97. Data refers to those who answered either 'yes – in the last year' or 'yes – but not in the last year'.

Intersectionality

Our data suggest some gender differences in the ways that adults experience PDA, which are not as visible in the data for children. This suggests that as PDAers grow older, their experiences of PDA are impacted by broader societal trends, inequities and differences around gender and sex. For example:

- Female and non-binary adults were more likely to report experiencing sensory differences in the last year (94% and 100% respectively, compared to 84% of male adults).
- Female and non-binary adults were more likely to report challenges with eating or an eating disorder (76% and 78% respectively, compared to 64% of male adults).
- Male adults were more likely to report suicidal thoughts (64%, compared to 44% of female and 45% of non-binary adults).
- Male adults were more likely to report substance misuse (40% compared to 17% of female and 28% of non-binary adults).
- Male adults (56%) were more likely than female (14%) and non-binary (25%) adults to report being in trouble with the police at some point in their lives.
- Male adults were also more likely to report having been in the care of social services at some point (20% of males, compared to 12% of females and 9% of non-binary PDAers).

Our data also suggest that exacerbated challenges may be faced by PDA adults from ethnically minoritised backgrounds, particularly around mental health.[33] For example:

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[33] It is important to note the small sample size of survey respondents from ethnically minoritised backgrounds. 86% of our sample were from a white ethnic background. Survey respondents whom we have categorised as from ethnically minoritised communities or backgrounds include the 1% of our sample who chose the category 'Asian/Asian British'; the 0.5% of our sample who chose Black/African/Carribbean/Black British; and the 7% who chose 'mixed or multiple ethnic background'.

- Parents and carers of PDA people over the age of 18 from ethnically minoritised backgrounds were more likely to indicate that their PDAer had needed mental health services (100% compared to 93% of parents of PDA young people from white backgrounds).
- PDA adults from ethnically minoritised backgrounds were more likely than those from white backgrounds to report having needed in-patient care (50% compared to 31%).
- PDA adults from ethnically minoritised backgrounds were more likely to have experienced school exclusion (33% of adults compared to 19% of adults from a white background). This pattern was also reported by parents/carers of over 18s (65% of ethnically minoritised over 18s compared to 44% of white over 18s).

The most commonly mentioned health concern for PDA adults related to mental health.[34] Respondents described how they had lived for decades not understanding how PDA was impacting their daily lives, with this lack of understanding having a devastating impact on their mental health:

> *I didn't understand what it was. I thought it was depression. I tried to keep up with university and pushed through the often daily and multiple panic attacks, I barely made it through high school. I would fall apart, sometimes have to keep working while I could barely manage any part of my life and slide into suicidal depression because I was so tired. And then push myself again*. (PDA adult)
>
> *I've been suicidal for over twenty years, just because I find every day such a struggle. Before discovering PDA, I used to push myself into everything, because that's what I thought I had to do. Advice like 'if something scares you, you just have to do it, and it will get less scary' never worked for me, but I still followed it, because I thought if I would just keep at it, eventually it would change and I could go on being less anxious*. (PDA adult)

In their open-ended responses, PDA adults described how their health and wellbeing was impacted not only by the crippling anxiety associated with PDA, but also by the challenges they faced in meeting 'demands' around self-care and healthy lifestyles:

> *I had weight problems because I just couldn't eat sometimes but others I ate perfectly healthily, personal hygiene is very tough my teeth are in such bad shape, I have uncommon epilepsy which started at around 14 where I have seizures only ever in my sleep. Lots went wrong no matter how I tried and no one could ever work out why.* (PDA adult)
>
> *My avoidance affects my health, with unable to keep up with creams, ointments or health devices, personal hygiene when not meeting people or for going out etc. I would be criticised by family and friends, when they (or myself) didn't understand my avoidance. I didn't understand about executive functioning problems, until I learnt about autism and PDA. Before my mum passed away and my divorce, she would be the person who would nag me to get up, but living on my own, I've realised that I was able to do the things because of her support with doing things as a joint effort. I didn't understand why I was only able to wash at the washbasin and have a bath or shower once every three or four weeks, when most people shower every day.* (PDA adult)

Diagnosis, services and support

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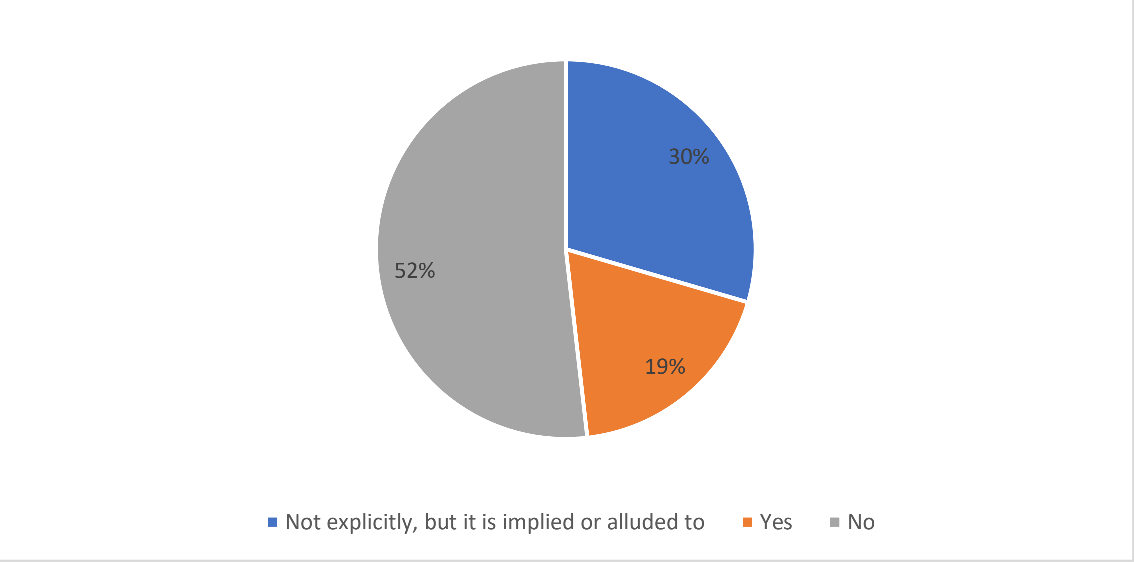
[34] More data on mental health and PDA is available in our research briefing on this topic. PDA Society (2023), PDA and mental health research briefing. Published online: PDA Society

> *My life was a rollercoaster before knowing about PDA. I received an autism diagnosis from the skin of my teeth, but even then I felt out of place from the rest of the autistic community.* (PDA adult)

This section contains our survey data on diagnosis, services and support. A PDA profile of autism is usually identified during an autism assessment. Because there is still academic and clinical debate about the terminology and classification of PDA, recognition of PDA is currently inconsistent. Identifying PDA can also be difficult because it may present in forms that may be different to the way some people, including clinicians, currently think of autism and there are overlaps in presenting characteristics between a PDA profile of autism and other conditions.[35]

Figure 14 shows that 19% of the self-reporting PDA adults in our sample have a formal diagnosis that explicitly refers to PDA, while 30% have a diagnosis that alludes to or implies PDA.

Figure 14: Do you have a formal diagnosis that includes or refers to PDA? (PDA adults – self-reporting)



Sample size: 166

As figure 15 illustrates, the percentage of those with a formal diagnosis that explicitly refers to PDA is, at 43%, higher among the sample of over 18s as reported by parents and carers. In addition, 20% of this sample have a diagnosis that alludes to or implies PDA.

Figure 15: does the person you care for have a formal diagnosis that includes or refers to PDA? (Parents/carers of over 18s)

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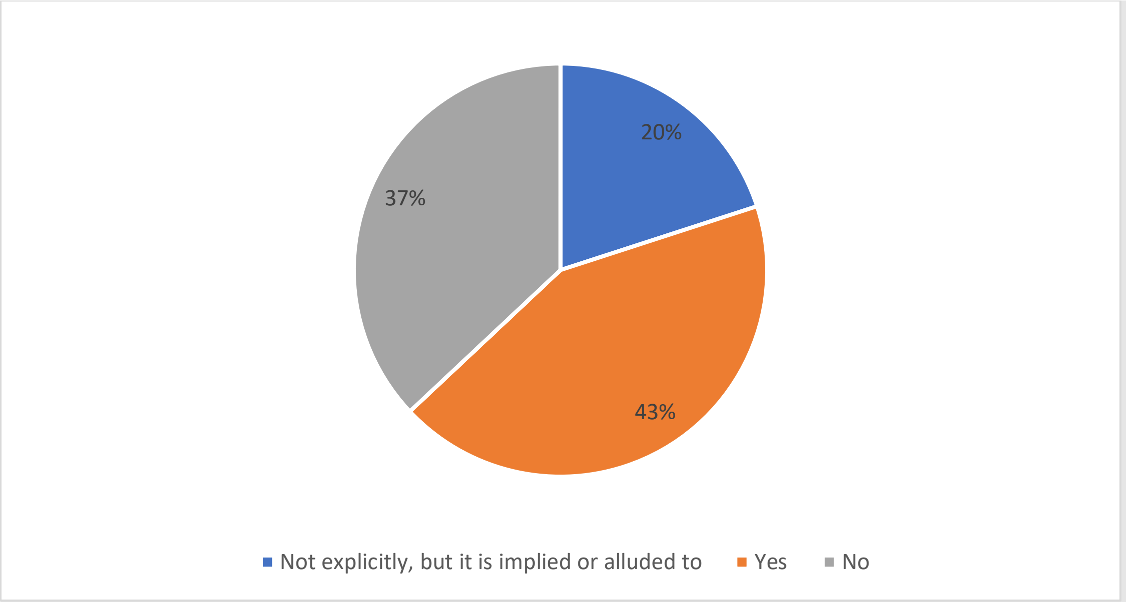
[35] Despite these difficulties, a PDA profile can, and should, be taken into consideration when undertaking autism assessments. This is in accordance with NICE Guidelines, which list demand avoidance as a 'feature of possible autism'. Autism assessments should consider all the presenting strengths and challenges, including demand avoidance. The extent of, and reasons for, demand avoidance should be determined in collaboration with the individual and, in children's services, their parents. Demand avoidance can occur for different reasons, so it is important to understand that a PDA profile may not always be the best explanation. More information is available on the PDA Society website, and in the practice guidance for clinicians on identifying and assessing a PDA profile.



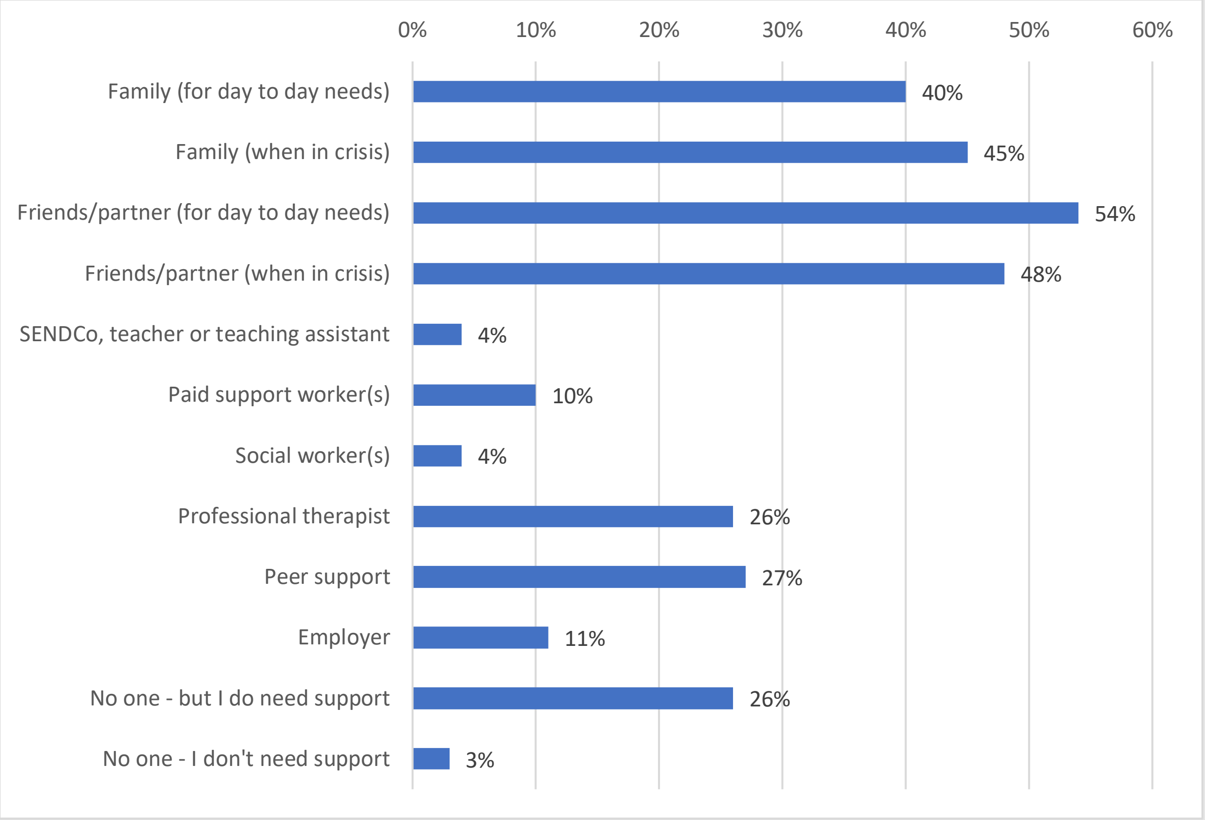
Sample size: 100

In their open-ended responses, PDA adults spoke about the difficulty of getting a diagnosis for PDA, and they also described how the struggles they faced had been misdiagnosed by medical professionals:

> *Life was tough in every way. I wasn't diagnosed till in my 40s and spent 25 years or so bouncing between psych hospitals and failing life. I was misdiagnosed with BPD, bi polar, chronic depression, anxiety disorders and constantly medicated, never finding anything that helped in the slightest. It was a constant cycle of fails.* (PDA adult)
>
> *I was misdiagnosed with manic depression - it felt like it just did not fit. Knowing about PDA made sense and helped me to be able to be confident in who I am and understand that I am not a horrible controlling person at all.* (PDA adult)

We asked PDA adults and parents and carers of over 18s about the support that they/their child receives. As figure 16 shows, 55% of PDA adults said they rely on friends or their partner for emotional or practical support on a day to day basis, and 49% said they rely on friends or their partner for emotional or practical support when in crisis. 40% said they rely on family for day to day support needs and 46% said they care for relies on family support when they're in crisis. Peer support (27%) and support from a professional therapist (26%) were also important for PDA adults. Worryingly, 26% of self-reporting PDA adults said they had no support at all, despite being in need of it.

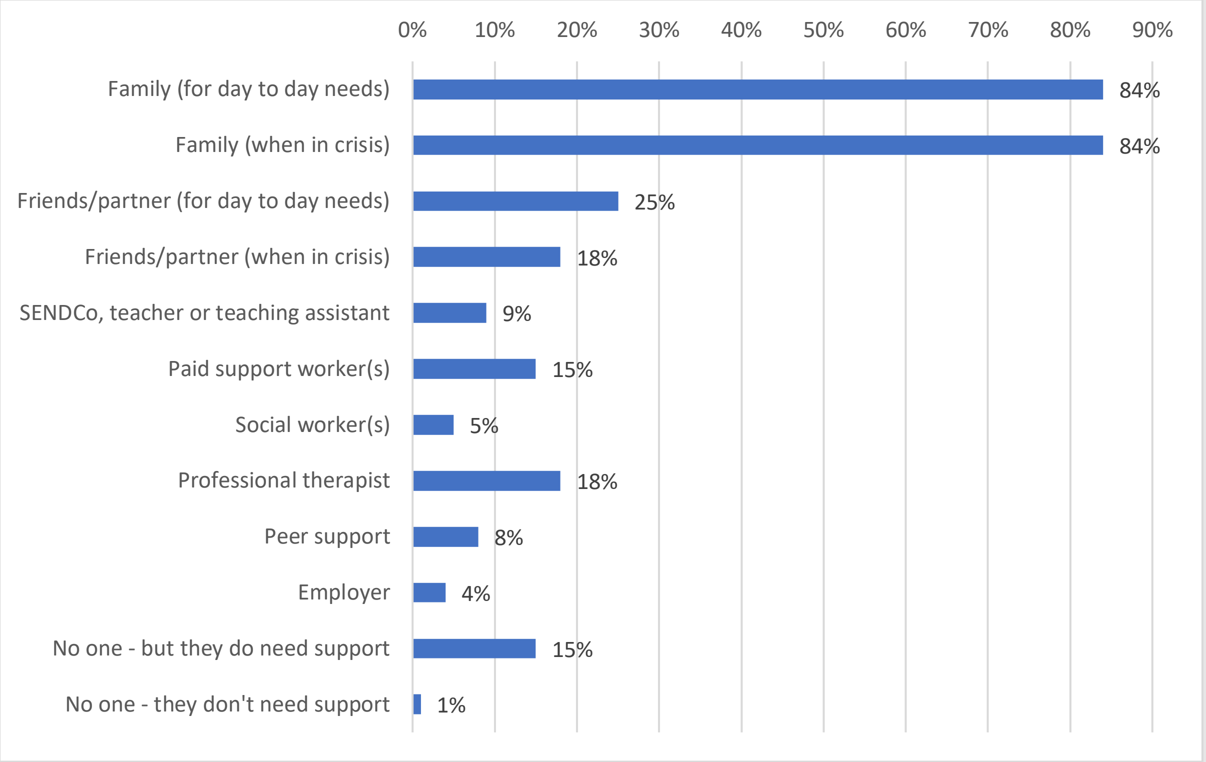
Figure 16: Who supports you? (PDA adults – self-reporting)



Sample size: 161

As figure 17 illustrates, parents and carers of PDA over 18s were more likely to report that family was the main source of support for their PDAer, likely reflecting the younger average age of the PDA person in question, and the possibility that they have a strong supportive relationship with family (which may not be in place for all of the self-reporting PDA adults). However, 15% of this sample said that their PDAer had no support, despite needing it.

Figure 17: Who supports them? (Reported by parents/carers of over 18s)



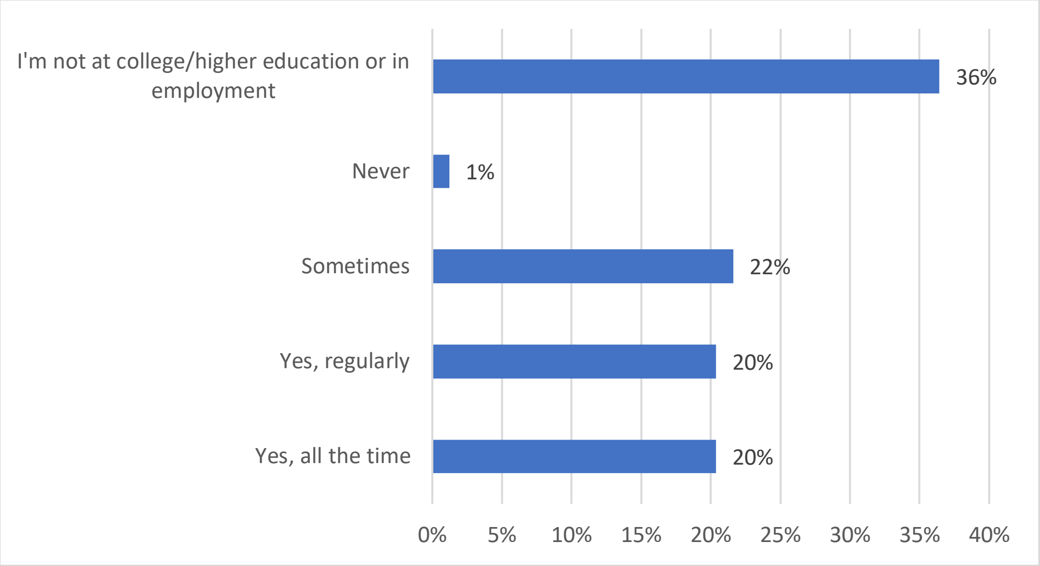
Sample size: 105

Employment and finances

> *The most positive thing for us as parents would be for employers to be more understanding of PDA. They just do not understand the condition at all so it makes it difficult for our son to explain why he feels the way he does so he just gives up and quits his job.* (Parent of over 18)

This section presents our survey data on employment, finances and subsistence for PDA adults. As figure 18 highlights, 36% of self-reporting PDA adults were not in further/higher education or employment at the time of the survey. Of those adults who were, 40% said they always or regularly struggled to attend.

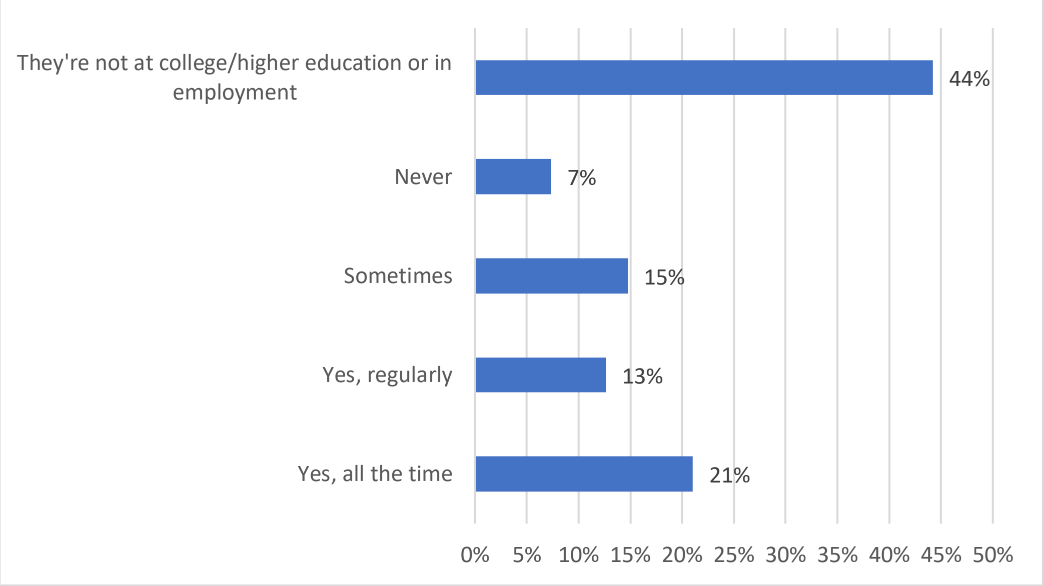
Figure 18: If you are in college/higher education or employment, do you ever struggle to attend? (PDA adults – self-reporting)



Sample size: 162

Figure 19 shows data on the same subject for over 18s as reported by parents and carers. In this sample, 44% of PDAers were not in further/higher education or employment, and of those who were, 33% said they always or regularly struggled to attend.

Figure 19: If the PDA person you care for is in college/higher education or employment, do they ever struggle to attend? (Reported by parents/carers of over 18s)



Sample size: 95

As figures 12 and 13 above showed, 77% of self-reporting PDA adults said they had experienced financial hardship at some point (52% in the last year), and 50% of parents/carers of over 18s said their PDAer had experienced financial hardship (39% in the last year).[36] The financially precarious nature of daily life as a PDA adult was illustrated in respondents' open-ended responses:

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[36] This is higher than statistics representing the general adult population in the UK. The Financial Conduct Authority states that 24% of all UK adults have low financial resilience.

> *I am intelligent, passionate, caring - there is so much I want to do […] If I wasn't concerned about being homeless. I fear if I lose my apartment I will not be able to stabilise again.* (PDA adult)
>
> *Having to work is a big, scary demand with lots of negative consequences if I can't do it. It's basically impossible to live without a partner or free housing through friends or family. Neither of which are really options for me.* (PDA adult)
>
> *My parents told me I could do anything I wanted and I believed them, but had trouble figuring out what I wanted to do. I have prepared for careers in political science, ministry, carpentry, human services, and organisational psychology, but none of those resulted in more than a year of employment […] I have a lot of student debt.* (PDA adult)

Respondents who were, or had been in employment told us about the impact that working had on their health and wellbeing:

> *I would love to be able to stop working. It's not feasible, but I've always found it really difficult how much of my energy goes into my job - even though I've found one I enjoy, one where I have complete control over my workday - which means there's so much less for me.* (PDA adult)
>
> *I would fall apart, sometimes have to keep working while I could barely manage any part of my life and slide into suicidal depression because I was so tired. And then push myself again. I didn't know how to access most welfare supports and the ones that do exist are so abysmal it hardly seemed worth it. Most recently I was lucky to have disability through my work.*[37] *Though work itself caused the majority of it.* (PDA adult)
>
> *A part time job for me was not three days a week but a constant line in my head of panic and hopelessness, a cycle of meetings about my poor attendance and medical history and expectations that I wanted to remain employed. In between working days I was able to do nothing and move nowhere.* (PDA adult)

PDA adults also described how they experienced demand avoidance and anxiety in employment situations, and how these experiences were not understood by employers:

> *I lost count of how many jobs I had - and the same again for jobs I was offered but didn't even turn up on the first day.* (PDA adult)
>
> *I loved my job, it really was the best job in the world. But because they didn't believe me when I said that I got massive anxiety doing a job, I had to leave. The manager wasn't following the accommodations that had been put in place to help and no one else was listening to me. I have always said "I would do anything for anyone, if they ask right" - this manager didn't have a clue!* (PDA adult)
>
> *Some managers know how to talk to me to get results, and some just get my back up. I do well with being given choices and options.* (PDA adult)

Many adults said that the one thing that would make the most positive difference to their lives would be better economic support – relief from the financial pressure of daily subsistence so that they could focus on their own wellbeing:

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[37] Welfare benefits vary across different countries and contexts. In some countries, employees are able to access disability support as a workplace benefit.

> *I think that even though I'm not at all a materialistic person, having more money would make a huge difference because we could afford to engage with supports that cost money. So we could have food delivered more frequently or subscribe to a health meal plan service. We could hire someone to clean the house regularly. We could outsource some/many of the domestic tasks that I struggle with and that would free up my 'spoons' for when they're really needed.* (PDA adult)

Intersectionality

- Female and non-binary PDA adults were more likely to say they were not in education, training or employment (39% for both female and non-binary PDAers, compared to 24% of males).[38]

- However, those female and non-binary PDA adults who were working were more likely to report successful employment experiences in the last year (38% of female and 47% of non-binary PDAers, compared to 25% of male PDA adults).

- Male PDA adults were more likely to report struggling to attend work on a daily or regular basis (56% of male PDAers compared to 39% of female and of 23% non-binary PDAers).

What happens when we get it right for PDA adults?

As the ‘before and after’ excerpts included at the beginning of this section show, living with PDA can be challenging throughout the lifecycle. Many survey respondents described the difficulties they continue to face after learning about PDA. Some respondents told us about times when people had ‘got it right’ for them, however.

As discussed above, 63% of self-reporting PDA adults and 25% of over 18s as reported by parents and carers have had positive employment experiences at some point. We asked some of these people to tell us more about their experiences, which are summarised in the examples below. Interestingly, all four of these involve examples where a PDA adult has been successful and happy working in a role that benefits other neurodivergent people. The examples also demonstrate the types of working conditions that help PDAers to thrive in employment or self-employment. These, and other examples, are presented in more detail in Appendix 2.

Example 5: A PDA-friendly work environment

I work part-time with disabled kids. It’s exhausting (I struggle a lot with fatigue), and I don’t think I could manage it full-time, but I really love it.

The policies and general atmosphere are positive (inclusion for all, all behaviour is communication, prioritising communication and choice in whatever form works, just generally treating the kids as ‘equals’- we aren’t above them). I have very strong moral values and have struggled before working in places which don’t share them, even though it didn’t affect me personally in any way.

Also I just love working with kids. They’re fun and insightful and every day is different, and I think the novelty within a safe environment helps to motivate me. Sometimes there are PDA kids, and I find that I ‘get’ them – even when they’re instructing me exactly what to do and where to stand, which

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[38] Part of the reason for this difference may be that it reflects broader trends in society for women to be out of the labour market or working part time due to their overrepresentation in the unpaid care economy.

normally would massively trigger my own PDA, somehow it doesn't because I understand that they need this to feel autonomy and that we are on equal footing. And often I see a little me in them a bit.

My boss is also very respectful – she often works directly alongside the rest of us, and she doesn't try to demonstrate 'power over us' or anything. I haven't told her about my PDA, but she knows I am autistic and gives me breaks if I ever get overwhelmed.

I'm lucky, because I just stumbled into my job but it's been really good for me, and really PDA-friendly despite not specifically trying to be. It's given me confidence and independence, and a sense of purpose – I actually feel like I'm doing something useful in the world.

I do struggle with some things, such as replying to emails and reliably getting there at the same time each day, but there is flexibility with that which works well for me. And it does exhaust me – I need a full day of absolutely nothing, not even getting dressed or cooking meals, to recover after a work day. But I'm glad I have it.

(PDA adult)

Example 6: A PDAer's thoughts on what works for them

I've been working as a teaching assistant in SEN/SEMH schools[39] for a couple of years. It hasn't been plain sailing by any means, and I faced bullying and discrimination in my first couple of workplaces, but I eventually found somewhere that was lovely, accommodating, and valued my lived experience, insight, and expertise.

What has worked well for me are things like flexibility in my hours, understanding that I can't do a 'full day' and need to leave when the children go home. I start to panic and will have a meltdown about my time being stolen from me if I end up sitting around in the staff room for two hours after the children go home, or if am forced to stay in meetings, so employers letting me go home with the understanding that I am honest and sincere and that my work will be done to a high standard and to the best of my ability, is really important to me. I don't expect to be paid the same as everyone else, so I don't see why it should be an issue.

Another thing that helps is having as minimally invasive of a hierarchy as possible. Employers who talk down to you, or do not respect or value your input, are absolutely unbearable for me. Clear instructions and expectations, open communication, not assuming ill-intentions if I come across blunt/mean/rude by accident, are all really vital to me.

It's also important to me that employers consult with employees when making decisions that directly affect us, and are willing and able to explain the reasoning behind their decisions. I cannot enforce rules I don't believe in, don't think are fair, or follow instructions I don't see the point in.

Also I need to be offered the standard sensory accommodations such as letting me wear my headphones/earplugs/sunglasses when I need to, and understanding that if I look angry or don't say hello in the morning, it's just my face and I don't hate you!

(PDA adult)

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[39] Special educational needs/ Social, emotional and mental health schools

Example 7: A PDA adult's career journey

I think I have been successful in employment because I have had a career path of *my* choosing. I was not diagnosed with any condition until later life so education was a huge struggle and trauma for me. Despite burning out regularly, I got excellent GCSEs, A-levels and a degree.

I have worked in a range of areas and roles. I've worked out that to be happy in employment, I need my work to involve autonomy, be meaningful, be helpful, be interest-based and fact-based. I need to be busy to have motivation but ADHD means I need tools to help with saying no, time management, prioritisation and organisation. I can hyperfocus and my output can be incredibly high. But I bore easily and get overwhelmed easily so I need to have 'just right challenge'.

If I am to work with others, I prefer to lead and/or have trusting-collaborative relationships and a sense of equality. I need to be explicitly told (or shown in a way I understand) that I am liked, valued and my opinion matters. I have terrible self-esteem. Years of masking has meant I actually come across very confidently to the point it's sometimes misread as arrogant. I am extremely sensitive to rejection so criticism needs to be carefully managed. A result of this is, I like to know everything I can about my work so I cannot be wrong. I am goal-orientated but shy away from competition with others (fear of failure). I have impossibly high expectations of myself so need others to help me with boundaries. I am dyslexic so rely on ICT. I forget to stay hydrated and fed so need verbal or visual clues. I need mental health days.

I recently started a new role at a company offering mentoring for young people. With this role I work flexibly, creatively, there are no set hours, there are no expectations other than ones I impose, no timeframes per se, and as most of the staff are neurodivergent, we support each other mentally and physically. I can be my authentic self. I come into the office if needed or when I need some human interaction. The position is evolving as the company does; responding to the needs of the young people we serve and to match the ever changing, educational landscape. There is constant novelty, the work is never mundane, I'm constantly being challenged. I have a new special interest, direction and a meaningful project!

(PDA adult)

Example 8: Self-employment

Being self-employed and running my own business supporting SEND families allows me to pick the times I work and this lessens the demand of having to work at set times. It gives me flexibility – on bad days I can scale back and on good days I can scale up again.

I don't have anyone giving me deadlines I have to stick to, or bosses telling me how my work is - I don't mean just criticism, I mean praise too as I find this just as bad a criticism.

Being self-employed means I don't need permission to take time off or need to explain on bad days why I may be slower or less with it. It means I don't have to put a mask on all the time I work, and I can hide in the comforts of my own home where no one sees me.

(PDA adult)

Of course, employment and work is only one area of PDA adults' lives, and many survey respondents had not had positive experiences in this area. Some told us about other ways that people had 'got it right' for them. This could involve small changes in the ways that friends and family members engaged with the PDAer, as the example below demonstrates:

> *Life was lonely, confusing and hard. I felt like an alien who landed on the planet without a road map. Acceptance from others and myself I suppose has made me feel like I'm okay. Having people in my life willing to make little changes in how they communicate, willing to make some accommodations puts tears in my eyes. I didn't know I could be accepted and it with me makes me feel I can be loved and wanted. I'm starting to feel like the PDA is okay. I can work with it instead of trying to snuff it out.* (PDA adult)

5. The picture for parents and carers of PDA children and young people

Key points:

- Parents and carers of PDA people are carrying out heavy loads of unpaid care responsibilities, with high social, physical, economic and emotional consequences.
- Parents see clear and positive differences in their children when they implement collaborative and person-centred approaches, but find that progress is stalled or reversed when these approaches are not understood or followed by professionals.
- Parents and carers are vulnerable to parent blame when professionals do not have adequate knowledge about neurodiversity broadly, and PDA specifically.
- Some parents and carers are particularly vulnerable to parent blame; these include parents and carers of PDA children from ethnically minoritised backgrounds, and single or separated parents, particularly single mothers.

Content warning: The sections below discuss topics that might be upsetting for some readers, including parental blame and child removal.

Before and after: What changes?

> *I stumbled across an article on PDA late one night and realised that I'd been holding my breath whilst I read. This was it. I finally knew. I cautiously followed links to further articles, half afraid that I would read something that wouldn't fit and would cast doubt that this might not be it after all. But everything I read was describing my child. I felt huge relief that we knew what was going on, coupled with the grief of knowing that this wasn't just a 'difficult phase'. We knew from that moment on that our lives were permanently on a different trajectory and that took some getting used to.* (Parent of under 18)

Parents and carers of PDA children and young people described what life was like for them before, and after, they found out about PDA. The examples below demonstrate how understanding about PDA can change everything for parents and carers – what's often called the 'lightbulb moment'. They also show, however, that the story does not end with that one moment. Even when parents and carers understand PDA and parent accordingly, they remain subject to judgement, scepticism and blame from others. There are more examples of before and after stories in Appendix 1.

Before I knew about PDA	**After I knew about PDA**
I felt like a total failure, as a person and as a parent. We were burnt out, mentally exhausted and in crisis. I'd followed all the regular parenting and nothing changed, or even sometimes made worse. (Parent of over 18)	It's so much better than it was. Following advice on the PDA society website, listening to other PDA folks, being able to make changes to implement support that helped us both and our family as a whole. We no longer exist in shame and blame and we have closer, stronger relationships as a result.
I thought I was a terrible parent and others were doing and coping so much better than me. (Parent of under 18)	I can understand, have more patience, realise it isn't my parenting, take the pressure off myself and my child, advocate for my child better and better able to understand their needs. However, other people still parent blame.

I felt like a failure as a mother. I had years of teaching experience including in SEN schools so I thought I should know what I was doing. But my strategies to make our family life harmonious weren't working and we were all struggling. (Parent of under 18)	Life is still very challenging. I spend a lot of time fighting with education professionals or trying to get the right kind of support for my son. But our home life is 90% joyful and happy for everyone. My son laughs more and plays more. We laugh together more.
As parents, we felt that we were failing at every step and education, the medical world and society as a whole was only too happy to let us feel that way. Every interaction with 'professionals' of any kind left us feeling like we just needed to try harder, be better and to just manage what others were apparently achieving with such ease. For our child, he must have been so frightened trying to cope in a world where not even his parents could understand him. (Parent of under 18)	Life now is completely different. Life is happier and calmer. Connection and trust is being restored. But there are long-term wounds, inflicted by the system of education and medicine, that are still healing in us all as a family. Our son has left formal schooling due to sheer lack of knowledge, training and quite frankly, any willingness within educational staff to know better and do better.
Before we knew about PDA, we still had neurotypical expectations of our daughter and put unnecessary pressure on her which only made things worse. We interpreted her symptoms and behaviours as either strictly mental health-related or as purely anxiety in the traditional sense. We tried to use logic and reason as well as rewards. We also worried she might be bipolar, again looking at things through only a mental health lens. (Parent of under 18)	We now understand PDA as a nervous system disability and a profile of the autism spectrum. We try to provide our daughter with accommodations and supports including giving her more autonomy, reducing demands, using declarative language, proving lots of co-regulation, recognising and supporting her sensory needs, and letting go of ableism and traditional parenting models.

The impacts of being an advocate and carer

> *My world has shrunk dramatically. I am unable to work due to my son's needs. I left my professional career but I am adjusting. I rarely go out socially at all, spend most of my time in the home environment as a result. We have not been able to go on holiday now for several years as the demand level is too high for my son and it's expensive to book and repetitively cancel.* (Parent of under 18)

This section highlights what the parents and carers who responded to our survey said about the impacts of caring. These impacts are multidimensional, covering health, wellbeing, finances and careers.

23% of those responding as parents or carers told us they had experienced family breakdown at some point. In their open-ended responses, parents described how their role had impacted on relationships with spouses and partners:

> *My husband and I were constantly fighting because he thought traditional parenting techniques would work but I knew they were making things worse.* (Parent of over 18)
>
> *There was often a lot of conflict between me and my husband as well, because he favoured more "traditional," do-this-because-I-said-so disciplinary techniques, and he often criticized me for not disciplining our son enough and forcing him to comply with typical standards of behaviour. We argued a lot about how rigid he (my husband) was in his approaches to our son compared to how flexible I was, and I tried to persuade him that his rigid methods weren't working and explain why I was taking more creative approaches. It created a lot of conflict and discord.* (Parent of under 18)

There were also impacts on broader relationships - with other children/siblings, wider family members and even friends and neighbours:

> *Holding family relationships together by a thread a lot of the time. Overwhelming and exhausting not just as parents but for siblings and my son too. Neighbours and friends, even some extended family members would sometimes think they could give their opinions and these were always that everything looked fine, they were lovely children and then later young people.* (Parent of over 18)

Parents and carers also described the economic impacts of caring. Many had had to reduce their working hours or give up work all together, as their child was unable to attend school. This had a knock-on effect on finances and the daily subsistence needs of the whole family:

> *I've had to halve my working hours and significantly reduce the size of my job. My career is over and I'm just surviving in my job to pay the bills.* (Parent of under 18)
>
> *I had to give up my career and become a full-time carer and my husband became self-employed so that he could manage his work hours and be more flexible, but financially it was difficult to manage.* (Parent of under 18)

In addition to the financial penalties experienced by parents and carers, respondents also told us about the emotional and health impacts of their caring responsibilities. Parents and carers had experienced both physical and mental health problems:

> *I suppose the best way to describe it would be that as a parent I felt not only like every day was like balancing on the edge of cliff not knowing what we were going to endure, but I felt like a failure as a parent. Not only was I portrayed as a failure by certain professionals at points through our journey but hearing from your child some harrowing reasons why he no longer wants to live was devastating and took a massive toll on my mental health.* (Parent of under 18)
>
> *It's dealing with the outside world (especially my son's mainstream school) which is making me physically unwell. I am fighting injustice on a daily basis and am "batted away" / made to feel like a fussing parent because it feels as though everyone has a one-dimensional view of what autism looks like.* (Parent of under 18)

At the same time as they were experiencing the financial, health and emotional consequences of caring for their PDA child, parents and carers were also undertaking the role of advocate for their child. This role comes with a number of challenges, as the next section discusses.

Being an advocate and experiencing parent blame

> *School was a nightmare. One problem was people believing my child had attachment disorder, thereby implying that my parenting had been damaging or neglectful, when the opposite was true - this was incredibly hurtful. I was already suffering because my child never, ever did what he was told or what was expected of him etc. I had very low esteem because I seemed to be a rubbish parent in spite of doing my best. Looking back over 8 years I can see that I was actually incredible - and so is my child!* (Parent of under 18)

This section gives an overview of our survey data on parents' experiences of advocating for their PDA child. Parents and carers told us that when they implement approaches that help at home and see success, the next challenge they face is to get these strategies and approaches understood by professionals in settings such as education. This requires that parents/carers become an advocate for their child, which can be a challenging role.

Figure 20 shows that 61% of those responding to the survey as parents or carers[40] have experienced disputes over their child's education/schooling at some point, and 16% have experienced an education tribunal. 24% have experienced a social services investigation, 13% have experienced allegations of fabricated or induced illness (FII),[41] and 13% have experienced allegations of parental alienation.[42] These data concur with other recent work on the topic of parental blame and the PDA profile of autism.[43]

Figure 20: Have you, as a parent/carer of a PDA child, young person or adult, experienced any of the following?

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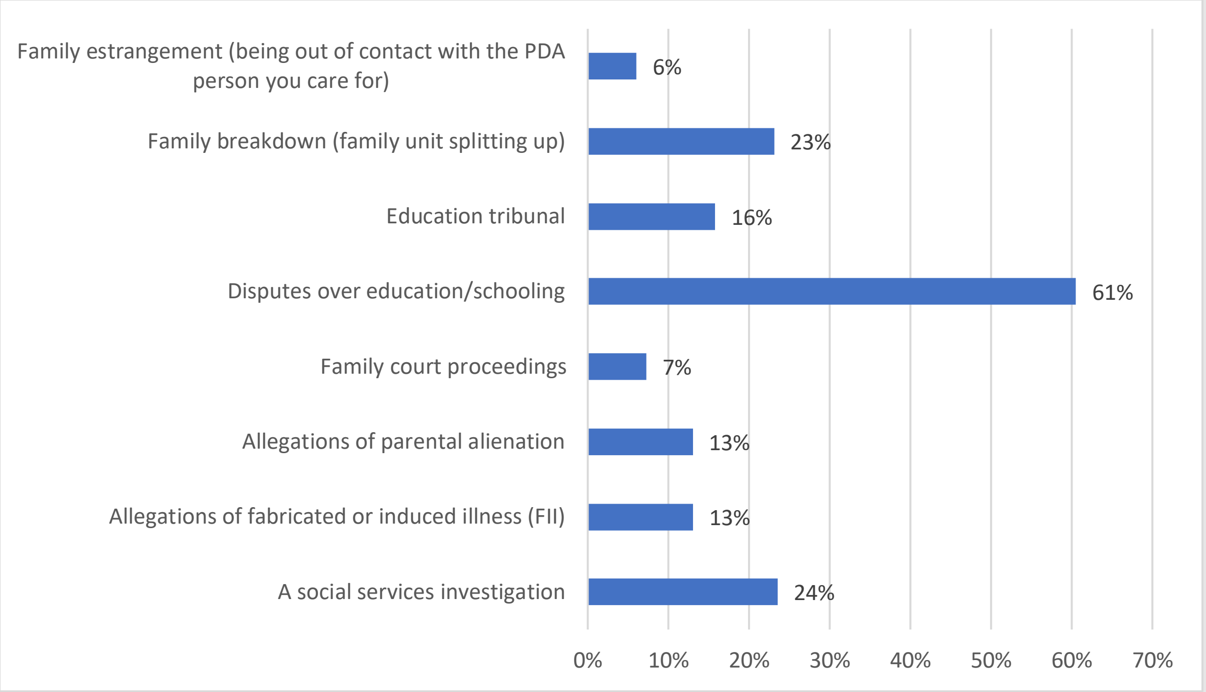
[40] Parents/carers of PDA people both under and over 18 years old (727 respondents in total).

[41] The Royal College of Paediatrics and Child Health describes FII as 'a clinical situation in which a child is, or very likely to be, harmed due to parent(s) behaviour and action, carried out in order to convince doctors that the child's state of physical and/or mental health and neurodevelopment is impaired (or more impaired than it actually is)'. In practice, allegations of FII occur when professionals suspect a parent is creating or exaggerating their child's difficulties, with no identifiable evidence to substantiate their existence. There is a lack of evidence for currently used indicators for FII and there are concerns about the high incidence of these indicators identifying children where illness is neither fabricated nor induced (Long et al, Fabricated or Induced Illness and Perplexing Presentations, 2022).

[42] There is no commonly accepted clinical or scientific definition of "parental alienation". Broadly speaking, parental alienation is understood to refer to deliberate or unintentional acts that cause unwarranted rejection by the child towards one of the parents, usually the father. The concept has been dismissed by medical, psychiatric and psychological associations, and in 2020 it was removed from the International Classification of Diseases by the World Health Organization. Nevertheless, it has gained considerable traction within family court systems on a global scale (Report of the UN Special Rapporteur on violence against women and girls, its causes and consequences, 2023)

[43] Running, A. and Jata-Hall, D. (2023) Parental blame and the PDA profile of autism. Published online



Sample size: 727

Parents and carers' open-ended responses provided many examples of the challenges of advocating for their child, and how parents can be disbelieved or blamed in the process:

> *I felt disapproval from other parents and teachers, who said I should be more disciplined with him, set hard boundaries and equally rigid consequences to 'teach him to obey'. I felt pressured to comply with their advice, even though I knew it wouldn't work, and would make things worse. I felt like I was failing him, because I could see his pain and distress, but I didn't know what to do to help him, or how to connect with him in a way that he could cope with.* (Parent of under 18)

> *When I spoke to doctors about it, I was told that it was a parenting issue and that I needed to set more boundaries. They didn't understand that the boundaries themselves were the problem, as my son's meltdowns appeared to be centred around his need for control.* (Parent of under 18)

> *The difficulties my child faced were labelled as being our fault, because of poor parenting and parental mental health struggles. We were sent on lots of parenting courses and professionals tried to shame us into changing our child's behaviour and presentation.* (Parent of over 18)

Parents and carers also explained how the disbelief and blame could accelerate into social services investigations and dangerous allegations of FII:

> *Mainstream primary was hell on earth for both my son and me. As is becoming more and more common, I devastatingly got falsely accused of FII. It was easier for the head teacher to blame me. Our doctors were fantastic and there was no case to answer to BUT I will take it to my grave!* (Parent of under 18)

> *Two social workers sat with the NHS diagnosis in hand insinuating I had Munchausen Syndrome and was putting it all on my child.* (Parent of over 18)

> *One time l called the duty social services to say we had reached a limit as my son was hurting his siblings a lot at this point and one was becoming anxious. This social worker said they would have to look at removing my youngest son and would visit the following Tuesday. I was terrified and honestly thought they were going to take my youngest away but on the day, no one turned up and a letter arrived two weeks later to say the case was closed and it was not safeguarding. That was it.* (Parent of under 18)

Intersectionality

Some parents and carers are particularly vulnerable to parent blame. Parents and carers of PDA children from ethnically minoritised backgrounds were more likely to report being subject to a social services investigation (36% compared to 21% of parents of children from white backgrounds).[44]

Our data also showed marked differences between parents who had experienced family breakdown and those who had not.[45] As figure 21 illustrates, parents and carers who had experienced family breakdown were more likely to report: being subject to a social services investigation (50% compared to 19% of parents/carers reporting no family breakdown); being accused of fabricated or induced illness (FII) (27% compared to 8% of parents/carers reporting no family breakdown); being accused of parental alienation (35% compared to 10% of parents/carers reporting no family breakdown); disputes over education (84% compared to 62% of parents/carers reporting no family breakdown); and experience of education tribunal (22% compared to 17% of parents/carers reporting no family breakdown).

Figure 21: Have you, as a parent/carer of a PDA child, young person or adult, experienced any of the following?

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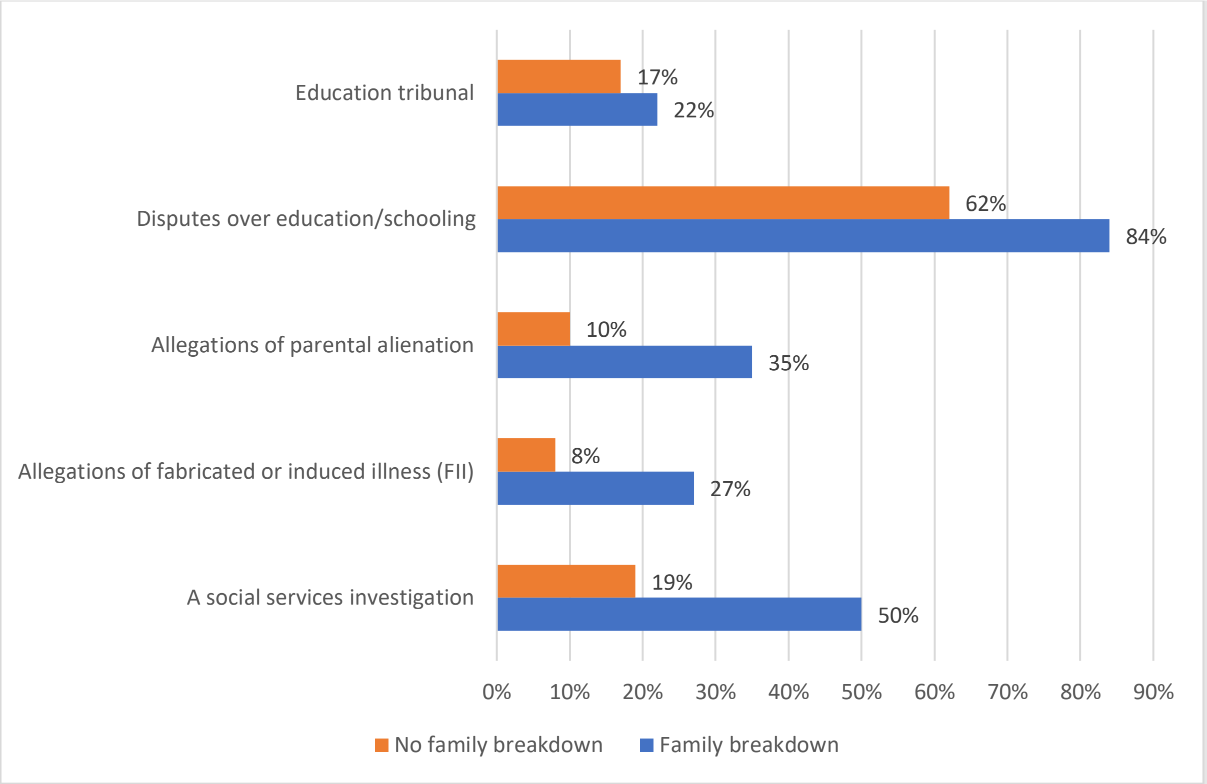
[44] It is important to note the small sample size of survey respondents from ethnically minoritised backgrounds. 86% of our sample were from a white ethnic background. Survey respondents whom we have categorised as from ethnically minoritised communities or backgrounds include the 1% of our sample who chose the category ‘Asian/Asian British’; the 0.5% of our sample who chose Black/African/Carribbean/Black British; and the 7% who chose ‘mixed or multiple ethnic background’.

[45] We compared parents and carers who said they had experienced family breakdown with parents and carers who selected ‘no, not at all’ for family breakdown. Total sample size: 679 (511 who had not experienced family breakdown, and 168 who had)



Sample size: 679

As single or separated parents, it is likely that blame and accusations are directed at these parents who have experienced family breakdown by both professionals and the child's other parent. There is also likely to be a gender element to this, given that the majority of single and separated parents with primary parenting responsibilities are female.[46]

In addition, the analysis showed that where parents and carers reported family breakdown, children and young people were much more likely to be, or have been, in foster care, or 'looked after' in some other way by social services. 30% of parents of over 18s who had experienced family breakdown reported this, compared to 10% of parents of over 18s without family breakdown. This, when combined with the evidence above on parent blame, may indicate that single parents are more likely to have their PDA children removed from their care.

What happens when we get it right for parents and carers?

As the 'before and after' excerpts included at the beginning of this section show, understanding about PDA can change everything for parents and carers. However, even when parents and carers understand PDA and parent accordingly, they remain subject to judgement, scepticism and blame from others. A small number of respondents told us about times when people had 'got it right' for them, and they had felt believed and supported. The examples below show what a difference being believed and listened to can make, as well as the importance of professionals who understand and have expertise in PDA. These, and other examples, are presented in more detail in Appendix 2.

> *Having a professional who understands PDA, and agrees that my son has it, has been so validating. It has made it easier for me to get support for him at school and elsewhere. Having a professional on side means that I don't feel crazy, there are less people gaslighting*

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[46] Single parent facts and figures, Gingerbread, 2019

me into thinking it's all in my head and that my parenting is wrong. We need more professionals to understand and recognise PDA – especially in schools and childcare settings. (Parent of under 18)

I had been constantly knocking on professionals' doors, saying that my son reminded me of the children I knew who were autistic but at the same time, he seemed to have a completely different set of needs. I was constantly dismissed. Until one kind and understanding professional did take notice. My GP agreed to refer me out of area to a different CAMHS. There we worked with a brilliant child clinical psychologist, who agreed that my son fitted the PDA profile and wrote a report hinting at PDA. Following this, other services began to take me more seriously. (Parent of under 18)

Example 9: The positive difference that professionals can make

We spent quite a few years trying to engage in 'normal' family life, to be like other people who sat down at family meals, followed rules and traditions, went on holidays, welcomed surprises and generally did what was expected. During this time, we were asked by family members things like: "When is she going to start listening to you?" or "Why are you giving in to her all the time?" We didn't know the answer to these questions, and they made us feel like we were failing.

When our daughter started school, we were told by teaching staff that she was "absolutely fine" at school, there were no problems at all. So we couldn't understand why she had such huge meltdowns as soon as she came out of the school gate. It was so confusing, seeing how difficult everything was for her, but having professionals say there was nothing wrong.

I don't know what would have happened if my partner hadn't started doing her own research at that stage, and actively seeking out professionals who understood PDA. As is the case for many families, we found out about PDA through the internet! We were very lucky in that we had some savings and could pay for a private assessment with a paediatrician who recognised the PDA profile of autism. She changed everything for our family. As soon as we met her, we felt believed, understood and not blamed. Our daughter also seemed to know that this person understood and would help, and she opened up to her. The paediatrician spoke to us all for hours, I'm sure for longer than we had paid for, and explained everything to us and our daughter in a child-friendly way. She wrote an extremely detailed diagnosis report with recommendations, which has been such a useful tool in getting our child the support she needs.

We changed schools and found education professionals who understood about PDA and were willing to think outside of the box and allow our daughter the flexibility, understanding and compassion that she needs. They don't always get it right but they are open to feedback and we now feel confident enough to give it.

Having access to understanding and knowledgeable professionals has been a game changer. Our confidence in advocating for our daughter is now so much higher, not only because we know our instincts are right, but also because we feel we have the back up of these wonderful people who have believed and helped us.

(Parent of under 18)

6. What needs to change?

This report illustrates the challenges that PDA people and their families are facing a number of areas including education, employment and healthcare. It also clearly shows what the impact can be when PDA people's needs are not met or understood.

PDA people of all ages are not having their needs met in education and employment. They experience high levels of anxiety around the 'demand' to participate in education institutions and in workplaces designed by and for neurotypical people, and they do not feel understood or supported. For many PDAers, this anxiety is a constant pattern throughout the lifecycle as they are expected, and try, to 'fit in' to different settings.

PDA people and their families also told us how struggling and being misunderstood in education and employment settings impacts negatively on their health and wellbeing. Mental health challenges were a commonly cited issue. We heard about children as young as five with such high anxiety levels that they began to self-harm or have suicidal thoughts. As PDAers grow older, mental distress can become more ingrained – we heard from adults who had felt suicidal for decades.

In addition, PDA people and their families face significant difficulties in accessing timely and appropriate assessment, diagnosis and support. Children and young people face long waiting lists for diagnosis, and are not always assessed by clinicians with knowledge of the PDA profile of autism. Adults gave examples of their PDA not being recognised; instead many had received misdiagnoses of mental health conditions. The main source of support for the vast majority of PDA people is family and friends, rather than professional support.

However, we also heard from our survey respondents about times when a person or institution had 'got it right' for them – in education, employment, health services or family life. These examples demonstrate what can happen when we understand PDA, listen to and act on lived experience, and think outside of the box.

Everyone deserves to get timely support that meets their needs when they are struggling, especially when this is having a long-term and detrimental impact on their daily lives.

There is no legal requirement to have any diagnosis to be able to access appropriate support in the UK; in the Families Act, the Health and Social Care Act and the Equalities Act, access to support is based on identified needs alone.

With services stretched to capacity however, diagnosis is being used unlawfully to gatekeep vital support in education, work and healthcare, and waiting lists for assessments are longer than they have ever been.

We believe that a renewed focus on individual strengths and needs would be life-changing for PDA people and the autistic community as a whole. This would allow everyone to get help quicker, wherever they are on their diagnosis pathway, and would encourage more flexible and varied provision to respond to the diverse experiences of autistic people.

To achieve this, we need to support collaborative partnerships between PDA adults, parents and professionals, which reflect the value of lived experiences, and have the flexibility to adapt when the current approach isn’t working. When we get this balance right, the impact can be truly transformational.

Appendix 1. Before and after: What changes?

Before we knew about PDA	**After we knew about PDA**
Children and families	

Stress, trauma, meltdowns, autistic burnout, anxiety, depression, violence, property destruction, aggression, panic attacks, school avoidance - for us as parents and our children. Our family was falling apart. Financial and marital stress. Confusion, disappointment, anger, guilt. Constant searching, trying to "fix" everything, endless appointments, professionals, diagnosis, parenting courses, books. From the outside it might have looked like we were holding it all together but we weren't!	Very different now. Acceptance, understanding, a whole new way of living. Home schooling our PDA child. Giving up a career. Making financial and living changes for our family. More peace, happiness, calm. Letting go of unrealistic expectations. Listening to the voices of PDAers and finding PDA affirming professionals for guidance and support. Truly seeing our son for who he is. Understanding his needs. Supporting in a PDA friendly way. Eager to keep learning more.
Our family lived in utter turmoil. We found no support. Even from calling child mental health crisis lines. We were judged by family, we were hanging on by a thread. Our marriage almost ended several times. I had been researching for a few years, trying to figure out what was going on. We saw three different paediatricians and they just shrugged their shoulders. Then I stumbled across PDA. I cried as I read the diagnostic criteria. Everything made sense.	Life is still a rollercoaster. But we have learnt how to lower demands, meet our child where they are at. We are brave enough to face judgement from others about our parenting and way if being. Our child has begun to emerge from a long period of burnout. We see their sparks of self again. We still face obstacles with schooling. Obstacles of finding allied health professionals who understand and care. Hearing lived experiences of older PDA individuals has been a window of hope and reassurance that we are doing a better job of being parents and companions on my child's journey in life. That I can be that co-regulating, trusted person for my child.
Before we found out about PDA, life was still magical and full of joy, before our PDAer hit the mainstream school system. Then our lives were turned upside down as they inflicted school trauma on our child and our family.	My son has found the safety at home to unmask completely. However, we have discovered that this world is very unforgiving for PDAers. I have come across very few people that have a genuine interest in understanding us and our neurodivergent needs. They judge, they ridicule. They dismiss, they invalidate. They shame us, exert power over us, and ensure that we remain marginalised and vulnerable.
Chaotic, emotional and my son was truly not getting his needs met. Everything came to a head almost a year ago and although my son was able to go to school the majority of the time, he was not able to leave his room/bed the rest of the time. We had a no demand household for him but feel like we lost him since he was unable to participate in anything outside of gaming. We missed him.	Life is calmer and my son has slowly been able to re-engage. Once we decided to home school and the demand of school has been removed, he is slowly engaging. This last week he went to dinner with the family, played chess with his dad, went on walks with me and the dog. He was able to brush his teeth twice in his own. He is thankful he is being heard and I am sure we are doing the right thing to protect his mental health.
My child was dysregulated all the time. School was a disaster, and staff were at a loss to know how to support my daughter. They	We are home educating. My child is starting to show us her personality and blossom, now that she isn't in fight or flight mode 24/7. Our family

were using behavioural interventions in response to her meltdowns and challenging behaviours, and it only escalated the situation.	has moved out of a crisis mode and into a more stable maintenance phase.
Our son seemed to struggle with everyday life. It was all hard for him. Moving from one room to another, leaving the house, wearing certain clothes, shoes, being around a lot of people, visiting new places - everything seemed difficult for him. He understood the rules of life, but couldn't engage in them. There were lots of tears, for him and myself as mum. I didn't know how to reach him, to help him. He hated being comforted, as he doesn't like touch. I felt very isolated in my parenting of him.	We now know his refusal is due to anxiety. We understand that change and transitions are difficult for him to navigate, unless it's something he is 100% on board with. We plan for this. He no longer goes to school, due to EBSA, and we are trying to get the right support, but no one "sees" him like we do. We have a very low demand life, and he is now thriving after 18 months' recovery from school trauma. He hugs us goodnight – it's my favourite part of the day, after so many years of not touching. He is interested in learning again (a little). He has started to leave the house again.
My son seemed un-helpable and his distressed behaviours were escalating. There was no help from anyone, anyone. The few services I could get help from had no idea either, and everything that was suggested just made things worse for my son and family.	My son has a better understanding of his brain, his needs, and is slowly letting that mask down in public; therefore, his mental health has improved. It has been difficult getting his PDA needs to be understood and supported at his primary school, we are hopeful his secondary school will be more understanding and knowledgeable.
School was challenging for my son, he was misunderstood and he wasn't given the correct support for his PDA. School involved autism outreach once my son had a diagnosis of autism but all the strategies they suggested weren't working. PDA was never mentioned by school, autism outreach or the paediatrician.	Since learning about PDA and getting informed professionals involved such as SaLT, OT and educational psychologist, things have got better. We now use PDA strategies and have a good understanding of our son's needs. However, I still feel PDA is generally misunderstood by professionals and school especially.
At home we naturally adapted to him, and found what worked without any conscious effort. As soon as he started school, things went downhill rapidly. He was excluded twice but eventually got support and learned well, although he will hate school for the rest of his life. The school have no understanding of PDA.	The best thing is having the words to describe/ articulate my son's experience and the adjustments that help him. However, in terms of school and wider societal understanding, there is much work to be done. In my experience, doctors, counsellors, and school SENCos have been worse than useless as they act as a barrier to much needed support.
Our four-year-old barely slept, he was explosive, and getting him to school was becoming more and more difficult. The turning point was school. Despite what everyone was telling us, he didn't get used to it and things became harder and harder.	Discovering PDA and then later receiving diagnosis for my child gave me the confidence to embrace a low demand way of living. My child never returned to school following the lockdowns, I applied for an EHCP and spent nearly 2 years fighting for EOTAS. I trusted my gut

	again, which I should have done all along, but is often easier said than done. We brought my child back from the brink.
My daughter's secondary school education was so traumatic at times I find it difficult to describe the words to describe it all. The misunderstanding and false promises made by professionals caused another layer of school based trauma. Family and friends' lack of understanding and refusal to educate themselves led to a reduction in contact with them and our safe circle being reduced.	We constantly come up against people who do not understand PDA and do not want to understand it. Schools, doctors, professionals, family and friends cause constant hurt and I try to protect my daughter from it all. I have huge concerns of how my daughter will do at college and in her future - I worry what more trauma she will experience and the lasting impact of it. She is intelligent, articulate and a wonderful human being. She hopes to raise awareness of PDA and change the future for young PDAers.
Hard work. Lots of questions as a parent, doubting myself and my parenting style. Lots of parental blame for the challenges my child faced, especially within school. Diagnosis's we're explored and ASD was diagnosed but it never felt quite right. Lots of people would subsequently question his diagnosis which then felt like I was going mad - "he doesn't look autistic." Or "Autistic strategies don't work so he can't be autistic, it's attachment disorder and mum is to blame." School life was incredibly hard because he was misunderstood and labelled a naughty challenging child. He reached burnout resulting in EBSA because the school didn't think he needed support, even though we were crying out for some help as things were so challenging at home. It was only when he reached crisis that we discovered PDA and they started to understand him more and put in the support he needed. But by then it was too late. Mental health crisis for over 2 years-self harming, suicidal ideations and an attempt. No support was given because professionals didn't know how to engage him and their language and approaches only made things harder. CAMHS weren't willing to accept PDA.	Much more settled. More support in general and professionals understand him. They have been able to take training courses in PDA and PACE, and the approaches are then used to support him correctly. This has meant that he's more regulated, the pressure is lower and he is happy again. At home, I understand when we need to lower demands and just knowing about PDA has validated my gentle approach to parenting him. I don't feel criticised for using a 'soft' approach, because it works. I've learnt everything from other PDA families and the PDA society! His mental health is in a MUCH better place.
Very challenging, upsetting, confusing, exhausting, depressing for myself and my son. I felt caught between knowing instinctively what my son needed and yet having family members, professionals and the education system telling me he was the	I stood my ground when dealing with health professionals and education departments regarding his needs. I listened to him and took on board the things that gave him anxiety and never forced him to do anything that severely affected his mental health. I parented him in a completely different way to my eldest which was a challenge

way he was because of my inadequate parenting skills.	but I was guided by him and we worked together as a team despite criticisms from others. Against all the odds my son who is 18 now has recently passed his driving test, attended college to become an electrician, has now an apprenticeship with a large engineering company and is doing exceptionally well despite all his challenges and refusing to go to mainstream school from the age of 8 for 3 years. I'm so incredibly proud of him and how much he's taught me not only about PDA and autism but about myself and the resilience I had to draw upon to get through some very difficult times.
Adults	
My life was a rollercoaster before knowing about PDA. I received an autism diagnosis from the skin of my teeth, but even then I felt out of place from the rest of the autistic community. School was extremely demanding. I masked what I know now as my demand avoidance and hid it extremely well, but the demands of homework, schoolwork, talking to different people and GCSE exams wore me down. I would come home every day either stimming for hours or falling asleep because I was too exhausted. I did receive support at college and uni from mentors, but conventional autism strategies weren't effective. I still left sessions stressed and confused as to why I couldn't manage my life as effectively. I always felt that I was overreacting to everything, even the smallest requests and end up hating employment due to the demands of attending work and communicating with people.	Since fully knowing about PDA, my outlook on life has improved and my feelings of work and daily living are much more positive. I am aware of what triggers me and I know when to take a step back. On the flipside, the majority of professionals that I speak to about PDA have never even heard of it and the fact that it's hardly understood by so called experts baffles me.
I found life incredibly challenging, even the easiest tasks seemed so impossible, and I treated myself so badly, telling myself I was useless when I couldn't manage to do certain things, or when I had meltdowns because I couldn't cope with getting somewhere with the demand of getting there by a certain time. So full of stress, high levels of anxiety and depression.	I have only recently found out about PDA and identified myself with this. Since then, we are approaching life from a low demand angle and already life in general feels like I can cope a lot better, that I don't have to force myself to fit into a neurotypical way of living because I know I am neurodivergent and there is nothing 'wrong' with me, my neurobiology just means I need to live in a way that enables my nervous system to feel safe.

I struggled more with the anxiety, impatience, anger, fear that I believed were personality flaws that I needed to mend. Most of my attempts to ‘fix’ myself ended up nowhere.	I realise I’m not broken. I have these reactions for a reason. I no longer feel broken, repulsive, or like an ugly duckling. I feel grateful for my gift, love for the 10-year-old child that struggled with social situations, school, bullying, abuse, projects, assignments, reading, homework, and my family. I want to help all PDAers get the inputs and skills they need to succeed.
I always felt 'off' somehow. Different. Lots of periods of what I now know as burnout and somatic manifestations of anxiety. I had no diagnosis or vocabulary for how I felt. I can see now how much PDA impacted my life and how I managed to adapt and cope the best I could. But I've always felt like an outsider, and now I know why.	It's both better and worse actually. Knowledge is power, so knowing why I am how I am is helpful. However, since I've been working on not masking, I'm not quite as 'functional'. I think a lifetime of masking and pushing through and meeting demands and expectations (and parenting a PDAer who's now a struggling teen) has taken its toll. Many things I used to do I can't any longer. So although on the surface, I'm more aware, I'm more at peace with my neurotype and I understand myself much better than I did when I was younger, everything comes with a price.
Life was really difficult. I have struggled with the daily things since forever. It felt like life was so much harder for me than for other people, yet there seemed to be no true reason for it. I've been suicidal for over twenty years, just because I find every day such a struggle. I used to push myself into everything, because that's what I thought I had to do. Advice like 'if something scares you, you just have to do it, and it will get less scary' never worked for me, but I still followed it, because I thought if I would just keep at it, eventually it would change and I could go on being less anxious.	Some things are different and some things aren't at all. The biggest difference is that my experience makes more sense to me, which is making it a little easier to deal with. I'm still suicidal on a near-daily basis, I still find life incredibly difficult, but there have also been moments of joy, moments that were easier because I could understand what I needed to make life a little easier. I often find it incredibly difficult to deal with that this is who I am, and that my dream of overcoming this struggle will never be reached, so I'm trying to work on acceptance first.
Depressing. People thought (think) I'm just lazy and I didn't understand how to explain there's something that just shuts down and/or feels the need to fight or rebel against the demands.	I'm still waiting for an official diagnosis because of the waiting list but PDA describes me completely. It's stressful. People don't understand and I don't have the support to deal with it.
I did not understand any emotions I was feeling. I could not understand how anxious I felt majority of my life. So many people who worked with me blamed me for my behaviour. They could not understand my	The hard parts are still professionals not understanding PDA. The good parts are when others do understand and use the right strategies. I feel I am really starting to understand myself properly now.

profile of autism as the strategies did not work.	
Unrelenting judgemental. I would be told that not showering every day or brushing my teeth was disgusting and offensive. I knew all of these things were unacceptable, and I wanted to be a person who did those things, but that always felt like an unattainable goal, like I wanted to be someone I never could. It propagated through my entire life: struggles with law enforcement, with parents, with friends and partners. The more expectations there were for me, the less I was able to meet even basic ones.	I still struggle with all of those things, and in some ways struggle even more now that I'm aware of my masking. The world isn't structured for people like us, and the everyday demands of getting up to go to work and look a certain way, act a certain way, do meaningless things over and over. It's exhausting and terrifying and it feels like the entire world is a prison.
Full of guilt and shame, wondering why I couldn't function on the same level everyone else did. Wondering why I had not the slightest desire to work; why I actively avoided everyday demands. Why life felt like spinning plates, utterly exhausting and totally unrewarding. The overwhelming certainty that I was definitely not like everyone else, but the reason why remaining a stubborn mystery. Finally finding I was skilled and talented, but that there still wasn't really a place in the world for me.	I can be kinder to myself and better advocate for myself, although in a world without any concept of PDA this is still exceptionally difficult. I feel as though I am in persistent burnout - any day of greater activity causes such exhaustion, the days of recovery that follow seem wasted with inactivity and consumed with guilt. The inability to bounce back and get on with everyday life becomes harder.
Confusing. I spent years in therapy trying to figure out what was "wrong" without a lot of change. Needless to say, it wasn't overly helpful for the most part and at times very damaging. Which hurt all the more because my suggestions of neurodivergency fell on deaf ears. I felt like a hopeless, contrarian puzzle. I couldn't get past certain points in romantic relationships without starting to have major panic attacks without clear originating reasons. And then they would fall apart. Nothing helped my distress except space. No amount of journaling or processing or self-awareness. I felt broken and unfixable. I would find myself feeling deeply claustrophobic from life, it's been that way as long as I can remember. My mum says I was born with a foot out the door. It was as though the routine was slowing snuffing out	Acceptance from others and myself I suppose has made me feel like I'm okay. Having people in my life willing to make little changes in how they communicate, willing to make some accommodations puts tears in my eyes. I didn't know I could be accepted and it with me makes me feel I can be loved and wanted. I'm starting to feel like the PDA is okay. I can work with it instead of trying to snuff it out. Things are still hard but I at least understand why they are hard most of the time and that in itself makes it all easier. I still beat myself up sometimes but now am able to say " oh, it's PDA" and that helps. I've slowly worked to reduce as many demands as I can, I feel like I have permission to buy paper plates now and live off of sparking water and tea when drinking water is hard. I don't push myself to have a regular bedtime or eat home-cooked meals. Fed is best, sleep comes easier when I have no expectations. I am finding my flow, it's

my life, and so I moved and changed jobs over and over again and I had no idea why. I felt alone most of the time, like there was a barrier I couldn't get past. A deep longing to connect in the ways people around me did but some unclear inability to handle the pressure. I always stayed at the fringes, a bit distant and removed. I had friends but made sure I was never needed to be the safe, dependable one. I both liked and hated myself. I liked my joy and creativity, my intelligence and determination. But it felt like there was a boulder inside me, I couldn't shake and I hated it. I didn't realize I was actually hating myself. The world was too bright, too loud too scratchy. But I didn't fully understand that was what I was experiencing. I wouldn't go out in the mid-afternoon sun but couldn't give you a good explanation why. I would wear some clothes over and over but just thought it was me, I didn't actually process it had to do with sensory reasons even through I would be constantly fiddling and adjusting anything that felt "wrong." And on and on. Life was lonely, confusing and hard. I felt like an alien who landed on the planet without a road map.	still fraught with my one internalize ableism but it's getting easier each day. I feel like I can advocate for myself - most of my friends are ADHD and/or autistic and it helps. I am still reluctant to make too many requests but even smaller things like low-pressure texting and feeling like I can opt out or come last minute to group plans has really helped me feel safer and more able to show up. Realising I'm not alone and there are people who really, really get it have helped me feel like I have a place in the world. It also feels like I am actually learning real social skills in these places rather than masking to fit in. It feels more okay to make mistakes, and misstep. I am working to find employment that better fits my needs, though I am admittedly scared I will find out I'm unable to support myself without going through cycles of burnout. But I'm not there yet. I think people who say diagnosis (be it self or professionally) isn't important can stuff it. I am 33 and only now figuring out what my needs are. It has changed my life.
Full of guilt and shame, wondering why I couldn't function on the same level everyone else did. Wondering why I had not the slightest desire to work; why I actively avoided everyday demands. Why life felt like spinning plates, utterly exhausting and totally unrewarding. The overwhelming certainty that I was definitely not like everyone else, but the reason why remaining a stubborn mystery. Finally finding I was skilled and talented, but that there still wasn't really a place in the world for me.	I can be kinder to myself, better advocate for myself (although in a world without any concept of PDA this is still exceptionally difficult). Things ebb and flow; you kind of find your place in your own world. It may not be most people's idea or normal, but being PDA is not normal. Support those who really need it, but also allow those that don't function like everyone else the security of support, but with their own autonomy, if that makes sense. Maybe one day there will be better understanding of PDA, but trying to force square pegs into round holes hurts the square pegs. Understanding, acceptance, undemanding support and encouragement without judgement might make things a whole lot easier.
Parents and carers	

My child would scream and cry all the time and I thought I was going insane. Normal parenting didn't work, discipline didn't work, everyone thought I was just a bad parent and that I needed to be firmer, yet my child was just getting worse whenever I tried to be firmer, at 5 years old he talked of wanting to die because life was just hell for him, and people still wanted me to be firmer with him.	Having a professional who understands PDA, and agrees that my son has it has been so validating, it has made it easier for me to get support for him at school and elsewhere. Having a professional on side, means that I don't feel crazy, there are less people gaslighting me into thinking it's all in my head and that my parenting is wrong. We need more professionals to understand and recognise PDA - especially in schools and childcare settings.
I was lost. I couldn't understand what was going on with my child or how to help them. There was constant conflict in the house as well as school refusal, restricted eating and rage.	Since learning about PDA strategies we have brought the stress level down in the house significantly. We have fewer conflicts and are all around happier.
Life was confusing. So many things did not make sense. Simple tasks were increasingly becoming difficult, and for reasons without any explanation. Suddenly we found our entire family walking on eggshells, trying to accommodate someone we didn't understand.	Loads different. We have learned from PDA adults - so many wonderful things. We have reduced demands, we allow for autonomy, and we trust. We have also learned to be really great listeners.
It was desperate, filled with guilt, anger and confusion. It felt that I was constantly failing in supporting my son, but I couldn't work out why.	Still complex and exhausting but so much better than before we understood and advocated our son's true needs. It has changed everything about how we support our son, understand his needs and cope as a family.
We considered our PDA daughter to be highly spirited, sensitive to emotions in others, sensory sensitive, and strong willed. We believed our poor parenting was the cause of her sleep troubles since birth.	We have been freed from the belief that our parenting is the problem. We can approach our daughter with empathy and from a base of ensuring perceived and felt safety. We accommodate her as much as we are able and are thrilled to see she is able to access more aspects of life (improved sleep and bathing).
It was much tougher before we had an understanding of what our child was experiencing. There was a lot of yelling, throwing things, self-harm, all around disregulation most of the time. We were trying to parent in a traditional way. Everything was a struggle. We had a really bad relationship.	Understanding has allowed us to parent in a different way. It is much calmer. My husband and I take a low demand approach whenever we can. We do slip up and it's by no means perfect but there are less fights. We still have to explain things to others which is met with a lot of scepticism (teachers, family members). Our child is not currently attending school due to burnout.
Chaotic and stressful. We were burnt out, mentally exhausted and in crisis. I'd followed all the regular parenting and nothing changed, or even sometimes made worse. I	It's so much better than it was. Following advice on the PDA society website, listening to other PDA folks, being able to make changes to implement support that helped us both and our

felt like a total failure, as a person and as a parent.	family as a whole. I have community support on a parental level, and a group of PDA friends for myself who provide peer support and understanding. We no longer exist in shame and blame and we have closer, stronger relationships as a result.
I thought I was a terrible parent and others were doing and coping so much better than me.	I can understand, have more patience, realise it isn't my parenting, take the pressure off myself and my child, advocate for my child better and better able to understand their needs. However, other people still parent blame.
I thought I had defiant children, who just didn't like to do what they were told. Traditional parenting strategies just didn't work. Why did other parents have children that did what they asked them to do, why were my children so difficult? Why did they not brush their teeth, make their bed, put their clothes away, shower regularly, want to go to school?	Since learning about PDA and all of these 'refusals' coming from a place of deeply rooted anxiety, we have changed our parenting style and do not follow the traditional parenting trajectory. Having an understanding of ‘can't not won't’ has changed our relationship with our children for the better. Unfortunately, although school staff mean well, they just don't understand and they believe that we need to push them to make them resilient to the real world. So in fact they make it worse.
I felt like a failure as a mother. I had years of teaching experience including in SEN schools so I thought I should know what I was doing. But my strategies to make our family life harmonious weren’t working and we were all struggling.	Life is still very challenging. I spend a lot of time fighting with education professionals or trying to get the right kind of support for my son. But our home life is 90% joyful and happy for everyone. My son laughs more and plays more. We laugh together more.
I had an eight-year-old daughter who was not able to attend school anymore, who I was repeatedly told needed to be told that she must do things and that I was letting her get away with not doing things. I felt like a terrible parent who was unable to control her child.	Life is starting to make a bit more sense now that we know. We are finding ways to help my daughter come out of burn out and ways to help her be able to engage in some things. We are changing the way we speak to her and the way our family life works. Really frustratingly, though, we spend a lot of time banging our head against brick walls when it comes to talking to professionals. Absolutely nobody wants to hear about PDA.
Before we learned about PDA we were very confused about how our child presented, whether he was or was not autistic, and how we could help him live a better life.	Understanding PDA, largely by learning from adult PDAers, has been absolutely critical to our understanding of our son. We know how to support him better and have improved all of our emotional health.
Utter misery. Nobody understood our day to day battles. My parenting was always being judged. We were isolated from friends and	I'm prepared now to walk alongside my son and share his worries and fears as they come. The

family. Everyone thought my child was just naughty and a product of bad parenting. I felt hopeless. No one was willing to help or even knew how to help. I was just sent on more and more parenting courses.	greatest comfort I can give him is to be by his side, to know he's not alone.
As parents, we felt that we were failing at every step and education, the medical world and society as a whole was only too happy to let us feel that way. Every interaction with ‘professionals’ of any kind left us feeling like we just needed to try harder, be better and to just manage what others were apparently achieving with such ease. For our child, he must have been so frightened trying to cope in a world where not even his parents could understand him.	Life now is completely different. Life is happier and calmer. Connection and trust is being restored. But there are long-term wounds, inflicted by the system of education and medicine, that are still healing in us all as a family. Our son has left formal schooling due to sheer lack of knowledge, training and quite frankly, any willingness within educational staff to know better and do better. Everything that has happened to improve our son’s life, well-being and future has been entirely down to our family and our unwavering commitment to support him. That and the support of the PDA Society and the wider PDA community.
Terrible for the entire family. We didn’t know what our child was struggling with, we didn’t understand why she behaved the way she did, no-one believed there was a problem as she was ‘fine’ in school and it was just getting worse day by day. But life was getting harder for all of us, she was having more and more frequent and increasingly physical meltdowns and all the strategies we were being told to use were just making things worse.	We are in a much better place to support her, help her heal, learn in a way that suits her, advocate for her when she can’t and back her up when she is able to. Life is still hard for all of us, because the world isn’t setup for autistic people but the more we learn and understand the more we can help her be herself.
Before we knew about PDA, we still had neurotypical expectations of our daughter and put unnecessary pressure on her which only made things worse. We interpreted her symptoms and behaviours as either strictly mental health-related or as purely anxiety in the traditional sense. We tried to use logic and reason as well as rewards. We also worried she might be bipolar, again looking at things through only a mental health lens.	We now understand PDA as a nervous system disability and a profile of the autism spectrum. We try to provide our daughter with accommodations and supports including giving her more autonomy, reducing demands, using declarative language, proving lots of co-regulation, recognizing and supporting her sensory needs, and letting go of ableism and traditional parenting models.

1. Appendix 2

2. Case studies: What happens when we get it right?

What happens when we get it right for PDA children and young people?

As section 3 of our report highlights, one of the key areas where change is needed for PDA children and young people is education. 72% of children and young people covered by our survey sample were not able to tolerate their school environment or were home educated.[1] The case studies below illustrate some examples of positive stories we heard from parents and from young people themselves, about the impact of 'getting it right' in education for PDA children and young people. What 'getting it right' means will differ for each individual child and their family, so we have included four very different 'success stories', in settings ranging from home education to mainstream school.

Case study 1: Provisions put in place by a mainstream primary school

School life was incredibly hard because before he was diagnosed, my son was misunderstood and labelled a naughty challenging child. He reached burnout resulting in EBSA[2] because the school didn't think he needed extra support, even though we were crying out for help as things were so challenging at home. It was only when he reached crisis point that we discovered PDA and they started to understand him more and put in the support he needed. But by then he'd been in mental health crisis – self-harming, suicidal ideations and an attempt.

He ended up being signed off by CAMHS and was out of full time school for around 18 months. During that time, and after some time to put together a plan, the school started to send his favourite TA to meet us, and she would play with him in the park. After a while he started going into school to play games with her. The school built a sensory room; we would go in there together with his TA, and they would spend time playing together. Once my son had his PDA diagnosis, the school brought in an outreach teacher who specialised in PDA and she gave training to school staff.

However, although my son was happy in the sensory room with his TA, he still didn't feel able to go into the classroom or to engage with his class teacher. At this point we didn't yet have an EHCP. The school and the local authority inclusion team decided to arrange alternative provision for him. He did a dual placement, going into school for an hour, half an hour, 15 minutes – depending on the day and how well he could tolerate it, and then the mentor from the alternative provision would come and pick him up and take him out. They'd do swimming, rock climbing, hiking, treasure hunts, go to the forest or the beach. They had a building where they could meet with other children and do things like baking or games. It was this that positively impacted on my son's mental health and wellbeing the most – it was all: "Let's work on you as a person" rather than: "Let's do work". At first they used to send a schedule about what would be happening that week, but when they realised that didn't work for him they just said "Ok, we'll pick you up and you decide".

He had the alternative provision for around nine months, while school were preparing behind the scenes for him to eventually return. We would have liked to continue, but once the EHCP was granted, the school allocated a full time 1:1 to my son as requested, so it was no longer deemed necessary. He was ready to go back then, so it was a natural progression for him. His 1:1 did PDA training and PACE training whilst she worked with him, and she has turned his life around! She's put in so much effort to learn about PDA and understand it/him as a person, and to acknowledge that he doesn't need traditional autism strategies like visual timetables and now and next boards. That just doesn't work for him.

He has a very bespoke timetable - if he does maths in the classroom on Monday but he doesn't want to do that on Tuesday, it's fine, they take it out to the practical area, or the sensory room. He doesn't have to be in the classroom, he can dip in and out. His 1:1 is really good at gauging his tolerance levels and thinking about how to accommodate him and keep his focus. If she can see that he's having a really bad day she'll remove the demand and they'll go and build dens instead, or do baking or junk modelling. He loves teddy bears, so his 1:1 frames learning around this – for example they'll make a den for the teddy and then do some work inside the den. If his 1:1 thinks he can tolerate work in the classroom, they'll try, but there's no pressure to stay, which is really nice. We don't do homework, and for activities he finds hard he has a lot of scaffolding. The class teacher has had PDA training too, but she is clear that my son's 1:1 is the person whose lead she follows, as the 1:1 knows him best and he trusts her.

My son has specialist education on his EHCP, but the specialist schools in our area aren't very well equipped for PDA. I thought: "Better the devil you know – we'll stick with the support we've got and keep trying". And most importantly, it was what he wanted. I knew it was a risk doing this but it's really working so far. He's still with his peers and he has a good little group of friends who understand him. Hopefully we can get him through to the end of Year 6.

I know this is a very rare set up – we've been so lucky with the school. Although I had to argue every step of the way for this kind of support during the EHCP process! They kept saying: "We don't want him to feel excluded by being out of the classroom" and: "We don't want him to be reliant on the 1:1" which is a hard narrative to change. I wanted them to understand that It doesn't matter what *you* want, what matters is what *he* needs. I said: "I know it's not typical and it's probably not an ideal setup, but otherwise we are going to be battling a child that climbs the fences every day, and kicks and screams and fights with everybody, and it's just not worth it, for anyone". So yes, I really did have to advocate for him. When I see the statistics about the number of PDA children out of school it makes me so sad, because it's not impossible to accommodate these kids. It's just making the effort, and his school – his 1:1 especially – have made so much effort. If his 1:1 hadn't made the effort he wouldn't be in education now. 18 months ago we were under CAMHS for suicidal attempts, but now he's so much happier and he doesn't have those thoughts as frequently anymore. He's so much better in himself because he feels understood and validated. That's what all these kids want – they just want someone to 'get' them.

Case study 2: EOTAS[3]

It was quite a journey to get to this point, because we didn't really know what we needed at first. School definitely wasn't working for my son, but no one else understood, and it really made me doubt myself because everyone was saying "he has to go to school". I even had a head teacher telling me that not forcing him in could be counted as child abuse. But I knew that no matter how much we lowered demands at home, it was never going to work while school was still there. And as I was the one making him go, he lost trust in me completely. By the time we stopped sending him in, he already had a lot of trauma from school. There was so much negativity around school for him, we knew that there was no way he'd get through the door of any other schools.

Then the COVID lockdowns came, which were very difficult for so many people, but for us it provided an opportunity. I'd discovered PDA, and was reading everything I could find, but accommodating PDA involves such a change of lifestyle – it's quite scary, the thought that you're going against the grain and everyone you know, so dramatically. I knew that was what we needed to do, but we both worked and we needed both incomes. It was the unknown and it was scary, and it seemed impossible at the time. But the lockdowns gave us that opportunity – I didn't have to be at work, so I thought: "Right, we're going to do it". At first there was a lot of regression. My son wanted to spend time completely by himself in his room with the curtains shut. We had to enter very carefully. He was down to only two safe foods. But slowly he came back – he started coming out of his room, wanting to come on walks with us. This gave me more trust in my own instincts, because I could see that yes, this was what he needed. When the schools re-opened he didn't return. We got him diagnosed privately and did a parental application for an EHCP. I carried on researching and found out about EOTAS. I visited local alternative provisions and decided what we needed to ask for.

It took 60 weeks to get the EHCP agreed, and then another six months to get the EOTAS package in place. This sounds very long, but I now know I was quite lucky compared to others, and I didn't have to go to tribunal. It was a long learning curve for me. I'm not the sort of person who likes complaining, and I used to dread the meetings and phone calls, but for this I just had to do it. I used all the templates I could find, I collected people's email addresses and was very persistent. I had to learn how to change my mind set, distance myself from my emotions, and take away the personal element. This made me a better advocate from my son. Now I know what I need to do, which is a horrible situation but it's a 'needs must' situation.

We're now in our second year of EOTAS, and the difference is amazing. My son has built a lovely relationship with his learning support assistant at the alternative provision. She is very knowledgeable about PDA, and after me and my husband, she's probably my son's next most-trusted person. The first year at his alternative provision was all about relationship building. It's very child-led, and he was nature a lot – climbing trees, stick collecting. His learning support assistant completely understood about masking and how to approach it. He gradually started to unmask more and more. He started to feel able to say when something was too much for him, and so his learning support assistant could start to offer more unstructured learning-based tasks – just a couple of minutes here and there – because she knew he was better able to say no. Now he is able to do things like crosswords and worksheets when he's with her. He also now feels able to spend time at a 'base' with other children, and he enjoys this. He knows that he has choice and that if it's too much for him he can leave. The slow build-up really worked.

I can't describe the difference in our home life. Obviously having my son at home with me comes with its logistical challenges, but it's worth it ten times over because he is ten times happier. While previously he was in constant fight or flight mode, now his anxiety levels are so much lower – his distressed behaviours have reduced dramatically. The way I'd describe it is, it's difficult but we're all really happy. There's no more constant worry. As a family we're just happy.

Case study 3: Home education

Once I started reading about PDA everything made sense. I read as much as I could – I found PDAers online, support groups, professionals, books, organisations. Listening to voices of PDAers and learning about ableism was the most life changing part though. It was the part that made me "radically accept" and make the major life changes that needed to happen. Up until that point I was trying to "fix everything". I learnt no one needed "fixing". We just needed to accept and embrace a new lifestyle. And letting go of mainstream schooling was the big one.

I have found that home schooling in an "unschooling", child-led, self-directed style suits my child, as they can have the autonomy they need to feel safe. In my experience as a teacher, I will sadly admit that I don't think there is much about schools that suit most PDAers. The schooling system has a *very* long way to go to be right for them.

Since beginning home schooling, my child is more relaxed, calm and settled. They have been able to better regulate their emotions, are able to understand their sensory likes/dislikes, and can advocate for themself. They are far less irritable and angry. Violent outbursts are now very infrequent (they used to be multiple times per week). They no longer talk of hating themself or their life. They no longer say they are "stupid".

Their anxiety levels are now manageable. They still have the same anxieties but they are able to communicate them now. This could be that they are getting older but I think the fact they are more settled and calmer has helped too. And now that they can explain the anxieties, we can support and accommodate them properly. In some ways, they actually seem "more autistic" now as it is like they were given permission to take off the mask, be true to themself, be seen and heard.

Physically they seem more settled, happy and relaxed. They used to exist in a heightened, stressed state, to the point where their body was physically tensed all the time. This is no longer the case. Their speech is also better and they are more talkative and social since the pressure of school was lifted.

Their attitude towards learning is similar in that they still dislike "school work" and resist bookwork, maths, reading or writing. However, by giving them control and letting go and not making them do "work", they have actually developed a great attitude towards learning, in their own way, on their own terms. My child will pour themself into projects of interest in which they web-research, read, watch videos, plan, draw, write, budget. They will spend hours and hours for several weeks on each of their projects; for example, setting up a fish tank, building a garden pond, building terrariums. In their areas of interest they have grown and grown beyond what they could have at school. In other areas there is minimal progress but perhaps that is the trade-off. There are no guarantees they would have made progress in those areas if still at school either.

They are now able to better engage with friends and family and better engage with the community. It was like they were so exhausted just getting through a school day they had nothing left for anything else. Now they do.

I had been reluctant to give up my job to home school, even though it was always in the back of my mind as our backup plan. I was worried about what people would think or say. I wanted my child to have the chance to try and make it work at school. We were concerned about the shift to home schooling being too demanding on me as a mum. That it would be too difficult to spend so much time one on one. But that hasn't been a problem as the child I spend so much time with is a much happier, calmer, connected person so it has worked out better for everyone.

Giving up my career (teaching) was easy in the end. We were in crisis and we could not live the way we were. We desperately needed to change it so it was easy to walk away. My changing perception of the schooling system, my learning about ableism, my learning about PDA, my listening to autistic voices had changed me so much that I no longer felt I belonged in or agreed with the school system anyway. The financial hit hasn't been great but we've just made sacrifices and choices based on what we value and what works for us, not necessarily what "everybody else" is doing.

The change has been positive for everyone. My husband and I are calmer, happier, less stressed, less anxious. We've always been on the same page and everything has made us closer and stronger, thankfully. Family and friends have all noticed the positive changes so the impact has spread to them too.

We no longer feel like we are trying to force a life that didn't fit. We've accepted who we are and what suits our family. I've let go of controlling how it "should be". We've leant into what works for us. We've simplified our lives. We're trying to not compare, or wish or want. We're not all the way there and I know there will be ups and downs and we've still got troubles but compared to how things were, it's a huge positive change.

Case study 4: A young person's view on education and the college 'getting it right' for them

In Year 10 I stopped going to school. I was really unwell. I was diagnosed with anorexia – I wasn't eating at all, and on top of that I wasn't sleeping either. My secondary school was very mainstream – massive classes and they didn't want anyone whose attendance was bumpy as they just wanted the best grades. So they neglected anyone who was not doing well, not looking like they were going to get good grades. They saw us as either 'good' students or 'bad' students. The 'bad' students were always being told off, got low grades, were always in detention. Lots of the teachers seemed power hungry, and seemed to hate children which is really weird. They would get angry at the most random things – one time because I had the wrong colour hair clip! The craziest rules that didn't make any sense, but were all about power and authority and control. There was so much underlying tension and hierarchy. It's a sickening environment to be in for anyone, but with PDA, I hated it. I despised the whole hierarchy thing. There was no trust, you couldn't question anything, it was all built on a bunch of rules that didn't make sense. There was no communication, you weren't valued as a human. The system is very factory-esque, very prison-esque. Kids leaving the house at 8am and coming back at 4pm, and having that all day, from the age of five – it's crazy to expect kids to do that and be fine! You don't matter when you're in a system like that.

But things got so much better when I started at the college I'm at now. It's amazing. It's private so it's very small, and most of the kids there have struggled with education in some way. It's not specifically for neurodivergent students, but lots of them are, and many are funded by EHCPs. They're very catering towards the individual, and it's a really beautiful, close-knit environment. There are no authority figures. The classes are small and the teachers are called by their first names and don't have many rules. Some of the kids there were kicked out of their old schools for misbehaviour, but the teachers are very smart – they know that punishments don't work. They encourage students, and they don't look down on them or lash out and get angry with them for behavioural things. They recognise that students don't misbehave for no reason. There are no students who are disliked by the teachers or are picked on by the teachers. Students know they won't be rejected and so their behaviour improves. It's very accepting. Being accepted like that is a really nice feeling. I don't want to take it for granted because often the rest of the world is not like this.

I've found that this low demand environment works really well and my attendance has improved a lot. I know that the problems I have around eating and sleeping aren't going to just go away, but sometimes you just need to feel happy and fulfilled in your life, then you won't need to seek fulfilment in other ways. And that's what I've found – things have got so much better, when before they were really bad. I can't imagine any other school being able to help me in the way the college has.

What happens when we get it right for PDA adults?

As discussed in section 4 of our report, 63% of self-reporting PDA adults and 25% of over 18s as reported by parents and carers have had positive employment experiences at some point. We asked some of these people to tell us more about their experiences, which are summarised in the case studies below. Interestingly, all four of the case studies involve examples where a PDA adult has been successful and happy working in a role that benefits other neurodivergent people. All four also demonstrate the types of working conditions that help PDAers to thrive in employment or self-employment.

Case study 5: A PDA-friendly work environment

I work part-time with disabled kids. It's exhausting (I struggle a lot with fatigue), and I don't think I could manage it full-time, but I really love it.

The policies and general atmosphere are positive (inclusion for all, all behaviour is communication, prioritising communication and choice in whatever form works, just generally treating the kids as 'equals'- we aren't above them). I have very strong moral values and have struggled before working in places which don't share them, even though it didn't affect me personally in any way.

Also I just love working with kids. They're fun and insightful and every day is different, and I think the novelty within a safe environment helps to motivate me. Sometimes there are PDA kids, and I find that I "get" them – even when they're instructing me exactly what to do and where to stand, which normally would massively trigger my own PDA, somehow it doesn't because I understand that they need this to feel autonomy and that we are on equal footing. And often I see little me in them a bit.

My boss is also very respectful – she often works directly alongside the rest of us, and she doesn't try to demonstrate "power over us" or anything. I haven't told her about my PDA, but she knows I am autistic and gives me breaks if I ever get overwhelmed.

I'm lucky, because I just stumbled into my job but it's been really good for me, and really PDA-friendly despite not specifically trying to be. It's given me confidence and independence, and a sense of purpose – I actually feel like I'm doing something useful in the world.

I do struggle with some things, such as replying to emails and reliably getting there at the same time each day, but there is flexibility with that which works well for me. And it does exhaust me – I need a full day of absolutely nothing, not even getting dressed or cooking meals, to recover after a work day. But I'm glad I have it.

Case study 6: A PDAer's thoughts on what works for them

I've been working as a teaching assistant in SEN/SEMH schools[4] for a couple of years. It hasn't been plain sailing by any means, and I faced bullying and discrimination in my first couple of workplaces, but I eventually found somewhere that was lovely, accommodating, and valued my lived experience, insight, and expertise.

I unfortunately had to leave that job, as new management were not on the same wavelength, and it made it intolerable for me to work there. They very much brought a corporate culture to the school that ruined the experience entirely. I'm now studying part time and doing TA work part time.

What has worked well for me are things like flexibility in my hours, understanding that I can't do a 'full day' and need to leave when the children go home. I start to panic and will have a meltdown about my time being stolen from me if I end up sitting around in the staff room for two hours after the children go home, or if am forced to stay in meetings, so employers letting me go home with the understanding that I am honest and sincere and that my work will be done to a high standard and to the best of my ability, is really important to me. I don't expect to be paid the same as everyone else, so I don't see why it should be an issue.

Another thing that helps is having as minimally invasive of a hierarchy as possible. Employers who talk down to you, or do not respect or value your input, are absolutely unbearable for me. Clear instructions and expectations, open communication, not assuming ill-intentions if I come across blunt/mean/rude by accident, are all really vital to me.

It's also important to me that employers consult with employees when making decisions that directly affect us, and are willing and able to explain the reasoning behind their decisions. I cannot enforce rules I don't believe in, don't think are fair, or follow instructions I don't see the point in.

Also I need to be offered the standard sensory accommodations such as letting me wear my headphones/earplugs/sunglasses when I need to, and understanding that if I look angry or don't say hello in the morning, it's just my face and I don't hate you!

Case study 7: A PDA adult's career journey

I think I have been successful in employment because I am well-educated and that has afforded me a career path of *my* choosing. I was not diagnosed with any condition until later life so education was a huge struggle and trauma for me. Despite burning out regularly, I got excellent GCSEs, A-levels and a degree.

I have worked in a range of areas and roles. I've worked out that to be happy in employment, I need my work to involve autonomy, be meaningful, be helpful, be interest-based and fact-based. I need to be busy to have motivation but ADHD means I need tools to help with saying no, time management, prioritisation and organisation. I can hyperfocus and my output can be incredibly high. But I bore easily and get overwhelmed easily so I need to have 'just right challenge'.

If I am to work with others, I prefer to lead and/or have trusting-collaborative relationships and a sense of equality. I need to be explicitly told (or shown in a way I understand) that I am liked, valued and my opinion matters. I have terrible self-esteem. Years of masking has meant I actually come across very confidently to the point it's sometimes misread as arrogant. I am extremely sensitive to rejection so criticism needs to be carefully managed. A result of this is, I like to know everything I can about my work so I cannot be wrong. I am goal-orientated but shy away from competition with others (fear of failure). I have impossibly high expectations of myself so need others to help me with boundaries. I am dyslexic so rely on ICT. I forget to stay hydrated and fed so need verbal or visual clues. I need mental health days.

I recently started a new role at a company offering mentoring for young people. With this role I work flexibly, creatively, there are no set hours, there are no expectations other than ones I impose, no timeframes per se, and as most of the staff are neurodivergent, we support each other mentally and physically. I can be my authentic self. I come into the office if needed or when I need some human interaction. The position is evolving as the company does; responding to the needs of the young people we serve and to match the ever changing, educational landscape. There is constant novelty, the work is never mundane, I'm constantly being challenged. I have a new special interest, direction and a meaningful project!

Case study 8: Self-employment

Being self-employed and running my own business supporting SEND families allows me to pick the times I work and this lessens the demand of having to work at set times. It gives me flexibility – on bad days I can scale back and on good days I can scale up again.

I don't have anyone giving me deadlines I have to stick to, or bosses telling me how my work is - I don't mean just criticism, I mean praise too as I find this just as bad a criticism.

Being self-employed means I don't need permission to take time off or need to explain on bad days why I may be slower or less with it. It means I don't have to put a mask on all the time I work, and I can hide in the comforts of my own home where no one sees me.

Of course, employment and work is only one area of PDA adults' lives, and many survey respondents had not had positive experiences in this area. Some told us about other ways that people had 'got it right' for them. This could involve small changes in the ways that friends and family members engaged with the PDAer, as the example below demonstrates:

> *Life was lonely, confusing and hard. I felt like an alien who landed on the planet without a road map. Acceptance from others and myself I suppose has made me feel like I'm okay. Having people in my life willing to make little changes in how they communicate, willing to make some accommodations puts tears in my eyes. I didn't know I could be accepted and it with me makes me feel I can be loved and wanted. I'm starting to feel like the PDA is okay. I can work with it instead of trying to snuff it out.*

What happens when we get it right for parents and carers?

As section 5 of our report demonstrates, many parents and carers of PDA children and young people feel subject to judgement, scepticism and blame from others. Only a very small number of respondents told us about times when people had 'got it right' for them, and they had felt believed and supported. The excerpts and case study below show what a difference being believed and listened to can make, as well as the importance of professionals who understand and have expertise in PDA.

> *Having a professional who understands PDA, and agrees that my son has it, has been so validating. It has made it easier for me to get support for him at school and elsewhere. Having a professional on side means that I don't feel crazy, there are less people gaslighting me into thinking it's all in my head and that my parenting is wrong. We need more professionals to understand and recognise PDA – especially in schools and childcare settings.* (Parent of under 18)
>
> *I had been constantly knocking on professionals' doors, saying that my son reminded me of the children I knew who were autistic but at the same time, he seemed to have a completely*

> *different set of needs. I was constantly dismissed. Until one kind and understanding professional did take notice. My GP agreed to refer me out of area to a different CAMHS. There we worked with a brilliant child clinical psychologist, who agreed that my son fitted the PDA profile and wrote a report hinting at PDA. Following this, other services began to take me more seriously.* (Parent of under 18)

Case study 9: The positive difference that professionals can make

We spent quite a few years trying to engage in 'normal' family life, to be like other people who sat down at family meals, followed rules and traditions, went on holidays, welcomed surprises and generally did what was expected. During this time, we were asked by family members things like: "When is she going to start listening to you?" or "Why are you giving in to her all the time?" We didn't know the answer to these questions, and they made us feel like we were failing.

When our daughter started school, we were told by teaching staff that she was "absolutely fine" at school, there were no problems at all. So we couldn't understand why she had such huge meltdowns as soon as she came out of the school gate. It was so confusing, seeing how difficult everything was for her, but having professionals say there was nothing wrong.

I don't know what would have happened if my partner hadn't started doing her own research at that stage, and actively seeking out professionals who understood PDA. As is the case for many families, we found out about PDA through the internet! We were very lucky in that we had some savings and could pay for a private assessment with a paediatrician who recognised the PDA profile of autism. She changed everything for our family. As soon as we met her, we felt believed, understood and not blamed. Our daughter also seemed to know that this person understood and would help, and she opened up to her. The paediatrician spoke to us all for hours, I'm sure for longer than we had paid for, and explained everything to us and our daughter in a child-friendly way. She wrote an extremely detailed diagnosis report with recommendations, which has been such a useful tool in getting our child the support she needs.

We also changed schools and found education professionals who understood about PDA and were willing to think outside of the box and allow our daughter the flexibility, understanding and compassion that she needs. They don't always get it right but they are open to feedback and we now feel confident enough to give it.

Having access to understanding and knowledgeable professionals has been a game changer. Our confidence in advocating for our daughter is now so much higher, not only because we know our instincts are right, but also because we feel we have the back up of these wonderful people who have believed and helped us.

3. Appendix 3: Survey questions

About this survey

This survey will take between 15 and 30 minutes to complete, depending on how much you'd like to tell us. You don't have to complete it all if you'd rather not -anything you tell us will be useful.
The survey will be open until 5pm (UK time) on Wednesday 31st May.
Please use the 'previous' and 'next' buttons to move through the survey.

What is the survey about?

We want to gain a more complete understanding of what life is like for the PDA community and what challenges you face. We'll use what we learn to advocate for the community and to ensure our work is focusing on the right things.

What is PDA?
PDA (Pathological Demand Avoidance) is widely understood to be a profile on the autism spectrum, involving the avoidance of everyday demands and the use of'social' strategies as part of this avoidance. You can find out more on our website:https://www.pdasociety.org.uk/

Who is the survey open to?
The survey is open to anyone age 17 or over who identifies with a PDA profile/as a 'PDAer'. It is also open to parents, carers or partners of PDA people. You don't need to have a formal diagnosis of PDA.

What will you do with the information I provide?
We will store the survey data in a secure IT system. We will analyse the survey data and report the findings anonymously. This means you will not be identified in the report that we produce.
We hope that the information we collect will be useful in future work to improve understanding of PDA. You can 'opt in' below if you would be happy for your anonymised data to be used in future research or awareness raising work. If you don't opt in, your survey responses will be deleted once the findings have been written up.

Can I change my mind about taking part?
If you change your mind, you can withdraw your survey response by letting us know before 9th June 2023.

What is the legal basis for processing my personal data?
The PDA Society is the data controller for the processing of personal data from this survey, which means that it is responsible for ensuring that the process complies with the General Data Protection Regulation (GDPR). More information is available here: https://www.pdasociety.org.uk/privacy-policy/

Where can I find out more about the survey?
If you have any concerns or feedback about the survey, please contact us at:
info@pdasociety.org.uk

Where can I find out more about PDA?
There is a wealth of information on the PDA Society website, including a list of frequently asked questions. If you would like further support please contact our free enquiry line.
* **1. Do you confirm that you understand why we are doing this survey, that it is voluntary, and who to contact if you have questions?**
Yes

*** 2. Do you give your consent for us to store the information you provide in a secure IT system for the duration of the project and to use this information anonymously in our report?**
Yes
My name and email address:
(We ask for these details so that we can get in touch with you in the future. Your contact details will be stored
separately from your anonymised data)

*** 3. Do you give your permission for us to store the information you provide in a secure**

database after the project has finished? This would mean that your anonymised information might be used in:
Future research conducted by academics who are experts in this field and 'allies' of the PDA Society.
Future awareness raising work done by the PDA Society.
If your anonymised information is to be shared with external academics, we will contact you to let you know. We may also email you occasionally to let you know of other research studies which we think you might be interested in supporting.
You can opt out of the database and any emails from us at any time by contacting the PDA Society at:
info@pdasociety.org.uk
No - please delete my data once the findings have been written up
Yes - please store my anonymised data for use in future work
(please add your contact details below)

Your experiences
If you have lived experience of PDA, as a PDA person or as someone living with/caring for a PDA person, please tell us about this below. Hearing your experiences is the main purpose of our survey (the questions after this are mostly tick-box). Please try to avoid using identifying names or places.

4. How was life before you understood about PDA?

5. What is life like for you now? Is anything different?

6. Which approaches and strategies help, and which don't help?

7. What one change would make the greatest positive difference to your life?

8. Which of the following describe you? You can choose more than one option
I identify as a PDA person and I'm over 17 years old
I am the partner of a PDA person who is over 17 years old
I am a parent/carer of a PDA person who is under the age of 18
I am a parent/carer of a PDA child/young person who is age 18 or over
I am a professional working in the area of autism and/or other forms of neurodivergence
I am none of the above (please let us know how you identify)

About you
There are four options for completing the rest of the survey. We don’t want to ask you questions that aren’t relevant to you. You can complete the rest of the survey from the perspective of:
A PDA person - someone who is diagnosed or identifies with a PDA profile and is 17 years old or over
A partner of a PDA person age 17 years old or over
A parent/carer of a PDA child/young person under the age of 18
A parent/carer of a PDA person age 18 or over
You can come back and fill in the survey again if you identify with more than one option / have more than one child.

*** 9. In what capacity are you completing the next sections of the survey?**
As a PDA person age 17 or over

As the partner of a PDA person who is age 17 or over
As the parent or carer of a PDA child/young person under the age of 18
As the parent or carer of a PDA person who is age 18 or over
None of the above - please take me to the final sections of the survey

About you
There are 20 further questions which are all helpful to us, but if you get stuck at any point, don't worry. Just skip to the end and press 'done'.

10. How old are you?
17-19 years old
20-24 years old
25-34 years old
35-44 years old
45-54 years old
55-64 years old
65 years old and over
Prefer not to say

11. How do you describe your gender?
Female
Male
Non binary
Other
Prefer not to say

12. How do you describe your ethnic background?
Asian / Asian British
Black / African / Carribean / Black British
Mixed / Multiple ethnic groups
White
Prefer not to say
Other (please specify)
13. What is your household set up?
Living with my spouse/partner
Living on my own
Living with my parents/extended family
Living in a residential home
Living in supported living
Living in an in-patient unit
Other (please specify)

14. Where do you live?
England
Scotland
Wales
Northern Ireland
Eire/Republic of Ireland
Not in the UK or Ireland (please specify)
PDA, neurodiversity and you
In this section we'll ask about how you identify and any diagnoses you have

15. Do you identify as neurodivergent?
Yes
No
Questioning

16. Do you have a formal diagnosis that includes or refers to PDA?
Yes
No
Not explicitly (but it is implied or alluded to) - tell us more in the next question

17. Please list all your formal diagnoses
18. Do these diagnoses reflect your understanding of yourself? If not, why not?
19. In your experience, do you feel that PDA is part of the autism spectrum?
Yes
No
Not sure

20. In your experience, do you feel you have traits of ADHD?
Yes
No
Not sure

21. If you have a PDA-related diagnosis, please tell us what clinic/who provided it

22. If you have had an assessment/diagnosis of PDA, how was it funded?
By the NHS
Privately
Not sure

More about your experiences
In this section, we'll ask you some more specific questions about things you may have experienced as a PDA person. This will help us understand how common these experiences are within the PDA community.

23. Have you experienced any of the following?
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

Needing mental health services (regardless of whether you were able to access them or not)
In-patient care
Social services investigation
Allegations of fabricated or induced illness (FII)
Allegations of parental alienation
Family court proceedings
Disputes over schooling/education
Education tribunal
Emotionally based school avoidance (EBSA) / school refusal

School exclusion
Been in trouble with the police
Family breakdown (family unit splitting up)
Family estrangement (being out of contact with your family)
Successful employment experiences
Being in the care of social services / a foster carer /supported living

24. If you are in college/higher education or in employment, do you ever struggle to attend?
Yes, all the time
Yes, regularly
Sometimes
Never
I'm not at college/higher education or in employment

25. Have you experienced any of the following?
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

Sensory differences
Mood swings
Challenges with sleep
Need to feel in control
Difficulty with daily tasks
Challenges with eating / eating disorder
Substance misuse(alcohol/drugs)
Difficulty getting out and about
Low self esteem
Depression
Severe anxiety
Self harm
Suicidal thoughts
Isolation and loneliness
Financial hardship

26. When most stressed, which of the following is your most likely response?
Meltdown (externalised response)
Shutdown (internalised response)
Other (please specify)

Your experiences of support
The next questions ask about what support you've had
27. Who supports you?
Emotional support
Practical support

Family (for day to day needs)
Family (when I'm in crisis)
Friends/my partner (for day to day needs)

Friends/my partner (when I'm in crisis)
Paid support worker(s)
Social worker(s)
SENDCo, teacher or teaching assistant
Professional therapist
Peer support (including online groups)
My employer
No one - but I do need support
No one - I don't need support
Other (please specify)

Your partner's characteristics
In the next section, we'll ask some demographic questions about your partner. We ask these so that we can understand more about any groups that are missing, and make efforts to include them. We will also use this information to help us identify if people with certain characteristics and experiences have anything in common.

28. How old is your partner?
17-19 years old
20-24 years old
25-34 years old
35-44 years old
45-54 years old
55-64 years old
65 years old and over
Prefer not to say

29. How does your partner describe their gender?
Female
Male
Non binary
Other
Prefer not to say

30. How does your partner describe their ethnic background?
Asian / Asian British
Black / African / Carribean / Black British
Mixed / Multiple ethnic groups
White
Prefer not to say
Other (please specify)
31. What is your partner's household set up?
Living with their spouse/partner
Living on their own
Living with their parents/extended family
Living in a residential home
Living in supported living
Living in an in-patient unit
Other (please specify)

32. Where does your partner live?

England
Scotland
Wales
Northern Ireland
Eire/Republic of Ireland
Not in the UK or Ireland (please specify)
PDA, neurodiversity and your partner
In this section we'll ask about any diagnoses your partner has, and ask about your views on PDA

33. Does your partner have a formal diagnosis that includes or refers to PDA?
Yes
No
Not explicitly (but it is implied or alluded to) - tell us more in the next question

34. Please list all their formal diagnoses

35. Do these diagnoses reflect your understanding of your partner? If not, why not?

36. Do you feel that PDA is part of the autism spectrum?
Yes
No
Not sure

37. Do you feel your partner has traits of ADHD?
Yes
No
Not sure

38. If your partner has a PDA-related diagnosis, please tell us what clinic/who provided it

39. If your partner has had an assessment/diagnosis of PDA, how was it funded?
By the NHS
Privately
Not sure

Your partner's experiences
In this section, we'll ask you some specific questions about things your partner may have experienced. This will help us understand how common these experiences are within the PDA community.

40. Has your partner experienced any of the following?
Yes - including in the last year
Yes - but not in the last year No - not at all Don't know Prefer not to say
Needing mental health services (regardless of whether they were able to access them or not)
In-patient care
Social services investigation
Allegations of fabricated or induced illness (FII)
Allegations of parental alienation
Family court proceedings
Disputes over schooling/education

Education tribunal
Emotionally based school avoidance (EBSA) / school refusal
School exclusion
Been in trouble with the police
Family breakdown (family unit splitting up)
Family estrangement(PDA person being out of contact with their family)
Successful employment experiences
Being in the care of social services / a foster carer /supported living

41. If your partner is in college/higher education or in employment, do they ever struggle to attend?
Yes, all the time
Yes, regularly
Sometimes
Never
They're not at college/higher education or in employment
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

42. Has your partner experienced any of the following?
Sensory differences
Mood swings
Challenges with sleep
Need to feel in control
Difficulty with daily tasks
Challenges with eating / eating disorder
Substance misuse (alcohol/drugs)
Difficulty getting out and about
Low self esteem
Depression
Severe anxiety
Self harm
Suicidal thoughts
Isolation and loneliness
Financial hardship

43. When most stressed, which of the following is your partner's most likely response?
Meltdown (externalised response)
Shutdown (internalised response)
Other (please specify)

Your partner's experiences of support
The next questions ask what support your partner has had
44. Who supports your partner?
Emotional support
Practical support

Family (for day to day needs)

Family (when they're in crisis)
Their partner/friends (for day to day needs)
Their partner/friends (when they're in crisis)
Paid support worker(s)
Social worker(s) SENDCo, teacher or teaching assistant
Professional therapist
Peer support(including online groups)
Their employer
No one, but they do need support
No one, they don't need support
Other (please specify)

Characteristics of the PDA person (age 18 or over) you care for

In the next section, we'll ask some demographic questions about the PDA person you parent/care for. We ask these so that we can understand more about any groups that are missing, and make efforts to include them. We will also use this information to help us identify if people with certain characteristics and experiences have anything in common.

45. How old is the PDA person you care for?

17-19 years old
20-24 years old
25-34 years old
35-44 years old
45-54 years old
55-64 years old
65 years old and over
Prefer not to say

46. How does the PDA person you care for describe their gender?

Female
Male
Non binary
Other
Prefer not to say

47. How do they describe their ethnic background?

Asian / Asian British
Black / African / Carribean / Black British
Mixed / Multiple ethnic groups
White
Prefer not to say
Other (please specify)

48. What is their household set up?

Living with their spouse/partner
Living on their own
Living with their parents/extended family
Living in a residential home
Living in supported living
Living in an in-patient unit
Other (please specify)

49. Where do they live?
England
Scotland
Wales
Northern Ireland
Eire/Republic of Ireland
Not in the UK or Ireland (please specify)
PDA, neurodiversity and the person you parent/care for
In this section we'll ask about any diagnoses the person you care for has, and ask about your views on PDA

50. Does the person you parent/care for have a formal diagnosis that includes or refers to PDA?
Yes
No
Not explicitly (but it is implied or alluded to) - tell us more in the next question

51. Please list all their formal diagnoses

52. Do these diagnoses reflect your understanding of the person you parent/care for? If not, why not?

53. In your experience, do you feel that PDA is part of the autism spectrum?
Yes
No
Not sure

54. Do you feel the person you parent/care for has traits of ADHD?
Yes
No
Not sure

55. If they have a PDA-related diagnosis, please tell us what clinic/who provided it

56. If they have had an assessment/diagnosis of PDA, how was it funded?
By the NHS
Privately
Not sure

The experiences of the PDA person you parent/care for
In this section, we'll ask you some specific questions about things the PDA person you parent/care for, and you as a parent/carer, may have experienced. This will help us understand how common these experiences are within the PDA community.

57. Has the PDA person you parent/care for experienced any of the following?
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

Needing mental health services (regardless of whether they were able to access themor not)
In-patient care
Emotionally based school avoidance (EBSA) / school refusal
School exclusion
Been in trouble with the police
Family breakdown(family unit splitting up)
Family estrangement (PDA person being out of contact with their family)
Successful employment experiences
Being in the care of social services / a foster carer /supported living

58. Have you, as a parent/carer of a PDA person, experienced any of the following?
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

A social services investigation
Allegations of fabricated or induced illness (FII)
Allegations of parental alienation
Family court proceedings
Disputes over education/schooling
Education tribunal
Family breakdown (family unit splitting up)
Family estrangement (being out of contact with the PDA person you care for)

59. If the PDA person you care for is in college/higher education or in employment, do they ever struggle to attend?
Yes, all the time
Yes, regularly
Sometimes
Never
They're not at college/higher education or in employment
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

60. Have they experienced any of the following?
Sensory differences
Mood swings
Challenges with sleep
Need to feel in control
Difficulty with daily tasks
Challenges with eating / eating disorder
Substance misuse (alcohol/drugs)
Difficulty getting out and about
Low self esteem

Depression
Severe anxiety
Self harm
Suicidal thoughts
Isolation and loneliness
Financial hardship

61. When most stressed, which of the following is their most likely response?
Meltdown (externalised response)
Shutdown (internalised response)
Other (please specify)

Support and the PDA person you parent/care for
The next questions ask what support the PDA person you care for has had

62. Who supports the PDA person you care for?
Emotional support
Practical support

Family (for day to day needs)
Family (when they're in crisis)
Their partner/friends (for day to day needs)
Their partner/friends (when they're in crisis)
Paid support worker(s)
Social worker(s) SENDCo, teacher or teaching assistant
Professional therapist
Peer support (including online groups)
Their employer
No one, but they do need support
No one, they don't need support
Other (please specify)

Characteristics of the PDA child/young person you parent/care for
In the next section, we'll ask some demographic questions about the PDA child/young person you care for. We ask these so that we can understand more about any groups that are missing, and make efforts to include them. We will also use this information to help us identify if people with certain characteristics and experiences have anything in common.

63. How old is the PDA child/young person you care for?
Under 5 years old
5-10 years old
11-16 years old
17-18 years old

64. How does the PDA child/young person you care for describe their gender?
Female
Male
Non binary
Other
Prefer not to say

65. What is their ethnic background?
Asian / Asian British
Black / African / Carribean / Black British
Mixed / Multiple ethnic groups
White
Prefer not to say
Other (please specify)

66. What is their household set up?
Living with their parents/extended family
In foster care
Living in a residential home
In supported living
In an in-patient unit
Living on their own
Other (please specify)

67. Where do they live?
England
Scotland
Wales
Northern Ireland
Eire/Republic of Ireland
Not in the UK or Ireland (please specify)

PDA, neurodiversity and the child/young person you care for

In this section we'll ask about any diagnoses the child/young person you care for has, and ask about your views on PDA

68. Does the child/young person you care for have a formal diagnosis that includes or refers to PDA?
Yes
No
Not explicitly (but it is implied or alluded to) - tell us more in the next question

69. Please list all their formal diagnoses

70. Do these diagnoses reflect your understanding of the child/young person you care for? If not, why not?

71. In your experience, do you feel that PDA is part of the autism spectrum?
Yes
No
Not sure

72. Do you feel the child/young person you care for has traits of ADHD?
Yes
No
Not sure

73. If they have a PDA-related diagnosis, please tell us what clinic/who provided it

74. If they have had an assessment/diagnosis of PDA, how was it funded?
By the NHS
Privately
Not sure

The experiences of the PDA child/young person you parent/care for

In this section, we'll ask you some specific questions about things the PDA child/young person you care for, and you as a parent/carer, may have experienced. This will help us understand how common these experiences are within the PDA community.

75. Has the PDA child/young person you care for experienced any of the following?
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

Needing mental health services (regardless of whether they were able to access them or not)
In-patient care
Emotionally based school avoidance (EBSA) / school refusal
School exclusion
Been in trouble with the police
Family breakdown (family unit splitting up)
Family estrangement (PDA person being out of contact with their family)
Being in the care of social services / a foster carer / supported living
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

76. Have you, as a parent/carer of a PDA child or young person, experienced any of the following?

A social services investigation
Allegations of fabricated or induced illness (FII)
Allegations of parental alienation
Family court proceedings
Disputes over education/schooling
Education tribunal
Family breakdown (family unit splitting up)
Family estrangement (being out of contact with your PDA child/young person)

77. What type of education is the child/young person you care for in?
Mainstream (state funded)
Mainstream (independent)
Specialist
Home educated - by choice
Home educated - our only option
EOTAS (education other than at school)/Alternative provision

Pupil referral unit (PRU)
Other (please specify)

78. Does the child/young person you care for struggle to get into school?
Yes, all the time
Fairly regularly
Sometimes
Occasionally
Never
Not applicable - they are not in school

79. Does the child or young person you care for have an education, health and care plan (EHCP)?
Yes
In the process of applying
No - no application has been made
No - application was refused
Other (please specify)

80. Has the child/young person you care for experienced any of the following?
Yes - including inthe last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

Sensory differences
Mood swings
Challenges with sleep
Need to feel in control
Difficulty with daily tasks
Challenges with eating / eating disorder
Substance misuse (alcohol/drugs)
Difficulty getting out and about
Low self esteem
Depression
Severe anxiety
Self harm
Suicidal thoughts
Isolation and loneliness
The impacts of financial hardship

81. When most stressed, which of the following is their most likely response?
Meltdown (externalised response)
Shutdown (internalised response)
Other (please specify)

Support and the PDA child/young person you parent/care for
The next questions ask what support the PDA person you care for has had

82. Who supports the PDA child/young person you care for?

Emotional support
Practical support

Family (for day to day needs)
Family (when they're in crisis)
Their friends/partner (for day to day needs)
Their friends/partner (when they're in crisis)
Paid support worker(s)
Social worker(s) SENDCo, teacher or teaching assistant
Professional therapist
Peer support (including online groups)
No one, but they do need support
No one, they don't need support
Other (please specify)

Anything else?
In this final section, you can tell us about anything you haven't yet had chance to, but think we should know. We'd also like to hear about whether and how the PDA Society has been useful for you.

83. Has the PDA Society ever been useful to you or your family? In what way?

84. Is there anything else you'd like to tell us about?

Please click on the "done" button to submit your answers. Thank you very much for completing our survey.

If you would like to fill in the survey again, from another perspective (for example you may have completed it as a PDA person but also want to fill it in as a parent of a PDA child), you are very welcome to do so.

If you have any questions, concerns or feedback about the survey, please contact us at: info@pdasociety.org.uk

There is a wealth of information on the PDA Society website, including a list of frequently asked questions. If you need further support please contact our free enquiry line.

Appendix 1. Before and after: What changes?

Before we knew about PDA	**After we knew about PDA**
Children and families	
Stress, trauma, meltdowns, autistic burnout, anxiety, depression, violence, property destruction, aggression, panic attacks, school avoidance - for us as parents and our children. Our family was falling apart. Financial and marital stress. Confusion, disappointment, anger, guilt. Constant searching, trying to “fix” everything, endless appointments, professionals, diagnosis,	Very different now. Acceptance, understanding, a whole new way of living. Home schooling our PDA child. Giving up a career. Making financial and living changes for our family. More peace, happiness, calm. Letting go of unrealistic expectations. Listening to the voices of PDAers and finding PDA affirming professionals for guidance and support. Truly seeing our son for who he is. Understanding his needs. Supporting

parenting courses, books. From the outside it might have looked like we were holding it all together but we weren’t!	in a PDA friendly way. Eager to keep learning more.
Our family lived in utter turmoil. We found no support. Even from calling child mental health crisis lines. We were judged by family, we were hanging on by a thread. Our marriage almost ended several times. I had been researching for a few years, trying to figure out what was going on. We saw three different paediatricians and they just shrugged their shoulders. Then I stumbled across PDA. I cried as I read the diagnostic criteria. Everything made sense.	Life is still a rollercoaster. But we have learnt how to lower demands, meet our child where they are at. We are brave enough to face judgement from others about our parenting and way if being. Our child has begun to emerge from a long period of burnout. We see their sparks of self again. We still face obstacles with schooling. Obstacles of finding allied health professionals who understand and care. Hearing lived experiences of older PDA individuals has been a window of hope and reassurance that we are doing a better job of being parents and companions on my child's journey in life. That I can be that co-regulating, trusted person for my child.
Before we found out about PDA, life was still magical and full of joy, before our PDAer hit the mainstream school system. Then our lives were turned upside down as they inflicted school trauma on our child and our family.	My son has found the safety at home to unmask completely. However, we have discovered that this world is very unforgiving for PDAers. I have come across very few people that have a genuine interest in understanding us and our neurodivergent needs. They judge, they ridicule. They dismiss, they invalidate. They shame us, exert power over us, and ensure that we remain marginalised and vulnerable.
Chaotic, emotional and my son was truly not getting his needs met. Everything came to a head almost a year ago and although my son was able to go to school the majority of the time, he was not able to leave his room/bed the rest of the time. We had a no demand household for him but feel like we lost him since he was unable to participate in anything outside of gaming. We missed him.	Life is calmer and my son has slowly been able to re-engage. Once we decided to home school and the demand of school has been removed, he is slowly engaging. This last week he went to dinner with the family, played chess with his dad, went on walks with me and the dog. He was able to brush his teeth twice in his own. He is thankful he is being heard and I am sure we are doing the right thing to protect his mental health.
My child was dysregulated all the time. School was a disaster, and staff were at a loss to know how to support my daughter. They were using behavioural interventions in response to her meltdowns and challenging behaviours, and it only escalated the situation.	We are home educating. My child is starting to show us her personality and blossom, now that she isn't in fight or flight mode 24/7. Our family has moved out of a crisis mode and into a more stable maintenance phase.
Our son seemed to struggle with everyday life. It was all hard for him. Moving from one room to another, leaving the house, wearing certain clothes, shoes, being around a lot of	We now know his refusal is due to anxiety. We understand that change and transitions are difficult for him to navigate, unless it's something he is 100% on board with. We plan for this. He no

people, visiting new places - everything seemed difficult for him. He understood the rules of life, but couldn't engage in them. There were lots of tears, for him and myself as mum. I didn't know how to reach him, to help him. He hated being comforted, as he doesn't like touch. I felt very isolated in my parenting of him.	longer goes to school, due to EBSA, and we are trying to get the right support, but no one "sees" him like we do. We have a very low demand life, and he is now thriving after 18 months' recovery from school trauma. He hugs us goodnight – it's my favourite part of the day, after so many years of not touching. He is interested in learning again (a little). He has started to leave the house again.
My son seemed un-helpable and his distressed behaviours were escalating. There was no help from anyone, anyone. The few services I could get help from had no idea either, and everything that was suggested just made things worse for my son and family.	My son has a better understanding of his brain, his needs, and is slowly letting that mask down in public; therefore, his mental health has improved. It has been difficult getting his PDA needs to be understood and supported at his primary school, we are hopeful his secondary school will be more understanding and knowledgeable.
School was challenging for my son, he was misunderstood and he wasn't given the correct support for his PDA. School involved autism outreach once my son had a diagnosis of autism but all the strategies they suggested weren't working. PDA was never mentioned by school, autism outreach or the paediatrician.	Since learning about PDA and getting informed professionals involved such as SaLT, OT and educational psychologist, things have got better. We now use PDA strategies and have a good understanding of our son's needs. However, I still feel PDA is generally misunderstood by professionals and school especially.
At home we naturally adapted to him, and found what worked without any conscious effort. As soon as he started school, things went downhill rapidly. He was excluded twice but eventually got support and learned well, although he will hate school for the rest of his life. The school have no understanding of PDA.	The best thing is having the words to describe/ articulate my son's experience and the adjustments that help him. However, in terms of school and wider societal understanding, there is much work to be done. In my experience, doctors, counsellors, and school SENCos have been worse than useless as they act as a barrier to much needed support.
Our four-year-old barely slept, he was explosive, and getting him to school was becoming more and more difficult. The turning point was school. Despite what everyone was telling us, he didn't get used to it and things became harder and harder.	Discovering PDA and then later receiving diagnosis for my child gave me the confidence to embrace a low demand way of living. My child never returned to school following the lockdowns, I applied for an EHCP and spent nearly 2 years fighting for EOTAS. I trusted my gut again, which I should have done all along, but is often easier said than done. We brought my child back from the brink.
My daughter's secondary school education was so traumatic at times I find it difficult to describe the words to describe it all. The misunderstanding and false promises made by professionals caused another layer of	We constantly come up against people who do not understand PDA and do not want to understand it. Schools, doctors, professionals, family and friends cause constant hurt and I try to protect my daughter from it all. I have huge

school based trauma. Family and friends' lack of understanding and refusal to educate themselves led to a reduction in contact with them and our safe circle being reduced.	concerns of how my daughter will do at college and in her future - I worry what more trauma she will experience and the lasting impact of it. She is intelligent, articulate and a wonderful human being. She hopes to raise awareness of PDA and change the future for young PDAers.
Hard work. Lots of questions as a parent, doubting myself and my parenting style. Lots of parental blame for the challenges my child faced, especially within school. Diagnosis's we're explored and ASD was diagnosed but it never felt quite right. Lots of people would subsequently question his diagnosis which then felt like I was going mad - "he doesn't look autistic." Or "Autistic strategies don't work so he can't be autistic, it's attachment disorder and mum is to blame." School life was incredibly hard because he was misunderstood and labelled a naughty challenging child. He reached burnout resulting in EBSA because the school didn't think he needed support, even though we were crying out for some help as things were so challenging at home. It was only when he reached crisis that we discovered PDA and they started to understand him more and put in the support he needed. But by then it was too late. Mental health crisis for over 2 years- self harming, suicidal ideations and an attempt. No support was given because professionals didn't know how to engage him and their language and approaches only made things harder. CAMHS weren't willing to accept PDA.	Much more settled. More support in general and professionals understand him. They have been able to take training courses in PDA and PACE, and the approaches are then used to support him correctly. This has meant that he's more regulated, the pressure is lower and he is happy again. At home, I understand when we need to lower demands and just knowing about PDA has validated my gentle approach to parenting him. I don't feel criticised for using a 'soft' approach, because it works. I've learnt everything from other PDA families and the PDA society! His mental health is in a MUCH better place.
Very challenging, upsetting, confusing, exhausting, depressing for myself and my son. I felt caught between knowing instinctively what my son needed and yet having family members, professionals and the education system telling me he was the way he was because of my inadequate parenting skills.	I stood my ground when dealing with health professionals and education departments regarding his needs. I listened to him and took on board the things that gave him anxiety and never forced him to do anything that severely affected his mental health. I parented him in a completely different way to my eldest which was a challenge but I was guided by him and we worked together as a team despite criticisms from others. Against all the odds my son who is 18 now has recently passed his driving test, attended college to become an electrician, has now an apprenticeship with a large engineering company and is doing exceptionally well despite all his challenges and refusing to go to mainstream

	school from the age of 8 for 3 years. I’m so incredibly proud of him and how much he’s taught me not only about PDA and autism but about myself and the resilience I had to draw upon to get through some very difficult times.
Adults	
My life was a rollercoaster before knowing about PDA. I received an autism diagnosis from the skin of my teeth, but even then I felt out of place from the rest of the autistic community. School was extremely demanding. I masked what I know now as my demand avoidance and hid it extremely well, but the demands of homework, schoolwork, talking to different people and GCSE exams wore me down. I would come home every day either stimming for hours or falling asleep because I was too exhausted. I did receive support at college and uni from mentors, but conventional autism strategies weren’t effective. I still left sessions stressed and confused as to why I couldn't manage my life as effectively. I always felt that I was overreacting to everything, even the smallest requests and end up hating employment due to the demands of attending work and communicating with people.	Since fully knowing about PDA, my outlook on life has improved and my feelings of work and daily living are much more positive. I am aware of what triggers me and I know when to take a step back. On the flipside, the majority of professionals that I speak to about PDA have never even heard of it and the fact that it's hardly understood by so called experts baffles me.
I found life incredibly challenging, even the easiest tasks seemed so impossible, and I treated myself so badly, telling myself I was useless when I couldn't manage to do certain things, or when I had meltdowns because I couldn't cope with getting somewhere with the demand of getting there by a certain time. So full of stress, high levels of anxiety and depression.	I have only recently found out about PDA and identified myself with this. Since then, we are approaching life from a low demand angle and already life in general feels like I can cope a lot better, that I don't have to force myself to fit into a neurotypical way of living because I know I am neurodivergent and there is nothing 'wrong' with me, my neurobiology just means I need to live in a way that enables my nervous system to feel safe.
I struggled more with the anxiety, impatience, anger, fear that I believed were personality flaws that I needed to mend. Most of my attempts to ‘fix’ myself ended up nowhere.	I realise I’m not broken. I have these reactions for a reason. I no longer feel broken, repulsive, or like an ugly duckling. I feel grateful for my gift, love for the 10-year-old child that struggled with social situations, school, bullying, abuse, projects, assignments, reading, homework, and my family.

	I want to help all PDAers get the inputs and skills they need to succeed.
I always felt 'off' somehow. Different. Lots of periods of what I now know as burnout and somatic manifestations of anxiety. I had no diagnosis or vocabulary for how I felt. I can see now how much PDA impacted my life and how I managed to adapt and cope the best I could. But I've always felt like an outsider, and now I know why.	It's both better and worse actually. Knowledge is power, so knowing why I am how I am is helpful. However, since I've been working on not masking, I'm not quite as 'functional'. I think a lifetime of masking and pushing through and meeting demands and expectations (and parenting a PDAer who's now a struggling teen) has taken its toll. Many things I used to do I can't any longer. So although on the surface, I'm more aware, I'm more at peace with my neurotype and I understand myself much better than I did when I was younger, everything comes with a price.
Life was really difficult. I have struggled with the daily things since forever. It felt like life was so much harder for me than for other people, yet there seemed to be no true reason for it. I've been suicidal for over twenty years, just because I find every day such a struggle. I used to push myself into everything, because that's what I thought I had to do. Advice like 'if something scares you, you just have to do it, and it will get less scary' never worked for me, but I still followed it, because I thought if I would just keep at it, eventually it would change and I could go on being less anxious.	Some things are different and some things aren't at all. The biggest difference is that my experience makes more sense to me, which is making it a little easier to deal with. I'm still suicidal on a near-daily basis, I still find life incredibly difficult, but there have also been moments of joy, moments that were easier because I could understand what I needed to make life a little easier. I often find it incredibly difficult to deal with that this is who I am, and that my dream of overcoming this struggle will never be reached, so I'm trying to work on acceptance first.
Depressing. People thought (think) I'm just lazy and I didn't understand how to explain there's something that just shuts down and/or feels the need to fight or rebel against the demands.	I'm still waiting for an official diagnosis because of the waiting list but PDA describes me completely. It's stressful. People don't understand and I don't have the support to deal with it.
I did not understand any emotions I was feeling. I could not understand how anxious I felt majority of my life. So many people who worked with me blamed me for my behaviour. They could not understand my profile of autism as the strategies did not work.	The hard parts are still professionals not understanding PDA. The good parts are when others do understand and use the right strategies. I feel I am really starting to understand myself properly now.
Unrelenting judgemental. I would be told that not showering every day or brushing my teeth was disgusting and offensive. I knew all of these things were unacceptable, and I wanted to be a person who did those things, but that always felt like an unattainable goal, like I wanted to be someone I never could. It	I still struggle with all of those things, and in some ways struggle even more now that I'm aware of my masking. The world isn't structured for people like us, and the everyday demands of getting up to go to work and look a certain way, act a certain way, do meaningless things over and over. It's

propagated through my entire life: struggles with law enforcement, with parents, with friends and partners. The more expectations there were for me, the less I was able to meet even basic ones.	exhausting and terrifying and it feels like the entire world is a prison.
Full of guilt and shame, wondering why I couldn't function on the same level everyone else did. Wondering why I had not the slightest desire to work; why I actively avoided everyday demands. Why life felt like spinning plates, utterly exhausting and totally unrewarding. The overwhelming certainty that I was definitely not like everyone else, but the reason why remaining a stubborn mystery. Finally finding I was skilled and talented, but that there still wasn't really a place in the world for me.	I can be kinder to myself and better advocate for myself, although in a world without any concept of PDA this is still exceptionally difficult. I feel as though I am in persistent burnout - any day of greater activity causes such exhaustion, the days of recovery that follow seem wasted with inactivity and consumed with guilt. The inability to bounce back and get on with everyday life becomes harder.
Confusing. I spent years in therapy trying to figure out what was "wrong" without a lot of change. Needless to say, it wasn't overly helpful for the most part and at times very damaging. Which hurt all the more because my suggestions of neurodivergency fell on deaf ears. I felt like a hopeless, contrarian puzzle. I couldn't get past certain points in romantic relationships without starting to have major panic attacks without clear originating reasons. And then they would fall apart. Nothing helped my distress except space. No amount of journaling or processing or self-awareness. I felt broken and unfixable. I would find myself feeling deeply claustrophobic from life, it's been that way as long as I can remember. My mum says I was born with a foot out the door. It was as though the routine was slowing snuffing out my life, and so I moved and changed jobs over and over again and I had no idea why. I felt alone most of the time, like there was a barrier I couldn't get past. A deep longing to connect in the ways people around me did but some unclear inability to handle the pressure. I always stayed at the fringes, a bit distant and removed. I had friends but made	Acceptance from others and myself I suppose has made me feel like I'm okay. Having people in my life willing to make little changes in how they communicate, willing to make some accommodations puts tears in my eyes. I didn't know I could be accepted and it with me makes me feel I can be loved and wanted. I'm starting to feel like the PDA is okay. I can work with it instead of trying to snuff it out. Things are still hard but I at least understand why they are hard most of the time and that in itself makes it all easier. I still beat myself up sometimes but now am able to say " oh, it's PDA" and that helps. I've slowly worked to reduce as many demands as I can, I feel like I have permission to buy paper plates now and live off of sparking water and tea when drinking water is hard. I don't push myself to have a regular bedtime or eat home-cooked meals. Fed is best, sleep comes easier when I have no expectations. I am finding my flow, it's still fraught with my one internalize ableism but it's getting easier each day. I feel like I can advocate for myself - most of my friends are ADHD and/or autistic and it helps. I am still reluctant to make too many requests but even smaller things like low-pressure texting and feeling like I can opt out or come last minute to

sure I was never needed to be the safe, dependable one. I both liked and hated myself. I liked my joy and creativity, my intelligence and determination. But it felt like there was a boulder inside me, I couldn't shake and I hated it. I didn't realize I was actually hating myself. The world was too bright, too loud too scratchy. But I didn't fully understand that was what I was experiencing. I wouldn't go out in the mid-afternoon sun but couldn't give you a good explanation why. I would wear some clothes over and over but just thought it was me, I didn't actually process it had to do with sensory reasons even through I would be constantly fiddling and adjusting anything that felt "wrong." And on and on. Life was lonely, confusing and hard. I felt like an alien who landed on the planet without a road map.	group plans has really helped me feel safer and more able to show up. Realising I'm not alone and there are people who really, really get it have helped me feel like I have a place in the world. It also feels like I am actually learning real social skills in these places rather than masking to fit in. It feels more okay to make mistakes, and misstep. I am working to find employment that better fits my needs, though I am admittedly scared I will find out I'm unable to support myself without going through cycles of burnout. But I'm not there yet. I think people who say diagnosis (be it self or professionally) isn't important can stuff it. I am 33 and only now figuring out what my needs are. It has changed my life.
Full of guilt and shame, wondering why I couldn't function on the same level everyone else did. Wondering why I had not the slightest desire to work; why I actively avoided everyday demands. Why life felt like spinning plates, utterly exhausting and totally unrewarding. The overwhelming certainty that I was definitely not like everyone else, but the reason why remaining a stubborn mystery. Finally finding I was skilled and talented, but that there still wasn't really a place in the world for me.	I can be kinder to myself, better advocate for myself (although in a world without any concept of PDA this is still exceptionally difficult). Things ebb and flow; you kind of find your place in your own world. It may not be most people's idea or normal, but being PDA is not normal. Support those who really need it, but also allow those that don't function like everyone else the security of support, but with their own autonomy, if that makes sense. Maybe one day there will be better understanding of PDA, but trying to force square pegs into round holes hurts the square pegs. Understanding, acceptance, undemanding support and encouragement without judgement might make things a whole lot easier.
Parents and carers	
My child would scream and cry all the time and I thought I was going insane. Normal parenting didn’t work, discipline didn’t work, everyone thought I was just a bad parent and that I needed to be firmer, yet my child was just getting worse whenever I tried to be firmer, at 5 years old he talked of wanting to	Having a professional who understands PDA, and agrees that my son has it has been so validating, it has made it easier for me to get support for him at school and elsewhere. Having a professional on side, means that I don’t feel crazy, there are less people gaslighting me into thinking it’s all in my head and that my parenting is wrong. We need more professionals to

die because life was just hell for him, and people still wanted me to be firmer with him.	understand and recognise PDA - especially in schools and childcare settings.
I was lost. I couldn't understand what was going on with my child or how to help them. There was constant conflict in the house as well as school refusal, restricted eating and rage.	Since learning about PDA strategies we have brought the stress level down in the house significantly. We have fewer conflicts and are all around happier.
Life was confusing. So many things did not make sense. Simple tasks were increasingly becoming difficult, and for reasons without any explanation. Suddenly we found our entire family walking on eggshells, trying to accommodate someone we didn’t understand.	Loads different. We have learned from PDA adults - so many wonderful things. We have reduced demands, we allow for autonomy, and we trust. We have also learned to be really great listeners.
It was desperate, filled with guilt, anger and confusion. It felt that I was constantly failing in supporting my son, but I couldn’t work out why.	Still complex and exhausting but so much better than before we understood and advocated our son’s true needs. It has changed everything about how we support our son, understand his needs and cope as a family.
We considered our PDA daughter to be highly spirited, sensitive to emotions in others, sensory sensitive, and strong willed. We believed our poor parenting was the cause of her sleep troubles since birth.	We have been freed from the belief that our parenting is the problem. We can approach our daughter with empathy and from a base of ensuring perceived and felt safety. We accommodate her as much as we are able and are thrilled to see she is able to access more aspects of life (improved sleep and bathing).
It was much tougher before we had an understanding of what our child was experiencing. There was a lot of yelling, throwing things, self-harm, all around disregulation most of the time. We were trying to parent in a traditional way. Everything was a struggle. We had a really bad relationship.	Understanding has allowed us to parent in a different way. It is much calmer. My husband and I take a low demand approach whenever we can. We do slip up and it’s by no means perfect but there are less fights. We still have to explain things to others which is met with a lot of scepticism (teachers, family members). Our child is not currently attending school due to burnout.
Chaotic and stressful. We were burnt out, mentally exhausted and in crisis. I'd followed all the regular parenting and nothing changed, or even sometimes made worse. I felt like a total failure, as a person and as a parent.	It’s so much better than it was. Following advice on the PDA society website, listening to other PDA folks, being able to make changes to implement support that helped us both and our family as a whole. I have community support on a parental level, and a group of PDA friends for myself who provide peer support and understanding. We no longer exist in shame and blame and we have closer, stronger relationships as a result.

I thought I was a terrible parent and others were doing and coping so much better than me.	I can understand, have more patience, realise it isn't my parenting, take the pressure off myself and my child, advocate for my child better and better able to understand their needs. However, other people still parent blame.
I thought I had defiant children, who just didn't like to do what they were told. Traditional parenting strategies just didn't work. Why did other parents have children that did what they asked them to do, why were my children so difficult? Why did they not brush their teeth, make their bed, put their clothes away, shower regularly, want to go to school?	Since learning about PDA and all of these 'refusals' coming from a place of deeply rooted anxiety, we have changed our parenting style and do not follow the traditional parenting trajectory. Having an understanding of ‘can't not won't’ has changed our relationship with our children for the better. Unfortunately, although school staff mean well, they just don't understand and they believe that we need to push them to make them resilient to the real world. So in fact they make it worse.
I felt like a failure as a mother. I had years of teaching experience including in SEN schools so I thought I should know what I was doing. But my strategies to make our family life harmonious weren’t working and we were all struggling.	Life is still very challenging. I spend a lot of time fighting with education professionals or trying to get the right kind of support for my son. But our home life is 90% joyful and happy for everyone. My son laughs more and plays more. We laugh together more.
I had an eight-year-old daughter who was not able to attend school anymore, who I was repeatedly told needed to be told that she must do things and that I was letting her get away with not doing things. I felt like a terrible parent who was unable to control her child.	Life is starting to make a bit more sense now that we know. We are finding ways to help my daughter come out of burn out and ways to help her be able to engage in some things. We are changing the way we speak to her and the way our family life works. Really frustratingly, though, we spend a lot of time banging our head against brick walls when it comes to talking to professionals. Absolutely nobody wants to hear about PDA.
Before we learned about PDA we were very confused about how our child presented, whether he was or was not autistic, and how we could help him live a better life.	Understanding PDA, largely by learning from adult PDAers, has been absolutely critical to our understanding of our son. We know how to support him better and have improved all of our emotional health.
Utter misery. Nobody understood our day to day battles. My parenting was always being judged. We were isolated from friends and family. Everyone thought my child was just naughty and a product of bad parenting. I felt hopeless. No one was willing to help or even knew how to help. I was just sent on more and more parenting courses.	I'm prepared now to walk alongside my son and share his worries and fears as they come. The greatest comfort I can give him is to be by his side, to know he's not alone.

As parents, we felt that we were failing at every step and education, the medical world and society as a whole was only too happy to let us feel that way. Every interaction with ‘professionals’ of any kind left us feeling like we just needed to try harder, be better and to just manage what others were apparently achieving with such ease. For our child, he must have been so frightened trying to cope in a world where not even his parents could understand him.	Life now is completely different. Life is happier and calmer. Connection and trust is being restored. But there are long-term wounds, inflicted by the system of education and medicine, that are still healing in us all as a family. Our son has left formal schooling due to sheer lack of knowledge, training and quite frankly, any willingness within educational staff to know better and do better. Everything that has happened to improve our son’s life, well-being and future has been entirely down to our family and our unwavering commitment to support him. That and the support of the PDA Society and the wider PDA community.
Terrible for the entire family. We didn’t know what our child was struggling with, we didn’t understand why she behaved the way she did, no-one believed there was a problem as she was ‘fine’ in school and it was just getting worse day by day. But life was getting harder for all of us, she was having more and more frequent and increasingly physical meltdowns and all the strategies we were being told to use were just making things worse.	We are in a much better place to support her, help her heal, learn in a way that suits her, advocate for her when she can’t and back her up when she is able to. Life is still hard for all of us, because the world isn’t setup for autistic people but the more we learn and understand the more we can help her be herself.
Before we knew about PDA, we still had neurotypical expectations of our daughter and put unnecessary pressure on her which only made things worse. We interpreted her symptoms and behaviours as either strictly mental health-related or as purely anxiety in the traditional sense. We tried to use logic and reason as well as rewards. We also worried she might be bipolar, again looking at things through only a mental health lens.	We now understand PDA as a nervous system disability and a profile of the autism spectrum. We try to provide our daughter with accommodations and supports including giving her more autonomy, reducing demands, using declarative language, proving lots of co-regulation, recognizing and supporting her sensory needs, and letting go of ableism and traditional parenting models.

4. Appendix 2

5. Case studies: What happens when we get it right?

What happens when we get it right for PDA children and young people?

As section 3 of our report highlights, one of the key areas where change is needed for PDA children and young people is education. 72% of children and young people covered by our survey sample were not able to tolerate their school environment or were home educated.[1] The case studies below illustrate some examples of positive stories we heard from parents and from young people themselves, about the impact of ‘getting it right’ in education for PDA children and young people. What ‘getting it right’ means will differ for each individual child and their family, so we have included four very different ‘success stories’, in settings ranging from home education to mainstream school.

Case study 1: Provisions put in place by a mainstream primary school

School life was incredibly hard because before he was diagnosed, my son was misunderstood and labelled a naughty challenging child. He reached burnout resulting in EBSA[2] because the school didn’t think he needed extra support, even though we were crying out for help as things were so challenging at home. It was only when he reached crisis point that we discovered PDA and they started to understand him more and put in the support he needed. But by then he’d been in mental health crisis – self-harming, suicidal ideations and an attempt.

He ended up being signed off by CAMHS and was out of full time school for around 18 months. During that time, and after some time to put together a plan, the school started to send his favourite TA to meet us, and she would play with him in the park. After a while he started going into school to play games with her. The school built a sensory room; we would go in there together with his TA, and they would spend time playing together. Once my son had his PDA diagnosis, the school brought in an outreach teacher who specialised in PDA and she gave training to school staff.

However, although my son was happy in the sensory room with his TA, he still didn’t feel able to go into the classroom or to engage with his class teacher. At this point we didn’t yet have an EHCP. The school and the local authority inclusion team decided to arrange alternative provision for him. He did a dual placement, going into school for an hour, half an hour, 15 minutes – depending on the day and how well he could tolerate it, and then the mentor from the alternative provision would come and pick him up and take him out. They’d do swimming, rock climbing, hiking, treasure hunts, go to the forest or the beach. They had a building where they could meet with other children and do things like baking or games. It was this that positively impacted on my son’s mental health and wellbeing the most – it was all: “Let’s work on you as a person” rather than: “Let’s do work”. At first they used to send a schedule about what would be happening that week, but when they realised that didn’t work for him they just said “Ok, we’ll pick you up and you decide”.

He had the alternative provision for around nine months, while school were preparing behind the scenes for him to eventually return. We would have liked to continue, but once the EHCP was granted, the school allocated a full time 1:1 to my son as requested, so it was no longer deemed necessary. He was ready to go back then, so it was a natural progression for him. His 1:1 did PDA training and PACE training whilst she worked with him, and she has turned his life around! She’s put in so much effort to learn about PDA and understand it/him as a person, and to acknowledge that he doesn’t need traditional autism strategies like visual timetables and now and next boards. That just doesn’t work for him.

He has a very bespoke timetable - if he does maths in the classroom on Monday but he doesn’t want to do that on Tuesday, it’s fine, they take it out to the practical area, or the sensory room. He doesn’t have to be in the classroom, he can dip in and out. His 1:1 is really good at gauging his tolerance levels and thinking about how to accommodate him and keep his focus. If she can see that he’s having a really bad day she’ll remove the demand and they’ll go and build dens instead, or do baking or junk modelling. He loves teddy bears, so his 1:1 frames learning around this – for example they’ll make a den for the teddy and then do some work inside the den. If his 1:1 thinks he can tolerate work in the classroom, they’ll try, but there’s no pressure to stay, which is really nice. We don’t do homework, and for activities he finds hard he has a lot of scaffolding. The class teacher has had PDA training too, but she is clear that my son’s 1:1 is the person whose lead she follows, as the 1:1 knows him best and he trusts her.

My son has specialist education on his EHCP, but the specialist schools in our area aren’t very well equipped for PDA. I thought: “Better the devil you know – we’ll stick with the support we’ve got and keep trying”. And most importantly, it was what he wanted. I knew it was a risk doing this but it’s really working so far. He’s still with his peers and he has a good little group of friends who understand him. Hopefully we can get him through to the end of Year 6.

I know this is a very rare set up – we’ve been so lucky with the school. Although I had to argue every step of the way for this kind of support during the EHCP process! They kept saying: “We don’t want him to feel excluded by being out of the classroom” and: “We don’t want him to be reliant on the 1:1” which is a hard narrative to change. I wanted them to understand that It doesn’t matter what *you* want, what matters is what *he* needs. I said: “I know it’s not typical and it’s probably not an ideal setup, but otherwise we are going to be battling a child that climbs the fences every day, and kicks and screams and fights with everybody, and it’s just not worth it, for anyone”. So yes, I really did have to advocate for him. When I see the statistics about the number of PDA children out of school it makes me so sad, because it’s not impossible to accommodate these kids. It’s just making the effort, and his school – his 1:1 especially – have made so much effort. If his 1:1 hadn’t made the effort he wouldn’t be in education now. 18 months ago we were under CAMHS for suicidal attempts, but now he’s so much happier and he doesn’t have those thoughts as frequently anymore. He’s so much better in himself because he feels understood and validated. That’s what all these kids want – they just want someone to ‘get’ them.

***Case study 2: EOTAS*[3]**

It was quite a journey to get to this point, because we didn’t really know what we needed at first. School definitely wasn’t working for my son, but no one else understood, and it really made me doubt myself because everyone was saying “he has to go to school”. I even had a head teacher telling me that not forcing him in could be counted as child abuse. But I knew that no matter how much we lowered demands at home, it was never going to work while school was still there. And as I was the one making him go, he lost trust in me completely. By the time we stopped sending him in, he already had a lot of trauma from school. There was so much negativity around school for him, we knew that there was no way he’d get through the door of any other schools.

Then the COVID lockdowns came, which were very difficult for so many people, but for us it provided an opportunity. I’d discovered PDA, and was reading everything I could find, but accommodating PDA involves such a change of lifestyle – it’s quite scary, the thought that you’re going against the grain and everyone you know, so dramatically. I knew that was what we needed to do, but we both worked and we needed both incomes. It was the unknown and it was scary, and it seemed impossible at the time. But the lockdowns gave us that opportunity – I didn’t have to be at work, so I thought: “Right, we’re going to do it”. At first there was a lot of regression. My son wanted to spend time completely by himself in his room with the curtains shut. We had to enter very carefully. He was down to only two safe foods. But slowly he came back – he started coming out of his room, wanting to come on walks with us. This gave me more trust in my own instincts, because I could see that yes, this was what he needed. When the schools re-opened he didn’t return. We got him diagnosed privately and did a parental application for an EHCP. I carried on researching and found out about EOTAS. I visited local alternative provisions and decided what we needed to ask for.

It took 60 weeks to get the EHCP agreed, and then another six months to get the EOTAS package in place. This sounds very long, but I now know I was quite lucky compared to others, and I didn't have to go to tribunal. It was a long learning curve for me. I'm not the sort of person who likes complaining, and I used to dread the meetings and phone calls, but for this I just had to do it. I used all the templates I could find, I collected people's email addresses and was very persistent. I had to learn how to change my mind set, distance myself from my emotions, and take away the personal element. This made me a better advocate from my son. Now I know what I need to do, which is a horrible situation but it's a 'needs must' situation.

We're now in our second year of EOTAS, and the difference is amazing. My son has built a lovely relationship with his learning support assistant at the alternative provision. She is very knowledgeable about PDA, and after me and my husband, she's probably my son's next most-trusted person. The first year at his alternative provision was all about relationship building. It's very child-led, and he was nature a lot – climbing trees, stick collecting. His learning support assistant completely understood about masking and how to approach it. He gradually started to unmask more and more. He started to feel able to say when something was too much for him, and so his learning support assistant could start to offer more unstructured learning-based tasks – just a couple of minutes here and there – because she knew he was better able to say no. Now he is able to do things like crosswords and worksheets when he's with her. He also now feels able to spend time at a 'base' with other children, and he enjoys this. He knows that he has choice and that if it's too much for him he can leave. The slow build-up really worked.

I can't describe the difference in our home life. Obviously having my son at home with me comes with its logistical challenges, but it's worth it ten times over because he is ten times happier. While previously he was in constant fight or flight mode, now his anxiety levels are so much lower – his distressed behaviours have reduced dramatically. The way I'd describe it is, it's difficult but we're all really happy. There's no more constant worry. As a family we're just happy.

Case study 3: Home education

Once I started reading about PDA everything made sense. I read as much as I could – I found PDAers online, support groups, professionals, books, organisations. Listening to voices of PDAers and learning about ableism was the most life changing part though. It was the part that made me "radically accept" and make the major life changes that needed to happen. Up until that point I was trying to "fix everything". I learnt no one needed "fixing". We just needed to accept and embrace a new lifestyle. And letting go of mainstream schooling was the big one.

I have found that home schooling in an "unschooling", child-led, self-directed style suits my child, as they can have the autonomy they need to feel safe. In my experience as a teacher, I will sadly admit that I don't think there is much about schools that suit most PDAers. The schooling system has a *very* long way to go to be right for them.

Since beginning home schooling, my child is more relaxed, calm and settled. They have been able to better regulate their emotions, are able to understand their sensory likes/dislikes, and can advocate for themself. They are far less irritable and angry. Violent outbursts are now very infrequent (they used to be multiple times per week). They no longer talk of hating themself or their life. They no longer say they are "stupid".

Their anxiety levels are now manageable. They still have the same anxieties but they are able to communicate them now. This could be that they are getting older but I think the fact they are more settled and calmer has helped too. And now that they can explain the anxieties, we can support and accommodate them properly. In some ways, they actually seem “more autistic” now as it is like they were given permission to take off the mask, be true to themself, be seen and heard.

Physically they seem more settled, happy and relaxed. They used to exist in a heightened, stressed state, to the point where their body was physically tensed all the time. This is no longer the case. Their speech is also better and they are more talkative and social since the pressure of school was lifted.

Their attitude towards learning is similar in that they still dislike “school work” and resist bookwork, maths, reading or writing. However, by giving them control and letting go and not making them do “work”, they have actually developed a great attitude towards learning, in their own way, on their own terms. My child will pour themself into projects of interest in which they web-research, read, watch videos, plan, draw, write, budget. They will spend hours and hours for several weeks on each of their projects; for example, setting up a fish tank, building a garden pond, building terrariums. In their areas of interest they have grown and grown beyond what they could have at school. In other areas there is minimal progress but perhaps that is the trade-off. There are no guarantees they would have made progress in those areas if still at school either.

They are now able to better engage with friends and family and better engage with the community. It was like they were so exhausted just getting through a school day they had nothing left for anything else. Now they do.

I had been reluctant to give up my job to home school, even though it was always in the back of my mind as our backup plan. I was worried about what people would think or say. I wanted my child to have the chance to try and make it work at school. We were concerned about the shift to home schooling being too demanding on me as a mum. That it would be too difficult to spend so much time one on one. But that hasn’t been a problem as the child I spend so much time with is a much happier, calmer, connected person so it has worked out better for everyone.

Giving up my career (teaching) was easy in the end. We were in crisis and we could not live the way we were. We desperately needed to change it so it was easy to walk away. My changing perception of the schooling system, my learning about ableism, my learning about PDA, my listening to autistic voices had changed me so much that I no longer felt I belonged in or agreed with the school system anyway. The financial hit hasn’t been great but we’ve just made sacrifices and choices based on what we value and what works for us, not necessarily what “everybody else” is doing.

The change has been positive for everyone. My husband and I are calmer, happier, less stressed, less anxious. We’ve always been on the same page and everything has made us closer and stronger, thankfully. Family and friends have all noticed the positive changes so the impact has spread to them too.

We no longer feel like we are trying to force a life that didn’t fit. We’ve accepted who we are and what suits our family. I’ve let go of controlling how it “should be”. We’ve leant into what works for us. We’ve simplified our lives. We’re trying to not compare, or wish or want. We’re not all the way there and I know there will be ups and downs and we’ve still got troubles but compared to how things were, it’s a huge positive change.

Case study 4: A young person’s view on education and the college ‘getting it right’ for them

In Year 10 I stopped going to school. I was really unwell. I was diagnosed with anorexia – I wasn't eating at all, and on top of that I wasn't sleeping either. My secondary school was very mainstream – massive classes and they didn't want anyone whose attendance was bumpy as they just wanted the best grades. So they neglected anyone who was not doing well, not looking like they were going to get good grades. They saw us as either 'good' students or 'bad' students. The 'bad' students were always being told off, got low grades, were always in detention. Lots of the teachers seemed power hungry, and seemed to hate children which is really weird. They would get angry at the most random things – one time because I had the wrong colour hair clip! The craziest rules that didn't make any sense, but were all about power and authority and control. There was so much underlying tension and hierarchy. It's a sickening environment to be in for anyone, but with PDA, I hated it. I despised the whole hierarchy thing. There was no trust, you couldn't question anything, it was all built on a bunch of rules that didn't make sense. There was no communication, you weren't valued as a human. The system is very factory-esque, very prison-esque. Kids leaving the house at 8am and coming back at 4pm, and having that all day, from the age of five – it's crazy to expect kids to do that and be fine! You don't matter when you're in a system like that.

But things got so much better when I started at the college I'm at now. It's amazing. It's private so it's very small, and most of the kids there have struggled with education in some way. It's not specifically for neurodivergent students, but lots of them are, and many are funded by EHCPs. They're very catering towards the individual, and it's a really beautiful, close-knit environment. There are no authority figures. The classes are small and the teachers are called by their first names and don't have many rules. Some of the kids there were kicked out of their old schools for misbehaviour, but the teachers are very smart – they know that punishments don't work. They encourage students, and they don't look down on them or lash out and get angry with them for behavioural things. They recognise that students don't misbehave for no reason. There are no students who are disliked by the teachers or are picked on by the teachers. Students know they won't be rejected and so their behaviour improves. It's very accepting. Being accepted like that is a really nice feeling. I don't want to take it for granted because often the rest of the world is not like this.

I've found that this low demand environment works really well and my attendance has improved a lot. I know that the problems I have around eating and sleeping aren't going to just go away, but sometimes you just need to feel happy and fulfilled in your life, then you won't need to seek fulfilment in other ways. And that's what I've found – things have got so much better, when before they were really bad. I can't imagine any other school being able to help me in the way the college has.

What happens when we get it right for PDA adults?

As discussed in section 4 of our report, 63% of self-reporting PDA adults and 25% of over 18s as reported by parents and carers have had positive employment experiences at some point. We asked some of these people to tell us more about their experiences, which are summarised in the case studies below. Interestingly, all four of the case studies involve examples where a PDA adult has been successful and happy working in a role that benefits other neurodivergent people. All four also demonstrate the types of working conditions that help PDAers to thrive in employment or self-employment.

Case study 5: A PDA-friendly work environment

I work part-time with disabled kids. It's exhausting (I struggle a lot with fatigue), and I don't think I could manage it full-time, but I really love it.

The policies and general atmosphere are positive (inclusion for all, all behaviour is communication, prioritising communication and choice in whatever form works, just generally treating the kids as 'equals'- we aren't above them). I have very strong moral values and have struggled before working in places which don't share them, even though it didn't affect me personally in any way.

Also I just love working with kids. They're fun and insightful and every day is different, and I think the novelty within a safe environment helps to motivate me. Sometimes there are PDA kids, and I find that I "get" them – even when they're instructing me exactly what to do and where to stand, which normally would massively trigger my own PDA, somehow it doesn't because I understand that they need this to feel autonomy and that we are on equal footing. And often I see little me in them a bit.

My boss is also very respectful – she often works directly alongside the rest of us, and she doesn't try to demonstrate "power over us" or anything. I haven't told her about my PDA, but she knows I am autistic and gives me breaks if I ever get overwhelmed.

I'm lucky, because I just stumbled into my job but it's been really good for me, and really PDA-friendly despite not specifically trying to be. It's given me confidence and independence, and a sense of purpose – I actually feel like I'm doing something useful in the world.

I do struggle with some things, such as replying to emails and reliably getting there at the same time each day, but there is flexibility with that which works well for me. And it does exhaust me – I need a full day of absolutely nothing, not even getting dressed or cooking meals, to recover after a work day. But I'm glad I have it.

Case study 6: A PDAer's thoughts on what works for them

I've been working as a teaching assistant in SEN/SEMH schools[4] for a couple of years. It hasn't been plain sailing by any means, and I faced bullying and discrimination in my first couple of workplaces, but I eventually found somewhere that was lovely, accommodating, and valued my lived experience, insight, and expertise.

I unfortunately had to leave that job, as new management were not on the same wavelength, and it made it intolerable for me to work there. They very much brought a corporate culture to the school that ruined the experience entirely. I'm now studying part time and doing TA work part time.

What has worked well for me are things like flexibility in my hours, understanding that I can't do a 'full day' and need to leave when the children go home. I start to panic and will have a meltdown about my time being stolen from me if I end up sitting around in the staff room for two hours after the children go home, or if am forced to stay in meetings, so employers letting me go home with the understanding that I am honest and sincere and that my work will be done to a high standard and to the best of my ability, is really important to me. I don't expect to be paid the same as everyone else, so I don't see why it should be an issue.

Another thing that helps is having as minimally invasive of a hierarchy as possible. Employers who talk down to you, or do not respect or value your input, are absolutely unbearable for me. Clear instructions and expectations, open communication, not assuming ill-intentions if I come across blunt/mean/rude by accident, are all really vital to me.

It’s also important to me that employers consult with employees when making decisions that directly affect us, and are willing and able to explain the reasoning behind their decisions. I cannot enforce rules I don’t believe in, don’t think are fair, or follow instructions I don’t see the point in.

Also I need to be offered the standard sensory accommodations such as letting me wear my headphones/earplugs/sunglasses when I need to, and understanding that if I look angry or don’t say hello in the morning, it’s just my face and I don’t hate you!

Case study 7: A PDA adult’s career journey

I think I have been successful in employment because I am well-educated and that has afforded me a career path of *my* choosing. I was not diagnosed with any condition until later life so education was a huge struggle and trauma for me. Despite burning out regularly, I got excellent GCSEs, A-levels and a degree.

I have worked in a range of areas and roles. I’ve worked out that to be happy in employment, I need my work to involve autonomy, be meaningful, be helpful, be interest-based and fact-based. I need to be busy to have motivation but ADHD means I need tools to help with saying no, time management, prioritisation and organisation. I can hyperfocus and my output can be incredibly high. But I bore easily and get overwhelmed easily so I need to have 'just right challenge'.

If I am to work with others, I prefer to lead and/or have trusting-collaborative relationships and a sense of equality. I need to be explicitly told (or shown in a way I understand) that I am liked, valued and my opinion matters. I have terrible self-esteem. Years of masking has meant I actually come across very confidently to the point it's sometimes misread as arrogant. I am extremely sensitive to rejection so criticism needs to be carefully managed. A result of this is, I like to know everything I can about my work so I cannot be wrong. I am goal-orientated but shy away from competition with others (fear of failure). I have impossibly high expectations of myself so need others to help me with boundaries. I am dyslexic so rely on ICT. I forget to stay hydrated and fed so need verbal or visual clues. I need mental health days.

I recently started a new role at a company offering mentoring for young people. With this role I work flexibly, creatively, there are no set hours, there are no expectations other than ones I impose, no timeframes per se, and as most of the staff are neurodivergent, we support each other mentally and physically. I can be my authentic self. I come into the office if needed or when I need some human interaction. The position is evolving as the company does; responding to the needs of the young people we serve and to match the ever changing, educational landscape. There is constant novelty, the work is never mundane, I'm constantly being challenged. I have a new special interest, direction and a meaningful project!

Case study 8: Self-employment

Being self-employed and running my own business supporting SEND families allows me to pick the times I work and this lessens the demand of having to work at set times. It gives me flexibility – on bad days I can scale back and on good days I can scale up again.

I don't have anyone giving me deadlines I have to stick to, or bosses telling me how my work is - I don't mean just criticism, I mean praise too as I find this just as bad a criticism.

Being self-employed means I don't need permission to take time off or need to explain on bad days why I may be slower or less with it. It means I don't have to put a mask on all the time I work, and I can hide in the comforts of my own home where no one sees me.

Of course, employment and work is only one area of PDA adults' lives, and many survey respondents had not had positive experiences in this area. Some told us about other ways that people had 'got it right' for them. This could involve small changes in the ways that friends and family members engaged with the PDAer, as the example below demonstrates:

> *Life was lonely, confusing and hard. I felt like an alien who landed on the planet without a road map. Acceptance from others and myself I suppose has made me feel like I'm okay. Having people in my life willing to make little changes in how they communicate, willing to make some accommodations puts tears in my eyes. I didn't know I could be accepted and it with me makes me feel I can be loved and wanted. I'm starting to feel like the PDA is okay. I can work with it instead of trying to snuff it out.*

What happens when we get it right for parents and carers?

As section 5 of our report demonstrates, many parents and carers of PDA children and young people feel subject to judgement, scepticism and blame from others. Only a very small number of respondents told us about times when people had 'got it right' for them, and they had felt believed and supported. The excerpts and case study below show what a difference being believed and listened to can make, as well as the importance of professionals who understand and have expertise in PDA.

> *Having a professional who understands PDA, and agrees that my son has it, has been so validating. It has made it easier for me to get support for him at school and elsewhere. Having a professional on side means that I don't feel crazy, there are less people gaslighting me into thinking it's all in my head and that my parenting is wrong. We need more professionals to understand and recognise PDA – especially in schools and childcare settings.* (Parent of under 18)
>
> *I had been constantly knocking on professionals' doors, saying that my son reminded me of the children I knew who were autistic but at the same time, he seemed to have a completely different set of needs. I was constantly dismissed. Until one kind and understanding professional did take notice. My GP agreed to refer me out of area to a different CAMHS. There we worked with a brilliant child clinical psychologist, who agreed that my son fitted the PDA profile and wrote a report hinting at PDA. Following this, other services began to take me more seriously.* (Parent of under 18)

Case study 9: The positive difference that professionals can make

We spent quite a few years trying to engage in ‘normal’ family life, to be like other people who sat down at family meals, followed rules and traditions, went on holidays, welcomed surprises and generally did what was expected. During this time, we were asked by family members things like: “When is she going to start listening to you?” or “Why are you giving in to her all the time?” We didn’t know the answer to these questions, and they made us feel like we were failing.

When our daughter started school, we were told by teaching staff that she was “absolutely fine” at school, there were no problems at all. So we couldn’t understand why she had such huge meltdowns as soon as she came out of the school gate. It was so confusing, seeing how difficult everything was for her, but having professionals say there was nothing wrong.

I don’t know what would have happened if my partner hadn’t started doing her own research at that stage, and actively seeking out professionals who understood PDA. As is the case for many families, we found out about PDA through the internet! We were very lucky in that we had some savings and could pay for a private assessment with a paediatrician who recognised the PDA profile of autism. She changed everything for our family. As soon as we met her, we felt believed, understood and not blamed. Our daughter also seemed to know that this person understood and would help, and she opened up to her. The paediatrician spoke to us all for hours, I’m sure for longer than we had paid for, and explained everything to us and our daughter in a child-friendly way. She wrote an extremely detailed diagnosis report with recommendations, which has been such a useful tool in getting our child the support she needs.

We also changed schools and found education professionals who understood about PDA and were willing to think outside of the box and allow our daughter the flexibility, understanding and compassion that she needs. They don’t always get it right but they are open to feedback and we now feel confident enough to give it.

Having access to understanding and knowledgeable professionals has been a game changer. Our confidence in advocating for our daughter is now so much higher, not only because we know our instincts are right, but also because we feel we have the back up of these wonderful people who have believed and helped us.

6. Appendix 3: Survey questions

About this survey

This survey will take between 15 and 30 minutes to complete, depending on how much you'd like to tell us. You don't have to complete it all if you'd rather not -anything you tell us will be useful.
The survey will be open until 5pm (UK time) on Wednesday 31st May.
Please use the 'previous' and 'next' buttons to move through the survey.

What is the survey about?

We want to gain a more complete understanding of what life is like for the PDA community and what challenges you face. We'll use what we learn to advocate for the community and to ensure our work is focusing on the right things.

What is PDA?

PDA (Pathological Demand Avoidance) is widely understood to be a profile on the autism spectrum, involving the avoidance of everyday demands and the use of‘social’ strategies as part of this avoidance. You can find out more on our website:https://www.pdasociety.org.uk/

Who is the survey open to?
The survey is open to anyone age 17 or over who identifies with a PDA profile/as a 'PDAer'. It is also open to parents, carers or partners of PDA people. You don't need to have a formal diagnosis of PDA.

What will you do with the information I provide?
We will store the survey data in a secure IT system. We will analyse the survey data and report the findings anonymously. This means you will not be identified in the report that we produce.
We hope that the information we collect will be useful in future work to improve understanding of PDA. You can 'opt in' below if you would be happy for your anonymised data to be used in future research or awareness raising work. If you don't opt in, your survey responses will be deleted once the findings have been written up.

Can I change my mind about taking part?
If you change your mind, you can withdraw your survey response by letting us know before 9th June 2023.

What is the legal basis for processing my personal data?
The PDA Society is the data controller for the processing of personal data from this survey, which means that it is responsible for ensuring that the process complies with the General Data Protection Regulation (GDPR). More information is available here: https://www.pdasociety.org.uk/privacy-policy/

Where can I find out more about the survey?
If you have any concerns or feedback about the survey, please contact us at: info@pdasociety.org.uk

Where can I find out more about PDA?
There is a wealth of information on the PDA Society website, including a list of frequently asked questions. If you would like further support please contact our free enquiry line.
*** 1. Do you confirm that you understand why we are doing this survey, that it is voluntary, and who to contact if you have questions?**
Yes

*** 2. Do you give your consent for us to store the information you provide in a secure IT system for the duration of the project and to use this information anonymously in our report?**
Yes
My name and email address:
(We ask for these details so that we can get in touch with you in the future. Your contact details will be stored
separately from your anonymised data)

*** 3. Do you give your permission for us to store the information you provide in a secure database after the project has finished? This would mean that your anonymised information might be used in:**
Future research conducted by academics who are experts in this field and 'allies' of the PDA Society.
Future awareness raising work done by the PDA Society.
If your anonymised information is to be shared with external academics, we will contact you to let you know. We may also email you occasionally to let you know of other research studies which we think you might be interested in supporting.
You can opt out of the database and any emails from us at any time by contacting the PDA

Society at:
info@pdasociety.org.uk
No - please delete my data once the findings have been written up
Yes - please store my anonymised data for use in future work
(please add your contact details below)

Your experiences
If you have lived experience of PDA, as a PDA person or as someone living with/caring for a PDA person, please tell us about this below. Hearing your experiences is the main purpose of our survey (the questions after this are mostly tick-box). Please try to avoid using identifying names or places.

4. How was life before you understood about PDA?

5. What is life like for you now? Is anything different?

6. Which approaches and strategies help, and which don't help?

7. What one change would make the greatest positive difference to your life?

8. Which of the following describe you? You can choose more than one option
I identify as a PDA person and I'm over 17 years old
I am the partner of a PDA person who is over 17 years old
I am a parent/carer of a PDA person who is under the age of 18
I am a parent/carer of a PDA child/young person who is age 18 or over
I am a professional working in the area of autism and/or other forms of neurodivergence
I am none of the above (please let us know how you identify)

About you
There are four options for completing the rest of the survey. We don’t want to ask you questions that aren’t relevant to you. You can complete the rest of the survey from the perspective of:
A PDA person - someone who is diagnosed or identifies with a PDA profile and is 17 years old or over
A partner of a PDA person age 17 years old or over
A parent/carer of a PDA child/young person under the age of 18
A parent/carer of a PDA person age 18 or over
You can come back and fill in the survey again if you identify with more than one option / have more than one child.

*** 9. In what capacity are you completing the next sections of the survey?**
As a PDA person age 17 or over
As the partner of a PDA person who is age 17 or over
As the parent or carer of a PDA child/young person under the age of 18
As the parent or carer of a PDA person who is age 18 or over
None of the above - please take me to the final sections of the survey

About you
There are 20 further questions which are all helpful to us, but if you get stuck at any point, don’t worry. Just skip to the end and press ‘done’.

10. How old are you?
17-19 years old
20-24 years old
25-34 years old
35-44 years old
45-54 years old
55-64 years old
65 years old and over
Prefer not to say

11. How do you describe your gender?
Female
Male
Non binary
Other
Prefer not to say

12. How do you describe your ethnic background?
Asian / Asian British
Black / African / Carribean / Black British
Mixed / Multiple ethnic groups
White
Prefer not to say
Other (please specify)
13. What is your household set up?
Living with my spouse/partner
Living on my own
Living with my parents/extended family
Living in a residential home
Living in supported living
Living in an in-patient unit
Other (please specify)

14. Where do you live?
England
Scotland
Wales
Northern Ireland
Eire/Republic of Ireland
Not in the UK or Ireland (please specify)
PDA, neurodiversity and you
In this section we'll ask about how you identify and any diagnoses you have

15. Do you identify as neurodivergent?
Yes
No
Questioning

16. Do you have a formal diagnosis that includes or refers to PDA?
Yes
No

Not explicitly (but it is implied or alluded to) - tell us more in the next question

17. Please list all your formal diagnoses
18. Do these diagnoses reflect your understanding of yourself? If not, why not?
19. In your experience, do you feel that PDA is part of the autism spectrum?
Yes
No
Not sure

20. In your experience, do you feel you have traits of ADHD?
Yes
No
Not sure

21. If you have a PDA-related diagnosis, please tell us what clinic/who provided it

22. If you have had an assessment/diagnosis of PDA, how was it funded?
By the NHS
Privately
Not sure

More about your experiences
In this section, we'll ask you some more specific questions about things you may have experienced as a PDA person. This will help us understand how common these experiences are within the PDA community.

23. Have you experienced any of the following?
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

Needing mental health services (regardless of whether you were able to access them or not)
In-patient care
Social services investigation
Allegations of fabricated or induced illness (FII)
Allegations of parental alienation
Family court proceedings
Disputes over schooling/education
Education tribunal
Emotionally based school avoidance (EBSA) / school refusal
School exclusion
Been in trouble with the police
Family breakdown (family unit splitting up)
Family estrangement (being out of contact with your family)
Successful employment experiences
Being in the care of social services / a foster carer /supported living

24. If you are in college/higher education or in employment, do you ever struggle to attend?
Yes, all the time

Yes, regularly
Sometimes
Never
I'm not at college/higher education or in employment

25. Have you experienced any of the following?
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

Sensory differences
Mood swings
Challenges with sleep
Need to feel in control
Difficulty with daily tasks
Challenges with eating / eating disorder
Substance misuse(alcohol/drugs)
Difficulty getting out and about
Low self esteem
Depression
Severe anxiety
Self harm
Suicidal thoughts
Isolation and loneliness
Financial hardship

26. When most stressed, which of the following is your most likely response?
Meltdown (externalised response)
Shutdown (internalised response)
Other (please specify)

Your experiences of support
The next questions ask about what support you've had
27. Who supports you?
Emotional support
Practical support

Family (for day to day needs)
Family (when I'm in crisis)
Friends/my partner (for day to day needs)
Friends/my partner (when I'm in crisis)
Paid support worker(s)
Social worker(s)
SENDCo, teacher or teaching assistant
Professional therapist
Peer support (including online groups)
My employer
No one - but I do need support
No one - I don't need support

Other (please specify)

Your partner's characteristics
In the next section, we'll ask some demographic questions about your partner. We ask these so that we can understand more about any groups that are missing, and make efforts to include them. We will also use this information to help us identify if people with certain characteristics and experiences have anything in common.

28. How old is your partner?
17-19 years old
20-24 years old
25-34 years old
35-44 years old
45-54 years old
55-64 years old
65 years old and over
Prefer not to say

29. How does your partner describe their gender?
Female
Male
Non binary
Other
Prefer not to say

30. How does your partner describe their ethnic background?
Asian / Asian British
Black / African / Carribean / Black British
Mixed / Multiple ethnic groups
White
Prefer not to say
Other (please specify)
31. What is your partner's household set up?
Living with their spouse/partner
Living on their own
Living with their parents/extended family
Living in a residential home
Living in supported living
Living in an in-patient unit
Other (please specify)

32. Where does your partner live?
England
Scotland
Wales
Northern Ireland
Eire/Republic of Ireland
Not in the UK or Ireland (please specify)
PDA, neurodiversity and your partner
In this section we'll ask about any diagnoses your partner has, and ask about your views on PDA

33. Does your partner have a formal diagnosis that includes or refers to PDA?
Yes
No
Not explicitly (but it is implied or alluded to) - tell us more in the next question

34. Please list all their formal diagnoses

35. Do these diagnoses reflect your understanding of your partner? If not, why not?

36. Do you feel that PDA is part of the autism spectrum?
Yes
No
Not sure

37. Do you feel your partner has traits of ADHD?
Yes
No
Not sure

38. If your partner has a PDA-related diagnosis, please tell us what clinic/who provided it

39. If your partner has had an assessment/diagnosis of PDA, how was it funded?
By the NHS
Privately
Not sure

Your partner's experiences
In this section, we'll ask you some specific questions about things your partner may have experienced. This will help us understand how common these experiences are within the PDA community.

40. Has your partner experienced any of the following?
Yes - including in the last year
Yes - but not in the last year No - not at all Don't know Prefer not to say
Needing mental health services (regardless of whether they were able to access them or not)
In-patient care
Social services investigation
Allegations of fabricated or induced illness (FII)
Allegations of parental alienation
Family court proceedings
Disputes over schooling/education
Education tribunal
Emotionally based school avoidance (EBSA) / school refusal
School exclusion
Been in trouble with the police
Family breakdown (family unit splitting up)
Family estrangement(PDA person being out of contact with their family)
Successful employment experiences
Being in the care of social services / a foster carer /supported living

41. If your partner is in college/higher education or in employment, do they ever struggle to attend?
Yes, all the time
Yes, regularly
Sometimes
Never
They're not at college/higher education or in employment
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

42. Has your partner experienced any of the following?
Sensory differences
Mood swings
Challenges with sleep
Need to feel in control
Difficulty with daily tasks
Challenges with eating / eating disorder
Substance misuse (alcohol/drugs)
Difficulty getting out and about
Low self esteem
Depression
Severe anxiety
Self harm
Suicidal thoughts
Isolation and loneliness
Financial hardship

43. When most stressed, which of the following is your partner's most likely response?
Meltdown (externalised response)
Shutdown (internalised response)
Other (please specify)

Your partner's experiences of support
The next questions ask what support your partner has had
44. Who supports your partner?
Emotional support
Practical support

Family (for day to day needs)
Family (when they're in crisis)
Their partner/friends (for day to day needs)
Their partner/friends (when they're in crisis)
Paid support worker(s)
Social worker(s) SENDCo, teacher or teaching assistant
Professional therapist
Peer support(including online groups)
Their employer
No one, but they do need support

No one, they don't need support
Other (please specify)

Characteristics of the PDA person (age 18 or over) you care for
In the next section, we'll ask some demographic questions about the PDA person you parent/care for. We ask these so that we can understand more about any groups that are missing, and make efforts to include them. We will also use this information to help us identify if people with certain characteristics and experiences have anything in common.

45. How old is the PDA person you care for?
17-19 years old
20-24 years old
25-34 years old
35-44 years old
45-54 years old
55-64 years old
65 years old and over
Prefer not to say

46. How does the PDA person you care for describe their gender?
Female
Male
Non binary
Other
Prefer not to say

47. How do they describe their ethnic background?
Asian / Asian British
Black / African / Carribean / Black British
Mixed / Multiple ethnic groups
White
Prefer not to say
Other (please specify)

48. What is their household set up?
Living with their spouse/partner
Living on their own
Living with their parents/extended family
Living in a residential home
Living in supported living
Living in an in-patient unit
Other (please specify)

49. Where do they live?
England
Scotland
Wales
Northern Ireland
Eire/Republic of Ireland
Not in the UK or Ireland (please specify)
PDA, neurodiversity and the person you parent/care for

In this section we'll ask about any diagnoses the person you care for has, and ask
about your views on PDA

50. Does the person you parent/care for have a formal diagnosis that includes or refers to PDA?
Yes
No
Not explicitly (but it is implied or alluded to) - tell us more in the next question

51. Please list all their formal diagnoses

52. Do these diagnoses reflect your understanding of the person you parent/care for? If not, why not?

53. In your experience, do you feel that PDA is part of the autism spectrum?
Yes
No
Not sure

54. Do you feel the person you parent/care for has traits of ADHD?
Yes
No
Not sure

55. If they have a PDA-related diagnosis, please tell us what clinic/who provided it

56. If they have had an assessment/diagnosis of PDA, how was it funded?
By the NHS
Privately
Not sure

The experiences of the PDA person you parent/care for
In this section, we'll ask you some specific questions about things the PDA person you parent/care for, and you as a parent/carer, may have experienced. This will help us understand how common these experiences are within the PDA community.

57. Has the PDA person you parent/care for experienced any of the following?
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

Needing mental health services (regardless of whether they were able to access themor not)
In-patient care
Emotionally based school avoidance (EBSA) / school refusal
School exclusion
Been in trouble with the police
Family breakdown(family unit splitting up)
Family estrangement (PDA person being out of contact with their family)
Successful employment experiences

Being in the care of social services / a foster carer /supported living

58. Have you, as a parent/carer of a PDA person, experienced any of the following?
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

A social services investigation
Allegations of fabricated or induced illness (FII)
Allegations of parental alienation
Family court proceedings
Disputes over education/schooling
Education tribunal
Family breakdown (family unit splitting up)
Family estrangement (being out of contact with the PDA person you care for)

59. If the PDA person you care for is in college/higher education or in employment, do they ever struggle to attend?
Yes, all the time
Yes, regularly
Sometimes
Never
They're not at college/higher education or in employment
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

60. Have they experienced any of the following?
Sensory differences
Mood swings
Challenges with sleep
Need to feel in control
Difficulty with daily tasks
Challenges with eating / eating disorder
Substance misuse (alcohol/drugs)
Difficulty getting out and about
Low self esteem
Depression
Severe anxiety
Self harm
Suicidal thoughts
Isolation and loneliness
Financial hardship

61. When most stressed, which of the following is their most likely response?
Meltdown (externalised response)

Shutdown (internalised response)
Other (please specify)

Support and the PDA person you parent/care for
The next questions ask what support the PDA person you care for has had

62. Who supports the PDA person you care for?
Emotional support
Practical support

Family (for day to day needs)
Family (when they're in crisis)
Their partner/friends (for day to day needs)
Their partner/friends (when they're in crisis)
Paid support worker(s)
Social worker(s) SENDCo, teacher or teaching assistant
Professional therapist
Peer support (including online groups)
Their employer
No one, but they do need support
No one, they don't need support
Other (please specify)

Characteristics of the PDA child/young person you parent/care for
In the next section, we'll ask some demographic questions about the PDA child/young person you care for. We ask these so that we can understand more about any groups that are missing, and make efforts to include them. We will also use this information to help us identify if people with certain characteristics and experiences have anything in common.

63. How old is the PDA child/young person you care for?
Under 5 years old
5-10 years old
11-16 years old
17-18 years old

64. How does the PDA child/young person you care for describe their gender?
Female
Male
Non binary
Other
Prefer not to say

65. What is their ethnic background?
Asian / Asian British
Black / African / Carribean / Black British
Mixed / Multiple ethnic groups
White
Prefer not to say
Other (please specify)

66. What is their household set up?

Living with their parents/extended family
In foster care
Living in a residential home
In supported living
In an in-patient unit
Living on their own
Other (please specify)

67. Where do they live?
England
Scotland
Wales
Northern Ireland
Eire/Republic of Ireland
Not in the UK or Ireland (please specify)

PDA, neurodiversity and the child/young person you care for
In this section we'll ask about any diagnoses the child/young person you care for has, and ask about your views on PDA

68. Does the child/young person you care for have a formal diagnosis that includes or refers to PDA?
Yes
No
Not explicitly (but it is implied or alluded to) - tell us more in the next question

69. Please list all their formal diagnoses

70. Do these diagnoses reflect your understanding of the child/young person you care for? If not, why not?

71. In your experience, do you feel that PDA is part of the autism spectrum?
Yes
No
Not sure

72. Do you feel the child/young person you care for has traits of ADHD?
Yes
No
Not sure

73. If they have a PDA-related diagnosis, please tell us what clinic/who provided it

74. If they have had an assessment/diagnosis of PDA, how was it funded?
By the NHS
Privately
Not sure

The experiences of the PDA child/young person you parent/care for

In this section, we'll ask you some specific questions about things the PDA child/young person you care for, and you as a parent/carer, may have experienced. This will help us understand how common these experiences are within the PDA community.

75. Has the PDA child/young person you care for experienced any of the following?
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

Needing mental health services (regardless of whether they were able to access them or not)
In-patient care
Emotionally based school avoidance (EBSA) / school refusal
School exclusion
Been in trouble with the police
Family breakdown (family unit splitting up)
Family estrangement (PDA person being out of contact with their family)
Being in the care of social services / a foster carer / supported living
Yes - including in the last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

76. Have you, as a parent/carer of a PDA child or young person, experienced any of the following?

A social services investigation
Allegations of fabricated or induced illness (FII)
Allegations of parental alienation
Family court proceedings
Disputes over education/schooling
Education tribunal
Family breakdown (family unit splitting up)
Family estrangement (being out of contact with your PDA child/young person)

77. What type of education is the child/young person you care for in?
Mainstream (state funded)
Mainstream (independent)
Specialist
Home educated - by choice
Home educated - our only option
EOTAS (education other than at school)/Alternative provision
Pupil referral unit (PRU)
Other (please specify)

78. Does the child/young person you care for struggle to get into school?
Yes, all the time
Fairly regularly
Sometimes

Occasionally
Never
Not applicable - they are not in school

79. Does the child or young person you care for have an education, health and care plan (EHCP)?
Yes
In the process of applying
No - no application has been made
No - application was refused
Other (please specify)

80. Has the child/young person you care for experienced any of the following?
Yes - including inthe last year
Yes - but not in the last year
No - not at all
Don't know
Prefer not to say

Sensory differences
Mood swings
Challenges with sleep
Need to feel in control
Difficulty with daily tasks
Challenges with eating / eating disorder
Substance misuse (alcohol/drugs)
Difficulty getting out and about
Low self esteem
Depression
Severe anxiety
Self harm
Suicidal thoughts
Isolation and loneliness
The impacts of financial hardship

81. When most stressed, which of the following is their most likely response?
Meltdown (externalised response)
Shutdown (internalised response)
Other (please specify)

Support and the PDA child/young person you parent/care for
The next questions ask what support the PDA person you care for has had

82. Who supports the PDA child/young person you care for?
Emotional support
Practical support

Family (for day to day needs)
Family (when they're in crisis)
Their friends/partner (for day to day needs)
Their friends/partner (when they're in crisis)

Paid support worker(s)
Social worker(s) SENDCo, teacher or teaching assistant
Professional therapist
Peer support (including online groups)
No one, but they do need support
No one, they don't need support
Other (please specify)

Anything else?
In this final section, you can tell us about anything you haven't yet had chance to, but think we should know. We'd also like to hear about whether and how the PDA Society has been useful for you.

83. Has the PDA Society ever been useful to you or your family? In what way?

84. Is there anything else you'd like to tell us about?

Please click on the "done" button to submit your answers. Thank you very much for completing our survey.

If you would like to fill in the survey again, from another perspective (for example you may have completed it as a PDA person but also want to fill it in as a parent of a PDA child), you are very welcome to do so.

If you have any questions, concerns or feedback about the survey, please contact us at: info@pdasociety.org.uk

There is a wealth of information on the PDA Society website, including a list of frequently asked questions. If you need further support please contact our free enquiry line.