



PDA in our words

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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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.

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. 72% of children and young people in our sample were not able to tolerate their school environment or were home educated.² 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 are overwhelmingly supported by their families, rather than support services or professionals. 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. Only 30% of parents/carers 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.

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 attend. 77% of self-reporting PDA adults said they had experienced financial hardship at some point.

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

² 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.

- 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.

Altogether, 727 parents and carers of PDA people responded to the survey.³ 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 low demand parenting strategies, but find that progress is stalled reversed when these strategies 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),⁴ and 13% have experienced allegations of parental alienation.⁵

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 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

³ Parents/carers of PDA people both under and over 18 years old (727 respondents in total).

⁴ Discussion of the term "FII" is included in section 5.

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

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,⁶ 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.

⁶ 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/Caribbean/Black British; and the 7% who chose ‘mixed or multiple ethnic background’.

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.⁷

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.⁸

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:⁹

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

⁷ 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/>

⁸ The survey questions can be found in Appendix 3.

⁹ 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.

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

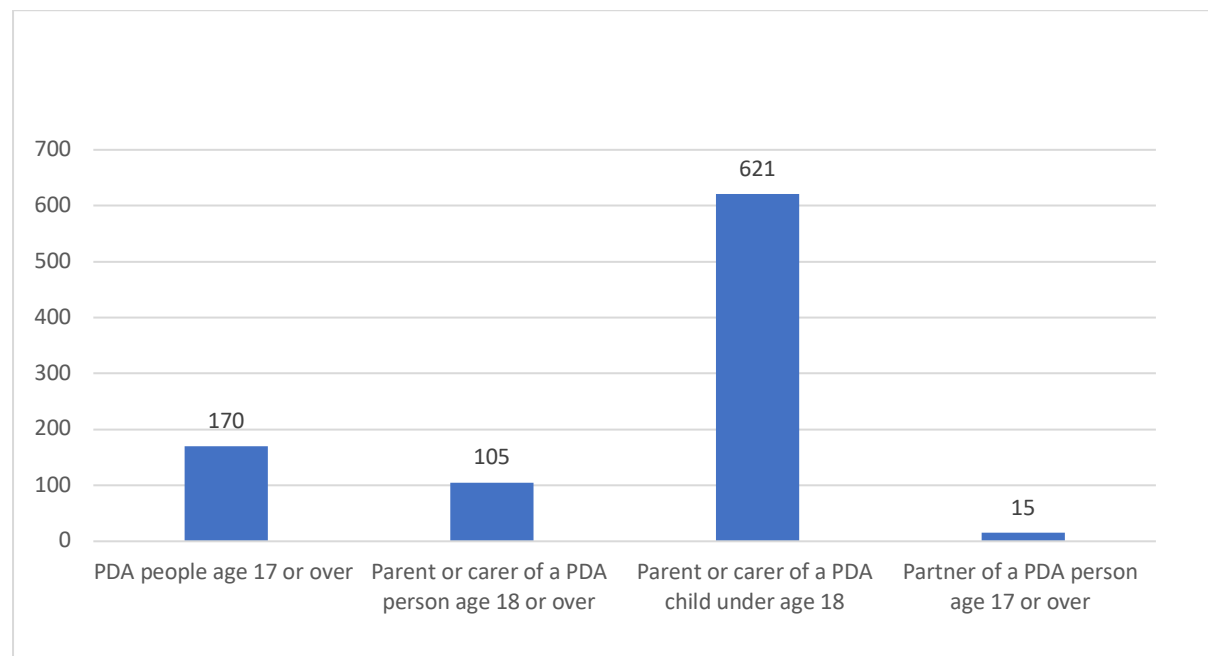
Whose experiences have we captured?

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.¹⁰ 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 PDAs, and 15 partners of PDA people.¹¹¹²

Figure 1: Category of survey respondent



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.

¹¹ 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.

¹² 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



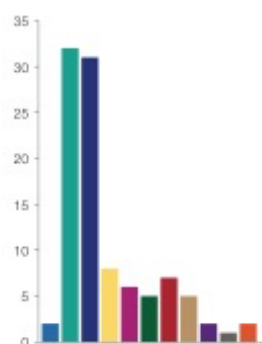
Gender	
Male:	48%
Female:	39%
Non-binary	7%
Other	3%
Prefer not to say/missing data	3%



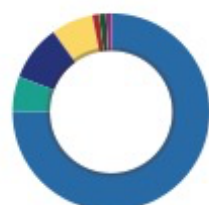
Ethnicity	
White	86%
Mixed/multiple	7%
Other	3%
Prefer not to say/missing data	3%
Asian/Asian British	1%
Black/African/Caribbean/Black British	-1%



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	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 of 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.

stumbled across PDA. I cried as I read the diagnostic criteria. Everything made sense.	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!	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.	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.¹³

- In 2018, 70% of children and young people were not able to tolerate their school environment or were home educated.¹⁴ 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.¹⁵
- 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%.

¹³ 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.

¹⁴ 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.

¹⁵ 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.¹⁶ 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.¹⁷ Recent government education policy has focused on improving attendance rather than tackling the root causes of school avoidance and anxiety.¹⁸ 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,¹⁹ 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.

¹⁶ 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

¹⁷ <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/>

¹⁸ <https://notfineinschool.co.uk/attendance>

¹⁹ 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/Caribbean/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.
- Children with a PDA profile 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.

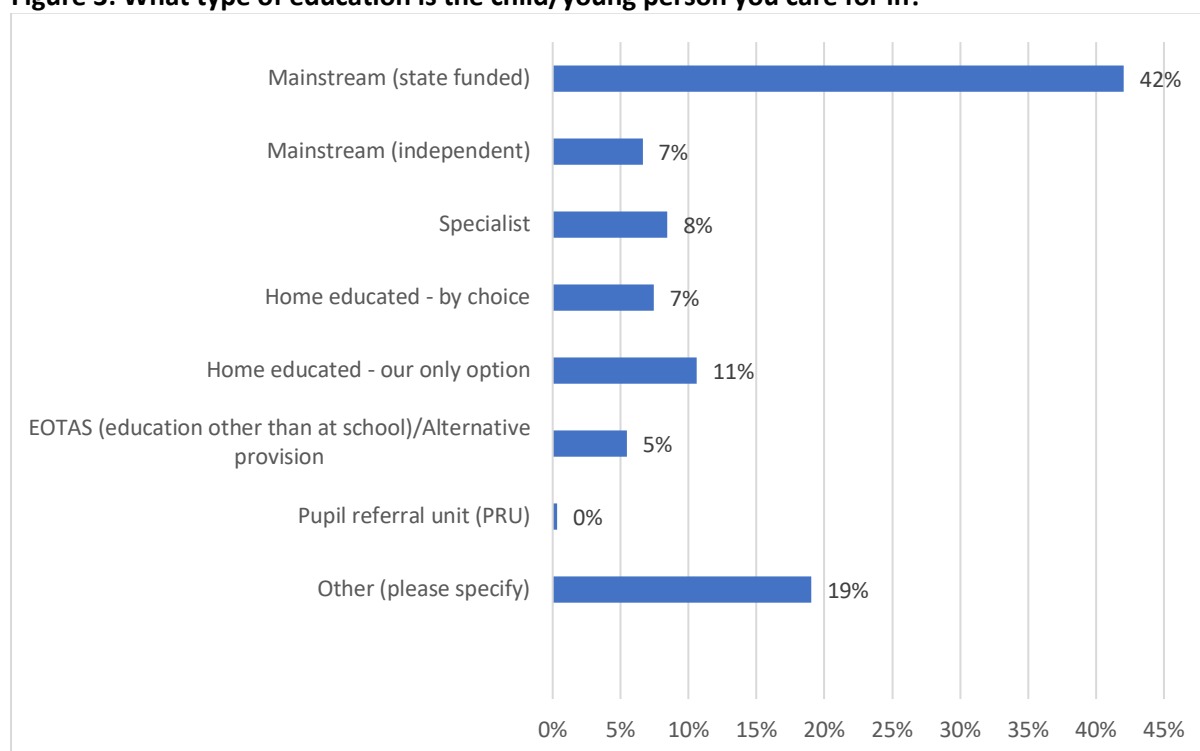
Before we knew about PDA	After we knew about PDA
Chaotic, emotional and my son was truly not getting his needs met. Everything came to a Ohead almost a year ago and although my son was able to go to school the majority of the time, he was not able to leave his room/bed the rest of the time. We had a 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.
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.
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.

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.

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?

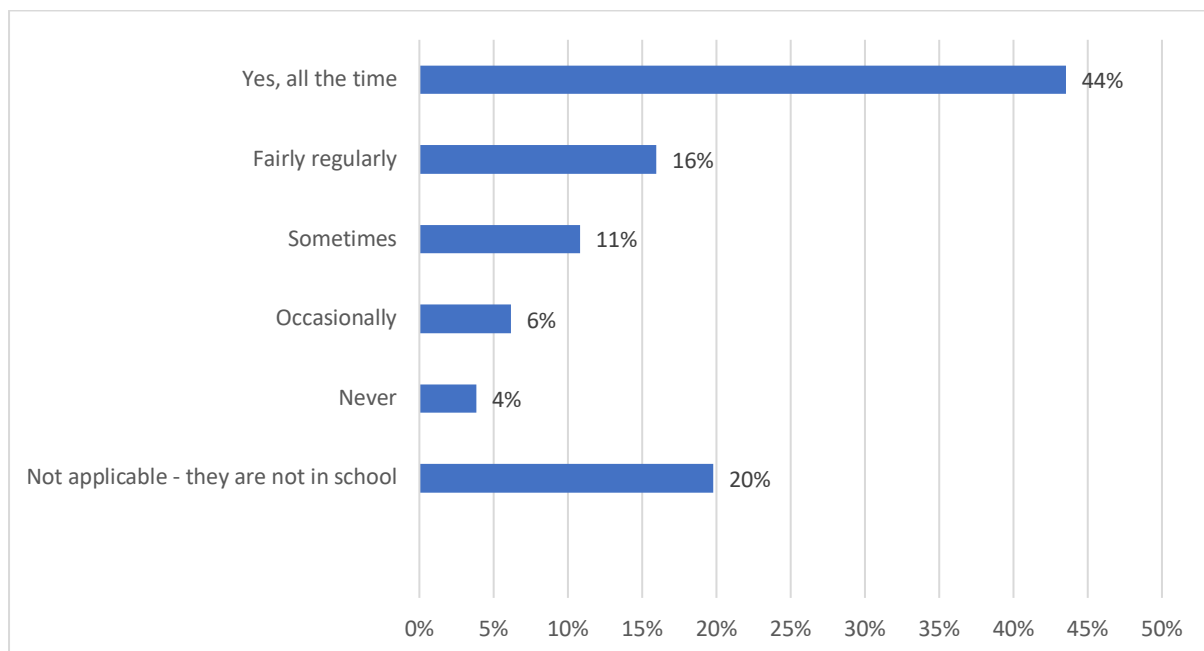


Sample size: 604

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.

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 their child had experienced EBSA at some point in their lives (and 74% had experienced it in the last year).

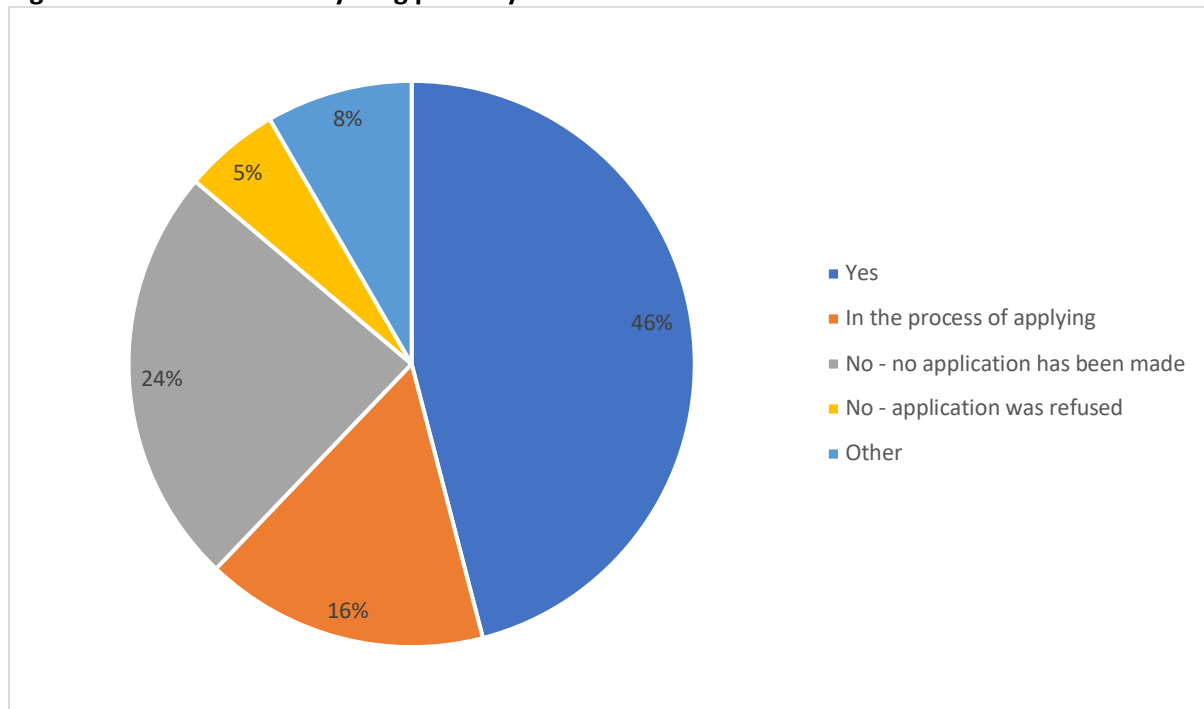
Figure 4: Does the child/young person you care for ever struggle to get into school?



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.²⁰ 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 EHCP?



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

²⁰ 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](#)

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.

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).

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.

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 (x) below shows, only 30% of parents/carers 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.

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 SEMH²¹ 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

²¹ Social, emotional and mental health

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.

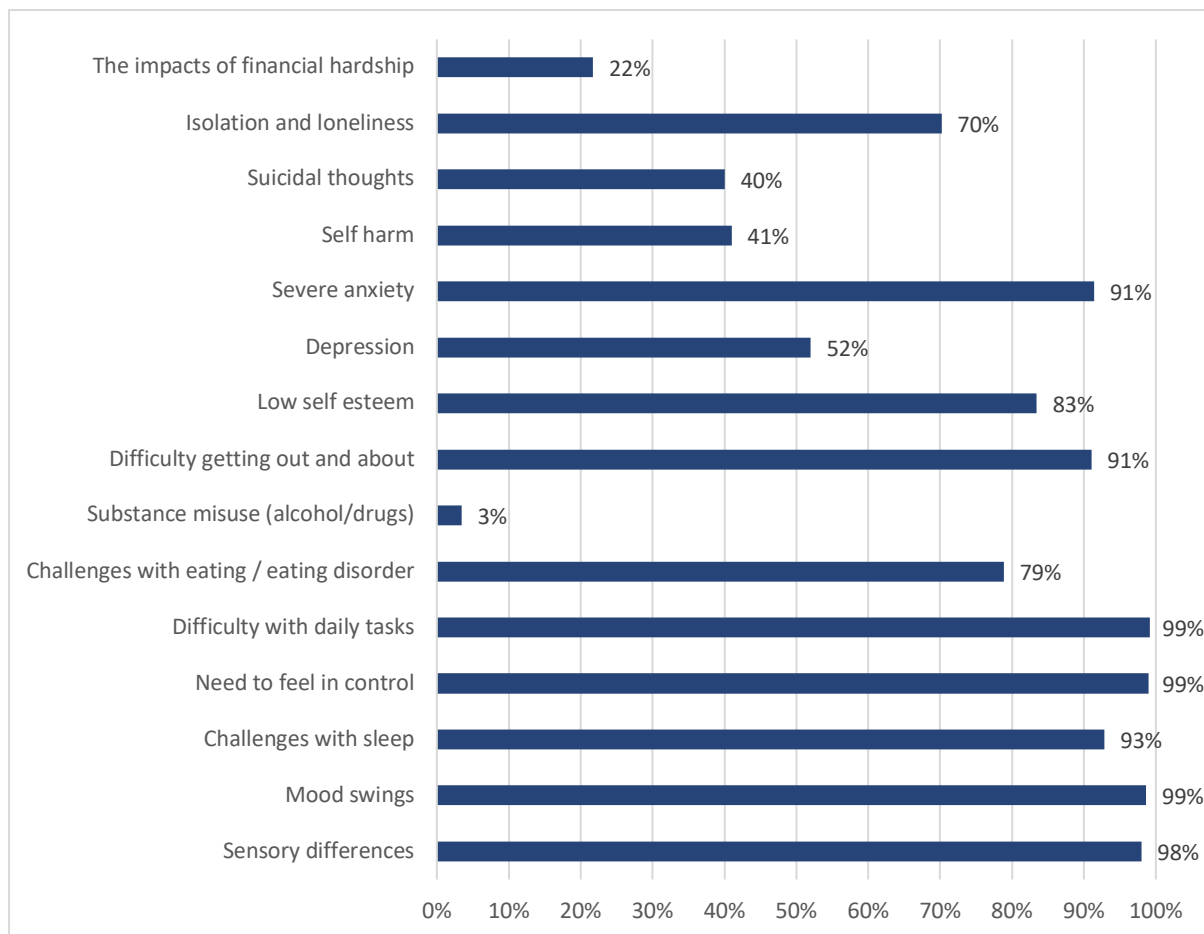
Health and wellbeing

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.

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.

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.

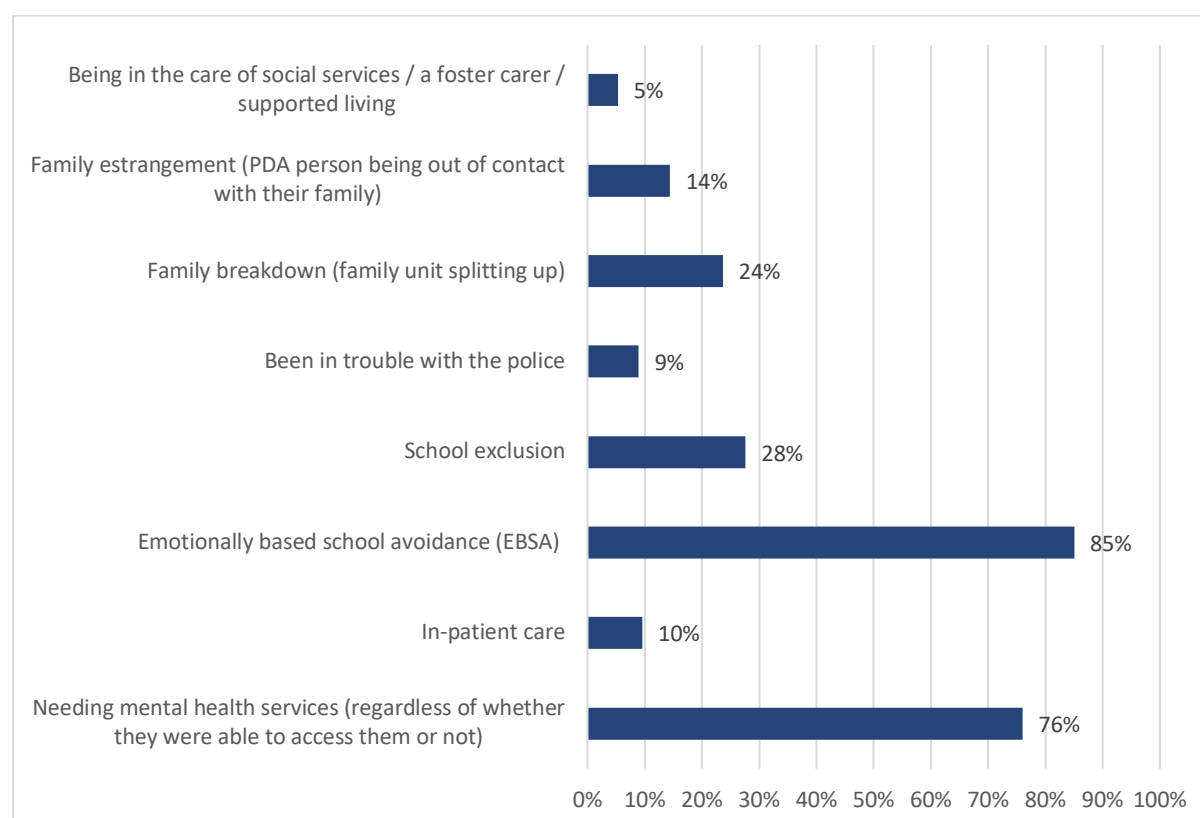
Figure 6: Has the child/young person you care for experienced any of the following?



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).²²

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.

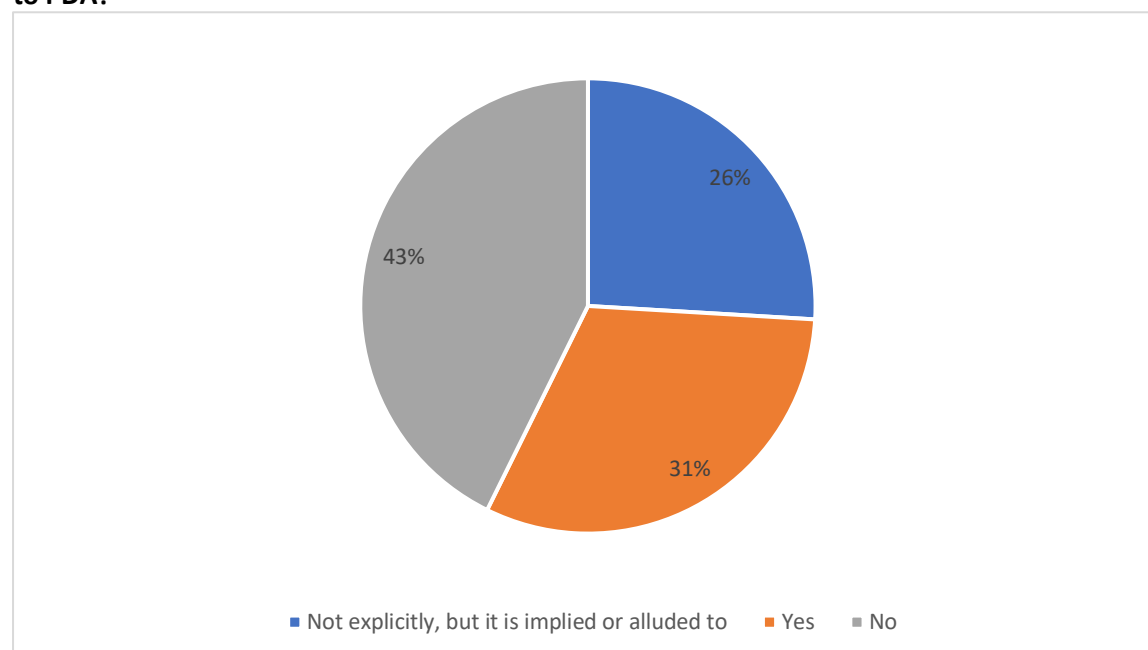
This section contains our survey data on diagnosis, services and support. A PDA profile of autism is usually identified during an autism assessment. Because there is still academic and clinical debate about the terminology and classification of PDA, recognition of PDA is currently inconsistent. Identifying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

²² 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/Caribbean/Black British; and the 7% who chose 'mixed or multiple ethnic background'.

way many people, including clinicians, currently think of autism and there are overlaps in presenting characteristics between a PDA profile of autism and other conditions.²³

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).

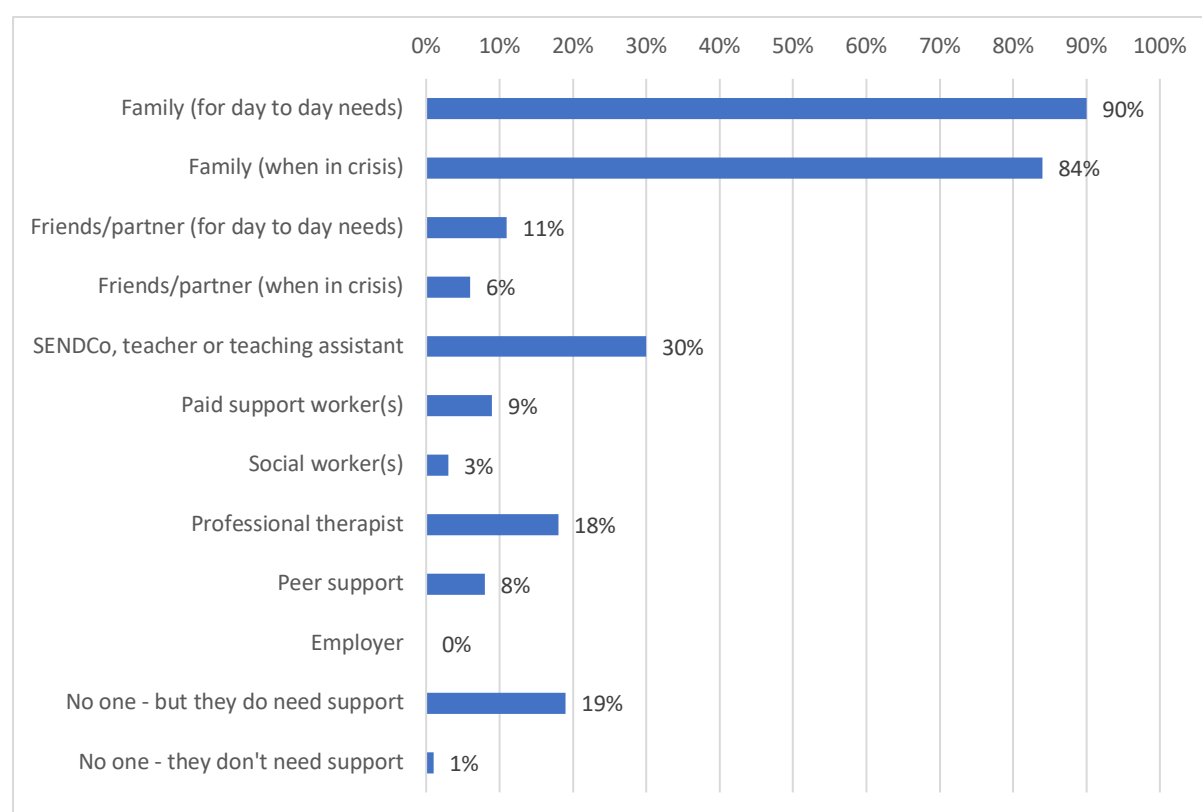
We struggled for a long time to get support and an ASD diagnosis for our child because PDA doesn't display in the way people expect autistic children to be. Our PCT doesn't diagnose PDA, just ASD with demand avoidance mentioned in the diagnostic report.

²³ 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](#).

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.

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 said their child was supported by a SENCO, teacher or teaching assistant.²⁴

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.

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

²⁴ 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.

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.

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.

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.

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."

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.

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.²⁵ 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.

²⁵ Emotionally based school avoidance/anxiety

Example 2: EOTAS²⁶

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.

²⁶ Education other than at school

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 ‘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 themselves. They are far less irritable and angry. Violent outbursts are now very infrequent. They no longer talk of hating themselves 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 themselves 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.

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.

4. The picture for PDA adults²⁷

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 bring 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.	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 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.	The hard parts are still professionals not understanding PDA. The good parts are when others do understand and use the right

²⁷ 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.

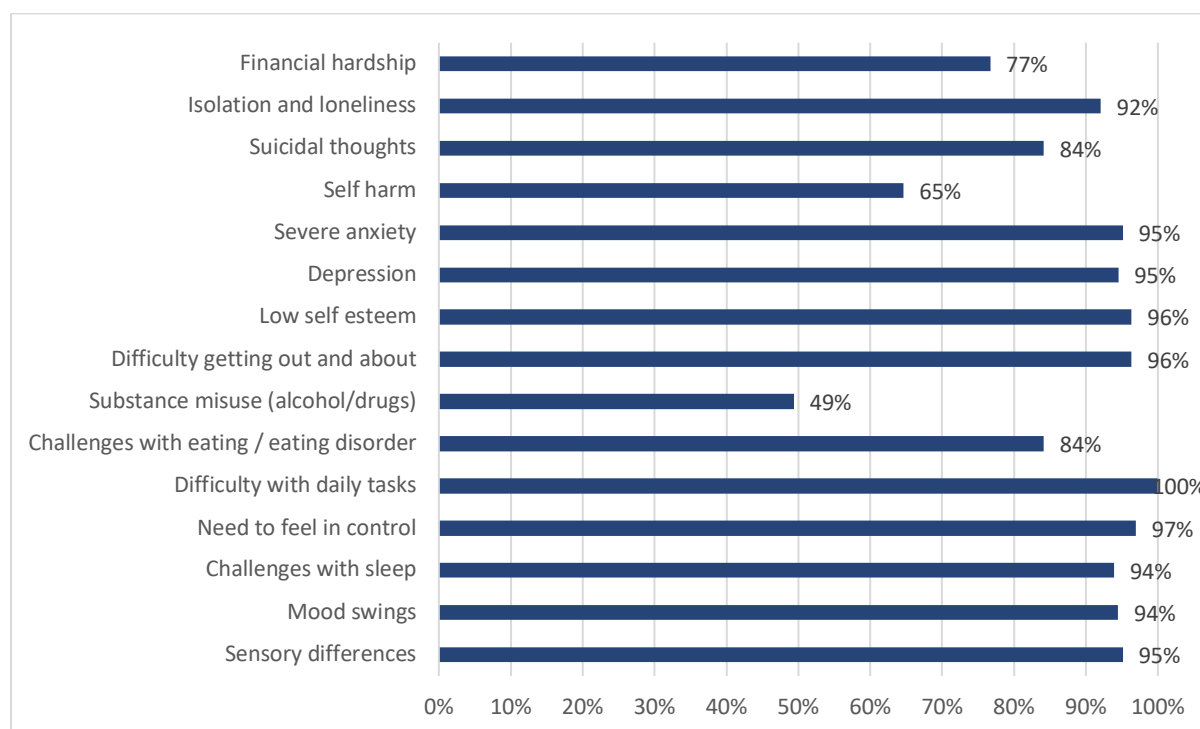
They could not understand my profile of autism as the strategies did not work.	strategies. I feel I am really starting to understand myself properly now.
Unrelenting judgemental. I would be told that not showering every day or brushing my teeth was disgusting and offensive. I knew all of these things 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.	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.

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.

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)

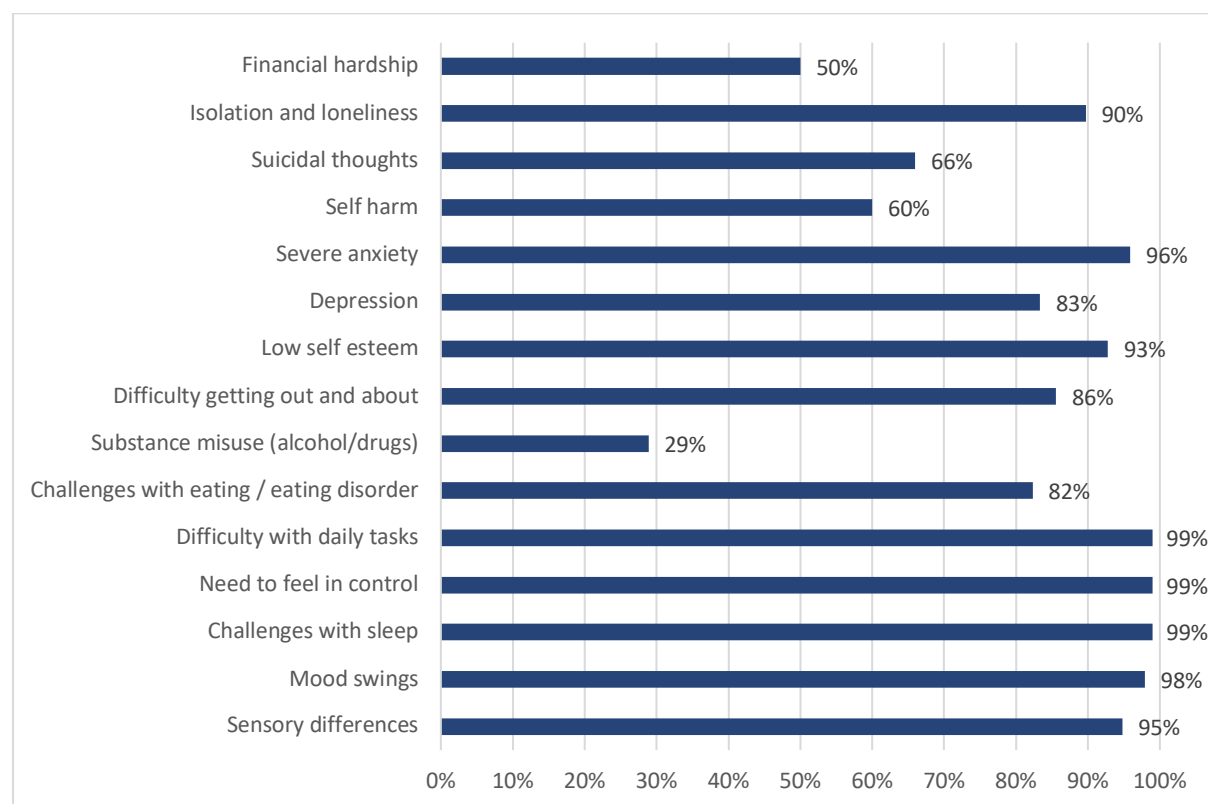


Sample size: 164. Data refers to those who answered either 'yes – in the last year' or 'yes – but not in the last year'.

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.²⁸

²⁸ 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.

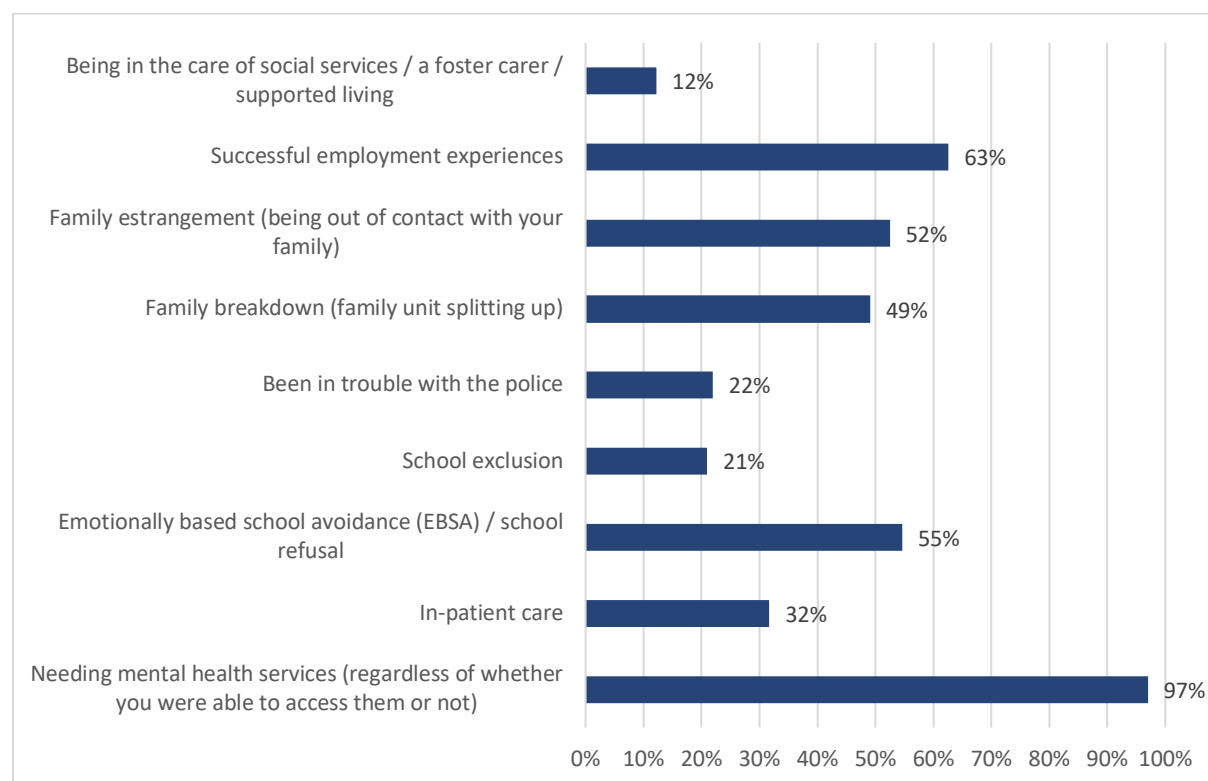
Figure 11: Has the PDA person you care for experienced any of the following? (Parents/carers of over 18s)



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)

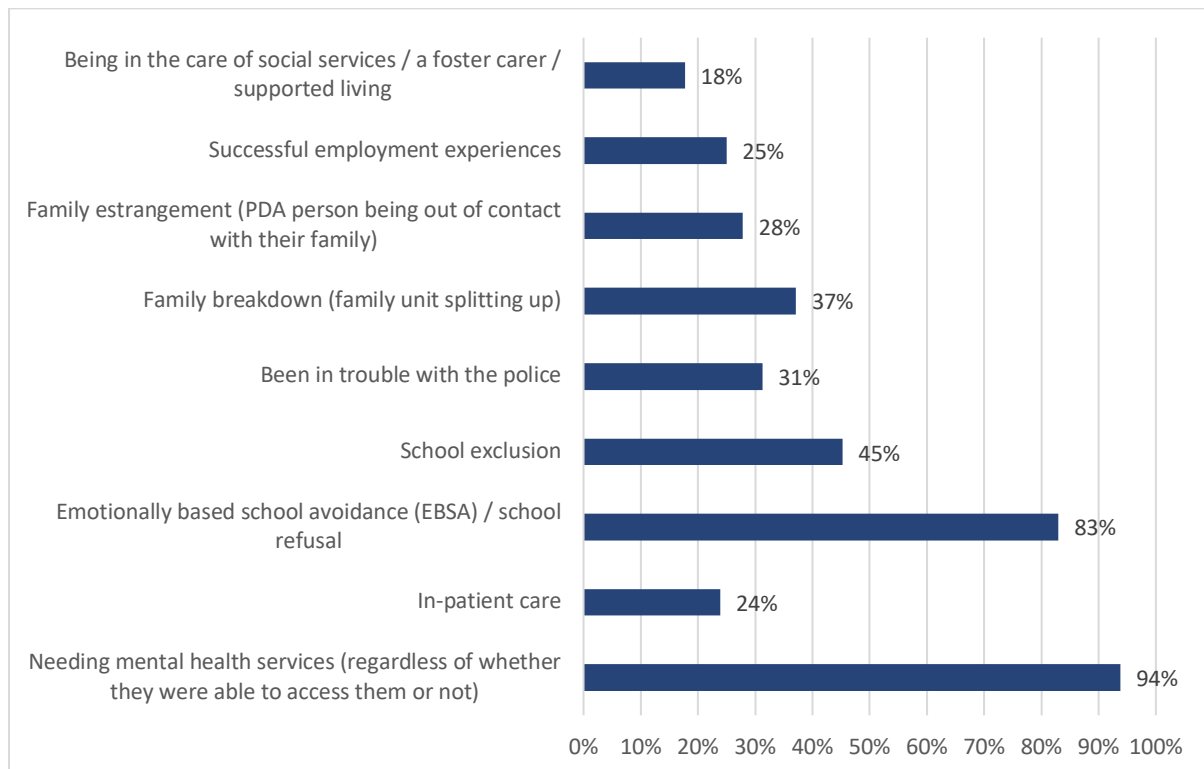


Sample size: 165. Data refers to those who answered either 'yes – in the last year' or 'yes – but not in the last year'.

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.²⁹

²⁹ 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.

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



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.³⁰ For example:

- 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).

³⁰ 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/Caribbean/Black British; and the 7% who chose 'mixed or multiple ethnic background'.

The most commonly mentioned health concern for PDA adults related to mental health.³¹

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.

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.

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.

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.

³¹ 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

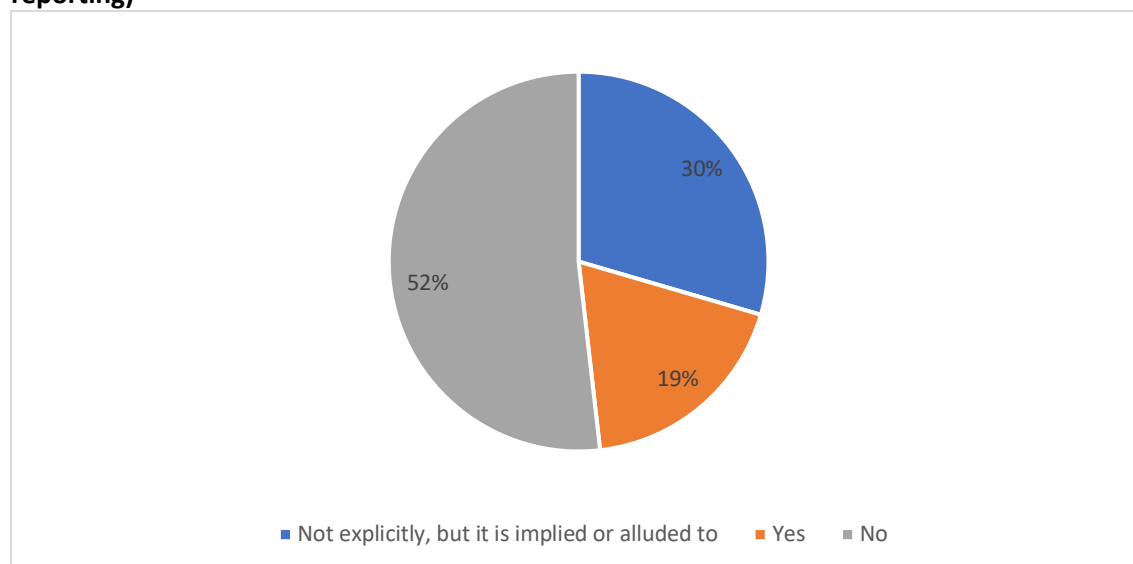
Diagnosis, services and support

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.

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 many people, including clinicians, currently think of autism and there are overlaps in presenting characteristics between a PDA profile of autism and other conditions.³²

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)

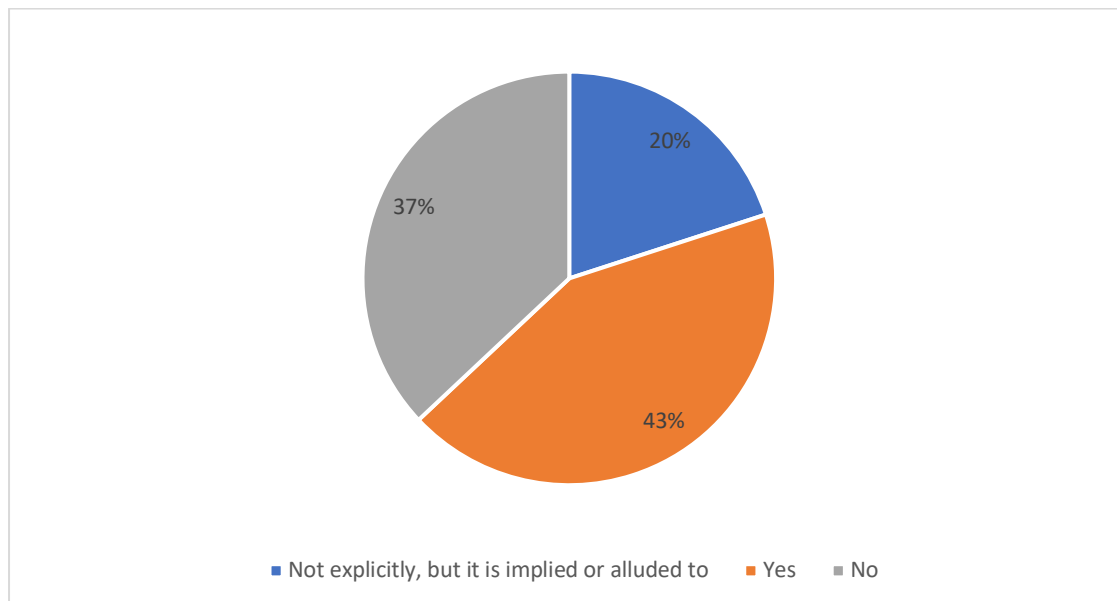


Sample size: 166

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.

³² 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](#).

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



Sample size: 100

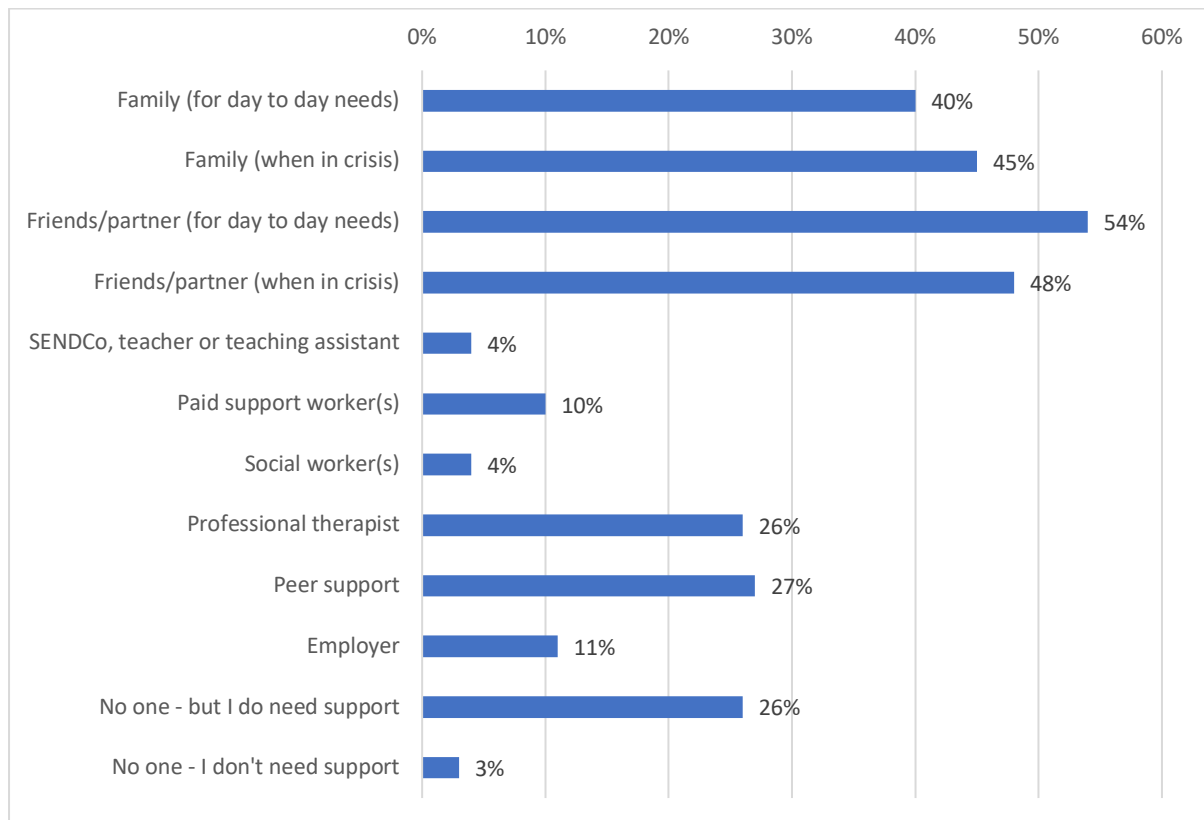
In their open-ended responses, PDA adults spoke about the difficulty of getting a diagnosis for PDA, and they also described how the struggles they faced had been misdiagnosed by medical professionals:

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.

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.

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.

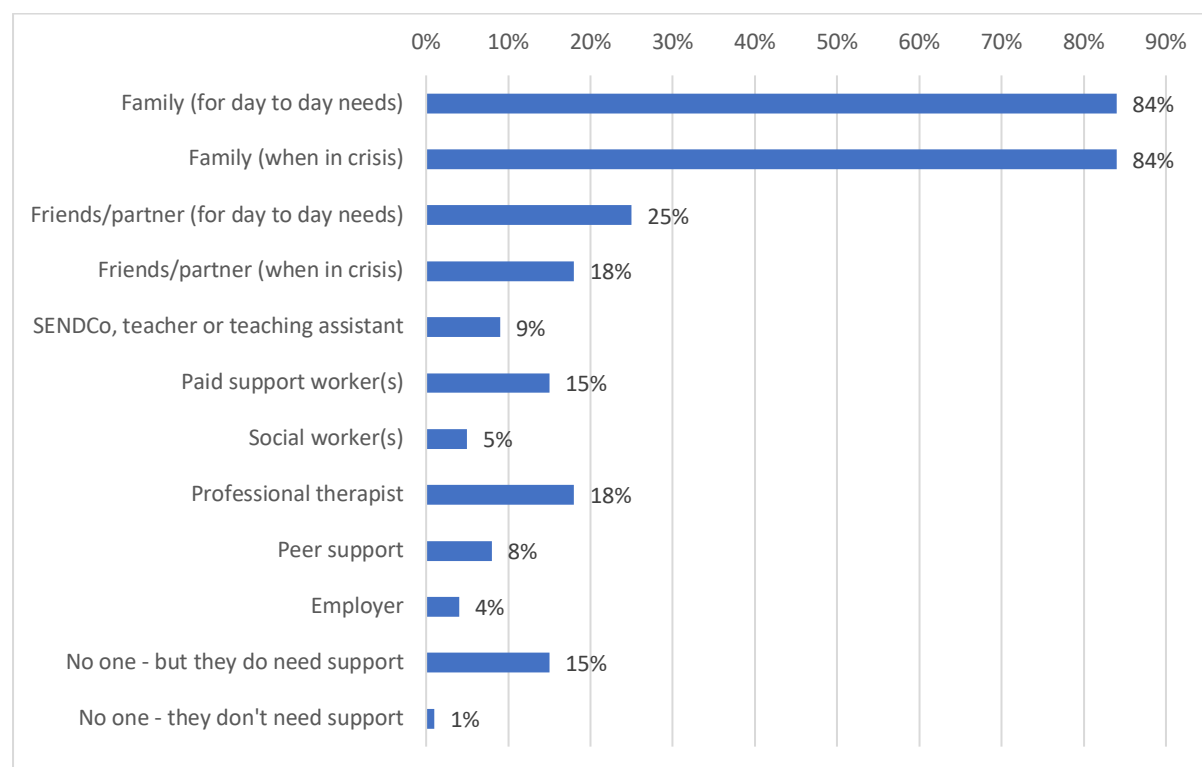
Figure 16: Who supports you? (PDA adults – self-reporting)



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)



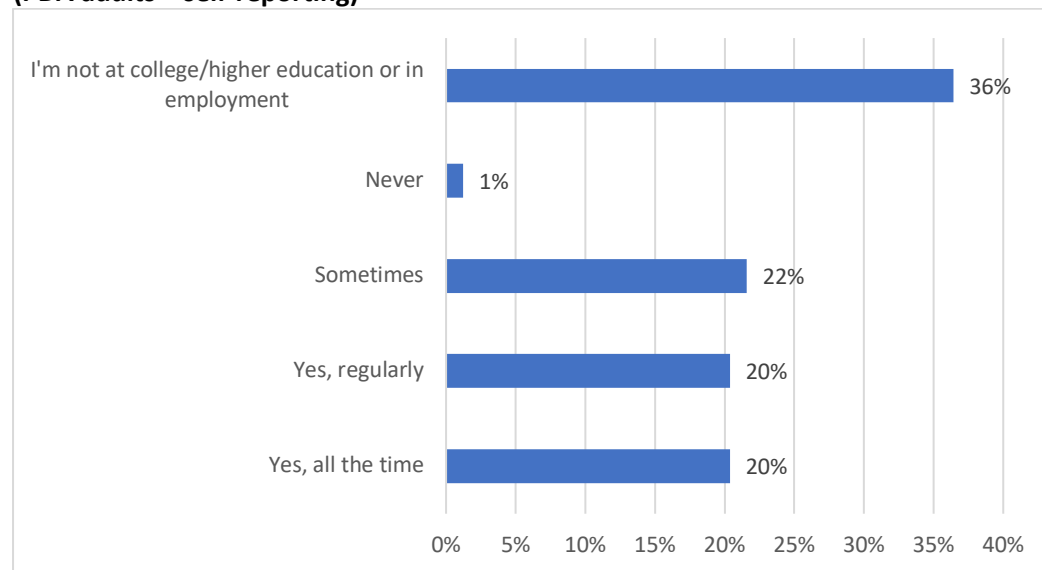
Sample size: 105

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.

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.

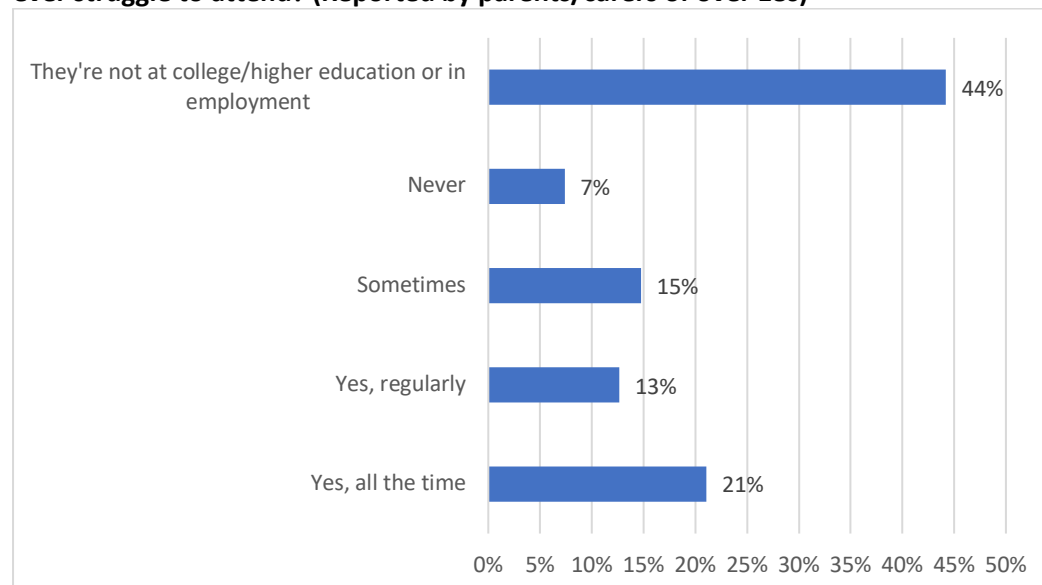
Figure 18: If you are in college/higher education or employment, do you ever struggle to attend? (PDA adults – self-reporting)



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). The financially precarious nature of daily life as a PDA adult was illustrated in respondents' open-ended responses:

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.

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.

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.

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.

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.³³ Though work itself caused the majority of it.

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 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.

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!

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.

³³ Welfare benefits vary across different countries and contexts. In some countries, employees are able to access disability support as a workplace benefit.

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:

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.

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).³⁴
- 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.

³⁴ 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.

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 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.

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

I've been working as a teaching assistant in SEN/SEMH schools³⁵ 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!

³⁵ 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!

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.

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.

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 low demand parenting strategies, but find that progress is stalled reversed when these strategies 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.

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.	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.	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.	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.	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.	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.

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.

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.

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.

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.

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.

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.

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 "battered away" / made to feel like a fussing parent because it feels as though everyone has a one-dimensional view of what autism looks like.

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!

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 PDA strategies 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 carers³⁶ 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),³⁷ and 13% have experienced allegations of parental alienation.³⁸ These data concur with other recent work on the topic of parental blame and the PDA profile of autism.³⁹

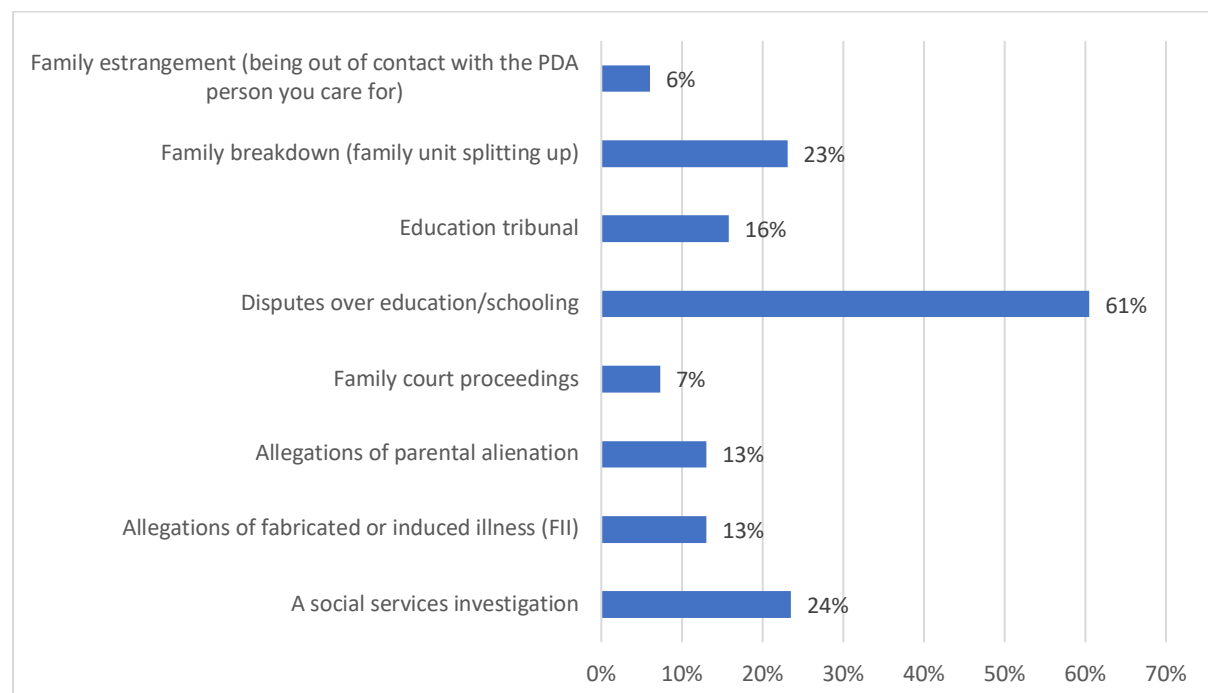
³⁶ Parents/carers of PDA people both under and over 18 years old (727 respondents in total).

³⁷ 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](#)).

³⁸ 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](#)).

³⁹ Running, A. and Jata-Hall, D. (2023) Parental blame and the PDA profile of autism. [Published online](#)

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



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.

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.

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.

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!

Two social workers sat with the NHS diagnosis in hand insinuating I had Munchausen Syndrome and was putting it all on my child.

One time I 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.

Intersectionality

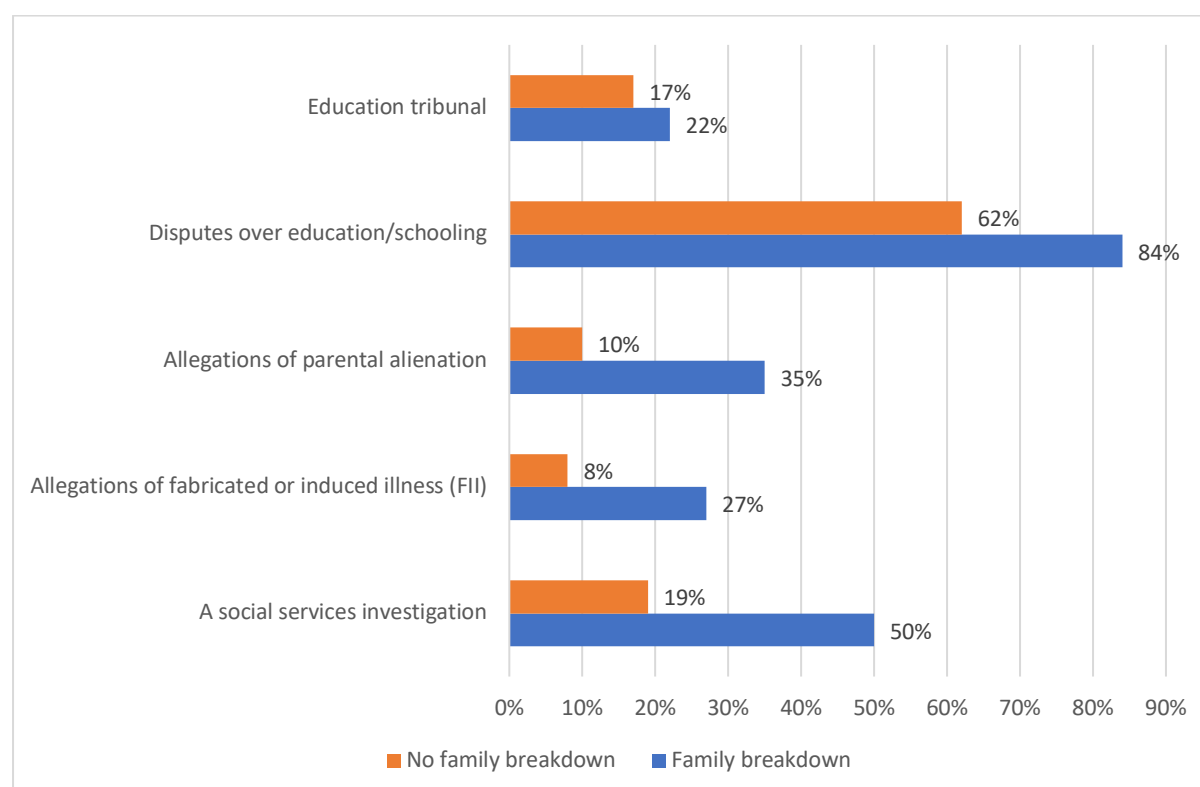
Some parents and carers are particularly vulnerable to parent blame. Parents and carers of PDA children from ethnically minoritised backgrounds were more likely to report being subject to a social services investigation (36% compared to 21% of parents of children from white backgrounds).⁴⁰

Our data also showed marked differences between parents who had experienced family breakdown and those who had not.⁴¹ 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).

⁴⁰ 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/Caribbean/Black British; and the 7% who chose 'mixed or multiple ethnic background'.

⁴¹ 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)

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



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.⁴²

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.

⁴² [Single parent facts and figures, Gingerbread, 2019](#)

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 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.

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.