



PDA and Mental Health

Research briefing, November 2023

This briefing presents an overview of findings around mental health from the PDA Society's 2023 'Being Understood' survey.

Key messages

- PDA people of all ages are experiencing high levels of mental distress and mental health challenges, including: anxiety, depression, isolation and loneliness, low self-esteem, self-harm and suicidal thoughts.
- The mental distress experienced by PDA people is often caused by a cross-societal lack of awareness and understanding around PDA.
- PDA people need access to tailored support and services, as well as timely assessment and diagnosis conducted by professionals with a sound understanding of the PDA profile of autism.

Introduction

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 May 2023, the PDA Society launched the 'Being Understood' survey to help us gather up to date information about what life is like for the PDA community. PDA people (age 17 years or over) and parents, carers and partners of PDA people were invited to take part and share their lived experience of PDA. 921 people responded to our survey, and mental health is one of the key themes emerging from our analysis of responses. This briefing provides an overview of what survey participants told us about mental health. We will publish a broader report, exploring all of the key themes, in spring 2024.

Survey methodology and responses

Our ‘Being Understood’ survey ran for three weeks in May 2023. 921 people responded to the survey. 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:¹²

- PDA people age 17 or over (170 responses)
- Parent or carer of a PDA person age 18 or over (105 responses)
- Parent or carer of a PDA child under age 18 (621 responses)
- Partner of a PDA person age 17 or over (15 responses)³

48% of survey participants identified as male, 38% as female and 7% as non-binary. 86% of participants were from a white ethnic background, and 6% from a mixed or multiple ethnic background. 60% of those completing the survey were living in England, and 32% were living outside of the UK or Ireland.

The survey was hosted online and data was stored securely and analysed 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.

What did the PDA community tell us about mental health?

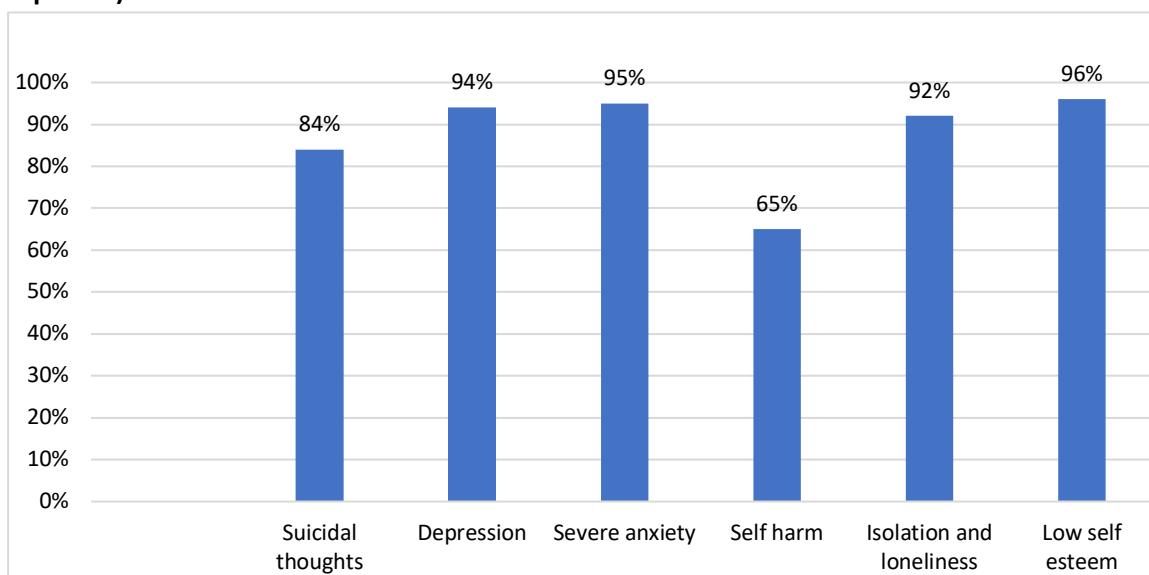
Survey participants reported high levels of mental health challenges and distress; either relating to themselves or the PDA person they care for. As Figure 1, below, shows, almost all PDA adults completing the survey on their own behalf had experienced depression, severe anxiety, isolation and loneliness, and low self-esteem at some point in their lives. The number of PDA adults reporting suicidal thoughts and self-harm was also high – 84% and 65% respectively.

¹ 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.

² 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.

³ Data from partners of PDA people have been excluded from the analysis presented in this briefing due to the small size of this group.

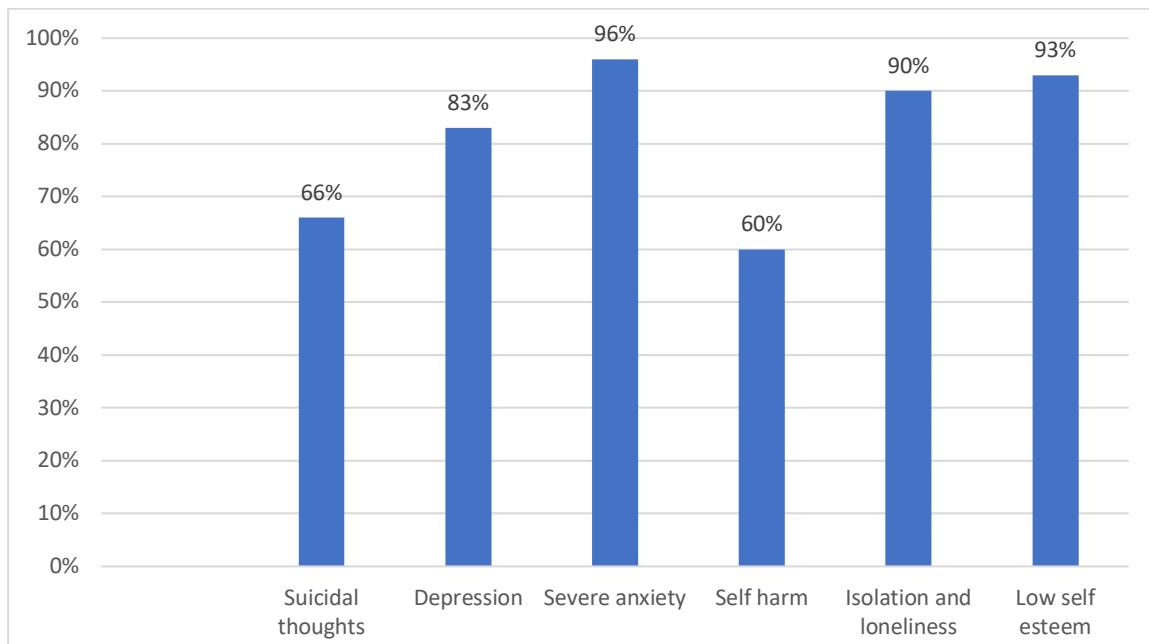
Figure 1: Mental health issues experienced by PDA adults at some point in the life course (self-reported)



Sample size: 164 PDA adults

Levels of mental distress reported by parents/carers about the PDA adults they care for were slightly lower in all categories except severe anxiety; perhaps reflecting that PDA adults may not wish to disclose everything to their parents or carers. Even accounting for this, however, the numbers are worrying. As Figure 2 highlights, 93% of parents/carers said the adult they cared for had low self-esteem, 90% said they were isolated and lonely, and 66% said they had suicidal thoughts.

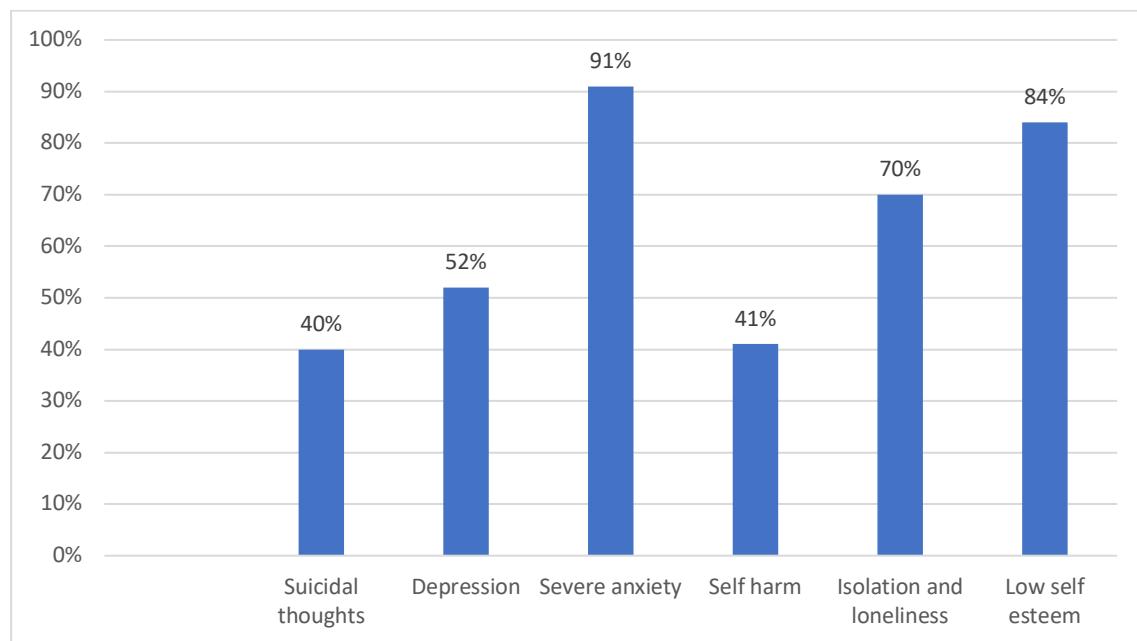
Figure 2: Mental health issues experienced by PDA adults at some point in the life course (as reported by parents/carers)



Sample size: 97 parents/carers of PDA people age 18 and over

As Figure 3, below, demonstrates, worryingly high levels of anxiety (91%) and low self-esteem (84%) were also reported by parents/carers of PDA children and young people under the age of 18. 41% of this group said the child or young person had self-harmed, and 40% said they had had suicidal thoughts at some point.⁴

Figure 3: Mental health issues experienced by PDA children at some point in the life course (as reported by parents/carers)

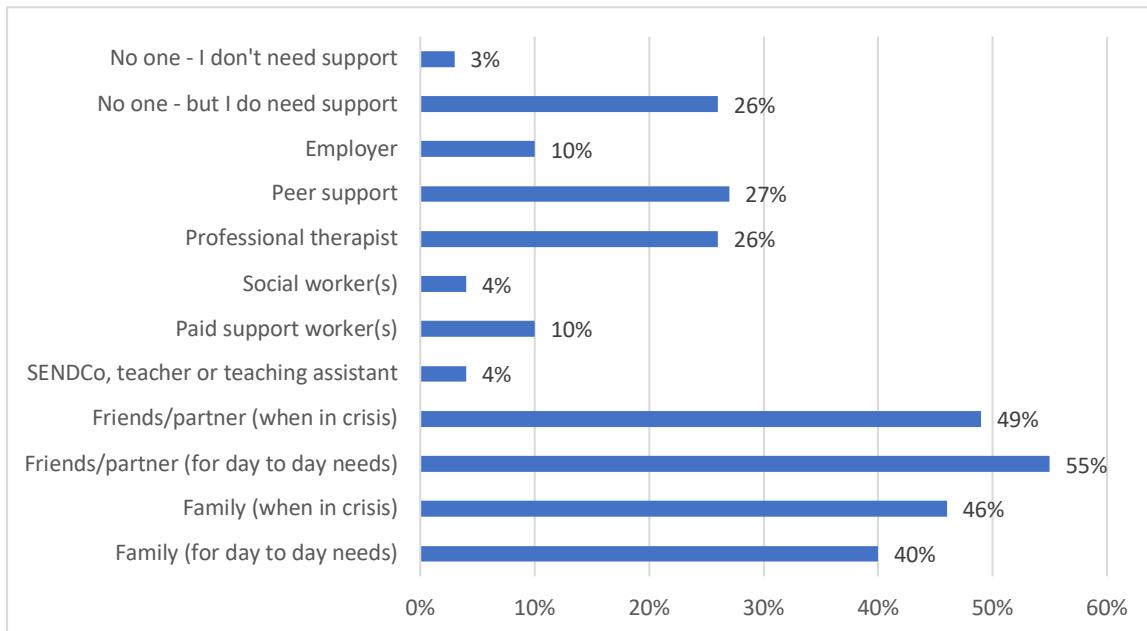


Sample size: 605 parents/carers of PDA children under 18

Survey participants were also asked where they, or the PDA person they care for, go to for support. Participants could choose as many options as relevant. As Figure 4, below, shows, the source of support most often called upon by PDA adults is friends or partners (55% of PDA adults chose this option for day to day needs, and 49% for support when in crisis), followed by family (40% for day to day needs, and 46% when in crisis). 27% of adults used peer support, and 26% were supported by a professional therapist. However, 26% said they had no one to support them, despite having a need for support.

⁴ Lower reports of some mental health issues among this group may reflect the fact that some of the children referred to will be very young, and not yet exhibiting clearly recognised or articulated signs of mental distress.

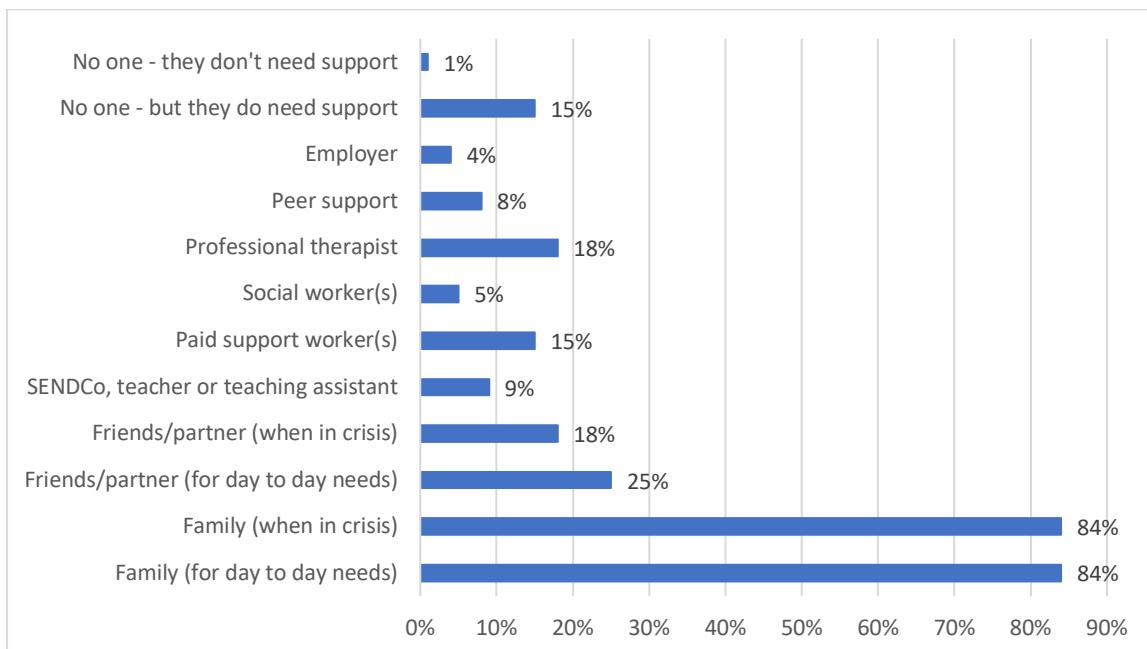
Figure 4: Sources of support for PDA adults (self-reported)



Sample size: 161 PDA adults

Parents and carers of PDA adults were more likely to say that the person they cared for received day to day and crisis support from family members (84% chose each of these options), perhaps reflecting the fact that this group of parents and carers have a close supportive relationship with the PDA person they care for, demonstrated by their engagement with the survey. It may also reflect the fact that the majority of PDA adults being cared for by this group of parents and carers were young adults between the age of 18 and 25. However, Figure 5, below, also highlights that 15% of parents and carers said that the person they care for has no support, despite needing it.

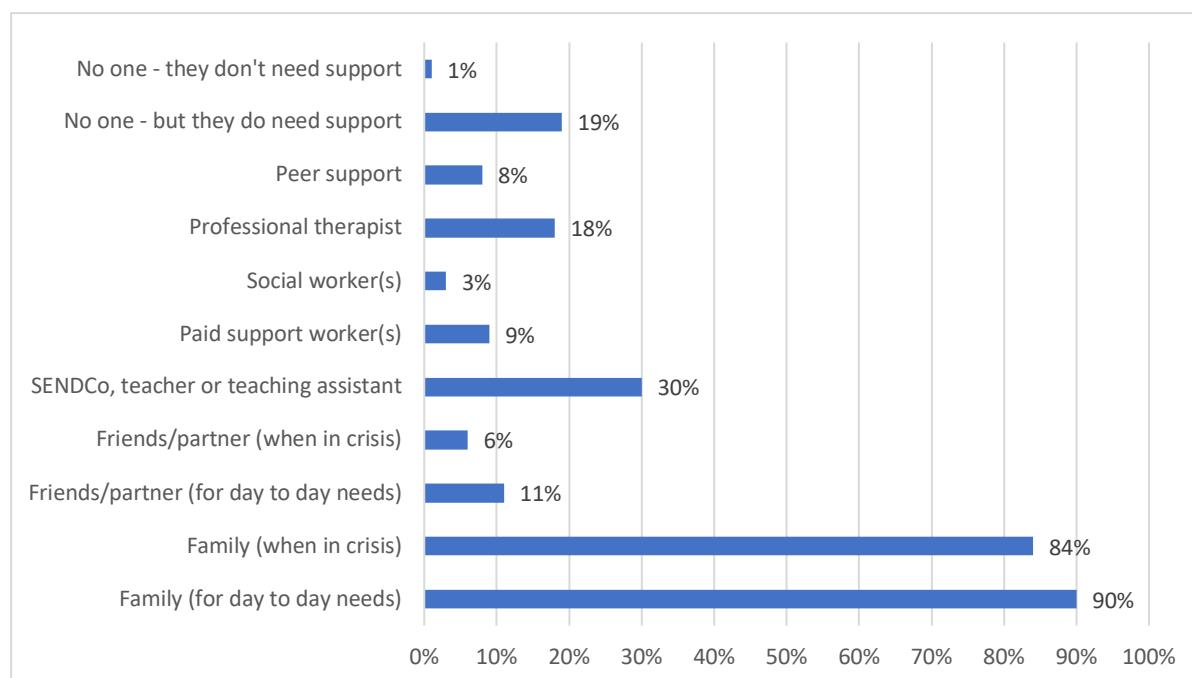
Figure 5: Sources of support for PDA adults (reported by parents/carers)



Sample size: 96 parents/carers of PDA people age 18 or over

Parents and carers of PDA children were also more likely, unsurprisingly, to say that the person they care for were largely supported by family members. As Figure 6, below, shows, 90% of this group said the child they care for received support from family for day to day needs, and 84% said family support was also important when the child was in crisis. Another important source of support for PDA children was SENDCos, teachers and teaching assistants, with 30% of parents/carers selecting this option. 19% of this group, however, said that the PDA child they cared for did not receive support, despite needing it.⁵

Figure 6: Sources of support for PDA children (reported by parents/carers)

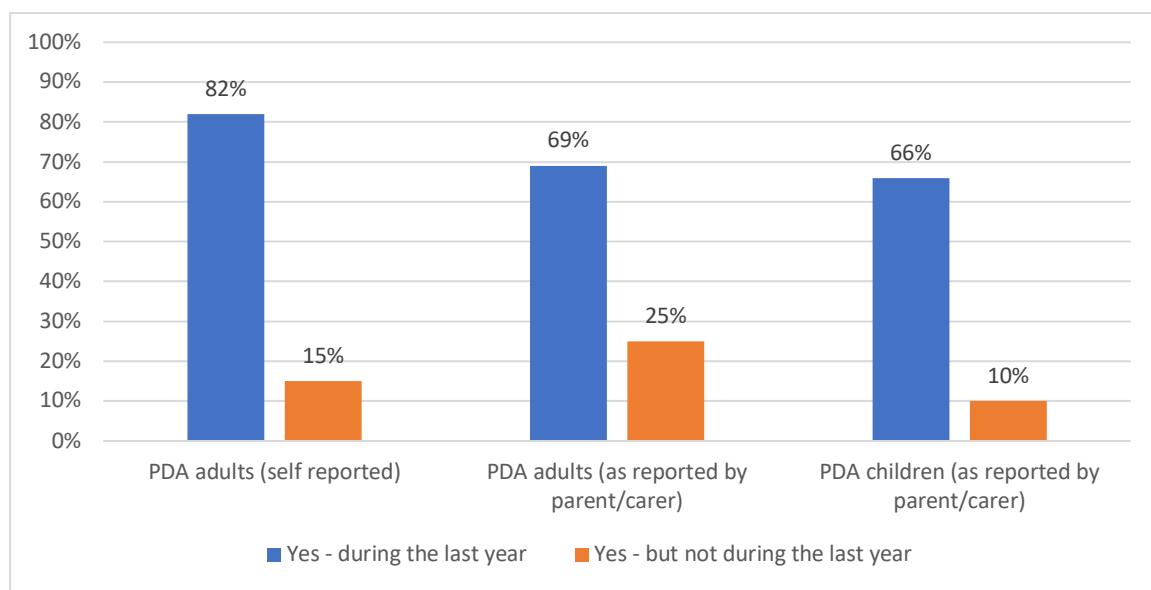


Sample size: 592 parents/carers of PDA children under 18

We also asked survey participants to tell us if they, or the PDA person they care for, had needed mental health services, regardless of whether they were able to access them or not. As Figure 7, below, highlights, demand for these services was high across all groups of participants. 82% of PDA adults reported needing mental health services in the last year alone, while 69% of parents/carers of PDA adults and 66% of parents/carers of PDA children chose this option.

⁵ These results contain an anomaly in that 19% of parents/carers said that the child they care for does not have any support, at the same time as 90% saying that family supported the child with day to day needs and 84% saying family supported the child when in crisis. It is likely that some parents/carers chose both the 'family support' and the 'no support' options because they wanted to show that the child did not have any support outside of their family.

Figure 7: Needing mental health services (regardless of whether able to access them)



Sample size: 165 PDA adults, 97 parents/carers of PDA adults, 605 parents/carers of PDA people under 18,

In the open-ended sections of our survey, participants added information that provided context to their answers around mental health. PDA adults described many years of struggling to understand what they were experiencing, often being misdiagnosed along the way:

Life was tough in every way. I wasn't diagnosed till in my 40s and spent 25 years or so bouncing between psych hospitals and failing life. I was misdiagnosed with BPD, bi polar, chronic depression, anxiety disorders and constantly medicated, never finding anything that helped in the slightest. It was a constant cycle of fails (PDA adult).

I didn't understand what it was. I thought it was depression. I tried to keep up with university and pushed through the often daily and multiple panic attacks, I barely made it through high school. I would fall apart, sometimes have to keep working while I could barely manage any part of my life and slide into suicidal depression because I was so tired. And then push myself again (PDA adult).

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

Meanwhile parents and carers of PDA children and young people described heart breaking situations where the mental health of those they cared for had deteriorated because PDA had not been recognised:

At the age of seven he talked about not deserving to live, and the world being a better place without him (Parent of under 18).

My son had a mental health crisis for over two years- self harming, suicidal ideations and an attempt. No support was given because professionals didn't know how to engage him and their language and approaches only made things harder. CAMHS weren't willing to accept PDA (Parent of under 18).

Normal parenting didn't work, discipline didn't work, everyone thought I was just a bad parent and that I needed to be firmer, yet my child was just getting worse whenever I tried to be firmer, at five years old he talked of wanting to die because life was just hell for him, and people still wanted me to be firmer with him (Parent of under 18).

Questions around mental health in our survey focused on PDA people themselves, rather than parents and carers. But it was clear from some of the answers from parents and carers that they also experienced mental health challenges and felt unsupported in these.

None of the parenting strategies I was told to use worked. I felt like a failure as a mum. I had no support. I asked for help and got given a leaflet about tantrums. I became severely depressed (Parent of under 18).

Hearing from your child some harrowing reasons why he no longer wants to live was devastating and took a massive toll on my mental health (Parent of over 18).

What has changed over time?

When we compare some of the data in the figures above with data collected by the PDA Society in 2018, we can see that the mental health of PDA people has not improved over the last five years.⁶ In 2018, 19% of parents/carers of PDA children reported severe depression in those they cared for, compared to 52% saying in 2023 that their child had experienced depression at some point.⁷ 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%. 73% of parents/carers reported their child had low self-esteem in 2018, and in 2023 this has risen to 84%. Levels of reported self-harm among PDA children has risen from 23% in 2018 to 41% in 2023.⁸

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 pandemic, the cost of living crisis, and continuing cuts to the funding of health and support services.⁹ In addition, the latest data

⁶ It is important to note, however, that the PDA Society 2018 survey questions were not identical to those used in 2023. Therefore, the 2018 survey cannot be used as a baseline for all data in the 2023 survey.

⁷ 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.

⁸ Our 2018 survey did not include a question about suicidal thoughts, so we have no comparable figures for this.

⁹ 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](#)

shows that the number of people in contact with mental health services, as well as the number of children and young people accessing mental health services, is rising.¹⁰ As we know that autistic adults and children experience mental health issues in higher numbers than the general population,¹¹ and autistic people have been identified by the UK government as a priority group for targeted intervention for prevention of self-harm and suicide,¹² the experiences of PDA autistic people within this worsening mental health landscape is cause for great concern.

What changes do survey participants want to see?

Mental health services and support tailored to PDA

PDA adults and children should be able to access mental health support and services that are appropriate and tailored to their needs. Survey participants told us that mental health interventions and therapies designed for neurotypical people often do not help, and can even cause harm. Participants described situations where they or their child had tried talking therapies, anxiety management strategies, and ‘calming’ techniques such as meditation, with no positive results. They also told us that therapies often used for ‘typical’ presentations of autism, such as ‘social skills’ and ‘behaviour’ training, did not work for them or their children, and had a negative impact on self-esteem and mental health.

CAMHS’ CBT approach to anxiety is aimed at neurotypical children and young people, and is unsuitable for neurodiverse people (Parent of under 18).

Cognitive and reasoning therapies - asking her to dwell on the negative thought patterns or emotions behind her behaviours - is generally counterproductive. She gets frustrated because she cannot express herself and this just leads to her feeling that the therapist doesn't understand her (Parent of over 18).

We asked survey participants to tell us what one change would make the greatest positive difference to their lives. Improvements to mental health services was a commonly expressed theme:

Mental health support for our child from someone who actually understands PDA. Most have not either heard of it or learned anything about it. And their approaches tend to be typically behaviourist approaches which just don't help (Parent of under 18).

More mental health support. The level of care my young person has is negligent/dangerous. I am left trying to single-handedly support their mental health and I am not an expert (Parent of over 18).

¹⁰ NHS England (2023) [Mental health services monthly statistics dashboard](#), May 2023

¹¹ Autistica (2019) [Children and young people's mental health](#); Autistica (2019) [Adult mental health](#)

¹² Department of Health and Social Care (2023) [Suicide prevention in England: 5-year cross-sector strategy](#)

PDA-friendly environments

Our survey participants told us that when environments are ‘PDA-friendly’ and PDA approaches are followed – in the home, in education, in the workplace and in service provision, mental health outcomes improve.

Among parents and carers of PDA children and young people, there were two areas that were frequently chosen to demonstrate how a PDA-friendly environment can improve mental health. The first was education.¹³ Parents and carers described the benefits of child-led approaches, unschooling and home education, attributing the mainstream education system as a major contributor to poor mental health outcomes in PDA children:

We de-registered to home educate. By that point my daughter's mental health was in serious decline - she was depressed and started to self-harm as well as have suicidal ideation. Very slowly she started to recover from what I now believe was autistic burnout. Another three years on from that point and she is now well enough to consider part-time college courses (Parent of under 18).

Child-led home education has provided more calm, less demand on our young person. Self-harm has completely disappeared (Parent of under 18).

The second area frequently mentioned by parents and carers of PDA children and young people was parenting approaches and strategies:

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 (Parent of under 18).

We stopped forcing, implemented a low demand approach. We gave him choice, we take his lead, we gave him the autonomy he craved. We are still a work in progress, he carries a lot of trauma with him from school but we have a young boy who has gone from multiple a day physical meltdowns to very minimal a week. We have a young boy that can step into the outside world some days. We have a young boy that is eating at least once a day. We have a way to go and it's taken two years to get to this point but by making the changes we have so much positive progress (Parent of under 18).

PDA adults described how their mental health improved in low-demand environments. When talking about work or study, they told us that having options for flexible, part-time and home working, or being self-employed, had benefits for their mental health. They also fared better in work or study places with less hierarchy and more autonomy:

The college I'm at now is great because there are no authority figures. The classes are small and the teachers are called by their first names and don't have many rules. I've found that

¹³ Education will be one of the themes discussed in the full report of survey findings, due to be published in spring 2024.

this low demand environment works really well and my attendance has improved a lot (PDA adult).

I try to lower my demands at home so work isn't as exhausting. Some managers know how to talk to me to get results, and some just get my back up. I do well with being given choices and options (PDA adult).

Often participants found, however, that in environments that were not PDA-friendly, they needed to make a change themselves, in order to protect their mental health:

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 (PDA adult).

Accessible and appropriate assessment, diagnosis and follow on support

As some of the excerpts above from PDA adults highlight, failure to diagnose PDA at the right time can lead to decades of mental distress and misdiagnosis. In response to our question about one change that would make the greatest positive difference to lives, many participants stressed the importance of diagnosis from trained, knowledgeable professionals:

A diagnosis would be good. I'm 43 now so not sure it will make any difference but I feel I owe it to the younger me to help them understand that I wasn't crazy, weird, too emotional - just misunderstood by myself and others (PDA adult).

If other people understood PDA better and it wasn't a lottery for diagnosis. It's a fight to get a diagnosis. We have been turned down by the NHS for an autism assessment as she doesn't present like a typical male presentation of autism. Being both female and PDA means it's going to be challenging to get a diagnosis (Parent of under 18).

Just as important as diagnosis to our survey participants was follow-on support (and support while waiting for diagnosis) from knowledgeable professionals and services. They told us that the one change that would make a positive difference to their PDA person's life was:

Having access to support services and benefits without having to constantly fight against the system to prove our case (Parent of under 18).

Having a full-on pathway map of support going forward. To know that my son can live a happy and meaningful life, especially when I'm gone (Parent of under 18).

When PDA is accurately diagnosed within a reasonable timeframe, and PDA people and their carers are given appropriate and meaningful support, the impact on mental health can be profound. As one parent told us:

Since diagnosis we've had more support in general and professionals understand him. They have been able to take training courses in PDA and PACE, and the approaches are then used to support him correctly. This has meant that he's more regulated, the pressure is lower and he is happy again. His mental health is in a much better place (Parent of under 18).

Survey participants were also keen to stress that the structural and institutional changes needed to make sure that all PDA people can access diagnosis and support that is appropriate for their needs

must be accompanied by societal changes in attitudes, understanding and awareness around PDA. One PDA adult told us:

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 makes me feel I can be loved and wanted. I'm starting to feel like the PDA is okay. I can work with it instead of trying to snuff it out (PDA adult).

To find out more about the changes needed to improve the mental health and wellbeing of PDA people, see our briefing PDA Lives Worth Living.

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