



Hannah's reflections:

The story for PDA adults





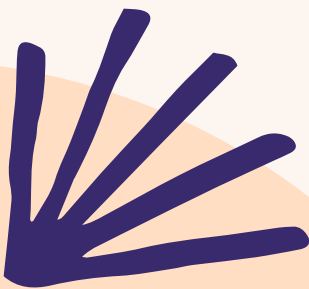
Hannah

I'm Hannah and I am a PDA autistic ADHDer neurodivergent woman. I help neurodivergent people and their families own who they are and understand themselves so they can create happier futures for their family. I'm also a teacher of neurodivergent children, predominantly PDA autistics, autistics, ADHDers and learning disabled people.

In this section of the report I will look at what PDA adults have said about their lives in their responses to PDA Society's 2023 survey and try to help you understand the statistics through the lens of my lived experience.

I hope this report can be a place for you to safely learn about PDA, and to understand that our experiences are layered. I can find discussion of PDA harrowing because people describe us as complex and that can be heard as (and meant as) difficult - and this can be a barrier to caring or trying to help. There are simple ways to be supportive of, or co-exist with, PDA people. I hope for people reading this report that seeing people speaking so openly and honestly will show you two things:

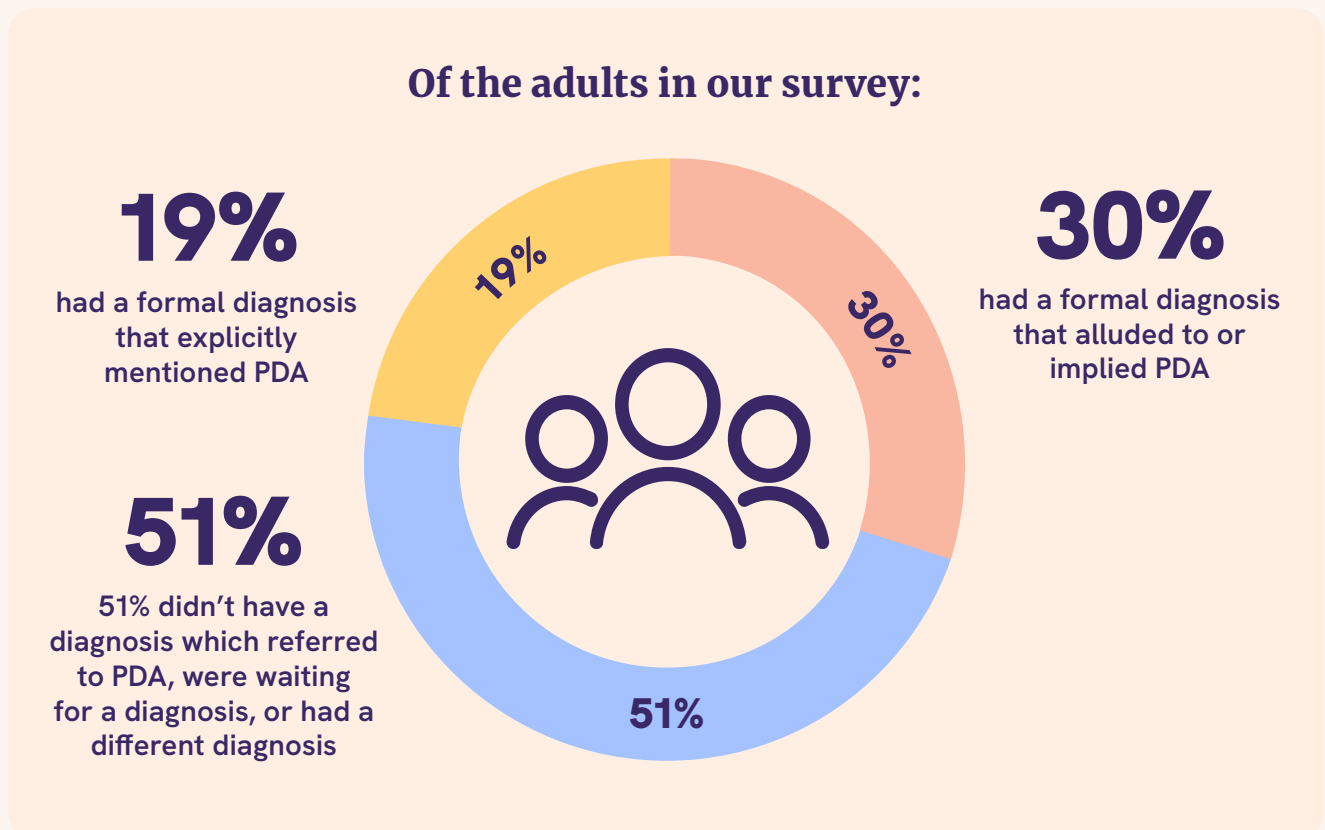
- That PDAers are a group in their own right that need to be accounted for and supported
- That we are members of the general community who have value and deserve kindness as much as everybody else does





Knowing ourselves

The adults who responded to our survey identified as PDAers. Some have a formal diagnosis of autism, with or without a PDA profile, and some were self-identified.



“My life was a rollercoaster before knowing about PDA. I received an autistic diagnosis from the skin of my teeth, but even then I felt out of place from the rest of the autistic community.”

- Billie

“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, bipolar, chronic depression, anxiety disorders and constantly medicated, never finding anything that helped in the slightest. It was a constant cycle of failures.”

- Jake



Hannah

Here are two 'before and after' examples from the survey which I thought were good examples of the difference knowing we are PDA can make to our lives.

Charlie's story

“Before 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.

Now I know: 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.

Ben's story

“Before I knew about PDA: I did not understand any emotions I was feeling. I could not understand how anxious I felt for the majority of my life. So many people who worked with me blamed me for my behaviour. They could not understand my profile of autism as the strategies did not work.

Now I know: The hard parts are still professionals not understanding PDA. The good parts are when others do understand and use the right strategies. I feel I am really starting to understand myself properly now.”



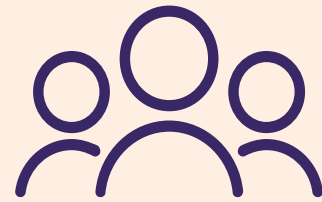
Daily challenges and mental health



Hannah

When I read the statistics in this report, I wasn't surprised. Most of my PDA friends, including myself, have had periods of isolation and, for me, all the other things we experience are connected to that. It's the experiences listed here that make us isolated and lonely, and the need to feel in control. For me there is often safety in isolation. I'm not going to speak for other people in the 8% who don't experience this, but I do wonder how many of those people are saying 'I'm not isolated or lonely because I've made the choice to be alone'? There were times where I would isolate myself and choose to be alone because I didn't have anything left to just manage, or when it felt like that was my only option because if I did anything else it would make everything worse.

Of the PDA adults who responded to the survey



92%
experience
loneliness and
isolation



94%
experienced
mood swings



95%
have sensory
differences



96%
have low
self-esteem



94%
have challenges
with sleep



96%
have difficulty
getting out
and about



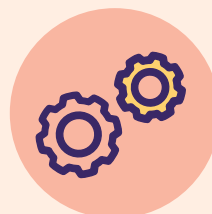
97%
have needed
mental health
services



84%
experienced
suicidal
thoughts



65%
had self-harmed
at some point
in their lives



97%
need to be
in control



There were clear gender and ethnic disparities in the mental health experiences of PDA people:

Male adults were more likely to report suicidal thoughts



64%

Male adults

44%

Female adults

45%

Non-binary adults

Male adults were more likely to report substance misuse



40%

Male adults

17%

Female adults

28%

Non-binary adults

The impact of ethnic disparities was clear in the survey data



50%

PDA adults from ethnically minoritised backgrounds reported having needed in-patient care

31%

PDA adults from white backgrounds reported having needed in-patient care



Hannah

Another experience that was very relatable was that 97% of PDA adults have needed mental health services at some point. People in the survey 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.”

- Kendal



84%

PDA adults have experienced suicidal thoughts

“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.”

- Ali



97%

PDA adults have needed mental health services



Hannah

I know it's hard to get help. I've been to the GP when they aren't sure what to do. You try and carry on without help and then after four months, five months, six months you ask again and then they might refer you somewhere. The referral might say, 'we're not specific enough for you', and discharge you to nowhere. You might go another six to twelve months and then build up the courage again to back to the GP, who still doesn't really know where to send you. When finally you do see someone and they don't understand it takes time for me to build trust. They might say to you, 'do you really want this? Because you don't seem like you want this to me'. Ultimately, if you ask me if I want to be engaging with mental health professionals I'm going to answer, 'no of course I don't, who does?', and so I get discharged. It's not about want it's about need, and about asking autistic people the right questions. Otherwise, we won't get the help so many of us need.

“My avoidance affects my health, with being 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 everyday.”

- Dev



Networks and support



Hannah

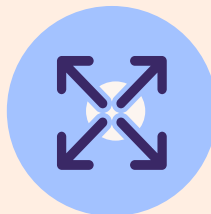
I recognise a lot of the experiences in this list. I have been estranged from family since I was about 17, and I didn't have a clue who I was. I didn't understand about anything really. I was so desperately lost, because I was told this is how you needed to be, and this is how you needed to behave.

I had that very traditional parenting that 'you do not embarrass us because you are a reflection of us. It's not about how you feel, it's about how everybody else is viewing us'. That was what I interpreted from how I was parented and, for me in my autistic brain, that was the most consistent message I received. I could never bring to the table that I didn't feel the same as everyone else. It was awful. And that led to ultimately the breakdown of the family unit, and me at 17 leaving the family home.

Of the PDA adults who responded to the survey



52%
experienced family estrangement (being out of contact with their family)



49%
experienced family breakdown (the family unit splitting up)



49%
rely on friends or their partner for emotional or practical support when in crisis



55%
rely on friends or their partner for daily emotional or practical support



40%
rely on family for day-to-day support needs



26%
said they had no support at all, despite being in need of it



Hannah

If I think of my life growing up as a PDAer, I got so used to not having help. Or if I did get help it wasn't the right help, and if I said anything, then I was told I was ungrateful or difficult.

Getting support as an adult is really hard - I worked out I hadn't had support for two and a half years when my PA left. Agency support was never going to work because it's so prescriptive and not flexible at all, and since then nothing has happened. So in January, I was like, I'm not going to have this anymore, and I've driven it all the time. I said to my friend today, I do not work for the county council, I'm disabled. I'm not meant to have to work this hard to get support. It's literally like a full-time job. How is that in any way accessible?

So really and truthfully, that **26%** of people that don't have anything - that doesn't surprise me at all.



26%

of self-reporting PDA adults said they had no support at all, despite being in need of it



40%

rely on family for day-to-day support needs





Money and work

“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.”

- Kai

“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.”

- David

“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.”

- Sali



77%

self-reporting PDA adults said they had experienced financial hardship at some point



63%

had successful employment experiences at some point



36%

self-reporting PDA adults were not in further/higher education or employment at the time of the survey



Hannah

Again I really empathised with what other PDA adults are saying. It's expensive being PDA autistic, it affects me economically, the shoes I need to wear, the socks that I can manage, the activities, the amount of people, the way I need to travel, the support that I need to do that. When I added up my disability-related expenditure it was huge. Once you look at pre-chopped vegetables, specific shoes, orthotic insoles, my assistance dog, the wider seats if I go to the cinema because I can't have anyone too close to me. And it goes on and you don't really realise until you properly sit and add it up. These are expenses that other people do not have. There isn't much I'd change about myself, but I'd love to be able to 'make do' - but it's not a choice for me. We need help to cover the extra costs not because we want little luxuries, but because those things are the difference between being able to work and not, being able to eat healthily and socialise.

Some of the most positive and negative experiences from PDA adults in this report are about employment; some people found it really hard, but for others it was a point of light when everything else was a struggle.

"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."

- Rubi





“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.”

- Ali

“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!”

- Fiona

“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.”

- Hanife

“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 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!”

- Iona



Hannah

These examples show how different working life can be for different PDA autistic people. I know that when it goes right it makes a huge difference. I've had great experiences at work, and as a result some disposable income to help me tackle the extra costs that come with being a PDA autistic person. I'm a teacher, and that can be really good for autistic people like me in a sense of there's a timetable. You start the same, you end the same. There's a lot of sameness, but there's also a lot of variety. For me and my PDA, too much sameness bores me but too much variety overstimulates me. Working in school lets me keep what I need really consistent but to be flexible in other things.

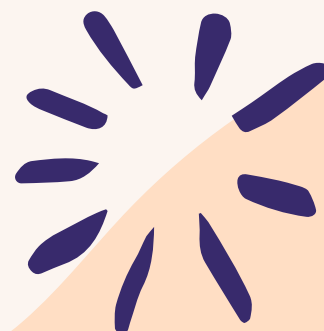
What also worked was being part of a team where we all genuinely wanted to know each other, and for everything to work for every individual we had within the team. That allowed me to be a part of a support system in which the system supported me, and I supported it. It didn't just exist to hold me up. I was needed as much as I needed others, and I think that was the same for everybody. Reading the examples in this report, it feels like what lots of PDA autistic people need.

What I hope you've gained from reading this section

PDA adults shared so much about their lives in this survey. I fundamentally believe to understand any community of people you have to talk with them, you have to listen, and then you have to act on the information you've been given. People will create a toolkit of how to support them if we listen.

Listening also gives us a new way of speaking and learning about people who are often medicalised and seen as problems to be solved or cured. It's important that our voices are heard because so often we only hear the voices of professionals. I don't dispute that professionals have knowledge and skill sets, but I and other PDA people experience this every day.

Listening to us is worthwhile.





Case study:

What getting it right for adults can look like



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.