



Being Misunderstood

West Midlands Report

Experiences of the
Pathological Demand Avoidance Profile
of ASD

May 2019

Introduction

There is a group of autistic people for whom the conventional highly structured approaches are not only unhelpful but can lead to increased and debilitating stress. Instead, collaborative approaches to learning and daily living tasks are significantly more effective.

This need for a different approach makes it essential for this group to be identified, even though research into causation and relationship to other conditions is in its infancy.

The PDA Society conducted an online survey for two weeks in March 2018 through their website and social media. 1,445 parents, professionals, adults with PDA and their partners or family members contributed. The results are available online via the PDA Society in a report entitled 'Being Misunderstood'.

This regional report details some of the experiences described by parents living in the West Midlands. The comments powerfully demonstrate the impact that the lack of understanding can have.

Overall, the results demonstrated that in practice, a constellation of traits is being identified by some who diagnose ASD. When identified it is most often done through use of terminology which reflects the idea of a 'Pathological Demand Avoidance profile of ASD'.

However, parents report that a lack of understanding (and sometimes acceptance of the profile) is the biggest barrier to getting support. Adults and children are regularly being misunderstood, with services consequently failing in their duty to be needs-based and outcomes-focused.

For outcomes to improve, professionals need to know that they can speak openly about this group using unambiguous terminology and, most importantly, promote appropriate strategies.

For this to happen, local leaders of adult and children's services which support autistic people must frame the way in which this complex autism can be managed. This is likely to be best achieved through publication of a 'position statement' for professionals and service users, along with resources for staff development.

National Key Findings:

70% of 969 young people were not able to tolerate their school environment or were home educated.

71% of 79 adults and 70% of 1194 parents reported that they had found a lack of acceptance or understanding of PDA a barrier to getting relevant support

67% of 675 parents reported that they were dissatisfied with the help received from their Child and Adolescent Mental Health Service (CAMHS); only 20 individuals reported that a CBT-type approach had helped.

49% of 768 young people with diagnoses had been given one that included PDA or a demand avoidant profile, or used similar terminology.

Survey of Parents in West Midlands

About the respondents

Demographic questions indicated that respondents were fairly representative of the population as a whole in terms of income and geography, but not of ethnicity, with just a handful of individuals from minority ethnicities involved.

The sample size was significant with 1,445 participants, and so this represents the largest survey on this topic conducted to date. The largest group were parents of children and young people who they had identified as or suspect may have a PDA profile of ASD. These made up 1,194 of the respondents, including 92 families from West Midlands

1. Diagnoses

Answer Options	W Mids	National
Yes, given what I feel is a correct diagnosis	43%	32%
Yes, but I feel it is incomplete	16%	22%
Yes, but not one I agree with	1%	3%
Still waiting for a formal diagnosis	13%	14%
Not requested / been offered a formal diagnosis	5%	7%
Other... (shown below)	22%	23%

- 1 *Have a provisional working diagnosis but discharged from CAMHS without formal diagnosis*
- 2 *The psychiatrist is reluctant to give a diagnosis as he feels the 'label' may hinder any future placement for college or employment.*
- 3 *Our area don't believe it's existence so trying really hard to find funding to pay the £2,000 + needed for the diagnosis? I'm disabled & so fed up of not being able to work & pay for the diagnosis, It's so not fair?*
- 4 *I had to fight to get this put in place...not an easy battle.*
- 5 *Correct diagnosis but had to be worded in a way that the local authority would accept as they don't officially recognise PDA.*
- 6 *Formal diagnosis of asd and adhd been told pda is not recognised however I am insisting at our next visit to Paediatrician that he is assessed for this dealing with lot of demand avoidance and aggressive behaviour*
- 7 *This Local Authority will not acknowledge or diagnose PDA.*
- 8 *Yes, he has a diagnosis of ASD - we have no PDA diagnosis; however, I am certain his traits and problems sit within the PDA criteria*
- 9 *Has been diagnosed ASD, our camhs do not/will not diagnose PDA (Walsall)*
- 10 *So far ASD diagnosis at 3 years, then general and social anxiety diagnosis at 6 years. Now seeking a PDA diagnosis so we can get the right support at school*
- 11 *ASC working diagnosis*

12 Formally diagnosed with autism aged three, currently on waiting list for ENC for pda diagnosis

13 Diagnosed adhd and add and mild learning difficulty. I think he's PDA as well

14 No, it is not recognised in my area, many health professionals have agreed with me that he has pda though

15 Told no way to formally diagnose on NHS by paediatrician as has never been in a formal educational setting. Will be seeking private diagnosis this year

16 Offered to add 'demand avoidant traits' but not PDA on the report

2. Challenges faced

These young people face significant challenges, with all parents identifying a range of issues including school refusal and eating problems. The **top 5 concerns** were in line with the national picture.

Answer Options	W Mids	National
Need to feel in control	98%	96%
Challenging behaviour	93%	89%
Severe Anxiety	83%	81%
Sensory Issues	82%	91%
Difficulty with daily routine e.g. morning / bed	75%	78%

3. Getting into school

Parents were asked whether their child had difficulty getting into school. These figures include children who are home-schooled.

Answer Options	W Mids	National
Yes, all the time	49%	41%
Regularly	21%	25%
Sometimes	14%	15%
Occasionally	9%	10%
Never	7%	8%

4. Involvement of local services

81% of families had involvement from local services, often multiple services, over the past 2 years. This included just over half (58%) who had attended CAMHS services.

Respondents were asked whether the help they had from local services had enabled them to understand their child better and/or enabled them to manage any difficulties better. The responses demonstrate the ineffectiveness of services.

Answer Options	W Mids	National
Completely	1%	1%
Very	4%	4%
Moderately	20%	13%
Slightly	26%	24%
Not at all	39%	45%
Not applicable	10%	12%

Of those who had visited CAMHS, the satisfaction levels were generally poor.

Answer Options	W Mids	National
Very satisfied	1%	3%
Fairly satisfied	9%	14%
Neither satisfied nor dissatisfied	19%	15%
Fairly dissatisfied	38%	19%
Very dissatisfied	32%	48%

Some explained their experiences of local services.

1 *I have recently completed a course on the growing teenage brain, which has given me a little more insight as to how my son is developing.*

2 *The diagnosis itself was extremely helpful - I had not really looked into it/thought about it as a possibility (despite knowing a child who had the diagnosis already) and we were looking into ADHD. It was the psychiatrist diagnosing him that had us looking at the descriptions and finding we were reading an accurate description of our son was very enlightening.*

He had had an earlier diagnosis of ASD but it just didn't seem to fit (in particular, advice on keeping routines and regularity just did not gel with a child who would do anything to avoid repeating an action already performed once!) hence looking into ADHD, but PDA did just fit perfectly and we were grateful for the extremely unfraught diagnosis. (though the time frame could have been better - he was referred when he was 4 but huge waiting lists meant he wasn't diagnosed as ASD until he was 7, and PDA at 8) I was also very happy that the psych offered to come to our home to observe our son in his normal education environment - a previous psych at the same CAMHS branch hadn't even mentioned that idea despite it being good practice to observe a child in a learning situation - and he gave the diagnosis of PDA immediately after watching us.

The psych also said that from what he saw I was already doing all the things they recommend for dealing with PDA kids which was extremely reassuring and perhaps the best support of all. A psychologist at CAMHS was also helpful above and beyond, getting us an appointment with the new psychiatrist without forcing us to go through a new referral procedure after I found the previous one had discharged my son without letting us know and looking into the possibility of getting the LA ed psych do an IQ test with our son on our behalf.

As CAMHS is mainly geared up towards helping children in school though, and home ed means we don't have access to certain things that schooled children do (for instance, the LA ed psych was unavailable to us because of this and CAMHS could not persuade them otherwise. We would need to pay privately for any ed psych evaluations) so there were limits to what we could be offered. Within those limits, however, plus our current low need for extra support, we were very satisfied.

3 *I have had professionals at forward thinking tell me it doesn't exist and my son isn't diagnosed and I don't know what I'm talking about. I have had social workers blame me for poor parenting...maybe I should try a reward chart etc go on a parenting course even though I've brought up 6 children with dyspraxia adhd odd ld mh asd.*

4 *I normally have to explain to them about PDA. Was told by the post-diagnosis team that the PDA Society course I attended will have been more detailed and useful than anything they could offer.*

5 *Not had any meaning help from local (NHS) services. They were dismissive of his threats to self-harm and harm others*

6 *Professionals e.g. doctors aware but sadly few carers, nurses, providers understand especially given lack of PDA as a real diagnosis.*

- 7 *Had an initial meeting with camhs but could only offer support in a group setting. My daughter would not want to discuss her difficulties with other children. Waiting list for support was 18 months + So funded ourselves*
- 8 *We only understood our child better when we found out about PDA about 4 years ago.*
- 9 *We are very pleased to have a diagnosis from CAMHS, but we had to push very hard for this, and as a result we have received no extra support that we haven't sorted ourselves (and that is very little).*
- 10 *I am trained in Childcare and recognised there was something out of the norm in my daughter's behaviour. I referred her for assessment at an early age, but the school and Education authorities just saw her as badly behaved, devious and manipulative.*
- I fort for recognition of her disorder, but despite my daughters diagnosis, she was just treated has a badly behaved child throughout her schooling.*
- She has now finished school and, with my encouragement applied for several apprenticeships and college courses. Throughout this time she has walked out on college and placements. She now seems settled in a placement, but has to be encouraged to continue, when having anxiety moments.*
- I feel let down that she has not had the encouragement to show her potential, which is something I feel young people with PDA need.*
- I also feel parents get very little support. I have been through poor health, in the way of stress, anxiety and depression, due to the lack of support and understanding.*
- 11 *Skillshare have been amazing, we went to a day about PDA with Ruth Fidler and subsequently other sessions on things like Non-Violent Communication and Functional Reflexology. CAMHS sessions were useless and the FRIENDS course staff at CAMHS completely failed to recognise PDA and adjust to his needs - negative experience for his self-esteem and anxiety.*
- 12 *The autism outreach worker attached to his school has been helpful and made useful everyday suggestions.*
- 13 *The best support we got was paediatric physio and speech and language - this was excellent and helped us so much - we didn't get any other help from specialists following diagnosis - I felt that once the diagnosis was complete (ASD) no one was that interested any more. He goes to mainstream school, he copes well and behaves well, he's quite academic and clever. So school is great. Home life? Absolutely awful, stressful, difficult.....obviously I'm aware that he lets off steam after a day of self-discipline at school (he seems happy and well able to exercise this level of sustained control at school, though I do worry) but at home? It is a war zone, but it is safe and private, I understand that he can 'be himself' here.....but what price family life?*
- 14 *We had one trainee psychologist involved for a while who completely 'got it' as she'd worked with children with a PSA diagnosis in another area (our area don't recognise PDA) and an excellent Educational Psychologist who seemed to really understand our son and gave excellent advice.*
- 15 *Help from clinical psychology has helped us see challenging behaviours from "panic" point of view and not defiance and helped us be more empathetic and deescalate situation. Also, we have had ABA therapy at home and although many of the formal techniques have turned out to not work to support our son's behaviours what has been helpful has been collecting data via functional analysis so we can see the pattern of demand avoidance behaviours and antecedents. Which has further clarified our knowledge of triggers and helped us to understand and use the PDA strategies to support*

- 16 *I know my daughter inside out and no one has helped me understand her any better, it has been the case where I am always trying to get 'them' to understand her*
- 17 *Both the primary and secondary school have been hopeless/hostile and we have had to fight for every single thing. The Local Authority SEND department has been really unhelpful and again have made us fight for every inch of ground. We have had significant help from a family support worker who became involved only because I had called the police three times when I felt that my younger daughters were in danger. She was supposed to do a six week intervention but two years later she is still with us as she does not want to cut my son adrift.*
- 18 *We have had next to no support CAMHS said we have a diagnosis and refused to see my son*
- 19 *OT is only person we have seen for support after referral from Paed. OT agreed possible demand avoidance going on. Said some sensory therapy might help but they would only suggest what I was already doing at home and had learned from Books/Internet/FB PDA support groups/PDA blogs etc.*
- 20 *My son has a good psychiatric consultant and Camhs keyworker who are proactive. The problem is that everything takes such a long time - EHCP, referrals, assessments, etc.....*
- 21 *We understand him very well, and don't need any additional help understanding.*
- 22 *The dx's allowed me to research and (1) find that very little was available to my son from professionals, and (2) find lots of things I can do at home (PDA strategies, unschooling, sensory integration, anger options lists, grounding techniques, meditation stories, hypnotherapy, etc.)*
- 23 *The private psychologist we have seen thinks he has asd with pda but Camhs say asd traits and do not say pda.*
- 24 *CAMHS have been consistently brilliant. But they stand alone amongst other professionals. I do think this is down to the attitude of one CAMHS worker though. Social services nearly destroyed my family. Schools were clueless and refuse to accept that some issues were happening because of their handling. Masking has caused as much, if not more problems.*

5. The Challenges

90 people described the challenges they faced. A few examples are included here.

- 1 *Up to now - watching him long for friends and try to make them, only to sabotage his own efforts by being too controlling, too emotional, too different in his thinking, too disconnected from the needs/wants of others and, increasingly as he and his peers get older, too immature in his behaviour for the other children (who also seem to have become less tolerant of difference in any form as they have increased in age). I also worry a huge amount about his future as an adult, caring for himself and holding down a job and staying on the right side of the law will be enormous challenges for him.*
- 2 *Lack of knowledge with professional's lack of support lack of training available to parents. Being blamed for a medical condition, that clearly is no one's fault. Ignorance from professionals thinking a reward chart will work exclusions etc. Teachers being authoritarian making matters worse. No support no help no understanding.*
- 3 *Isolation/depression. As a single parent, I struggle to have a social life or look after myself in a way that supports my own well-being. It's difficult to take part in standard family activities.*
- 4 *I think it's been the worry and stress of not knowing if we're doing the right thing and if there's other things we should be doing. While the PDA profile absolutely fits our son because of the lack of*

support from CAMHS and the time it took to assess for ASD we were constantly questioning if we were doing the right things to meet his needs long term. Having one to one support for him at school has helped this thankfully.

- 5 *Trying to remain in control and not be manipulated. My son is so clever it is mentally tiring try to predict how he will respond so I can prepare*
- 6 *Having to decide, plan, analyse everything we do, to minimise the risk of a meltdown. Reducing our social circle and activities given the above. The level of stress, the fact that outside our home, no one really understands what it is like to live with my child*
- 7 *Not being listened to. People being judgemental. Feeling isolated and ignored. Trying to do our best for our wonderful son with very little help and support.*
- 8 *People don't accept or recognise it schools etc so aren't willing to try the strategies. Trying to manage melt downs and behaviour outburst. Trying to cope with his need for control.*
- 9 *Realising that all of the institutions which you thought were there to help and support will put every effort into pushing you away, ignoring, lying, evading, and refusing any request for support and realising that not only do you have to cope with a child with an extremely difficult condition but that you have to go into battle with said organisations in order to force them to help. I feel like a battered wife who is made to go into battle with the authorities and I fear for the effect that all this has on my 3 daughters.*
- 10 *Being judged by everyone as a rubbish parent when I am trying my hardest to manage my sons needs and difficulties*
- 11 *The high degree of emotional masking my daughter demonstrates in public makes it hard to be taken seriously when describing her difficulties to most professional or anyone else.*
- 12 *Not having the challenges both my daughter and I face due to her PDA.*
Feeling isolated alone.
Not knowing what support would help, what is available and how to access it.
Not being able to even enter into the diagnosis process because of home educating (as a response to my daughter's needs and knowing she would not cope in a school setting).
- 13 *Managing simple day to day requests on my son to complete simple daily task such as washing dressing etc*
- 14 *Having struggled to keep her in school for 8 yrs, we then found that home ed works for her but we can't access any financial support and the LA just want her back in school. They don't understand or want to understand what it's like to struggle every day! Why would I put my child through that again?*

6. Final comments

At the end of the survey, respondents were asked if they had anything to add. These are the comments provided.

- 1 *We were discharged by CAMHS without our consent because they didn't feel they wanted to progress diagnosis (our daughter was not cooperating at that stage) even though they recognised there was a problem because she was too high functioning. We were told we*

would have to go through the entire referral process again if we wanted any further support from CAMHS. Local Authority funded support has been dismantled and anything else relies on the school "buying in" services - which doesn't work if the problems are more social and seen at home rather than in a school setting. This leaves us without support and pretty much abandoned by the system with consequent impacts on our family life, wellbeing and mental health.

2 Unfortunately, I probably have experienced the same battles as most people with a child with special needs. As well as dealing with your child, you also have a bigger battle always striving to get the help you need and having to justify your parenting skills.

3 Please please please tell us if there is any way of getting funding for a PDA Assessment x Thank you for this chance to tell you what we all go through x

4 I have just got Social Services involved. I am just coping Day to day .. Very difficult to cope with everyday life . One step forwards , two back ..

5 Parents are scared to be honest with professionals in case the child is taken away from them. It's like living with domestic violence but you can't speak out for fear of social services intervening

6 Our son is affected by the weather. My husband and daughter are also affected, so there is probably a hereditary component, but while my husband and daughter get headaches and depression during periods of low pressure, my son becomes 'more PDA' and is generally out of his own control. His behaviour is always at it's worst when atmospheric pressure is low (it was my husband who spotted the connection, noticing our son was always at his most hyper and unreasonable when my husband had a low pressure headache. It is now at a point that after a day of awful behaviour with no obvious cause from my son I will ask my husband when he gets home if he had a headache today and he will invariably say yes!)

Our son loves animals, but can't be trusted around them as no matter how much you tell him he can't seem to not treat them like a sort of mobile cuddly toy. Most animals compensate - they tend to actually act like cuddly toys when he is showing them affection, putting up with it as scratching/biting/etc has no desernible effect and hoping he will put them down soon. He can get aggressive with them too, though, throwing things, poking them, making loud noises by their ears etc and just can't see to grasp that this behaviour can hurt and scare the animal.

Our son has absolutely no sense of time. He forgets what has happened in the past and can't conceive the future, living solely in the now. Sometimes this is a benefit - he quickly forgets/recovers from emotional incidents - but mostly it is a problem because he simply cannot learn from experience or understand preventative measures. Consequently, he will repeat dangerous behaviour because he can't remember that it went badly last time, struggle to learn a lot of new skills because he can't remember what was taught and he will fail to understand why he needs to do things like brush his teeth and use the toilet because he can't visualise what might happen later if he doesn't do them now (even if you tell him - he forgets). He lives on pure instinct most of the time and is incredibly impulsive which we believe is very much tied in with the 'living in the now' issue.

7 I am a parent of 6 children.
My children are diagnosed PDA, ASD, Dyspraxia, LD, MH.
PDA has been extremely challenging for me and my family every day is exhausting and the stress encountered by the whole family is debilitating.

It is so very frustrating as there is no support for families from health and social care and

families often become isolated especially where a child with PDA shows extreme challenging behaviour.

Many professionals refuse to acknowledge it even exists well i can assure you its very real...can you imagine everything i life is a demand get up have a wash brush your teeth eat your breakfast its time for school english maths break time...the list goes on. Put yourself in that childs shoes teachers shouting you have to follow the rules...oh look another demand...now you have a detention...another demand. The anxiety our kids have is huge and is not helped by ignorance.

I also help run a support group in xxx..the amount if people we see that are receiving little or no support is shocking.

PDA needs recognising and awareness needs to be raised help our children and future generations by getting healthcare professionals to diagnose and support this condition and their families appropriately.

8 Our experience of support in mainstream school was awful. My son's school refused to believe that he couldn't choose to stop his behavioural problems or appreciate that the sensory challenges he has were a real cause for unwanted behaviour. It seems that learning difficulties are accepted and supported but mainstream schools can't cope and don't want to cope with behavioural problems. Even after diagnosis my son was treated as though he was just making bad choices and being deliberately disruptive and my parenting skills were constantly called into question.

9 Our son was only diagnosed at age 15, and discovering PDA was the light bulb moment. His whole life made more sense once we had researched the condition. Things were very difficult at school behaviour and achievement wise, and he was in danger of exclusion. School suggested an EP, who was brilliant and suspected PDA from her very first meeting with him. Our journey through GP and community paediatrician was actually quite straightforward, and the whole process took about a year (it may have been less if he had actually attended some of the meetings!). School was a little more difficult and involved lots of research and lots of frustration. We used Education Rights and SENDIASS quite a bit, and just kept talking to school until we got what we wanted. Whilst he isn't exactly thriving, he is at least still in school.

10 My son had shown signs of pda for a long time but professionals just say it is not recognised however the need to get it recognised and assessed for confirmation is now my mission I am a single parent and live with this everyday thinking of blogging my daily experience

11 Normal state schools are incapable of supporting children with special needs. Access to support is near impossible

12 PDA is real.

Its cruel to everyone affected and changes lives.
Few believe its a real thing.
Because of this people are treated as having ASD which makes everything worse.

As parents who KNOW its real this is like treating a broken leg with an arm splint.

My daughter has been in Seclusion in xxx for 18 months. They admit its not suitable but are waiting for Social Services to sort a placement but given the last 16 have failed in the last 6 years, we are sceptical to say the least.

Social Services aren't rushing as clearly in their eyes she is safe where she is. She is simply "warehoused".

I believe her future will be return to the community where at some point she will be arrested when she has a violent meltdown in public. This will end in custody or another secure unit. Sadly I don't see another outcome. This kills me inside.

- 13 Camhs signed our daughters case off when my daughter was 3 after one observation at nursery and 30 minutes at our home. She was very well behaved in nursery and very challenging at home. They signed her case off telling me she was just strong willed and we needed firmer boundaries. When our daughter was 6 life had become unbearable so we paid privately to have her assessed and she has pda. I feel earlier intervention would have saved her from years of trauma (it was noted in her file that she has suffered catastrophic trauma) from the way the treatment of her chronic illness was managed.

She was diagnosed with type 1 diabetes aged 2 and had years of extreme demands placed on her daily. Now we know she has pda the hospital have reduced the demands on her massively and the way they treat her during hospital visits. She's had hospital admissions where she has been pinned down to have cannulas fitted. For a child with pda this is unbearable. Now we know she has pda unless it's a life threatening situation she has as much time as she needs for treatments. If it's blood test time they arrange a play specialist and get her a gift for after. But if she doesn't want it they don't pressure her they let her take her time or rearrange. Our daughter built up so much resentment towards us for what she saw as us inflicting pain on her. It's taken us a very long time to build her trust back up.

- 14 We need to have PDA acknowledged and Diagnosed in Herefordshire. I am not the only parent who feels this is important. Please could you advise me how I can help to make this happen.

- 15 No additional help in school we tried 2. No help via CAHMS after being diagnosed at 4 and now 11 there has been NO help from any professional and are waiting for some now. Communities, doctors and many individuals have no concept or understanding of pda leaving us feel isolated and alone, no support available my daughter is only doing well for the sheer amount of hours I put in, I'm a fulltime carer and home educator and facilitator for her.

- 16 My 'child' is completely disowning their diagnosis/label and this is in part due to other people deciding they are not autistic as they 'don't behave like they have autism'. This is causing severe damage to my child's mental health and has pretty much destroyed our relationship as they blame me for making them 'socially inept and unable to deal with life'. This is in part due to lack of information and ignorance. PDA is not well known about outside the PDA community/some CAMHS staff.

- 17 Due to the lack of support my health has affected my work. I had a year off with stress; ended up in hospital which resulted in me being left unemployed due to the lack of understanding by Employers who closed ranks, making out I was mentally ill and not fit to do the work.

- 18 Not sure if my son has pda

- 19 Your website has been really helpful especially the questionnaire and education bit - thank you!

- 20 Seeking help was extremely difficult via our gp, Camhs, school and social services. In the end we paid private as we were so desperate.

- 21 Our daughter had a complete breakdown when she was 10 years old. Camhs have treated us really badly, telling us we needed to go on parenting courses, we have had little support and are still trying to gain an EHCP for our daughter after being refused every time we've applied. We first applied for a EHCP in June 2016.
- 22 I hate the recent 'fashion' for novels and articles which suggest there is an upside to ASD - take it from me, there isn't. I cringe when people say "he's a bit autistic" or make jokes about OCD - they are clueless. Finally, older relatives in our family don't even think ASD exists.....they think he's 'grown out of it' sure he's different at 12.....however, it is a lifelong condition and the jury is out as to what he will be like as an adult? Will he live an independent life.....form relationships, have a job, family? Will I ever get my life back? Not hugely sure any of this will ever happen. But hopeful.
- 23 Just constant struggle to get help & a lack of understanding of the issues with our daughter especially as a lot of the disruptive & bad behaviour is displayed at home & not at school or with other professionals.
- 24 Thank you so much to Jane Sherwin and the PDA Society for all the information you have put out there. We were going insane, not knowing what was wrong, what to do and our family was falling apart, but the information we found and Jane's wonderful book pointed us in the right direction and we were finally able to stand up for our son and his needs. It's been a huge fight and we're still fighting to get him the help he needs but we're still here and still together and we love our son so very much. Thanks for giving us strength and the guts to fight when we were at our very lowest.
- 25 My most distressing part of PDA as a parent is to be completely helpless in your child's low self esteem. It breaks my heart to hear him tell me he is worthless and know there is nothing I can do to change his view. I worry that I have failed him.
- 26 Don't get me started! I have been absolutely shocked and disappointed in how we have had to fight for every inch of help and how no-one really cares that our extremely intelligent son who is desperate for help spends most of his days at home, lonely, bored and extremely unhappy. It is like being in a Kafka novel, absolutely surreal. Our son is desperate for help and such a lovely boy underneath but extremely difficult in the day to day and this has had such an impact on our life as a family, we can't live normally and I fear that it has such an impact on the girls. I have read as much as I can find and I've been on a one-day training course and will be at the PDA conference. These things are of enormous help.
- 27 Levels of ignorance throughout society but particularly with regards to health and education concerning autism in general and particularly PDA.
- 28 I felt isolated as a parent with a Sen child who couldn't comply within mainstream. Mainstream did so much damage as they simply don't understand and have no expertise just staff who have had a couple of hours training! The specialist school is not an ASD or PDA specialist school and although much better there are negative implications of our son interacting with some of the other children at this school such as language, disrespect for adults, fighting etc.
- 29 God bless the founders of the PDA society!
- 30 We have had an awful time when my child was younger life has been so hard we lost his money was refused PIP. We had to jump from hurdle to hurdle with no support from any services. It was only when my son attended an independent autism specific school out of county though did he truly meet his full potential it has been hard and it shouldn't be. There should be far more support out there and I hope no one else has a struggle like we did as a family.

31 I'm the grandmother of a PDA 14 year old. I worry on two fronts...my daughter's and granddaughters. I know there are times PDA is the cause of her meltdowns but also know there are other factors in the family that impact on her behaviour. This is hard.

32 Highly recommended study day we attended I Norwich on pda and meeting other parents

33 I am saddened at the lack of support available from places that we instinctively turn to for support...how friends are quick to judge...
I'm exhausted mentally by the constant having to think outside the box and be three moves ahead!
I have some of the best non-judgemental friends now and they're not my old friends.
I have an amazing daughter, she has so many inward struggles and sensory challenges, she hates me with the most venom possible and would stab me with a knife multiple times but she loves me.
She has taught my husband and i a new way of parenting, far, far from the traditional "do as you're told" way that we were raised.
Our son, her younger brother gets the pooey end of the stick, he is frightened by her outbursts of swearing and threats but he would defend her to the death.

There are many days that I would want to wave a wand and turn her NT but she is who she is, I wouldn't want her to mask like she did at school and at places like CAMHS, if society were more understanding, our PDAers wouldn't have to mask and could just "be"

There are probably other things to add but that's all I can manage for now...executive functioning isn't my strong point!

34 People need to understand what pda is so they can stop judging children and start helping them instead

35 Massive gap in provision for mental health (especially anxiety) and its affect on activities of daily living. In Worcestershire, CAMHS nit commissioned for ASD and no other service other than diagnostic.

36 Nobody listen neither CAMHS nor school they think you are just after an additional diagnosis

37 There is a gap in schooling provision for those with severe neurodevelopmental/behavioural disorders who are academically bright.

It took me 6 years to get ASD-PDA dx - this significantly delayed my understanding of/being able to research the correct strategies/being able to support my son correctly

38 I have been fighting since my son was tiny. Its been such a struggle and it impacts on every part of family life. My son has mix of so many issues but doesn't meet threshold for asd diagnosis.

39 We have social services involvement and have done for years. My daughter will be going to a specialist residential school soon, such is her level of need. But we have not been entitled to respite as the disabled children's team threshold only covers those with a severe physical or severe learning disability.

Conclusions

This report illustrates the experiences of those with a PDA profile of ASD who are living in the West Midlands.

Reading about these experiences should be a wake-up call to those supporting and providing services to the autistic community. Individuals who may be described as having a PDA profile are being neglected and even discriminated against because of a lack of acceptance and understanding of their needs, leading to a failure to put in place reasonable adjustments.

At the same time, the results demonstrate that explanatory terminology is being very widely used in some parts of the country. Where this happens, understanding of strategies can follow. Even then, much more support is needed for local services to become sufficiently familiar with useful interventions.

It is unacceptable that 70% of young people in families surveyed are either at home or struggling to access school environments, and because their needs are being misunderstood, many are missing out on education. Local services, including children and adolescent mental health services were found to be largely ineffectual, which compounds problems and leads to parents finding themselves unable to cope.

It is in the interest of everyone that professionals are empowered to see the individual and focus on improving outcomes. The national report provides a detailed list of recommendations for action, summarised here:

Local Authorities and Commissioners across the country must urgently communicate their position on the PDA profile of ASD to service providers and their clients, to clear up the confusion over assessments and service availability that currently exists.

Government and autism leaders must consider why so many people are being failed and press Local Authorities and Commissioners to create the conditions so that needs are assessed fully and in a collaborative manner, so services can be truly outcomes-focused.

Education services and schools must increase their awareness of the needs of individuals with a PDA profile of ASD, and how to make reasonable accommodations.

Autism education and training providers should ensure that differing responses of individuals across the autism spectrum, including those with a PDA profile, should be included in autism courses and literature.

Providers of mental health and autism services need to ensure that their staff are equipped to identify and work with those with a PDA profile, whatever terminology they choose to use.

Professionals should ask themselves what more they can do to develop their own understanding and that of others, and challenge themselves to be open to the explanations of individuals and parents.

About the PDA Society

The PDA Society was set up to provide information and advice to parents and is currently in touch with over 14,500 people through its membership, forum and social media. Its volunteers directly advise up to 2,000 people each year and training courses are available for parents and professionals. The Society's website includes a range of resources including webinars, links to books and academic papers.

www.pdasociety.org.uk

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