

Survey of Pathological Demand Avoidance in Hampshire and Sussex

Contents

About the survey	2
What is PDA?	3
What was the point of the survey?	4
So what can we agree on?	4
Label or signpost?	5
Why is PDA not being diagnosed?	6
The NICE guidelines	7
So what about the manuals?	8
Government position on PDA	8
Sussex Partnership position on PDA	9
So what is going wrong?	10
Getting referred	10
Parent blaming	13
PDA Strategies are disregarded	14
Assessment blocking / Incorrect Diagnosis	15
Jumping hoops	18
Parenting courses	20
Too young to diagnose	22
Demand avoidance not being acknowledged	24
How long is too long?	25
Lack of knowledge to provide support	28
Lack of provision	29
Need to engage to obtain support	32
Pushed to use private services	34
Conclusion	37
What can be done?	39
Appendices	41
DHSC Response to the petition to Raise awareness and understanding of PDA among health care professionals	41
Survey Data	43
References	44

Survey of Pathological Demand Avoidance in Hampshire and Sussex

About the survey

This survey was designed to find out about the experiences of people with Pathological Demand Avoidance in Hampshire and Sussex. The survey was limited to Hampshire and Sussex as they both have CAMHS services provided by Sussex Partnership NHS Foundation Trust. It was completed by people who live or have lived in Hampshire or Sussex and are a diagnosed or self-identified PDA person or on behalf of a PDA child or young person.

It was filled in by or on behalf of 110 PDA people within the region. 66 of the survey responses were completed fully, with the remaining 34 being abandoned at different stages of the survey. For the questions where they have provided data these incomplete responses are included as not finishing the survey is not considered to invalidate their response.

Of the 110 responses, 58% were from Hampshire, 39% were from Sussex while the remainder were ex-residents.

The majority of responses (86%) were about a PDA child but it would be a mistake to extrapolate that PDA is more prevalent in children from this. PDA as an autism spectrum condition is a neurological condition and does not disappear once the person reaches adulthood. Those undiagnosed, unrecognised PDA adults are likely to either have found a way to cope and 'mask' their PDA or will have been misdiagnosed with other disorders.

The fact that the survey figures are heavily skewed towards reporting on children is partly a limitation of the survey because it was circulated mainly among PDA and autism groups where parents were the main contributors. It is also likely to be an indication of the increasing awareness of PDA in recent years: it is being driven by parents looking for support for their children who are struggling, so they are the ones being identified. 66% of those surveyed were age 5-11 when PDA was first suggested.

Survey of Pathological Demand Avoidance in Hampshire and Sussex

What is PDA?

PDA or Pathological Demand Avoidance was a term first used by Professor Elizabeth Newson in the 1980s and according to the NAS:

“PDA is increasingly, but not universally, accepted as a behaviour profile that is seen in some individuals on the autism spectrum.

People with a demand avoidant profile share difficulties with others on the autism spectrum in social communication, social interaction and restricted and repetitive patterns of behaviours, activities or interests.

However, those who present with this particular diagnostic profile are driven to avoid everyday demands and expectations to an extreme extent. This demand avoidant behaviour is rooted in an anxiety-based need to be in control.”ⁱ

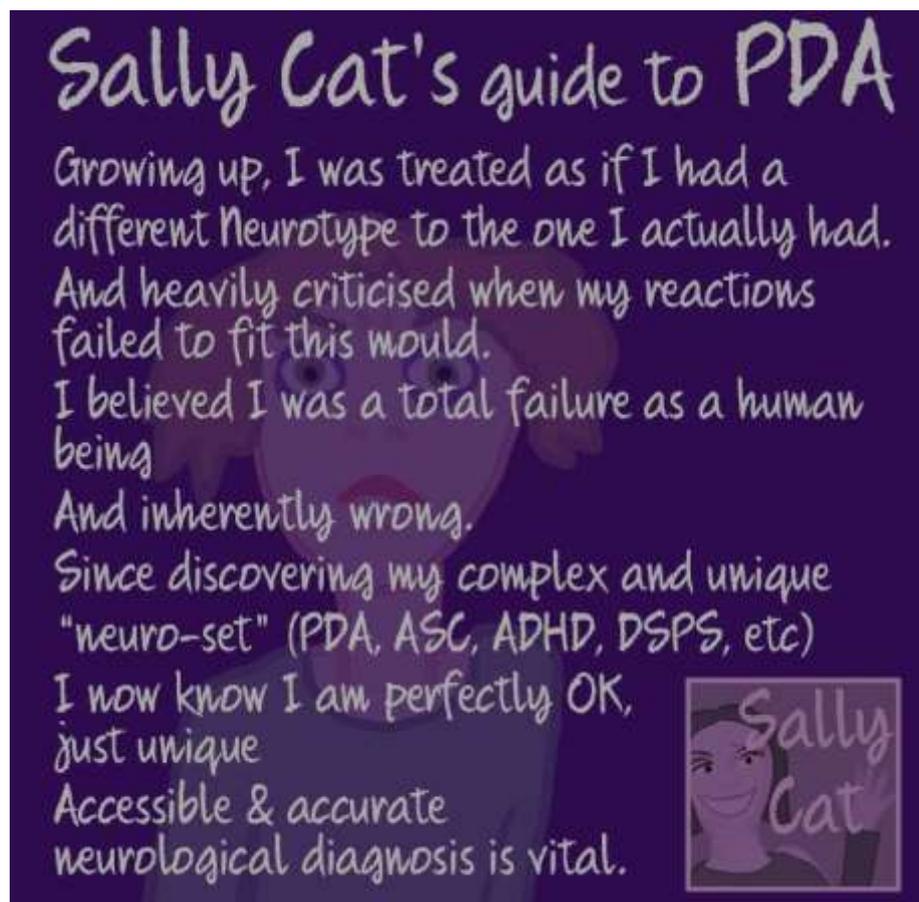


Figure 1 (Image credits to Sally Cat)

Survey of Pathological Demand Avoidance in Hampshire and Sussex

What was the point of the survey?

PDA is recognised as a profile of autism by the NAS, many high-profile autism specialist centres within the UK such as the Elizabeth Newson Centre and Lorna Wing Centre. It is recognised by some government agencies including the Department for Education but most notably not by Department for Health and Social Care, although it is recognised by some but not all individual health care trusts across the UK.

The Sussex Partnership have issued a Position Statement on PDA explaining why they feel PDA should not be recognised, which is addressed in a separate document. Prior to the creation of this survey the author had been in discussion with CAMHS Hampshire and indirectly with the Sussex Partnership regarding their position on the PDA profile. This survey is the output of those discussions designed to highlight the difficulties that the lack of recognition of PDA among healthcare providers is causing for PDA families in the region. It hopes to show the extent and depth of these problems and the effect this is having on PDA children and their families in the Sussex Partnership area.

So what can we agree on?

The Sussex Partnership Position Statement on PDA, while concise, does contain some statements that we can all agree with:

“Demand avoidant behaviour of whatever type can be very difficult to manage at home, at school and within the community, and needs to be fully investigated so that the right treatment and management strategies can be identified.”

“It is really important that the reasons for your child’s behaviour are fully investigated so that treatment can be targeted. If we consider PDA behaviours alone when developing a care plan we may not offer the most effective treatment.”ⁱⁱ

PDA families are well aware of how difficult the behaviour is to manage and most, if not all, are crying out for help. They want their child’s condition to be properly evaluated and to be given appropriate strategies. They don’t want (and are not asking for) other issues to be ignored but when the medical professional appear to be dismissing or ignoring what they see is the most significant aspect of their child’s presentation it is easy to understand how it might appear they are fixated on this.

Survey of Pathological Demand Avoidance in Hampshire and Sussex

Label or signpost?

PDA parents and PDA campaigners are told by schools, healthcare professionals, government officials that there is no need to recognise PDA: that children are assessed and supported on an individual needs basis and the PDA “label” is not needed.

This idea of ‘labelling’ being bad is seen all across the autism spectrum. Nobody wants their child to be labelled as broken or defective, as ‘wrong’. It is the stigma of autism (and the cure narrative) that makes this argument seem valid but autistic kids are none of those things. Autism is a neurological difference not a fault.

Integral to the idea of diagnosis as a label is the idea that without the label somehow autism disappears. This is clearly nonsense. Undiagnosed autistic people are still autistic – they just get a different kind of label: weird, naughty, aggressive, loner, control freak... the list goes on.

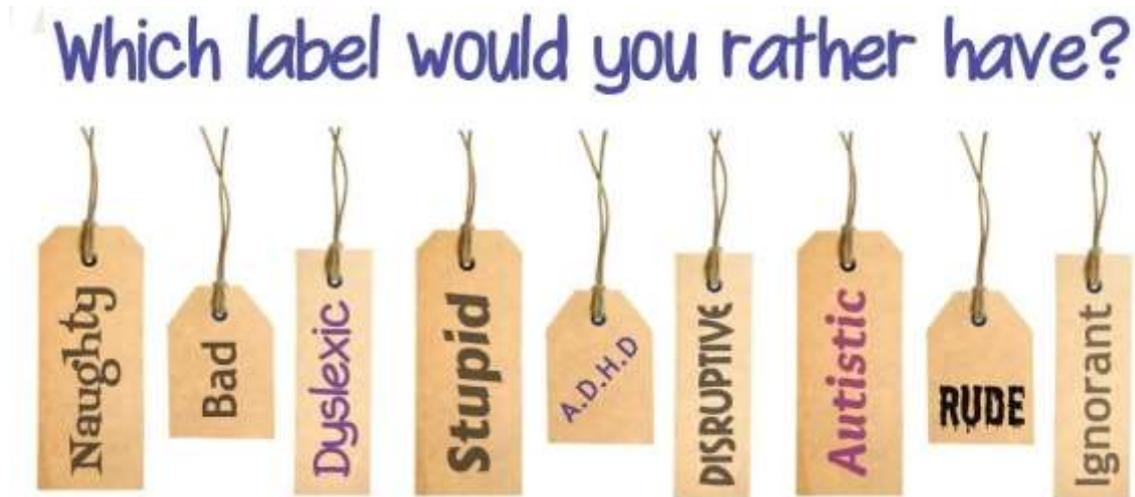


Figure 2 Neuro-diverse labels - Which would you rather have?
(Image credit: <http://www.mccas.co.uk/why-specialise-in-neuro-diversity.html>)

“It took too long for the paediatrician to even suggest autism, and I had an NHS OT warning me not to label my children.”

Enabling autistic people to get a diagnosis is beneficial in many ways. It enables to them access support where it is available, be able to ask for reasonable adjustments in their day-to-day lives and possibly most importantly to understand themselves so they can recognise their strengths and weaknesses and stop feeling ‘wrong’.

Survey of Pathological Demand Avoidance in Hampshire and Sussex

Why is PDA not being diagnosed?

An undiagnosed PDA person still has the cluster of behaviours associated with the PDA profile and still needs the same levels of support. So, if a diagnosis is a good thing, then why is this being denied to PDA people?

The reasons given that PDA cannot be diagnosed are many and some of them even conflict. They include:

- PDA is not in the diagnostic manuals
- PDA is the same as autism and doesn't need a separate diagnosis
- PDA is the same as ODD
- The PDA profile can't be distinguished from other disorders with demand avoidant traits like ODD, Conduct Disorder, Trauma, other ASD etc
- PDA doesn't exist

It is beyond the scope of this document to rebut all of these reasons and will focus on the first two, overlapping, issues. This document assumes that the PDA profile does exist and that an experienced and knowledgeable clinician can distinguish it from other disorders including non-PDA ASD, even those displaying autistic demand avoidance.

“Been told that PDA isn't real and is a made up American thing to try to get money out of people!”

“Unit consultant said it did not exist.”

“Seem to lump ODD and PDA together. If you're not violent or very disruptive you can't have PDA.”

Survey of Pathological Demand Avoidance in Hampshire and Sussex

THE NICE GUIDELINES

The NICE Clinical guideline [CG128]: Autism spectrum disorder in under 19s: recognition, referral and diagnosis states:

1.5.5 Include in every autism diagnostic assessment: [...]

development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context.

This sounds great: individualised care for everyone and no need to pigeonhole anyone. It sounds like the perfect system for everyone.

But if we don't need labels, just an individual record of strengths and weaknesses, and a personalised management plan, then why do we even need the ASD label? Or for that matter any diagnosis?

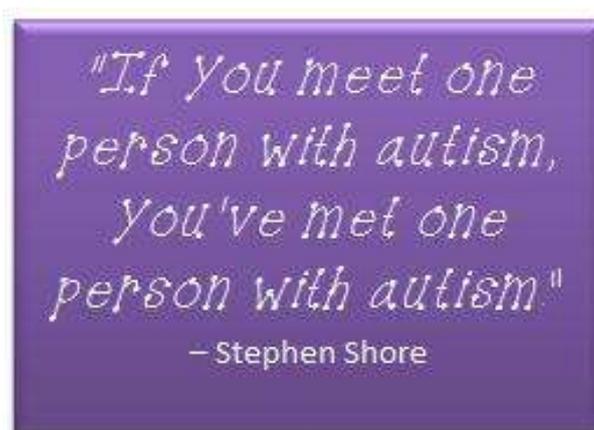


Figure 3 (Image credit: <http://brittanyfichterwrites.com/autistic-spectrum-disorders-asd-part-ii/>)

Because while every autistic (and every individual) is unique, there are always patterns of symptoms or behaviour that can be grouped together and provide a short cut for effective management. Medicine would not work if we had to learn by first principles in every case.

The Autism Spectrum 'umbrella' diagnosis in the DSM-V was created with room to allow clinicians to detail the profile (or multiple profiles) of autism their patient displayed. But while it is common to still talk about Asperger's or Kanner's or High Functioning profiles within the autism spectrum this same argument is being used to prevent recognition of PDA.

Survey of Pathological Demand Avoidance in Hampshire and Sussex

SO WHAT ABOUT THE MANUALS?

If we assume that PDA is an autism spectrum condition, then we have to assume that PDA *is* in the diagnostic manual – just wrapped up and invisible under ASD in the same way Asperger's is.

Which looks like job done: PDA is the same as autism and does not need its own diagnostic code in manuals like the DSM - no need for PDA or PDA campaigners.

But it does not mean that PDA does not need to be recognised; it only means it does not need a unique code in the DSM.

GOVERNMENT POSITION ON PDA

The government has a mixed position on PDA. In one single, recent statement¹ in response to a national petition to get PDA recognised the Department for Health and Social Care stated the following things (paraphrased for clarity):

- That PDA was a type of autism
- That PDA was a type of autism and was also ODD (Oppositional Defiance Disorder)
- That when assessing PDA clinicians should check for diagnoses that are not autism including ODD
- NICE do not have PDA specific guidelines because of lack of evidence and because PDA is not in the manuals
- There has not been a final verdict on the position of PDA

Clearly these statements can't all be true.

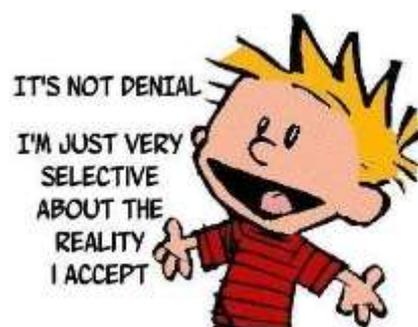


Figure 4 It's not denial (Image credit to Bill Watterson)

¹ See Appendix for full statement by DWSC

Survey of Pathological Demand Avoidance in Hampshire and Sussex

Other government departments recognise PDA. It is specifically mentioned in the Department for Work and Pensions (DWP) guidance document for assessors on medical conditions in children ⁱⁱⁱ and also by the Department for Education to the point that they have a whole 11-page report dedicated to best practise written in association with the Autism Education Trust.^{iv}

PDA is also diagnosed on the NHS in other areas. At least 31 people have obtained PDA diagnoses on the NHS according to one community managed map.^v

SUSSEX PARTNERSHIP POSITION ON PDA

CAMHS in Hampshire and Sussex under the management of the Sussex Partnership NHS Foundation Trust follow the individualised approach and say they do not need to recognise PDA because they assess each child or young adult on their individual strengths and provide suitable strategies for managing demand avoidance where it is identified, regardless of the cause.

This document argues that the approach taken by CAMHS is not working for PDA individuals and is failing them by not recognising the PDA profile.

The system failings are not unique to PDA and affect families with autism and other neurodevelopmental conditions like ADHD etc but due to the lack of awareness of PDA across all areas (parents, schools, medical professionals) it affects PDA families to a much greater extent.

The problems start from before referral, at the very beginning where PDA behaviours are not being identified effectively right through to the diagnosis stage where incorrect diagnoses are being given.

These problems are then compounded by the lack of resources available to provide support for autistic people generally, and the expectation that PDA people should be able to engage as well as other autistic people with no regard for their demand avoidance.

Survey of Pathological Demand Avoidance in Hampshire and Sussex

So what is going wrong?

GETTING REFERRED

Before a PDA child can even reach an NHS paediatrician, psychologist or multi-disciplinary team for assessment they need to be referred by someone.

Parents are sometimes actively dissuaded from seeking an assessment. They might say that it is not fair to give a child a 'label' that will stick with them forever, or that it is not needed because they will meet the child's individual need with or without a diagnosis. Parents can self-refer but this is not commonly known to parents and anyway, without supporting evidence from a professional the chances of it being accepted are very slim.

"I was told that the diagnosis of PDA or PDD as it was then known was not helpful for an educational statement"

Without PDA being recognised both nationally and locally, knowledge of PDA and its presentation will not filter down to schools, primary healthcare and other support networks. Without knowledge of PDA being as common as knowledge of classic autism and Asperger's early intervention can never be achieved for the majority of PDA children.

PDA is not being included as part of the autism training given to teachers, GPs, SENCOs, health visitors etc. It is a virtual postcode lottery as to whether the professional first approached has even heard of PDA, never mind knows how to accurately identify it.

In Q6 of the survey only 28% of the respondents said that they first had PDA suggested to them by any kind of healthcare providers, this includes private healthcare providers. Only 14% heard about PDA from someone in the school environment, which will include SENCOs. This compares to the 26% of people who found out about PDA online by either searching or from an online support group and 20% who heard about it from friends or family.

As many parents found out about PDA from online support groups (from strangers on the internet) as were told about PDA in their child's school. It is not acceptable that such a high proportion of children are reliant on having proactive parents that

Survey of Pathological Demand Avoidance in Hampshire and Sussex

are either persistent or fortunate enough to read the right information at the right time. How many children not that lucky, are currently being treated as 'bad children' being criticised, punished, suspended, expelled for things that are beyond their ability to control?

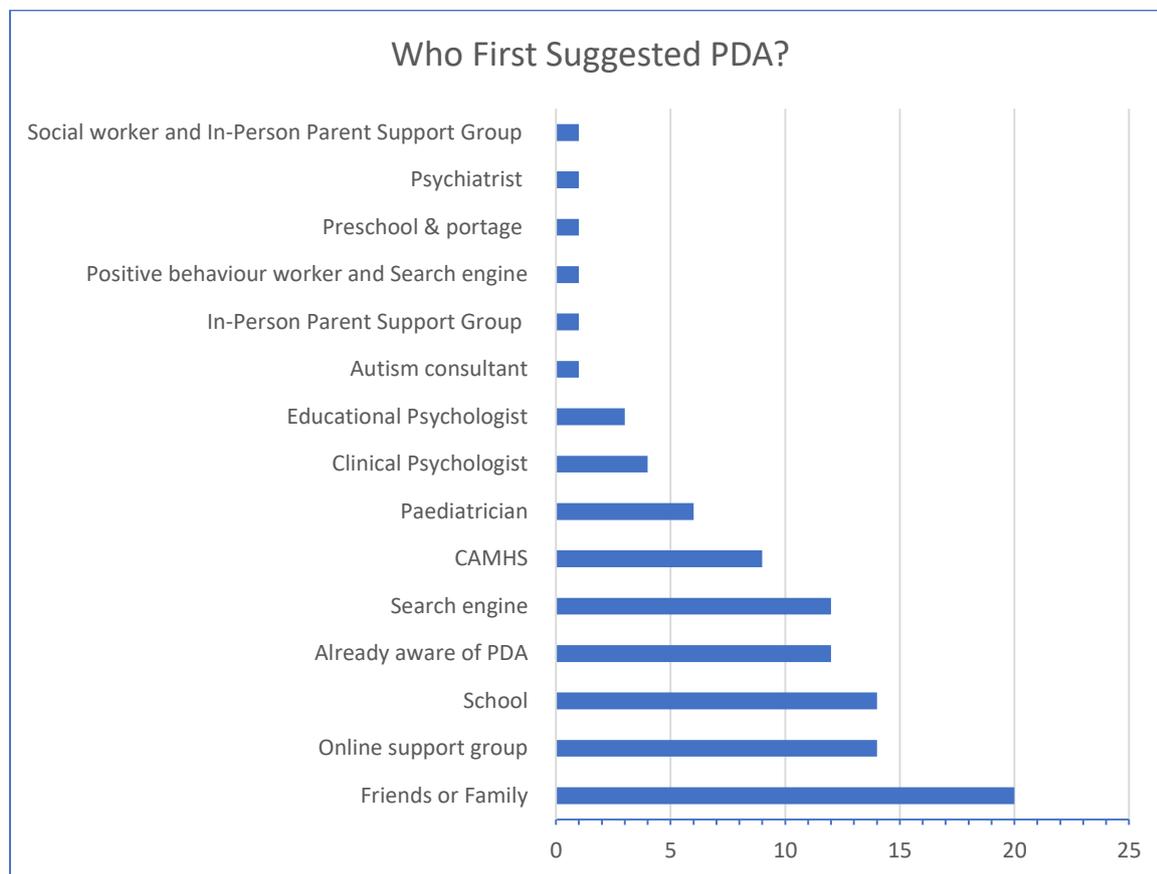


Figure 5 Survey Q6 Who first suggested PDA?

In Q11 of the survey only 6% of 79 respondents said they were satisfied with the knowledge and understanding of PDA among the primary care providers they had seen on the NHS. (None were very satisfied.) This compares to 73% who were dissatisfied or very dissatisfied.

This lack of knowledge is not just damaging for the child but is a costly process for the NHS as parents are driven to request help from more and more professionals as their needs are not being met by their initial point of contact. 31 out of 75 (41%) respondents who answered Q7 of the survey had seen 5 or more professionals while seeking an assessment for their child. Only 22 (29%) reported seeing 2 or fewer professionals. These figures include people who have not yet obtained an assessment.

Survey of Pathological Demand Avoidance in Hampshire and Sussex

“No knowledge of PDA. After two years (one year wasted as referral forgotten by doctor) still waiting for answer from a counsellor as to available support.”

“GP had never heard of it, Community Paediatrician said it did not exist.”

“GP was not aware but has spent time to learn about it via his CPD”

“I was told my son is 'nice' and wouldn't be like that when meeting people. I was told on another occasion that PDA is not really a condition.”

“No one will listen to me and thinks she's just going through a phase”

“GP clueless about any ASD but especially never heard of PDA.”

“Not enough awareness of PDA, not taken seriously. Having to tell GP what PDA is. Not enough support given for coping strategies.”

“GP has been understanding and completed several referrals to CAMHS for autism but no knowledge of PDA.

“School SENCO and GP had never heard of it which made it very difficult to get referred. We had to be referred for ASC.”

“Hard to get the right referral - went via self-referral with support of the health visitor in the end but it should be GP”

“We haven't got a PDA diagnosis and as yet I haven't pushed for one as I been told that it makes getting a School place even harder... now I'm not so sure!”

Survey of Pathological Demand Avoidance in Hampshire and Sussex

PARENT BLAMING

Many parents are made to feel like bad parents when they first ask for help. Many have been trying traditional parenting strategies, or even strategies for autistic children, with no success. Their lack of success is often put down to not trying hard enough, not enforcing strict enough boundaries: bad parenting causing badly behaved children.

And for parents that are already aware of PDA and are trying to implement PDA strategies this is seen as even more evidence of bad parenting as PDA strategies are based on giving the PDA child as much control as is reasonable over their life and environment, which is viewed as parent lacking proper boundaries.

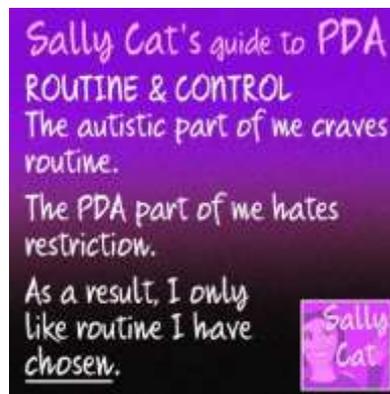


Figure 6 Control (Image credit Sally Cat)

“I had a home visit with the Parent Support Worker to discuss my daughter’s anxiety during her first few months of Year R. The support she offered me was to tell me that I was the cause of my daughter’s anxiety, and if not then I was certainly making it worse.”

“Behaviour was attempted to be blamed on parenting/ home life/ my mental health as I had had a breakdown due to the stress of my son’s behaviour.”

“It is always assumed that it’s a parenting issue and nobody looks beyond that.”

“Nursery said of my 3-year-old: ‘He is in control not you. He says jump and you say how high.’ They don’t see how I am listening to his needs and managing his anxiety.”

“Dismissed as bad parenting”

Survey of Pathological Demand Avoidance in Hampshire and Sussex

PDA STRATEGIES ARE DISREGARDED

In reality, because PDA strategies are so radically different from normal educational strategies schools and require such a lot of input, there is a limit to the support they will offer before they start to question the validity of PDA. The experience of PDA children in school was not within the scope of the survey but the high levels of suspension, exclusion among children with ASD reflect this, and the recent report, *Being Misunderstood*^{vi}, by the PDA Society states that 70% of 969 young PDA people were not able to tolerate their school environment or were home educated.



Figure 7 70% of young PDA people are not able to tolerate their school environment or are home educated
(Image credit PDA Society's *Being Misunderstood* report)

“When choosing a new nursery, I was open about my concern of PDA for my son, his sensory issues and the impact this had on our lives and the strategies we used to manage them. Initially they seemed supportive but when he started to refuse nursery or refuse to let me leave him this all changed. I got told I needed to be firmer, to let him cry. When I said that using these types of approaches would not be helpful and could be damaging if he was PDA. I got asked was I sure he has PDA, and told we had to try the other ways first and show they don’t work.”

“Local CDC refused to accept the things I and school were saying about my son. My son was excluded several times the school asked for him to be seen again and the CDC then discharged us. We eventually got a second opinion in London and he has several diagnoses now.”

Survey of Pathological Demand Avoidance in Hampshire and Sussex

ASSESSMENT BLOCKING / INCORRECT DIAGNOSIS

One of the biggest barriers to getting appropriate support is the belief among some healthcare providers that PDA doesn't exist. PDAs existence as a sub-type of autism is under discussion it is true, there is not yet enough evidence yet to say for sure exactly where in the spectrum of neurodiversity it fits. But that does not mean it doesn't exist, just that there needs to be more research to determine how it relates to other conditions, and whether distinct boundaries can be drawn or not.

The refusal to acknowledge the PDA **profile** as a distinct set of traits which can be reliably assessed and differentiated is having a terrible knock on effect in blocking or delaying vulnerable children (and adults) from the assessment pathway or causing them to be incorrectly diagnosed and given incorrect strategies for management.

“Not even offered ASD assessment which I now understand they could have done as you need that diagnosis before the PDA”



Figure 8 (image credit to PDA Society)

In the survey 56 respondents reporting having diagnosis either instead of or in addition to ASD or ASD/PDA. Out of those 56, 25% reported that they felt that one or more of those other diagnoses were incorrect due to lack of knowledge about PDA.

In fact, CAMHS identified fewer cases of demand avoidance in our sample than parents who already knew about PDA.

Survey of Pathological Demand Avoidance in Hampshire and Sussex

In some cases, the incorrect diagnosis will have led to incorrect strategies being suggested which at best is unhelpful, at worst will be doing significant harm to the child involved, and may result in the child being medicated unnecessarily.

“They dismissed PDA within minutes and went straight to BPD”

“My son was unable to fully complete the Standard ADOS due to avoiding all but 2 tasks. The clinical psychologist suggested demand avoidance and further assessments would be required before a full assessment/diagnosis could be completed. (She was a locus at our CAMHS). Received a letter from CAMHS to then say being discharged as no diagnosis. I queried PDA and was told not recognised at our CAMHS and no funding or services for any further assessments which we were told my son needed.”

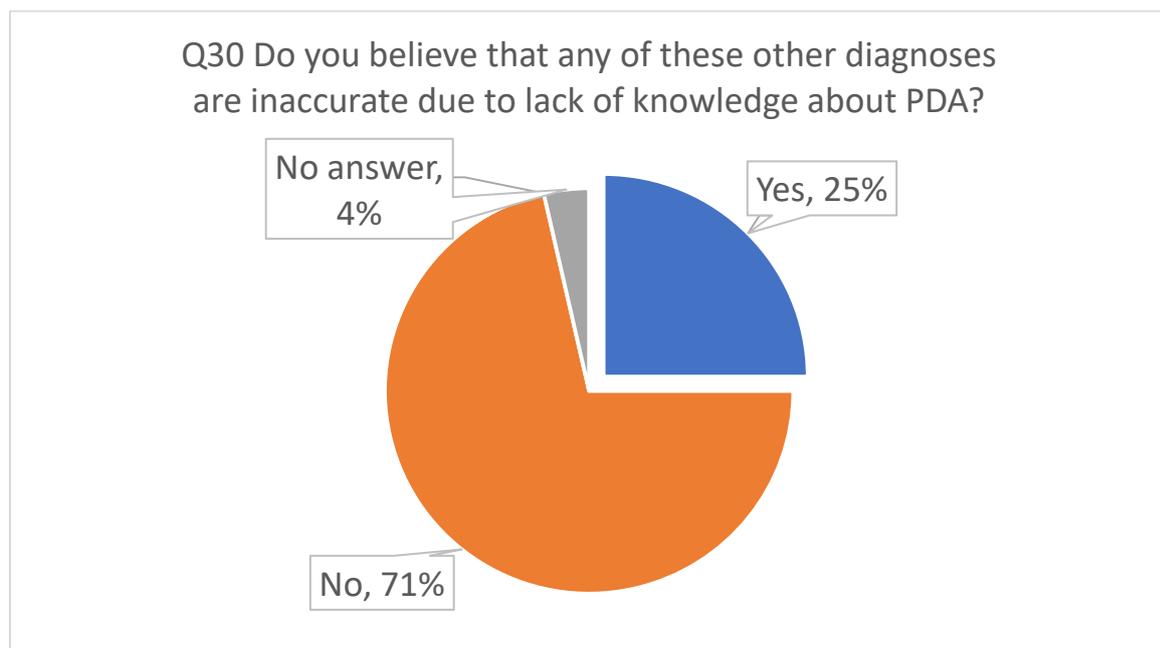


Figure 9 Survey Q30 Do you believe any of these diagnoses are inaccurate?

Survey of Pathological Demand Avoidance in Hampshire and Sussex

“Basically, totally dismissed”

“My son's consultant told me he could not have PDA as it's an American thing. This consultant later discharged him, and it took several attempts to be referred elsewhere for a second opinion.”

“Self-referred to CAMHS who said did not meet their criteria, I mentioned PDA in my referral. They suggested I speak to the ed psych and community paediatrician who had completed her EHCP. I had already mentioned PDA to them, ed psych gave no feedback and failed to return any of my calls at least 6. It was community paediatrician who told me to self-refer to CAMHS.”

“Dismissed”

“I had to keep pestering to be told it wither wasn't real or wasn't recognised in area, was turned down for funding out of area before I had to call consultant directly”

“He may have autism but it's not typical and professionals don't know how to manage my child”

“They know about PDA profile but won't diagnose specifically. Try to put everything down to poor parenting, attachment disorder, oppositional defiant disorder!”

“Anxiety is linked to demand avoidance in my son. No diagnosis for ASC was given. My son was not able to complete almost all the ADOS tests due to demand avoidance. This concluded into no diagnosis not further exploration into demand avoidance or repeating ADOS.”

“I don't think my son is ADHD I think it's a combination of PDA, anxiety and SPD.”

Survey of Pathological Demand Avoidance in Hampshire and Sussex

JUMPING HOOPS

Once a parent gets someone to agree to do a referral that is only the first hurdle. Depending on where the referral is sent (usually determined by the age of the child) the case is then assessed by a team of community paediatricians or by CAMHS.

Only 45% of respondents to Q9 of the survey reported that they were accepted for assessment the first time. Let's be clear about this: less than half of parents who suspect their children have PDA are taken seriously the first time they try to access services.

Even worse 20% of children have had their cases reviewed five or more times. Every time their case is pushed back for further information to be provided, or any other reason this causes a delay of several months at the least, so each one adds significantly to the wait time.

And what is the financial cost of all the extra review meetings, extra reports by other professionals, additional meetings with schools, nurseries and parents by other professionals?

Q9 If you were referred to PATCH or CAMHS or other NHS assessment service how many times was your case reviewed before being accepted onto the waiting list for assessment?

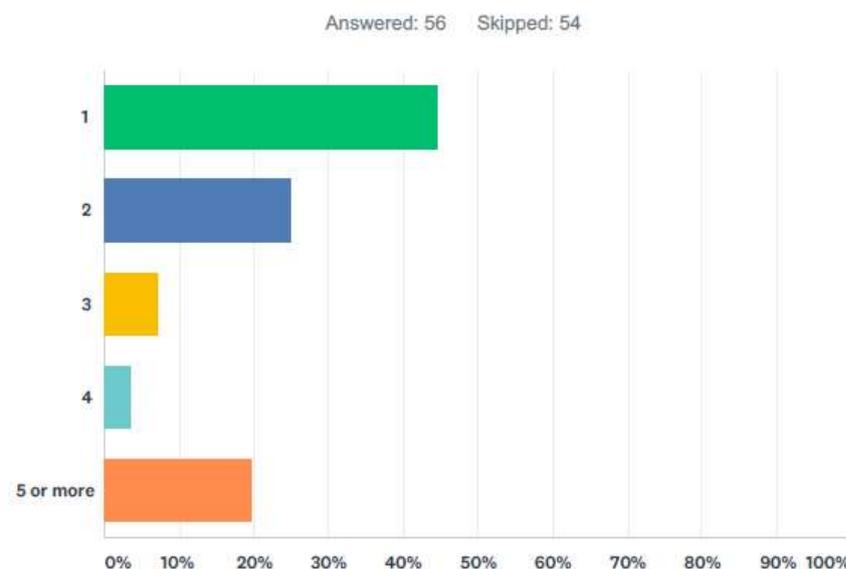


Figure 10 Survey Q9 How many times was your case reviewed before being accepted onto the waiting list?

Survey of Pathological Demand Avoidance in Hampshire and Sussex

“I contacted the school SENCO first who then told me to see the GP. The GP then told me to speak to school... I went round in circles for several months before anyone would refer. “

“The first referral in Jan was sent back requesting a hearing test and visit from a health visitor and for her to report on his progress after starting nursery (due at Easter). After a few months at nursery the HV provided the requested report after liaising with nursery. This report was also pushed back saying that they now wanted a report from the nursery, which they could have requested the first time if they had wanted that. This took until late October to obtain. This resulted in his case being reassessed in January the following year and refused again with a referral to Portage and SALT. These two referrals had already been done by HV and completed by this point, so when this action was questioned by me they conceded and offered an appointment in June. 18 months from first referral to appointment and only because of the amount of chasing and pressure I did and the support of a caring and persistent HV.”

“My son was initially referred to CAMHS who then referred to child development centre because they said they can't diagnose ASD as it is a developmental disorder. I feel a lot of time could have been saved if he was referred there in the first place and do not understand why CAMHS assessed him if they can't diagnose ASD!”

“It took a long time for us to be able to get an assessment as they kept saying it was anxiety. They asked my daughter if she wanted an assessment but after her saying yes they just discharged her and said come back in 6 months if you're still concerned! 5 months later we had an emergency referral as my daughter had become suicidal and self-harming. 2 months later she was finally seen by a psychiatrist for the first time (this was after having been under CAMHS for 2 years suffering severe anxiety problems) and after reading her history he felt certain she was autistic, and she was put on the assessment pathway.”

Survey of Pathological Demand Avoidance in Hampshire and Sussex

PARENTING COURSES

Another hoop that parents are made to jump is that of the Parenting course. Linked to the idea of PDA behaviour being caused by bad parenting, some parents are being made to complete parenting courses before their child is put onto the waiting list.

It is not that PDA parents are against doing parenting courses: your average PDA parent has probably done more reading and learning about parenting than most.

The first issue with the parenting course is that the course offered in most cases is a standard parenting course. So even if their child is waiting to be assessed for ASC they are not allowed to do the course for parents of autistic children: you can only do that after a diagnosis. In the meantime, all these families of undiagnosed autistics are made to do a course with parenting strategies that are not suitable for their child; encouraged to try the techniques that are doomed to fail in order to prove that there is something more there than bad parenting.

But the biggest problem is when access to waiting lists is blocked until the course is completed. Courses take 3 months to complete and depending on when you are referred for a course you may have to wait up to 6 months for the next one to start, and if you are really unlucky the course may be full, and you will need to wait an additional 3 months for the course after that. **This could add up to a year to the time a child is waiting to be assessed – before they even get onto a waiting list.**

In discussions with CAMHS I was told that this is not or should not be happening and that parenting courses should be accessed alongside the child going onto the waiting list.

In Q8 of the survey 34 (43%) parents said they were required to, or believed they were required to, complete a parenting course before their child could access a waiting list for services. Whether or not it should be happening

Survey of Pathological Demand Avoidance in Hampshire and Sussex

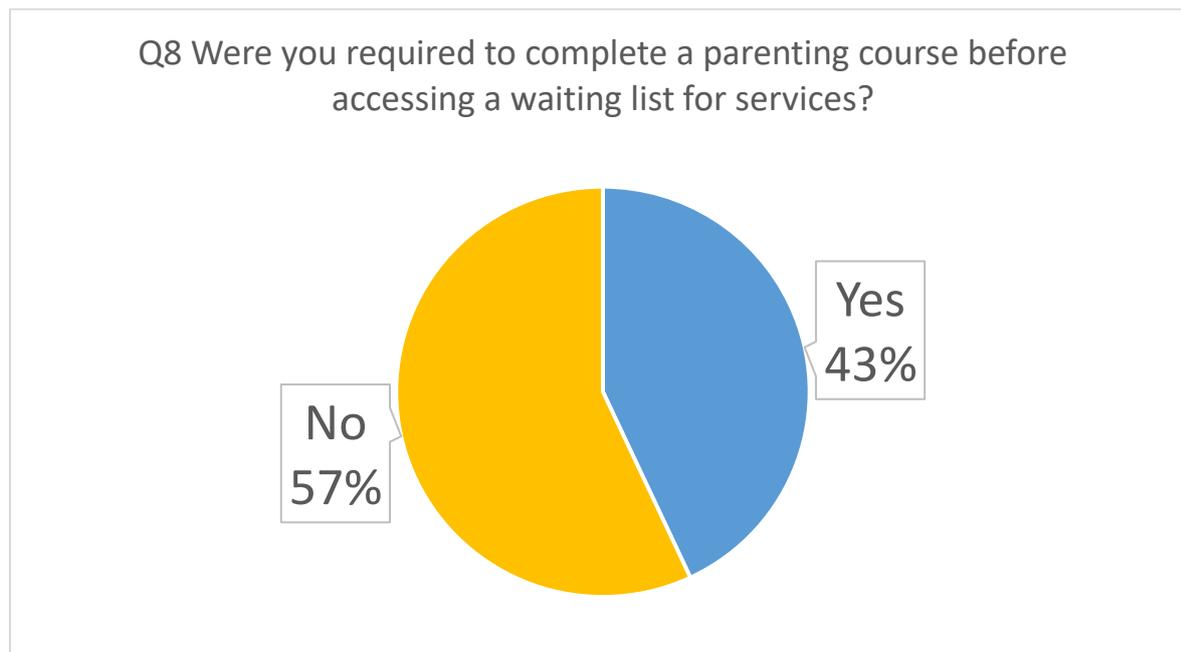


Figure 11 Survey Q8 Were you required to complete a parenting course?

The Unit Costs of Health and Social Care 2016 report ^{vii} state that the average cost to the NHS for a Triple P parenting course is £1,000 per attendee. £1,000 for a course which will be of minimal help to the parents of PDA and autistic children referred to them.

In comparison, a private ASD assessment (with a clinician experienced in PDA) including an ADOS-2, sensory screen, cognitive screen and full diagnostic report and follow up appointment can be obtained in less than 4 months for approximately £1,500.

It is a fair and valid question to ask whether spending £1,000 on a parenting course when there is a reasonable suspicion of ASD is a good and efficient use of tax payers money.

To get my daughter on the CAMHS waiting list I had to be assessed by Family Links (who couldn't help us) and do the standard parenting course. There were 4 other parents on the course in the same situation. All 5 of us had children who were suspected or diagnosed with ASD, PDA or another neurodevelopmental condition. The course leaders knew very little about PDA and asked to borrow my PDA Handbook to show their manager, so they could get a copy for their own use.

Survey of Pathological Demand Avoidance in Hampshire and Sussex

TOO YOUNG TO DIAGNOSE

For those lucky enough to be identified young and who make it to see a clinician in a reasonable time there is one more hurdle: being 'too young to diagnose'. In the United States they have routine screening of all 2-year olds for ASC. In our region children much older than 2 are routinely told that it is not possible to know if they are autistic yet, and are put on a call back to return in a year.

Out of 71 respondents in the survey 38% said that after their first appointment with a community paediatrician or CAMHS further assessment was delayed based on their child's age and being too young to make an assessment.

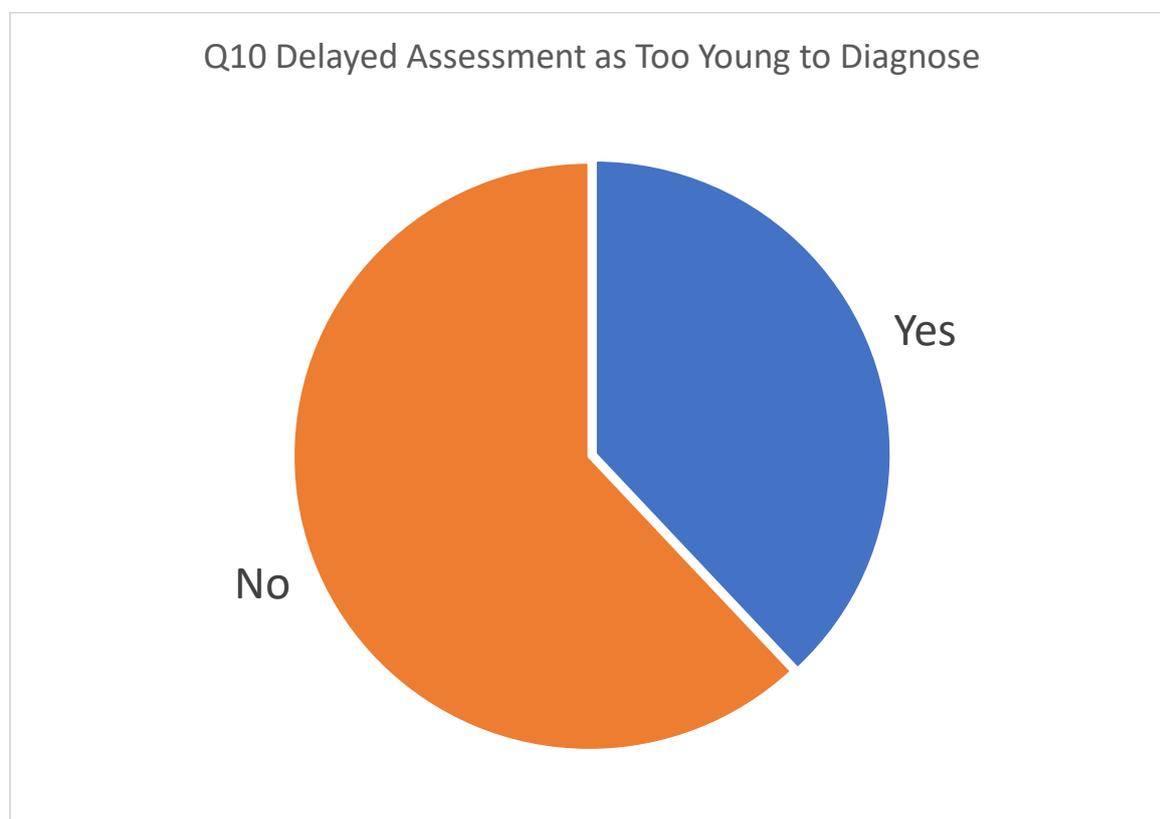


Figure 12 Survey Q10 Was the assessment delayed as child was "too young to diagnose"?

"Had to wait several years until son was "old enough" and then struggled because his behaviour at home and school are different."

"I requested input age 3, a long period of watchful waiting until put on list to see a specialist pages to start process at 6 but went private at 7 and then received paws appointment 2 months later who said, I am glad you have done the ADOS as it saves me putting you on the long list."

Survey of Pathological Demand Avoidance in Hampshire and Sussex

Being considered too young to diagnose is a problem general to 'higher functioning' ASDs and not just PDA. It seems that training or the need to restrict access to services has not kept up with the broadening of criteria for ASDs. Being dismissed because the person can make eye contact or has a friend or has good language capacity is not uncommon.

For the PDA profile especially, it is a massive problem as its 'atypical presentation' of autism are among its defining features including being able to make eye contact; having a surface level of sociability; and having an ability and enjoyment of role play.

Raising awareness of PDA and providing PDA specific training would alleviate this problem reducing blocking and delay to accessing services at the assessment stage.

“Child was asked to do a drawing of a face then we were immediately told that son didn't have ASD?! Saw 3 paediatricians in our area who refused to acknowledge ASD or PDA as his eye contact was too good (he was masking behaviours in front of them).”

“The CAMHS person who was doing the ASC assessment was useless. She was referring to eye contact and no special interests. Since then several experts have assessed or worked with my daughter and they immediately saw she was ASC and demand avoidant”

“After a 3-hour appointment with my 5-year-old the paediatrician said that she wasn't able to tell if she was autistic or if her behaviour was still in the realms of age appropriate behaviour. She wanted to see her again in a year as it would be clearer then. The report mentioned making good eye contact and the fact she liked having friends.”

Survey of Pathological Demand Avoidance in Hampshire and Sussex

DEMAND AVOIDANCE NOT BEING ACKNOWLEDGED

As mentioned earlier, Sussex Partnership CAMHS say they do not need to recognise because they identify demand avoidance as part of individual report and provide suitable strategies for managing demand avoidant behaviour.

While this may be their aim and may be happening in some cases it is certainly not happening across the board. The evidence from this survey shows that there are plenty of cases where

- demand avoidance is not being included in reports
- private ASD/PDA diagnoses are being ignored

“Not accepting PDA as a diagnosis [after private assessment]”

“Even though child psychologist gave parents a print-out explaining PDA, when queried why this was not mentioned in the diagnostic report, told PDA is not in diagnostic manuals and not recognised by local Trust. Original report only gave diagnosis of ASD, so parents asked for Demand Avoidance to be added, which they did, as we knew different strategies should be used to those with ASD only.”

“I recognised PDA later on and requested referral to centre of excellence and they decided to use CAMHS and still didn't recognise PDA (they didn't deny it existed, tested for it, said demand avoidance but used totally invalid reasons to state it wasn't PDA). Private consultation later confirmed [he] matched the PDA profile.”

“They all know what it is, but don't acknowledge it officially”

“Private diagnosis of ASD- PDA was accepted but the PDA part out in the summary section rather than in statement of diagnosis- ‘everyone will want it’ I was told by paediatrics”

“Refusal to write it down as an actual diagnosis “

Survey of Pathological Demand Avoidance in Hampshire and Sussex

HOW LONG IS TOO LONG?

The three strategies of refusing referrals, enforcing parenting courses and delaying assessments result in extreme rationing and gatekeeping of services so that only the most desperate or most determined make it through to get assessed. And for those that do the waiting times both to get on a list and after getting on the list are abysmal.

The National Institute for Health and Care Excellence (NICE) specifies in its clinical guidelines – Autism Spectrum Disorder in Under 19s – that, for children and young people, diagnostic assessment for autism should be started within three months of the referral from the patient's GP or health visitor referral to the autism team. ^{viii}

Nationally the average time to diagnosis is 3.6 years as highlighted in research by academics from City and Goldsmiths. ^{ix} It is safe to assume that waiting times for children with PDA will be as long or longer than those for children with Asperger's for the same reason given in the quote below but also the confounding factors relating to PDA awareness stated above.

The average delay between first contacting a healthcare professional and receiving a diagnosis was 3.6 years. However, we found that those children who were given the diagnosis of 'Asperger syndrome' tended to experience longer delays (over four years) than children who were given a diagnosis of 'autism' (between two and three years). This may be related to the signs of autism being more subtle in children who do not have intellectual impairments and who appear to show good language abilities.

Locally, out of the 24 survey respondents that reported they had a PDA diagnosis in Q15 and then answered Q18, none reported being seen within the 3-month guideline. 58% said they waited longer than 3 years. This included those who had paid for a private diagnosis.

Parents are aware of the financial pressures on NHS budgets and how this increases waiting times, but that doesn't make it any easier to accept when it is your child struggling without any help.

Even referrals for children in crisis were reported to take months. One respondent reported it took 7 months of waiting for a child that was repeatedly hospitalised due to their condition during that time.

Survey of Pathological Demand Avoidance in Hampshire and Sussex

Q18 How long was it from first approaching a healthcare professional to getting diagnosed?

Answered: 24 Skipped: 86

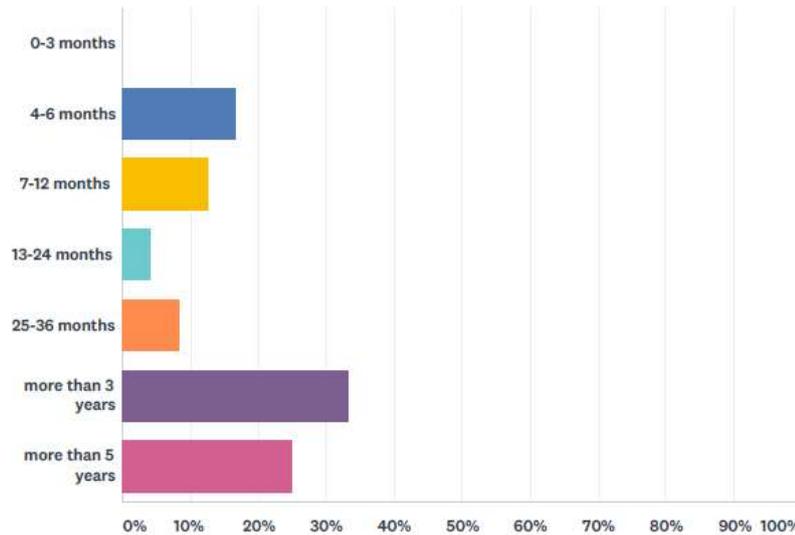


Figure 13 Survey Q18 How long was it from first approaching a healthcare professional to getting diagnosed?

Out of the 48 survey respondents that reported they had not got a PDA diagnosis in Q15 and then answered Q24 40% had been waiting more than 3 years so far for a diagnosis.

Q24 How long is it from first approaching a healthcare professional to now?

Answered: 48 Skipped: 62

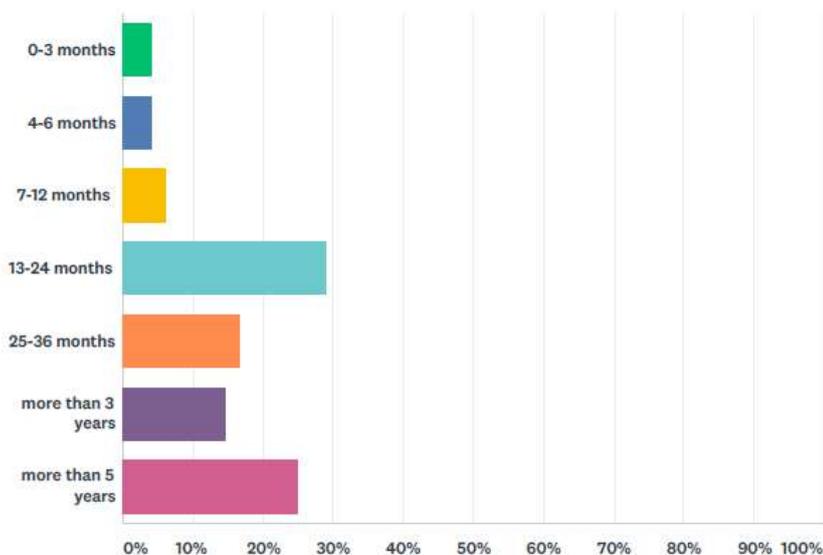


Figure 14 Survey Q24 How long is it from first approaching a healthcare professional to now?

Survey of Pathological Demand Avoidance in Hampshire and Sussex

“We seemed to spend years justifying why he needed assessment”

“Waited 4 years”

“Waiting for assessment is too long. Meanwhile you're left in limbo with no support or resources to help manage behaviour, emotional and physical aspects. A diagnosis opens up more doors but waiting for it and jumping through so many hoops is draining.”

“Had to chase many times and had to insist it be done”

“Family really at crisis point and we're being told that needed to watch and wait.”

“We were turned down for assessment but then told even if we tried again it was an 18month - 2 year waiting time. As our child was 4 and already struggling a great time we did not feel this wait was acceptable when we could try and support her as soon as possible.”

“My son was diagnosed with ADHD and autistic traits at the age of 10. We were told that there wasn't the funding for an ASD assessment at that time. He was finally diagnosed with ASD with a PDA profile at the age of 14.”

“Emergency referral - done in ONLY 7 months during which time child was hospitalised 3 times (12 nights in total)”

“We waited 2yrs for an assessment, while school refused to believe us.”

“I feel my son was lucky enough to be diagnosed at an early age 7/8”

“Very long waiting lists due to lack of services and we had to go as far as being willing to make a formal complaint because of the damaging effect on our son's mental health at the time.”

Survey of Pathological Demand Avoidance in Hampshire and Sussex

LACK OF KNOWLEDGE TO PROVIDE SUPPORT

While PDA is not recognised properly it is virtually impossible for proper knowledge and training to be made available anywhere within the system. How can personnel be trained on something which the organisation refuses to recognise or fund?

As has been shown this lack of knowledge filters down throughout the system from secondary care providers down to GPs, health visitors and into school environments but even with demand avoidance nominally being recognised by CAMHS there is still a lack of knowledge within CAMHS and this is affecting the support given.

“All through CAMHs but all focused around ASD and anxiety as there is a lack of knowledge around PDA. We were signposted to other organisations but had already accessed what we could ourselves.”

“Very piecemeal. Some pockets of helpful advice from some professionals but not cohesive and not meaningful enough”

“Very high levels of professionalism and ASD knowledge and support for our son’s anxiety. Huge reliance on us when it came to knowledge and information about PDA.”

“No coordination of care/support and certainly no real effort to understand the theory of mind / cognitive / executive functioning issues that may be barriers to reaching to child through therapeutic approaches. Our child has a range of co-morbid MH issues that are being ‘treated’ via CAMHS but unsuccessfully as no one has either ask or listened to what works well for our kid and adjusted their approaches accordingly.”

“Just been given handout sheet, no specific help or support tailored to child's individual needs.” “Comments like ‘x seems unwilling to engage’, ‘x won’t help themselves’, ‘x needs to listen and implement these strategies otherwise we can’t help’ ‘x has had enough CBT sessions now; we can’t help any more’ ‘oh yes, I think x definitely has a demand avoidant profile but we don’t diagnose that’.”

Survey of Pathological Demand Avoidance in Hampshire and Sussex

LACK OF PROVISION

While this is not a PDA specific issue, it is a significant problem for PDA families.

One problem is that autistic children who need help and support are being discharged as soon as they are diagnosed because their symptoms are 'normal' for autism. Parents need to prove that their difficulties are significantly greater than expected for autism to qualify for support. Families who have waited years to get a diagnosis and help are given their report and showed the door.

Of the 24 respondents who reported having a diagnosis 58% reported not being offered any treatment or support on the NHS after receiving their diagnosis.

Q22 After diagnosis have you been offered any treatment options or support via the NHS?

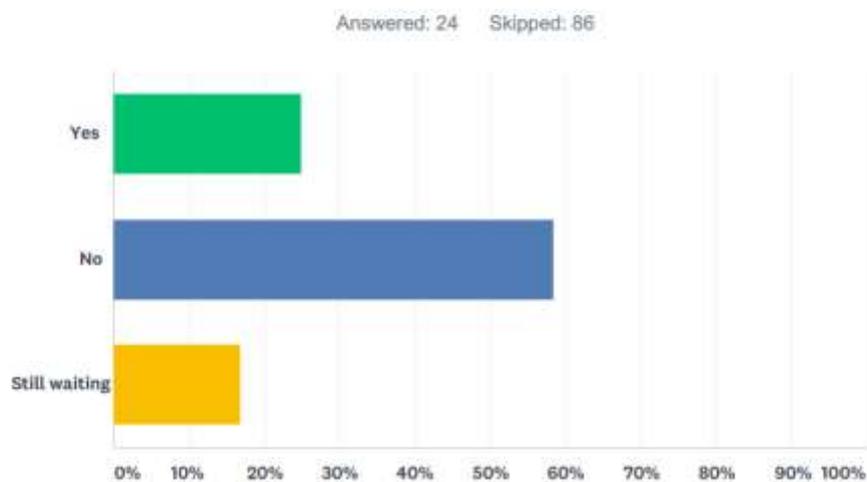


Figure 15 Survey Q22 Were you offered treatment or support via the NHS after diagnosis?

“We gave up waiting for CAHMS. Private diagnosis. Letter from CAHMS then simply to say my son would be removed from their list. Psychologist wrote to GP who accepted diagnosis. Horrific experience!”

“Diagnosed age 4 before starting school. Accessed a range of services at this point. However, this was 17 years ago and have had to fight to keep services involved. Now been told it’s just the autism (i.e. no point in seeing him because his difficulties are due to the autism which can’t be treated)”

“Was advised to research PDA strategies myself as they might help”

Survey of Pathological Demand Avoidance in Hampshire and Sussex

Of the 50 survey respondents who had not had a PDA diagnosis and replied to Q25 66% had not been offered any services and 14% were still waiting. These figures will include those with an ASD only diagnosis plus those with other conditions.

Q25 Have you been offered any NHS support despite not having a PDA diagnosis?

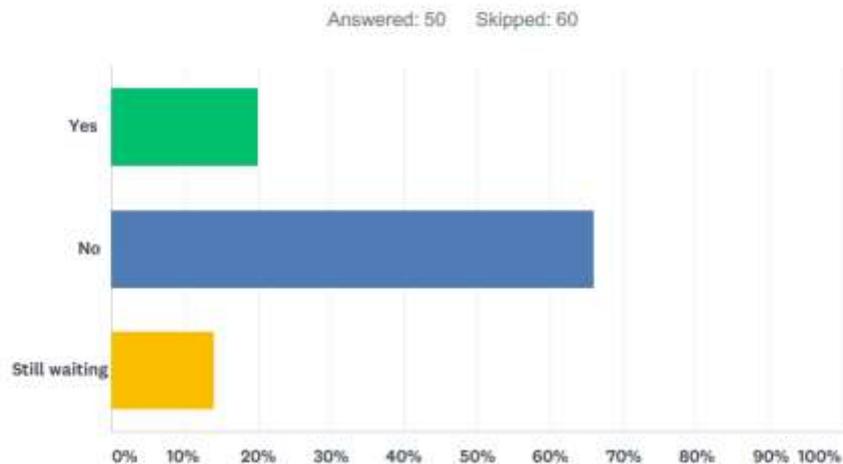


Figure 16 Survey Q25 Have you been offered support on the NHS despite not having a PDA diagnosis?

“Only probably due to his ADHD & anxiety meds management”

Another issue is the lack of support for sensory issues within the region. Sensory Processing Disorder as a stand-alone condition is not funded but neither are the sensory issues relating to an autism diagnosis. 80% of autistics experience sensory issues ^x which can be severe and life limiting. Despite there being suitable treatments for sensory issues such as sensory integration this is not available on the NHS.

“Long wait times for CAMHS for anxiety; referral to OT for severe sensory issues resulted in no support as problems are “behavioural not functional” and sensory issues are not supported locally”

“NHS Occupational Therapist said that sensory integration therapy could be beneficial but that she was not able to provide it. Although sensory issues stop her doing many things because she is physically capable of them we cannot get help.”

Survey of Pathological Demand Avoidance in Hampshire and Sussex

For those that are fortunate enough to get referred for support the wait times are again a huge problem. Of the 26 respondents that had been referred for support on the NHS 38% were still waiting and a further 31% had received some but were still waiting for other services.

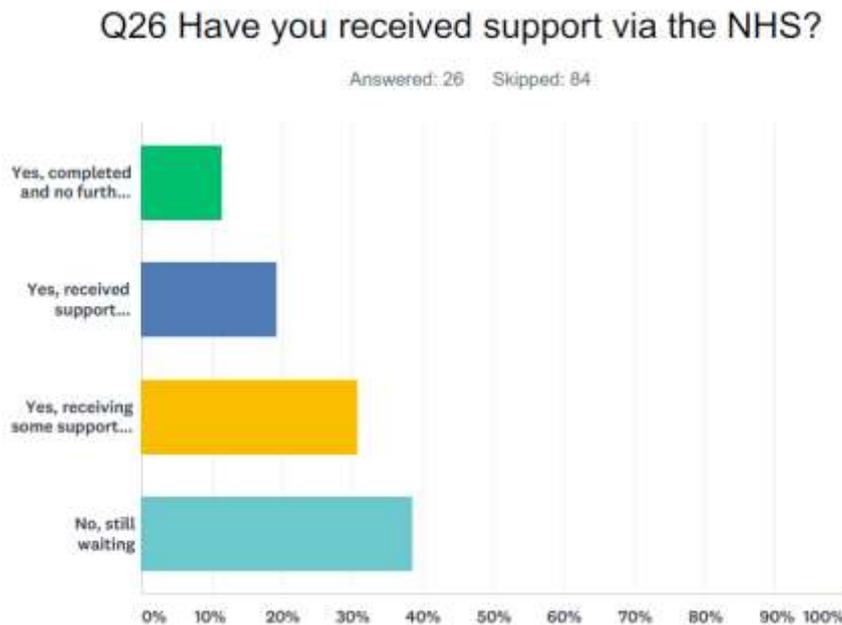


Figure 17 Survey Q26 Have you received support via the NHS?

Of those respondents who had been referred for support and answered Q27, 68% had been waiting more than 1 year; including 26% who had been waiting more than 2 years. This compares to only 26% who were seen within 3 months.

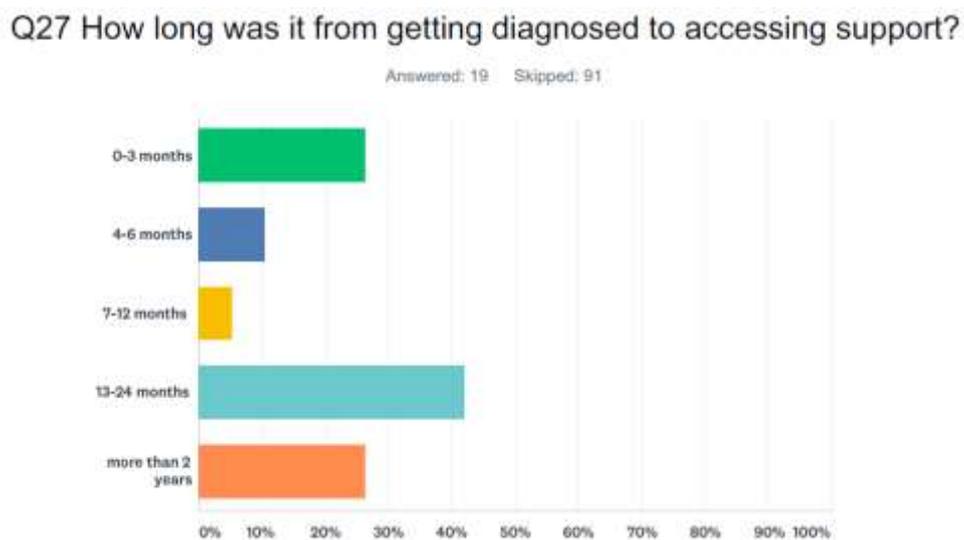


Figure 18 Survey Q27 How long was it from diagnosis to accessing support?

Survey of Pathological Demand Avoidance in Hampshire and Sussex

“We paid for a private diagnosis but even then, we have to wait 18 months or more to get assistance for her anxiety”

“Commissioned via the hospital but it has taken a year to get a speech and language assessment and now we have expert reports we are still waiting for therapy to start”

“Been on portage waiting list for 8 months not yet received. Get speech therapy but that’s only once every 4 months which doesn’t seem sufficient to me as [my child] is completely nonverbal and I feel he needs a one to one specialist or help every day which he doesn’t get as is in a standard nursery.”

“This is a condition that presents new challenges as he grows up. Advice given for a child is not so relevant now he’s an adult so now much harder to manage but no support available.”

“The woeful lack of provision for high functioning but complex children with comorbid mental health problems, like my daughter, means she has learned many more problem behaviours in hospital and has become institutionalised.”

NEED TO ENGAGE TO OBTAIN SUPPORT

Lack of understanding of PDA and PDA strategies can cause problems after diagnosis, as well as when accessing services prior to or without an ASD assessment.

PDA children who are referred for support to CAMHS are often referred due to their high levels of anxiety, but traditional methods of support for anxiety such as CBT are often unsuccessful (and is sometimes traumatic) for autistics generally, but particularly PDA children. It is possible for them to access CBT but the practitioner needs to have experience of modifying it for use with autistic people. There are also alternative options, but without an understanding of PDA the clinician may not understand the need for this.

Even if suitable treatment options are offered the clinician needs to find a way to work with and around the patient’s demand avoidance. This can mean that PDA patients find it hard to comply with requests during the session, may comply in an

Survey of Pathological Demand Avoidance in Hampshire and Sussex

unusual or unexpected way or can be so severe that even trying to attend sessions causes panic attacks and meltdowns.

Lack of compliance / not attending sessions is seen as not engaging and can end up with the PDA patient being discharged when instead it needs to be seen through the lens of their disability. If you help a mobility clinic on the top floor of a building with no lifts it would be unfair to penalise the patients for not attending. In the same way accommodations need to be made to help PDA people access services even – and especially - when they are struggling most to access them.

“Daughter was eventually given medication for anxiety - this was agreed to as CAMHS had said they were not prepared to offer CBT due to her anxieties/rigid thinking and thought medication may facilitate this. Daughter had only 2 sessions as they thought she wasn't engaging! CBT stopped and then family systemic therapy was offered but we didn't think this would help with daughter's issues, but may change our minds.”

“You cannot assess a child with ASD who masks in one relatively quick session. You also shouldn't place so much emphasis on what the school have noticed or think, they are not experts!”

“We did not meet the ‘criteria’ for assessment as our child masked at school and they would not see her without the school's input. We have only now just seen one to confirm the private diagnosis we had to seek given the refusal to assess and 18 month waiting list. I had to apply for the EHCP myself and confirmation of our child being Autistic through the NHS only came about because of this.”

“Diagnosed ASD by paediatrician at age four but then two year wait to see CP. School brought in Outreach Worker from local ASD specialist school to help eleven times. When he did the ADOS test this was after two years of school using strategies to help him. He refused to do at least half of the test yet the CO still deemed him borderline!”

“It is so hard to get services unless it's typical autism”

Survey of Pathological Demand Avoidance in Hampshire and Sussex

PUSHED TO USE PRIVATE SERVICES

The lack of recognition for PDA and long waiting times are driving parents to pay for private assessments and services.

Out of the 74 respondents who answered Q31 on the survey 42% had paid to see a private healthcare provider for something connected to PDA, autism or a related condition.

Q31 Have you seen any health care practitioners privately for anything related to PDA, Autism or related conditions?

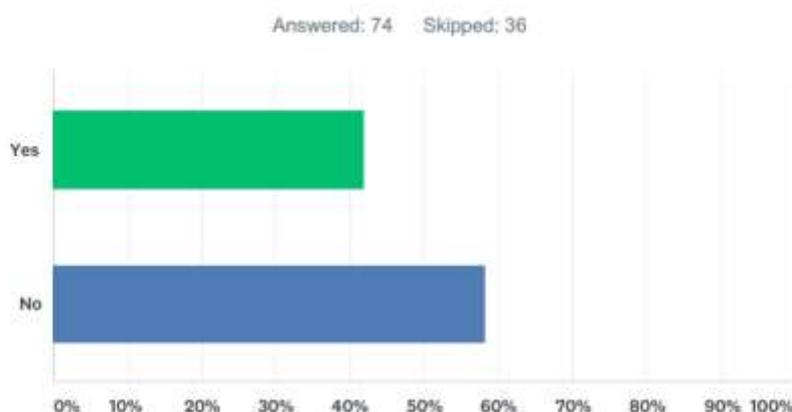


Figure 19 Survey Q31 Have you seen a private healthcare practitioner for anything related to PDA, Autism or a related condition?

“The NHS paediatricians are reluctant to see us. We have had to pay to go private”

“Private diagnosis was most useful to us as parents”

“Had to seek private diagnosis due to waiting list”

“We were offered an ADOS by a community paediatrician just before attending private clinic but paediatrician said they would not recognise demand avoidance in any form in the report so we continued with the private assessment.”

“Prior to the private appointment GP referred to CAMHS - turned down; Our GP won't refer her back - he has heard too many negative things. Our paediatrician (she has physical health needs as well) had also referred us to our local community paediatricians at Frimley Park. But Virgin Care was in disarray and we were advised there would be a 2 year wait.... Hence we went privately.”

Survey of Pathological Demand Avoidance in Hampshire and Sussex

The most commonly paid for were Occupational Therapist, Speech & Language and Psychologist services.

Q32 Which professionals have you seen privately? (Select all that apply)

Answered: 41 Skipped: 69

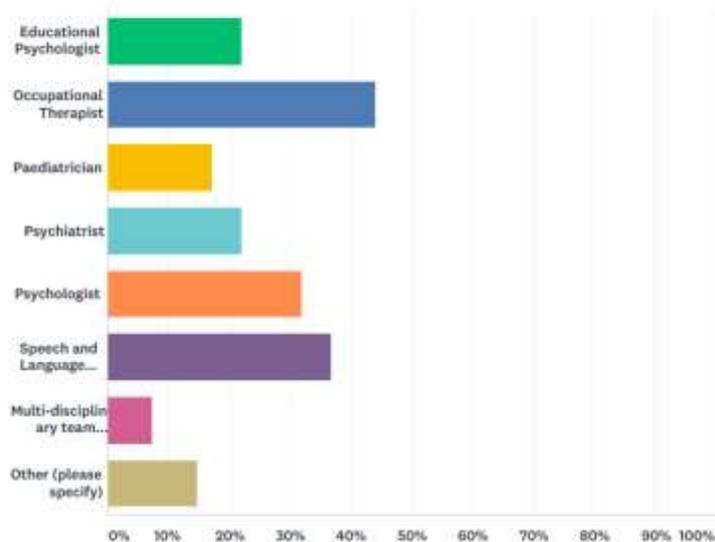


Figure 20 Survey Q32 Which professionals have you seen privately?

“I believe it helped that we had a private OR report initially and our daughter was not a masker”

“CAMHS were a disaster, [the private clinic] was excellent” “Not accepting PDA as a diagnosis”

Of the 40 survey respondents who answered Q33 on why they paid for private services:

- 91% agreed strongly or strongly agreed that it was because they were at crisis point and had no choice
- 63% agreed or strongly agreed it was because of perceived lack of knowledge of PDA within local NHS
- 58% agreed or strongly agreed it was because of long wait times on NHS
- 43% agreed or strongly agreed it was because of NHS refusal to diagnose PDA and because of the refusal of the NHS to acknowledge their issues
- Nobody strongly agreed with the statement that they had money freely available for services

Survey of Pathological Demand Avoidance in Hampshire and Sussex

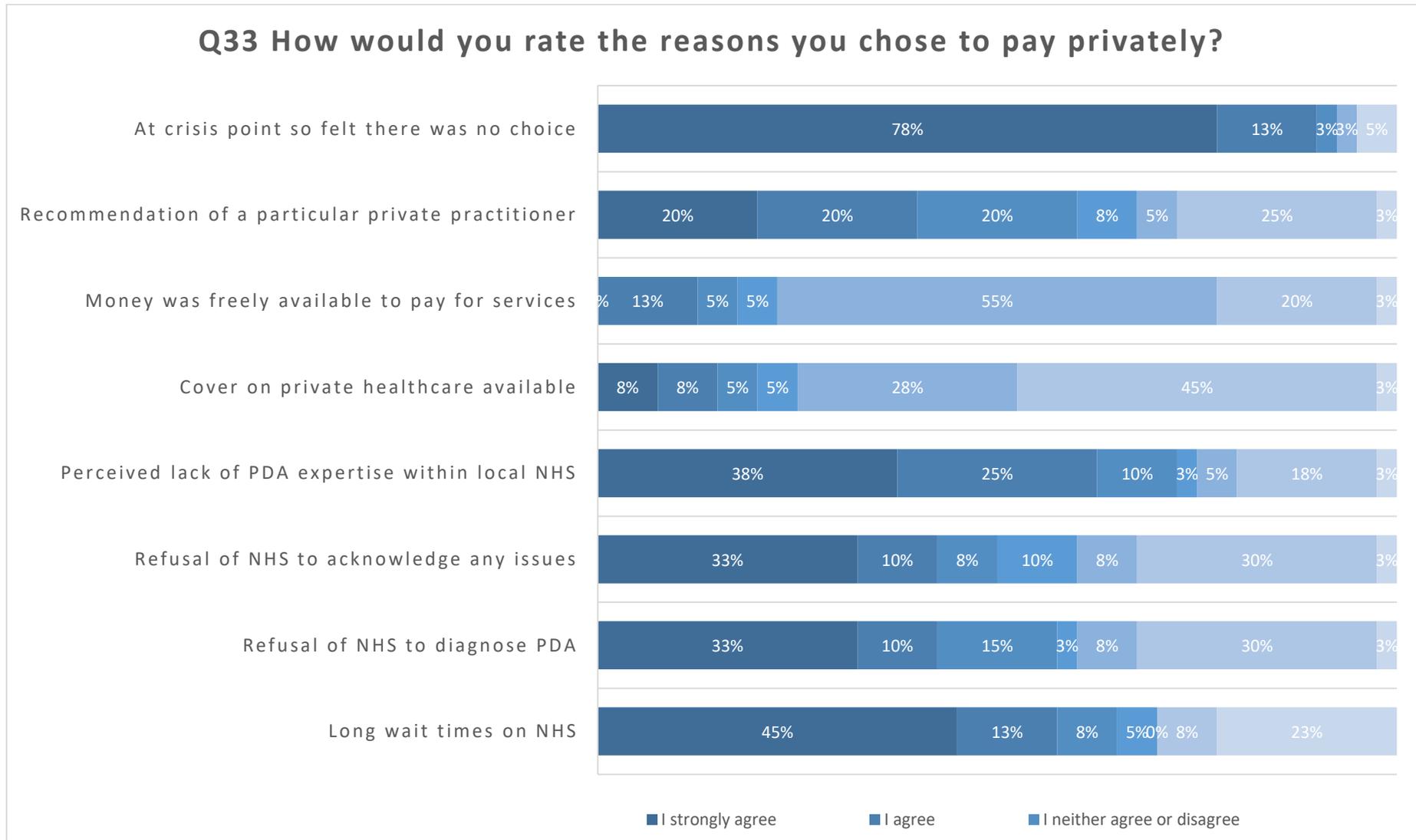


Figure 21 Survey Q33 How would you rate the reasons you chose to pay privately?

Survey of Pathological Demand Avoidance in Hampshire and Sussex

Conclusion

In summary, the lack of recognition of the PDA profile of ASD by CAMHS, community paediatricians and related services within the Sussex Partnership is having a huge impact on the quality of services received by PDA families.

The argument that there is no need to recognise it specifically when individuals can be assessed and treated without this is flawed as the results of this survey show. A significant proportion of PDA families are routinely being failed by the services put in place to support them.

CAMHS may on occasions be able to appropriately identify and support PDA children, but it is not clear that they have sufficient training to separate causes of demand avoidance properly and it takes far too long for them to actually reach CAMHS and many are blocked from accessing their services. In the meantime, PDA families are left (for years in many cases) floundering and being judged by education and health professionals without the knowledge to support them appropriately.

By identifying 'demand avoidance' as a characteristic CAMHS are already grouping and making assumptions on behaviour and effective treatments rather than just an individual level.

We ask that CAMHS and the Sussex Partnership take this one step further and officially recognise PDA as a profile of autism.

It can be done. Other NHS Trusts in the region do recognise it. Surrey, bordering on our region, recognise PDA but will not accept NHS referrals from within the Sussex Partnership region. PDA is diagnosed and even researched as nearby as the University of Reading Centre for Autism.

PDA is already being diagnosed on the NHS in this area in some cases. In fact, nearly as many survey respondents (15%) said they had received an NHS diagnosis specifying demand avoidance compared to those who had obtained a private one (19%). All but one of those NHS diagnoses were reported to be obtained in-area.

Survey of Pathological Demand Avoidance in Hampshire and Sussex

Q15 Have you got a diagnosis which specifies some kind of demand avoidance

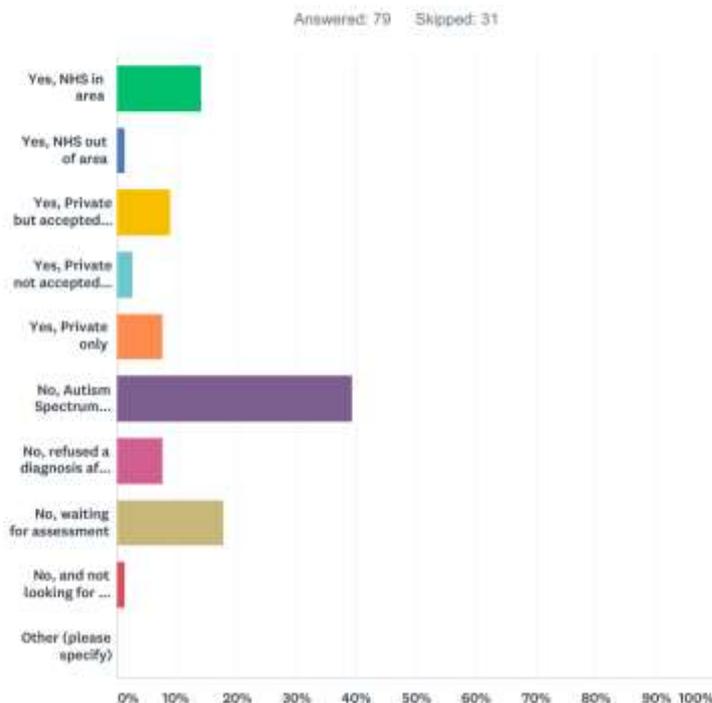


Figure 22 Survey Q15 Do you have a diagnosis specifying demand avoidance?

Out of the 10 respondents who had an in-area diagnosis and gave details of their exact diagnosis in Q16 70% had PDA or Extreme Demand Avoidance (a synonym for PDA) specifically mentioned in the diagnosis. The remaining 3 respondents only had demand avoidance mentioned in the report.

A general consensus around ASCs, including PDA, is that early intervention is key. Early intervention is not being achieved for PDA children in this region. Timely intervention is not being achieved for PDA children.

What is seen for a vast majority is that PDA children and young people are only being helped when they are at crisis point: when they are self-harming, violent or out of control; when their families are at breaking point; when they themselves are broken.

It is not PDA that has broken them.

It is a broken system that is not meeting their needs.

Survey of Pathological Demand Avoidance in Hampshire and Sussex

What can be done?

Lack of recognition of PDA leading to lack of knowledge and understanding of PDA and PDA strategies can be traced as the root cause for the majority of problem outlined in the report.

All the survey respondents who completed the survey (66) agreed that they thought PDA should be recognised as a subtype of autism both nationally and locally by the Sussex Partnership.

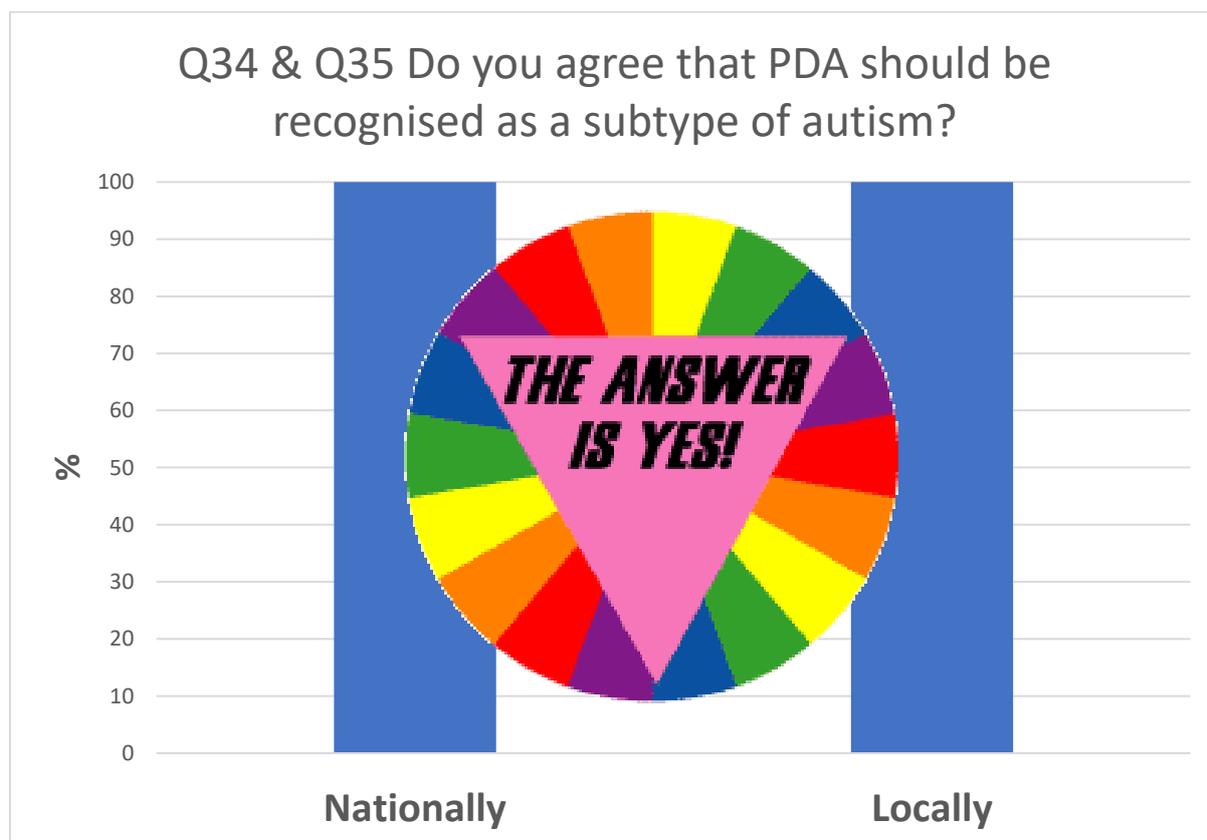


Figure 23 Survey Q34&35 Recognition for PDA as a subtype of autism

The report demonstrates why Sussex Partnership should make the following changes:

1. Recognise the 'PDA profile of autism'
2. Enable and allow clinicians to use diagnostic formulations and terminology which states 'ASD with a PDA profile' where clinically indicated, creating consistency
3. Ensure that autism training delivered by or on behalf of Sussex Partnership

Survey of Pathological Demand Avoidance in Hampshire and Sussex

- mentions the PDA profile
 - has sufficient information (at a level appropriate to the training) to raise awareness and help the course participants identify and support PDA people
4. Improve training for clinicians so they can identify and diagnose the PDA profile adequately
 5. Fund out of area assessments with clinicians that are knowledgeable and experienced in this complex form of ASD for all suspected PDA people while the training in point 4 is carried out
 6. Ensure that parenting courses are not being used as a barrier to their child getting on a waiting list
 7. Ensure case reviews are not being used as a barrier to children being accepted on a waiting list
 8. Allow parents of children suspected to be ASD to attend the autism specialist parenting course instead of the standard one
 9. Ensure that children who due to autism or demand avoidance:
 - Mask
 - Display challenging behaviour in only one setting
 - Refuse to engage with assessment or treatment

are treated fairly, with appropriate strategies and not blocked from services at any point

10. Ensure that regardless of a child's age the diagnostic process and criteria are aligned between community paediatricians and CAMHS (and any other related departments) so that they are following the same policy and guidelines

It is believed that making the above changes will make a significant difference to the lives of PDA people and PDA families throughout Hampshire and Sussex. By improving clinical outcomes there can be a corresponding improvement in happiness, health, educational attainment and life chances.

We believe they deserve this – do you?

Survey of Pathological Demand Avoidance in Hampshire and Sussex

Appendices

DHSC RESPONSE TO THE PETITION TO RAISE AWARENESS AND UNDERSTANDING OF PDA AMONG HEALTH CARE PROFESSIONALS

“We appreciate the deep frustration that you must feel in the failure to provide appropriate recommendations and care for your son’s complex needs. The Government is committed to supporting children and young people with autism, under which PDA is categorised, to enable the right support to be put in place early and reduce the longer term impact.

We acknowledge that the complexity of autism, and the multi-faceted nature of the needs of those on the spectrum, poses particular challenges to professionals and commissioners. The Government wants to make sure that clinicians have the best possible knowledge and resources available for them to make recommendations on the care and management of children and young people on the autism spectrum.

In the NHS, clinicians will diagnose in line with guidance such as the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the American Psychiatric Association's classification and diagnostic tool, or the International Statistical Classification of Diseases and Related Health Problems (ICD-10), a medical classification list developed by the World Health Organization

The National Institute for Health and Care Excellence (NICE) publishes a number of guidelines that provide evidence-based recommendations for the diagnosis and management of autism in children, young people and adults. These can be found at www.nice.org.uk, by searching for ‘autism guidance’.

The NHS is clinically-led, and, as such, decisions such as formulating a diagnosis will be taken by clinicians in line with the relevant clinical guidelines.

In the course of the development of the (NICE) clinical guideline on the treatment of autism in children and young people (CG128), the developers looked at differential diagnoses for autism. In this, they did consider PDA, identifying it as a particular subgroup of autism that could also be described as oppositional defiant disorder (ODD). The guidance recommends that consideration should be given to differential diagnoses for autism (including ODD) and whether specific assessments are needed

Survey of Pathological Demand Avoidance in Hampshire and Sussex

to help interpret the autism history and observations. However, due to the lack of evidence and the fact that the syndrome is not recognised within the DSM or ICD classifications, NICE was unable to develop specific recommendations on the assessment and treatment of PDA.

The Department of Health and Social Care has launched Disability Matters, an innovative programme providing free online e-learning and face-to-face training resources. It covers over 30 topics related to disability and special educational needs, including autism, and the aim is to provide a basis for professional development for anyone working with people with complex needs. Disability Matters can be found at www.disabilitymatters.org.uk. This resource is being kept under review, and officials will ensure that information and guidance on PDA are considered for inclusion once a verdict regarding this condition has been reached.

Additionally, The Children and Families Act 2014 places a renewed focus on the early identification of needs and under the SEND Code of Practice schools are expected to identify and support needs such as communication and social skills.”

Department of Health and Social Care

20th April 2018

<https://petition.parliament.uk/petitions/202680>

Survey of Pathological Demand Avoidance in Hampshire and Sussex

SURVEY DATA

The survey consisted of 35 questions and was answered by a total of 110 respondents. 66 respondents completed the survey.

The survey was active between 3rd and 31st May 2018.

All respondents reported having a connection with either Hampshire or Sussex.

55% of the responses were about PDA males; 42% were about PDA females with the remainder reporting as another gender. This highlights the more even gender balance thought to be seen in PDA compared to what is currently diagnosed in the general autistic population, particularly with regards to classic autism.

The data presented in this document for Q32 has been adjusted to remove invalid responses caused by a slight error in survey design.

The submitted survey responses were cleaned to remove any names and personal references to ensure anonymity for the respondents.

The quotes within this document were either submitted as part of the survey or were collected from the respondents via other media as part of the survey process. Some quotes have been slightly edited for clarity.

The survey data and this report remain the property of the author.

The survey data (original, formatted and corrected, along with calculated figures) can be obtained by contacting the survey author on pda@attitudeforchange.co.uk.

Finally, a huge thanks to all the survey respondents and the people who have helped with this project. You are all awesome!

Survey of Pathological Demand Avoidance in Hampshire and Sussex

REFERENCES

- ⁱ What is pathological demand avoidance (PDA)? | National Autistic Society | <http://www.autism.org.uk/about/what-is/pda.aspx>
- ⁱⁱ Pathological Demand Avoidance (PDA) | Sussex Partnership Children & Young People CDS | 18th October 2017
- ⁱⁱⁱ DWP | Medical guidance for DLA and AA decision makers | https://docs.wixstatic.com/ugd/5143d7_e222975eb349455690179638d0cb3af4.pdf
- ^{iv} Autism Education Trust / DoE | The Distinctive Clinical and Educational Needs of Children with Pathological Demand Avoidance | <http://www.aetraininghubs.org.uk/wp-content/uploads/2012/05/5.2-strategies-for-teaching-pupils-with-PDA.pdf>
- ^v PDA Diagnosis UK | Zeemaps | <https://www.zeemaps.com/map?group=1558150#>
- ^{vi} Being Misunderstood | PDA Society | <https://www.pdasociety.org.uk/resources/research-summary/2018-survey>
- ^{vii} Unit Costs of Health and Social Care 2016 | PSSRU | <https://www.pssru.ac.uk/project-pages/unit-costs/unit-costs-2016/>
- ^{viii} Autism spectrum disorder in under 19s: recognition, referral and diagnosis | NICE (National Institute for Healthcare and Excellence) | <https://www.nice.org.uk/guidance/cg128>
- ^{ix} “Results of our parent survey” | Diagnosis of Autism project website | <http://www.autismdiagnosis.info/parents-results>
- ^x Sensory Processing Disorder Explained | <https://aspergers101.com/sensory-processing-disorder/>

Credit for PDA image on title page to Sally Cat and the PDA Society and it displays the words of 84 parents and carers when asked to name three of their child’s positives in the “Peaceful Parenting Place for PDA Parents & Carers” group on Facebook.