

Call for the Hertfordshire All Age Autism Partnership Board to recognise Pathological Demand Avoidance as a profile within the Autism Spectrum

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Supported by:



Recognition of Pathological Demand Avoidance as a diagnostic profile within ASD

Hertfordshire's All Age Autism Strategy starts by describing the County's commitment to helping those with Autism realise their potential and explains that for this to be done there will be improvements in understanding of the individual variation in presentation, that care should be needs-led and outcome-focussed and parents should be involved as equal partners.

Hertfordshire is known for its significant efforts to bring services together in the area of Autism, and the creation of the Partnership Board has been a welcome advance. However, the strategy is not being implemented for the young people whose parents suspect they have Autism with a Pathological Demand Avoidance (PDA) profile. Indeed, for many, the experience is the very opposite of the Authority's objectives. The strategy has a blind spot.

The National Autistic Society suggests that 1 in 68 children are diagnosed with ASD, a significant proportion of the population and amongst whom traits and needs will vary widely. They highlight the fact that those whose autism is characterised by extreme demand avoidance (or with Pathological Demand Avoidance, PDA) will require **different strategies** from others on the spectrum in order to thrive. This is why it is essential to be identifying these individuals.

A survey of parents of 38 children and young people in Hertfordshire demonstrated:

- **Lack of consistency in approach to diagnosis** – some practitioners will diagnose PDA, some do not address the possibility, while others are told the diagnosis is constrained because 'the council don't recognise PDA'
- **Ineffective services** - having multiple difficulties means many are involved with a range of services, yet a majority of parents say that the services have not helped them. This is a waste of resource and leads to greater needs in future.

These children are failed because their needs aren't properly understood, and while 5 or 10 years ago there was understandable hesitancy in accepting 'PDA' as a diagnostic term, professionals across the country are increasingly using the **PDA profile, as a sub-type of ASD** to identify those with a common set of characteristics. Many have participated in training and professional development around PDA and now have a good understanding of how to support these children, so it was distressing to hear that so many within the County have little or no knowledge of the condition and find they are unable to support some of our most vulnerable children.

For this to change the All Age Autism Partnership Board must:

- 1. take a leadership role in recognising PDA as a 'diagnostic profile' within ASD, working with diagnostic teams and Autism service providers to develop a common understanding, and*
- 2. ensure staff within the County have the training and expertise to fully support both young people and adults with the condition.*

This report provides evidence of the current state of local services, and also provides some context with information on the work being done nationally. We would ask that the Board considers the evidence carefully, and urgently takes steps to ensure the local authority, NHS, and local service providers are provided with the understanding and direction needed. For this to happen, it will be essential to have the agreement of clinicians responsible for diagnosis, and to that end a meeting with fellow professionals with specific expertise in this area will be helpful.

The following organisations represent families in Hertfordshire and support this call for action:

ADD-vance

Angels Support group

Carers in Herts

Guideposts

HARC – Herts NAS

Hertfordshire Parent Carer Involvement (HPCI)

PDA Society

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Introduction to the National Picture

History

Pathological Demand Avoidance (PDA) was first identified in the 1980s by Professor Elizabeth Newson at The University of Nottingham and is recognised by the National Autistic Society as being a condition on the autistic spectrumⁱ. Professor Newson worked with a group of children for whom autism had been considered a possible diagnosis but were “somewhat different”, and who also proved very challenging for parents and carers to look after, with different strategies required for effective intervention. This led her to publish a series of papers, describing and naming the condition, and for subsequent researchers to progress this work furtherⁱⁱ.

Research

Some of the most respected academics in Autism are contributing to work in this field, with Prof. Happé from King’s College initiating the most recent series of research, and new studies now being taken forwards in a number of Universities.

Professor Christopher Gillberg highlighted the need in his paper from June 2014ⁱⁱⁱ

“PDA is already a very real clinical problem...Intervention and treatment currently rest almost entirely on guesswork, clinical experience and trial and error. It is one of the most ‘difficult to treat’ constellations of problems in the whole of child and adolescent psychiatry.

Strategies developed for ASD, ODD and ADHD are often ineffective and parents, teachers and clinicians may be driven half crazy by the child’s stubborn refusal to cooperate and by avoidant...behaviours”

Dr Judy Gould, Lorna Wing Centre for Autism described the importance of diagnosis at an NAS conference:

“Diagnostically the PDA sub-group is recognisable and has implications for management and support.”

The eighteen papers published in peer-reviewed journals are available on the PDA Society website and there are further studies due for publication in the next few months. While research is still in its infancy (rather like work being done on Asperger’s in the 1950’s), it is making strides forwards and the ‘Extreme Demand Avoidance questionnaire’^{iv}, while not a *diagnostic* tool, has helped to develop understanding further and supports the diagnostic process.

Experience

The PDA Society now has well over 4,000 members who share information and find common ground in the difficulties that their children face. The combined members of the many Facebook groups run into thousands from across the globe and consist of parents, carers and family members supporting individuals with PDA and individuals who themselves have PDA.

Nevertheless, this form of Autism is relatively uncommon, and so an individual practitioner is unlikely to come across many cases. To support professionals in their work, the PDA Society has recently published a series of case studies to illustrate the nature of the condition and the benefits of using appropriate management strategies.

Training and professional development events are continuing apace, with the National Autistic Society holding its 5th annual conference in 2016 and more than 1,600 professionals participating in courses and training events in the past year by 'Autism Associates' alone. In addition, the PDA society has run courses for around 600 parents, including parents in Hertfordshire. Indeed, within Hertfordshire, the Authority's own Communications Advisory Team runs courses on PDA and schools and DPSLs are providing workshops and inset days on the subject for staff.

Resources

There are now a range of materials available for clinicians, practitioners, parents and those with the condition. There are books and guidelines from the Autism Education Trust through to descriptive tools, blogs and articles. Each has contributed to clarifying the specific needs of those with PDA.

National Imperative

Phil Christie, who has worked on PDA since those early days with Prof Newson, recently provided his expert view to the Scottish Government, drawing on comments made by Liz O'Nions and colleagues in an article published in the British Psychological Society DECP Debate issue in 2016. This is as relevant to Hertfordshire as it is to the rest of the UK:

"It is widely recognised that individuals with PDA and their families are exceptionally vulnerable to being misunderstood, not having their needs met and of experiencing exclusion from educational settings.

Wider recognition and assessment that leads to appropriate description and formulation of the child's difficulties and needs is the starting point for the provision of appropriate support. With this support the lives of individuals and their families can be transformed."

Phil Christie, December 2016

A Note on Terminology

It is not necessary to have completely consistent diagnostic terminology in order to lead to the most suitable support and approach. The diagnostic formulation might be PDA, ASD characterised by Extreme Demand Avoidance, ASD with a PDA Profile, ASD sub-group PDA. Each of these terms, alongside a detailed description of a child's individual profile and needs, can be sufficient as long as it is clearly a signpost to the most appropriate management strategies that will help the individual.

It is also important that in understanding the diagnostic profile, clinicians are not only considering the demand avoidance element. It is also necessary to be aware of the other diagnostic characteristics, including: lability of mood, being comfortable in role play, obsessive behaviour, and the likelihood that the difficulties in social interaction and social understanding can be 'masked' by surface sociability and are likely to be atypical to those more commonly observed in the typical male ASD profile.

Survey of Hertfordshire Parents

About the respondents

The survey was placed online between 26th Jan and 1st Feb 2017 and was completed by 38 parents who are known to the PDA Society as they have an interest in Pathological Demand Avoidance.

It may well be that not all of these young people have PDA, even though they exhibit demand avoidance, but the survey was intended to find out about their experience of services and not to determine the accuracy of a diagnosis. While some have had good experiences, many have faced significant difficulties.

Children ranged in age from preschool to 19 years, with 15 in the 8-10 age group and they come from across the County, but predominantly the South and West. Of the 31 who reported where they live, 10 were in Dacorum, 10 in St. Albans, 4 in Watford, 3 in Hertsmere, 2 in Stevenage, and 2 in Welwyn Hatfield.

Current Diagnoses

28 currently have a diagnosis of something and others are waiting. Only two said they hadn't been offered or asked for a diagnosis as yet. Of these, 21 already had an ASD diagnosis, 7 had ADHD diagnoses and there were 9 with multiple diagnoses.

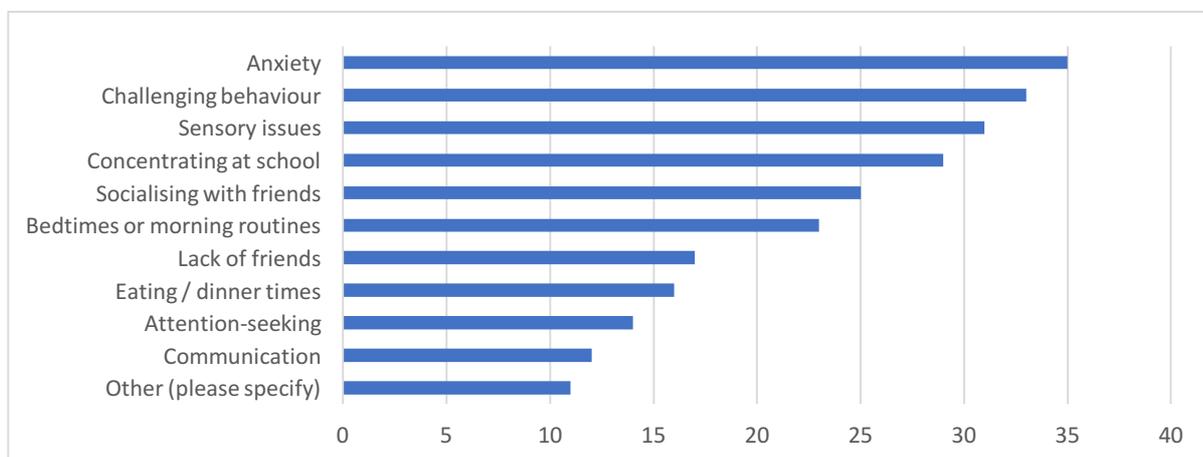
Six had been diagnosed as having PDA (a profile within ASD); three were through local paediatricians, one out of county, and two through private specialists.

In addition, there were two who reported that PDA was suspected or 'informally' diagnosed. One told us:

"Formal: ASD Informal: with PDA features. Dr is unable to formalise PDA diagnosis because 'the county doesn't recognise it'"

Challenges faced

These young people face significant challenges, with all parents identifying a range of issues. Those providing additional information highlighted avoidance, need for control, violent outbursts, OCD and school refusal.



Involvement of local services

All 38 families had been involved with local services in the past couple of years, with a total of 92 contacts or interventions identified from the information available.

CAMHS (Child and Adolescent Mental Health Service)	42%	16
Educational special needs	42%	16
Communications Advisory Team/Autism Advisory/Communications Disorder Team	34%	13
PALMS (Positive behaviour, Autism, Learning disability and Mental health Service)	34%	16
Family support worker	32%	12
Speech and Language Therapist	26%	10
Social care	11%	4

Responses under 'other':

Assessed by CAMHS, salt, OT but no service she or support offered
 Been waiting for palms initial appt with palms for 6 months
 ADD-vance, DESC
 Online groups and blogs eg ADD-vance/families in focus
 School have just started to tackle issues (recent diagnosis)
 Physio, OT
 Desc Support
 Challenging behaviour service; Harper House;
 Steps2 intervention. Behavioural therapy sessions. DSPL7 and
 ADD-vance
 Families in Focus
 Ed Psych and OT

Helpfulness of services

Respondents were asked '*Has the help you've had from local services enabled you to understand your child better and enabled them to manage any difficulties better as a result? Tell us about your experiences.*'

Seven reported some positive experiences, four suggested it was too early to tell, and 20 indicated that they had not been helped. Seven did not reply to this question.

Had a positive experience of local services

1.	Yes Add-vance family coaching was a life saver!!
2.	Support from Family Support Worker and Families in Focus has been amazing supportive but not specific to PDA
3.	Yes, but not enough. 6 weeks with psychologist helped with self harming and suicidal tendencies but needs more help with building resilience to cope with rejection and

	difficulties arising at work when she is treated differently and as if she is not as good as her peers.
4.	I've had no specific PDA training, but I've done a sensory workshop which was interesting (referred by paed), an evening course on anger and ASD, and a ten week Families in Focus course on parenting with additional needs. These were all really useful, especially the Families in Focus course as it was great to get to know other parents.
5.	Camhs have helped but mainly drug treatment. My son has just started sessions with camhs high risk nurse
6.	Somewhat but hides lots of traits well from others when outside the home
7.	She has a buddy through CAMHS. It enables my daughter to have someone other than me to talk to.

Still waiting or it is early days

8.	Just started with ADD-Vance so too early to tell. No help been useful from other services.
9.	We are still on initial visits at the moment (3rd time seeing autism and communication team) so early days. Still awaiting further appointments for speech therapy and awaiting an overdue appointment to see paediatrician (for diagnosis)
10.	We only got diagnosed a while ago so still trying different strategies
11.	We are at the beginning of our journey with PALMS. Any understanding I have has come from my own personal research and reading

Did not find support helpful

12.	I know more about his condition and behaviour than the local services do
13.	Help from charities that I have sourced myself has enabled me to understand my child better with his autism. I haven't been to any pda courses as haven't found any.
14.	Not at all, it has been from all of my own research and implementation of strategies that has led us to where we are. Nobody has believed me of the difficulties and I have had to challenge every part of the way. It has affected our family's mental health and place in society.
15.	Variable success. What works for a while does not work forever. Always firefighting new issues or recurrence of issues.
16.	No - they all mean well but never seem to have answers that make a difference
17.	CHAMS couldn't help transferred to palms waiting for home assessment doing a positive behaviour course at present
18.	No. Everything I have learnt about PDA I have learnt and researched myself.
19.	It's encouraged me to do my own extended research. But I feel I have had no support otherwise. Lots of promises no action. Finally Camhs have just started some psychotherapy. I've been asking for help since my daughter was 2.
20.	No - Harper House was very damaging and we had waited over a year- they offered to teach us about social stories even though they had already been tried to no avail; they

	refused to acknowledge PDA; PALMS has taken nearly a year from referral to treatment and although the staff are sympathetic I feel they are constantly looking for opportunities to discharge us and I am not sure if they have a strategy for the case
21.	These services have had a very small effect. Without a full assessment and diagnosis systems don't get put into place. Getting a full assessment and diagnosis locally on the NHS is impossible!
22.	Made very little difference
23.	We've not had any help from local services
24.	Only through support groups and my own research
25.	Only recently moving to Herts, we have only accessed services via the LA and ehcp process. Our Dr tried to refer to OT in Herts but we got refused as they said they think that everything has been done for him already ! Quite sad at the age of 10 to be cast aside ! We have dealt with a Advisory teacher of autism who did a report for Herts LA who didnt seem to know anything about ASD and went along to write a report slinging mud at myself the parent to try and discredit me, this has greatly upset me as she works at XXXXXX with children with SEN !
26.	No. Complete lack of understanding. Counterproductive "help". Failure of school to fully support ending in son being de-registered from school to be home educated.
27.	We've had no significant help from local services
28.	No support whatsoever
29.	Nope
30.	No
31.	No

Process of Diagnosis in Hertfordshire

Respondents were asked 'Tell us more about your experience of diagnosis in Hertfordshire. Has the process been helpful, have you felt 'part of it' and listened to, has it given you a better understanding of your child? Perhaps you are still waiting? What has that meant in terms of services available?'

The replies demonstrate the difficulties of getting a diagnosis in a timely way, and the lack of follow-up once a diagnosis is given and some specific problems around the process or outcome of the diagnostic assessment.

1.	We have been very lucky and got diagnosis we expected easily.
2.	Thrilled that the paediatrician was aware of PDA and able to diagnose it. Have had no useful further help as PDA is not recognised. Have been on waiting list for Palms for months.
3.	No, diagnosis needed since birth but very little support available from Herts.
4.	Still trying to get a diagnosis. Have been working on it for 1.5 years.

5.	Been under paediatricians for about 2 years but no further along in any diagnosis so no support. On a waiting list (approx 10 months so far) for an ADOS assessment. This is despite developmental issues, eg, speech & language and developmental milestone delays since a baby but never been "bad enough"
6.	I think it's ridiculous that my child could have something he needs help and support with to manage like pda but Herts county council don't recognise it as a diagnosis so the paediatrician won't formally diagnose
7.	Private diagnosis, but with support from school in accessing other services.
8.	It took a good few months from referral by GP to be seen, and in that time things reached crisis point at school with exclusions. Eventually he reached the top of the list and thankfully he was diagnosed on the spot with ASD by the NHS paediatrician. We still kept our appointment with XXXX as we knew Hertfordshire would not diagnose PDA and it was important we get that part of his diagnosis.
9.	Had to fight all the way and my parenting was blamed at 1st no one would listen
10.	I have not felt listened to and have been branded a 'bad parent' - it has taken a long fight to be listened to and evidence the difficulties my daughter was experiencing. I feel totally let down by the services around me. I have applied twice for an OT to assess my daughter and that has been refused even though she has documented the difficulties she faces in this area. I have felt like giving up on many occasions.
11.	I've never seen the same paediatrician twice and nobody wants to meddle with someone else's diagnosis
12.	Of all the services we have seen, nothing has really helped in terms of providing strategies that actually work.
13.	Initial diagnosis easier and quicker than we expected. No follow up. I had to offer our report to school so they could instigate measures. Feel like I'm fighting alone.
14.	Feel continually passed from pillar to post. Constantly waiting for latest acronym to 'hold a meeting/decide whether they have the budget'
15.	No formal diagnosis. Camhs don't seem to want to know about PDA. Probably due to lack of formally understood diagnostic tool that has been validated by larger clinical trials?
16.	I have been listened to, however, once the diagnosis was given we were left hanging. There is a massive waiting list to see the community paediatrician. We were supposed to see her in October and still waiting for an appointment
17.	Process is awful. All push away unless you are a pushy parent.
18.	Terrible journey. Daughter finally diagnosed at 12 years old and only after being admitted to hospital for self harm. She had been under CAMH for 4 years prior to this with no diagnosis.
19.	CAHMS have been useless. On a long waiting list for PALMS. Seen an autism advisory teacher who was unaware he "has" PDA so waiting for a referral to a colleague. Seen lots of people but no one has actually helped.
20.	Diagnosed by CDC in hertford 12 years ago discharged the same day with leaflets only supported by Angels until last summer when doctor referred to CHAMS due to school refusal and weight issues
21.	Still waiting for appointment from Pat Lewis Centre to come through
22.	I am not happy with the diagnosis process like I said I have known my child is different from being a baby saw paediatricians when she was young to no avail. Had autism test

	and was told they don't think she's autistic but has tendencies. They believe it's attachment. I was diagnosed with BPD just before my daughter seeing paed. I'm not sure of my diagnosis either and feel that she has been pigeon holed. I have not been given any more understanding of my child through professionals but have done my own research I'm hoping for more support from camhs??
23.	I have achieved most of the progress through privately funded practitioners and it is constantly a struggle to be taken seriously. I have had to fight for everything and feel that the LA will as policy undermine parents and families rather than offer appropriate support. My GP is quite I embarrassed to advertise that she doesn't really know about this sort of thing. When first diagnosed with ASD we were told flatly that there were no services
24.	With no assessment and diagnosis available locally my daughter hasn't had any help.
25.	Herts diagnosis slow and felt like deliberate attempts to avoid initially. No further support after diagnosis until we fought for statement and then in crisis when statement ignored by school in 6 th form.
26.	We have visited the GP twice with our concerns for our son's behaviour. The first time we were referred to a paediatrician, however we never received an appointment. The second time we were referred to Single Point of Access who 'reviewed' our case (without actually speaking to us) and recommended the Hertfordshire Strengthening Families Project. We did not feel this was the appropriate route given that we feel our son needs an assessment. We dont feel we have been helped in the right way, and are therefore having to seek a private assessment & diagnosis for our son.
27.	Were initially passed backwards and forwards from CAHMS to Piediatrician and eventually got an appointment at Pat Lewis Center, Hemel Mid November - now waiting another 6 months or so for ADOS but no mention of PDA yet.
28.	Herts still don't officially recognise PDA in my experience and therefore don't offer anything for parents and teachers to support it
29.	Passed from pillar to post. Very frustrating. All professionals agreed assessment needed but no-one would take responsibility for assessment. As a result, assessments being done elsewhere.
30.	Although we live in Herts and our daughter goes to school here, our doctor is in Beds and CAMHS is in Bucks. So a bit of a mish mash really. I would like her to be seen in Herts if at all possible
31.	Unable to get diagnosis for PDA. Autism diagnosis took too long and then no services were able to get involved due to late diagnosis age 13
32.	I have been given no help or support whatsoever.

Professional Acceptance of PDA

The question was asked: *'Have the professionals you've met 'accepted' either 'ASD with demand avoidance' / or 'PDA' as useful descriptors? Tell us more...'*

The responses demonstrate significant inconsistencies in the approach of professionals. In a further question about how they first learned of PDA and who helped in their understanding, only two parents mentioned a Paediatrician, and two mentioned ADD-vance.

1.	Family Worker and school are supportive but no other professionals seems to acknowledge PDA. School sent their senior member of SEND on a course
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2.	They have ignored our suggestion of PDA and do not seem to have knowledge or understanding of it as we were told the approach would be the same (we know is not true and find PDA strategies work best with our son).
3.	No.....consider his behaviour to be part of his SLD
4.	Have just begun the process of getting an appropriate diagnosis from a new paed when I asked for a second opinion
5.	Recognised traits of PDA but assessing for asd as PDA isn't recognised
6.	Verbally have been told he most probably has pda but then told it isn't recognised in Herts.
7.	Our nannies have without question. The school (which is a very good school) has been very open to listening and researching the condition. As a result, he is a lot more settled in school and we are very very grateful as he was being regularly excluded before we realised he had PDA.
8.	Communication and autism advisory team said to use PDA strategys
9.	Some professionals have accepted it, but others not and believe that 'demand avoidance' is how a girl with ASD presents. The EP that saw my daughter refused to come in, then when she did she wrote general strategies for the EHCP to suit an ASD diagnosis. This made the situation worse. The Communications team had to go away and research more of a bespoke strategy plan in order to alleviate the anxieties in school.
10.	Child development centre wouldn't diagnose ASD without an ADOS and after 6 months waiting we went privately. When we received the ASD diagnosis they didn't feel that PDA would bring 'anything new'.
11.	commonly used PDA
12.	No. I suggested it and she said they only give general ASD diagnosis now. She added in the past she might have said Aspergers but if PDA techniques worked for us we could try a private diagnosis.
13.	Yes - diagnosed by paediatrician and referred to Elizabeth Newson Centre. All professionals we deal with appear to accept diagnosis
14.	No. Camhs do not recognise PDA nor test for it as far as I am aware
15.	PDA hasn't been diagnosed yet
16.	Awaiting ADOS
17.	No. We are at CAMH in St. Albans and they don't recognise PDA as a diagnosis for anyone
18.	Yes but can't formally test it
19.	No either not aware of it or not happy to consider it as not recognised as a formal diagnosis
20.	Some professionals (not ones that matter have agreed with PDA)
21.	The LA questions the existence of PDA or minimises it and seeks to conflate it with ODD/EBD leading to wrong headed strategies which are counterproductive and harmful
22.	No, they have said my daughter hasn't got it without testing for it and that it wouldn't benefit her even if she did get a diagnosis

23.	No. We have used the example that when she is feeling overwhelmed and anxious she can display PDA traits. This was allowed in her ECHP document but only with a rider that it was our opinion.
24.	Initial appointment with paediatrician suggested ASD but no reference to PDA even though we sent supporting information
25.	Only ASD...was discreetly told by communications and autism team XXXX that I may wish to research PDA myself. I now share PDA info with professionals who support XXXX but it isn't formally acknowledged or supported.
26.	Herts LA dealing with Ehcp do not seem to accept PDA diagnosis and it is frequently ignored.
27.	No
28.	Yes. Accepted (in theory, but we don't feel well understood) by CDC paediatrician, Communication Disorders team, CAMHS, PALMS, senco.
29.	Yes, but only informally, as above.
30.	No
31.	Not at all. It doesn't exist...apparently and my daughter doesn't have autism, aspergers or ADHD
32.	Refused to recognise anything except autism
33.	Psychologist from local PALMS service has written reports stating he 'struggles with demands'. They explained they felt 100% he had PDA but Hertfordshire LA do not recognise the condition so they would not even refer for an assessment.

In Summary

More and more parents are finding out about PDA through online research, friends and from some of the professionals they meet. Their aim is to learn about the source of their child's difficult behaviours and what might help and they find that they identify with the descriptions of ASD traits along with an 'anxiety-led avoidance of everyday tasks to an extreme degree'.

Many are then faced with an inability to explore the possibilities effectively because services and individuals are lacking in knowledge or simply do not consider it worthy of discussion. Parents of PDA children are often blamed for poor parenting, or difficulties can be put down to attachment problems because of certain similarities in presentation, and parents often feel that they are not being listened to.

At the same time, those professionals working with children or families on a regular basis, are recognising the benefits of using PDA-related strategies. Schools and SEN groups across the County are arranging training to learn more.

It is essential that services become joined up and develop a common understanding. These are the young people who are the most complex and difficult to help, and without a good foundation are likely to need support for many years to come.

We need to consign to history stories like these from parents in Hertfordshire:

"I first became aware of PDA on a television programme and thought that was exactly like my son. I was then astonished/disgusted that professionals involved with my son all agreed he had problems with demands (understatement) but that Hertfordshire did not accept PDA. My son has been out of school for the past two years as he couldn't cope."

"Verbally we have been told he most probably has PDA but then told it isn't recognised in Herts."

Call to Action

It may take some time for the Partnership Board to meet, gather evidence and provide overarching guidance. It is hoped that as part of the process they will consider what additional support can also be provided to the families that completed this survey.

In the meantime, supporters call for:

Service leads and CCGs to

- issue a statement to staff to explain that within their field the PDA profile is recognised as a valid descriptor of an individual's needs;
- make further information available to their staff (the PDA Society can help with this);
- stress that these young people require different strategies than would generally be used for someone with ASD.

ⁱ <http://www.autism.org.uk/about/what-is/pda.aspx>

ⁱⁱ Elizabeth Newson et al (2003) [Pathological Demand Avoidance Syndrome: a necessary distinction within the pervasive developmental disorders](#); Archives of Diseases in Childhood.

ⁱⁱⁱ Gillberg, Christopher. (2014). [Commentary: PDA – Public Displays of Affection or Pathological Demand Avoidance?](#) Journal of Child Psychology and Psychiatry.

^{iv} O'Nions, E., Christie, P., Gould, J., Viding, E. & Happé, F. (2013) [Development of the 'Extreme Demand Avoidance Questionnaire' \(EDA-Q\): Preliminary observations on a trait measure for Pathological Demand Avoidance](#); Journal of Child Psychology and Psychiatry.