



Being Misunderstood

Experiences of the
Pathological Demand Avoidance Profile
of ASD

Acknowledgements

Thanks go to the PDAers and their families who helped in the development of the survey, to Jon Spiers and Autistica, Phil Christie, Ruth Fidler and Dr Judy Eaton for all their input and advice, and Sally Cat and Geoff Gibbs for their generous support in the design and printing.

Finally, and most importantly, to all those who completed the survey and shared their experiences.

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Executive Summary

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

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

The PDA Society conducted an online survey for two weeks in March 2018 through their website and social media. 1,445 parents, professionals, adults with PDA and their partners or family members contributed.

The results of this survey demonstrate that, in practice, a constellation of traits **is** being identified by some who diagnose ASD, and that this is most often done through use of terminology which reflects the idea of a 'Pathological Demand Avoidance profile of ASD'.

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

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

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

One person described what would help

“Understanding my difficulties, accepting that what I describe is truthful and accurate and not trying to make what I describe fit with their understanding of the world. If I can do it I will, if I can't I might ask for help (or not).”

Key findings:

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

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

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

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

Introduction

The term autism or Autism Spectrum Disorder (ASD) is widely recognised but understanding what the condition means in practice is still very much evolving. Those with complex presentations of autism can struggle to make sense of themselves, and professionals sometimes draw incorrect conclusions which adds to the confusion and can be detrimental.

This report looks at a particularly difficult area, that of the Pathological Demand Avoidance (PDA) profile of ASD.

It is difficult in so many ways:

- difficult for individuals with the condition to function well;
- difficult for clinicians to understand the causes of the behaviour they are seeing;
- difficult for them to give a name to it;
- and difficult for parents to explain and get support for the child and family.

The National Autistic Society describe the distinctive features of a demand avoidant profile as:

- resists and avoids the ordinary demands of life
- uses social strategies as part of avoidance, eg distracting, giving excuses
- appears sociable, but lacks understanding
- experiences excessive mood swings and impulsivity
- appears comfortable in role play and pretence
- displays obsessive behaviour that is often focused on other people⁽¹⁾

Individual features, or traits, of autism impact people to varying degrees and in different ways. Nevertheless, the PDA profile has become established as it has a high 'pattern recognition'.⁽²⁾ The constellation of symptoms in adults and children with a PDA profile leads to specific challenges.

The PDA Society was set up to provide information and advice to parents and is currently in touch with over 14,500 people through its membership, forum and social media. Its volunteers directly advise up to 2,000 people each year. The Society's website includes a wide range of resources including links to books and academic papers. The National Autistic Society (NAS) also includes detailed information about the PDA profile on its website.

This report describes the findings from 2018 survey work conducted with almost 1,500 people on the topic of the PDA profile.

The survey explored experiences around difficulties, diagnosis, how health and education services were helping or not, and the impact on family.

It concludes with a call to action and makes recommendations for improved support.

About the survey

A single survey was conducted to explore the experiences of four groups with separate strands of questions for each.

The survey was placed online and promoted through the PDA Society website and social media networks for two weeks in March 2018. The survey provides a snapshot of the current situation with the usual limitations of a self-selecting sample. Demographic questions indicated that respondents were fairly representative of the population as a whole in terms of income and geography, but not of ethnicity, with just a handful of individuals from minority ethnicities involved.

The sample size is significant with 1,445

participants, and so this represents the largest survey on this topic conducted to date.

The largest group were parents of children and young people who they identified with, or suspect may have, a PDA profile of ASD. These made up 1,194 of the respondents.

Adults with PDA, their partners or carers and professionals were the other three groups.

A detailed account of the survey results is published in a separate PDA Society report, which is available to download from the Society website.

The challenge

In some ways, this is 'just another autism report', showing similar difficulties that all of those with ASD can experience, and an associated failure of services to provide support.

However, in this case, the exact nature of the profile and its relation to other conditions is debated and so the usual lack of resources and professional training are exacerbated by feelings of professional challenge and an inability to engage.

The PDA profile is an uncommon form of ASD, so there is little experience amongst front-line professionals. In addition, similar behaviours can be seen in other conditions. Complex presentations of ASD are hard to tease out.

There has not yet been sufficient research to assign a place in classification systems. However, the latest contribution on the topic talks of the high 'pattern recognition' which can positively help parents and clinicians to identify issues and explains that referrals should not be turned away but encompass a full assessment of the features identified in the profile.⁽²⁾

Most parents describe the 'lightbulb moment' when they read a description of the PDA profile for the first time.⁽³⁾

More importantly, parents overwhelmingly find that the so-called 'PDA strategies' help; calm, collaborative parenting which decreases anxiety and works indirectly to allow activity to happen. While there needs to be an acceptance of what cannot be done at any given moment, the aim is to increase tolerance to demands over time.

Unfortunately, the usual ASD approaches which encourage a high level of structure and directness can exacerbate issues.

Adults and their partners reported that having an understanding of these strategies was helpful:

“Very very helpful. It has helped me to depersonalise some aspects of behaviour, it has given me strategies to use (when "conventional" autism strategies have failed/do not always help) and it has helped me to adjust my expectations of my partner's abilities, which has helped him.”

While acceptance and understanding is increasing, this report demonstrates that the reality for most is that being misunderstood is leading to extremely poor outcomes. This is affecting the hundreds who completed this survey, so can be expected to translate to thousands across the country.

Government guidance and expectations are that we should have a needs-based and outcomes-focused system, but for this group, this often isn't happening in practice.

The report concludes with practical solutions and a call to action.

Section 1

The Experience

Life for those with a PDA profile is challenging. Parents almost universally described their children as having a need to be in control, with 80% experiencing severe anxiety, 80% challenging behaviour and 80% with sensory issues. The difficulties of getting through daily tasks, morning and bedtime routines, dinner times, and getting into school were also significant problems.

For adults, according to their partners, the ability to do daily tasks becomes the most common difficulty (87%), while severe anxiety (80%) and mood swings (83%) were also significant issues.

With children and young people it may appear that not wanting to get dressed or come to the table and eat dinner could be the normal actions of a 'belligerent' child, but there are a number of pointers which suggests this 'avoidance' of daily tasks is somehow part of their biological makeup, and not simply a reaction to their environment.

It is known that the avoidant reactions are often out of proportion, sometimes resulting in violent meltdowns to seemingly tiny everyday requests⁽³⁾. This survey illustrates the consistency and extent of the difficulties, with 82% of parents reporting significant problems with meal/bedtime or morning routines.

The fact that these persist into adulthood suggests that it is not purely a response to requests from others or an act of defiance.

While this survey cannot demonstrate the cause of avoidant behaviour, this does illustrate the complexities, and need for further research.

Adults themselves were not asked about their specific difficulties, but invited to explain their

What is 'Demand Avoidance'?

The incapacity to take some actions, either for yourself or other people, and the use of techniques to avoid doing so. Triggers causing this need to avoid can be any or all of the following:

Requests:

"have you packed your bag yet?"

Expectations:

"she's looking to see if I've packed my bag"

Thoughts:

"I ought to pack my bag"

Desires:

"I really want to pack my bag"

Praise:

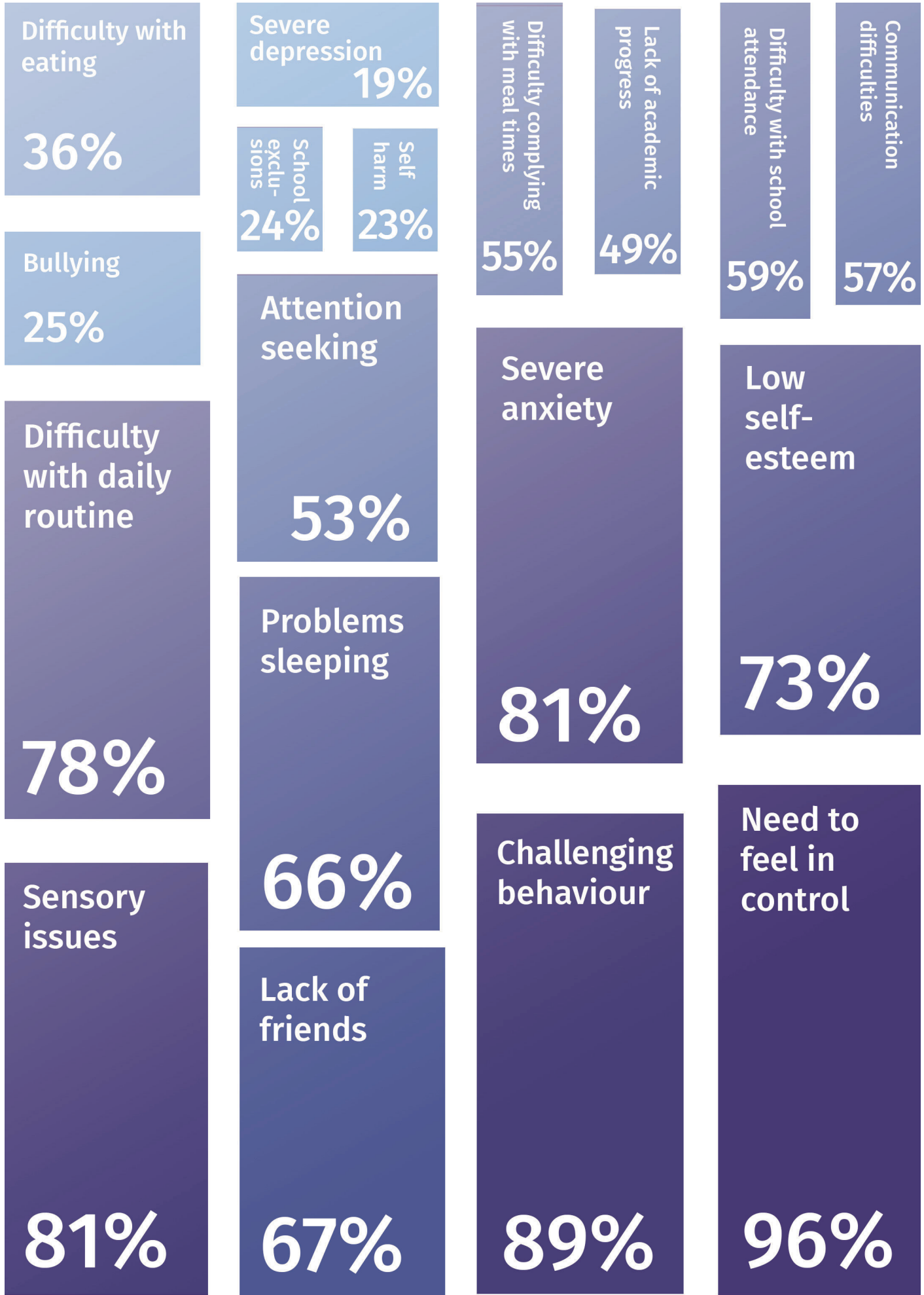
"you packed your bag brilliantly yesterday"

level of independence. Around half could live independently, with the other half needing more support, often living with parents or partners and including 10% who had the support of professional carers.

"Very independent. Everyday chores are exhausting though."

"It depends. I can manage by myself but I have a lot of anxiety and might miss bills and deadlines or my house might be very messy or I might not eat meals properly. I'm better off when I get help."

"Can't do basic things like washing, need to live in care."



Section 2

Education Outcomes

Education outcomes usually relate to the degree of learning and skills development, but the focus of this survey was on access. The school environment is especially problematic, to the extent that many young people can't access school at all.

Parents reported that 70% of young people of school age (686 children) were either not enrolled in a school or were struggling 'all the time' or 'regularly' to get in.

Only 7% said they never having trouble accessing school. 6% were being home-educated by choice.

This is school refusal at much higher levels than you would expect to see in the overall ASD population.

Indeed, special schools that are set up to support those with ASD were also often unable to help; attendance at special schools was especially poor, with 67% of young people struggling to get in all the time or regularly.

Rightly or wrongly, the first measure of education success is attendance, so there is little sign of positive outcomes in these figures.

Two questions arise: is the problem that the needs of these young people aren't being met, or even when being supported properly, do they fail to cope with a school environment? Leading on from that, what learning environment is more tolerable to them and what accommodations make an educational placement more sustainable?

Are needs not understood?

The National Autism Standards refer to a detailed description of the different support requirements for young people with a PDA profile.⁽⁴⁾ Parents were invited to explain whether, in their experience, educationalists accepted and understood the PDA profile of ASD as a useful descriptor and whether they implemented appropriate strategies.

Analysis showed that almost two thirds (66%) of parents said that very often the needs of their child were either not considered, not properly understood, or not properly implemented. Some also explained that attempts to use ASD strategies had been found not to work.

"We bang our heads against a brick wall on a regular basis. The school ignores our advice and prefers to listen to the area autism outreach team who have never met our son! Strategies for classic ASD make his behaviour worse..."

"Partially accepted the PDA profile but only recognised as part of ASD and subsequently specific PDA strategies not even considered by Local Authority."

In special schools, there was greater understanding and acceptance, as you would expect, but still only half of parents described positive experiences.

Even then, having an understanding school was not a guarantee of successful engagement.

"They recognise it but still think the onus is on him to adapt/conform. I anticipate he'll be permanently out of education soon, even an independent specialist autism placement is breaking down."

Almost all of the adults surveyed explained that their personal school experience was very poor, using terms like ‘hated it’ and ‘torture’.

“Bullying by teachers and peers. Spent most of time withdrawn, nose in a book, daydreaming, trying to escape... Less fighting in teenage years as it was more in my power to just leave the premises.”

Can the school environment work?

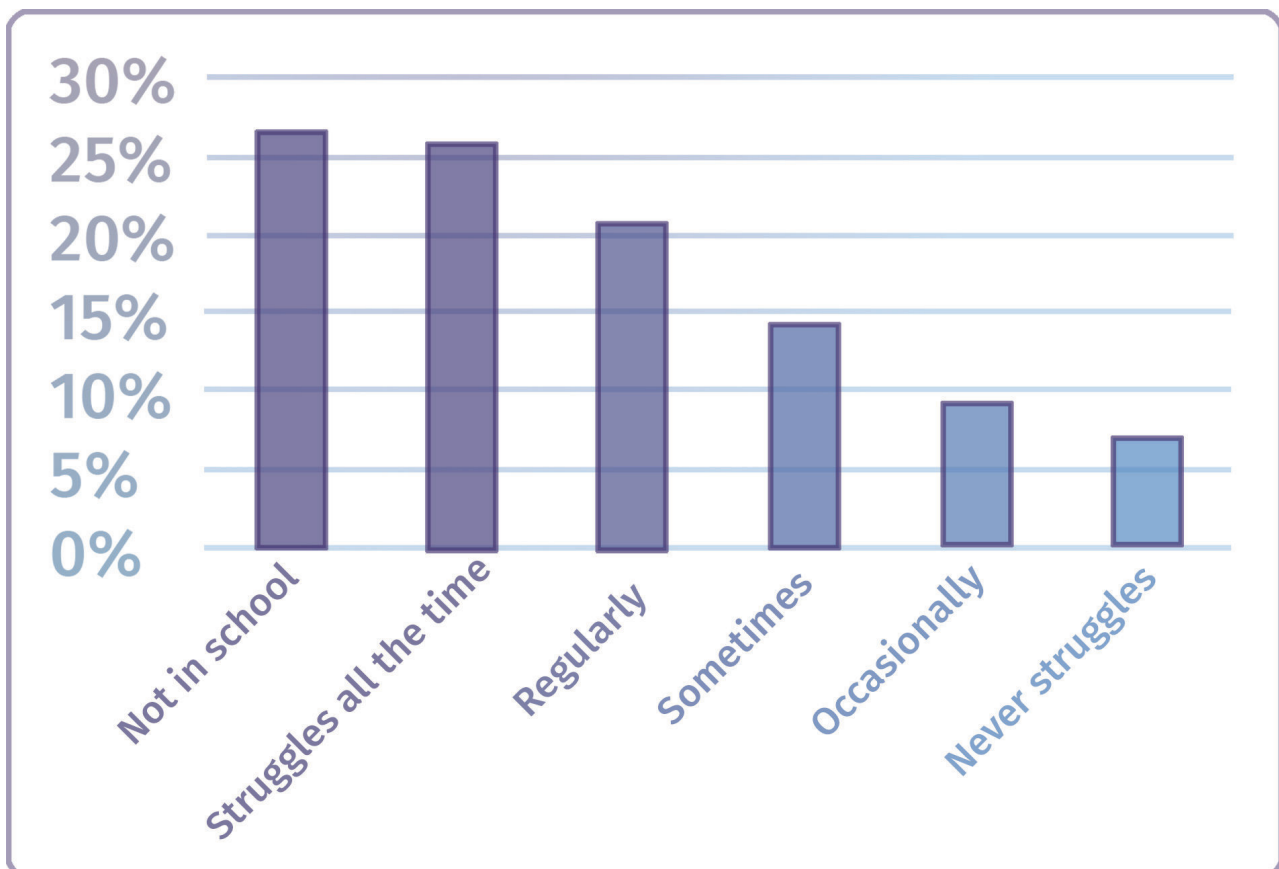
Some young people were able to attend school once the right approach was implemented.

“The school have been very willing to work with the correct strategies which have enabled him to attend school full time.”

This is both encouraging for others and reinforces the need for schools to be far more effective in understanding the needs of this group. When the right support is provided early-on, less intervention is needed in the long term.

However, as the attendance figures above reveal, even an ASD specialist school environment often does not work and with such an enormous proportion of young people not able to attend schools, it may also be that suitable alternatives need to be found.

The data from parents is irrefutable; the school environment does not work for the majority of these young people, even in special schools.



CASE STUDIES

The Hub, NAS Robert Ogden School

The Hub successfully engages with young people who have been previously excluded from or refused to attend other mainstream and special schools. Three quarters have a PDA profile (J. Davis, pers comm) The Hub allows students to create their own learning environments. They build a different type of relationship with staff, based on equality and collaboration. The acceptance and flexibility enables students to engage.

Details of the approach can be found in a research report which looked at the reasons for success, published by CRAE at the Institute of Education, UCL.⁽⁵⁾

Spectrum Space

This alternative provision based in Surrey supports young people with complex ASD, and most have a PDA profile diagnosis.

Two learning support assistants support the child in their own home, in their 'home from home' centre or in the community according to the child's preference. They find creative ways to use the student's interests and what they want to do that day to generate opportunities for learning.

Success results from the strong relationships that are built, and the ability to adjust programmes as tolerance to demands fluctuates, both through the day and from day to day.⁽⁶⁾

Section 3

Health Outcomes

It is not surprising that families who have young people with severe anxiety, difficulties with sleeping, eating, and attending school and with challenging behaviour, are looking for support.

More than 8 out of 10 families had been engaged with local services in the past couple of years, and often multiple services. Parents were asked whether those contacts had helped them understand their child better or manage their difficulties better.

Only 6% identified services as being very helpful while 50% said that they had not helped at all.

CAMHS

Almost half of respondents said that their child had visited their Child and Adolescent Health Service (CAMHS) in the past couple of

years, which was more used than any other service.

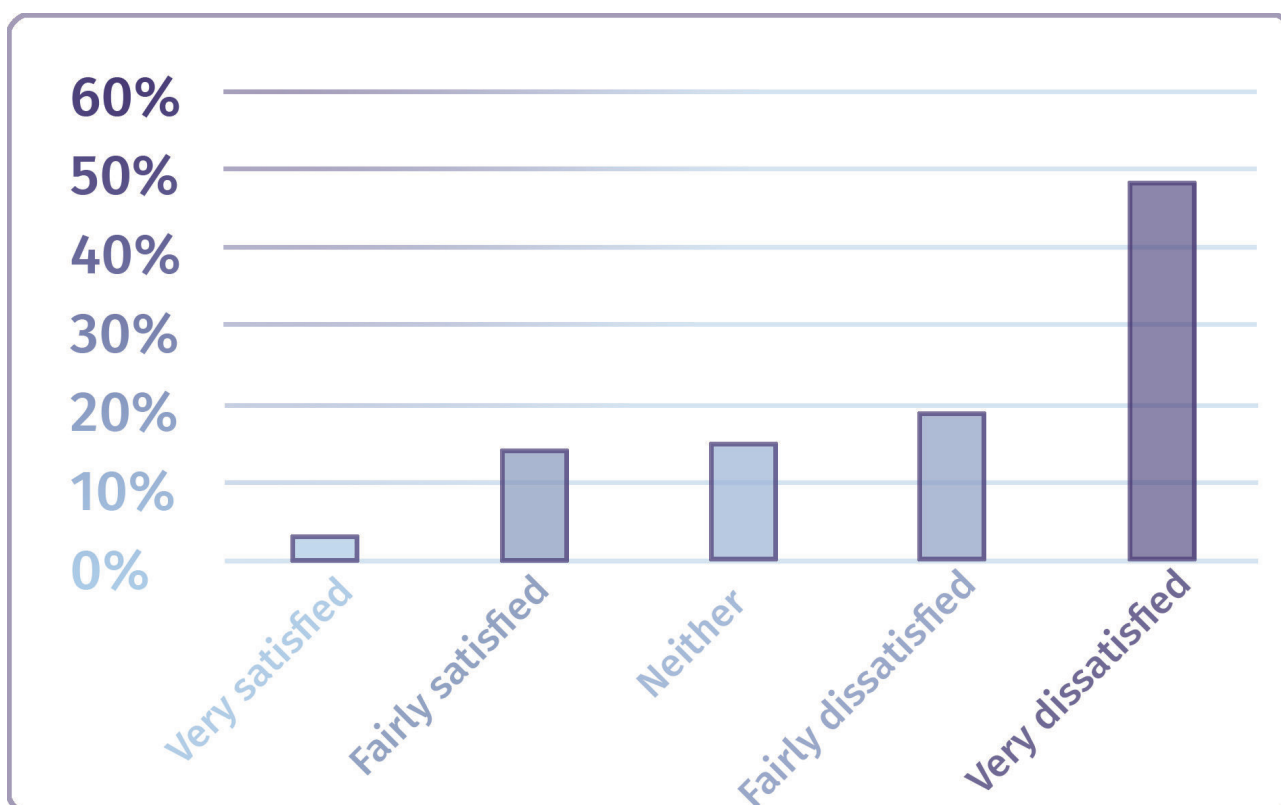
The outcomes described were very poor. Of those who visited CAMHS, 67% were dissatisfied with the service (almost half said they were very dissatisfied).

“Our experience of local services/ support for child mental health has been that it is unhelpful, wasteful, ignorant, and professionally arrogant - in short, disgraceful.... No health service worth the name should be allowed to refuse to even assess someone with clear health problems.”

Therapy

Most families couldn't list any therapies that had been helpful.

Sadly, very few described psychological interventions that had helped, in fact only 20 people identified either CBT or a CAMHS psychologist as having helped their child.



CAMHS are unable to provide interventions that help these young people; they are not getting them back on track when things go wrong.

Of those who benefitted from some type of intervention, almost a quarter (57 respondents) cited occupational therapy and especially the understanding it provided to tackle sensory issues.

Small numbers described a range of activities had been useful: from play and equine therapy to engaging in sports or art activities.

Adults were also asked what they had found helpful, and here CBT was listed by a number of people. In fact, six types of therapy were listed, most of which explored relationships between emotions and the body's responses. Other help mentioned included: use of self-care, including self-acceptance and spirituality; yoga and mindfulness; online support groups; talking; and 'not thinking'.

Medication

Medication was helpful for 305 young people (29%), 177 of whom were finding melatonin helpful to aid sleep. Anti-depressants were prescribed (often for anxiety) and 66 found it to be helpful and 50 were taking ADHD medication.

A further 291 (28%) were prescribed medication that they weren't finding particularly helpful.

PDA Strategies

PDA strategies is the term given to the specific approaches to communicating and working with those with a PDA profile which may be very different from approaches used with others on the autism spectrum.

What are PDA strategies?

Usual strategies which don't work include:

High level of structure
Usual boundaries
Rewards and consequences
Praise

Collaborative strategies which work include:

Flexibility around structure
Limited ground rules
Negotiation
Indirect affirmation

The overwhelming need to avoid tasks and instructions means that parents, teachers and others need to find ways to minimise triggering that response or to work around it. This requires careful use of language, frequent negotiation and other flexible and indirect techniques. The aim is to increase tolerance and to stay in-tune so that more can be achieved when it is possible to do so.

Parents mentioned the effectiveness of the use of these strategies throughout the survey – in response to questions about therapy, with regard to the success or failure of school environments, and in their personal experiences of the change in their children once they were implemented in the home. They were also very clear about the ineffectiveness and even damage caused by traditional parenting and ASD strategies.

The health and education professionals surveyed gave some examples:

- Constant patience, caring attitude
- Few expectations shared
- Providing choice over how work is done; choices about seating, pens, objects to use
- Allowing a change of plan part way through

- Spotting small behavioural cues that anxiety is on the rise so I can change direction
- Being honest, providing space and using limited dialogue
- Personal daily planner and own tutorial rooms
- Negotiating and incidental learning
- Never use the word no
- Humour
- Indirect speech and asking the child for help because I can't do something

The aim is not to reduce all demands, leaving the individual to be entirely demand-free, but to change the perspective by re-framing and facilitating tolerance, and working in collaboration to achieve.

Behaviour is a form of communication and PDA management strategies recognise the cognitive need to avoid and be in control, almost as if they are sensory needs.

This is not easy, however. Ceding control to a child turns parenting norms upside down, which is difficult for adults to adapt to. It is also anathema to professionals who don't have experience of the PDA profile, and this can lead to parents being criticised for poor parenting or behaviours being ascribed to attachment problems.

“The diagnosis allowed me to research and (1) find that very little was available to my son from professionals, and (2) find lots of things I can do at home (PDA strategies, unschooling, sensory integration, anger options lists, grounding techniques, meditation stories, hypnotherapy, etc.)”

Section 4

What's in a Name?

Within neuro-disabilities including Autism, the focus has shifted to understanding the traits that most challenge and, particularly within the family support and education sector, finding accommodations.

Indeed, disability discrimination laws require accommodations to be provided by institutions and employers, and Government mandates that SEN and health services be needs-based and outcomes-focused.

With this in mind, why are outcomes so poor for this group?

Causes of Poor Outcomes

1) The nature of the profile

Some level of challenge is inevitable given that this profile is so difficult for individuals to manage.

Supporting someone with PDA requires a nuanced use of language, creativity and patience. Even then, the slide to entrenchment and isolation can be difficult to prevent and while adults can find ways to overcome many barriers it can be profoundly disabling. There are no simple solutions.

2) Failure to explore the profile

This form of ASD is not common and likely to be outside many professionals' own sphere of experience, and so they fail to recognise the profile when they see it.

For some, the controversy about diagnostic terminology means they are put off fully exploring the presenting impairments.

Lack of knowledge and experience is a significant barrier and when this is coupled with professional scepticism it can

be insurmountable.

3) Failure to understand

Even when the impairments are identified and support offered, the unusual emphasis of the recommended strategies mean it can be very difficult for people to grasp the subtleties needed to be effective.

4) Lack of agency

This survey demonstrated that parents are told 'we don't diagnose that in this area'.

The precise diagnostic terminology is not so significant provided that there is an understanding of difficulties and needs, but some professionals seem to believe that they are not able to specify actions or consider the meaning of 'avoidance' as it goes against current medical opinion.

The problem is that when professionals say 'we don't diagnose that' they also don't assess for impairments properly or give appropriate advice. On top of this, families find that services are unavailable as a result.

This appears to be discriminative and at the very least is a failure to implement NICE Guidelines which require an assessment of impairments, which NICE identifies can include 'demand avoidance'

Adults and parents find the constellation of traits are a recognisable pattern and the concept of a PDA profile of ASD makes sense to the community.

Academics have so far been unable to produce sufficient research to demonstrate how these traits are best framed within neuro-disability classifications, and debate whether and how it should be named. Meanwhile, clinicians are making daily judgements and giving opinions, so what is happening in practice?

Current use of diagnostic terminology

The survey demonstrated the wide variation in approach to diagnosis and identification of the profile.

768 parent respondents listed the formal diagnoses that their child had received, and these were then categorised to provide the following statistics:

1. Those whose diagnosis included demand avoidance (49%) either where PDA was identified, where ASD + a PDA profile was included, or where the word pathological wasn't included eg 'ASD with a demand avoidant profile'
2. Those who had a diagnosis of ASD, (43%)
3. Those who didn't have a diagnosis of either Autism or pathological demand avoidance (8%)

Demand avoidant behaviour was identified as part of the diagnosis in 376 cases. The most

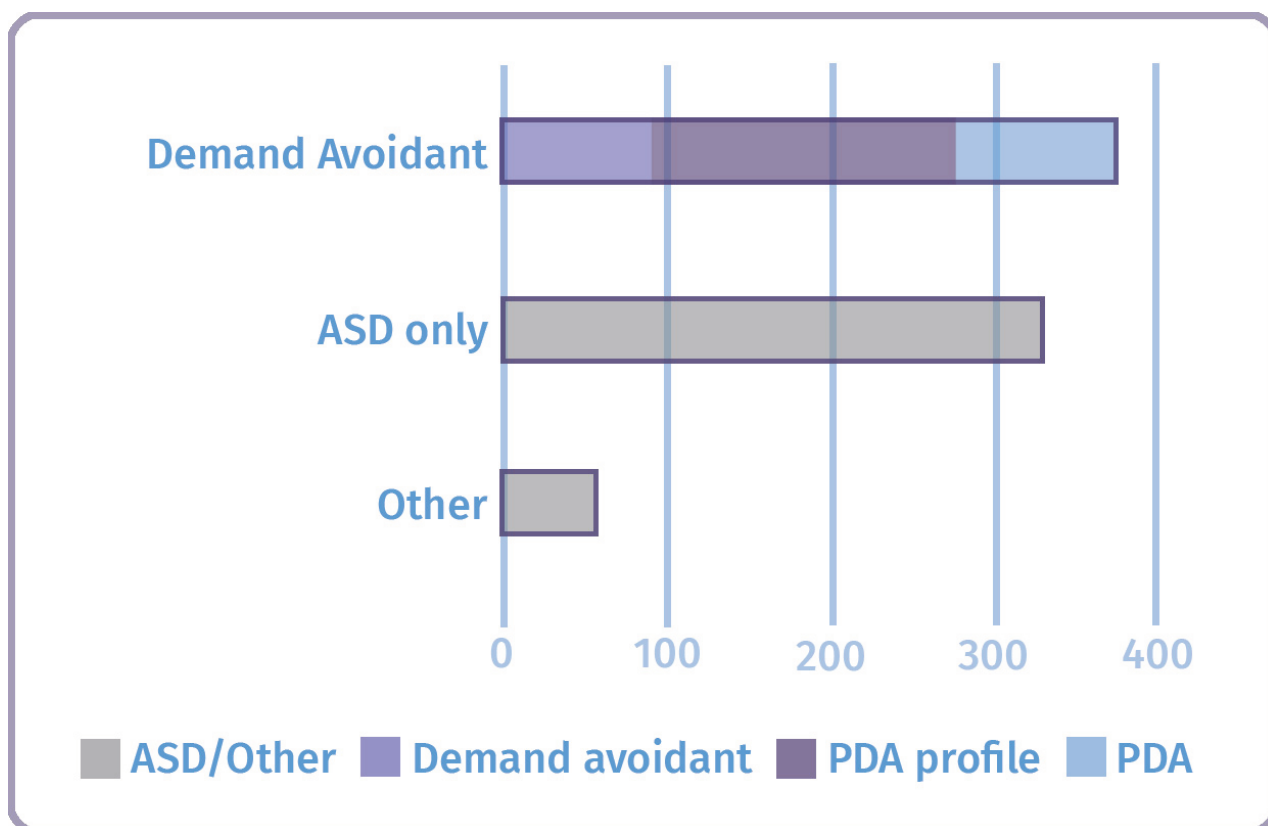
common terminology was equivalent to 'ASD with a PDA profile', provided for 25% of individuals, so these more descriptive phraseologies were found to be in widespread use.

The alternative would be to use the same assessment procedures but describe impairments through already existing psychiatric diagnoses; using the ASD umbrella diagnosis and also providing other diagnoses as co-morbidities.⁽²⁾

As such someone might receive a diagnosis, for example, of ASD, Sensory Processing Disorder (SPD), Generalised Anxiety Disorder (GAD), Disruptive Mood Dysregulation Disorder (DMDD) and Oppositional Defiance Disorder (ODD). The ODD is intended to signal the avoidant behaviour.

Analysis found that only 27 individuals had a diagnosis of ODD of which 16 (2%) were co-morbid with ASD (and 2 with PDA).

In total, 41% had some co-morbid diagnoses and the survey found that anxiety was diagnosed in 17% of cases and SPD in 14%.



There was a more significant overlap with ADHD, with almost a quarter (23%) having this diagnosis.

The adults who had a diagnosis, often given some years ago, listed PDA, Asperger's, Depression/anxiety, and ADHD.

Having a diagnosis which includes demand avoidance or PDA is widespread in practice. The alternative use of co-morbidity as a way of signalling the trait of extreme demand avoidance was found to be rare.

Satisfaction with diagnosis

Of those whose child had been given a diagnosis, more than half felt it was the correct one and most of the rest felt that what they had was incomplete.

There was also a large proportion undiagnosed and there will be a proportion for whom the PDA profile diagnosis would not have been correct - indeed some of those surveyed were not sure themselves that their child had a PDA profile.

Only 10% of adults had a diagnosis that they felt was correct and they highlighted the difficulty in getting a diagnosis as an adult.

Geographical variation

Diagnoses and services are being refused in some areas with some professionals telling people 'we don't recognise that here'; individuals mentioned they had experienced this in Dorset, Kent, Bristol, Brighton and Hove, North Yorkshire and Wales, for example. The situation is often complex, though, with different services and individual professionals within the same area having different viewpoints.

Failure to clarify challenges through a diagnosis is very unhelpful, but failure to even assess all impairments is unforgiveable.

Failure at this stage leads to a cascade with services being unavailable, or misdirected, and advice not being specific and so actually often being counterproductive.

Of the parents surveyed, 70% said that they had found that a "lack of acceptance of PDA as a valid 'thing'" was a barrier to getting support.

Why does having a name matter?

With a name comes understanding and knowledge, a way to find common experiences and an identifier ...even just something to search for online. For those with the condition, it can also provide more of a sense of identity.

This reinforces rather than detracts from the essential need in any assessment to look at individual traits and their underlying causes, to ensure the best possible advice and support is provided.

"Before this wording in the diagnosis we had no support, 5 school exclusions and very part time school timetable and LA refused an EHCP assessment but with the wording they changed their minds and assessed and now in specialist school with support - nothing changed just words"

The impacts on families

Caring for a child with complex autism can deplete personal resilience and lead to poor health. 94% of parents said that their emotional health had been affected. 80%

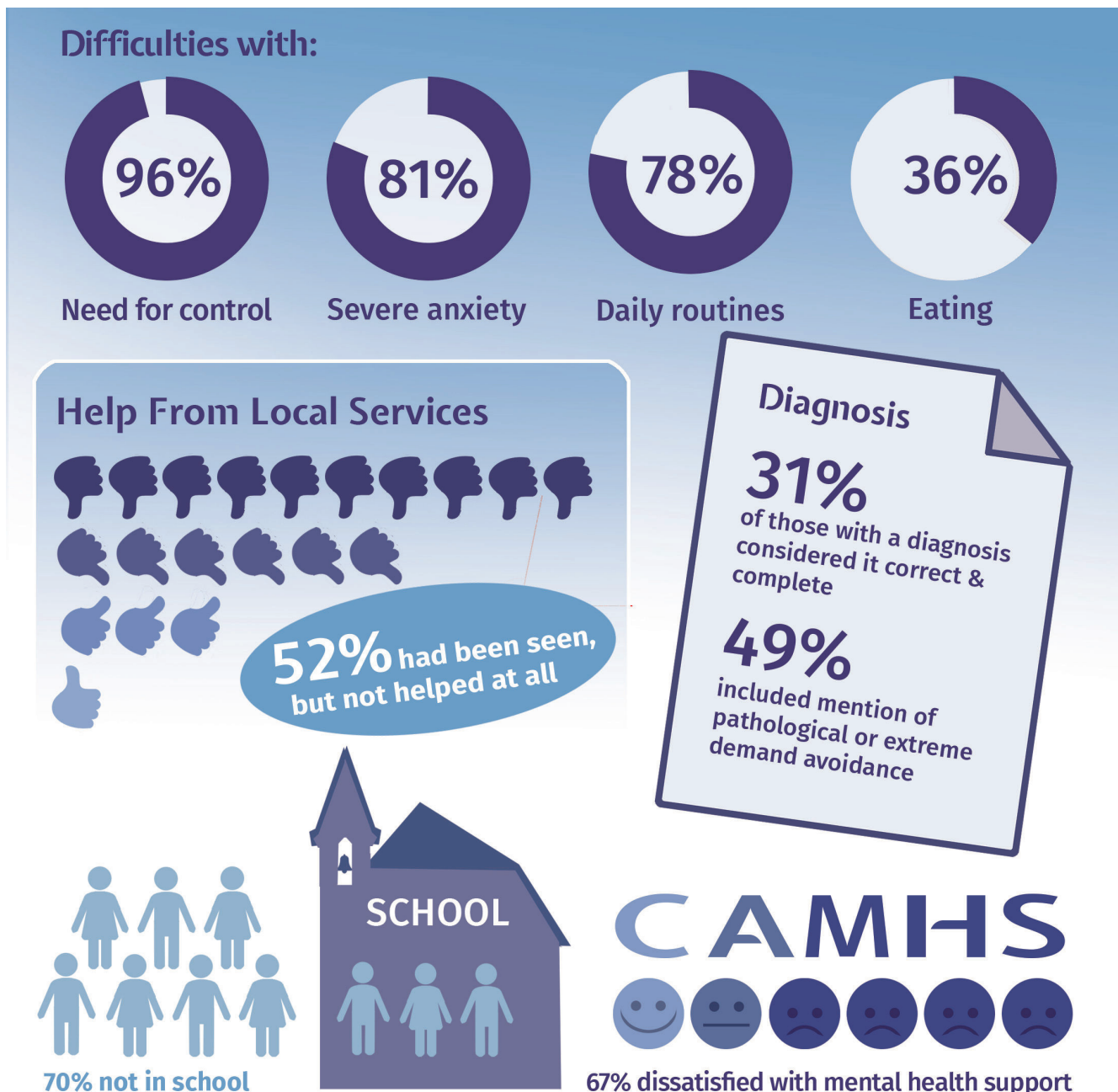
reported that their relationships and 80% that their mental health had been affected.

More than half said they were 'struggling' or 'not coping' and for those wanting to work only 7% said that their caring had not affected their ability to do so.

Autism comes with a set of strengths and difficulties. The positives mean many children and adults lead wonderful and fulfilling lives. At the same time, quite often young people and adults find themselves in need of some sort of long-term support or even professional care.

Adjusting to needs and challenging behaviours as they develop is generally a difficult process for families, especially if they are still trying to understand what is happening. The survey found that difficulties with parenting are often compounded by lack of support and understanding from others.

Living with this complex Autism is very stressful, and more so because it is misunderstood. Services can and must become more effective.



Next Steps

The term 'PDA' used to describe a profile of ASD is in common usage. This has developed only because it identifies the need for significantly different and unusual management strategies and, for adults, coping strategies.

When the constellation of traits is understood individuals can be better supported at home and sometimes in school as well. This is in contrast to when other traditional ASD and parenting strategies are used, which generally only serve to increase distress.

Adults with PDA are increasingly explaining their experiences and needs which is further shining a light on the details of the profile.

Services must know how to better support adults, children and their families.

For this to happen, the following steps are necessary, the first being the most essential:

Local Authorities, Autism Boards and Clinical Commissioning Groups across the country must urgently communicate their position on the PDA profile of ASD to service providers and their users, to clear up the confusion over assessments and service availability that currently exists.

- This should recognise that: assessments should follow NICE Guidelines through fully considering presenting traits. They should be conducted collaboratively with individuals and parents;
- Diagnosticians have the professional competence to use the terminology which they think best fits and should be sufficient to highlight needs to post-diagnostic services.
- Leaders must confirm that those who have a PDA or PDA profile diagnosis

should not be barred from services, and referrals for PDA assessments should not be rejected.

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

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

- Educational psychologists and SEN coordinators should have training available in the PDA profile of ASD and feel confident to support staff to work in appropriate ways with individuals.
- Ways of engaging that are very different from the norm may be needed, such as allowing part-time attendance and student-led learning. Special schools should consider the development of new educational environments where existing ones fail.
- Staff should be encouraged to work together with parents of those with a PDA profile to truly understand their needs.
- Schools, including special schools, should review cases of young people they are currently excluding or who are unable to attend to see whether a PDA profile of ASD may be an explanation.
- Local authorities and attendance officers should identify those with a PDA profile and offer suitable tailored support.

- PDA-friendly education schemes, with a focus on how best to support learning, should be developed for those who cannot thrive in schools.

Autism education and training providers

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

- Professional training should raise awareness of the PDA profile and ensure further information can be found when needed.

Providers of mental health and autism services

need to ensure that their staff are equipped to identify and work with those with a PDA profile, whatever terminology they choose to use.

- Providers of diagnostic services will understand how diagnosis works as a signpost. Those that incorporate terminology around avoidance are better able to signal the type of support needed. The use of ASD alone points to accommodations which don't work.

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

- Those who have experiences of working with individuals who may have a PDA profile should be encouraged to share their experiences.

Parents should feel able to recognise and assert their expertise, both individually and collectively, and continue to provide information to those they meet.

Autism advocates and adults with PDA (some of whom prefer the term 'PDAers') should be

encouraged and enabled to use their voices.

Researchers are aware that the specific issues around the PDA profile remain relatively unexplored and the unique nature of these autistic responses neglected. Identification of research priorities for this area will help to focus attention and much-needed funding on a group who are often being unwittingly discriminated against.

- Research to date has largely focused on the 'can we call this a syndrome?' question, with little on helpful interventions. A collaborative effort amongst all those with an interest in this area should investigate the profile from the perspective of the social model as much as the medical model.
- When designing more general autism intervention studies, researchers should consider how to include atypical profiles.

In conclusion:

This report describes the key findings of a survey into the experiences of those with a PDA profile of ASD and makes specific recommendations.

Reading about the experiences of nearly 1,500 individuals should be a wake-up call to those supporting and providing services to the autistic community. Individuals who may be described as having a PDA profile are being neglected and even discriminated against because of a lack of acceptance and understanding of their needs, leading to a failure to put in place reasonable adjustments.

At the same time, the results demonstrate that explanatory terminology is being very widely used in some parts of the country, following assessments done in accordance with NICE Guidelines. Where this happens, understanding of strategies can follow. Even

then, much more support is needed for local services to become sufficiently familiar with useful interventions.

It is unacceptable that 70% of young people in families surveyed are either at home or struggling to access school environments, and because their needs are being misunderstood, many are missing out on education.

Local services, including children and adolescent mental health services were found to be completely ineffectual, which compounds problems and leads to parents finding themselves unable to cope.

It is in the interest of everyone that professionals are empowered to see the individual and focus on improving outcomes.

References

- 1) <http://www.autism.org.uk/about/what-is/pda.aspx>
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- 6) www.spectrumspace.co.uk

Top tips you would like to share with other professionals

Comments from professionals:

“Despite the ‘controversy’ it exists. These children are so anxious and working so hard to feel ok. You won’t “ win” and why would you want to? People do things for very good reasons. Everyone needs an individual approach. Don’t bunk down and think consequences and ‘seeing things through’ will work. They won’t. And you’re just strengthening the anxiety and creating mistrust. And some of my most difficult yet rewarding work has been with people with this presentation. In fact some of my most favourite people have this presentation!”

“Try PDA strategies and if PDA strategies work, use them!”

“Work 'with' the Autism (PDA profile) rather than trying to work 'against' it! There will be no winners and the child will endure further frustration and distress. Any support is about an 'approach' rather than definite 'strategies' - everyone is different!”

“Be flexible. Build up a trusting relationship with the child. Don’t ‘force’ classic autism strategies onto the child if it is not working. Research, research and research!! There’s help out there but you need to look for it!”

“Always remember it’s not that the child won’t it’s that they can’t!! It’s not easy but patience, humour and not taking their actions personally are a must.”

What would make the biggest difference to you?

Comments from PDA adults

“Recognition of what PDA is and how it affects people, and freely available counselling with individuals/groups who can offer strategies which are tailored for those with PDA & can provide support for the challenges of dealing with PDA (or living with others who have PDA). Materials I can share with my husband and family members helping them understand what I am experiencing, how to cope & how to better communicate with me.”

“Understanding not just of the condition but how to convey information to me without causing a PDA reaction.”

“Just the validation of formal diagnosis would pay dividends in catharsis alone. Other than that I went to get a diagnosis as I planned to go back to university, as I dropped out of a degree once before and know I can't get through one without a disability mentor. But now I can't go back to university.”

“Widespread acceptance and understanding of PDA. Access to diagnosis. Widespread institutional accommodations for PDAers.”

“People having more understanding and knowledge of the condition, PDA and other autistic spectrum disorders in general. Know that it is a colour wheel with different shades. Because I do tend to cope or seemingly cope with day to day things and can go under the radar, doesn’t mean that I won’t/don’t have wobbles, or stress/have anxiety about the same things as someone on the spectrum who does show it more.”

What has been the biggest challenge?

Comments from Parents

“Nobody else realises what PDA is = as a mum trying to educate professionals is difficult.”

“My whole life has changed. I am stressed constantly and no longer have any patience or tolerance for anybody other than my children. My marriage has broken down and I have no friends. I don't even get any support from my family.”

“Other people not understanding what is going on with him, teachers and staff at school making things worse, school damaging his self-esteem, not being able to talk to him about what is going on with him because he will dismiss it like everything else, seeing him not able to do anything - wasting his potential and all the things he can do and does enjoy.”

“Reprogramming yourself to parent in a completely counter-intuitive way. The impact on our family life and our eldest daughter (not PDA)”

“Not recognising it until she was 14 - then that was autism - didn't even discover PDA until she was 15. Then it all made sense but her mental health has deteriorated so low that it's very difficult to know where to start to bring things back up - especially when you have to do it all on your own. The biggest challenge now is having no one recognise it or know how to help. Our CAMHS has recognised it is PDA, but have told us the LA doesn't acknowledge PDA so there is no training or support. So while they may recognise that is what it is, their hands are tied by those above that decide these things.”

“The 10 year wait and threat of removal of children from us by Social Services as they thought I had Munchausens (after 18 months they decided they shouldn't have been involved in the first place).”

What's the best thing about having them in your life?

Partners and parents of adults

“Every second together, every conversation. The wit, the courage facing day after day of stress, the delight in language, the bizarre determination to hang in there and learn whilst simultaneously having to utterly avoid everything. Everything. He is just awesome in every way.”

“He is a complete original. Endlessly curious, interested in life, intelligent, funny, accepting, non-malicious, non-jealous (his need for control does not manifest in this way). I am never bored!”

“She has taught me patience, a different perspective (people do not always behave as you expect or want them to) she has taught me to expect the unexpected. To be compassionate to others as everyone coping abilities with different levels of stress vary - what seems easy for me to cope with is not necessary easy for another. She has taught me how to love unconditionally. Despite the difficulties of every day I am blessed to have her in my life.”

“Inspired by the way he accepts people regardless of status and the way he never gives in when he wants to achieve something and watching his body fill with delight once he has done it. The way he still loves to hug his mum even though he is 22. He is amazing.”

To find out more about the PDA profile of ASD, please visit the PDA Society website at www.pdasociety.org.uk

The website includes a wide range of resources including:

- Guidance for clinicians
- Education guidelines
- Support strategies for families
- Information for adult PDAers
- Case studies
- Research and peer-reviewed papers

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Find out more at www.pdasociety.org.uk

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