Research Meeting

Record of meeting held 8th January 2019

Content

1.0 About the meeting

1.1 Introduction

A research meeting was held on Tuesday 8th January 2019, bringing together 31 people with an interest in autism and demand avoidance. This account is intended to provide a record of the presentations and a summary of key points as recorded on the day by participants. The PDA Society have committed to continuing to work with all those interested in the topic to facilitate constructive dialogue and the development of further research work. For further information, please contact the Society using comms@pdasociety.org.uk

1.2 Purpose

The aim of the meeting was to share current findings, thinking and insights around the 'PDA profile' of ASD by academic researchers and other stakeholders in order to build greater common understanding, identify research priorities and move towards a resolution of the PDA debate.

This area of research is important to our understanding of autism as a whole and a range of perspectives are evident currently. Research is in its infancy and is needed to generate understanding and reduce the possibility of autistic individuals being disadvantaged or discriminated against through misunderstanding. The extreme demand avoidance trait leaves individuals particularly vulnerable, often unable to access education (even specialist settings) or employment in later life. As adults, there is some evidence that individuals with this profile are more likely than others with autism to end up in mental health institutions or the criminal justice system. Local and national campaigns consistently demonstrate the failure of services to meet the needs of individuals with a PDA profile of ASD.

The PDA Society seeks to work collaboratively with all those with an interest in autism and neurodiversity and provides support to individuals and families and information to professionals and services. It hosted this research meeting to bring together all interested parties so that we might all learn from each other.

1.3 Structure

The day comprised a series of short presentations interspersed with discussions amongst small groups and opportunities for those who wanted to, to talk to all participants. Facilitators led the meeting, ensuring that there was support for all present, to enable them to input fully.

1.4 Thanks

Our thanks go to:

- Kevin Cooper whose generous donation allowed the Society to fund the meeting
- Prof Happé who hosted us at King's College London
- Dame Uta Frith who chaired the meeting
- The team from 'The Collective' who facilitated the meeting
- All those who gave their time so generously to speak, and all the participants for their positive contributions.

2.0 Presentations

Speakers were invited to provide short accounts of work conducted to date.

2.1 Prof Francesca Happé and Dr Liz O'Nions

King's College London and University of Leuven

Summary by Liz O'Nions

I was unable to attend the PDA Society meeting due to work commitments, so Francesca Happé presented a summary of our work on my behalf. The first talk focused on the work that we did during my PhD.

The initial motivation for our research came from discussions with Dr Lorna Wing and Dr Judith Gould, which alerted Francesca to the existence of children who were described as obsessively resistant to demands, were often the hardest to help/teach, were sometimes excluded from expert autism settings, and were as often girls as boys. What intrigued her most was that the usual autism strategies were said to be less effective in this group. As a result, there was a clear need for better understanding and help.

During my PhD, we encountered some of the inherent difficulties in studying a group of people who are demand avoidant! Our work has since identified some traits that seem to differentiate this group, including very high anxiety, need for control, and distress that doesn't stop when the desired result is achieved (e.g. O'Nions et al., 2018).

Our initial starting point was to think about whether PDA represents a sub-group (which is categorical) or a dimension – we are now leaning towards the latter based on our current data. Our findings from a paper using data from the DISCO assessment suggested that just over 40% of individuals are reported by informants to show a reduction in PDA features at present compared to in the past (O'Nions et al., 2016). However, other work has suggested that the number of individuals who show a decline in PDA features in adulthood could be much higher (Gillberg et al., 2015). A great deal more research is needed to investigate longitudinal trajectories of demand avoidance.

We suspect that a range of different terminologies are used in other countries where the term PDA isn't known about. Children with this profile may receive the label oppositional defiant disorder (ODD), reactive attachment disorder (RAD), conduct disorder, pervasive refusal syndrome, intermittent explosive disorder, either alongside a diagnosis of ASD, as a standalone diagnosis, and/or in combination with other diagnoses (e.g. ADHD, anxiety). Therefore, when looking at the research literature for studies that are relevant to this profile, or which describe children who may fit this profile, we may need to use a collection of different search terms.

Although interest in the concept of PDA has largely centred on the UK, interest in demand-related problem behaviour in the context of ASD has also arisen in the US. Chowdhury et al. (2016) have developed a measure called the "Home Situations Questionnaire - ASD", which allows parents to report reactivity to instructions, commands or rules, in a variety of everyday situations. Two underlying components have been identified - one is 'socially inflexible' - reflecting difficulties with demands in social situations, and the other one is 'demand specific', reflecting problems in the context of everyday demands. The subscales were robustly correlated with each other and with irritability. The correlation with ASD traits was more modest.

Although research on this topic is clearly at an early stage, reports in the UK suggest that there are enormous challenges being faced by individuals and families, including anecdotal reports of a lack of understanding of differences in sensitivity to demands, mishandling of distress, and individuals who show this pattern being labelled as naughty, or their difficulties being attributed to bad parenting. As such,

there is a desperate need for evidence-based interventions to help children with this profile and their families.

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2.2 Dr Vince Egan

The assessment of adult PDA: implications from studies in the general population

Vincent Egan with Omer Linenberg, Grace Trundle, Eleanor Bull
University of Nottingham

Because of their challenging externalised behaviour, adults with PDA may end up being cared for by homelessness hostels, secure wards, and prisons. There are more persons with Autistic Spectrum Disorder (ASD) in the criminal justice system (3.9%) than in the general population (1%). This is also very likely the case for persons with a PDA presentation. Services for troubled children are limited, and for difficult adults provision is even more limited, nor helped by adults becoming regarded as 'bad' rather than 'vulnerable'. The PDA presentation is complex and suggests comorbidity, but is not in DSM. Until recently there has not been an assessment tool for adults with possible PDA. This has prevented clinical research examining persons identified with the condition, along with following them on treatment pathways to see which are most helpful for these individuals.

A new measure, the EDA-QA, is an adaptation of the EDA-Q developed by O'Nions. The EDA-QA is a highly reliable (0.9) self-report measure of PDA-associated symptoms, which comprises 26 items rated on a 5-point scale. It correlates with carer ratings of the same individual. The EDA-QA is predicted by difficult and antagonistic personality traits like high emotional instability, and low agreeableness. One notable aspect of correlations with the EDA-QA and the AQ measure of ASD is that many persons scoring highly on the EDA-QA are NOT in the clinical range for ASD, and the EDA-QA is not greatly correlated with AQ scores. This suggests that while PDA will exist in some persons with ASD, pathological demand avoidance also exists in persons who do not meet caseness for ASD, so PDA should be researched across a variety of clinical populations as an expression of general psychopathology. It may be that some children presenting with PDA are in fact showing emerging personality disorder, and would benefit, as early as possible, from emotional regulation work.

2.3 Dr Judy Eaton

Exploring the concept of a Pathological Demand Avoidance profile in Autism

Consultant Clinical Psychologist & King's College London

This brief presentation pulls together assessment data collected from 351 children and young people assessed at a tertiary neurodevelopmental service over the last two years.

Approximately one third of the children were referred for specialist assessment by the local Clinical Commissioning Group. These were all children with a documented history of attachment difficulties or developmental trauma who were referred because it had been speculated they may have Autism. The remaining two thirds of the sample were privately referred children and young people, usually due to long wait times in their local area. All were referred for Autism assessment.

All of the children were seen by the same multi-disciplinary team, using the same assessment tools. The assessments carried out included a full developmental history, a cognitive assessment, a pragmatic language assessment, a sensory screen and the ADOS (Autism Diagnostic Observation Schedule). 157 of the sample also completed the EDA-Q.

Some of the children seen were presenting with behaviour that parents, or other clinicians described as 'complex'. A number of parents were specifically questioning if their child was displaying the Pathological Demand Avoidant profile.

156 children met criteria for a diagnosis of Autism Spectrum Disorder, of which 111 fitted the PDA profile. 95 children did not meet criteria for Autism. Those who had a documented history of trauma/attachment difficulties were allocated to an 'Attachment' group.

Performance scores on the cognitive, sensory and communication assessments revealed few differences between the ASD versus the ASD/PDA groups, but significant differences between these two groups and the 'Attachment' group. Certain questions on the ADOS did appear to predict ASD/PDA. Qualitative analysis of the developmental histories using a grounded theory approach identified a number of 'themes' associated with the PDA profile. Multinomial logistic regression extracted nine key 'themes' which appear to distinguish between the ASD/PDA and Attachment groups.

2.4 Dr Damian Milton

PDA and alternative explanations – a critique

The Tizard Centre, University of Kent

This short presentation looked to both situate my own critique of PDA theory and that of alternative explanations that have been offered in relation to autistic people and their reactions to both external and internal 'demands'. In an essay that I wrote in 2013 (see Milton, 2017), there were a number of contentions that I raised in regard to PDA theory: most importantly the pathologising of resistance (and this potentially of self-advocacy), the issue of identifying with a pathological medicalised view of oneself, and how the PDA profile could be explained as part of autism, but demand avoidant behaviour could also be seen for differing reasons in non-autistic people. I also raised issues in regard to categorical thinking in relation to support strategies for autistic people. In this respect the issues raised by the PDA community relating to the 'tried and tested methods' used with autistic people being ineffective may well be because these methods are not as robust and effective as many would like to portray. Indeed, many of the strategies related to PDA would potentially be good strategies for those across the autistic spectrum and beyond.

When I first wrote this essay the existent literature regarding PDA concentrated on the avoidance of 'external demands' rather than 'internal'. In response to this, I saw the avoidance of them as often

'rational' from the perspective of an autistic person, as often such demands did not take into account autistic ways of being and perspectives. In terms of avoiding external demands, this could also be connected in some circumstances to 'changing gears / activities' which can be related to theories such as executive functioning and monotropism (Murray et al. 2005).

More standard alternative explanations regarding demand avoidant behaviour may relate to Oppositional Defiance Disorder (ODD) or Attachment Disorder, yet these may lead to problematic interpretations when working with autistic people and their sensibilities, particularly the ever-present danger of parent blame, which for me however we theorise these issues is unfortunately likely to continue given cultural prejudices.

In terms of the avoidance of internal demands, such phenomena are well known amongst the autistic community and have been referred to for nigh on twenty years. Unfortunately, much of this work seems to have been lost to current discussions. Originating in the work of Kalen (2001) and Sullivan (2002), autistic 'inertia' as it was called was said to have differing manifestations rather than being a singular experience or thing, but potentially linked to issues already mentioned, but also low energy, proprioception and catatonia. Issues remarked upon in this early work included starting tasks, getting one's body in motion, changing focus or tasks, performing tasks without a full understanding of what needs to be done and why, and also most importantly in this context, doing something despite knowing how and wanting to. Such issues can then lead on to issues with prioritising, perfectionism, disorganisation, overwhelm, and depression.

In conclusion, I suggest that there are many issues with attempts to sub-type autism and such efforts can also impact upon solidarity amongst the autistic community. For me, one needs to be aware of the potential harms that could come from the application of the PDA narrative, and that a well-informed person-centred practice is preferable to one based on categorical subtyping. Where I would agree with others here would be in the need for high-quality research in this area to help elucidate these issues and inform practice in future.

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2.5 Prof Jonathan Green

Pathological demand avoidance – sceptical viewpoint

University of Manchester

I take a 'transactional' view of ASD development. All children with ASD of course grow up within family and social contacts and relationships and the range of developmental experience for neurotypical children also applies to ASD; including attachment relationships, family relationships, the social context of development and the impact of maltreatment or trauma in any setting. 'Transactional' influences go both ways and the nature of ASD is that social transactions with the environment are particularly vulnerable to difficulty.

'Demand-avoidant' behaviours in are ubiquitous across human transactions. Many aspects of ASD (such as sensory sensitivities, anxiety, resistance to change or the need for sameness) can impact on interactions and create avoidant behaviours. Assessing the nature of this relationship and generating strategies in response should be basic to all clinical practice in ASD.

So why is the concept of PDA problematic in this context? Firstly, PDA too easily reifies these transactional processes as a 'thing in the child'. This can obscure what is going on, lead to misleading conclusions, and can set up dynamics which can entrench rather than help change.

Secondly, there is a lack of convincing evidence that PDA is in fact a separate entity at all within ASD (whether thought of as diagnosis, syndrome or profile). This matters because clinical language has real consequences and categories now do need to be evidenced properly to be ethically used. Resistant and avoidant behaviours are common in many contexts not specific to autism, have many origins, and it is misleading to think of them in as a reified entity here.

Thirdly, the idea of PDA as advocated in social media and elsewhere now has a gone way beyond any evidence, and can result in a mind-set for families and practitioners that assumes a specific formulation and treatment which is not evidenced and can close off opportunities for other understanding.

However behind this advocacy I completely accept there are very real problems for children and families and frequent frustrations with service responses. Professional services have been working with these for decades but we can and need to do better. The PDA idea importantly highlights the need for relational sensitivity and transactional management (for all children with ASD) and the need for holistic clinical care beyond just social impairments.

I advocate not using the PDA term – but advocates for the concept and professionals such as myself can and need to come together and make common cause in this issue by:

1. recognising the often very difficult predicaments for autistic children, adolescents and families during development,
2. conducting focused research into the specifics of autistic experience and reactions and responses to their environments.
3. advocating for improved autism awareness and evidenced intervention practice in CAMHS, schools and social life as well as improved capacity CAMHS.
4. generating a shared, evidenced conceptualization that can guide assessment and treatment.

2.6 Paula Sanchez

PDA: a critical insider perspective

London South Bank University

As an autism researcher and autistic mother of an autistic child, both of us presenting with a PDA-profile of autism, I have an interest in the tensions between the personal, clinical and academic usefulness of PDA as a construct. My contribution here is a shortened form of a talk I gave in May 2018 (Sanchez, 2018).

When Newson first started to characterise PDA, autism was conceptualised as a narrow and rare condition, and she recognised that some children appeared to be differently autistic. At the time, Asperger's work had yet to be formally translated into English, and Newson would not have seen the similarities between their case studies. Elements of Asperger's 'syndrome', like imagination, creativity, humour and guile, which did not fit with the classification of autism at the time, but which could have shed light on the PDA-profile, were ignored and dismissed as anomalies by Newson's contemporaries

(see Philippe and Contejean, 2018 for further discussion). Yet, we now accept and acknowledge that autistic people can indeed be imaginative, creative, funny and ingenious, so when PDA is described as different to 'typical autism' it often appears reliant on outdated notions of autism, ignoring its vast heterogeneity.

My primary argument is that PDA is not a discrete condition, that instead it presents a transitional category, of some pragmatic use, but without firm foundations. This is similar to how 'Asperger's Syndrome' and the 'female autism phenotype' did not identify new forms of autism, but instead helped highlight previously misunderstood and missed groups. I conclude by suggesting that PDA is not a sub-type of autism, but that demand-avoidance is one of many responses to the (often misunderstood and minimised by non-autistic people) high stress and anxiety experienced by autistic people.

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2.7 Dr Michael Absoud

Pathological Demand Avoidance: Clinic prevalence and characteristics

Evelina Children's Hospital, Guy's and St Thomas'

I presented a summary of three as yet unpublished clinical research and service evaluation syntheses relating to demand avoidant behaviours (including externalising and internalising forms) from a clinical population of children assessed for neurodevelopmental conditions.

1. Parent reported online qualitative questionnaires- frequency of terms related to demand avoidance (n=37 cases with demand avoidance out of 1030 neurodevelopmental cases)
2. A cross-sectional cohort clinic audit involving a tertiary neurodevelopmental clinic and a national children's inpatient mental health unit in the UK, where 72 children with problematic behaviours completed the Extreme Demand Avoidance Questionnaire (EDA-Q).
3. Trans-diagnostic questionnaires in a neurodevelopmental clinic population.

- Profile of problematic behaviours not confined to autism. Trans-diagnostic traits likely important:
  - Emotional regulation difficulty
  - Rigidity and need for routines and rituals
  - 'Just rightness', sameness, need to control, compulsions
  - Anxiety related to problem of toleration
  - Alexithymia - inability to recognise own emotions
  - ADHD, impulsivity
  - Oppositionality (minus provocative behaviour/vindictiveness), with a lack of sense of reward/desire from compliance/pleasing adults
  - Limited prosocial development, occasional callous unemotional traits

- Parental difficulty tolerating child's distress and reactivity (may be reinforcing)

- Understanding individualised formulation - different mechanisms which cluster to produce different 'types of demand avoidance' needing nuanced intervention as opposed to blanket

recommendation (inadvertent undesirable effects of blanket PDA suggestions). Rewards may help along with rules.

- There is often an untested assumption that it is the demands that are aversive and anxiety-provoking.

- Context - need to consider: home vs school vs other daily activity participation.

2.8 Clare Truman

Comparing the educational experiences of children with autism and/or pathological demand avoidance

CRAE, Institute of Education, UCL

This research focuses on the value of a diagnosis of Pathological Demand Avoidance for families attempting to access special educational support for children displaying extreme demand avoidance. Using an online survey completed by parents, it compares the educational experiences of students with and without a diagnosis of Pathological Demand Avoidance who display extreme demand avoidance as described by Newson et al (2013), to identify similarities and differences in their ability to access appropriate educational support.

Having a diagnosis of Pathological Demand Avoidance did not lead to any statistically significant differences in the number of failed educational placements a child had or the number of times a child was formally excluded from school. However, children with a diagnosis of Pathological Demand Avoidance did experience more informal exclusions (sometimes called “illegal exclusions”) than those autistic children who did not display extreme demand avoidance.

Those who displayed extreme demand avoidance also displayed more behaviour that challenges (such as hurting themselves or others, absconding from the classroom or the school site or refusing to attend school) during their most difficult term at school, than those who did not display extreme demand avoidance. Those with a diagnosis of Pathological Demand Avoidance displayed the highest levels of behaviour that challenges during their worst term at school.

The research found overwhelmingly negative experiences of school for participants whether or not they displayed extreme demand avoidance or had a diagnosis of Pathological Demand Avoidance. This suggests that children with autism are struggling to access appropriate educational support regardless of whether or not they display extreme demand avoidance. However, children with a diagnosis of Pathological Demand Avoidance may be more likely to experience informal exclusions and display behaviour that challenges when they are finding school difficult.

2.9 Omer Linenberg

Pathological Demand Avoidance: Forensic and Creative Contexts

University of Nottingham

Key point was around creativity and what form it took in PDAers - scholarly, mechanistic/scientific, performance and artistic but not self/everyday. This refers to PDAers being interested in how things and systems work, and ability to analyse and synthesise information coherently. Self-everyday creativity refers to ability to mitigate and cope with social demands and conflicts, which historically and anecdotally PDAers find difficult.

Performance scores were high but extroversion scores were low in the sample, suggesting that PDAers may feel more comfortable interacting with the world in specific roles. Masking refers to a form of this,

and is prevalent in contexts where the PDAer may feel they need to exert control in a specific way without compromising their need for it.

It is particularly important to remember that as there is a predictive link between presence of PDA traits and delinquent behaviour (although no link as of yet has been established with whether presence of PDA traits leads to a higher presence of individuals with the traits in the criminal justice system) the aspect of creativity may enable understanding PDA in a different way which may enable the community to have protective factors against engaging in delinquent behaviours.

2.10 Dr Lisa Summerhill and Kate Collett

Developing a multi-agency assessment pathway for children and young people thought to have the PDA profile

University Hospitals Birmingham, NHS Trust

In the Solihull Borough there has been an increasing demand for assessment for Pathological Demand Avoidance (PDA). The highest demand has been for children and young people (CYP) who have already been diagnosed with an ASD.

There have been concerns about CYP not being supported with their diagnosis of ASD as recommended by the assessment service and the post diagnostic team. In addition, there has been increasing recognition that for some CYP who have a PDA profile of needs that they are challenging families and schools to meet these complex needs and often have placement breakdowns in education and are eventually out of school, which needs to be prevented through appropriate intervention and placement.

In Solihull there needed to be a clear assessment and diagnostic pathway to respond to this increasing demand and to challenge systems to work differently to meet the complex needs of CYP referred for this type of assessment.

A multi-agency approach involving 'assessment over time' was agreed. This has ensured that there is a process of evidence building up to the point of referral for a multi-agency consultation meeting to determine if a CYP should receive a diagnosis of PDA. Evidence was required in relation to outcomes of the strategies that had been implemented; that any differential/co-occurring difficulty was ruled out/supported; and that PDA strategies had been used successfully. Then a referral could be made for a multi-agency consultation meeting. This has ensured the balance between cost effectiveness and uses the knowledge, skills and experience of the most appropriate professionals to advise children/families and schools about how best to support the child/young person in Solihull. It is also believed that this model of assessment will avoid any further unnecessary direct assessment with a child/young person.

2.11 Prof Francesca Happé and Dr Liz O'Nions

King's College London and University of Leuven

Summary by Liz O'Nions

In the second talk, Francesca gave a brief outline of a possible developmental model, which considers factors that might contribute to the types of behaviours described by Newson in accounts of PDA, in particular avoidance strategies and attempts to escape from demand situations. This model is summarised in a commentary by O'Nions and Noens (2018), and was informed by models of the development of phobias, work on anxiety-driven non-compliance in ASD by Lucyshyn et al., (2004), and observations and clinical accounts of behaviours in children described as having PDA.

The starting point for the model is that individuals with ASD may experience demands as aversive, and as a result, anxiety provoking, for several reasons. These potentially include, but are not limited to, sensory

sensitivities, intolerance of uncertainty, and frustration arising from "rich to lean" transitions, i.e. preferred to non-preferred activities (e.g. Brewer et al., 2014). Other possible triggers could include things particularly described in accounts of PDA, e.g. a tendency to experience others' expectations as aversive, or an extreme need for control (Newson et al., 2003). Therefore, the function of avoidance would be the reduction in anxiety associated with escape of demands – something often reported in the literature on functional analysis of problem behaviour in ASD.

Based on the theoretical model, we predict that, once anxiety has been triggered by a demand, attempts to persuade the child to comply by being strict, threatening consequences or offering rewards contingent on complying run the risk of increasing distress, and as a result, the likelihood of demand avoidance. This is because increasing pressure to comply may increase the child's anxiety that is already elevated by the demand, and as a result, increase their motivation to escape. This could (a) intensify avoidance behaviours and (b) make it more likely that demands provoke avoidance in the future.

Over repeated episodes, avoidance behaviours may get triggered by a wider range of stimuli, such as parental comments, or contextual cues signalling imminent demands. In extreme cases, this could lead to chronic anxiety or irritability. Eventually, avoidance may become a habit - an automatic response cued by demands.

More research is needed to see whether this model is accurate, in particular studying individuals who are followed-up over time. Notably, the model presents one possible developmental account that could apply where avoidance is driven by anxiety. It is possible that other factors, such as failing to accept the demand, may also lead to avoidance without anxiety.

Francesca concluded the second talk by summarising perspectives from the other speakers, and highlighting the need for more research on themes including compliance/ non-compliance, as well as developmental processes relevant to the emergence of very severe forms of demand avoidance described in PDA.

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2.12 Sally Cat

In addition to the formal presentations, all participants were invited to contribute in 'soapbox sessions'. Sally Cat's talks were prepared in advance and are reproduced here.

Talk 1:

There has been a move to substitute the term pathological (which has negative connotations) for extreme:

However, myself and a majority of fellow adult PDAers I have talked with, prefer the word pathological because it signifies that our demand avoidance is caused by the way our brains are built. The word extreme does not convey the fact that our demand avoidance underlies our every thought and action, like heartbeats: a constant "no" "no" "no"; which we must battle in order to do anything and everything, even saying the next word... in... this... sentence.

Most of the time, my internal battle against demand avoidance passes unnoticed, even to myself: it is my normal. It has always been there; just as my anxiety has always been there, and my masking-drive has always been there.

I have attended hundreds of hours of person-centred counselling, and trained as a person-centred counsellor; during which my self-awareness-ability was actively assessed by experienced tutors: so I know I have excellent self-awareness:

And I would like you to know that my demand avoidance; my anxiety and my masking are not trauma reactions.

I unravelled myself through person centred counselling enough to realise there was something about me that past trauma could not account for. It was this that led me to seek and gain an adult autism diagnosis 5 years ago.

I then learned of PDA, and found that this described me more; in greater, more accurate detail than autism alone.

Yes, the autism spectrum is broad; but PDA is not just our entrenched demand avoidance; it entails a cluster of traits that are, I believe, quite distinct: wordplay; role-play; impulsiveness; charm; hard-wired masking; disregard of hierarchy; hatred of imposed routine; massive need for control… even a shared love of room design!

Talk 2:

There has been lots of talk here about theories based on researching PDA children. I'm a PDA adult and author of the only book yet written about adult PDA. I believe adult PDA has been ignored far too much by researchers.

The focus has been on observing children and speculating upon these observations (apart from the team at Nottingham University).

Needless to say, assumptions have been made. And I believe that a large number of these assumptions are wrong.

Adult PDAers represent, in my opinion, a vital research resource. We can tell you how our PDA works. Please, therefore, listen to us and involve us in your research.

3.0 Outcomes

Participants shared existing research work in a positive and collaborative manner, started to consider 'what helps' (including interventions) as well as 'what it is or isn't' and ensured all interested parties have a voice, including PDA individuals.

The PDA Society hopes that as a result:

- *academics will respond by making the case for funding and taking the next steps;*
- *together we can develop a road map to be able to answer key questions;*
- *individuals will have a sense of there being a research community interested in the topic, and that PDA individuals are involved to a greater extent;*
- *the work will contribute to better understanding of autism generally.*

The results of the table discussions were recorded by participants and these were transcribed/summarised and sorted into themes.

3.1 Understanding more about demand avoidance in general

- Contextual nature of demand avoidance – pervasive or situation (school/home) specific?
- General understanding of demand avoidance across the board (eg. terrible twos) and as part of normal developmental trajectory
- How does compliance work? Is compliance always good?
- How does compliance in ASD/PDA fit with neuro-typical social expectations?
- More research into 'internal' demands
- Does PDA exist outside of ASD?
- What about masked/introverted PDA?
- How to disentangle 'core' from reactive experiences?
- Different drivers can underlie behaviours that look similar
- Are (strong) interests and (extreme) avoidance opposites?
- Do neuro-typical 'everyday demands' feel unreasonable to autistics?
- Understand key traits across different neurodevelopmental disorders which cause extreme demand avoidance and pilot intervention trial

3.2 Policy, practice and mending bridges

- How to foster positive & collaborative relationships between families and professionals around 'demand avoidance'?
- Much richer account of what autism is and what interventions are helpful
- Person-centred approach and individualised programme required for all (autistic) people and from all services – how do we facilitate this? How deliver support based on dimensional difficulties rather than labels?
- The need to talk about PDA is symptomatic of systemic failure – schools have become very restrictive, autism strategies have become too rigid and PDA is showing up more as a result. Autism needs aren't being met so shows up as PDA. Pathway issues. 'Industrialisation' of diagnosis.
- How do we change policy and practice so that organisations can work towards flexibility and tailored approaches?
- Change in school culture to a child-centred approach (Jonathan Green is doing a trial in schools and planning a conference on it in March 2020). Schools have a phobia of any form of challenging behaviour and immediately go into an anxiety-driven clamp down with no flex

- What constitutes 'evidence'? Are case studies just as effective as RCTs? Gap between medical evidence required for DSM category and anecdotal evidence. Absence of evidence isn't evidence of absence
- How do we change professional culture to be more knowledgeable/accepting?
- Concerted reinforcement of NICE guidelines – not enough diagnosticians are following guidelines properly
- Concerted drive to shift CAMHS practice should be key priority – there is a 'window of opportunity' because of PDA having a high profile
- Need more commissioners to understand the issues
- Preventative early investment to promote better adult outcomes
- Identify cases of PDA profile in vulnerable/cared-for/criminal justice settings as a means of improving outcomes

3.3 Co-morbidities

- Importance of considering other, compounding difficulties – anxiety, ADHD, OCD …
- Sensory understanding in ASD/PDA
- Social thinking profile?

3.4 Practical/support/strategies

- Evidence-based interventions that ameliorate demand avoidance
- Research evaluation of why particular strategies work and why more common strategies don't
- How can strategies be made 'replicable'
- Do the same strategies work for people outside PDA/ASD?
- Would children with PDA benefit from emotional regulation work early on? (are some showing emerging personality disorders?)
- Researching effective therapeutic approaches
- Move on from the name ('what do we call it?') and deal with the challenge.
- How can we help PDA individuals fulfil their potential rather than just manage/contain them?

3.5 Inclusion of adults and changes over time

- If there's a 40% 'remission rate' look at what the factors have been in this
- What are the 'life outcomes'?
- What do adult outcomes, positive and negative, have in common? How can positive approaches be maximised?
- At times of difficulty or stress does demand avoidance go up again after 'remission'?
- Is age of onset a factor?
- What strategies do people learn to help them manage their PDA?
- What has happened to the children diagnosed by Elizabeth Newson?
- Do the nature of demands change over time?
- Longitudinal studies

3.6 Cross-cultural research

- Where have individuals with PDA been before now?
- In countries where PDA isn't a 'thing' do similar presentations/behaviours exist – what do they call it? what research has been done?

3.7 More lived experience

- Need more case studies, footage, personal experiences
- A film is a helpful way to share and develop understanding
- More examples of best practice and outcomes

3.8 Diagnosis/consensus on PDA

- Is it possible to develop objective measures for diagnosis of a PDA profile?
- Understanding the impact (both positive and negative) of recognising/diagnosing PDA
- Should we be thinking about a sub-group or only dimensions?
- Is it a state or a trait?
- Consensus on how to describe PDA and how professionals talk about PDA and how we consistently communicate an up to date understanding of PDA? Need a shared voice.
- How does masked/introverted PDA get picked up?
- Want empathy from professional services – how can we have fewer PDAers falling between the pathways?
- Develop new EDAQ to identify PDA in introverts/maskers and different causes of demand avoidance (Judy Eaton is working on this)
- The 'we'll consider PDA after all other avenues and protocols have failed' (in people who are medically detained or otherwise) needs to change as by then trauma has been caused.
- Link next steps/approaches with assessment services.

3.9 Neuro science and genetics

- What are the cognitive traits?
- Is there a neurophysiological explanation?
- Is there a genetic explanation?
- Neuro-imaging

3.10 Prevalence

- Indication of magnitude of need/size of the problem to be managed

3.11 Schools and Teaching

- There's something particular about PDA and education – get to the bottom of this. Tailored strategies important for all – but for PDA child this matters much more.
- Ask individuals who experience the autistic world what their ideal educational environment might look like?
- Training in SEN for teachers

3.12 What needs to be done to move forward?

- Directory of research – existing and ongoing with summary and contact details
- Ability to keep in touch and continue dialogue
- Move away from 'them and us' within autism
- All research needs to make a positive difference to people's lived life
- Broaden understanding of heterogeneity of autism
- Need multi-disciplinary approach

3.13 Include next time

- More lived experience
- Teacher perspective
- Neuroscience