Identifying & Assessing a PDA profile - Practice Guidance

Produced by the PDA Society, collating the professional practice and experience of a multidisciplinary group of professionals working in the NHS and private practice, January 2022.

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1. Introduction

This practice guidance is intended for clinical practitioners, including those working in neurodevelopmental assessments as part of a multidisciplinary team. It may also be helpful for other healthcare, social care or education professionals.

The goal of this document is to aid identification and assessment of the 'constellation of traits' commonly known as a PDA (Pathological Demand Avoidance) profile; to distinguish PDA from other presentations of marked demand avoidance; and to signpost appropriate support and guidance for individuals and families.

The document was produced by the PDA Society collating the professional practice and experience of a multidisciplinary group of professionals – with representation from psychiatry, clinical and educational psychology, paediatrics, occupational therapy and speech and language therapy - working in the NHS and private practice in England. All the contributors have extensive experience of working with and supporting PDA individuals, and were invited to contribute because either they had recently published on the topic or had long-standing professional contact with the PDA Society. An initial meeting was held in October 2020 to outline the process for developing the guidance, followed by a detailed survey to gather inputs from all contributors. The survey information was analysed and summarised with a further consultation meeting in December 2020. This guidance was drawn from those discussions and reviewed/revised by all contributors during the course of 2021.

The contributors acknowledge the paucity of clinically-based research on demand avoidance and PDA, and call for further research to inform both theory and clinical practice. This guidance, therefore, is based on the contributors' considerable clinical experience and expertise and represents their consensus view of current practice and understanding. It is intended for practical clinical purposes with the aim of improving outcomes via personalised interventions and support. Whilst the norm is for practice guidance to be produced separately for adults and children/young people, it was decided to make this all-age because the more limited evidence base on identifying a PDA profile in adulthood means it would be difficult to produce a separate document.

Identification of PDA across the country is variable. There are some services and professionals who do not recognise PDA as a diagnostic term. Equally contributors have noted that, with increased awareness, there has been some over-identification by other practitioners. Both can be problematic, therefore it is also hoped that this guidance will lead to some harmonisation of practice.

Lastly, the contributors recognise that the language used in this document is necessarily medical in style, as it is written for practitioners, and therefore not always as reflective of neurodiversity as they may like.

Terminology

Use of the term 'pathological', in relation to marked demand avoidance, is not without controversy. Indeed Professor Newson herself later expressed regret over her use of the term. Many individuals who identify with the profile feel that the term is accurate and appropriate, as the demand avoidance they experience is innate and all-consuming. Some clinicians prefer to use the term 'pervasive' or 'extreme' as an alternative, or simply refer to a 'demand avoidant profile'. All these are valid diagnostic formulations, and the use of different terminology may also be expedient where the PDA profile is not recognised by commissioners. In reality, the terminology used is less important than the understanding it provides, and so it is important to use whatever is acceptable.

Acknowledgements

The PDA Society would like to thank the following contributors for sharing their experience and expertise in producing this practice guidance (in alphabetical order): Phil Christie, Dr Gloria Dura-Vila, Dr Judy Eaton, Alison Hart, Libby Hill, Keith Howie, Dr Ann Ozsivadjian, Dr Georgie Siggers, Pat Smith, Dr Lisa Summerhill, Dr Vicki Wingrove and Dr Julia Woollatt.

The contributors to this guide all have professional interests in neurodevelopmental assessments. Appendix 3 provides details.

These practitioners did not contribute to the guidance but endorse the document as reflecting their current understanding and practice (in alphabetical order, details in Appendix 3): Kimberley Ashwin, Dr Linda Buchan, Dr Alison Doyle, Raelene Dundon, Dr Sarah Glew, Dr Fiona Gullon-Scott, Claire Howell, Dr Jo Jones, Laura Kerbey, Dr Theresa Kidd, Katy Laing, Dr Anita Marsden, Dr Michelle Muniz, Jude Philip, Dr Richard Soppitt, Ben Truter.

This guidance was produced in January 2022 and a review is planned in January 2024 at which point consideration will be given to any updates required.

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2. Context

Health, social care, education and other professionals are likely to have come across a small number of individuals whose presentation includes unusual and/or perplexing behaviours around marked demand avoidance (i.e. demand avoidance which has a significant impact on an individual's everyday life and wellbeing).

Understanding the aetiology of these behaviours, and where they may or may not 'fit' in relation to 'umbrella conditions' including ASD, means that intervention and support can be personalised, thus improving outcomes. 'Pathological Demand Avoidance' (PDA) may be one explanation.

2.1 Origins of the term 'Pathological Demand Avoidance'

The concept of PDA was first discussed in the 1980s by the psychologist Professor Elizabeth Newson OBE when she was assessing children for autism at her Nottingham clinic. At that time the terms 'Pervasive Developmental Disorders Not Otherwise Specified' (DSM IV) and 'atypical autism' (ICD-10) were being used. Drawing on her extensive experience and detailed research, Newson identified a group of children who fitted some, but not all, of the criteria for 'classic' autism. The key characteristics of this group, as initially outlined, included[1]:

- Resists and avoids ordinary demands of life
- Strategies of avoidance are essentially socially manipulative
- Surface sociability, but apparent lack of sense of social identity, pride or shame
- Lability of mood, impulsive, led by need to control
- Comfortable in role play and pretending
- Obsessive behaviour

Newson formulated the term 'Pathological Demand Avoidance' and called for it to be recognised as a separate, but related, condition or 'syndrome' within the broader category of Pervasive Developmental Disorders. Newson's research and clinical work was continued by her colleague Phil Christie and a team of clinicians and educationalists who sought to further develop understanding of PDA, increasing specificity of 'key features' and reflecting evolving terminology[2]. Further supporting research was published by a team at University College London in 2014[3] and 2016[4].

2.2 PDA as a profile on the autism spectrum

The most recent diagnostic manual, DSM-5, has moved from the term Pervasive Developmental Disorder to Autism Spectrum Disorder (ASD), reflecting the complexity and heterogeneity of autism. As such, the current use of the term 'autism' is much broader than it was in Newson's day. As a result of this broadening of the way that autism and the autism spectrum are seen, the contributors' view is that PDA is currently best understood as a 'profile' (or cluster of traits) on the autism spectrum.

The contributors report that all the individuals they have signposted as having a PDA profile met the diagnostic criteria for ASD, even though initial presentations may be misleading in some cases (see section 4.3). This concurs with the observations from the team at University College London who noted that their work 'suggests that those with substantial features of extreme/pathological demand avoidance have similar levels of autistic traits to those with ASD who do not show this pattern'[4].

Both academics and clinicians describe a cluster of recognisable traits that include social communication and interaction difficulties and 'obsessive' interests, which by definition fit the ASD criteria. Further, Schedule 3 of NICE Guidance on Autism Spectrum Disorder in Under 19s (CG128) describes 'signs and symptoms' of autism which includes 'demand avoidance' as a trait or dimension to look for.

The primary reasons for identifying a PDA profile are to help individuals, and those living and working with them, make sense of a complex presentation that is otherwise difficult to explain; and to signpost the differentiated strategies and approaches - based on an indirect, low arousal style that gives an individual more choice and control (see section 5) - that can prove transformational, as these quotes highlight:

> "Once I understood about PDA I was better able to articulate my experience of the world to my psychiatrist and take a proactive approach to managing the daily demands I face. Previously I'd forced myself into mental, financial and physical ruin too many times, just because the world tells me that I 'should be able to do it because everybody else can'." – PDA adult
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> "We started to change our parenting approach (which was hard) and started to see a difference in our son's behaviour and emotions. Now our family is a calmer place, he is in a mainstream school with teachers who use PDA approaches, and when his anxiety goes up for whatever reason we know how to respond (and how not to respond). It's been life-changing." – parent
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> "We thought one of our pupils may be autistic but her needs were very different to other autistic pupils we'd supported in school before and none of our usual approaches helped. Searching for answers led us to PDA. Seeing her through this lens enabled us to truly understand her and successfully adapt our practices by building trust and embracing a flexible and collaborative approach." - teacher
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> "We were increasingly perplexed by the complex presentation of one of our service users and our team's inability to meet her needs despite our very best efforts. Whilst she doesn't have a formal diagnosis, following PDA training we were able to devise some unique approaches that have been highly effective. Using these approaches is the difference between her being able to live in her own home and being held in a secure hospital." - social care manager

Identifying a PDA profile forms part of the 'personalisation and contextualisation' of an autism diagnosis and the use of 'specifiers' to identify individual characteristics. This approach is fundamental to high quality clinical standards in relation to ASD, and is recommended in the ESCAP (European Child & Adolescent Psychiatry) practice guidance for autism[5].

The contributors readily acknowledge the lack of, and need for, clinically-based research, and that at present there is a range of academic and clinical perspectives about PDA. For instance, in 2018, Professor Jonathan Green et al[6] concluded that there was insufficient evidence to support classifying PDA as a separate syndrome and that it was unlikely to be identified as a discrete diagnosable 'sub-type' in future. They acknowledged the existence of 'complex presentations' in children and young people, and proposed an alternative formulation through the use of co-occurring diagnoses alongside ASD, including ODD (Oppositional Defiant Disorder) and anxiety. Others, including Soppitt et al[7] propose a formulation including co-occurring diagnosis of ADHD, trauma and sensory processing difficulties alongside ASD.

Whilst waiting for further research to be undertaken, the contributors to this guidance take the view that seeing differences and difficulties holistically, rather than addressing traits in isolation, will lead to the most helpful intervention and support[8]; and also that the cluster of traits in the PDA profile is sufficiently distinctive and easy to identify in practice.

The latest guidance from the Royal College of Psychiatrists (The Psychiatric Management of Autism in Adults (CR228)) and the British Psychological Society (Working with Autism: best practice guidelines for psychologists) includes information on PDA, acknowledging the areas of debate and confusion as well as describing what to look out for[9].

Post hoc analysis of the assessment results of 351 children who had been assessed for autism, led by Dr Judy Eaton and Kaylee Weaver[10] in 2020, concluded that there were statistically significant differences on the Autism Diagnostic Observation Schedule (ADOS-2) scoring between autistic children with and without a PDA profile. Further work is being done to see if this can help provide a consistent framework for aiding the identification of a PDA profile. Their paper went on to identify the ‘themes’ garnered from developmental histories that were very much more common in a PDA profile of autism, and which help to distinguish PDA from other conditions such as attachment disorders (see section 4.3).

3. Marked demand avoidance

Avoidance of demands is not unusual. Most of us will at some point avoid an activity that we do not consider interesting or find aversive. Many individuals can present as 'oppositional' and unwilling to follow instructions at certain times or developmental stages, or if their needs are not recognised and appropriately supported. With dull/routine tasks, most of us manage to fulfil our obligations eventually, but specific activities that are highly anxiety-provoking (which will vary from one individual to the next) may be permanently avoided. It is important to differentiate this sort of 'ordinary' demand avoidance from the marked demand avoidance which has a significant impact on an individual's everyday life and wellbeing.

Marked demand avoidance may have multiple underlying causes, as explained below, and by no means all individuals displaying these behaviours will have a PDA profile. In fact, whilst there is no specific prevalence data, a PDA profile appears to be relatively rare[11].

3.1 When to consider a PDA profile

A PDA profile is usually identified as part of an ASD or more holistic neurodevelopmental assessment, when marked demand avoidance has been mentioned in referrals or screening questionnaires. However, there may be other times when a health, education, social care or other professional involved with an individual and their family should be encouraged to consider a PDA profile as being an underlying cause for behaviours or presentations which include marked demand avoidance. These times may include, but are not limited to:

- Reports of 'stubborn' refusal around ordinary, everyday tasks including things an individual is known to like/enjoy or things they need to do (eat, drink, wash, use the bathroom).
- Individuals with a list of previous diagnoses, or indeed no formal diagnoses at all, but who are still considered as 'perplexing'.
- Those who have an ASD diagnosis but it 'doesn't quite fit' or who are on the cusp of, but do not meet, ASD diagnostic criteria (see section 4.3 for further context).
- Someone with an ADHD diagnosis - ADHD often co-occurs alongside ASD and can sometimes overshadow autistic traits in early childhood.
- Someone for whom no previous suggestions for support have helped (regardless of existing diagnosis) or for whom 'usual' autism strategies have been tried but not worked (for those with an autism diagnosis).
- A history of missed appointments where the individual has been unable to access/attend.
- In childhood, regular school refusal and/or repeated school exclusions.
- In childhood, where very different presentations are reported between the school and home environments and/or where a breakdown in communication has occurred between school and home.
- Where concerns have been raised around unconventional parenting approaches and where it is perceived that a child is being accorded too much control. In some cases this may have led to consideration being given to investigating parents for FII (Fabricated or Induced Illness).
- Individuals with complex needs who are seemingly 'stuck' within inpatient units or having difficulty managing in other settings.
- Individuals with perplexing presentations who are in the criminal justice system.

3.2 Key features of a PDA profile

Clinical practice and much of the research literature describe PDA as a ‘constellation of traits’ within autism - this is commonly described as a ‘profile’.

Key features of a PDA profile

a. Resists and avoids the ordinary demands of life
b. Uses social strategies as part of the avoidance
c. Appears sociable on the surface, but lacking depth in understanding
d. Experiences excessive mood swings and impulsivity
e. ‘Obsessive’ behaviour, often focused on other people
f. Appears comfortable in role play and pretend, sometimes to an extreme extent (*this feature is not always present*)

It is important to note that:

- a **PDA profile is also a spectrum** and presents differently in different people - for instance, sometimes it may be internalised, where avoidance may seem more subtle/passive, and in other cases it may be externalised and obvious
- marked demand avoidance is **the most significant, but not the only, trait** in a PDA profile.

With experience and knowledge, PDA is relatively easy to distinguish. The following commentary and observations from the contributors provides more context to each of the key features of PDA to help ‘capture the essence’ of the profile and aid identification and assessment.

a. Resists and avoids the ordinary demands of life

It is not just ‘demand avoidance’ but the avoidance needs to relate to the ordinary demands of life like making/attending appointments, everyday activities like washing, dressing or using the bathroom, that may be possible one day and not the next.

Demands are typically avoided simply because they are demands, not only because there is something about the activity that makes it aversive.

Demands may be verbal or visual, internal or external, whether ‘wanted’ or not; the pervasive nature of PDA is notable across a range of things (i.e. not just in relation to one aspect of the day/activity).

The avoidance is often associated with an intolerance of uncertainty and feelings of threats to autonomy and usually associated with high anxiety around this. Some PDA individuals refer to PDA as a ‘Pervasive Drive for Autonomy’.

Avoiding demands to an extreme extent and to their own detriment, including things they enjoy.

This is not part of a more generalised pattern of significant behavioural differences associated with ‘classic autism’.

Parents and teachers often refer to this 'need for control which is often anxiety related' when you ask them why the child avoids demands to such an extreme extent.

May present differently in different settings depending on anxiety levels, may also be very good at ‘masking’ difficulties with certain people or in certain situations and using social strategies as part of the avoidance.

The nature of demands changes over time. In adolescence, young people are expected to take more responsibility for themselves and not need support with basic everyday tasks; in adulthood that expectation is greater still. PDA individuals describe the feeling of 'I ought to …' triggering resistance and, beyond that, an anxiety response (with internal demands being as difficult to manage as requests from others).

b. Uses social strategies as part of the avoidance

Use of a variety of strategies – e.g. distraction, giving excuses (such as 'my legs don't work'), refusal, threats, entering into role play etc.

Avoidance is 'hierarchical' with different strategies employed depending on levels of anxiety and tolerance for demands. Initial approaches might include distraction, negotiation, delay and procrastination. Further efforts may include withdrawal into fantasy or entering into role play, perhaps taking control and giving direction to others and sometimes threats or apparent 'lying' (unsophisticated).

There can be rapid escalation to panic responses such as running, aggression, shutdown, self-harm; sometimes they have got to the point where they just shout/say no etc. as they are so overwhelmed and their original strategies have not worked.

They may make very elaborate excuses for not being able to do something and sabotage things that they really wanted to do.

Having an intellectual impairment or learning disability doesn't preclude identification of a PDA profile. Identification relates to consideration of 'social strategies' (such as distraction) that are within the individual's capabilities.

c. Appears sociable on the surface, but lacking depth in understanding

Verbal ability initially appears to be very good. Subtle difficulties with the social, or pragmatic, use of language soon become apparent.

Difficulties in social communication and understanding may be less obvious initially - may present as an atypical profile of ASD.

Likely to have good verbal fluency, disguising difficulties in understanding and processing verbal communication; expressive language may be fluent and articulate with more difficulties in receptive language. Good fluency of speech can often mask difficulties with processing.

Likely to struggle to appreciate or acknowledge social hierarchy (e.g. children see themselves as adult).

May be chatty, charming and extrovert, especially when feeling calm and safe, or may be more introvert and keen not to draw attention to themselves.

May copy or mimic social interactions as a way of coping and fitting in.

Can be controlling and dominating, particularly when they feel they are not in control.

In children, play may be rigid and inflexible. Especially when playing with peers, there may be a need to control or dominate play.

Potentially 'good at times' verbal surface level skills, good use of role play, can be skilled communicators, very able to debate and be charming.

In the early years a language delay as a result of passivity (not being socially 'motivated') with a catch up is sometimes seen, perhaps indicating that there was ability but not the desire to communicate with language. Also as children mature and

more is expected of them, language may become more expressive as avoidance strategies become more sophisticated.

Often see an overestimation of comprehension based on mistaken evaluation of expression, regardless of underlying cognitive functioning. Many children are over-reliant on the expressive use of questions, sometimes not waiting for, not understanding or not processing the responses given. This clearly impacts on their ability to deal with associated explicit and implicit demands.

d. Experiences excessive mood swings and impulsivity

Experience extreme emotional reactions, others around them may feel like they need to 'walk on eggshells'. Individuals often reported as appearing to lose control, the result of being triggered into a fight/flight response.

Some individuals are 'internalisers' and become quiet/withdrawn, others could be described as 'externalisers' and emotional reactions tend to be more obvious.

Parents and carers sometimes describe it as feeling like a 'Jekyll and Hyde' personality.

Individuals' flight, fight, freeze or fawn responses (including meltdowns and other distressed behaviours) are outward representations of the brain and body's instinctual response to physiological stress and are often associated with high levels of anxiety. Individuals may respond this way to apparently small triggers or ordinary occurrences, particularly when tolerance is low or stress has accumulated. At these times, some individuals can appear completely out of control and almost 'manic' in their behaviour.

e. 'Obsessive' behaviour, often focused on other people

Likely to have developed passionate interests and be able to be hyper-focused, but topics of interest may be atypical.

'Obsessive' behaviour that is often social in nature (e.g. can become obsessive about people, either real or fictional, from either a love or hate perspective).

In children and young people, they may be obsessed by a friend or a sibling, seeking to copy but also control the interaction.

Sometimes difficult to decipher, especially in girls or those who are cognitively able.

The obsessive behaviour can lead to extreme clinginess and controlling behaviour, usually of one parent (often the mother) or potentially a partner.

Whilst other people's strict routines and visual timetables may not be effective and may make the individual more avoidant, it may be that the person has their own, quite fixed ideas about how things should be. They often choose to do things 'in their own time', but in a specific way.

f. Appears comfortable in role play and pretend, sometimes to an extreme extent

This can be a key feature, but it is not always present and is not an 'essential' feature.

Role playing in some PDA individuals can be extreme, for instance living as another person or as an animal for a prolonged period of time.

Play can appear imaginative but tends to be based on things the young person has observed (e.g. re-enacting the school day or a TV programme/film). When they involve others in their role play, children with PDA are usually very controlling of the themes, roles and dialogue.

3.3 Other distinguishing factors

The following points do not form part of the key features of PDA, but are clinical observations which the contributors see sufficiently frequently to be noteworthy (although these factors may also be seen in other presentations as well):

- **First meetings** – for some individuals, few difficulties may be apparent initially and they may appear superficially socially very able. However, with time, social communication difficulties become more apparent and it often becomes clear that sociability cannot be maintained. Mannerisms and gestures may appear over-exaggerated or copied. Others can present as more visibly anxious and may be unwilling to enter the room or to take part in any assessment activities. Some may subtly, or more obviously, attempt to derail an assessment. At times individuals may present as bored or somewhat dismissive of the person trying to engage them (this may be less obvious when assessing adults).

- **Speech & language assessments** – these are likely to identify good concrete language skills with better than average vocabulary skills, but difficulties with higher level language processing and narrative. Social communication assessments reveal a good knowledge of what effective interaction looks like. Individuals are usually easily able to discuss what they would/should do, but have a slight social processing delay which means in a fast-paced, real world situation they may struggle to do or say these things.

- **Occupational therapy assessments** – these are likely to identify inabilities to self-regulate and to understand/organise sensory feedback. Sensory processing difficulties can create a sense of overwhelm in tasks, transitions and environments, which can then lead to avoidance when the sensory input or self-regulation is too hard. Also unrecognised Developmental Coordination Disorders, where motor-led tasks can be difficult to achieve, can lead to individuals avoiding tasks as a defence mechanism. It is important to distinguish this type of avoidance, which has its roots in sensory processing or physical coordination difficulties and can be supported with appropriate interventions, from avoidance that may be explained by a PDA profile (although the two can of course co-occur). Clinical experience also suggests that difficulties with interoceptive awareness and vestibular processing are key areas for many PDA individuals.

- **Social and emotional assessments** – these are likely to identify high levels of anxiety, particularly when individuals feel they are not in control or perceive a situation as being too demanding or unpredictable. As above, some may appear visibly anxious and/or be unwilling to enter the room; some may present with more physical symptoms such as feeling sick or sweating; others may attempt to leave the room or make excuses to leave. Research by Stuart et al[12] showed that intolerance of uncertainty may be a significant underpinning factor in demand avoidant behaviours in children and young people. A large proportion of cases will show very low self-esteem.

  Challenging and oppositional behaviour is frequently seen in children and ‘tantrums’ are a common, indeed normal, part of development. However, the lability of mood and intensity of ‘meltdowns’ can be extreme in some people with a PDA profile and may continue beyond the developmentally typical age/stage. This may be more contained in adulthood, but still present. Equally, not all individuals will experience ‘meltdown’, others may run away or shut down and withdraw from activities, including retreating to their bedrooms, becoming situationally mute and sometimes resorting to self-injurious behaviours when overwhelmed. In extreme cases, this can result in a person presenting with dissociation and no longer being able to engage when spoken to.

- **Masking** – Clinical experience suggests that masking – hiding or holding in difficulties, consciously or sub-consciously - is especially common in autistic individuals with a PDA profile. Sometimes this is just evident on initial meetings, as mentioned above, and subsequently the extent of an individual's differences becomes apparent over time. For others, accounts of presentations in different settings, or with different people, do not seem aligned. Often, though, with careful questions or observations these differences are less than they might seem to be at first sight. At other times, though, the extent of masking can be more significant and longer lasting. This is often a source of misunderstanding between professionals and families and can lead to misplaced parental 'blame'. It can also confuse staff who may see an individual seeming to cope in one situation (perhaps with more 'trusted' staff) and not in others, which can lead to mistaken assumptions that there is an element of 'choice' in the avoidance. Equally, masking may lead to failure to give a diagnostic formulation linked to PDA because of the difficulties in triangulating evidence and seeing the individual differences as being pervasive.

- **Ineffectiveness of traditional or 'ASD' approaches** – it is common across the board that neither traditional approaches from parents/carers, teachers, social workers, partners etc. (e.g. praise, boundaries, rewards/consequences), nor conventional 'ASD' approaches (e.g. consistency, structure, clarity, visual schedules), are effective with PDA individuals. Indeed they tend to exacerbate and escalate demand avoidant behaviours. Where those living and working with individuals have successfully modified their communication and interaction (adopting so-called 'PDA approaches', whether knowingly or not), and where this has led to positive outcomes, this can be confirmatory in formulating a PDA profile.

3.4 Additional considerations

Based on their collective experience and expertise, the contributors also shared these additional anecdotal points:

- **Strengths** – Whilst guidance such as this inevitably tends to focus on a list of 'deficits', the contributors would also like to note the range of significant strengths often seen in individuals with a PDA profile. This of course varies from one individual to another, but it is quite common to see individuals who have a strong sense of justice and fairness, are independent, charismatic, creative, compassionate, humorous, imaginative and tenacious, amongst other positive qualities.

- **Adult presentations** – currently evidence regarding presentation in adulthood is mostly limited to descriptions of the lived experience of adults who identify with a PDA profile, and more empirical research is needed. Presentation may depend on an individual's age and level of independence. Some manage to forge successful lives and careers, often by being self-employed or working in roles where they can determine what they do and how they work. Others appear to be far more impacted by their challenges and struggle to achieve independence or may experience breakdown.

- **Missed diagnosis and possible misdiagnosis** – any individual presenting in a way that does not conform to a conventional understanding of autism may initially be missed, misdiagnosed or have had previous referrals rejected. This includes some women and girls, those who do not identify with a particular gender or are transgender, and those from a minority ethnic background. In adults it is quite common to see a range of existing diagnoses, often (perhaps mistakenly) including borderline personality disorder, anti-social personality disorder or schizotypal personality disorder. It is not unusual for individuals to display features of trauma responses, particularly if they have experienced frequent adverse events during their childhood and early adulthood (which may result from having been previously misunderstood). Children may also have been assessed for and/or diagnosed with attachment disorders, ODD or conduct disorders. In all these cases, reconsidering whether a PDA profile could be a more accurate formulation, and whether seeing differences and difficulties more holistically rather than addressing traits in isolation, may be appropriate.

- **Co-occurring conditions** – Many individuals with a PDA profile have also been anecdotally reported as meeting the diagnostic criteria for ADHD (research is needed to establish whether there is any connection) and all those identified with a PDA profile should have ADHD considered as part of their presentation and management. As in all ASDs, co-occurring physical conditions including Ehlers Danlos Syndrome and Postural Orthostatic Tachycardia Syndrome can be seen.

- **In-patient settings** – It is important to be aware that in situations such as in-patient units, where individuals will be very stressed, the constant state of overwhelm is likely to mean that the distinctive use of social strategies in demand avoidance (as a key feature of PDA) may not be immediately visible. While the profile may then be less obvious, it should still be possible to explore the types of triggers and determine the approaches that will help. The contributors' experience suggests a relatively high prevalence of the PDA profile in such settings, because a spiral of increasing control by others may have led to individuals exhibiting increasingly harmful behaviours with no shared understanding of how to turn things around. In addition, perceived privileges (such as section 17 leave and access to various items) are very often dependent on the treating team observing a period of 'settled behaviour' which is frequently impossible for an individual with a PDA profile to achieve.

3.5 Other explanations for marked demand avoidance

Marked demand avoidance is only *one* feature of a PDA profile, as explained above.

If marked demand avoidance presents without many/most of the other key features, it is likely to have other explanations/underlying causes which would naturally lead to different formulations and recommendations.

Unpicking these complexities requires a combination of detailed evidence gathering, allowing plenty of time and exercising clinical judgement. It is not just a question of thinking about whether the demand avoidance is 'extreme' but taking into consideration more nuanced factors including …

… the point at which the marked demand avoidance was first noted by those living or working with the individual	
e.g. did it come to the fore at a certain time, such as post-lockdown or at key transitional points in schooling (e.g. around the age of 8-9; or at the transition from primary to secondary schooling; or at another transition point or change of setting) or at key developmental stages (e.g. toddler or teenage years)?	or has it always been there in some form? (may be indicative of PDA)
… when and where the marked demand avoidance presents	
e.g. is it in certain situations where, with some further exploration, there may be clearer triggers such as social anxiety, communication or learning difficulties, or sensory overwhelm?	or is it pervasive with the trigger being less obvious or seemingly more of an internal need for autonomy/control? (may be indicative of PDA)
… what is being avoided	
e.g. is it specific tasks or activities that may be in some way aversive or untimely, or (potentially in regard to school work, for example) impossible to complete?	or is it everyday things, somewhat 'illogical' (e.g. not being able to accept a drink when it's offered or put shoes on to leave the house) and/or extend to activities that the individual is known to like/enjoy or needs to do (e.g. use the bathroom)? (may be indicative of PDA)
… how the avoidance presents	
e.g. is it a case of being oppositional, saying no, walking off or shutting down?	or are social strategies being used (within an individual's own capabilities) or have they been used at some point along the way even if not now? (may be indicative of PDA)
… how anxiety around activities presents	
e.g. does anxiety present difficulties in accessing activities initially but engagement gets easier with time and gradual exposure?	or does the novelty of a new activity or setting help initially but once it becomes 'routine' then engagement becomes harder? (may be indicative of PDA)

Following exploration of questions such as these, clinicians may conclude that a PDA profile is not the correct formulation and may wish to consider some of the following alternatives:

- **ASD**, without the use of any specifier relating a PDA profile but acknowledging difficulties relating to marked demand avoidance, giving reasons for this (such as sensory processing difficulties or communications challenges) and including relevant recommendations in the accompanying report.

- In children, **Oppositional Defiance Disorder** or **Conduct Disorder** – here the avoidance often has roots in either early childhood trauma, neglect or poor parental boundaries and behavioural difficulties can often be intergenerational and/or linked to deprivation/poverty (and therefore not linked to poor parental boundaries). Children with ODD tend to refuse and be oppositional but not show the range of social strategies of avoidance that are characteristic of PDA; they also tend to have a sense of pride/shame that prevents them from being avoidant in front of their peers whereas this may not always be the case with a PDA profile (except when individuals are masking). Families of children with ODD are also more likely to be helped by positive parenting courses or behavioural approaches, which is not the case in PDA.

- **Anxiety** – this can often occur for autistic individuals who present as 'perfectionists' and become anxious when they cannot achieve a task to the level they feel they should. This level of 'perfectionism' can often become unsustainable especially as demands (for instance, academic or social) increase, and tasks may then be avoided as a result.

- In adults, **personality disorders** – Emotionally Unstable (or Borderline) Personality Disorder may explain why some aspects of behaviours are 'dysregulated' or perceived by others as 'attention seeking' though chronic emotional dysregulation may be better understood by a combination of neurodivergence and traumatic experiences. As discussed in 3.4 above, there may be cases where these are accurate formulations and others where a PDA profile is more appropriate – this highlights the importance of taking a detailed developmental history with both the individual and those who know them well, particularly with respect to the early developmental period.

- Attention Deficit Hyperactivity Disorder (**ADHD**) – when individuals may be unable to follow requests or instructions due to poor executive function and impulse control.

- **Specific learning difficulties** – when individuals may avoid certain tasks or activities due to their specific areas of difficulty.

- **Intellectual/learning disability** - where individuals may avoid certain tasks or activities due to cognitive impairment, difficulty understanding contexts or instructions or difficulty communicating their needs/wishes effectively.

- **Mental or physical health conditions** – where marked demand avoidance may have arisen as a result of other biopsychosocial difficulties. Rising demand avoidance is often seen in cases of low mood and depression.

- **Typical development** – it is important to consider the range of 'typical' development for the developmental stage a child has reached, particularly during the toddler period and the teenage years. In the current climate, consideration also needs to be given to the possible impact of the lockdowns and disruptions as a result of COVID-19.

In all these cases, individuals will require detailed assessments (with onward referral where required), formulations and personalised recommendations. Where individuals are in crisis, 'PDA approaches' may be helpful in reducing anxiety and lessening demand avoidant behaviours, regardless of formulation.

4. Assessments & formulations

Whilst commissioning and diagnostic pathways vary considerably from one locality to another, professionals working within any service established for the assessment of ASD should be in a position to signpost a PDA profile, since it should not be seen as a separate diagnosis but a formulation that is part of the description of how ASD presents in an individual case. Some pathways refer to more specialist services to undertake assessments, whilst others have developed a PDA pathway within the usual ASD pathway to consider the profile where relevant[13].

4.1 Adaptations to assessments

When a PDA profile is being considered, the assessment process may need to be adapted in a variety of ways. Contributors cite adaptations such as:

- **understanding that just getting to the assessment appointment can be very difficult and finding out what might make it easier** – e.g. time of day, location, providing advance information about what to expect (maybe with photos of people and activities) or how long the process will take or other adaptations which may help create a sense of safety. Contributors commented on the need to be quite creative at times, with assessments taking place outdoors or whilst individuals are engaged with a special interest.

- **using indirect approaches** - e.g. having a two-way mirror for observations and asking a familiar person to undertake some tasks with the individual so they are less conscious of the assessment; or asking family members/others professionals in contact with the person to conduct 'covert' observations; or using a toy/puppet to communicate with the individual.

- **using a more indirect/declarative style of language** and phrasing questions in a less demanding way – e.g. instead of 'we're going to …' or 'it's time to …' try 'I wonder whether we could try…' or 'Maybe we could investigate …'.

- **extending assessments** to include more observations and gathering information across a wider range of situations and/or over a longer period of time (including breaking assessments into shorter sessions).

- being **flexible and collaborative** according to the individual, e.g. giving them choices over which assessments are done in what order or where the assessment is undertaken, or following their lead more than would be usual. Introducing an element of fun and humour can work well.

- accepting that when an individual is particularly avoidant, it **may be difficult or even impossible to complete standardised assessment tools** such as the ADOS, though the scoring algorithm does allow the examiner to score the interaction as a '3' which reflects instances where the session was disrupted or where an individual refused to engage. The ADOS can still provide helpful information and be used to explore the overall nature of the interaction, even if it cannot be scored officially.

4.2 Developmental histories & other sources of information

As with all neurodevelopmental assessments, it is essential to combine direct observation with a detailed developmental history and evidence gathered from relevant sources including the individual themselves (where possible).

Each multidisciplinary team will use their preferred screening instruments for this process, but where a PDA profile is being queried additional questions relating to the key features of PDA will need to be included. This inevitably increases the time involved.

For children, information will be gathered from parents/carers and other relatives where relevant; other professionals who may be involved with a child; their educational and other settings. As well as asking for reports from these sources, direct discussion or observation may be needed.

In relation to school, teaching assistants, or others who work most closely with a child, are often the most valuable sources of information. Where possible, talking with these staff members directly and/or using open-ended qualitative questions, to understand the detail of reactions to different situations and the extent and nature of engagement, is most useful.

As mentioned in 3.3 above, it is essential to remember that many children with a PDA profile mask their behaviours, therefore there may be a significant discrepancy between the descriptions of behaviours between home and school, or equally between different parental homes where parents are separated. These inconsistencies can make triangulation (using multiple sources of information to develop comprehensive understanding) harder, so it is essential to obtain detailed accounts from a variety of settings, teasing out information by asking further exploratory questions and looking for evidence of masking in all interactions, including with you during the assessment. Equally it is important to explore behaviours which may have previously been attributed to 'naughtiness' – e.g. not completing homework - but that may in fact be a case of *can't* rather than *won't*.

A significant number of children and young people with a PDA profile are unable to tolerate their school environment, have been excluded (often because the necessary adaptations have not been made) or are home educated[14] , so it may not always be possible to obtain information from a school that the child currently attends, but it may be helpful to seek the views of previous provisions. For those who are home-educated, alternative sources of information might include observations from the organisers of any home education groups or classes attended, or from the parents/carers describing the children in these settings.

Usually adults will be more involved in their assessment than children and young people, though not always. They often have more complex histories, with multiple other diagnoses (some of which may be incorrect), so obtaining additional historical information and reports is very important. In some cases, they may not have a living parent which necessitates using other informants such as partners/siblings. There may be more difficulties in triangulating information as adults may not be in employment or education and/or may be alienated from their families and communities. This may require some creative approaches to gathering information, including past school reports, requesting medical records or looking at recordings such as videos of the individual as a child. Exploring details of what is difficult, what makes it difficult and what can help is key. It can be particularly helpful to ask the individual exactly how the demand avoidance 'feels' to them and what approaches they use to cope with this; and to ask for several examples of ways in which life is challenging. PDA individuals will have no difficulty doing this and are often glad to be able to talk about it with someone who is sympathetic and willing to listen.

4.3 Diagnostic tools

ASD tools

A variety of diagnostic tools are used to inform ASD assessments. However, as highlighted in the ESCAP practice guidance[5] and the British Psychological Society best practice guidelines: "clinicians should also be aware that there are circumstances when standardised procedures may be inadequate or misleading". The ESCAP guidance goes on to say that "while the use of these supporting instruments is highly recommended, it is important to recognise that none should be used, in isolation, to make the diagnosis. This requires expert clinical judgement based on information gathered from all relevant sources."

Whilst individuals with a PDA profile would be expected to meet the criteria for autism, the contributors' accounts show that they often present with:

- superficially better social interaction skills, often with good eye contact
- fewer repetitive behaviours and less obvious routines (routines may be their own, rather than someone else's, reflected in a strong need for control over their environment)
- interests that may be intense but not so long standing, or more focused on people than things.

In addition the masking referred to earlier may mean that it is harder, initially at least, to identify some of the characteristics of autism. This is particularly important for services where there is initial triage for referrals, as screening questionnaires may not score highly enough to meet the threshold for assessment. Particular caution is also needed where there is a significant difference between answers on screening questionnaires from school and home, and this should prompt further investigation by a clinician before a referral is dismissed.

PDA-specific tools

No clinician-rated instrument for identifying a PDA profile has yet been developed. However a range of tools has been developed for research purposes which can be a helpful aid for practitioners exploring a PDA profile.

Extreme Demand Avoidance Questionnaire (EDA-Q)

O'Nions et al[15] developed the Extreme Demand Avoidance Questionnaire (EDA-Q) to measure parent-reported behaviours in clinical accounts of extreme/'pathological' demand avoidance in ASD populations of children and adolescents.

This questionnaire sought to measure these traits consistently for research purposes, however it *should not* be considered a diagnostic test. Clinical practice has shown that in some cases with high EDA-Q scores the marked demand avoidance can be better explained by other underlying reasons and not a PDA profile. Equally, a lower score would not necessarily preclude PDA from being a factor, especially when presentations may be more subtle, for example when an individual internalises and may tend to shut down rather than exhibit any aggressive behaviours.

Nevertheless the EDA-Q is useful in assessments, particularly to provide a structure to qualitative information-gathering even if not formally scored. Some clinicians also use it to consider any difference in perspectives between family members or between school and home (e.g. around the 'weighting' given to behaviours when 'scoring').

In 2019, Egan et al adapted the EDA-Q as a self-report tool for adults, the EDA-QA[16]. Again, while useful for research purposes, in clinical practice it is expected that there would be the same difficulties in sensitivity and specificity and would therefore pick up those with avoidant behaviours which stem from a variety of causes.

In 2021, O'Nions et al further refined the EDA-Q to provide a caregiver report measure of 8 items, the EDA-8[17]. The items dropped were those which showed less consistency with child age, gender, ability or independence. The items retained were found to cover the features consistently described in accounts of PDA, though this has not been tested in clinical settings and so would need to be used with the same caution as the EDA-Q for now.

DISCO

The 2015 O'Nions, Gould et al paper identified eleven items in the Diagnostic Interview for Social and Communication Disorders (DISCO) which are more specific to PDA[18]:

- Lack of co-operation
- Harassment of others
- Awareness of own identity
- Socially shocking behaviour
- Behaviour in public places
- Repetitive acting out roles
- Inappropriate sociability (rapid, inexplicable changes)
- Using age peers as mechanical aids, bossy and domineering
- Difficulties with other people
- Fantasising, lying, cheating, stealing
- Apparently manipulative behaviour

The study found that autistic individuals scoring highly on these items showed characteristics that were consistent with those previously described by Newson et al, making the DISCO a useful tool in helping to identify PDA features.

Coventry Grid interview modification

The Coventry Grid[19] was developed to help clinicians distinguish autistic behaviours from attachment difficulties and the subsequent Coventry Grid Interview was developed as a more accessible questionnaire[20]. This was further modified in 2018 by Eaton et al[21] to include examples that may indicate the presence of a PDA profile.

The Coventry Grid interview covers the following areas:

- Routine
- Social interaction
- Motor
- Auditory
- Difficulties with eating
- Mind reading
- Eating
- Executive functioning
- Language
- Communication
- Motor
- Smell
- Treasured objects
- Executive function
- Movement
- Play
- Sensory issues
- Tactile

There are 63 individual questions, some with helpful commentary. For example, under play, the grid includes 'struggles to end role play games?' and identifies NO as expected for ASD and YES for attachment, the modification includes 'YES – can often stay in role for long periods of the day' for the PDA profile. Under communication, 'does s/he give detail in pedantic fashion and give excessive detail?' and identifies YES for ASD and NO for attachment, with PDA recorded as 'NO – however, they can 'over answer' questions in order to control an interaction'.

This is *not* a diagnostic tool but can be very useful in teasing out underlying issues that would benefit from further exploration. Although there is a scoring system for ease of analysis, in practice this instrument is most usefully employed as part of taking a developmental history, or as part of a multidisciplinary team discussion after an assessment has taken place to help with formulation.

Eaton & Weaver: ADOS scoring

Post hoc analysis carried out by Dr Judy Eaton and Kaylee Weaver[10] examined data on 351 children assessed for autism at Dr Eaton's clinic. This concluded that there were statistically significant differences in scores on Module 3 on the Autism Diagnostic Observation Schedule (ADOS-2) between those children who went on to receive an ASD diagnosis and those who received a diagnosis of ASD with a PDA profile.

Module 3 includes a variety of tasks including joint interactive play, telling a story from a book, conversation and reporting, and a series of questions examining a young person's understanding of their and others' emotions, as well as their perception of everyday social relationships. The differences appeared to occur because of an inability or unwillingness to engage in the assessment, with creative attempts made to disrupt, avoid or delay completing the module. Children with a PDA profile were more likely to score 3s ("minimal or no response to the examiner's attempts to engage the participant") rather than 2s or 1s.

Further work is being done to see if this can help provide a consistent framework for aiding the identification of a PDA profile.

Eaton & Weaver – Developmental History 'Themes'

In 2018, O'Nions carried out a number of interviews with parents who identified their children as having features of a PDA profile and outlined a number of 'themes' that occurred frequently in parental accounts:

Superficial/surface sociability	Communication through dolls/toys
Obsessively avoids/resists ordinary demands	Dominating/bossy towards peers
Blaming others	Strong fascination towards people
Socially shocking/outrageous behaviour	Rapid/inexplicable changes in mood
Manipulation	Comfortable in role play

In 2020, Eaton and Weaver analysed data from 161 developmental histories taken from parents of children assessed at their clinic and found a number of new 'themes' emerged that were seen significantly more frequently in children with a PDA profile[10].

The new 'themes' were:

- elaborate excuses
- ineffectiveness of traditional reward and consequence-based parenting strategies
- extreme aggression
- sabotaging

It is important to note that these 'themes' were seen infrequently in reports from parents whose children did not go on to receive a diagnosis of autism, but whose challenges were due to developmental trauma or attachment difficulties. These themes should be explored as part of a developmental history, and several specific examples of the types of behaviour should be sought. Not all children with a PDA profile will display all these characteristics and there is no 'cut-off' point or specific number of characteristics that presents in every child.

4.4 Formulations & terminology

As stated, the ESCAP practice guidance encourages ‘personalisation and contextualisation’ of an autism diagnosis and the use of ‘specifiers’ to identify individual characteristics.

If the multidisciplinary assessment leads to the conclusion that a PDA profile is the correct explanation for an individual’s marked demand avoidance within their autism diagnosis, there is a range of terminology that is used in formulations, including ASD with:

- a PDA profile/a Pathological Demand Avoidance profile
- a demand avoidant profile/a profile of demand avoidance
- extreme/pervasive demand avoidance

The contributors recommend not using the terms ‘traits’ or ‘symptoms’ as these have been taken to signify a lesser degree of difficulty than would be expected in a PDA profile.

Use of the term ‘pathological’, in relation to marked demand avoidance, is not without controversy. Indeed Professor Newson herself later expressed regret over her use of the term. Many individuals who identify with the profile feel that the term is accurate and appropriate, as the demand avoidance they experience is innate and all-consuming. Some clinicians prefer to use the term ‘pervasive’ or ‘extreme’ as an alternative, or simply refer to a ‘demand avoidant profile’. All these are valid diagnostic formulations, and the use of different terminology may also be expedient where the PDA profile is not recognised by commissioners. In reality, the terminology used is less important than the understanding it provides, and so it is important to use whatever is acceptable.

Sometimes a ‘working’ diagnosis may be the most appropriate decision (especially in younger children), in which case professionals may explain that a PDA profile looks probable, that ‘PDA approaches’ are likely to be helpful, and that when other things are in place (such as tailored approaches and appropriate education provision) a formulation can be finalised.

In addition, co-occurring conditions may need to be assessed for, and formulated, alongside a PDA profile.

Marked demand avoidance that is not thought to be best explained by a PDA profile is covered in 3.5 above.

5. Post-diagnostic support

The purpose of assessment is to provide a greater understanding of the drivers and characteristics that impact an individual's wellbeing and quality of life (both positively and negatively).

Conclusions should be reported back in whatever way works best for the individual, but ideally in person and including families, referrers and other professionals; with the follow-up report incorporating key points from this final consultation. It is important to cover any challenges experienced with daily living but also to discuss strengths to an equal degree. And it is essential to provide detailed, personalised information on what can help.

Post-diagnostic support will be the subject of later guidance, but it is hoped that the information below will be of some use in signposting appropriate recommendations. Many services are not commissioned to provide any longer-term support or review, but being able to review progress and tailor recommendations can be very helpful.

With a PDA profile, initial focus on ways to reduce situations that cause the individual to feel overwhelmed is likely to be helpful. The idea that reducing all demands or removing all boundaries is the answer to everything is erroneous. In short, the key is to reduce the 'perception' of demands and to provide a sense of control and autonomy. Adaptation of environments and the opportunity to develop self-management techniques are also important. It is vital to acknowledge that many 'PDA approaches' are counterintuitive, turning parenting, caring or teaching norms and coping strategies 'on their head'. However, as explained in section 2.2, they often prove transformational when nothing else has worked.

These are examples of the types of recommendations which might be helpful:

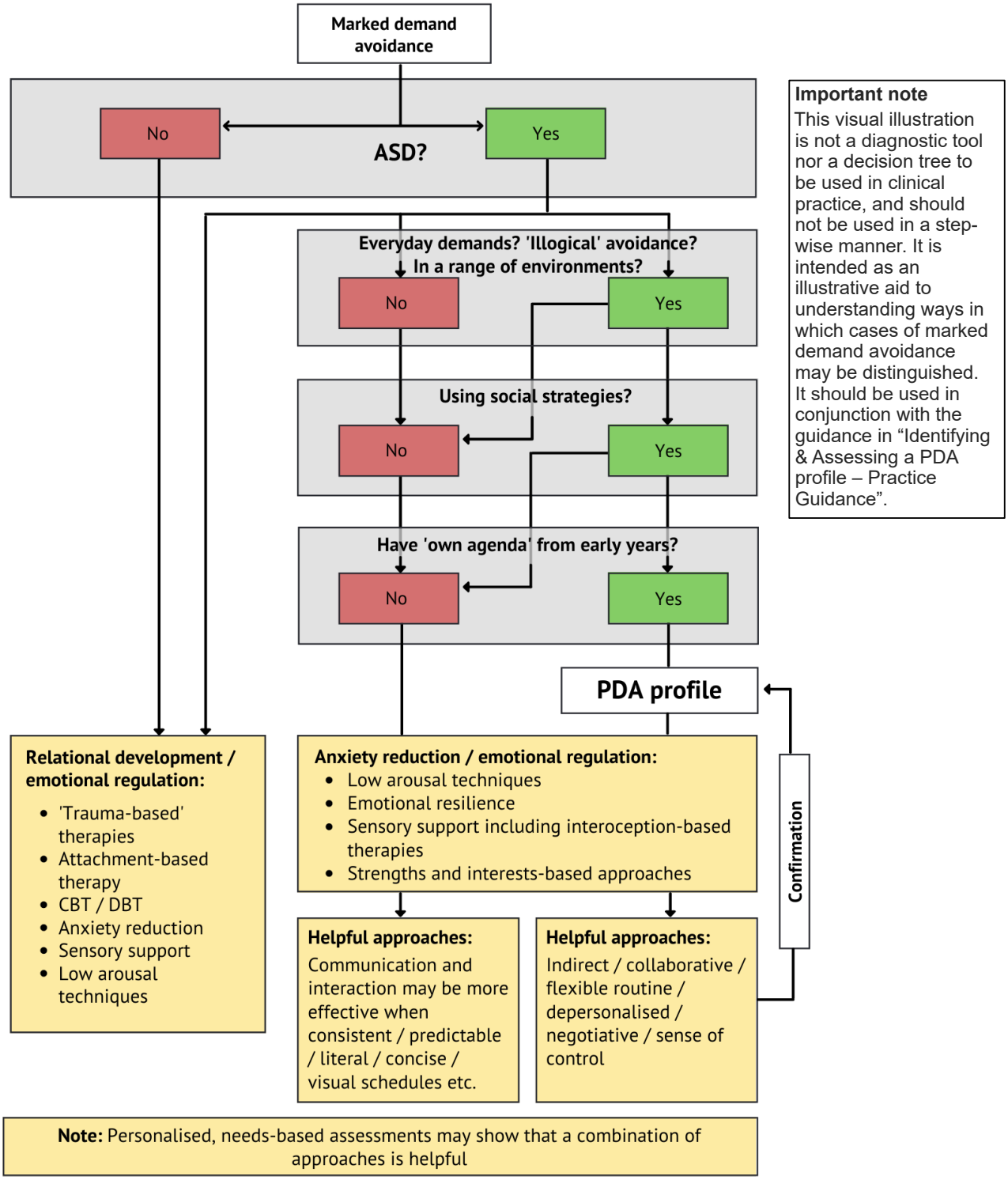
- Ensuring all involved have a good understanding of an individual's profile and how approaches and support may need to be tailored as a result
- Working with education, social care and other healthcare services to share understanding and encourage a coordinated approach to support
- Individualised planning, which identifies priorities and seeks to match demands to tolerance for demands and adjusts expectations to the level of anxiety being experienced
- Flexible, collaborative approaches, fostering a sense of autonomy rather than a feeling of being controlled by others, yet maintaining appropriate boundaries
- Indirect communication styles and depersonalising requests
- Employing low-arousal strategies
- Leaving plenty of time to process questions/information; not rushing communication
- Avoiding sensory overload
- Considering whether medication for co-occurring conditions such as anxiety and/or ADHD may be appropriate and whether occupational and/or speech and language therapy may also be helpful in some cases.

There is a wealth of information on the PDA Society website (www.pdasociety.org.uk) which may be helpful to sign, including general information about PDA, helpful approaches for families, self-help for adults and information for healthcare, social care, education and other professionals (Appendix 1). There are also many neurodivergent advocates, experts by experience, sharing their invaluable information and insights (Appendix 1).

6. Conclusion

In sharing their collective experience and expertise, the contributors' aim has been to aid fellow professionals in identifying and assessing a PDA profile, and in distinguishing PDA from other presentations of marked demand avoidance. In doing so, it is hoped that practice in this area will be harmonised to some degree and that a greater number of individuals will have their specific needs understood and met.

By way of a summary, this visual illustration is designed to show some of the ways in which a PDA profile can be distinguished from other cases of marked demand avoidance – please note that this is not a diagnostic tool nor is it a decision tree to be used in a step-wise manner.



Appendix 1 - Further reading

PDA Society website

The PDA Society website www.pdasociety.org.uk contains useful links including:

- What is PDA? booklet www.pdasociety.org.uk/resources/what-is-pda-booklet and information sheet www.pdasociety.org.uk/resources/what-is-pda-information-sheet
- Introduction to PDA video: www.pdasociety.org.uk/resources/introduction-to-pda-2021
- Demand Avoidance of the PDA kind video: www.pdasociety.org.uk/resources/whats-needed-better-understanding-of-pda
- Helpful approaches infographic: PANDA strategies: www.pdasociety.org.uk/life-with-pda-menu/family-life-intro/helpful-approaches-children
- Self-help, coping strategies & therapies for PDA adults: www.pdasociety.org.uk/life-with-pda-menu/adult-life-landing/self-help-coping-strategies-and-therapies-for-adult-pdaers
- Information for teaching professionals: www.pdasociety.org.uk/working-with-pda-menu/info-for-education-professionals
- Home Ed Hub: www.pdasociety.org.uk/resources/home-education-hub
- EHCP Guide: www.pdasociety.org.uk/resources/ehcp-guide
- Keys to Care for in-patient settings: www.pdasociety.org.uk/resources/keys-to-care
- Lists of books: www.pdasociety.org.uk/resources/resource-category/books
- Directory of third party support groups: www.pdasociety.org.uk/resources-menu
- Details of training: www.pdasociety.org.uk/events-training-landing

Experts by experience

These PDA adults share information and insights:

- Kristy Forbes: www.kristyforbes.com.au
- Julia Daunt: www.memyselfandpda.com
- Sally Cat: www.sallycatpda.co.uk
- Dragon Riko: www.dragonriko.wordpress.com
- Harry Thompson: www.harryjackthompson.com

Appendix 2 - References

1 Newson et al (2003) *Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders.* Archive of Diseases in Childhood.

2 Christie et al (2007) *The Distinctive Clinical and Educational Needs of Children with Pathological Demand Avoidance Syndrome: Guidelines for Good Practice*. Autism Education Trust

3 O'Nions et al (2014) *Development of the 'Extreme Demand Avoidance Questionnaire' (EDA-Q): Preliminary observations on a trait measure for Pathological Demand Avoidance.* The Journal of Child Psychology and Psychiatry.

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6 Green et al (2018) *Pathological Demand Avoidance: symptoms but not a syndrome.* The Lancet: Child and Adolescent Health.

7 Soppitt, R (2020) *Pathological/Extreme Demand Avoidance (PDA/EDA)* Chapter 18 in Special Educational Needs: A Guide for Inclusive Practice, 3rd edition. Sage Publications Ltd, eds Peer and Reid.

8 O'Nions, Happé et al (2018) *Demand avoidance is not necessarily defiance.* Commentary published to Green at al above.

9 Royal College of Psychiatrists: *The psychiatric management of autism in adults* CR228 (July 2020).
British Psychological Society *Working with autism: Best practice guidelines for psychologists* (August 2021).

10 Eaton & Weaver (2020) *An exploration of the Pathological (or Extreme) Demand Avoidant profile in children referred for an autism diagnostic assessment using data from ADOS-2 assessments and their developmental histories.* Good Autism Practice Journal.

11 Gilberg et al (2015) *Extreme ("pathological") demand avoidance in autism: a general population study in the Faroe Islands.* European Child and Adolescent Psychiatry

12 Stuart et al (2019) *Intolerance of uncertainty and anxiety as explanatory frameworks for extreme demand avoidance in children and adolescents.* The Association for Child and Adolescent Mental Health.

13 Local position statements on PDA: www.pdasociety.org.uk/resources/local-position-statements-on-pda

14 PDA Society Being Misunderstood survey report (2018): www.pdasociety.org.uk/resources/2018-summary

15 O'Nions et al (2014) *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.

16 Egan et al (2019) *The Measurement of Adult Pathological Demand Avoidance Traits.* Journal of Autism and Developmental Disorders.

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20 Flackhill, James, Soppitt & Milton (2017) *The Coventry Grid Interview (CGI): exploring autism and attachment difficulties*. Good Autism Practice.

21 Eaton et al (2018) *Modification of the Coventry Grid Interview (Flackhill et al, 2017) to include the Pathological Demand Avoidant profile.* Good Autism Practice Journal.

Appendix 3 - Contributor details

Phil Christie – Consultant Child Psychologist and Specialist ASD Adviser
Phil is now an independent consultant child psychologist and specialist ASD adviser, undertaking assessments and consultancy (where commissioned by Local Authorities or other bodies), also providing training for schools and other organisations to improve autism practice. Phil was previously Director of Children's Services for a regional autism charity, responsible for a specialist autism school and leading a team of consultants providing a diagnostic and assessment service at the Elizabeth Newson Centre. Phil is currently Vice Chair of the board of the Autism Education Trust and is Chair of the trust's Expert Reference Group. He has been an Associate Editor of 'Autism: The International Journal of Research and Practice' and of 'Good Autism Practice'. Phil has published widely in the field of autism and co-authored a number of books about autism and PDA.

Dr. Gloria Dura-Vila – Consultant Child & Adolescent Psychiatrist, Medical Lead for the ASD Pathway in Surrey and Borders Partnership NHS Foundation Trust
Dr Gloria Dura-Vila is a Consultant Child and Adolescent Psychiatrist and the Medical Lead for the ASD Pathway in Surrey and Borders Partnership NHS Foundation Trust (a role for which she was awarded a triple Clinical Excellence Award in 2020). She is a member of the Autism Education Trust's Expert Reference Group and of the executive committee of the Royal College of Psychiatrists' SIG for Spirituality & Psychiatry. Gloria combines her NHS and private clinical work with teaching and research in the fields of neurodevelopment and cultural psychiatry. She is a guest lecturer at Queen Mary University London and has lectured at Imperial College London, the Royal College of Psychiatrists and Great Ormond Street Hospital, amongst others. Gloria is passionate about communicating the autism diagnosis in the best possible manner and has written several books about autism and PDA.

Dr. Judy Eaton – Consultant Clinical Psychologist
Judy began her career as an academic before working as a lead clinical psychologist in the NHS and a low secure psychiatric hospital. She set up a private practice, Help for Psychology, in 2015 and has extensive experience of assessing, diagnosing and working therapeutically with adults, children and families across the ability spectrum with a specialism in areas of complex needs. Judy is a research associate at King's College London, has published a book on mental health in autistic girls and young women and is a member of NHS England's Strategic Oversight Board.

Alison Hart – Occupational Therapist and Associate Lecturer
Alison worked as an Occupational Therapist and Clinical Manager in the NHS for 20 years, and as Allied Health Professionals Lead for Children's Services in South Staffordshire. In 2009 she founded an independent practice, Children's Choice Therapy Service, where she continues to provide assessment and intervention services and provides training nationally. Alison is also an Associate Lecturer at the University of Derby and is a Fellow of the Higher Education Academy.

Libby Hill – Consultant Speech & Language Therapist
Libby has over 35 years' experience, working for much of that time as a lead speech and language therapist in the NHS before setting up an independent practice, Small Talk, in 2007. She specialises in autism, PDA and selective mutism and regularly acts as an expert witness. Libby founded Smart Talkers Communication Groups, franchised nationally and internationally, and created and edited S&L World, a global magazine for speech and language professionals.

Keith Howie – Educational Psychologist
Keith is an independent educational psychologist and member of the British Psychological Society and the Association of Educational Psychologists. After completing his training, he worked for eight years as a psychologist with Wakefield Metropolitan District Council and a further seven years working in more specialist roles, including with children and young people with autism. From 2002-2020 Keith was employed by Autism East Midlands as clinical coordinator of the Elizabeth Newson Centre. He is now an independent consultant psychologist, providing services to a variety of organisations both nationally and internationally.

Dr Ann Ozsivadjian – Clinical Psychologist
Ann Ozsivadjian is a Clinical Psychologist in independent practice who worked for several years as the senior psychologist in a specialist complex neurodevelopmental disorders team at the Evelina London Children's Hospital, providing assessments and treatments for a wide range of neurodevelopmental difficulties and co-occurring conditions. Her particular research interests and clinical specialism are mental health problems in ASD and adapting interventions for young people on the autism spectrum, and she regularly presents at conferences on these topics. Ann also provides training courses across the UK on the assessment and treatment of mental health problems in autism spectrum disorders. She has published a number of papers and co-authored book chapters, and has also produced a number of podcasts and webinars in conjunction with the Association of Child and Adolescent Mental Health. Ann currently works in independent practice and is also a visiting senior lecturer at King's College London.

Dr Georgie Siggers – Consultant Neurodevelopmental Paediatrician
Dr Georgie Siggers is a Consultant Neurodevelopmental Paediatrician who works in independent practice, having previously held several positions as an NHS Consultant in London and the South East. She is a fellow of the Royal College of Paediatrics and Child Health (RCPCH), a previous executive and council member of the British Association of Community Child Health (BACCH), member of the British Paediatric Mental Health Group and member of the George Still Forum for ADHD.

Pat Smith – Educational Psychologist
Pat is a chartered psychologist, registered with the Health Professions Council as a practising educational psychologist, and is a Member of the British Psychological Society. Pat has over 35 years of educational and clinical experience working with adults, children and families in multi professional settings. She has been employed as an educational psychologist by Local Authorities, charities, including the National Autistic Society (NAS), the Elizabeth Newson Centre, Autism East Midlands and by specialist providers. For the past 20 years, she has specialised in working with individuals with complex needs involving concerns around communication and social interaction.

Dr Lisa Summerhill – Consultant Clinical Psychlogist
Lisa is a Consultant Clinical Psychologist who has worked for the NHS for over 20 years. She has previously worked in a CAMHS service, and for the past 10 years held a lead position in an autism assessment service for children and young people. She currently works part time for the NHS leading a paediatric psychology service. Since 2019 she has also been offering private therapy face to face and virtually to children, young people, adults and families.

Dr Vicki Wingrove – Clinical Psychologist
Vicki qualified in 2005 and her clinical career has largely been working within multi-disciplinary neurodevelopmental assessment pathways. She currently works part-time within the NHS, in Rotherham CAMHS, and also undertakes a small amount of private work, with a focus on formulation, identification of strengths and needs and recommendations.

Dr Julia Woollatt – Clinical Psychologist
Julia has worked in the NHS and with some private service providers since 2002, spending much of her career in CAMHS (Child & Adolescent Mental Health Services). She has specialised in working with children, young people and adults with complex neurodevelopmental presentations, particularly Autism Spectrum Disorders.

Endorser details

Kimberley Ashwin – Autism Consultant Nurse and Director, Autism Oxford

Dr Linda Buchan – Consultant Clinical Psychologist, Axia ASD Ltd

Dr Alison Doyle – Educational Psychologist, Caerus Education, Ireland

Raelene Dundon – Clinical Director/Educational & Developmental Psychologist, Okey Dokey Childhood Therapy, Australia

Dr Sarah Glew – Clinical Psychologist, East Sussex Healthcare NHS Trust

Dr Fiona Gullon-Scott – Consultant Chartered Psychologist, Spectrum Specialist Consultancy Ltd and researcher

Claire Howell – Specialist Occupational Therapist & Clinical Team Lead, University Hospitals Birmingham NHS Foundation Trust

Dr Jo Jones – Consultant Paediatrician, Healthcare4Kids

Laura Kerbey – Autism and Education Consultant, NEST - Neurodivergent Education Support and Training

Dr Theresa Kidd – Director/ Principal Clinical Psychologist, The Kidd Clinic, Australia

Katy Laing – Consultant Speech and Language Therapist, Grow and Thrive Limited

Dr Anita Marsden – Principal Clinical Psychologist, East Sussex Healthcare NHS Trust

Dr Michelle Muniz – Consultant Clinical Psychologist, Purple House Clinic (Glasgow)

Jude Philip – Consultant Speech and Language Therapist and Clinical Lead, Grow and Thrive Limited

Dr Richard Soppitt – Consultant Child Psychiatrist, Sussex Partnership NHS Foundation Trust & Psychology Sussex Limited

Ben Truter – Clinical Director & Clinical Psychologist, The Neurodiversity Centre, South Africa

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