PDA – Current thinking, challenges and the lived perspective

Dr Judy Eaton, Consultant Clinical Psychologist and Sophie Leman

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About us

* I am a Clinical Psychologist and have been working in autism assessment and diagnosis since 2001, both in the UK National Health Service (NHS) and in inpatient services. I also work therapeutically with young people, and adults with a PDA profile
* I am also a mother and grandmother to autistic children and grandchildren.
* I will be sharing both my clinical experience and personal experience during this talk

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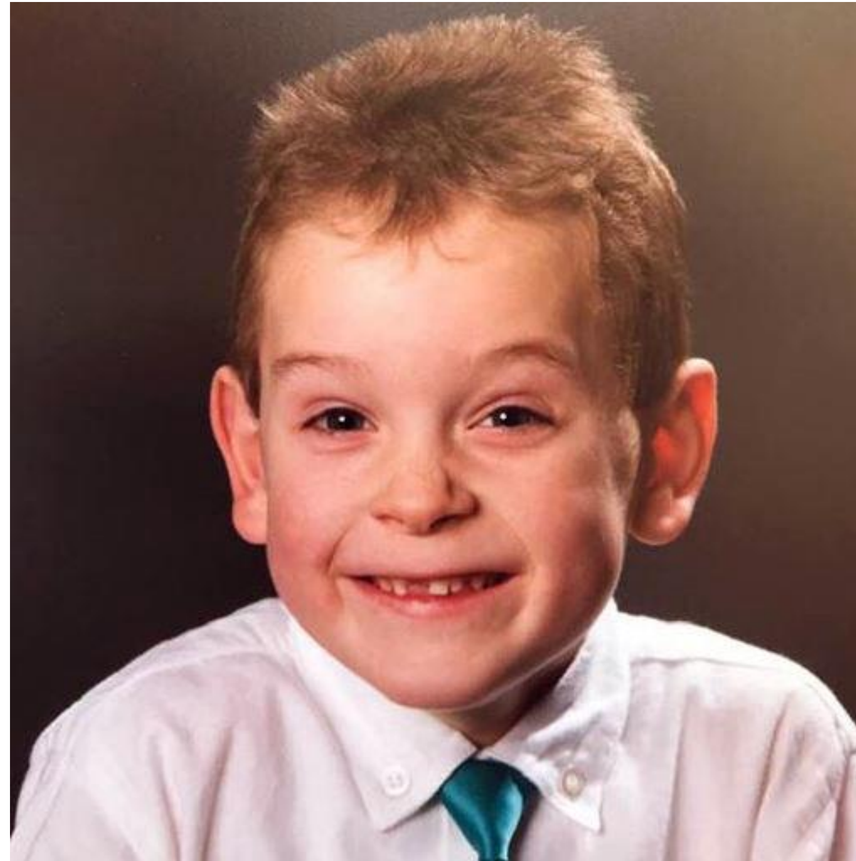
About us

* Sophie is a young autistic person with ADHD and a PDA profile
* She will be speaking today from a lived experience perspective
* She is committed to raising awareness and supporting other young people in her position



Where it all began

* This is David, my late son. He was born in 1983 at a time when autism had only just been included in the diagnostic manuals
* David was a 'character' – on his own agenda from day one.
* He could never, ever do what he was asked, or conversely, not do what he had been told not to do!
* School was challenging to say the least - every parent meeting was started with a sigh.

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Where it all began

* He was a happy, smiley boy who approached life at a million miles an hour.
* His anxiety only began to be apparent in his teenage years when the demands on him became greater.
* He was vulnerable and easily led and often got into trouble
* He left school with no qualifications and found it very hard to stay in any job for more than a few weeks

Where it all began

* He did eventually find a partner, managed to complete an apprenticeship and have two small boys
* However, the good times did not last, and his anxiety and depression became worse
* Sadly, he passed away from undiagnosed pneumonia at the age of 35.

Where it all began

* Throughout his childhood, as a young mother, I was constantly blamed for his ‘behaviour’.
* I recall a moment sitting in a psychologist’s office being told it was my fault he would not do as he was asked, and I clearly needed to have ‘stronger boundaries’
* It was at this point I decided to pursue a career in clinical psychology. The rest is history.

Let me introduce Reuben

* Fast forward thirty years and here is Reuben, David's son and my grandson. A beautiful soul and a wonderful example of genetics at work.
* Reuben is a free spirit, on his own agenda, an explorer, a Bear Grylls adventurer.
* He cannot be directed or contained. He loves his life.
* Sadly, I fear for his mental health as he gets older and, like his father, demands on him increase

Introducing Sophie

* Sophie is a young person I have known and whose mental health journey I have shared for the last six years. She is currently co-authoring my latest book, which explores mental health issues for autistic teens
* She is one of the most articulate, intelligent young people I have had the pleasure of working with
* She is diagnosed with Autism, ADHD and a PDA profile and has explained so much to me about how PDA 'feels', despite also having alexithymia

My understanding of PDA – the diagnostic perspective

* In the UK, as in the US, PDA does not appear in the diagnostic manuals
* It is often (wrongly in our view) labelled as Oppositional Defiance Disorder, or Conduct Disorder
* Young teenagers are often misdiagnosed as having Emotionally Unstable/Borderline Personality Disorder
* It has proved to be a controversial concept and, as such is a challenging area to work in diagnostically.

My understanding of PDA – the diagnostic perspective

* Very often even before considering a PDA profile, it can be challenging to justify why a child, or young person, meets criteria for autism
* They are often described as ‘too sociable’, or ‘too articulate’
* Their difficulties can be subtle and hard to identify in a standard diagnostic assessment appointment
* The challenge is not made any easier by a large social media audience, sharing their own views of PDA

My understanding of PDA – the diagnostic perspective

* A paper by Prof Jonathan Green and his colleagues (Green et al, 2018) published in the Lancet aimed to clarify this
* They concluded that, although as clinicians, they were aware of and had observed the types of challenge experienced by some families and young people, they did not feel there was sufficient evidence to consider PDA as a separate and discrete diagnostic category, but more as a constellation of behaviours.

My understanding of PDA – the diagnostic perspective

* There has also been debate about whether children and young people with PDA all meet the criteria for a diagnosis of Autism or whether extreme demand avoidance is seen in other groups
* Some 'Critical Autism' academics, such as Richard Woods have argued that PDA has no specificity and is better considered as a trauma response to adverse events in the environment

The ODD/CD debate

* Prof Green's paper stated:

* DSM-5 recognises that there is a subgroup of children with conduct disorder who have "limited prosocial emotions". The criteria for this subgroup are the following traits: callous, lack of empathy; lack of remorse or guilt; lack of concern about performance (eg, at school); and shallow or deficient affect. The 11th edition of ICD is likely to introduce this qualifier of "limited prosocial emotions" into both oppositional defiance disorder and conduct disorder diagnostic criteria.'

The ODD/CD debate

* This description does not resonate with parents of or individuals with a PDA profile
* If anything, many parents (and individuals) report hyper-empathic responses – they almost feel 'too much'
* There is a danger that it could lead to certain minority groups, or socio-economic groups being wrongly labelled as having conduct disorder without exploring autism or investigating the possibility of a PDA profile

My understanding of PDA – the diagnostic perspective

* I have now worked clinically for 25 years. I have assessed thousands of children
* My experience (and the small-scale research we conducted) to a large extent matches the early views of Elizabeth Newson, the pioneer of PDA as a diagnostic entity.
* Mainly because although the children assessed may not easily fit into a neat diagnostic category, they are SIMILAR TO EACH OTHER

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My understanding of PDA – the diagnostic perspective

* There are striking similarities in behaviour, presentation and the types of issues raised by both parents and young people.
* PDA is clearly 'something'
* However, that 'something' has not yet been fully, or clearly defined.
* There has also been a huge rise in interest in the topic and, sadly, much misinformation shared on some social media platforms.

My understanding of PDA – the diagnostic perspective

* Unfortunately, the lack of understanding, and lack of agreement at a basic level about what PDA is can lead to parents and young people not getting the support they desperately need.
* Often the wrong strategies are suggested and used
* This undoubtedly contributes to the number of young people suffering quite significant mental health challenges

So how does the PDA profile present?

* The term PDA was first used in the 1980’s by Elizabeth Newson
* It was used to describe a group of children referred for assessment who had some features of Autism or Asperger’s Syndrome but did not quite ‘fit’ either diagnosis
* These children were usually described as having ‘Atypical Autism’ or Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS), which was not particularly helpful for parent or professionals
* Elizabeth Newson found that although not typical of ASD or Asperger’s they were **typical of each other**

So, how does the PDA profile present?

* Children can appear passive (sometimes presenting as not socially motivated) in the first year or so.
* There can be some language delay but children with the PDA profile quickly catch up – almost as if they choose when to speak
* The first sign is often extreme avoidance of any demands (usually starting by about 18 months and much more than just the 'terrible two's', sometimes this can be apparent even earlier)

So how does the PDA profile present?

* There appears to be an overwhelming need for control, often driven by high levels of anxiety
* Moods can switch suddenly from calm to ‘meltdown’ often with no apparent trigger. Meltdowns can feel like a panic attack
* Young people may threaten or even attack teachers, family and friends and may have little or no recall of the event afterwards

So, how does the PDA profile present?

* Avoidance strategies when faced with any demands increase – ranging from excuses (my legs are broken, my tummy hurts) to outright refusal, to 'almost' doing something but not quite
* Children with the PDA profile can appear superficially sociable, particularly the girls. However, friendships often fail as they can become too controlling

So how does the PDA profile present?

* There may be periods of time when the child appears to have fewer difficulties, but this is often followed by a sudden and unexpected deterioration in mood and behaviour
* Pretend play tends to be better than in other autistic children, but on close examination it is often repetitive or copied
* Some children enjoy role playing, often 'becoming' a character and can be excellent actors and actresses
* Most children with the PDA profile will have some sensory difficulties

My understanding of PDA – the therapeutic perspective

* Over the years, my team and I have been working to establish the most effective therapeutic approach for young people with a PDA profile
* In the UK, young people are often offered a 'standard' therapy package, usually a course of CBT (Cognitive Behavioural Therapy)
* CBT aims to support young people to challenge negative thoughts and modify behaviour

My understanding of PDA – the therapeutic perspective

* This approach is used to ‘treat’ anxiety, depression and obsessive thoughts
* In its standard form, it does not always (if ever) work with young people with a PDA profile
* It is important to consider why this might be and what type of approach could be used instead to provide support for young people’s mental health

The lived experience perspective

* For CBT to work, the patient has to have the ability to act on the demands placed on them. This is one of the main problems for those with a PDA profile
* Content requires emotional understanding people with autism don't necessarily have
* Homework may be too demanding for individuals with a PDA profile to engage with and not therapeutically beneficial

Common mental health challenges and areas to be discussed

* **Trigger warning**

* Some of the areas to be discussed can be difficult to hear about and discuss.

How to provide neuroaffirmative therapy

* Anxiety
* Depression
* Mood swings
* ‘Meltdowns’
* Self-harm
* Suicidal thoughts
* Obsessive thoughts and rumination
* Low self-esteem and self-hatred
* Burnout and shutdown

What lies behind these difficulties?

* Arousal levels
* Alexithymia
* Interoceptive difficulties
* Genetic predisposition (anxiety/depression/bipolar)
* Rigid thinking
* Need for control
* Misunderstanding from others
* Complex trauma

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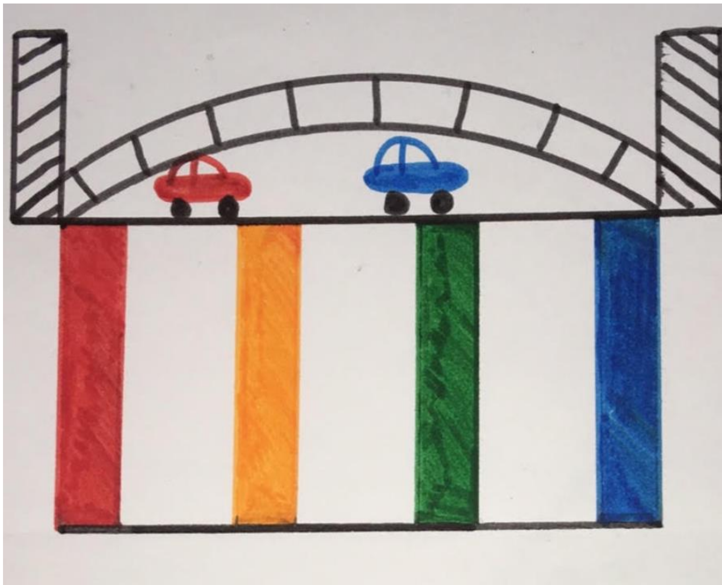
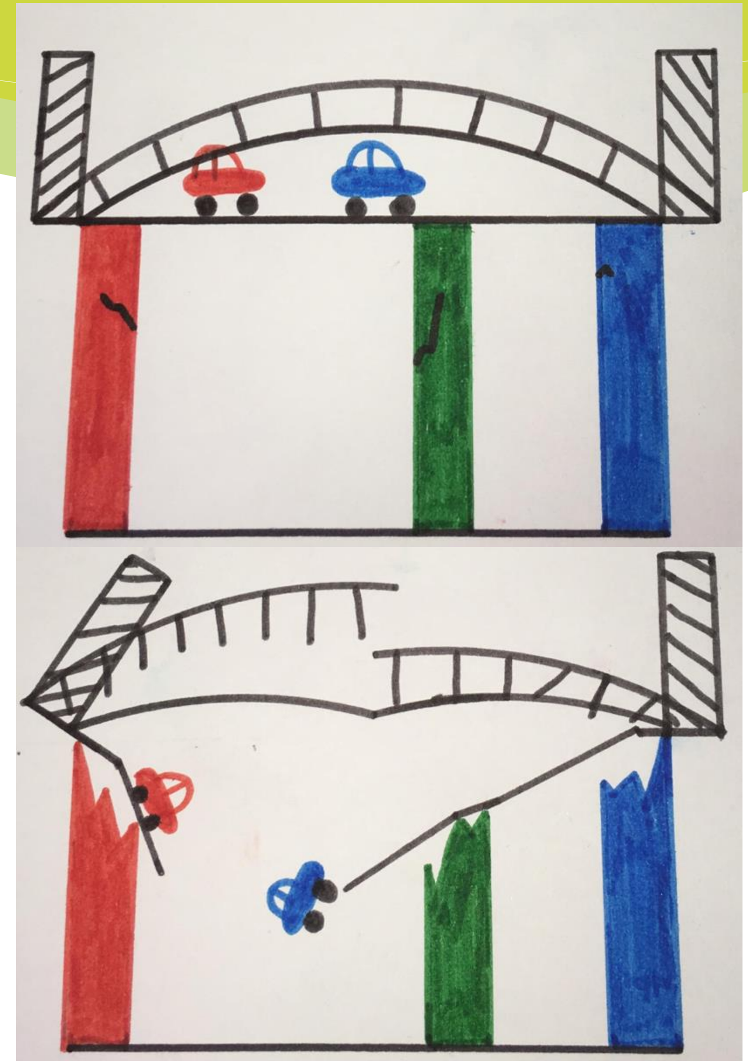
Neurodivergence (a spiky profile)





* Drawings done by Sophie in 2018 to explain how a 'Spiky profile' felt

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Arousal levels

* Several theories around this in terms of differences between autistic and non-autistic individuals
* Polyvagal theory is one such theory – claims that autistic persons are in a ‘chronic state of hyperarousal, with lower vulnerability to stress’
* Some recent challenges to this – may not be all autistic people and may be linked more to degree of anxiety experienced
* May also link to underlying GI difficulties
* However, key PDA feature – ‘emotional lability’

The lived perspective

* With 'emotional lability', the response is rarely unpredictable when accurately considering how demands are affecting the individual
* Reasons behind the dysregulation aren't always clear or logical
* Just because they don't make sense doesn’t mean they don't exist
* A build-up may be hidden by masking... until it's no longer possible

Alexithymia and interoception

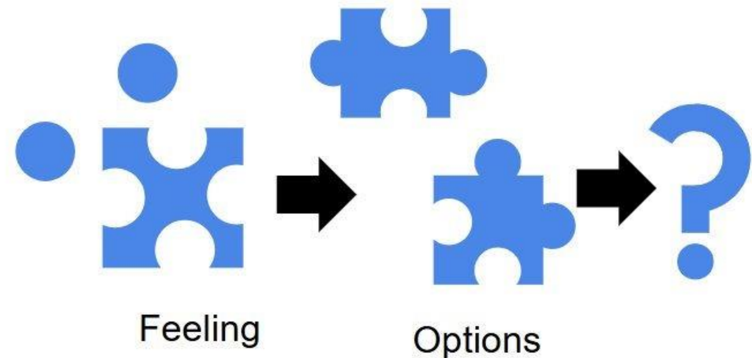
* Alexithymia is the inability to verbalise feelings. It is linked to autism, but not all autistic individuals will experience alexithymia
* Interoception refers to the sensation of internal bodily signals and can contribute to challenges describing how one's body 'feels'

Alexithymia and interoception

* Measuring interoceptive ability can be hard
* Some studies struggle to draw conclusions about interoceptive difficulties in autism because of alexithymia
* There is no doubt though that both will have an impact upon wellbeing and the ability to engage in therapy.

The lived perspective

- I have the feeling, I am aware of the words but I don't know how to put them together accurately
- Regulation is very difficult because getting the problem wrong means the answer is wrong
- I use communication functionally. If I'm not certain, I often don't say
- Communicating isn’t effective if I don't know what to communicate



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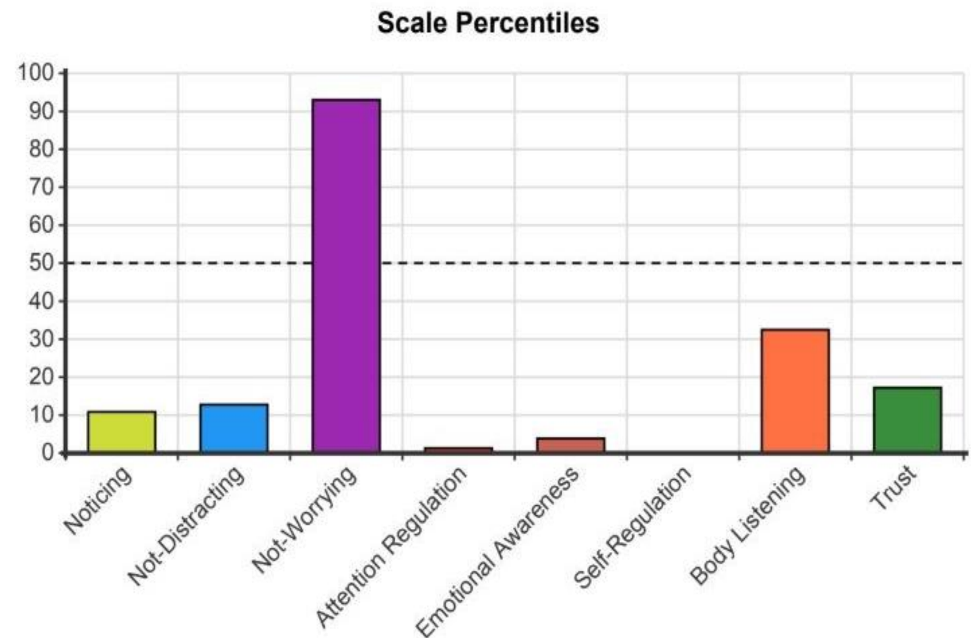
Measuring Interoception

- Measuring interoceptive challenges isn't straightforward or easy
- The results match my experience of not noticing different signals and not acting on them when I do



My results for MAIA v2 (Multidimensional Assessment of Interoceptive Awareness – Version 2)

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Genetic predisposition

* Anxiety disorders, depression and mood disorders run in families.

* It is possible that some people are simply genetically pre-disposed to experience high levels of anxiety and emotional lability.

Rigid thinking, need for control and misunderstanding by others

* These are all areas that can lead to challenges for clinicians working with autistic/PDA individuals, particularly when using standard therapeutic approaches
* It can be hard to move on from beliefs and thoughts
* There can be a need to control the therapy environment
* Long-standing misunderstanding from others can lead to automatic responses and trust issues

The lived experience perspective

* It is vital that the individual feels heard in the therapy environment and for the therapist to appreciate that someone with a PDA profile will need to feel in control to some extent.
* To help the individual access therapy, try giving choice and allowing some autonomy.
* The therapist may need to keep in mind that setting ‘homework’ or giving tasks to complete can be perceived as a ‘demand’
* If therapy isn't helping the individual, it shouldn't be on the individual to change
* IF THEY COULD THEY WOULDN'T NEED THERAPY

Lived Experience perspective

* It's too easy to assume the individual is making it up, manipulating those around them or attention-seeking
* PDA is more challenging for the individual with PDA than those around them
* Labelling me as manipulative or aggressive seemed to reflect personal opinions of me not deserving the help, not professional opinions
* I have faced recurring challenges surrounding personality in mental health support which clouded judgement and led to inappropriate and harmful care

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Complex trauma

* Complex trauma is described as
* ‘traumatic experiences involving multiple events with interpersonal threats during childhood or adolescence’.
* Trauma, or the experience of it, is intensely personal. What one person may find traumatic, another may not
* Many autistic (and ADHD) individuals have experienced multiple rejections, bullying or adverse childhood experiences
* The impact of this can be cumulative

The lived perspective

* My inability to benefit from 'prescribed' therapeutic models was labelled as non-compliance with the treatment
* This attitude reinforced negative self-beliefs
* Subsequent meltdowns/ shutdowns were viewed as behavioral and professionals' mistreatment traumatised me.
* The combination of not understanding how experiences impacted me and the lack of professional understanding led to repeated traumatic incidents I was unable to escape
* Creating the 'cycle' CBT aims to break!

Therapeutic approaches for the future

* Two approaches, which are beginning to be used together are:
  * ACT (Acceptance and Commitment therapy)
  * CFT (Compassion Focused Therapy)

Any questions?