

Perspectives on Demand Avoidance: Is it PDA, or something else?

*A two-day virtual conference hosted by POPARD,
in collaboration with ACT*

Session 1:

Supporting Learners with Pathological Demand Avoidance


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An Introduction to PDA

By Laura Kerbey – illustrations by Eliza Fricker



1

A little about me:

- Background in Psychology and Teaching
- Specialised in autism in 2009
- Surrey Autism Champion
- Head Teacher of Specialist School
- Founder of PAST
- Co-Founder of KITE Therapeutic Learning
- Co-Founder of NEST with Harry Thompson
- ADOS Trained



2

What is PDA?

The Main Characteristics of PDA include:

- Resists and avoids the ordinary demands of life, which might include getting up, joining a family activity or other day to day suggestions. This may be the case even when the person seems to want to do what has been suggested
- Using social strategies as part of the avoidance e.g. distracting, giving excuses
- Appearing sociable on the surface, but lacking depth in their understanding
- Excessive mood swings and impulsivity
- Being comfortable in role play and pretend, sometimes to an extreme extent
- 'Obsessive' behaviour that is often focused on other people.

3

What is PDA?

A profile of autism characterised by high anxiety and a need to avoid demands and remain in control.

4

PDA is NOT just about Demand Avoidance

- Avoiding demands is something we all do at times.
- People avoid demands which are boring, frightening, painful or otherwise.
- This is known as "rational" demand avoidance.
- Demand Avoidance' is listed as a sign or symptom to be considered in an autism assessment under NICE (*National Association for Health and Care Excellence*) guidance.
- With PDA – demand avoidance is often "irrational" and individuals with avoid the things they want to do, as well as the things that they DON'T want to do.
- In the UK most places will diagnose "Autism with Demand Avoidance" or "Autism with a PDA Profile" or similar. "Reasonable Adjustments" should be based on NEED not diagnosis.

5

Everyone with PDA is unique and different

autistic

SENSORY CHARISMATIC

WHAT IS PDA?

AUTONOMOUS HUMOUR

ANXIOUS

COMMUNICATION STRONG INTERESTS

6



7

The Antidote to Anxiety is Trust


- It is essential to remember the anxiety that PDAers are experiencing
- Anxiety takes many different guises
- Some of the most anxious children I have worked with do not present as "anxious."
- Relationships and connections are EVERYTHING when you work with PDAers
- You must take your time to build genuine, authentic and reciprocal relationships. An individual with PDA will not recognise authority or hierarchy as a neurotypical child will.

8

Remember the Anxiety Bucket Analogy

- It is essential to recognise an individual with PDA's "bucket fillers" and "bucket emptiers."
- The baseline of anxiety for an individual will be high - there is always anxiety in the bucket
- PDAers require autonomy and freedom – this helps them to feel in control.

9




PDA and Masking

- Individuals with PDA are very proficient maskers.
- Sometimes masking is used to comply with demands.
- Sometimes masking is used to avoid demands.
- Masking is sometime very subtle. Just because a child looks "fine" in school does not mean that they are!!


10

A child with PDA may not identify as a child and may see them self as an adult




11

For that reason, you must always present yourself as their equal.



12




The Importance of Humour

- Humour is a great leveller – it is a truly reciprocal form of communication
- Shared humour is a great way to build connections – it can help to remove any appearance of hierarchy
- Humour can relieve tension and anxiety
- Laughter releases endorphins


13

Non-Verbal Language

- Due to their anxiety and hypervigilance an individual with PDA is likely to be very sensitive to tone of voice, facial expression, gestures etc.
- Remember the "Smoke Detector" analogy
- It is essential to be aware of your own emotional regulation
- Be honest about your own emotions and talk about and demonstrate how you manage them




14



The Importance of Autonomy

- PDA is also known as a "Pervasive Drive for Autonomy" (Tomlin Wilding)
- Or a "Persistent Desire for Autonomy" (Dr Wenn Lawson)
- Offer choices – but be aware that decision making can be a demand
- Involve the individual with PDA as much as you can in decision making and planning – do not impose these things upon them
- Many children with PDA are autodidactic and can thrive with a child lead approach

15




Wondering, learning together and sharing demands

- A demand shared is a demand halved
- Shared goals increase reciprocity – do things and explore together
- Use language like, "I wonder what would happen if we tried....."
- As a teacher – think of yourself as a "Learning Partner" or a "Learning Facilitator."
- Use races, challenges and games – but be completely genuine in your participation – make the end goal as important to you as it is to them

16

INTEREST



Weaving in Interests and Learning from Each Other

- An individual with PDA will need to see the "point" or the "what's in it for me factor" of a demand or task.
- Demands and rules will be pointless and arbitrary without this
- Use interests to engage
- BUT- be wary of hijacking or tainting special interests
- Take a genuine interest in their special interest
- Remember that special interests can be transient and change regularly
- We should see the value in ALL special interests, even if they seem "inappropriate" to us

17



The Perfect Learning Environment for PDA

18

An honest reflection

- It is incredibly hard for most schools to create the right environment for individuals with PDA
- 70% of children with PDA in the UK are not able to access education in school
- As children move through the education system their autonomy is slowly removed
- This is why we HAVE to increase understanding of PDA in schools – because with the right approach it CAN work



19

Praise and Rewards



- Be wary of directly praising an individual with PDA
- Praise can set up an expectation to repeat or improve a task or demand
- Praise can feel patronising and disingenuous
- Praise can put someone in the spotlight
- Certificates, shared rewards etc can feel worthless to an individual with PDA

20

Find different ways to "praise."



- Reflect on what you like about a completed task or piece of work
- Talk about "natural consequences"
- Do not praise children with PDA for coming into school
- "Rewards" need to be high value and instantaneous
- Let an individual with PDA hear you talking about them in a positive way
- Once a solid, trusting relationship has been formed you can use humour as part of your praise

21


Scrap "Traditional Autism Strategies"



- Traditional Rewards and Sanctions systems will not work
- Public displays of attainment or consequences can cause huge anxiety
- Now / Next boards and Visual Timetables can feel very demanding – if they help with transitions ensure that the individual has input into their creation

22


Reducing Pressure and Picking your Battles



- It is essential to pick your battles when supporting an individual with PDA
- Always be aware of anxiety and the "bucket" capacity
- You will have good and bad days – this is normal
- Ask yourself "if it really matters" and why you are asking for something to be done
- Consider the "What's in it for Me" factor
- It's OK to have non-negotiables – these are most often around keeping people safe.

23

Be Flexible enough to Bend so that Neither of you Break



- Remember that an individual needs novelty, spontaneity, flexibility and autonomy
- Individuals with PDA are still autistic. Unexpected change and transitions may cause anxiety and disappointment
- Warn of change, and give factual reasons for them
- Offer autonomy with change and transition
- A daily "check in" and "check out" can help with the school day
- A "soft start" to the day when anxiety is high can help too
- Be prepared to change your plans!

24

Blame the Government!

- Remember that an individual with PDA will not see hierarchy or authority
- They may not see themselves as a child
- Use facts and not opinions to explain the importance of things
- "De-personalise" rules and explain some are out of your control
- Empathise that some rules are "annoying"
- Validate their response



25

Empathise and Validate

- There may be days when you are sworn at, hit, or ignored.
- Remember this is coming from a place of anxiety
- Reactions are in direct correlation with feelings
- We cannot punish individuals for being anxious
- Empathise with how the individual is feeling
- Remember there is always a trigger
- VALIDATE their emotions



26

Avoid.....

- Calm down
- It's not that bad
- You will be fine
- Don't overreact
- Stop stressing
- You were fine last time
- You will be fine when you get there



27

Remember the NEED behind the behaviour

- An individual displaying anxiety related behaviour may be seeking trust.
- An individual displaying "Attention Seeking" behaviour may be seeking connection.
- An individual displaying demand avoidant behaviour will be seeking control.
- An individual displaying aggressive behaviour may be seeking space.

28

Choose your words carefully – but never use to "trick" an individual into conforming

Instead of "Sit down" – "Where would you like to sit?"

Instead of "Start your work" - "Would you like to work with me or have a go on your own?"

Instead of "Stop talking" - "I wonder if we can work on this quietly for a few minutes?"

Instead of "Line up now please" - "Would you like to stand at the back of the line or near the front?"

Instead of "It's time to start your work now" – "Which task would you like to start on?"

Instead of "Let's all turn to page 7" – "Shall I find page 7 or can you?"

Instead of "We need to go to assembly now" - "Would you like to go to assembly or would you prefer to stay and help me in the classroom today?"

29

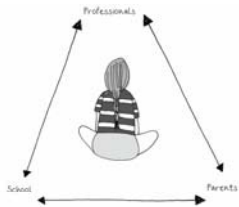
The Importance of Self Care

- Thinking on your feet, having your ideas rejected, being ignored or being hurt can be exhausting
- It is essential that you take care of yourself
- Your emotional regulation is essential in supporting an individual with PDA
- Take time out when you need it -for both of you
- Remember it is OK to make mistakes if you learn from them
- Talk about and share the things you are finding hard
- Don't be afraid to admit you are struggling
- Support each other (at home and in schools)

30

The Importance of Collaboration

- Everyone has their own area of expertise; teachers are experts in education, therapists and psychologists etc are experts in their chosen field, and it is essential we recognise that parents are the experts in their own children.
- Regular communication is essential
- Individuals with PDA should be included in decisions where possible
- The individual with PDA should be at the heart of all decisions relating to their care and education



31

Positive about PDA!!

- Sophie – Diagnosed with Autism when 8
- Severe mental health issues
- Violent and aggressive at home
- Parents “discovered” PDA at 14
- School was tough
- Opted for a “different path” to peers
- Recently awarded “Highly Commended Apprentice” at London Business Awards

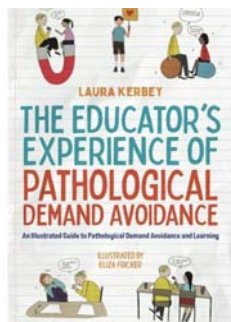


32



Thank you for Listening!

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33
