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PDA: Rethinking What We Know, What We Assume, and How We Help

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Hello! I'm Sandhya Menon. (she/her)

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  What's Up Flip Chart, The Brain Forest, The Rainbow Brain, My Body's Power Pack

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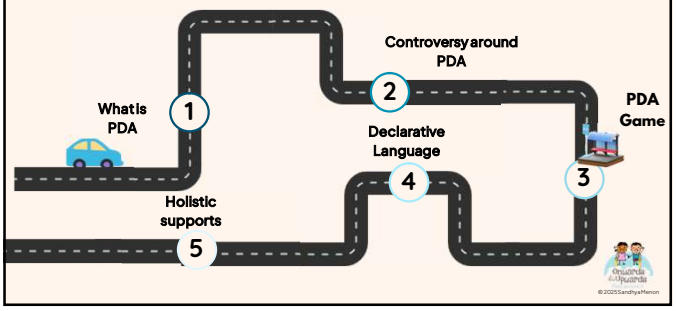
Our Journey Today



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What is PDA?

- **Pathological Demand Avoidance**
- **Not recognised by DSM-5 TR or ICD-10, but recognised in National Autism Strategy**
- **Other names are Rational Demand Avoidance, Extreme Demand Avoidance or Persistent Drive for Autonomy.**

Pathological Demand Avoidance	Pathological Demand Avoidance, or Persistent Drive for Autonomy (PDA), is considered a profile or subtype of autism. It is characterised by an extreme need for control and autonomy driven by high levels of anxiety or an automatic nervous system threat response, which results in demand avoidance, emotional regulation difficulties and a heightened reaction to stress. Although PDA is not captured within the current DSM5-TR, the PDA Society United Kingdom have developed guidelines to identify a PDA profile.[23] PDA is considered significantly impactful.

Department of Social Services. (2025). National autism strategy 2025-2031. Australian Government.

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45.8 Practitioners should consider all plausible explanations for a client's behaviour when establishing their strengths and support needs, as well as considering diagnostic characteristics. For example:

- A client may be engaging in behaviours that harm themselves, others, and/or property. Practitioners should consider the nature and possible functions of behaviour (e.g., what the client may be communicating through the behaviour), as well as individual and environmental factors that influence and maintain the behaviour. Consideration should also be given to aspects of the client's health and wellbeing, including medical conditions, that may cause and/or contribute to the behaviour (e.g., a child hitting their head due to earache, unrecognised constipation).
- A client may avoid demands and expectations in everyday life to an extreme extent. Rather than being viewed as the client being oppositional or defiant, practitioners should consider whether the behaviours are instead driven by an anxiety-based need to be in control. *Pathological (or extreme) demand avoidance* refers to a set of characteristics that can co-occur with autism and is recognised as a behavioural profile within autism. This profile is also referred to as *persistent drive for autonomy*, emphasising the function the behaviours serve.

Autism CRC (2023) National Guideline for the Assessment and Diagnosis of Autism in Australia. Retrieved from https://www.autismcrc.com.au/best-practice/assessment-and-diagnosis/recommendations/guiding-principles

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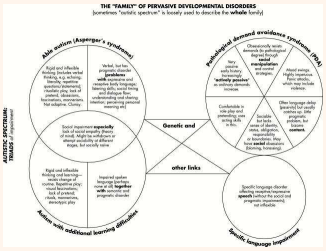
Origins of PDA



Research into PDA first started in the 1980s with Elizabeth Newson.

In 2003, in the first paper known to be published on PDA, Newson called PDA a necessary distinction, knowing that PDAers would often fail to be identified as Autistic.

In 2013, PDD-NOS became absorbed into the Autism Spectrum.

Newson, E., Le Marechal, K. & David, C. (2003). Pathological demand avoidance syndrome: A necessary distinction within the pervasive developmental disorders. Archives of Disease in Childhood, 88(7), 595–600.

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Recognising PDA

"Official" Traits

Table 5. Characteristics of PDA (Newson et al., 2003).

1.	Passive early history in first year.
2.	Continues to resist and avoid ordinary demands of life; strategies of avoidance are essentially socially manipulative.
3.	Surface sociability, but apparent lack of sense of social identity, pride, or shame.
4.	Lability of mood, impulsive, led by need to control.
5.	Comfortable in role play and pretending.
6.	Language delay, seems result of passivity.
7.	Obsessive behaviour.
8.	Neurological involvement.

Newson, E., Le Marechal, K., & David, C. (2003). Pathological demand avoidance syndrome: A necessary distinction within the pervasive developmental disorders. Archives of Disease in Childhood, 88(7), 595–600.

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Recognising PDA

Externalised	Internalised
externalising resistance of demands e.g. yelling, talking back, running away	internalising resistance of demands e.g. quiet refusal, can't do it if someone has asked, excuses – "My legs don't work!"

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What we don't know

Is PDA part of the Autism spectrum, or is it a stand alone neurotype that co-occurs frequently?

Is PDA anxiety-driven, or is it anxiety resultant?

What is PDA?

The term PDA stands for **Pathological Demand Avoidance**. This is widely understood to be a profile found within some autistic people. The most obvious characteristic of PDA is a determined avoidance of so-called "common" demands of life, including expectations and things the person enjoys doing.

This avoidance is often driven by **anxiety** or a **stress** response to demands, rather than choice.

PDAers may describe it as a tug of war between **brain, heart and body.**

What do well supported PDAers look like, and how can we support them before distress hits?

	Range	5–18	4–18	4–16	
Parent reported level of cognitive ability	Above average	21 (37%)	42 (46%)	28 (49%)	χ
	Average	22 (35%)	30 (33%)	18 (32%)	
	Mild or moderate intellectual disability	12 (19%)	15 (16%)	11 (19%)	

What does PDA look like across the cognitive abilities spectrum?

PDA Society. Identifying PDA. As retrieved from https://www.pdasociety.org.uk/wp-content/uploads/2025/06/What-is-PDA-updated.pdf

Truman, C. Crane, L., Howlin, P. & Pellicano, E. (2024) The educational experiences of autistic children with and without extreme demand avoidance behaviours, International Journal of Inclusive Education, 28:1, 57–77. DOI: 10.1080/13603116.2021.1916108

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Subject of Controversy

- **poor inter-rater reliability**
- **reluctance to diagnose amongst clinicians due to lack of certainty**
- **Researchers disagree on the origins of PDA – some believe it is manifestation of an illness (perhaps PANS/PANDAS conflation)(Kamp-Becker, 2024), some believe it is anxiety (Stuart et al, 2019)**
- **Very few studies have actually asked PDAers about their internal experiences**

families have said viewing their child through a PDA lens has been hugely helpful. Is this not practice-based evidence?

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Effective professional support for "children with PDA" and their families

Making sure to…
• Listen to parents from a no-blame perspective
• Be willing to learn more about PDA
• Allow families to build relationships and receive continuity of care
Staying outcome-focused by…
• Carrying out comprehensive assessment of children's needs
• Communicating our formulations clearly
• Offering direct interventions to improve children's day-to-day lives
• Giving practical strategies and advice to help family life run more smoothly
• Keeping the wellbeing of the whole family in focus
Opening doors by…
• Supporting families to obtain a diagnosis with reflects their child's needs
• Helping families to navigate the special educational needs system
• Referring to and liaising with other services which can meet families' health and care needs

Johnson, F. (2024). "There's some controversy around it": An exploration of Educational Psychologists' perspectives on pathological demand avoidance [Doctoral dissertation, University of Essex]. University of Essex Repository.

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Why recognise PDA if it's not in our manuals?

- Utility of recognising an individual as PDAer
- Ethical principle of Do No Harm
- Harm can be done by traditional autistic strategies (Iatrogenic harm)
- Functional understanding, not just a label
- Changes the support lens → harm reduction approach
- Backed by lived experience and growing amount of research

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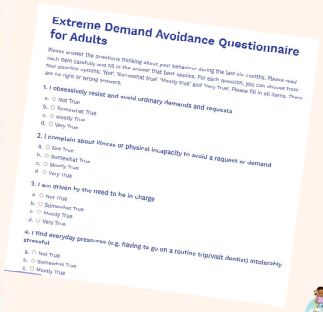
Measuring PDA

To date, we have the EDA-Q, which has a child, adolescent, caregiver reported and adult questionnaire too.



Extreme Demand Avoidance Questionnaire for Adults

Please answer the questions thinking about your behaviour during the last six months. Please read each item carefully and tick in the answer that best applies. For each question, you can choose from four possible options: 'Not', 'Somewhat true', 'Mostly true' and 'Very True'. Please fill in all items. There are no right or wrong answers.

1. I obsessively resist and avoid ordinary demands and requests
   a. ○ Not True
   b. ○ Somewhat True
   c. ○ Mostly True
   d. ○ Very True
2. I complain about illness or physical incapacity to avoid a request or demand
   a. ○ Not True
   b. ○ Somewhat True
   c. ○ Mostly True
   d. ○ Very True
3. I am driven by the need to be in charge
   a. ○ Not true
   b. ○ Somewhat True
   c. ○ Mostly True
   d. ○ Very True
4. I find everyday pressures (e.g. having to go on a routine trip/visit dentist) intolerably stressful
   a. ○ Not True
   b. ○ Somewhat True
   c. ○ Mostly True

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Can we think of PDA as more pervasive than simply demand avoidance?

PDA informs the way I move in the world. The intensity of my experiences may fluctuate over time, but remain consistent.

Is demand avoidance a symptom, with the trait being high neuroceptive or demand sensitivity?

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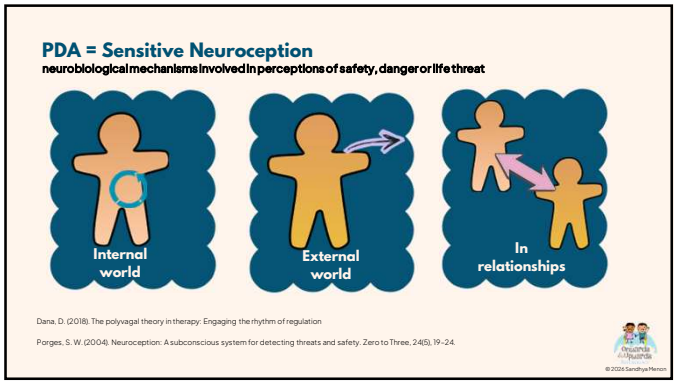
PDA = Sensitive Neuroception
neurobiological mechanisms involved in perceptions of safety, danger or life threat
Internal world
External world
In relationships
Dana, D. (2018). The polyvagal theory in therapy: Engaging the rhythm of regulation
Porges, S. W. (2004). Neuroception: A subconscious system for detecting threats and safety. Zero to Three, 24(5), 19-24.
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What's behind the demand avoidance?
fear of unknown
sensory challenges
loss of autonomy
perfectionism
executive functioning
low capacity
distrust

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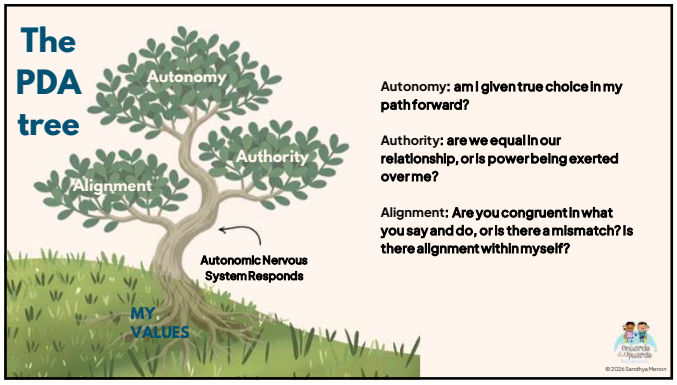
The PDA tree
Autonomy
Authority
Alignment
Autonomic Nervous System Responds
MY VALUES
Autonomy: am I given true choice in my path forward?
Authority: are we equal in our relationship, or is power being exerted over me?
Alignment: Are you congruent in what you say and do, or is there a mismatch? Is there alignment within myself?
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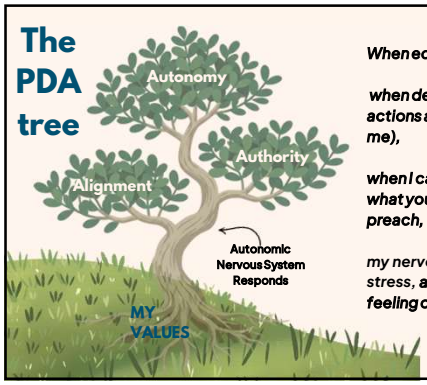
The PDA tree



When equality isn't there,

when demands on my behaviour and actions are placed on me (even by me),

when I can sense that you don't say what you mean, or practice what you preach,

my nervous system responds with stress, and can have a resultant feeling of anxiety.

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So what we know about the PDA profile is.....

It's currently considered to be part of the Autism spectrum, but there is emerging discussion that explores this as a standalone neurotype.

It requires its own set of strategies apart from the usual Autism-specific ones (e.g. increased predictability is helpful, but is it a demand for the PDAer?)

It has face validity and is genuinely helpful for families to be aware of the label

There is a high proportion of kids who are unable to attend traditional schooling who are PDAers, but equally important to look out for internalised presentations of PDA.

Now, how do we help?

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But first, let's play a PDA game.

P beats D
D beats A
A beats P

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Supports for PDAers

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Traditional Strategies for PDA

A low demand approach for supporting people with Pathological Demand Avoidance (PDA)—is a neurodiversity-affirming way to reduce anxiety and increase autonomy by minimising perceived pressure in day-to-day interactions.

Support strategies for parents

Parental reports[3] suggest that traditional parenting strategies involving clear, unequivocal boundaries and contingency-based reward systems imposed on the child often do not work. Some parents reported that following advice given during parenting courses had actually made their child's difficulties worse. What appears more effective is a low demand, low arousal approach, which tries to avoid strengthening habitual patterns of avoidance and

O'Nions E, Eaton J. Extreme "pathological" demand avoidance: an overview. Paediatr Child Health. 2020;30(12):411–5. 10.1016/j.paed.2020.09.002.

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Declarative Language can also be extremely helpful.

Declarative Language for The Classroom

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Declarative vs Imperative Language

Imperative
A command or direct instruction—tells someone what to do

Whilst helpful for Autistics, PDAers perceive imperative language as threats to their autonomy. Nervous system registers this as real threat.

Declarative
A statement, comment, or shared observation—invites thinking or collaboration.
Does not require the person to do anything.

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Declarative	Imperative
You need to brush your teeth now.	I wonder if your teeth are ready for minty goodness!
Put your shoes on, we're headed out.	Your shoes are by the door. We'll head out once they're on.
You've got to do the laundry so you have clean clothes.	Today the Laundry Dragon awaits for a brave knight to defeat her!

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Buuuuut....

Low demand is a nervous system approach.

Declarative language requires true choice at its centre.

It necessitates a change in beliefs *behind* the use of 'strategies'

It requires us to rethink our expectations around compliance and the 'must have's' for success and re-prioritise autonomy and safety.

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Shifting Questions

Reduced demand does not mean removing expectations, avoiding learning, or letting students do whatever they want. It means changing the pathway into participation so the student can access learning without unnecessary pressure, threat or loss of autonomy.

How do we make them do this?

How do we make this feel safe?"

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PDA = Sensitive Neuroception

neurobiological mechanisms involved in perceptions of safety, danger or life threat

Dana, D. (2018). The polyvagal theory in therapy: Engaging the rhythm of regulation

Porges, S. W. (2004). Neuroception: A subconscious system for detecting threats and safety. Zero to Three, 24(5), 19-24.

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What demands can look like

- Transitions
- Choices
- Expectations
- Instructions
- Authority

- Help
- Praise
- Pity
- Being perceived
- Social expectations

- Hunger
- Emotions
- Fatigue
- Thirst
- Decision making
- Desire to pursue goals

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Recognising demands

- **Internal demands**: "I should do better"; "I should be finishing this in time"
- **External Demands**: "You have 5 minutes"; "Get ready for school"
- **Relational Demands**: "You should look them in the eye when you say thank you"; "You should wear skirts and long hair"; Being polite and cheerful ;"You should be pleased when you get a present"; "You should have fun when you're in a fun place"

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What's behind the resistance?

- "No" may communicate threat, overwhelm, uncertainty, loss of autonomy, or lack of trust
- Negotiation may be an attempt to regain agency
- Silence may be a protective communication strategy
- Humour, distraction, fantasy, or role play may be regulation and avoidance at the same time
- Shutdown or selective mutism may indicate the communication system is overloaded

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A speechie's job is not first to improve communication output.

It is to improve communication safety and build bridges between nervous systems.

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Behaviourist assumptions PDA asks us to rethink

Avoidance is defiance	Avoidance may be a nervous system response to threat, pressure, uncertainty or loss of autonomy.
Compliance equals success	A student may comply while masking, panicking or exhausting themselves. Doing the task does not always mean the support worked.
The adult must stay in control of the situation	High control can increase threat. Sharing control can reduce resistance and make participation feel safer.

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Behaviourist assumptions PDA asks us to rethink

Rewards and consequences are neutral	Rewards, charts and consequences can add pressure, performance expectations or shame, even when intended positively.
The behaviour is the problem	Behaviour is often the visible signal of an unmet need, inaccessible environment or demand that feels too big.
Students need to build tolerance to demands	PDA friendly support reduces unnecessary demands so students have more capacity for learning, connection and regulation.

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Assessment with PDAers

- **Direct testing may create performance threat**
- **Rapport may need to come before data collection**
- **Standardised assessment may underestimate capacity under demand**
- **Refusal, humour, distraction, silence, or "silly" answers may be demand responses, not lack of skill**
- **Observation across contexts may be more informative than one pressured session**
- **Offer indirect participation, breaks, choice, movement, co-created tasks, and nonverbal response options**

Are the conditions right/necessary?
How do I create safe assessment spaces?
How do I report on data collected?

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What are we measuring if not compliance?

- increased felt safety
- increased communicative autonomy
- more flexible access to participation
- access to education
- reduced distress around communication demands
- increased ability to self-advocate
- improved repair after rupture
- more successful engagement across contexts
- increased capacity and trust
- reduced reliance on crisis-level avoidance

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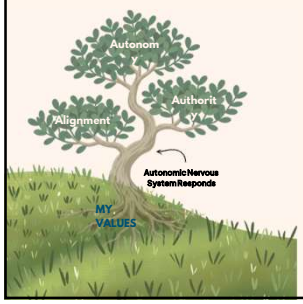
The PDA tree



Autonomy:

Where are the spaces where I don't get choice?

Is it obvious, hidden, relational, internal, sensory, social, emotional, or performance-based?

How can autonomy be restored? Choice, timing, method, role, exit option, collaborative planning, private participation?

How is control shared, especially in childhood? What does true choice look like?

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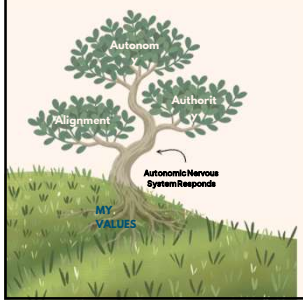
The PDA tree



Authority:

How is authority being perceived? Is it through tone of voice, through dress, through power, through praise and hierarchy, through achievement?

How is equalising behaviour showing up?

How do we reduce the power imbalance?

(consider: humour, Gen Z slang, dress, mannerisms etc)

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Equalising Behaviour

An attempt to level the power dynamic and equalise the power differential

Child responds by refusing to comply

SLP tells child to do something

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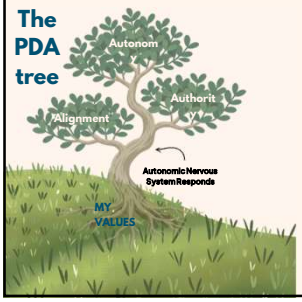
The PDA tree



Alignment:

Are adults congruent with what they say and do?

e.g. Do they promise something, but not deliver?

Are they telling me to trust them, but also keeping things from me?

(It's not just kindness and tone of voice, PDAers can sense a mismatch a mile away)

Are they masking, or trying on "a strategy" for control?

Do I know my values and am I acting in line with that?

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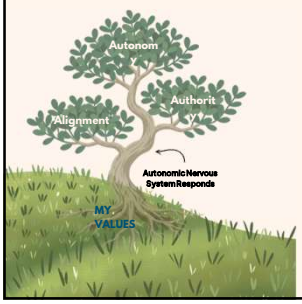
How is the Autonomic Nervous System responding?



- What is the student showing through refusal, negotiation, humour, shutdown, silence, aggression, or avoidance?
- How does anxiety and trauma show up, and why? When are they accurate responders to a situation, and when are they over-exaggerating a threat?
- Where does the nervous system feel safe, and with who? What are the factors that influence this level of safety?
- How do we reduce the threat - Language pressure, time pressure, audience, adult proximity, direct instruction, number of steps, uncertainty?

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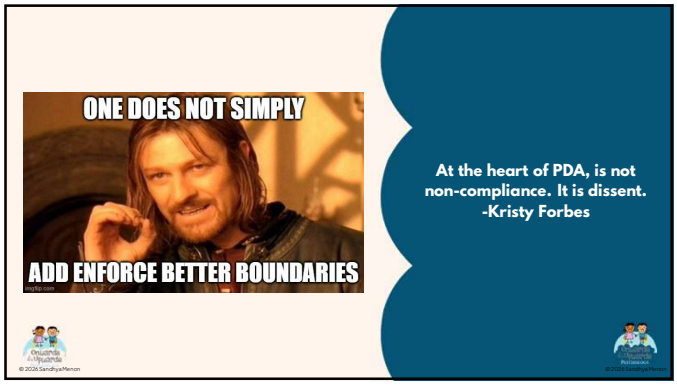
ONE DOES NOT SIMPLY
ADD ENFORCE BETTER BOUNDARIES
At the heart of PDA, is not non-compliance. It is dissent.
-Kristy Forbes

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PDA requires us to re-examine the degree of compliance we expect in children.
Not just about declarative language or learning to shift what we say, it's not about a strategy, it's about..... an entire paradigm shift in the way we view childhood and raising humans.
How do we come into relationship as equals and balance the power dynamic?

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Thank you for your attention!
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