



Supporting a Profile of Extreme, or
Pathological, Demand Avoidance



Aims & Learning Outcomes

To enable participants extend their knowledge and understanding of the different profiles of demand avoidance, and to further explore the nature of support necessary in a learning environment

- To understand the impact of (P)DA on a *CYP's capacity* to access school and engage with learning
- To explore a *supportive 'approach' model* when teaching a Child/Young Person with a DA profile



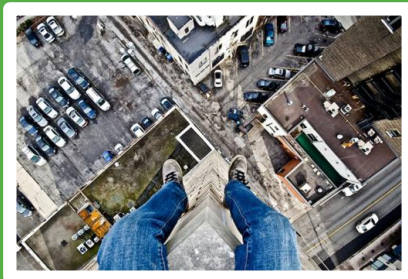
What is Demand Avoidance?

'Regular' DA!

Demand avoidance is a natural human trait - avoiding demands is something we all do to different degrees and for different reasons.

It involves *not wanting, or being able,* to do certain things at certain times, either for yourself or for others.

It can also refer to the things we do in order to avoid demands.





What is PDA?

PDA, or Pathological Demand Avoidance, is currently understood as a profile on the autism spectrum which is characterised by a fear response to demands.

PDA isn't an independent diagnosis, but it can be identified as part of an autism assessment to indicate the most helpful support approaches.

**PDA
IN OUR
WORDS**



The Power of 'words'!

Pathological Demand Avoidance

Persistent Drive for Autonomy

Thoughts?? Please share



Types of 'Avoidance'

PDA Profile in Autism

Resistance to everyday demands due to ***anxiety-driven need for control***: Individuals avoid everyday demands, including tasks that they enjoy, due to very powerful underlying anxiety that may or may not be within their awareness. The anxiety is driven by their perception that by following a request, they are losing control of their life/environment.

When calm, the person often shows insight, remorse and regret but does not see that they had any other choice. Impulsive behaviours, FFF

Oppositional Defiant Disorder (ODD)

ODD is a ***behavioural disorder*** marked by a 'persistent pattern of angry/irritable mood, argumentative/defiant behaviour, and vindictiveness' - often at authority figures.

When calm, the person continues to blame others, show defiance and does not recognise their own role in the problems that occur with others.



Types of Avoidance

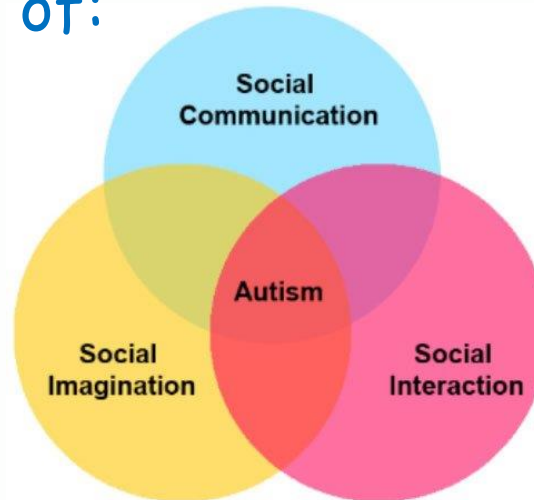
- Demand avoidance (DA) - This is a natural human trait, avoiding demands of something we don't want to do or feel able of doing at different times and in different circumstances.
- Extreme Demand Avoidance (EDA) - This is often a persistent and marked resistance to demands, it can impact on essential areas, triggered by anxiety and may be used to avoid sensory overload.
- Profile of Demand Avoidance (PDA) - This is a persistent and marked resistance to everyday demands, spoken, written *or perceived*, including activities that a person with this profile enjoys.



Autism Spectrum

PDA is considered a profile on the Autistic Spectrum. Individuals with PDA share the same differences with others on the spectrum in aspects of:

- Social Communication
- Social Interaction
- Processing & Flexibility



National
Autistic
Society

However the central *difficulty* for people with PDA is the way they are driven to avoid demands and expectations...because they have an *anxiety-based* need to be in control



PDA - Historical Context

Based on the work of Elizabeth Newson, who was a Professor at the *Child Development Centre* at the *University of Nottingham* and then worked at the *Early Years Centre* at *Sutherland House School*

About 35 years ago she noticed that some children *did not fit* the then defining criteria for *Autism* or *Asperger Syndrome*

She wrote a paper describing the characteristics that set these children apart

A key characteristic, *but not the only feature*, was described as the - **'need to avoid demands to a pathological degree'**



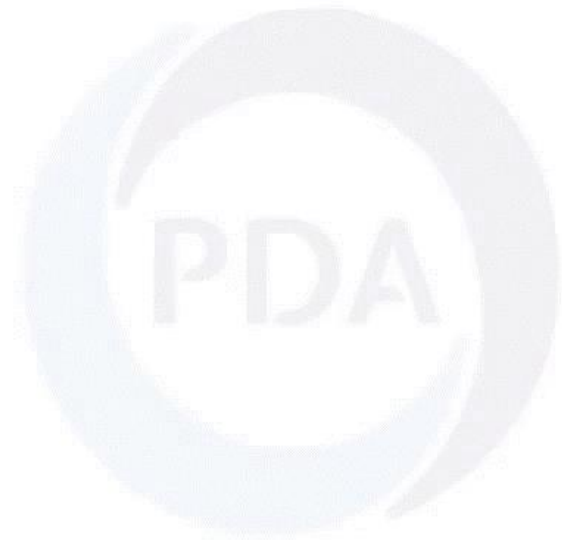


Defining characteristic

- Passive early history
- Resists and avoids ordinary demands of life
- Surface sociability
- Lability of mood
- 'Obsessive' behaviour

- Comfortable in role play and pretending
- Different sense of identity







Anxiety is a chemical response

- Chemicals are released by brain (from amygdala, 'worry alarm')
- Adrenalin & other cortisol hormones flow to the internal organs, joints, muscles.
- **BIG** effect on how we feel and on our capacity

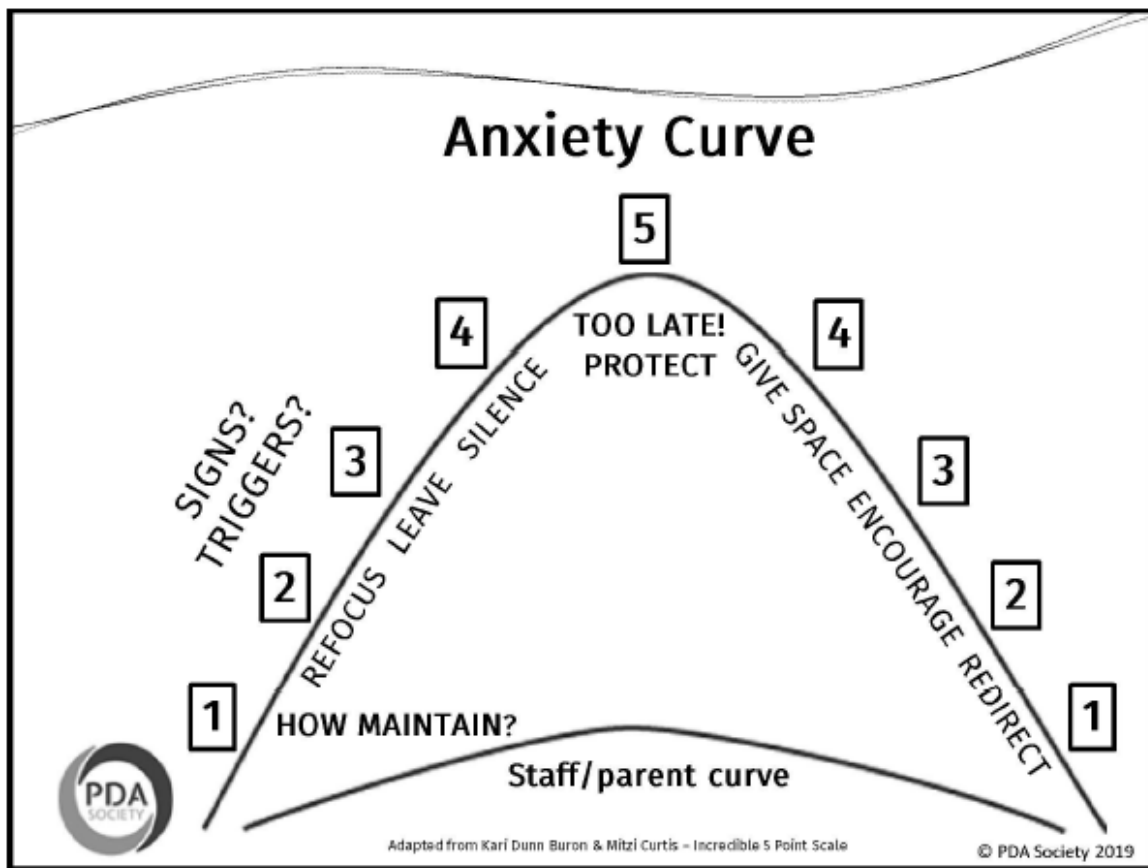
Anxiety affects:

- Concentration
- Listening
- Energy levels
- Sensory tolerance communication
- Appetite
- Cognitive processing
- Mood
- Tolerance levels



How is anxiety *different* for PDA?

- Heightened sensory awareness/high alert - not knowing how overwhelming these may be, can make it impossible to even try!
- Hyper awareness of the behaviour/responses of others
- Past memories and 'trauma' - past experiences that have not been positive
- Internal and External demands brings feelings of shame, embarrassment, failure. Anxiety about feeling these again - so inability to try
- How others treat you/perspective - 'bullying', dismissing (attitude has a huge impact - *not being believed!*)
- **School avoidance strategies will not work for PDA children**







Common ways of avoiding demands

DISTRACTION

- *'Look at that ...'*
- *'I'm tired'*
- *'I need the toilet'*
- *'I feel sick'*
- *'My pen won't work'*
- *'I can't, I'm busy....'*
- *'I'll do it later'*

BLOCKING

- *'Ignoring', no reply*
- *Hands over the ears*
- *Talking over the adult*
- *Leaving the room*
- *Hiding*
- *Pretending - to sleep*
- *Activity does not apply to them!*





Demands – a reminder

- **A direct demand** *‘Put your shoes on.’*
- **A subtle demand** *‘Shall we play on the Xbox or go on the trampoline’*
- **A silent demand** *Sleeping at a time that seems to fall in with when the rest of society sleeps*
- **A self-imposed demand** *Wanting to be clean and have a bath, or wanting to leave the house but being unable to comply with their own desires*



Effective teaching and everyday approaches



These young people are identified as very complex and it is a whole package of measures that makes the difference rather than isolating a few key issues or having a set of strategies.

There are no absolute or clear guidelines but a repertoire of approaches that can make a difference.

(Robert Ogden School)



Where to start ...

Autism + Environment = Outcome
(Luke Beardon)

Understand and remember that PDA is an anxiety driven need to be in control and to avoid other people's expectations, *inc. their own*

Create a collaborative, unified approach
Decide on your 'non-negotiables' then shrink all other demands right down!

Provide a highly individualised style of teaching - less directive and more intuitive than would be case with more typical Autism
Develop an informal, creative and non-directive 'teaching' style



Prioritising – think ‘Capacity’

Completing
adult-led task

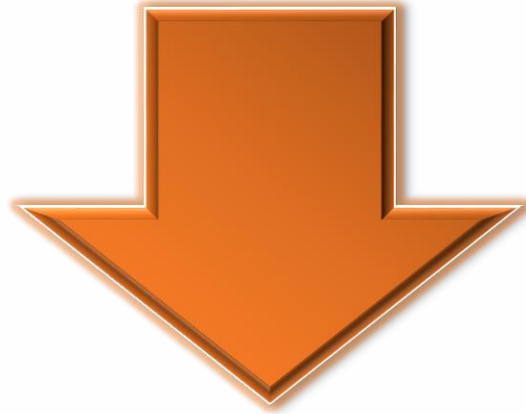
Joining an extra
curricular club

Not hurting self
or others

Wearing school
uniform

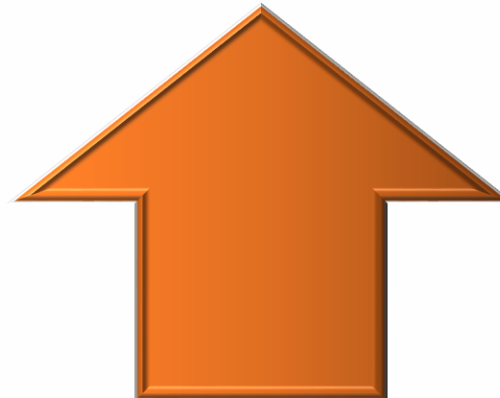
Categorise - *High / Medium / Low*

- High - legal rule, safety (more important than a school rule), depersonalises the rule setters. *Non-negotiables*
- Medium - optional: present in low demand way (*Capacity issue - if all energy is taken on staying safe!*)
- Low - Not important: can be left for now



Left completely alone
will become anxious
and will go off task

Too much supervision
or direction and s/he
will need to avoid



“A scenario I’ve used in the past is this: you and I are both given a bucket and someone keeps pouring in equal amounts of water (demands, anxiety . . .) into each bucket so consequently the buckets begin to fill up, the only difference is that your bucket has tiny holes in it so it never reaches the top and spills over unless the water in was to become greater than the water out. My bucket doesn’t have these holes and so can therefore only ever spill over so I must try and reduce the water in so it doesn’t overflow but at some point my bucket will be full and I will go into meltdown. That is a fact. It really is a daily balancing act. Some days are better than others.”

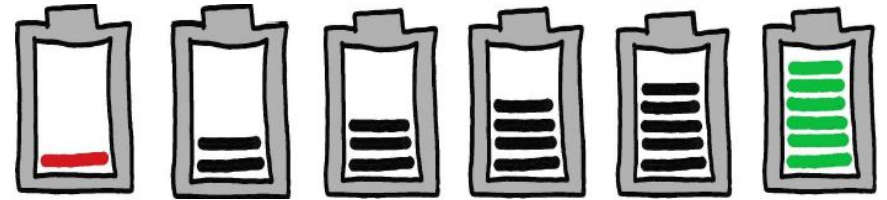
Julia Daunt - Energy Management











Energy Management

Julia Daunt continued ...



"...every day I must make choices on what 'demands' I can cope with. On a bad day that might mean even brushing my teeth is a demand too far. If I am having a bad day I just do what I can and I won't push myself because if I do, it will make matters worse. If I'm having a good day then I am able to push myself and I will have a fairly 'normal' day."

Energy Needed (Match for the activity)	My Energy (Where I am)
	Maxed Out : Frenzied His body and his engine move at 210+ MPH. Each time he does a race he makes one of the racers retire, but McQueen never retires!
	Amped Up : Fidgety His body moves at 200 MPH but he can slow down enough to communicate to others! He would always find a way to cheat in a race.
	Focused : Purposeful His body can go up to 198 MPH, but he's focused and knows how to get the job done! He gets it from his crew chief that isn't with him anymore the fabulous Hudson Hornet.
	Settled : Calm He goes up to 200 MPH, but rarely does. He likes to stay in control and enjoy the ride!
	Sleepy : Still His body only goes about 30 MPH. He often needs a cruise to get going!
	Super Tired This old rust bucket gets tired and just wants to rest, but sometimes he rests too much!

Autism Level UP! Energy Meter, copyright 2019 Cars Edition created by Jaco, October 2023

Autism Level UP! Energy Meter

Energy Accounting



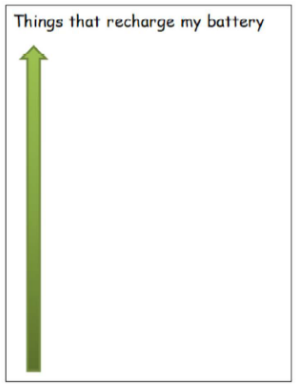
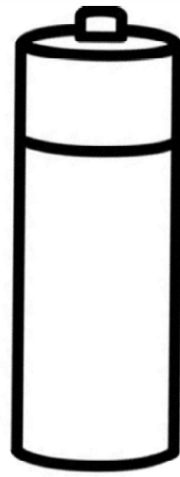
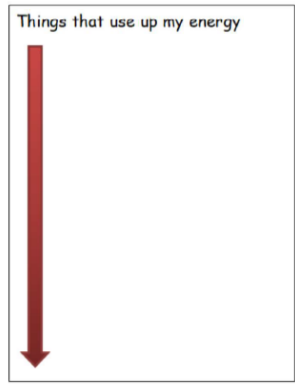
Too much energy out and not enough in is bad. It leads to overload, and exhaustion.



Balancing your energy using energy accounting is good. It leads to feeling regulated, calm and happy.



Social Spoons 	Language Spoons 
Physical Activity Spoons 	Sensory Spoons 
Executive Function Spoons 	My Spoon Drawer





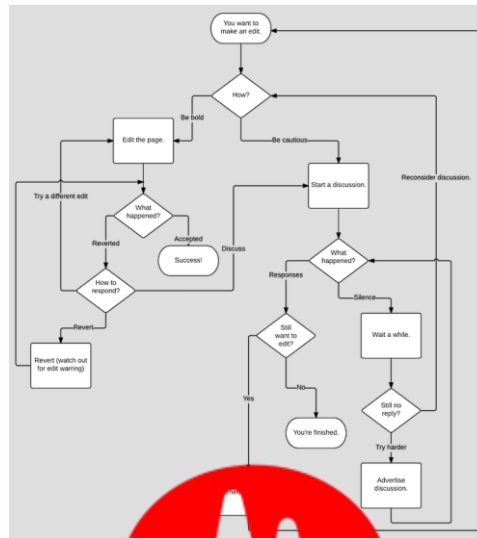
Be Consistently Flexible!

Personal, Safe
Space

Sensory regulation
resources

ZONES OF REGULATION!

Blue	Green	Yellow	Red
Sick Sad Tired Bored Moving Slowly	Happy Calm Good to Go Focused Ready to Learn	Frustrated Worried Silly/Wiggly Anxious Excited	Mad/Angry Mean Yelling/Hitting Out of Control I Need Time and Space

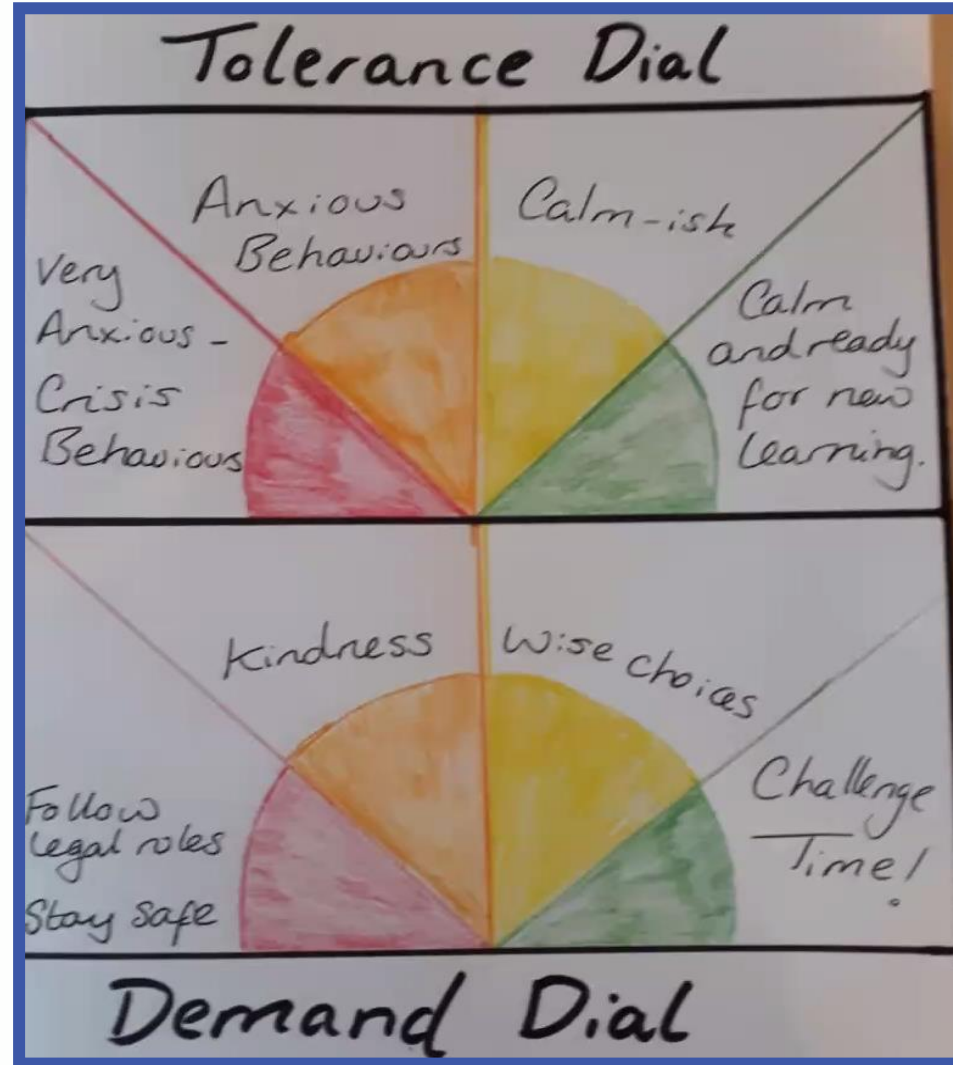
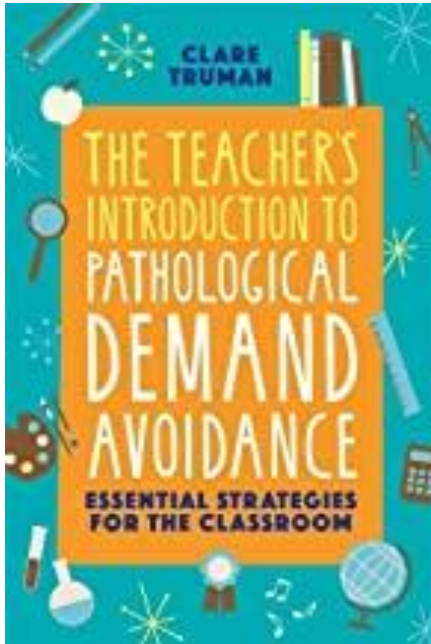


Provide structure and
routine BUT with
flexibility and autonomy

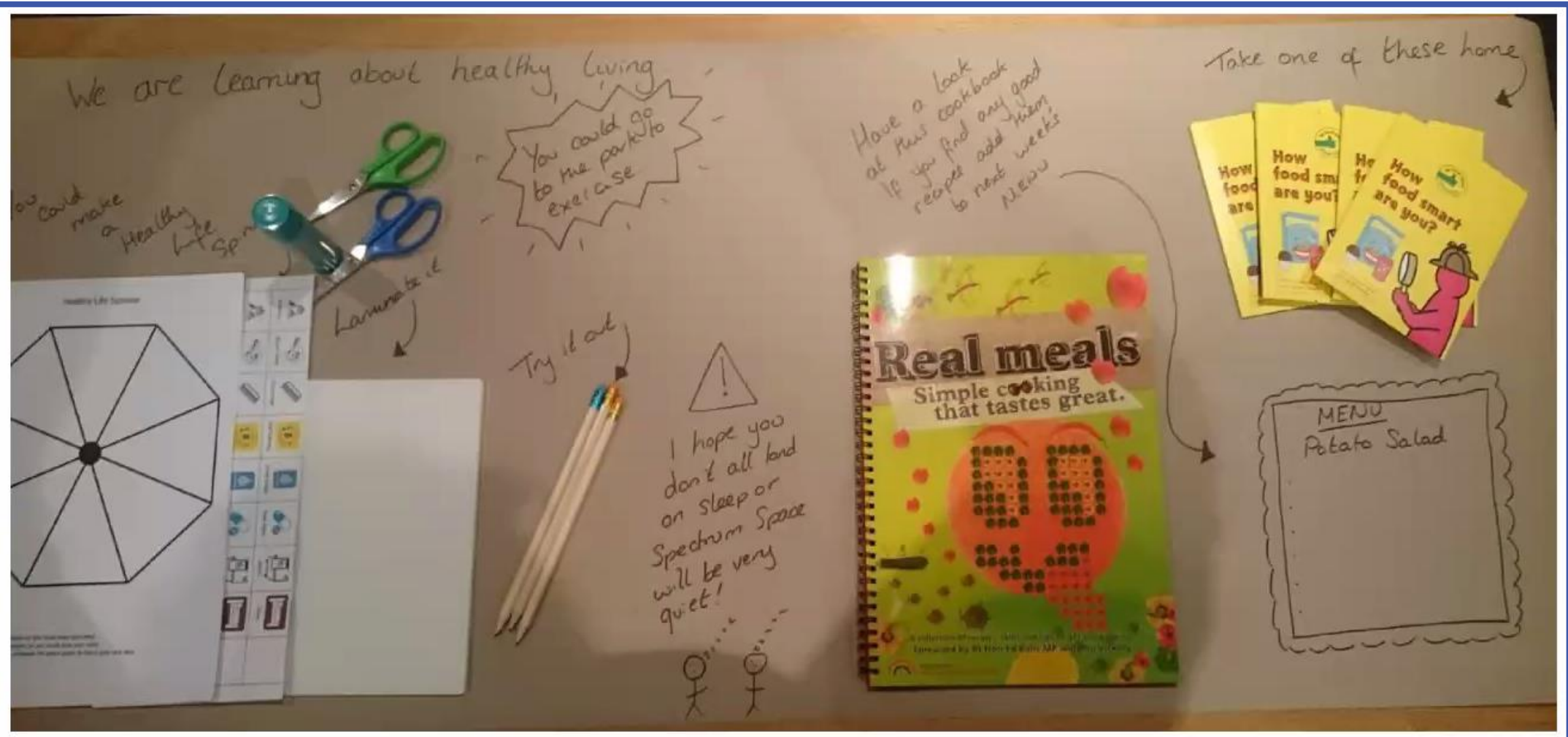
Responses need to be
consistent to build trust

Additional processing time
will ease anxiety and
increase capacity - 'No',
may not mean no! Just 'not
yet!'

Clare Truman -
*The Teacher's
Introduction to
PDA*



Invitation to learn table - Clare Truman





Making Indirect Demands

- Declarative language
- Depersonalise any expectations
- *Disguise* any expectations (e.g. problem solving)
- Ensure that the CYP *feel* they have a choice - including 'no' or 'later'
- Any options are relevant and meaningful to the CYP

Invite, not insist

Make appealing, fun, shared problem-solving, expertise





Indirect Affirmation

- Use indirect praise or affirmation
- Reframing what the CYP has done well in the hearing of their others/parents
- Acknowledge effort, not outcome
- Surprise rewards as a natural consequence of behaviour won't necessarily promote future compliance but will give a children a sense of well-being and feel-good factor.

Many children with PDA find direct praise difficult to process





What works best?

- Imperative language, triggers nervous system response - avoid questions
- Be careful not to single children out
- Indirect instructions
- Shape questions as comments (*I think that now would be a good time to ...*)
- Provide visual supports
- Flexibility of assignments
- Slow things down
- Assistant role - control & autonomy



Script ideas ...

Be aware of the child's behaviour as they become more unsettled, upset and/or overwhelmed

Use a neutral tone, stay calm, wondering 'out loud', use complex language, identify a safe place

Consider how to repair the situation / relationship

- How would it be if.....? Ooh, what happens if....?
- Would it be a good idea if we.....?
- I can't quite see how to....? How might we?
- Would it be possible to....?
- I really need some help with this.....
- What if.....?
- I wonder where that goes/if we could.....?
- I need to get this cleared up now because I have to
- Our next 'mission' is...?
- Where shall we.....?
- That might be easier to finish outside

Avoid

- ❖ You/We need ...
- ❖ Must/Must not ...
- ❖ Will/Will not
- ❖ By (a time/date)
- ❖ I want you to ...
- ❖ Lets ...



If something is optional it is more accessible than something presented as a must.

Making it 'no big deal', 'one way or the other' ... immediately stops it being demanding.

Choices



'Open' choices can be accessed on some occasions (when anxiety is low enough) -but be prepared and accept **No**, when you can

Saying 'please' does not lower, or remove the demand!



Take Aways

- Keyworker - needs to become an 'expert' on the pupil, Regular 'check ins'
- All support will be based upon a trusting, equal relationship
- Be *oblique* at all times - never direct; include body language & eye contact in this

- Learning outcomes need *disguising* - novelty is key! Addressed via special interests
- Exploit strengths e.g. role play. Enter the child's world - be prepared to play along
- Give time to process - follow their lead, flexibility

- Do not invest emotionally in a 'strategy' - be ready to change it rapidly
- Understand that this is a capacity, not a will issue

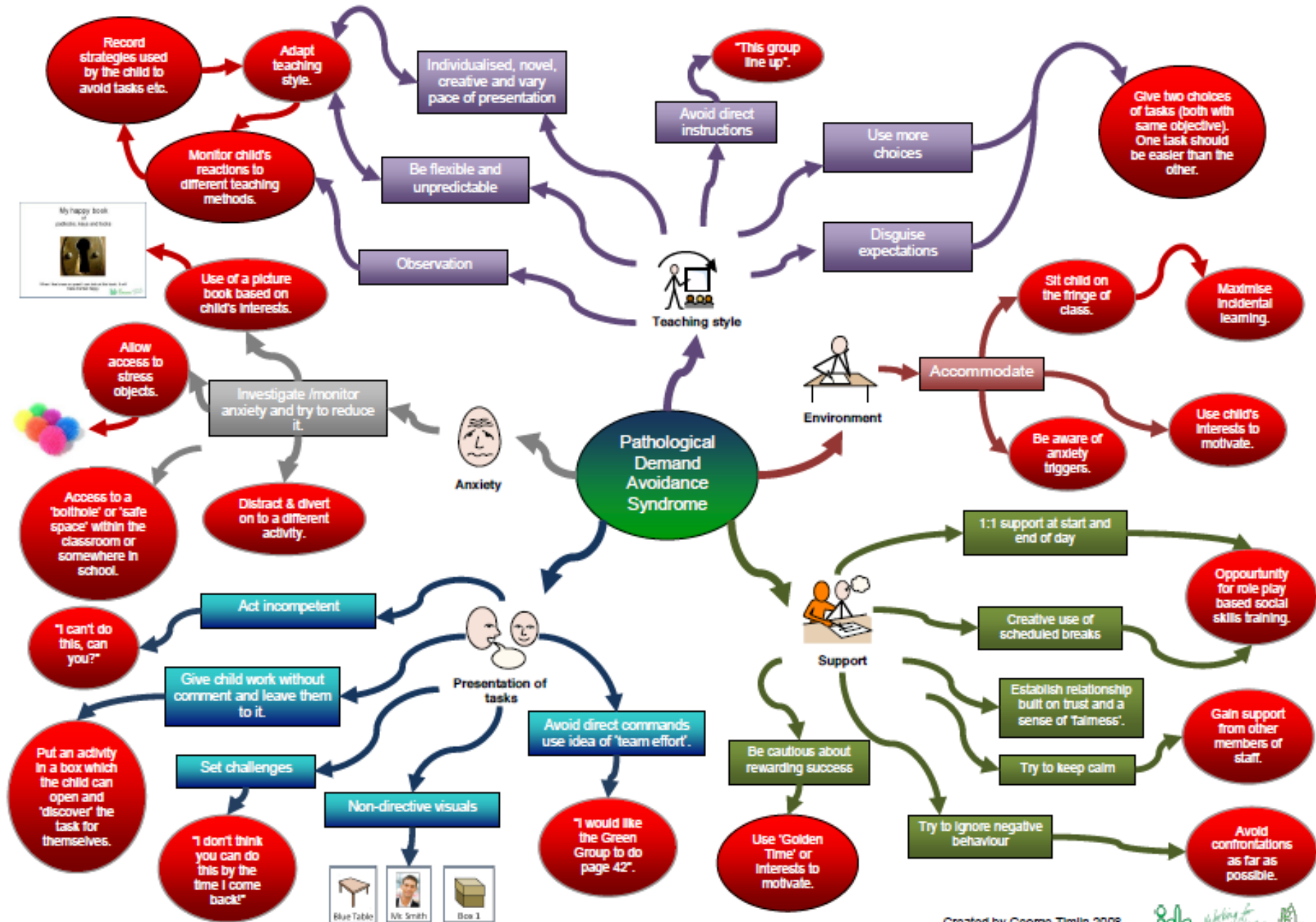


Keys to Care

Pathological Demand Avoidance (PDA) Profile of Autism

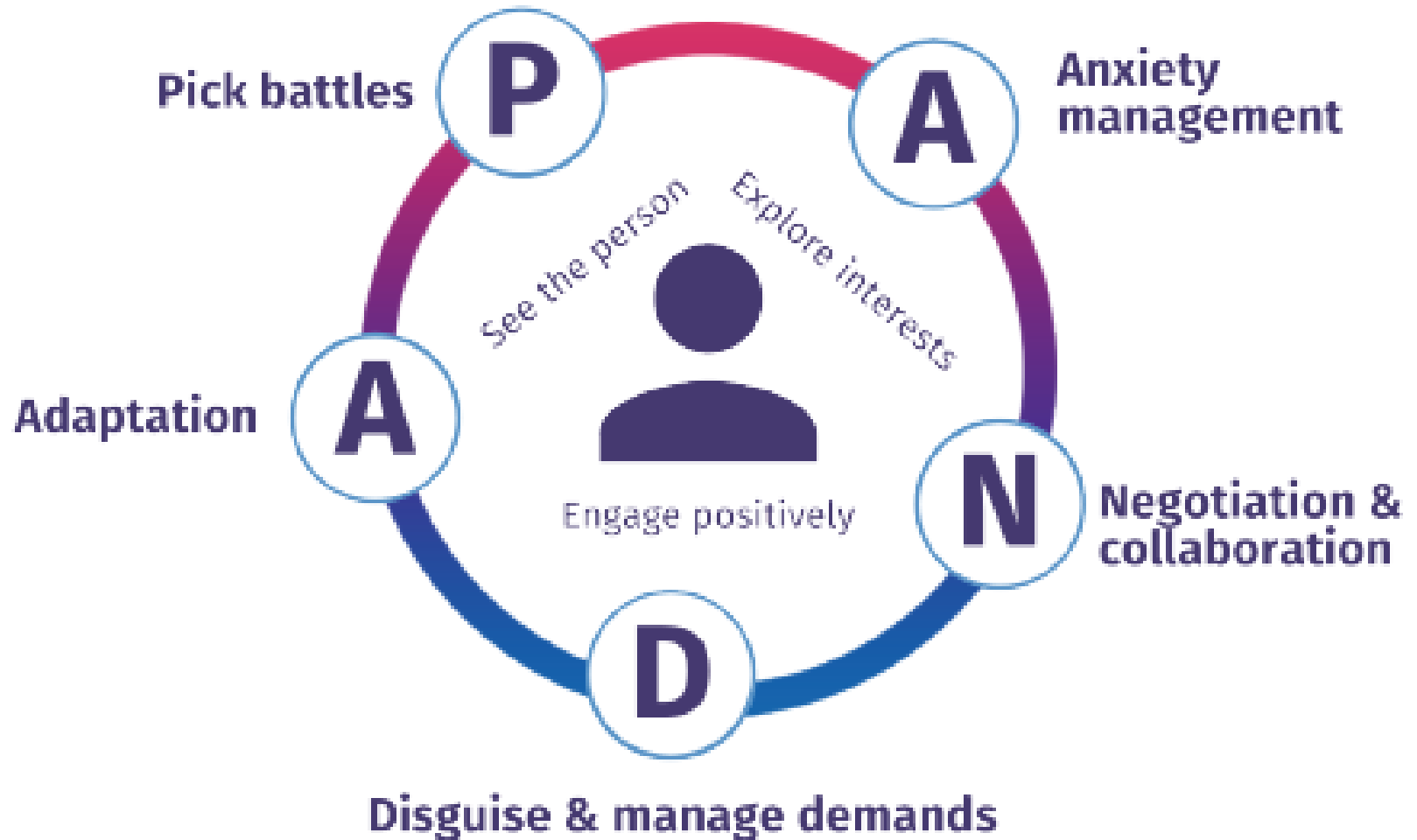
- ✓ The PDA profile turns care on its head and lack of understanding causes distress
- ✓ See the person, explore their interests and engage positively
- ✓ Approach PDA as you might caring for a panda – create the environment which will enable individuals to thrive
- ✓ Indirect ways of wording requests, or even silence, helps with completing tasks
- ✓ Sanctions and consequences (incl. rewards) do not work and make things worse
- ✓ Enable some control and choice, allow for negotiation
- ✓ Processing can take longer than expected: take and allow time
- ✓ Fairness and trust are central, if things change, be clear & honest about why
- ✓ Collaboration, flexibility, variety and humour all work well







PANDA is also a useful summary of helpful approaches for PDA.





Changing the narrative

Faye did not want to do the highlighting tasks as she said using highlighters in the magazine would ruin it. She ran out of the classroom and into the playground so we had to work with chalk on the ground instead. Faye refused to write anything down or even to try holding the chalk, so I had to do the writing. Faye got annoyed with me when I put the wrong punctuation at the end of the sentences and corrected it by telling me what I should have written instead

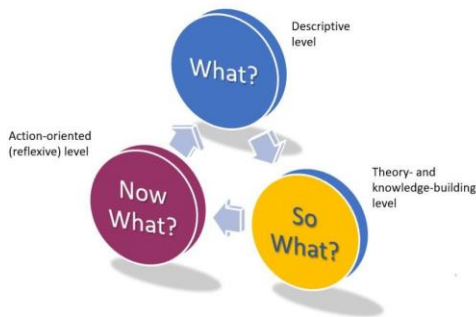
Working with chalk on the playground, Faye was able to correct the punctuation at the end of my sentences. She correctly identified when I needed to include a question mark, a full stop or a capital letter. She found it difficult to identify situations when I could have used an exclamation mark!



Reflective Practice

Reflective practice is considered to be the cornerstone of behaviour management strategies such as low arousal approaches (McDonnell, 2010).

Levels of reflection

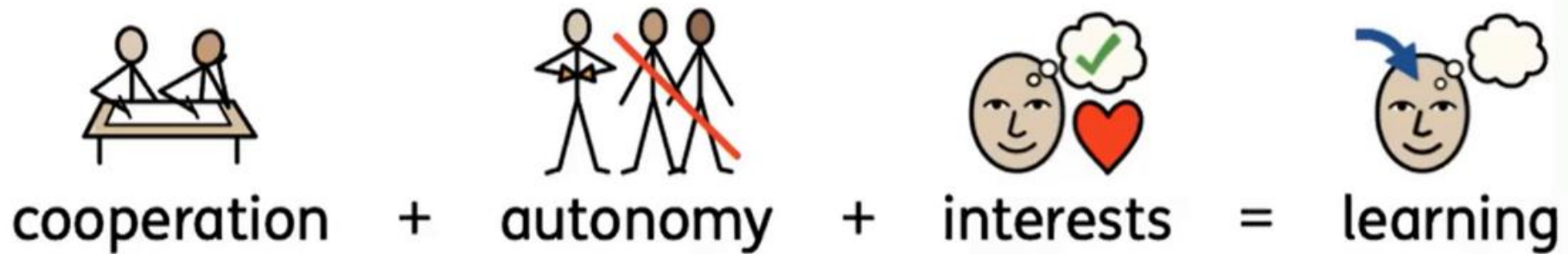


- ❖ *Should I stand by the boundaries set? If not, why not ?*
- ❖ *Are they realistic today ?*
- ❖ *Are they important enough to be non-negotiable?*
- ❖ *Did I over-react? If so, why?*
- ❖ *What did I do well?*
- ❖ *Are there any other approaches I wish I'd tried?*

Think outside of the box! - especially the 'cultural' box!



Helpful Approaches to support children with a PDA Profile



ReachOutASC - <https://reachoutasc.com/>

WHAT HAPPENS WHEN WE MEET NEEDS IN EDUCATION...

"In Year 10 I stopped going to school. There was no communication, you weren't valued as a human. It's a sickening environment to be in for anyone, but with PDA, I hated it. The craziest rules that didn't make any sense, but were all about power and authority and control.

But things got so much better when I started at the college I'm at now. They encourage students, and they don't look down on them or lash out and get angry with them for behavioural things. They recognise that students don't misbehave for no reason.

I've found that this low demand environment works really well and my attendance has improved a lot. Being accepted like that is a really nice feeling. I don't want to take it for granted because often the rest of the world is not like this."



PDA Society – PDA in our Words

(May 2024)



'Strengths' of a PDA Profile

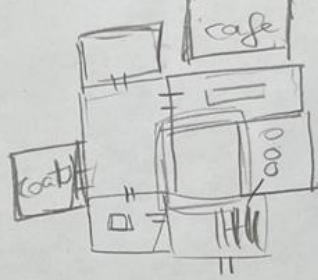
- Generates creativity
- Witty
- Problem solvers
- Put other people first, justice seekers, champions for the underdog
- Look at things in different ways
- Look/act beyond assumptions
- Explore other ways, challenge the norms - move society forward



Positive PDA



$$\begin{array}{l}
 1 \times 2 = 2 \checkmark \\
 2 \times 2 = 4 \checkmark \\
 3 \times 2 = 6 \checkmark \\
 4 \times 2 = 8 \checkmark \\
 5 \times 2 = 10 \checkmark \\
 6 \times 2 = 12 \checkmark \\
 7 \times 2 = 14 \checkmark \\
 8 \times 2 = 16 \checkmark \\
 9 \times 2 = 18 \checkmark \\
 10 \times 2 = 20 \checkmark
 \end{array}$$



Mrs Barnes has been a good today and she has and has not got stuck in her maths 🧮 in class today and she was very good at the maths game today and she was able to do it with a bit of help from me so I think she will get a dojo for the first week and then we will have dinner 🍔🍌🍕🍷