

EDA-PDA in school settings

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Autism Finland is a national expert and nongovernmental organization promoting the inclusion and equality of people with autism spectrum disorder and their close ones in society.

We support our member associations, influence in decision making, spread information on autism, launch projects, educate peer experts and experts by experience, and provide counselling and guidance.

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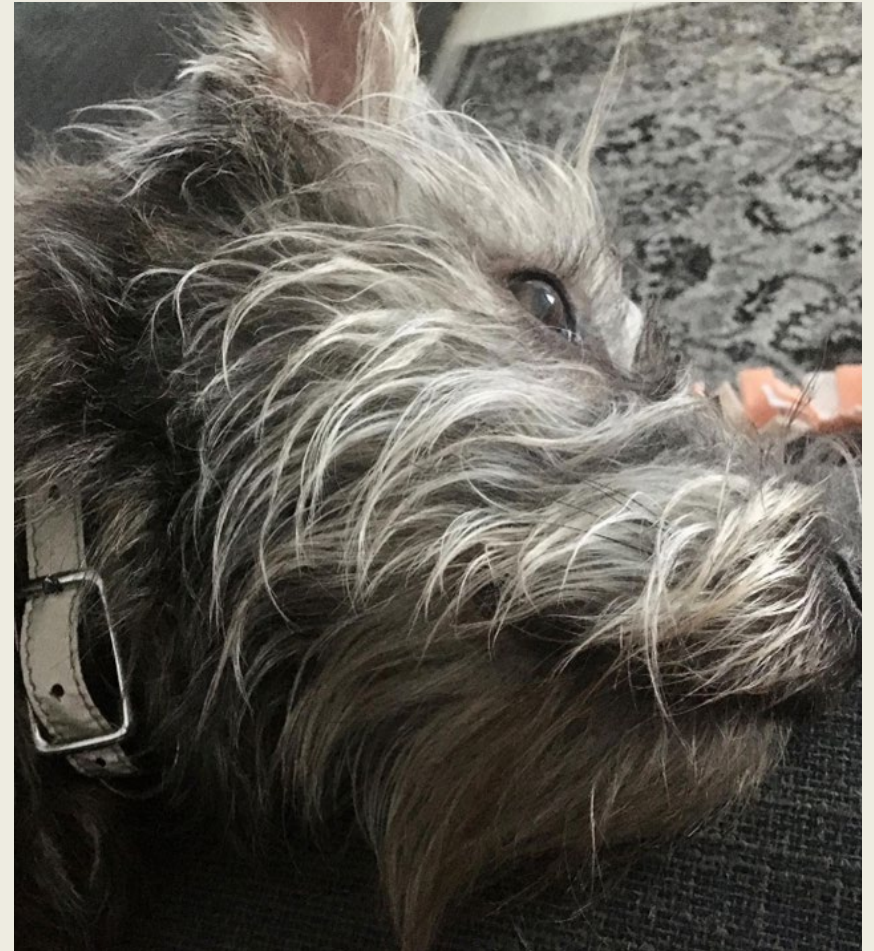


**AUTISMI-
LIITTO**

“I know I should, but I just can’t...”

Today:

1. How to recognise PDA in school settings?
2. Developmental and psychological factors
3. What adjustments to study environment and rules would help these children study better?
4. Practical suggestions for teachers and parents.
5. Challenges and solutions
6. Methods and approaches that help children feel safe.



What is EDA-PDA?

- Extrem sensitivity for everyday demands that can handicap everyday life.
- Demands can lead to a threat reaction, which can cause an individual to lock down.
- And even things that you genuinely want to do can feel like demands and lead to a lock down.
- It is anxiety-driven, related to stress, and this demand tolerance varies from moment to moment.
- EDA-PDA doesn't just involve demand sensitivity; it also includes other characteristics.

Extream Deamand Avoidance + Autism

A PDA profile of autism means that individuals share autistic characteristics:

Difficulties with social communication and social interaction and restricted and repetitive patterns of behavior, activities or interests.

Different sensory experience in relation to sight, smell, taste, touch, hearing, body movements, body awareness and interoception (e.g. hunger, thirst...)

PDA profile of autism can be **extrovert** where demand avoidance is very visible, or it may be **introvert** where demands are resisted quietly, and difficulties are masked.

What did Elizabeth Newson find in her research?

- The current information is strongly based on E:N's records and observations received from parents:
- Resists and avoids the ordinary demands of life (getting up in the morning, having breakfast...)
- Uses social strategies as part of avoidance e.g. manipulation, distracting, giving excuses (lies, shuts down, running away...)
- Appears sociable on the surface but lacks some understanding (eye contact).
- Experiences intense emotions and mood swings.
- Impulsive behavior
- Need to be "in control".
- Appears comfortable in role play, pretense and fantasy – sometimes to an extreme extent.
- Communication!!!
- Sometimes facial expressions and speech indicate panic.
- Unrecognizability of social hierarchy ("He doesn't know he is a child. She thinks she is an adult")

Demand Avoidances

- Autistic Demand Avoidance: Avoiding demands or situations that trigger anxiety /overload senses/disrupt routines /are related to transition
- Rational Demand Avoidance: Understandable and rational response to demands which cause distress, anxiety, discomfort, or are overwhelming
- EDA- PDA avoiding demands to extreme

Two key features of Extreme Demand Avoidance:

- Low tolerance for uncertainty
- Avoidance to the extreme of everyday normal demands

Extreme avoidance extends to the basic demands of everyday life, not just the avoidance of unpleasant, difficult, particularly distressing, or unpleasant tasks.

Once again: PDA-EDA is also a spectrum, and it manifests differently in different people: extroverted / introverted.

PDA-EDA in children and adolescents

- Manifests individually - symptoms can appear clearly on the outside or turn inward (masking).
- Many children have some challenges in their early development -> suspicions of ADHD, autism, delay in language development and possibly even diagnoses.
- Challenges appear individually -> often at some point in daycare/lower classes.
- Focus often turns to the family and parents, e.g. not attending school, poor parenting methods, etc.

Identifying PDA/EDA

- Interest in role play, pretending and fantasy – sometimes to extremes.
- Focuses intently, often on other people – “repetitive and restrictive interests” are often social in nature and may focus on either real people or fictional characters.
- The need to control other people and the environment caused by anxiety triggered by demands or the "fight/flight" reaction.
- Poor respond to conventional approaches in support, parenting or teaching

Identifying PDA/EDA

- Many everyday demands are avoided simply because they are demands.
- Expectation (from someone else or yourself) -> feeling of lack of control -> anxiety increases -> panic
- There can be an irrational quality to the avoidance. Dramatic reaction to a tiny request / hunger stops you from eating.
- Avoidance can vary, depending on an individual's capacity for demands (at the moment), level of anxiety person is experiencing, overall health and well-being or the environment (people, places and things).
- Demand avoidance is not a choice and is a lifelong condition.

Identifying PDA in classrooms

- PDA child may see themselves as equal to adults and not other classmates
- Poor sense of self-esteem – this may not look so from surface
- Very poor emotional regulation; extreme/sudden ‘mood swings’
- Ambivalence about success, typified by a child who destroys his/her work on completion (especially if praised)
- Lack of permanence and transfer of learning and experience; sudden/dramatic setbacks
- Desire for friendships, often failing through a need for control
- Extensive involvement in fantasy/role play
- Meltdowns/shutdowns/behavior that challenges – or equally a child may mask and internalise whilst at school
- School refusal

What are “the demands”?

Types of demands that a person with PDA-EDA experiences in everyday life:

- Direct demand or instruction
- Internal demand
- Indirect or implied demand
- Demands within demands

What are "the demands"?

- Time is a demand on top of the demand itself.
- Plans may lead to increased anxiety.
- Questions, being required to respond to a direct question.
- Decisions, knowing a decision **must** be made makes it a demand, or if you **must** choose between many options
- Internal bodily demands, thirst, hunger, need to go to toilet
- Thoughts/desires, deadlines
- Uncertainty

What are "the demands"?

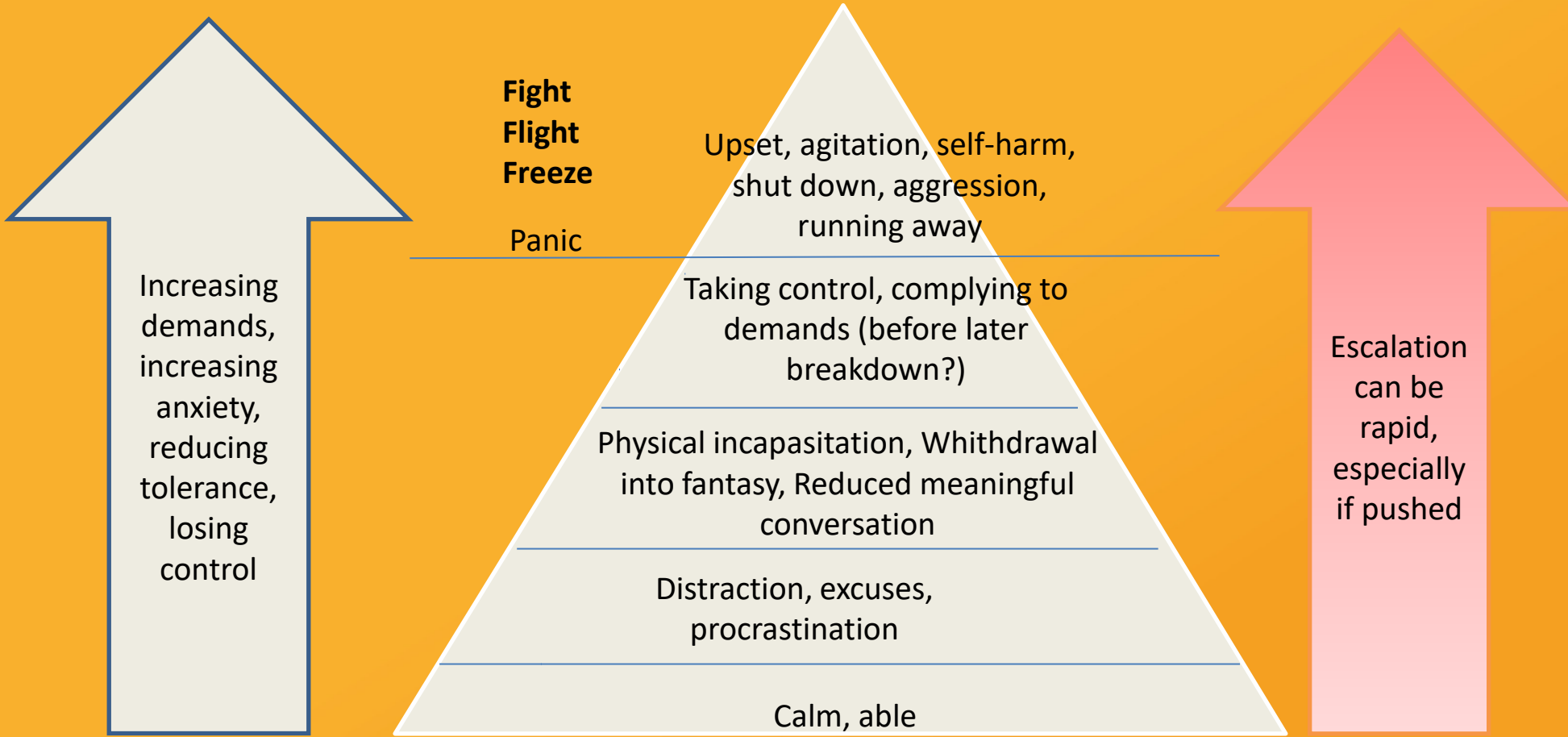
- Praise
- Transitions give you the demand to stop and switch what you're doing and also bring uncertainty.
- Expectations from others and of yourself
- Sensory overload & sensory integration difficulties
- Other people
- Own desires, hobbies, seeing friends or special occasions
- Demands within demands (if you want to see a movie you must do other things).

What are the demands in school?

- Going to school
- School environment (sensory and social issues)
- Accepting instructions, guidance, suggestions
- Being praised or not...
- Taken part to school work (reading, writing etc.)
- Social demands

PDA/EDA

Demands increase:



What happens in the nervous system when we feel threatened?

- Amygdala takes over- our instincts are faster than our thoughts.
- Contact to our "thinking part" of the brain closes down.
- Survival is our priority – Stoneage logic
- The sympathetic nervous system is activated - adrenaline and cortisol are pumped into our bodies.
- Automatic responses that we cannot control with reason.

F-responses that apply to everyone

- Fight - physically or mentally, adrenaline
- Flight - run away, panic attack, adrenaline
- Freeze - physical freezing/ sometimes mental dissociation, cortisol and adrenaline. Gives us time to think...
- Fawn – becoming a “People Pleaser”, putting your own needs last, hiding your own feelings being a good girl, teacher’s pet
-> complex-PTSD

Less known F- responses (Sally Cat)

- Flop - like freeze, except your muscles become loose and your body goes floppy
- Funster - playing the “Clown”
- Fibbing - lying when adrenaline and cortisol start to pump (in EDA questionnaire)
- Fantasy - fantasy and roleplay, diving into a role, daydreaming, blaming others (important PDA-feature in EDA questionnaire)
- Forget - dissociating, using alcohol or drugs to forget
- Flooding – PTSD meltdown, lot of crying

Masking happens in PDA too



- When one hides large parts of themselves
 - Shows only their best sides and suppresses everything else
 - Imitates others' ways of being, behaving, expressions, gestures, speech
 - Seeks ways that are more accepted, respected, cooler
 - A conscious strategy or an unconscious, automatic reaction to a stressful situation
 - For neurodivergent individuals, masking can be extremely exhausting and harmful in the long run
- > **Autistic masking** (sometimes called camouflaging)
- External guidance to cover autism-related behaviors (e.g., ABA, social pressure)
 - Masking as a personal choice (a conscious strategy in different situations, also to cover vulnerability)
 - Masking as a protection of the inner self (feeling of being wrong, minority stress)
 - Stigmatization (trauma, c-PTSD aka complex trauma)

(Rose, Pearson: Autistic Masking: Understanding Identity Management and the Role of Stigma. 2023)

Adjustments and rules to study environment

(Clare Truman: The Teacher's guide to pathological demand avoidance)

1. Prioritise Demands - PDA-Panda –model.
2. Include the child or young person in the discussion of priorities
3. Stick to your rules but make them as few as possible.
4. Decide what is non-negotiable and what is optional. Make sure that you keep the optional things truly optional.
5. Keep your demand dial in sync with the child's tolerance dial; remember their level of tolerance of demands will fluctuate so learn the child or young person's signs of decreasing tolerance.
6. Keep absolute language for absolute priorities, everything else is optional.



Helpful approaches for a PDA profile of autism

Conventional support strategies, including those often recommended for ASD, are often ineffective and counter-productive with a PDA profile. In place of structure, routine, firm boundaries, praise, rewards/consequences, is a person-centred approach based on negotiation, collaboration and flexibility.



The PDA PANDA symbolises the need to tailor the environment to meet needs and our P A N D A mnemonic is a simple reminder of helpful approaches.

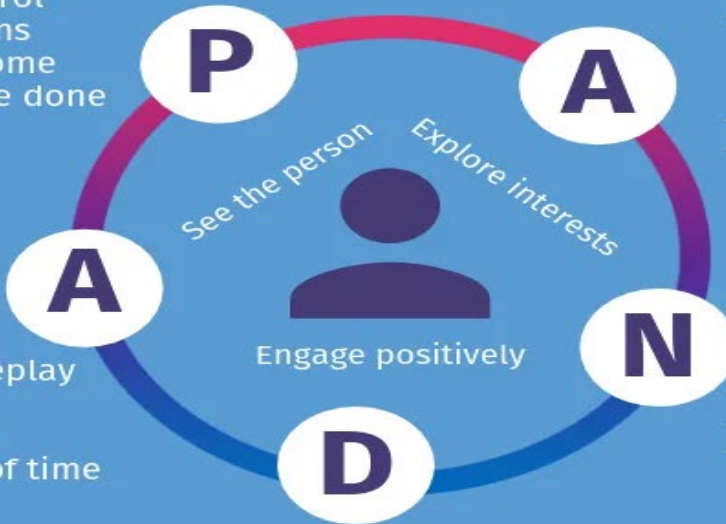
For more information please visit www.pdasociety.org.uk

Pick battles

- Minimise rules
- Enable some choice & control
- Explain reasons
- Accept that some things can't be done

Adaptation

- Try humour, distraction, novelty & roleplay
- Be flexible
- Have a Plan B
- Allow plenty of time



Disguise & manage demands

- Word & position requests indirectly
- Constantly monitor tolerance for demands & match demands accordingly
- Doing things together helps

Pick battles
Anxiety management
Negotiation & collaboration
Disguise & manage demands
Adaptation

Anxiety management

- Reduce uncertainty
- Recognise underlying anxiety & social/sensory challenges
- Think ahead
- Treat meltdowns as panic attacks: support throughout & move on

Negotiation & collaboration

- Keep calm
- Proactively collaborate & negotiate to solve challenges
- Fairness & trust are central

And more:

- Stay calm, be ready for anything and don't take it personally - always remember that the underlying behavior is anxiety and an attempt to avoid stressful situations, no matter how over the top it may be.
- Keep the rules to a minimum and choose your battles carefully. (E.g. Don't harm yourself/ Don't hurt others/ Don't break things).
- Offer as much choice as possible, as this helps to feel a sense of control.
- Use indirect language to reduce the feeling of demand. (E.g. "Let's see if we can get there / Let's think if we can do.../ Maybe we could find out together...")
- Set aside enough time to complete something. Time reduces the experience requirement.
- Take advantage of the PDA/EDA person's interests and initiatives.
- Use humor. (E.g. joking and fooling around and making a fool of yourself). With children, distraction from a difficult situation can also work.
- Fun things to soften the demands (pleasant things to do, e.g. tinkering with animals, etc.).
- Contingency plans (B-C-D)

What about the rules and boundaries in school?

- We keep everyone safe (Health and safety issues)
- We follow the legal rules (no hurting, no threatening, no damaging other people's things)
- We help each other to enjoy activities
- We don't make people to do things they don't want to do

How to follow the rules and boundaries?

Some tips, and if one doesn't work, try something new:

- There may be some rules to adhere to. However, give a sufficient sense of control to implement the rule (how many times a week do you brush your teeth, take a shower, etc.).
- Use physical prompts/stimulations instead of verbal ones, e.g. when getting dressed.
- Use characters/persons that are of special interest to the child as help in the prompts (Ryder from Paw Patrol thinks that....)

Some tips, and if one doesn't work, try something new:

- Ask to help yourself with something or invite cooperation. (I can't turn this device on now... Where is your shirt, I can't find it... Which of these options would you like to do first? What should I do in this matter?)
- Reduce the requirements (Let's do part of this first and then the rest later).
- Don't stay arguing about things. Everyone loses.
- Use your imagination (teach things indirectly, e.g. through stories, find ways to reduce demands on eating and other daily activities).

Some tips for school dealing with PDA-students

- Find out what they are interested in and take it to curriculum
- Be clear about target setting and make each target to small steps of learning - share your knowledge to other persons working with the child
- Make suggestions not demands when you are planning. Be prepared to change the plan.
- Find alternative ways to measure and evidence progress
- Always be target- focused not content –focused on your planning, delivery and assessment.
- Use imaginative ways to teach

PDA is much more than just demand sensitivity

- A strong sense of justice
- A dislike for hierarchies
- A vivid imagination and a desire for imaginative play
- A quick intellect, creativity and humor
- A need for control
- Social competence but on a superficial level
- Socially strategic (manipulative)

If PDA/EDA is not identified

- The features of the autism spectrum are not recognized, it does not fit the "picture" of a person on the autism spectrum.
- Covering up the features, i.e. masking and camouflage
- Behavior is misinterpreted – upbringing, inadequate parenting, etc.
- Misdiagnosis - PDA has the same features as some disorders such as defiant disorder, conduct disorder, attachment disorder, personality disorder or developmental trauma.

Mapping Experiences of Pathological Demand Avoidance in Ireland

https://www.researchgate.net/publication/336062996_Mapping_Experiences_of_Pathological_Demand_Avoidance_in_Ireland

- The respondents were 1445 parents, professionals of PDA age, partners:
- Difficulties: need for control 96%, severe anxiety 86%, daily routines 78%, eating 36%
- 31% think that the diagnosis was correct, 49% mentioned PDA
- 52% had not received any help or support from services, 70% did not go to school, 67% were dissatisfied with mental health services
- Key considerations:
- The professionals did not recognize or acknowledge the PDA profile
- They didn't want to discuss PDA or listen to experiences
- Dysfunctional parenting was seen as the reason for the behavior by 43% of the respondents
- Support was hindered by missing information on the diagnosis

...much else.

“Perhaps most importantly was the message that came across loud and clear to us – traditional parenting techniques do not tend to work with children with PDA. Maybe if just this point was acknowledged, and children were seen as Autistic with a quite distinct profile of strengths and difficulties, there might not be so many young people reporting that they feel ‘misunderstood’ when they are old enough to explain what it felt like for them when they were small.”

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Thank you!/Paldies!/Kiitos!

