

Understanding and Supporting Individuals with Pathological Demand Avoidance

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Webinar

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Agenda

- What is Pathological Demand Avoidance (PDA)?
- Characteristics & Common Behaviors
- Challenges for Individuals with PDA
- Understanding the Underlying Factors
- Research
- Diagnosing PDA
- Are PDA and Oppositional Defiant Disorder (ODD) the same?
- Interventions – Compassionate Care Approach
- Educational & Behavioral Supports
- Supporting Families
- Vignettes
- Questions & Answers



What is Pathological Demand Avoidance (PDA)?

PDA is a **behavior profile, not a diagnosis**. It is important to note that there is a difference between recognizing/identifying a profile compared to diagnosing PDA. Since PDA is not in the DSM-5-TR or ICD-11, it cannot be diagnosed yet.

Commonly associated with Autism Spectrum Disorder (ASD), yet also associated with other diagnoses such as ADHD, Oppositional Defiant Disorder (ODD), and Post-Traumatic Stress Disorder (PTSD)

Sharing autistic characteristics suggests that there are persistent difficulties with social communication and social interaction, restricted and repetitive patterns of behavior, activities or interests, and differences in sensory experiences.

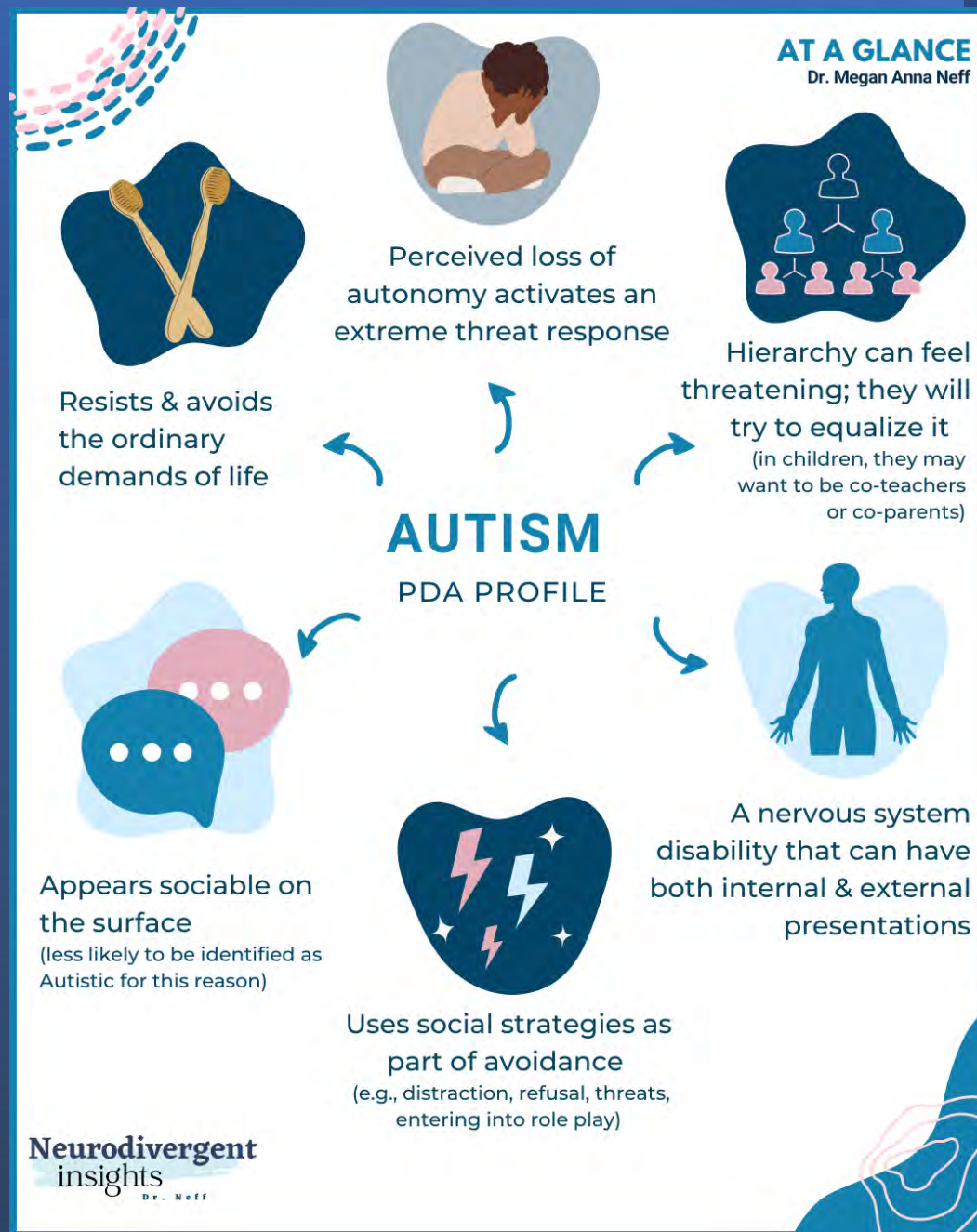
What is Pathological Demand Avoidance (PDA)?

Characterized by an extreme avoidance of everyday demands and expectations.

PDA individuals are understood to have a highly sensitive nervous system that triggers a threat response

AT A GLANCE

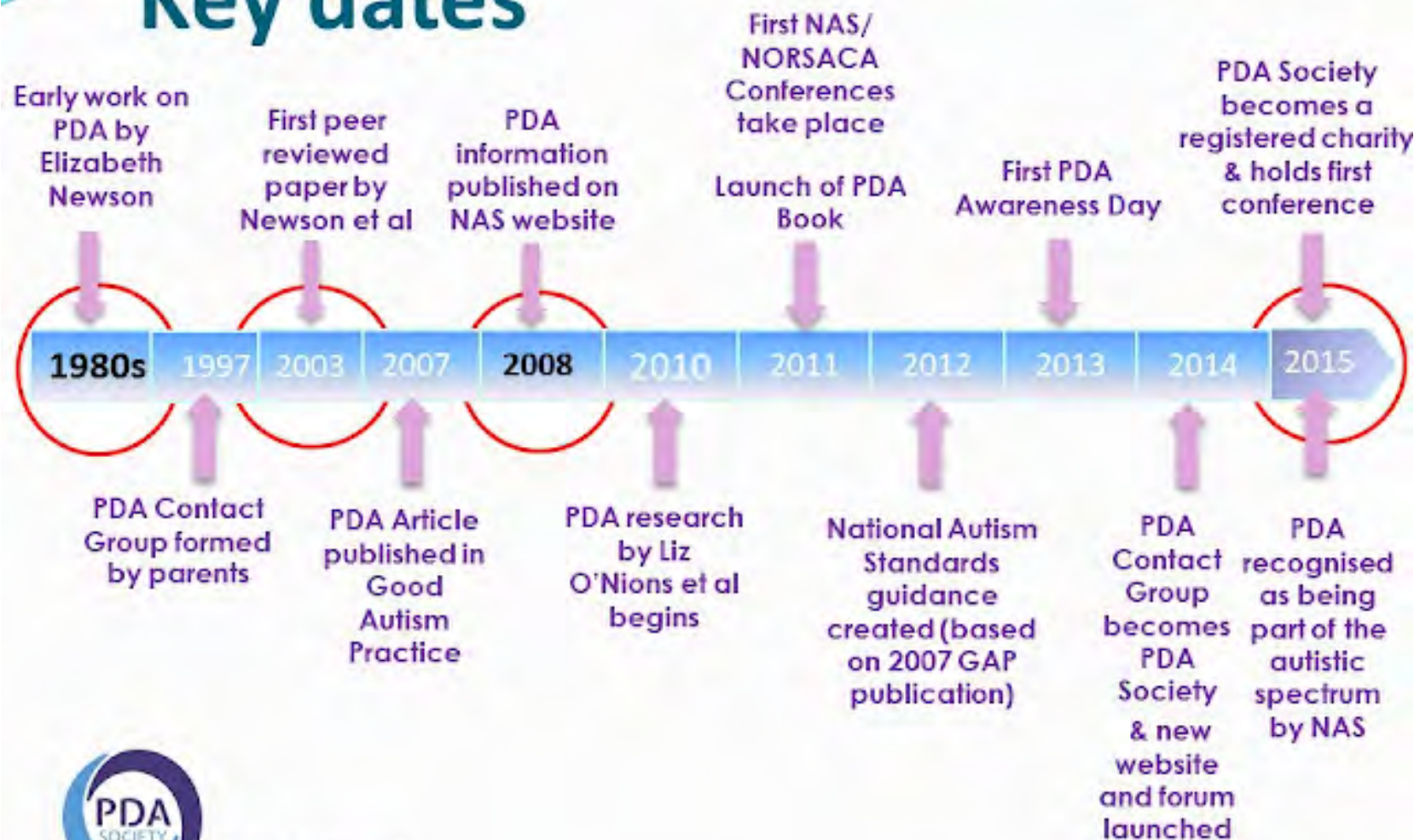
Dr. Megan Anna Neff



Historical Context

- PDA first described in the 1980s by Professor Elizabeth Newson, a clinical psychologist from England who worked extensively in developmental psychology.
- Newson used PDA to describe extreme avoidance behaviors and anxiety-driven control tactics displayed among some autistic people.
- More recently, alternative terms have been suggested to remove the word “Pathological”
 - “Persistent Drive for Autonomy,” to stress that the drive for autonomy is the most important feature to understand
 - “Extreme Demand Avoidance”
- United Kingdom’s PDA Society and Australia’s new national guidelines for autism have identified a PDA profile within Autism.

Key dates



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Characteristics of Pathological Demand Avoidance (PDA)

- **Persistent/Pervasive Demand Avoidance:** Intense reactions to daily demands; refusal, distraction, or withdrawal.
- **Driven need to control**
- **Perspective taking:** May be unable/unavailable to take others' perspective and be concerned about the impact of their behavior on others during extreme stress
- **Highly sensitive nervous system:** on high alert and often exhausted/overwhelmed by demands; triggered into survival mode (fight, flight, freezes, fawn)
- **Social Emotional Learning Strategies:** Use of social strategies (might be perceived as “manipulation” to avoid demands (e.g., distracting with affection, changing the subject)
- **Emotional Dysregulation:** Heightened anxiety and emotional outbursts in response to perceived demands.
- **Variable Cooperation/Compliance:** Cooperation/Compliance may vary depending on the situation, demand type, or mood.

Additional Behavior Presentations

- **Play and Imagination:**
 - Highly imaginative; may use role-play to deflect demands.
 - May have a heavy reliance on fantasy and role play to escape from demands and/or to relieve stress.
 - This may appear as a heightened interest in video games (common among individuals with ASD)



Additional Behavior Presentations

- **Inconsistent behavior across environments**
 - Fluctuations may be due to the different relationships with people, sensory levels, and anxiety levels associated with each.
 - Often described as a “Jekyll and Hyde” presentation
 - Look for early signs of overstimulation.
 - Those with PDA often get overstimulated long before they begin showing it.
 - Early signs: covering their ears, tired eyes, slowing down, or speeding up, increased irritability, silliness, resistance.
 - Consider assuming they are overstimulated in busy, large, noisy, complex environments
 - Proactively check-in, provide breaks, provide praise for when they’re calm.

Challenges Individuals with PDA Experience

- **Educational Settings:** Difficulty engaging with structured learning environments and educators' demands/expectations.
- **Social Relationships:** Challenges in developing and maintaining friendships due to misunderstanding of behavior.
- **Family Dynamics:** Strain on family relationships; often, caretakers feel isolated, unsupported, and unsuccessful.

How might demand avoidance emerge? – a theoretical model

(1) Routine demand

[Associated with feared or disliked activity/ having to cease preferred activity]



(2) Anxiety or distress



(3) Future demand



(4) Anxiety and avoidance & escape behaviours



reinforces avoidance & escape



(5) Reduction in anxiety



Contributing Factors

Anxiety: Significant anxiety regarding expectations contributes to avoidance (as well as to fight, flight, freeze, fawn)

Need for Control: Desire to maintain autonomy; feeling incredibly stressed by internal and external pressures/demands.

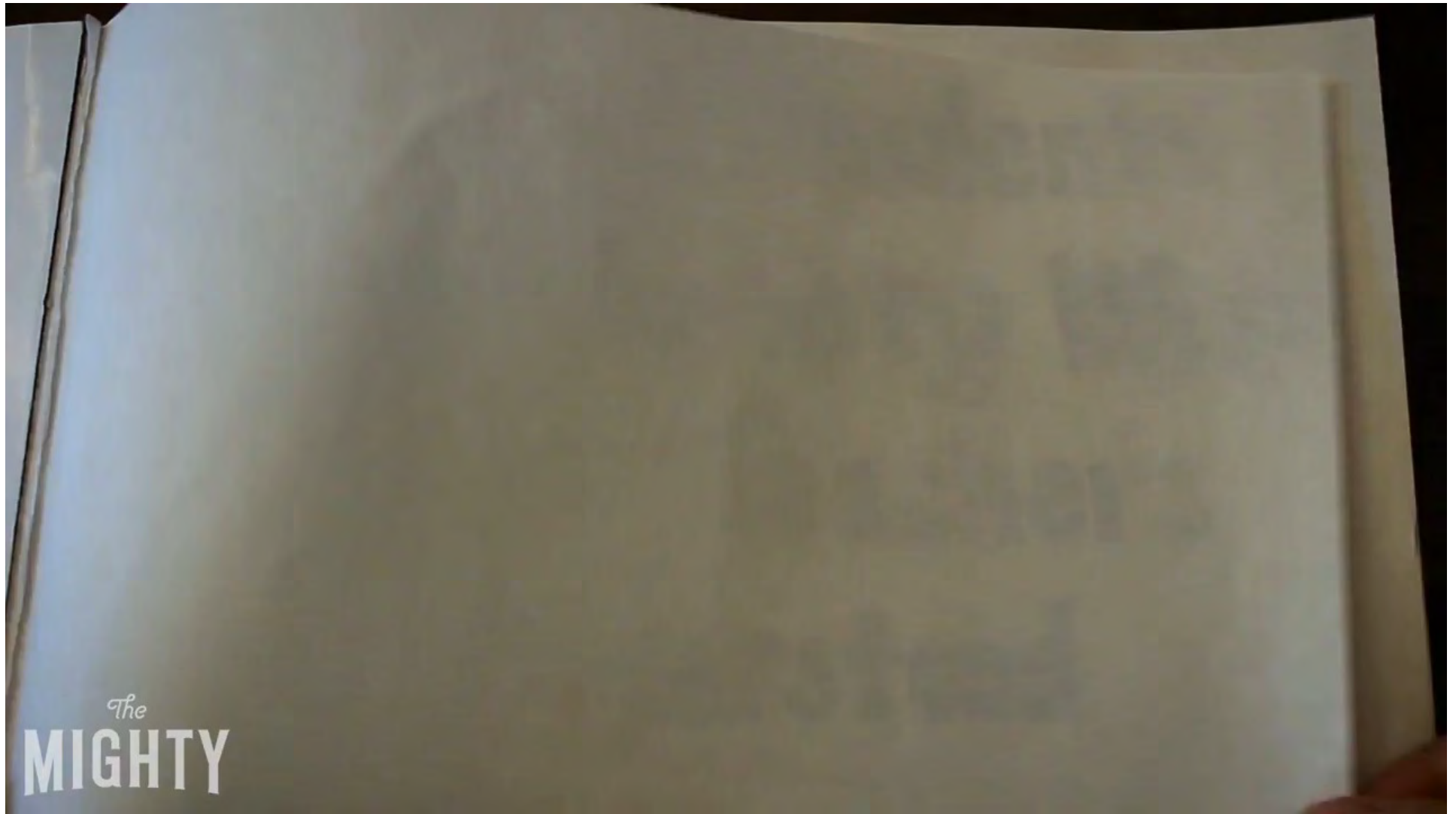
Sensory Sensitivities: Often sensitive to sensory stimuli, which may increase stress when demands are presented or implied.

Contingency Management: Rewards and punishments can be perceived as methods of control, thus increasing anxiety and behavior response.

What Type of Demands?

- 100s of demands/expectations everyday
 - Explicit directions/questions and socially-implied Demands can be present in many ways:
 - **Direct/External:** being told to do something by someone else; explicit demand/requests (e.g., get out of bed, get dressed, open your book, come here)
 - **Indirect:** socially-implied; an expectation, like responding to a question, plans for the day, time constraints (e.g., greet someone, engage in conversation, make eye contact, smile in response to someone's smile, wait in line, use utensils to eat, refrain from making bodily noises or body movements)
 - **Internal:** demands made by your mind or body ("I should get out of bed", "I should eat more veggies", "I need to start my work")

Video: Noticing What Students with Anxiety Wish Their Teachers Understood



Why Demands Can Be A Trigger?

Placing limits and putting *ourselves* in a position of authority may be a significant trigger.

Arousal/alert system is on high alert

Any real/perceived demands & expectations may be seen as a threat

Adults' attempts to use incidental teaching, shaping, and reinforcement *may* be perceived as coercive and trigger an increased threat response.

One's system may be overloaded.



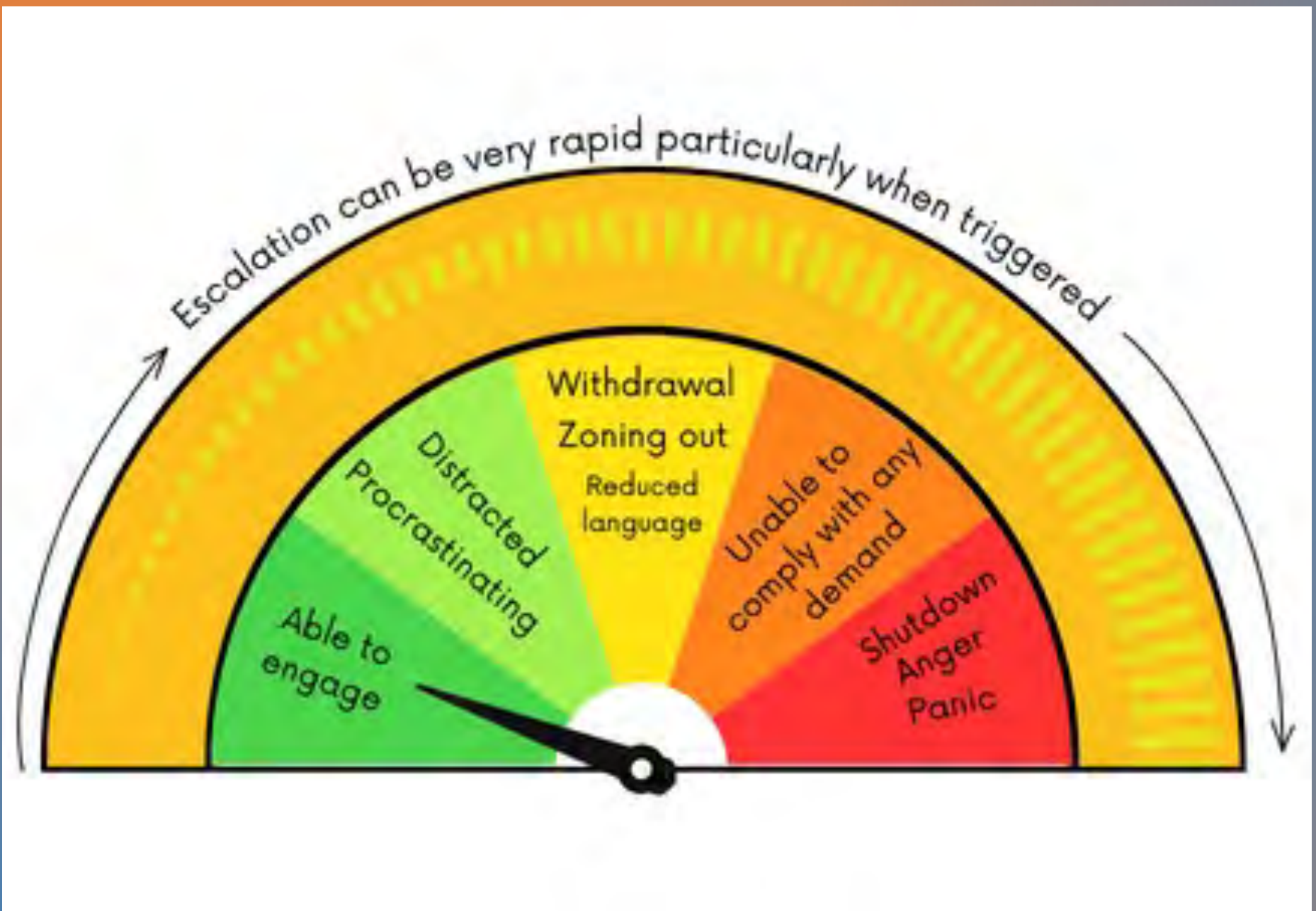
Why Demands Can Be A Trigger?

Be careful how you respond to the individual's threat/survival response.

Do NOT default to your own survival response by trying to extinguish the behavior.

It's important to:

- Step back to see the individual differently
- The individual is **not** “being oppositional and defiant”
- Instead, be compassionate and assume the individual is inherently a “good human”
- Learn to appreciate, understand, and honor what their behavior is telling us.
- Work toward greater cooperation, demonstrate empathy, and help the individual to become Happy, Relaxed, and Engaged (HRE) again



Avoidance of everyday demands and an anxiety-driven need to be in control.

- What would we expect to see if the individual is **denied** the ability to avoid such demands and/or to be in control?
 - Potential escalation in flight, fight, or freeze response.
 - May present as refusal, distraction, negotiation, and/or acting out.
 - “Meltdowns” (aggression toward self and others, property destruction, “shutdowns”, or elopement)
 - School refusal/avoidance
 - Refusal to engage in self-care / hygiene-related activities
 - Social avoidance/anxiety
 - Reluctance to go out with family or to allow family members to have others visit the house
 - Exert control over sensory stimuli in the house (noises, music, lights, talking, cooking, cleaning)
 - Frequent conflicts with siblings
 - Displaying control over food choices, mealtimes, holiday celebrations, etc.
 - Resistance to changes in routine

WHAT 'FIGHT, FLIGHT OR FREEZE' LOOKS LIKE IN THE CLASSROOM

FIGHT

- Acting out
- Behaving aggressively
- Acting silly
- Exhibiting defiance
- Being hyperactive
- Arguing
- Screaming/yelling



FLIGHT

- Withdrawing
- Becoming disengaged
- Fleeing the classroom
- Skipping class
- Day dreaming
- Sleeping
- Avoiding others



FREEZE

- Exhibiting numbness
- Refusing to answer
- Feeling unable to move or act
- Refusing to get needs met
- Giving a blank look
- Sense of stiffness
- Feeling numb



Fawn Response



- May also see a “Fawn” response
 - May occur when the student develops people-pleasing behaviors to avoid conflict and establish a sense of safety.
 - “Fawning” refers to consistently giving up (abandoning) your own needs to serve others to avoid conflict, criticism, or disapproval.

Trauma Responses



Fight: Confront the threat.

anger
rage
confrontation
high energy



Flight: Run away from the threat.

anxiety
panic
avoidance
high energy



Freeze: Shut down to block out the threat.

dissociation
numbness
shutdown
low energy



Fawn: Appease the threat.

people-pleasing
codependency
lack of boundaries

Extreme Demand Avoidance 8-item measure (EDA-8)

- EDA-8 was designed to measure EDA traits for research purposes and is not a diagnostic instrument
 - A brief caregiver-report measure of EDA traits for caregivers of children aged 5 – 17 years.
 - Consider behavior during the last 6 months
 - All items are scored as **Not true = 0; Somewhat true = 1, Mostly true = 2, Very true = 3.**
 - Scores over 19 could indicate the need for more in-depth measurement of EDA, but do not necessarily suggest a PDA-profile.
- 1) Obsessively resists and avoids ordinary demands and requests.
 - 2) Is driven by the need to be in charge.
 - 3) Tells other children how they should behave but does not feel these rules apply to him/herself.
 - 4) Has difficulty complying with demands unless they are carefully presented.
 - 5) Seems unaware of the differences between him/herself and authority figures (e.g. parents, teachers, police).
 - 6) Mood changes very rapidly (e.g. switches from affectionate to angry in an instant).
 - 7) Uses outrageous or shocking behavior to get out of doing something.
 - 8) Has bouts of extreme emotional responses to small events (e.g., crying/giggling, becoming furious).
- O’Nions, Happé, Viding & Noens (2021) Extreme Demand Avoidance in Children with Autism Spectrum Disorder: Refinement of a Caregiver-Report Measure. *Advances in Neurodevelopmental Disorders*, 5, 269–281 <https://link.springer.com/article/10.1007/s41252-021-00203-z>

Causes / Etiology

- Since PDA is a relatively new profile, research is limited.
- Most of the research is from the UK and is observational (from surveys) and not randomized/experimental.
- Indications that demand avoidant and anxious behavior was present beginning at a very early age
- Casey Ehrlich, Ph.D. is pioneering the first peer-reviewed studies of PDA in the United States with Noelle Carlozzi, Ph. D., at the University of Michigan School of Medicine
- PDA's exact causes are not yet fully understood.
- PDA may have unique genetic, neurological, and environmental influences.

Diagnosis vs. Profile

PDA is **not** a diagnosis recognized in the DSM-5-TR, the ICD-10-CM (the International Classification of Diseases, Tenth Revision, Clinical Modification) or ICD-11. Thus, there is no official diagnosis of PDA.

Recognized increasingly more in clinical practice, especially in the UK and Australia

Acknowledging the PDA profile may help clinicians, caregivers, and educators better understand and support individuals who exhibit these behaviors AND may contribute to the development of more effective interventions specific to their needs.

Diagnosis vs. Profile

Incidence and Prevalence are unknown due to the limited research, lack of diagnostic criteria, and the variations of profile criteria used among studies.

Some research has indicated that up to 30% of individuals with ASD may have PDA traits.

PDA profile may be under-recognized since profile symptoms often overlap with those of other conditions:

- *Oppositional Defiant Disorder (ODD)* -important to note that individuals with PDA are not being oppositional or defiant; instead, they are experiencing significant discomfort from overwhelming stress/pressure related to demands that may be real or imagined.
- *Attention Deficit Hyperactivity Disorder (ADHD)*
- *Anxiety Disorders*
- Some individuals with PDA may not meet ASD diagnostic criteria BUT may display similar PDA behavioral traits.

PDA vs ODD

- **If PDA is misdiagnosed as ODD:**
 - Inappropriate use of strategies may increase anxiety and avoidance behaviors.
 - Failure to address underlying anxiety could negatively impact one's mental health and coping ability.
 - Autism may be missed, leading to a lack of understanding of the person
 - Educational approaches might be too demanding and may lead to school refusal.
- **If ODD is misdiagnosed as PDA:**
 - Overly accommodating approaches might inadvertently reinforce oppositional behaviors.
 - Emotional regulation weaknesses might be overlooked and not treated.
 - Family dynamics could be misinterpreted, resulting in providing ineffective parenting strategies.

*Differentiating Pathological Demand Avoidance in Autism from Oppositional Defiant Disorder by Emma Hinze, Professor Tony Attwood and Dr. Michelle Garnett.

<https://attwoodandgarnettevents.com/differentiating-pathological-demand-avoidance-in-autism-from-oppositional-defiant-disorder/>

Strategies to Consider



It's too early to confidently state “evidence-based strategies / interventions” since there is insufficient research




However, emerging research provides some guidance, while also considering evidence-based strategies / interventions for individuals with ASD.



Clinicians, educators, and caretakers need to carefully consider the appropriateness of strategies/interventions for the individual.



Need to monitor progress via data collection and analysis, modifying approaches as appropriate.



Strategies to Consider

- **Flexible Approaches**
 - Tailor demands to reduce anxiety; offering choices and empowerment
 - Rules and expectations may need to be individualized and flexible
 - Be patient.
 - Since changes can be perceived as demands, gently interrupt activities and provide advanced notice when possible (prompt, cue card, timers)

Strategies to Consider

- **Flexible Approaches**

- Modify how requests/demands are presented
- Rephrase a demand and present it more cooperatively
 - “The clothes are on the bed, I’m happy to help” and then walk away, or phrases such as “I wonder whether ...” and “Let’s see if ...” and including words that suggest an element of choice, such as “Maybe we could ...” <https://www.pdasociety.org.uk/>
 - Talk to yourself/to no one in particular and 'plant seeds': "It's a lovely day outside, a good day for going to the park..." <https://www.pdasociety.org.uk/>
 - Avoid trigger words like “no”, “don’t”, “can’t”, "must" or "have to" – Instead, convey the same message using different words: “It’s not possible right now because ..., but we can try this afternoon and in the meantime would you like to ... or ...?” <https://www.pdasociety.org.uk/>



Helpful approaches for a PDA profile of autism

Conventional support strategies, including those often recommended for autism, 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
Anxiety management
Negotiation & collaboration
Disguise & manage demands
Adaptation

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
- Try to balance the amount of "give and take"



Disguise & manage demands

- Phrase any requests indirectly
- Constantly monitor tolerance for demands & match demands accordingly
- Doing things together helps

Anxiety management

- Use low arousal approach
- Reduce uncertainty
- Recognise underlying anxiety & social/sensory challenges
- Think ahead
- Treat distressed behaviours as panic attacks: support throughout & move on

Negotiation & collaboration

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

Strategies to Consider



- **Collaborative Problem-Solving**
 - Involve the individual in decision-making to foster a sense of control (this can reduce feelings of being coerced).
 - Co-regulation is important since the individual often can't do it alone

Strategies to Consider



- **Emotional Support**
 - Provide reassurance and validating feelings to help manage anxiety.
 - Open Communication – encourage routine, open dialogue with the student, allowing them to express their feelings and concerns without judgment.
 - Help individual learn to determine what is within their control and what isn't
 - Provide guidance to accept when they can't control situations, events, others' behavior, or their own thoughts.
 - Teach Coping Strategies (deep breathing, mindfulness, visual aids to recognize and manage anxiety)
 - Teach acceptance and psychological flexibility (mindfulness, acceptance and commitment therapy approaches).

THE BEHAVIOR ICEBERG

Behaviors (we can see)

Aggression
Raging
Screaming
Low tolerance
Frustration
Verbal abuse

Screaming
Crying
Avoidance
Refusal

Hiding
Self Isolation
Running/fleeing
Violence
Threatening
Loss of self control

Internal Emotional States (we cannot see)

Nervous
Exhausted
Trapped
Guilty
Scared
Insecure
Disappointed
Envious
Overwhelmed

Angry
Rejected
Alone
Embarrassed
Judged
Unloved
Fearful
Depressed
Anxious

Frustrated
Worries
Attacked
Shameful
Disrespected
Helpless
Disgusted
Offended
Sad

Emotional Regulation

- We are NOT going to teach people to **influence** which emotions they have and when they have them.
 - e.g., “You shouldn’t feel sad.”
“Stop feeling guilty.” “Now isn’t the time to be nervous.”
 - The goal seems to be to help someone “feel” better. But is that really helpful and does it work?



Emotional Regulation

- Instead, we can help people with how they **experience** their emotions and how they express their emotions.
- The goal is NOT to make them feel better. Rather, we are helping people learn new skills to reduce the influence of their emotions over their behaviors/actions.
- Primary goal is to help the person **better manage** the impact of their emotions over behavior.



How to Regulate

- Identify Replacement Behaviors
 - “I can feel _____ AND I can stay calm and safe.”
 - “I notice I’m thinking _____ AND I can keep my body calm and safe.”
 - “My feelings are angry/stressed/frustrated AND I’m going to be flexible by using my words, keeping my hands to myself, and asking for help.”
 - When language/cognitive skills are lower, use more visuals

Engaging in Alternative Behaviors

- WALK AWAY/TAKE A BREAK – remove yourself from the situation – separate yourself from what is making you angry
- GET HELP – talk to your teacher – seek the advice of an adult – remember to use an “I feel” statement (“I feel angry when...”)
- TALK IT OUT – sometimes just sharing your feelings with someone is enough to calm you down
- EXERCISE – release built up/excess energy via physical activity; can include use of squeeze ball
- DO SOMETHING FUN – if you are doing something you like, it is hard to be angry
- DRAW OR WRITE – you can draw or write out how you are feeling
- GET A DRINK/WASH OFF YOUR FACE – help your body cool down

LEARNING MY FEELINGS LOG

CHILD: _____ DATE: _____

ADULT HELPING TO COMPLETE FORM: _____

WHAT HAPPENED?

- Somebody teased me
- Somebody took something of mine
- Somebody told me to do something
- Somebody was doing something I didn't like
- Somebody started fighting with me
- Other: _____

WHO WAS THAT SOMEBODY?

- Another child
- Teacher
- Parent
- Another adult
- Sister/brother
- Other: _____

WHERE WERE YOU?

- Classroom
- Lunchroom
- Playground
- Street
- Hallway
- Bathroom
- House
- Other: _____

HOW DID YOU FEEL?

-  Happy  Sad  Scared  Embarrassed  Mad

HOW STRONG WERE YOUR FEELINGS? (circle best choice)

1	2	3	4	5	6	7	8	9	10
Weak			Medium				Strong		

WHAT DID YOU DO? (check all that apply)

- Hit back
- Screamed
- Ran away
- Cried
- Threw something
- Broke something
- Told adult
- Walked away
- Talked it out calmly
- Told another child
- Ignored
- Other: _____

HOW DID YOU HANDLE YOURSELF?

- Very poorly Not so well Okay Good Great

WHAT WILL YOU DO NEXT TIME? (Role Play this with child now)

My plan is to: _____

Situations in a Hat Activity



- *Situations in a Hat Role Play:* trigger situations listed on cards and placed in a hat for children to choose one at a time. Discuss the situation, state the problem, state the feeling (“I feel ___”), discuss possible solutions, choose a solution and put the solution in place; act out the situation from start to finish and provide behavior specific feedback
 - “I’m getting ready for school, and I can’t find my library book.”
 - “I want to go to soccer practice, and I can’t find my soccer ball.”
 - “I really want to buy a snack, and I forgot my money.”

Coaching Skills

- Coaching: Cue, Coach and Review
 - *Cue* (prompt or prepare) child prior to the situation what to expect, what social skills to use, reward if applicable
 - *Coach* throughout with behavior specific praise & gestures/visuals cues rather than verbal redirection
 - *Review* at the end via child's self-appraisal and adult feedback

What can you do?

- **The 4 P's:**
 - **Point Out**
 - **Prompt**
 - **Practice**
 - **Praise**

Christophersen, E. & Mortweet VanScoyoc, S. (2003).
Strategies for Teaching Important Social Skills to Young Children. Developmental and Behavioral News, Autumn 2003.



Strategies to Consider

- **Compassionate Approach**
 - Recognize that avoidance behaviors stem from anxiety rather than defiance.
 - Develop and improve the relationship
 - Foster cooperation instead compliance, as compliance is often viewed as a coercive process that increases stress
 - Honor individual's attempts to communicate

Strategies to Consider

- **Create environment that feels safe and predictable for the individual**
 - Calm Spaces - Designate a safe, quiet area where the individual can go when feeling overwhelmed
 - Make available sensory materials, comfortable seating, and calming resources
 - Gradually introduce new demands or activities in low-stress situations
 - Allow the student time to acclimate at their own pace



How to Regulate

- Identify Replacement Behaviors
 - Calm Area / Safe Haven (modifications should be made based upon age and cognitive level)

Strategies to Consider

- **Mindset of Clinician, Educator, Caretaker, Support Personnel**
 - Understands and is willing to modify environment and sensory stimuli
 - Appreciates that people are inconsistent in their behavior, energy, focus, and skills
 - Keep calm: don't personalize the behavior; accept that some things can't be done; treat every day with the individual as a fresh start.
 - Self-care

The kids
who need the
most love,
will ask for
it in the
most unloving
of ways

Whose goal is it?

- Is the adult trying to assert their goal?
- Is the student trying to assert their goal?
- If both are doing so, a power struggle often occurs, and a confrontation escalates.



Staff characteristics

Non-judgmental (avoid saying student is “good” or “bad”)

Empathic and validating feelings (“It looks like you are frustrated. Let’s see if we can work together to make things easier for you.”)

Establish positive relationships with students

Self-awareness (stay calm even when frustrated)

Respect students (even when they disrespect you)

Ensure students meet with educational success

Provide behavior specific praise

Identify and promote strengths

Frequent check-ins with the students emotionally



"When our
little people are
overwhelmed
by BIG emotions,
it's our job to
share our calm,
not join
their chaos."

L.R. Krost

“De-Escalating Confrontations”

- Everyone sit down
- Use soft “inside” voice
- Take turns speaking (speaker power)
- Listen to each person
- Try to understand one another’s perspective (“It sounds like you are feeling / saying...”) – acknowledge feelings
- Write out feelings if screaming occurs
- Find a good time to discuss feelings
- Use “I feel” statements rather than blaming “You” statements
- Problem-solve together possible solutions, then evaluate each based on whether it is safe, fair, how each person would feel, and whether it would work

Educational Approaches

- **Individualized Education Plans (IEPs) & 504 Accommodation Plan**
 - Customize plans that consider PDA traits and the individual's unique strengths and needs.
- **Engaging Learning**
 - Incorporate student's interests into lessons
 - Using hands-on activities.
 - Choice and Autonomy (e.g., how they engage with the material, whether through creative projects, oral presentations, hands-on tasks)
- **Positive Reinforcement**
 - Work together to set achievable, short-term goals
 - Celebrating small successes to build confidence.
 - Many parents report that firm boundaries and reward contingencies are ineffective and may escalate behavior (adds to their intolerance of demands/expectations).



Behavior / Stress Support Interventions

- Understand the behavior
 - *Create an operational definition of the behavior
 - Collect baseline data and analyze it
 - Understand the factors contributing to the behavior & functions of behavior
- Develop rapport and trusting relationship first
- Teach Social Emotional Learning (SEL) via direct and indirect way
 - May respond better to incidental teaching since direct SEL may be perceived as a demand.

Behavior / Stress Support Interventions

- Specific sensory modifications
- Use a calm voice tone
- Show empathy and talk about what helps and what does not
- Allow choice and cooperation to plan routines (wakeup, homework, bedtime)
- Learn and build on individual's interests
- Praise indirectly rather than directly
- Reduce pressures – i.e., allow extra time and flexibility
- Consider helper or leadership roles

Behavior / Stress Support Interventions

- Have an exit strategy or code word to signal pausing/ending situation
- Provide support during social activities
- Collaborate with family members, mental health professionals, support personnel, etc.
- Allow plenty of processing time
- Hands-off approach unless there is a clear emergency where harm is imminent.
- Follow a compassionate care approach when dealing with crises to respect individuals' dignity and maintain / establish safety.

Behavior / Stress Support Interventions

- Debriefing
 - List the demands / expectations which appeared to be overwhelming
 - Consider how to modify the adult-client interaction
 - Consider how to change the expectations and how these are presented
 - Focus on repairing/improving the relationship
 - Hands-off approach unless there is a clear emergency where harm is imminent.
 - Follow a compassionate care approach when dealing with crises to respect individuals' dignity and maintain / establish safety.
 - Provide individual with reassurance and recovery time.



Supporting Families

Consistency

- Share insights and strategies that have been working effectively and those that haven't.

Education for Parents

- Provide resources and training on PDA.

Community Support

- Connect families with support groups and networks.

Professional Guidance:

- Encourage consultation with specialists familiar with PDA.

Compassionate Care: Trauma-Sensitive Practices

- **Acute Trauma:** Event(s) that occurs at a certain time and place; commonly a short-lived experience, oftentimes sudden onset (e.g., death of someone close, accident, natural disaster, violence exposure/experience)
- **Chronic Trauma:** Repeated exposure/experience of traumatic events over prolonged periods of time (e.g., long-term health issues, chronic financial hardship, chronic homelessness, racism, chronic community-based violence, chronic emotional, physical, sexual abuse, chronic neglect).
- **Historical trauma:** When a specific group experiences collective and cumulative trauma across generations, and the individuals in the group are still suffering the impact (e.g., discrimination, racism, segregation).

Trauma-Sensitive Practices

- Trauma can contribute to feeling helpless, hopeless, afraid, anxious, and powerless.
- Trauma can interfere with the student's ability to cope effectively.
- Can impact attention, learning, relationships, emotional regulation, & behavior control
- Compromises emotional and physical well-being of the individual, peers, and staff
- Important to foster understanding, empathy, coping skills, resilience, and psychological flexibility

“I’ve learned that people
will forget what you said,
people will forget what you did,
but people will never forget
how you made them feel.”

Maya Angelou
1928 - 2014



Trauma-Sensitive Practices

- **To begin providing Trauma-Sensitive Practices, it's critical to:**
 - Understand the impact trauma has on individuals
 - Educate with awareness and sensitivity
 - Foster Social Emotional Learning (SEL), positive behavioral interventions, and restorative practices
- **Restorative practices**
 - An emerging social science that studies how to strengthen relationships between individuals and social connections within communities.
 - Can increase safety and sense of belonging
 - Can improve behavior and reduce bullying and violence



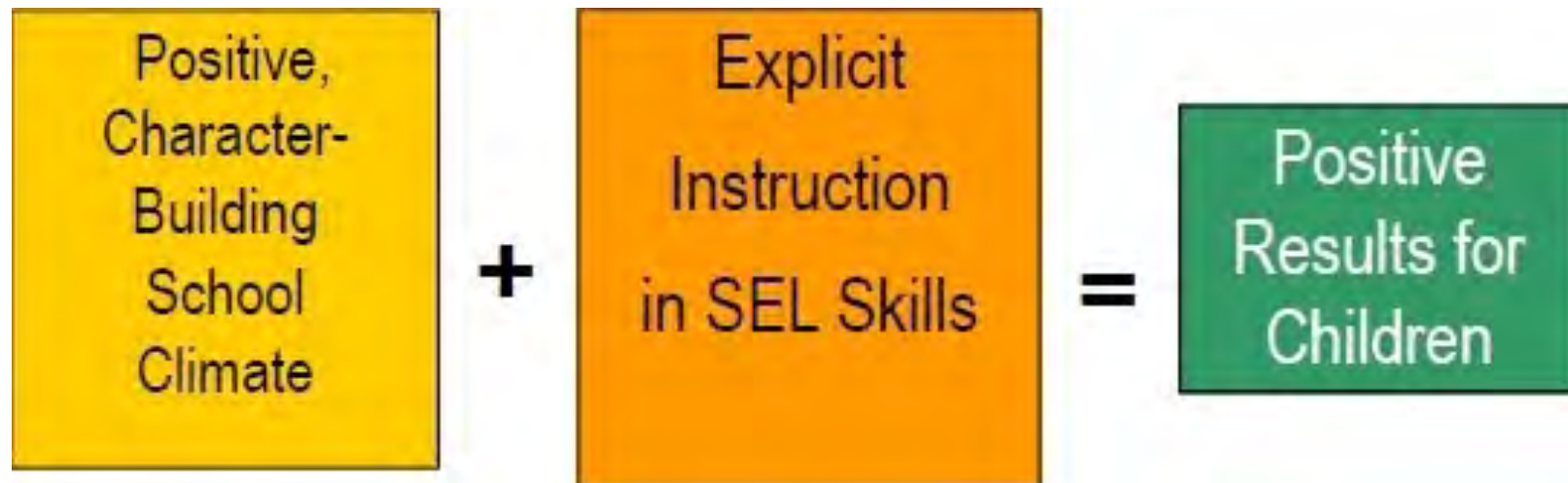
Trauma-Sensitive Practices

- **To begin providing Trauma-Sensitive Practices, it's critical to:**
 - Provide self-care for staff and individuals to increase self-awareness, mindfulness, Trauma can contribute to feeling helpless, hopeless, afraid, anxious, and powerless.
 - Collaborate with families/caregivers
 - Review and modify disciplinary policies and procedures to foster success and sensitivity, while recognizing individual differences.

Systematic Plan

- **Need a systematic plan that includes:**
 - Direct Instruction of Social Emotional Learning
 - Embedded Social Emotional Learning approaches throughout the day
 - Positive Culture and Climate





Social and Emotional Learning (SEL) Core Competencies (casel.org)



Vignette: “Mia”, the Family Navigator

- **Background:** “Mia” is a 7-year-old girl who has a passion for animals and nature.
- **Scenario:** At home, Mia’s parents set a routine for her that includes chores and homework. When asked to tidy her room, Mia feels overwhelmed and often reacts by throwing a tantrum or hiding in her closet.
- **Reactions:** Mia’s parents feel frustrated and helpless, unsure how to help her manage these situations. They decide to consult with a specialist who suggests a more flexible approach.
- **Coping Strategy:** They introduce a visual schedule with options and choices for Mia. For example, instead of saying, “Clean your room,” they ask, “Would you like to start with your toys or your clothes?” This approach reduces her anxiety and gives her a sense of control.

Vignette: “Emma”, the Creative Avoider

- **Background:** “Emma” is a 10-year-old girl who loves drawing and storytelling.
- **Scenario:** In school, Emma is often resistant to completing assignments. When her teacher asks her to write a story, she immediately shuts down and refuses. Instead of engaging, she starts doodling in her notebook.
- **Reactions:** Emma’s teacher notices her withdrawal and tries to coax her into participating, but this only escalates Emma’s anxiety, leading to a meltdown.
- **Coping Strategy:** To help Emma, her teacher shifts the approach. She allows Emma to create her own story through drawings and then encourages her to present it verbally. This way, Emma feels in control and is more willing to engage. Additionally, a quiet corner is created in the classroom where Emma can go when feeling overwhelmed. The teacher checks in with Emma regularly, using a visual schedule that highlights her choices for the day. She begins to feel more in control, and her challenging behaviors gradually decrease.

Vignette: “Liam”, the Social Strategist

- **Background:** “Liam” is a 14-year-old boy who enjoys video games and has a close group of friends.
- **Scenario:** During a group project at school, Liam feels overwhelmed when his teacher assigns specific tasks to each student. He becomes anxious and starts to avoid eye contact, saying he doesn’t want to participate.
- **Reactions:** His friends initially feel frustrated, but Liam employs his charm to negotiate his way out of the group work by suggesting a different, more engaging method: creating a game that encapsulates their project topic.
- **Coping Strategy:** By framing the project as a game, Liam redirects the demand into something he enjoys. His friends agree, and they all work together, leading to a successful project that excites them all.

Vignette: “Alex”, the College Student

- **Background:** “Alex” is an 18-year-old who has recently started college. He is passionate about photography and dreams of a career in the arts.
- **Scenario:** At the beginning of the semester, Alex receives a syllabus outlining assignments and deadlines. Immediately, he feels overwhelmed by the structure and expectations. When professors ask for participation in discussions, Alex feels intense pressure and avoids contributing.
- **Reactions:** During the first few weeks, Alex struggles with anxiety and often skips classes. He uses social media to express his frustrations but feels increasingly isolated from his peers.
- **Coping Strategy:** Recognizing his difficulties, Alex reaches out to a supportive advisor who helps him develop a personalized plan. They agree on flexible deadlines and alternative ways to demonstrate his understanding, like submitting visual projects instead of traditional essays. Additionally, the advisor connects him with a small group of students who share his interests, allowing him to engage socially in a less structured environment.

Vignette: “Sarah”, the Professional

- **Background:** “Sarah” is a 27-year-old graphic designer who thrives in creative environments but has struggled with typical workplace demands.
- **Scenario:** Sarah is part of a team at a design firm where projects come with tight deadlines and expectations for regular meetings. When her manager assigns a new project with specific milestones, Sarah feels an immediate urge to withdraw. Instead of collaborating, she avoids communication and misses deadlines, leading to tension with her team.
- **Reactions:** Sarah’s colleagues become frustrated with her lack of participation, unaware of her internal struggles. She feels misunderstood and anxious, leading to increased isolation.
- **Coping Strategy:** After an honest conversation with her manager about her anxiety, they agree to implement a more flexible approach. Sarah is allowed to set her own milestones and choose how she wants to communicate progress, whether through email or informal check-ins. She also starts using a visual project management tool that helps her break down tasks into manageable parts, reducing her anxiety.

Next Steps...

- What is the One Thing you can do after this workshop that will make a meaningful difference in your school/company/family?

- When will you do this?

- Schedule this now.

You make a
difference...keep inspiring
others!



Related Resources

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.) text revision*. Arlington, VA: American Psychiatric Association.
- Christie, P., Duncan, M., Fidler, R., & Healy, Z. (2012). *Understanding Pathological Demand Avoidance Syndrome in children: A guide for parents, teachers, and other professionals*. Jessica Kingsley.
- Eaton, J., & Weaver, K. (2020). An exploration of the Pathological (or Extreme) Demand Avoidant profile in children referred for an autism diagnostic assessment using data from ADOS-2 assessments and from their developmental histories. *Good Autism Practice*.
- Kamp-Becker, I., Schu, U., & Stroth, S. (2023). Pathological Demand Avoidance – aktueller Forschungsstand und kritische Diskussion. *Zeitschrift Für Kinder- Und Jugendpsychiatrie Und Psychotherapie*, 51(4), 321–332. <https://doi.org/10.1024/1422-4917/a000927>
- Kildahl, A. N., Helverschou, S. B., Rysstad, A. L., Wigaard, E., Hellerud, J. M., Ludvigsen, L. B., & Howlin, P. (2021). Pathological demand avoidance in children and adolescents: A systematic review. *Autism*, 25(8), 2162–2176. <https://doi.org/10.1177/13623613211034382>
- Newson, E., Le Maréchal, 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.
- O'Nions, E., Happé, F., Evers, K., Boonen, H., & Noens, I. (2014). *Extreme demand avoidance in autism spectrum disorder: A general population study*. *European Child & Adolescent Psychiatry*, 23(6), 553–561.
- Stuart, L., Grahame, V., Honey, E., and Freston, M. (2020). Intolerance of uncertainty and anxiety as explanatory frameworks for extreme demand avoidance in children and adolescents. *Child Adolesc. Ment. Health* 25, 59–67.
- Truman, C., Crane, L., Howlin, P., and Pellicano, E. (2021). The educational experiences of autistic children with and without extreme demand avoidance behaviours. *Int. J. Incl. Educ.* 1–21.

Related Resources

- **Raising Cooperative Kids: Proven Practices for a Connected, Happy Family** May 1, 2017
https://www.amazon.com/Raising-Cooperative-Kids-Practices-Connected/dp/1573246905/ref=pb_xggy_14_img_3/144-1587323-9939719?encoding=UTF8&pd_rd_i=1573246905&pd_rd_r=7daa4840-394f-4193-ba7a-275626af3209&pd_rd_w=2yZnb&pd_rd_wg=d6OT8&pf_rd_p=a2006322-0bc0-4db9-a08e-d168c18ce6f0&pf_rd_r=WD0KE689XGEDSMNNHR2N&psc=1&refRID=WD0KE689XGEDSMNNHR2N
- **The Joy of Parenting: An Acceptance and Commitment Therapy Guide to Effective Parenting in the Early Years** October 1, 2009
https://www.amazon.com/Joy-Parenting-Acceptance-Commitment-Effective/dp/157224593X/ref=sr_1_2?keywords=acceptance+and+commitment+therapy+parenting&qid=1567450892&s=gateway&sr=8-2
- **How to Talk So Kids Will Listen & Listen So Kids Will Talk (The How To Talk Series)** February 7, 2012
https://www.amazon.com/How-Talk-Kids-Will-Listen/dp/1451663889/ref=pb_xggy_img_sccl_1/146-8089752-1867604?pd_rd_w=LklDO&content-id=amzn1.sym.7757a8b5-874e-4a67-9d85-54ed32f01737&pf_rd_p=7757a8b5-874e-4a67-9d85-54ed32f01737&pf_rd_r=SFE4ZSKJHA9885MQEBYA&pd_rd_wg=NizSI&pd_rd_r=04ee62d1-e256-44bb-810d-33a722ac644b&pd_rd_i=1451663889&psc=1
- **The Explosive Child [Sixth Edition]: A New Approach for Understanding and Parenting Easily Frustrated, Chronically Inflexible Children Paperback** – August 17, 2021
<https://www.amazon.com/Explosive-Child-Sixth-Understanding-Chronically/dp/0063092468>

Related Resources

- **Understanding Pathological Demand Avoidance Syndrome in Children: A Guide for Parents, Teachers and Other Professionals**
[Amazon.com: Understanding Pathological Demand Avoidance Syndrome in Children: A Guide for Parents, Teachers and Other Professionals \(Audible Audio Edition\): Margaret Duncan, Zara Healy, Ruth Fidler, Phil Christie, John Telfer, John Murray: Books](#)
- **I'm Learning to Be Flexible!: A Book for Children Who Have a Pathological Demand Avoidance (PDA) Profile or Simply Like to Control (Behavior Science Children's Books)**
[I'm Learning to Be Flexible!: A Book for Children Who Have a Pathological Demand Avoidance \(PDA\) Profile or Simply Like to Control \(Behavior Science Children's Books\): Chan, Stephanie: 9781990237089: Amazon.com: Books](#)
- **No More Meltdowns: Positive Strategies for Dealing with and Preventing Out-of-Control Behavior** April 1, 2008
<https://www.amazon.com/More-Meltdowns-Strategies-Out-Control-ebook/dp/B00U10WU0C>
- **Anger Management for Parents: The ultimate guide to understand your triggers, stop losing your temper, master your emotions, and raise confident children** March 26, 2022
https://www.amazon.com/Anger-Management-Parents-understand-confident/dp/1958134023/ref=sr_1_1?keywords=anger+management+parents&qid=1663645059&s=books&sr=1-1

Related Resources

- PDA Society in the UK <https://www.pdasociety.org.uk/>
 - The PDA Society is the only specialist PDA charity in the UK. Our goal is to try and make life better for PDA people and their families because we believe that happy, autonomous lives are possible. Our strong commitment to research underpins every step we take towards improving understanding, support and outcomes for PDA people in the future.
- PDA North America <https://pdanorthamerica.org/> first conference March 2020
 - PDA North America offers a number of resources, trainings and supports to the PDA community while focusing on spreading awareness.

Behavior Therapy

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POWER-Solving® Curriculum:
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Michael C. Selbst, Ph.D., BCBA-D
Steven B. Gordon, Ph.D., ABPP

POWER-Solving®: Stepping Stones to Solving Life's Everyday Social Problems is a social problem-solving curriculum designed to teach children and adolescents to become independent problem-solvers via a hands-on, user-friendly, positive-practice, interactive approach. They are taught how to problem-solve first using their “toolbox” (i.e., the five steps of POWER-Solving®). Subsequently, they can apply this “toolbox” to various challenging social situations, which allows them to develop and enhance their social-emotional skills. The goal is for children and adolescents to learn valuable POWER-Solving® skills that they can apply to an infinite number of social situations throughout their lives.

For more information regarding the POWER-Solving® Curriculum, please contact Dr. Selbst or Dr. Gordon at power-solving@comcast.net or call 732-873-1212. or visit www.POWER-Solving.com