Support Strategies at School for Students with a Pathological Demand Avoidance (PDA) profile

KEY FEATURES OF PDA

- * Pathological Demand Avoidance (PDA) is described as an atypical presentation or profile of autism
- * Students with PDA profile show extreme resistance to, and avoidance of, everyday demands of life, based on an anxiety-driven need for autonomy (Understanding PDA Syndrome in Children, Christie et al, 2011)
- * **Emotional regulation** difficulties, with sudden or extreme mood swings, which can lead to meltdowns or shutdowns and seemingly "uncooperative" behaviour (or may manage tasks temporarily by "masking")
- * Explosive behaviour is best viewed as a panic attack (anxiety too high, tolerance too low = vulnerability)
- * Ambivalence towards success; **rewards or praise** and **punishment or withdrawal** of preferred items usually **ineffective** and increases anxiety (therefore even <u>less</u> likely to attend/cooperate/participate/engage)
- * Low self-esteem/worth, despite appearance of confidence or bossiness

KEY POINTS FOR EDUCATORS

- * 70% of students with PDA profile struggle to attend school or don't attend (UK PDA Society research)
- * Quality of relationship between teacher & child absolutely fundamental take time to build rapport
- * The child or young adult needs to **feel in control** as much as possible the issue is an **incapacity**, **NOT** wilful disobedience or naughtiness (can't at this time, not won't). Give opportunity to make choices.
- * Flexibility and adaptability by adults around them are critical
- * Frequently doesn't respond to conventional teaching approaches like schedules, timers, rewards
- * Believing, supporting and **working closely with families** is key to successful inclusion of autistic students with a PDA profile (pdasociety.org.uk)

WHAT WORKS?

- * Critical to choose priorities (let go of less important things) and reduce demands wherever possible
- * Constantly adjust your demands to suit their tolerance level, which changes often think of two dials that need to be in parallel (ie increase/decrease your "demands"/requests to suit the variable tolerance of child)
- * Use of humour and distraction often helps and novelty and variety are often effective
- * **Depersonalise** and **disguise** demands eg "I wonder what they're doing over there?" or "that looks like fun" or "pens/crayons are on the table" rather than "go and see what the others are doing" or "you need to get a pen/crayon from the box" or "can you do x?" and
- * Avoid directive language use **declarative** or **indirect language** (see Dec Language Handbook by Linda K. Murphy) Eg instead of "walk over there", you can try "there's a lego over there; or "here's the chalk if anyone needs" or "gosh I'm tired, I wish I had help to carry this" or "I can't quite work this out". Comment on observations.
- * Offer opportunity to make choices as much as poss BUT NOT when child agitated / very anxious / angry
- * Best when **invited** to participate, but not pressured to
- * May need extra time and support for processing and transitions between lessons/rooms
- * Heavy work for sensory and emotional regulation push, pull, carry, dig, lift (ask OT for other ideas)
- * Notify ahead of time of big changes to usual program, plan ahead anticipate potential triggers
- * **Reduced schedule** can be helpful (eg exemption from 2nd language / music / drama / activities which appear to exacerbate anxiety ideally should be done in conjunction with parents / treating health prof's)
- * Collaborate with parents as regular comm'n can make huge difference they'll know which strategies work
- * Use of drama / role play (characters, animals) can be effective to involve child, especially if a special interest
- * Without isolating, allow them to be on the fringes, gives opportunity to learn by osmosis
- * Lots of opportunities for **relaxation**, physical **exercise**, fidget toys, soothing music, yoga, gym balls, nature nature nature, ask for more ideas from OT/parents. **Sensory breaks** or **movement breaks** can be useful
- * Your expectations of your other students can be very different from those with PDA and that's ok
- * Verbal/auditory comprehension can be very different from verbal expression ability (which is often v strong)
- * Use interest-driven tasks best whenever possible
- * Always avoid power struggles; use **neutral posture**, **voice and facial expression** (relaxed face, relaxed body language, monotone voice or consider your tone, soft or moderate volume)

- * Safe, calm space (physical and psychological "refuge") & safe, calm mentor or time away as needed
- * **Negotiating** amount and type of work **with student** some days no / little work will get done that's ok!
- * Easier for parents than teachers, as **parents have more opportunities to trial** and see what works and what doesn't (this changes frequently!), however, remember parents deal with these issues 24/7/365 exhausting
- * When they're hard to like, that's when they need **your support** the most!
- * Overriding feeling towards school for PDA child is **MASSIVE ANXIETY** once the anxiety is reduced adequately, then you can increase their engagement/participation in learning **BUT not until then**

WHAT DOESN'T WORK?

- * Always AVOID using the words "No", "Can't" and "Don't"
- * Loud voice, agitated/angry tone, dominating body language, restraint, attempts to be "in charge" of child or exerting control (they generally do not confer automatic respect to "authority" figures, as they see themselves as equal to adults, due to impact of PDA on social understanding/hierarchy and self-identity)
- * Viewing child/young adult as defiant, manipulative or purposely oppositional is unhelpful

PERSONAL COPING STRATEGIES FOR ADULTS SUPPORTING PDA-ERS

- * Parents of PDA-ers tell us they deal with daily challenges by getting educated on PDA, exercising regularly, counselling with a psychologist, reading, Netflix, chocolate, music, journals, yoga, meditation, part-time work, medication when prescribed, face-to-face/online FB support groups & respite when possible
- * Need to look after yourself well first, then you can support the child well/better
- * **Don't take things personally** especially anger or aggressive behaviour *child is communicating to you that they aren't coping* you need to develop thick skin!
- * All research points to **early understanding** of strengths/needs, together with **appropriate support**, being the key to **positive long term outcomes** (PDA Society, 2023)

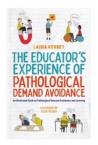
PROFESSIONAL STRATEGIES & WHERE TO GET HELP & INFO

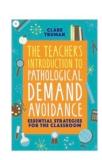
- * Many more strategies available from **PDA Society website** (<u>pdasociety.org.uk</u>) They have a free newsletter for professionals and links to excellent resources
- * For local Perth/WA support, please join us at **PDA Perth WA Interest Group for Educators & Health Professionals** (https://www.facebook.com/groups/3429189420657840) Currently 590 members.
- * Free, confidential Employee Assistance Program is available to DoE staff as needed
- * www.teachwire.net/news/understanding-pda/ (great brief introductory article)
- * https://www.pdasociety.org.uk/wp-content/uploads/2021/10/PDA-for-teaching-professionals.pdf
- * https://www.pdasociety.org.uk/wp-content/uploads/2021/04/What-is-PDA-booklet-website-v2.1.pdf
- * https://www.twinkl.com.au/resource/t-s-4063-managing-pathological-demand-avoidance-in-the-classroom-top-tips.
- * https://podcasts.apple.com/au/podcast/pathological-demand-avoidance-pda-georgina-durrant/id1598292028?i=1000579397090











THANK YOU for all you do to support our children; they <u>really</u> need it and we <u>really</u> appreciate it!

Collated by Heidi Brandis | January 2024

PDA parent | Former OT | Author WA Autism Parent Handbook | Member WA Department of Education Disability & Inclusion Consultative Committee Founder Northern & Western Suburbs Autism Mums Support Group & Eastern Suburbs Autism Network | Founder/Admin FB Perth Support Groups for Autism & PDA parents | Founder/Admin FB PDA Perth WA Interest Group for Educators & Health Profs