



Strategies and Support Needs For School

Adapted from PDAParents.com

The following is an adapted template created by a PDA parent, and shared on the blog, PDAParents.com. This was created as an important way to share information with the school during the IEP process. Please use and share and adapt as best meets your child's needs.

(Letter)

Overview, Strategies and Support Needs for the School Year

Our primary goal for [child name] this school year is that he/she will feel regulated, happy, and safe in an environment outside of our home. Given the daily challenges he/she faces, if [child name] is able to attend school and feel generally content during his/her time there, we will consider this a big success. [Child name] has a desire to make friends and is eager to learn academic skills, and these are certainly important goals as well.

[Child name] is autistic and has a profile of autism called Pathological Demand Avoidance (PDA). PDA children tend to present substantially different from what most people think of with autism. Kids with PDA (tend to) make (more) eye contact, appear social, have fierce negotiation skills and have strong expressive language capacities as well as the ability to read other's emotions well. PDA also differs significantly in the types of support needed and the types of strategies that are effective. At its core, the A in PDA (avoidance) is due to extreme anxiety caused by everyday demands. Daily tasks and routines like riding in a car, sitting in a classroom, brushing teeth, getting dressed, sharing attention, waiting, etc. can lead a PDA child to attempt a variety of strategies to avoid those demands. Avoidant strategies from the child might include distraction, negotiation, distressed behaviors such as yelling or aggression, and can lead to full-blown fight or flight responses that feel akin to a panic attack. The anxiety is cumulative, and when coupled with sensory processing differences, the distress can appear seemingly out of nowhere. An additional note about the perceived demands: these can also be from internal sources as well. The feeling of hunger (needing to eat), or the urge to use the bathroom can at times be overwhelming experiences for PDA children.

The types of strategies that are typically employed in autistic children produce anxiety in PDA children and can actually make things worse. Things such as set/recurring routines and behavioral approaches (rewards and consequences, charts, etc.) are all interpreted as demands on their nervous system and increase anxiety. Conversely, PDA-specific strategies focus on minimizing demands: allowing the child to have as much control as they can whenever possible, presenting choices and allowing the child to provide input, turning tasks into games or races, using indirect/declarative language, giving extra time and support for transitions, introducing novelty and

surprise, using humor, and paying attention to when dysregulation has visibly started to occur and giving space, distance, and quiet. As distress increases, the level of support required to de-escalate increases, and once a high level of distress has been reached, regulation becomes much more challenging and there is a tendency to return back to a higher level of stress.

[Child name] also has sensory processing differences. Loud noises, commotion, transitions, sitting still, having to regulate his/her own emotions and state of arousal without dedicated adult attention will be challenging. While [Child name] does have strong capacity to communicate verbally, his/her ability to access those communication skills will vary greatly depending on his/her state of regulation.

With so many demands and so much sensory input, school presents an incredible challenge for children with PDA autism, and without the proper support, many of these children end up homeschooling. The reason we have chosen to pursue the opportunity for [Child name] to attend [school name] is because he wants to be able to go to school, he/she is eager to learn, to make friends, to do the things he sees peers doing as well. We know with certainty that for him to be able to build on success, we go slowly, we help to alleviate pressure in every way possible, namely: reduced schedule (with intention to increase as tolerance allows), choices in little ways can make a big difference (“You may choose a pencil or pen to write your name on your paper” helps him feel in control and avoid the demand of one limited direct instruction), the option to leave the classroom when he/she feels overwhelm increasing -- the option to use a screen in the resource room, or take a sensory break in the sensory room or outdoors will all be very helpful in managing cumulative anxiety.

We hope that Oliver’s experience at school can be as positive as possible. It will help if he/she feels invited but not pressured to participate or engage with any activities; the basis of his/her struggles is anxiety, and it’s often that he/she cannot be forced into an activity without reaching a high level of distress. Conversely, if he/she feels freedom around it, he/she’s much more likely to be able to engage. While his/her desire to do something can at times motivate him enough to do it, it is important to note that his/her own desire is also perceived as a demand and therefore a threat, which he/she then feels compelled to avoid.

We also ask for information ahead of time with the option to decline attendance around any large all-school events including fire or active shooter drills, and other such events like assemblies or high-traffic areas which could be too overwhelming and lead to high levels of distress. To whatever extent possible, if there is a substitute teacher in charge of [Child name’s] instruction for the day, we ask to be notified ahead of time (even if it’s the morning of) because this alert to an upcoming change will be helpful for [Child name] to know ahead of time.

We see ourselves as partners with you and [Child name] in their education, and will do everything we can to work with you to accommodate and support him/her and your work with him/her throughout the school year. There are many seemingly paradoxical and fluctuating needs that are a part of [Child name's] disability, and open communication and an opportunity to build respect and trust between all of us will make such a positive impact in his/her school experience. I am also including quick strategies/supports in bullet points below.

[Child name] is curious, clever, energetic, logical, inquisitive, imaginative, caring, and quite funny. We know he/she will add something special to his/her classroom and overall learning environment. We look forward to working together and appreciate you taking the time to read through and consider the information shared in this letter.

Sincerely,

Strategies/Supports for School

- Start with reduced schedule and increase according to tolerance.
- Have places to retreat to when classroom environment is too much.
 - Private room: screen time is calming
 - Sensory needs: big, gross-motor movements (swinging, jumping, etc.)
 - Going outside
- Meet or at least see photos of teachers, aide, resource room teacher ahead of time
- Choice on where desk is in classroom
- Organize schedule so when [child name] is at school there are the minimum number of transitions possible. (Primarily with teacher, less time with specials/unfamiliar people/setting)
- If aide not available all the time, at least have aide available for transitions. Have a buddy (classmate? older student?) to help. Allow warning and extra time for transitions.
- Small amount of consistent caregivers including an “anchor person” who can provide 1:1 support
- Treat melt-downs as panic responses (indeed, this is what they are), rather than naughty tantrums.
- Trauma-informed responses to challenging behavior: signaling safety, building trust will be the keys to his/her ability to cope with his/her challenges.
- Option to not participate, but just sit on the sidelines and watch (a lot of learning can happen like this.)
- Have easy phrases or signals he/she can use with the teacher to signal when he’s needing a break or more support.
- Allowing him/her as much control as possible - presenting choices
- Turning tasks into games/races. Use novelty, surprise, humor.
- Having opportunities to take little snack breaks. Chewy foods are calming for him/her. (Could he/she chew gum while in class? What is the school policy on this?)
- Using indirect/declarative language, i.e. “I wonder how to spell the word “ball”” instead of “[Child name], how do you spell the word “ball””
- When dysregulation has visibly started to occur, give space, distance, quiet
- Behavioral/reward based strategies are often felt to [child name] as a demand and increase anxiety - if behavioral challenges occur, call parents. NO isolation without supportive adult. NO ABA strategies, these are counter-productive and harmful.
- Remove demands by making it clear he/she doesn’t have to do anything.
- Please understand [child name]’s behaviors in a PDA framework and support a positive neurodiverse identity.

- PDA involves:
- pervasive avoidance of daily demands
- Driven need for control and freedom (antidote to feeling out of control/overly anxious)
- Highly sensitive nervous system
- Frequently triggered into survival mode: fight/flight/freeze/fawn
- Exhausted by social, sensory and everyday demands