Not Defiance, But Distress

PDA, often known as pathological demand avoidance or pervasive drive for autonomy, is a subtype of autism spectrum disorder (ASD) characterized by extreme anxiety-driven avoidance of everyday tasks and demands (McConnell). PDA-type autism is a unique subtype, as autistic children with PDA often have different needs than children with other, more well-known subtypes of autism, such as Asperger's syndrome or “classic” autism (Kanner’s autism). Consequently, individuals with PDA are often misunderstood, and their behaviors may be mistaken for opposition or defiance rather than anxiety responses. PDA is not currently recognized as a formal DSM-5 diagnosis, even though people with PDA have needs distinct from other diagnostic categories. As such, individuals with PDA are often misdiagnosed with oppositional defiant disorder, generalized anxiety disorder, social anxiety disorder, borderline personality disorder, or autism without diagnostic recognition of a PDA profile. Awareness and formal recognition of PDA is necessary for PDA autistic children to receive support appropriate for them and avoid years of misdiagnoses and misunderstanding.

PDA was first identified by developmental psychologist Elizabeth Newson in the 1980s (Philippe). She observed ninety children referred to her with suspected autism or Asperger's syndrome and found that fifty of them had behavioral patterns distinct from the twenty diagnosed with Asperger's and the other twenty diagnosed with classic autism (Philippe). Newson considered PDA to be a specific, pervasive developmental disorder separate from Asperger's syndrome and classic autism, which all now fall under the autism spectrum disorder (ASD) diagnosis (Philippe). It is now estimated that approximately 18% of people with ASD have a PDA profile (Gillberg et al.).

Everyday demands, such as attending school, eating, or complying with directions from authority figures, cause individuals with PDA to feel trapped by intense anxiety. For a person with PDA, everyday losses of autonomy or demands cause their nervous system to enter survival mode, colloquially known as "fight-or-flight." In this fight-or-flight survival mode, PDA autistic people may alleviate this intense anxiety by exhibiting avoidance behaviors, such as negotiating, claiming physical incapacity, running away, or verbally or physically lashing out at others. Demands for a PDA person cause cumulative nervous system distress. The longer a PDA autistic person is exposed to demands, the more their capacity to tolerate these demands or new demands shrinks. When demands exceed a PDA person's window of tolerance, they may experience a meltdown, which may cause them to scream, cry intensely, throw or break objects, or physically act out towards others. While clinicians and parents may be tempted to label these "meltdowns" as deliberate "tantrums," PDA meltdowns are a result of extreme anxiety – PDA meltdowns are involuntary responses to internal distress, much like panic attacks. PDA is often mistaken for oppositional defiant disorder (ODD), a diagnosis categorized by excessive anger at authority and defiant attitudes and behaviors; however, avoidance behaviors and meltdowns in PDA individuals are not driven by defiant attitudes or anger at authority -- instead, they are driven by deep-rooted, involuntary anxiety. People with PDA may even experience extreme anxiety when facing self-imposed demands or attempting to do things they want to do. For example, people with PDA may avoid eating because it feels like a demand from their own body. Similarly, people with PDA may struggle to work toward goals they set for themselves because goals feel like a demand or expectation (PDA Society).

Further, PDA autistic people experience a myriad of other challenges in everyday life not inherently related to demand avoidance. Like those with more recognized forms of autism,

people with PDA struggle to understand traditional social relationships. Attempting to obey social rules that they do not understand can be a significant source of anxiety for people with PDA, triggering demand avoidance and cumulative nervous system activation. Despite struggles with social-communication skills, children with PDA often appear more sociable than those with Asperger's Syndrome or Classic Autism. Children with PDA are frequently described as intelligent, creative, or "unusually bright," and these characteristics may mask their surface-level social skills. Unlike people with more typical autism presentations, people with PDA often resist routines because routines inherently place demands on them. Despite being resistant to routine, people with PDA, like those with typical autism presentations, may still experience extreme anxiety or even meltdowns in response to unexpected change. As with classic autism and asperger's, people with PDA are prone to sensory overstimulation and sensory-seeking behaviors. Furthermore, sensory overload amplifies the anxiety and demand avoidance that individuals with PDA experience daily. People with PDA tend to be extremely sensitive to the emotions of others and experience overwhelming emotions and intense mood swings– this may lead to misdiagnosis of mood-related disorders, even though intense feelings are known to be common amongst PDA autistics (PDA Society).

PDA autistic children often do not respond to traditional parenting, therapy, or teaching methods. In fact, parents, clinicians, and teachers frequently fail PDA children by taking a behavioral approach to their challenges, using rewards and punishments to try to shape behavior. Unfortunately, rewards and punishments are perceived as losses of autonomy to PDA children, which may worsen their nervous system activation and ultimately lead to an increase in the behaviors their caregivers are trying to eliminate. For example, applied behavioral analysis (ABA) is considered the gold standard "treatment" for autism spectrum disorder; however,

ABA's heavy reliance on behavioral methods such as compliance, rewards, and praise is counterproductive for PDA autistic children. Behavioral treatments are clinician-led and tend to take control away from the child; this loss of control causes intense anxiety for PDA children and will ultimately cause an increase in meltdowns and avoidance behaviors, the opposite of what these treatments are intended to do. Instead, PDA children benefit most from parenting and treatment methods that prioritize their autonomy and choice.

Elizabeth Newson invented something called the PANDA method to support PDA autistic children:

Pick Battles: Minimize rules to eliminate expectation-related anxiety. Allow the child to have as much choice and control as possible. When an expectation or rule cannot be avoided, make sure to explain exactly why this rule or expectation must be in place.

Anxiety Management: Utilize low-arousal approaches. Reduce uncertainty. Recognize underlying anxiety, sensory, or social challenges that are driving behaviors. Treat meltdowns as panic attacks, providing co-regulation and moving on.

Negotiation & Collaboration: Proactively negotiate and collaborate to solve problems.

Disguise and manage Demands: Word requests indirectly. Monitor fluctuating demand tolerance and match accordingly. Complete tasks collaboratively.

Adaptation: Be as flexible as possible. Prioritize fairness and trust.

The PANDA method supports PDA children by prioritizing their autonomy and choice (PDA Society). Further, the PANDA method deviates from traditional behavioral methods by viewing behaviors as a result of underlying anxiety, sensory, and social challenges. Rather than trying to extinguish these behaviors or promote replacement behaviors through reward and punishment systems, the PANDA method treats these behaviors with anxiety management techniques, such as co-regulation. This method recognizes that PDA children must collaborate with their teachers, parents, and clinicians, and prioritizes healthy negotiation above blind compliance. PANDA is a necessary tool to help PDA children feel safe and supported, so that they can thrive.

PDA is a unique subtype of autism that requires awareness and support. People with PDA experience extreme anxiety triggered by everyday demands perceived as a threat to their autonomy. People with PDA do not avoid demands or expectations because they are oppositional or defiant, but because demands cause an involuntary fight-or-flight nervous system reaction that renders them unable to carry out demands without debilitating distress. Although people with PDA experience many of the same sensory and social challenges as those with typical presentations of autism, they do not respond to standard autism treatments. Standard ABA therapy is unable to support PDA children because it relies heavily on rewards, praise, and external consequences, which take control away from the child. Loss of control may lead PDA children to exhibit an increase in meltdowns and avoidance behaviors, rendering ABA therapy unhelpful or even harmful to them. Alternative methods, such as PANDA, that prioritize PDA children's autonomy and choice over compliance are most successful at supporting their needs. Unfortunately, most providers and educators do not know how to identify PDA and may continue the use of behavioral interventions even when they are not benefiting the PDA autistic

child. Formal recognition of PDA as a diagnosis and widespread awareness of PDA identification techniques are necessary to ensure PDA children receive the support they need.

Works Cited

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