

What is pathological demand avoidance?

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"Charlie" is an eight-year-old child with autism. Her parents are worried because she often responds to requests with insults, aggression and refusal. Simple demands, such as being asked to get dressed, can trigger an intense need to control the situation, fights and meltdowns.



Charlie's parents find themselves in a constant cycle of conflict, trying to manage her and their own reactions, often unsuccessfully. Their attempts to provide structure and consequences are met with more resistance.

What's going on? What makes Charlie's behavior—that some are calling "pathological demand avoidance"—different to the defiance most children show their parents or caregivers from time-to-time?

What is pathological demand avoidance?

British developmental psychologist Elizabeth Newson coined the term "pathological demand avoidance" (commonly shortened to PDA) in the 1980s after studying groups of children in her practice.

A 2021 <u>systematic review</u> noted features of PDA include resistance to everyday requests and strong emotional and behavioral reactions.

Children with PDA might show <u>obsessive behavior</u>, <u>struggle with persistence</u>, and <u>seek to control situations</u>. They <u>may struggle with attention and impulsivity</u>, alongside motor and coordination difficulties, language delay and a tendency to retreat into role play or fantasy worlds.

PDA is also known as "extreme demand avoidance" and is often described as a <u>subtype of autism</u>. Some people prefer the term <u>persistent</u> <u>drive for autonomy</u> or <u>pervasive drive for autonomy</u>.

What does the evidence say?

Every clinician working with children and families recognizes the behavioral profile described by PDA. The challenging question is why these behaviors emerge.



PDA is not currently listed in the two diagnostic manuals used in psychiatry and psychology to diagnose <u>mental health</u> and developmental conditions, the current Diagnostic and Statistical Manual of Mental Disorders (<u>DSM-5</u>) and the World Health Organization's International Classification of Diseases (<u>ICD-11</u>).

Researchers have <u>reported concerns</u> about the science behind PDA. There are no clear theories or explanations of why or how the profile of symptoms develop, and little inclusion of children or adults with lived experience of PDA symptoms in the studies. Environmental, family or other contextual factors that may contribute to behavior have not been systematically studied.

A major limitation of existing PDA research and case studies is a lack of consideration of overlapping symptoms with other conditions, such as autism, attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder, anxiety disorder, selective mutism and other developmental disorders. Diagnostic labels can have positive and negative consequences and so need to be thoroughly investigated before they are used in practice.

Classifying a "new" condition requires consistency across seven clinical and research aspects: epidemiological data, long-term patient follow-up, family inheritance, laboratory findings, exclusion from other conditions, response to treatment, and distinct predictors of outcome. At this stage, these domains have not been established for PDA. It is not clear whether PDA is different from other formal diagnoses or developmental differences.

Finding the why

Debates over classification don't relieve distress for a child or those close to them. If a child is "intentionally" engaged in antisocial behavior,



the question is then "why?"

Beneath the behavior is almost always developmental difference, genuine distress and difficulty coping. A broad and deep understanding of developmental processes is required.

Interestingly, while girls are <u>"under-represented" in autism research</u>, they are equally represented in <u>studies characterizing PDA</u>. But if a child's behavior is only understood through a "pathologising" or diagnostic lens, there is a risk their agency may be reduced. Underlying experiences of distress, sensory overload, social confusion and feelings of isolation may be missed.

So, what can be done to help?

There are no empirical studies to date regarding PDA treatment strategies or their effectiveness. Clinical advice and case studies suggest strategies that may help include:

- reducing demands
- giving multiple options
- minimizing expectations to avoid triggering avoidance
- engaging with interests to support regulation.

Early intervention in the preschool and primary years <u>benefits children</u> <u>with complex developmental differences</u>. Clinical care that involves a range of medical and allied health clinicians and considers the whole person is needed to ensure children and families get the support they need.

It is important to recognize these children often feel as frustrated and helpless as their caregivers. Both find themselves stuck in a repetitive cycle of distress, frustration and lack of progress. A <u>personalized</u>



approach can take into account the child's unique social, sensory and cognitive sensitivities.

In the preschool and early primary years, children have limited ability to manage their impulses or learn techniques for managing their emotions, relationships or environments. Careful watching for potential triggers and then working on timetables and routines, sleep, environments, tasks, and relationships can help.

As children move into later primary school and adolescence, they are more likely to want to influence others and be able to have more self control. As their autonomy and ability to collaborate increases, the <u>problematic behaviors tend to reduce</u>.

Strategies that build self-determination are crucial. They include opportunities for developing confidence, communication and more options to choose from when facing challenges. This therapeutic work with children and families takes time and needs to be revisited at different developmental stages. Support to engage in school and community activities is also needed. Each small step brings more capacity and more effective ways for a child to understand and manage themselves and their worlds.

What about Charlie?

The current scope to explain and manage PDA is limited. Future research must include the voices and views of children and adults with PDA symptoms.

Such emotional and behavioral difficulties are distressing and difficult for children and families. They need compassion and practical help.

For a child like Charlie, this could look like a series of sessions where



she and her parents meet with clinicians to explore Charlie's perspective, experiences and triggers. The family might come to understand that, in addition to autism, Charlie has complex developmental strengths and challenges, anxiety, and some difficulties with adjustment related to stress at home and school. This means Charlie experiences a fight, flight, freeze response that looks like aggression, avoidance or shutting down.

With carefully planned supports at home and <u>school</u>, Charlie's options can broaden and her distress and avoidance can soften. Outside the clinic room, Charlie and her family can be supported to join an inclusive local community <u>sporting</u> or <u>creative</u> activity. Gradually she can spend more time engaged at home, school and in the community.

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