

NEWS

# Pathological demand avoidance in autism, explained

BY PETER HESS

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Pathological demand avoidance (PDA) is a contentious term.

Over the past 40 years, some clinicians have used it to describe a set of personality and behavioral traits exhibited by autistic people who tend to refuse to cooperate with others' requests. But the term is missing from the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Diseases, which psychiatrists and psychologists use to make official diagnoses.

Those who favor the term say it has merit — if not as a diagnosis, then at least as a way to describe a personality type that is common among autistic people. Other professionals say it is too narrow and subjective to be clinically useful, and that it pathologizes an autistic person's preferences and autonomy.

Here we explain what scientists know about pathological demand avoidance and its connection to autism.

## How did the term originate?

The late **Elizabeth Newson**, professor of psychology at the University of Nottingham in the U.K., coined the term in 1983 to describe a syndrome in which a person resists and avoids the ordinary demands of life, even when complying is in their best interest. According to Newson, the syndrome's behaviors can include trying to distract the authority figure who made the request, making excuses, withdrawing into fantasy and avoiding meaningful conversations, possibly to such

a level as to lead to meltdowns or panic attacks. Signs of PDA typically manifest early in life, Newson noted.

Since then, she and other clinicians and researchers have **refined the definition** to emphasize how people with PDA use social strategies to avoid demands and to mask anxiety or underlying processing and communication issues. Newson and her colleagues also outlined how to deal with children who have a PDA profile, by using approaches that differ from those commonly used with autistic children, even though children described as having PDA have autism. Rather than providing the children with a highly structured routine, for instance, they emphasize novelty and variety.

Discussion of PDA has been **confined mostly to the U.K.** With social media dissolving international borders, though, people in the United States are gaining awareness of the concept.

### **What is the relationship between pathological demand avoidance and autism?**

Newson originally described PDA as a pervasive developmental disorder, different from ‘classic autism,’ as some then called it. She argued that it is a distinct syndrome on the autism spectrum — like Asperger syndrome, which was **folded into** ‘autism spectrum disorder’ with the publication of the DSM-5 in 2013.

More recently, clinicians and researchers have described PDA simply as a ‘**profile**,’ a group of behaviors that can be used to describe many autistic people, but not a distinct syndrome or diagnosis. The PDA Society, a U.K.-based nonprofit, describes PDA as “**a profile on the autism spectrum**.” And the U.K.’s National Autistic Society calls PDA a profile that first requires an autism diagnosis.

There is insufficient evidence to support PDA as an autism subtype or an independent condition, according to a 2018 **study**. Others say the concept is still useful, even if it is not concrete.

“My own clinical view is that it is a behavior profile seen in some autistic children and young people. However, it is not clear what this ‘profile’ is — it could be a personality type interacting with autism; it may be something else entirely,” says **Judith Eaton**, consultant clinical psychologist and research associate at King’s College London in the U.K. “I prefer to think about it as children with complex needs, who need an individualized support program, regardless of what we call it.”

### **Why is the term ‘pathological demand avoidance’ controversial?**

PDA has not found widespread acceptance with clinicians, especially in the U.S. Part of the issue is that even if PDA represents a real phenomenon, it means different things to different people, and it is unclear how useful the designation is, says **Catherine Lord**, distinguished professor of psychiatry and education at the University of California, Los Angeles.

More strident critics of the term argue that autistic people who assert their own choices that are contrary to their parents' or teachers' wishes are not exhibiting symptoms of a condition. They are simply **exerting their autonomy**, wrote **Damian Milton**, senior lecturer in intellectual and developmental disabilities at the University of Kent in the U.K. Calling this resistance 'pathological' rests firmly on the ableist preferences and values of the person whose demands are not being met.

Another problem is that PDA positions a pattern of behavior as a symptom of a diagnosable condition, without considering the context of the behavior, says **Devon Price**, clinical assistant professor of psychology at Loyola University in Chicago, Illinois.

This context includes which demands a child is refusing and why, Price says. Perhaps they need assistance or are exhausted. Or perhaps they do not want to go along with a task being forced on them, Price says. "If a child isn't on board with what's being demanded of them, then what we call PDA is actually a really powerful act of consent and self-advocacy."

Many educators and mental health providers expect children to comply with instructions, regardless of whether they understand or agree, Price says. "So any struggle or hesitation is pathologized."

### **What is the evidence in support of pathological demand avoidance?**

Few robust studies exist to either support or refute the validity of PDA, and those that do exist are small.

Children exhibiting a PDA profile likely make up a small percentage of the autistic population, and many seem to grow out of it by adolescence or adulthood, a 2014 population-wide **study** revealed. In a group of 27 children scoring high on measures associated with PDA, 26 had autism, according to a 2015 **study**. That study also showed that this group tended not to cooperate with authorities, using strategies such as apparent manipulation or attempts at shocking behavior to create a distraction. Avoidant behaviors in children described as having PDA are often triggered by phobias, novelty and uncertainty, a 2017 **study** reported.

Girls score higher on a measure of PDA traits, the Extreme Demand Avoidance Questionnaire (EDA-Q), than boys, according to a 2013 **study**. But researchers have not widely adopted the EDA-Q. Adults who score high on the EDA-Q tend to be antagonistic, disinhibited and disagreeable, according to a 2018 **study**.

"Larger-scale studies are needed, but I know from talking to people that there doesn't seem to be the interest or the appetite to pursue that as a research project," Eaton says.

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