# Reviewing the Current Evidence on Pathological Demand Avoidance in Children and Adolescents

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Over the past decade in the field of autism, there have been meaningful shifts in both our understanding and the language we use. There has been an increasing recognition of neurodiversity, a move toward strength-based approaches, and a deeper commitment to centering autistic voices in research and practice.

In recent years, in my own clinical work, I have seen a growing interest in "pathological demand avoidance" (PDA), also known as "pervasive drive for autonomy," among families, individuals, and colleagues. My work is primarily in diagnostic assessments (e.g., autism assessments for children 2 to 16), and during these assessments, families and individuals have often brought up PDA as a possible explanation for some of the challenges they face. Many also expressed concern that these experiences might be dismissed, and that they could leave the assessment process feeling unheard or unsupported. As such, I'm deeply grateful to the families who have trusted me to have these honest, often vulnerable discussions.

This article began as a personal effort to better understand PDA, shaped by ongoing conversations and shared questions within my clinical and professional network. The topics explored reflect the themes that often arise in my work with individuals and families seeking clarity and support. I was encouraged by my colleagues to share this information. As such, I hope this summary of current research offers helpful insights for both professionals and families. While not an exhaustive review, I've included references to key studies for those who want to explore further. If you find it useful, please feel free to share this document.

## 1. What Is PDA?

One of the ongoing challenges in understanding PDA is that it is not currently included in the DSM-5-TR (Diagnostic and Statistical Manual of Mental Disorders, published by the American Psychiatric Association) or the ICD-11 (International Classification of Diseases, published by the World Health Organization). These systems provide the standard frameworks for clinical diagnoses across mental health and medical settings. Without formal diagnostic criteria, there is less consistency in how PDA is identified and discussed.

That said, several groups and advocates describe PDA as a profile or subtype within the autism spectrum, often referencing the work of Dr. Elizabeth Newson, who first introduced the concept in her clinical research. The PDA Society describes it as:

"A profile found within some autistic people… [involving] a determined avoidance of so-called 'common' demands of life, including expectations and things the person enjoys doing. It is important to be aware that PDA is not just about demand avoidance."

(PDA Society, accessed July 13, 2025: https://www.pdasociety.org.uk/what-is-pda/)

Because there are several different definitions of PDA, I often ask the families and individuals I work with to share the specific description or source they're referring to. This helps me better understand their perspective and the particular behaviours or challenges they are concerned about.

## 2. A Historical Lens: Understanding PDA in the Pre-DSM-5 Era

Since the concept of PDA was first introduced by Dr. Elizabeth Newson, it is helpful to begin by understanding the diagnostic landscape during the time of her work. Dr. Newson coined the term in the 1980s, and her final study on the topic was published in 2003-well before the introduction of the current definition of Autism Spectrum Disorder (ASD) in the DSM-5 (2013).

At the time of her research, autism-related diagnoses were categorized under the broader term "Pervasive Developmental Disorders" (PDD) in the DSM-IV-TR (2000), which included:

- Autistic Disorder
- Asperger's Disorder
- PDD-Not Otherwise Specified (PDD-NOS)
- Rett's Disorder
- Childhood Disintegrative Disorder

Each of these subtypes had distinct diagnostic criteria. When the DSM-5 was released in 2013, these categories (excluding Rett's and Childhood Disintegrative Disorder) were merged into a single diagnosis: ASD. This shift aimed to improve diagnostic clarity, consistency, and access to services (Oberman & Kaufmann, 2020; Rosen et al., 2021).

It is important to recognize that Dr. Newson's work on PDA emerged in the context of these earlier diagnostic frameworks. As such, her findings should be interpreted within the DSM-IV context, rather than directly mapped onto the current definition of ASD.

## 3. What Newson's 2003 Study Actually Said

In Dr. Newson's original article, she proposed PDA as a separate entity within PDD, not as a subtype of autistic disorder or Asperger's syndrome. Her rationale included:

1. The term "autism spectrum" was too vague.
2. The diagnosis of PDD-NOS left parents in a state of uncertainty.
3. PDA presented differently enough from Autistic Disorder and Asperger's Syndrome to merit its own classification.

Dr. Newson emphasized the importance of labeling certain behaviours, arguing that by having PDA as a subtype, this grants more specific recognition to a large group of children and adults who might previously have been diagnosed with PDD-NOS. In doing so, the label helps validate the lived experiences of individuals and their families. Dr. Newson's 2003 study was based on observations of 150 children seen in her UK clinics between 1975 and 2000. At the time, children were described using the DSM-IV-TR framework, which focused on a "triad of impairment" in social interaction, communication, and repetitive behaviours.

While her study is often cited as a foundational source for understanding PDA, it is worth noting that Dr. Newson did not outline a specific diagnostic process for identifying PDA within her sample. Instead, her work reflected a clinical pattern she observed in some children that did not seem to fit neatly within the existing categories at the time.

PDA Criteria as reported by Newson (2003):

1) Passive early history in first year (e.g., often doesn't reach, drops toys, "just watches", delayed milestones)

2) Continues to resist and avoid ordinary demands of life (e.g., ranging from using words that are "socially manipulative" to physical outbursts)

3) Surface sociability but apparent lack of sense of social identity, pride, or shame (i.e., no negotiation with other children, doesn't identify with children as a category)

4) Liability of mood, impulsive, led by need to control

5) Comfortable in role play and pretending (e.g., behave with other children like the teacher-"thus seem bossy", enjoys dolls/toy animals)

6) Language delay, seems results of passivity (i.e., speech content usually odd or bizarre, repetitive questioning)

7) Obsessive behaviour (i.e., much or most of behaviour is carried out in obsessive way

8) Neurological involvement (e.g., clumsiness and physical awkwardness)

It is important to note that Newson's study was exploratory and had several methodological limitations, which is not uncommon in early-stage research. One key limitation was the lack of detailed information about her sample of 150 children. For example, she did not report cognitive ability, stating that "IQ in these children tends to be meaningless because of the severe demand avoidance, and alternative descriptive gauges of ability are used clinically." Additionally, the age at which children were identified varied widely (i.e., from 4 to 16 years) and no breakdown was provided, making it difficult to interpret the developmental context of the behaviours she described.

Without clear diagnostic characteristics of the sample, it is also challenging to understand whether some of the behaviours attributed to PDA may have been influenced by co-occurring difficulties. For instance: Was the avoidance driven by anxiety? Could differences in language or cognitive abilities have played a role? While these limitations do not diminish the value of Dr. Newson's early observations, they highlight the need for careful interpretation and further research to build a more complete understanding.

Dr. Newson's final study on PDA was published in 2003. Within the DSM-5 criteria of ASD, many of the challenges she described then would now fall within the broader ASD diagnosis. As such, whether she would have continued to view PDA as a distinct profile under today's ASD criteria is unknown.

**4. The Current Evidence Base: What We Know Now 22 Years Later**

Although Newson viewed PDA as distinct, recent literature often treats it as a profile within ASD. I've focused on two recent review papers examining the state of PDA research in children and adolescents (as I am a child psychologist):

**1) Kildahl et al. (2021)- Systematic Review**

- Included 13 peer-reviewed studies on PDA in youth,
- 11 of the studies were conducted in the U.K., 1 in the Faroe Islands, and 1 in Ireland.
- The studies reviewed indicate that some autistic children and adolescents show persistent avoidance of demands. However, the research reviewed was unable to clarify whether these

avoidant behaviours are distinct from anxiety, which is also commonly experienced alongside autism.

- Limitations of studies reviewed and areas for further research:

  -Most studies focused on parental reports

  -None of the studies explored the lived experiences of the individuals

  -Samples were drawn mainly from Western Europe

  -Overlapping samples recruiting through similar channels (e.g., Newson's clinic, the PDA Society UK and PDA conferences)

  -Lack of formal diagnostic processes or objective measures

  -Most studies only focused on the diagnoses of ASD and PDA and did not explore other neurodevelopmental conditions or mental health diagnoses

  -No study focused specifically on treatment

**2) Haire et al. (2024) – Scoping Review**

- Reviewed 22 studies (21 from the U.K., 1 from the Faroe Islands).
- Like Kildahl et al. (2021), Haire and colleagues also found that the research available points to a group of children and adolescents who exhibit extreme avoidance of everyday demands. Most of the studies reviewed focused on describing the symptoms and challenges associated with PDA, with less attention given to understanding its origins, triggers, or effective supports. More importantly, Haire and colleagues noted that the voices of PDA individuals were largely absent from the research.
- The authors noted that while the research reviewed provided some helpful foundational approaches to studying PDA in young people, there were still many methodological gaps that needed to be addressed prior to its use in clinical practice. Although avoidance behaviours were clearly observed, the authors indicated that further work is needed to determine whether PDA differs from other neurodevelopmental/mental health conditions where avoidance also occurs, and the team also highlighted a need to develop a clear and consistent definition of PDA.
- Limitations of studies reviewed and areas for future research:

  -Lack of standardized criteria for diagnosing PDA.

  -Use of convenience and clinical samples.

  -Minimal use of control groups or structured clinical assessments.

  -Overdependence on EDA-Q and DISCO (i.e., parent report measures)

**5. Clinical Impact and Considerations**

Dr. Newson's work on PDA emerged from a need to validate the experiences of families who were seeking explanations for behaviours that did not fit neatly within existing diagnostic categories at that time. The recent research studies clearly demonstrate that demand avoidant behaviours exist; however, the underlying causes remain uncertain. Ongoing research continues to investigate whether such difficulties stem from co-occurring conditions like anxiety, represent core features of autism, or reflect a distinct neurodevelopmental profile requiring a new label. The confusion and frustration often voiced by families

and individuals reflect just how important it is to deepen our understanding and refine our language. The growing interest in terms like PDA may also speak to something more personal-a sense that their experiences are not fully recognized or understood. From a clinical perspective, this may point to a need to consider assessing for co-occurring conditions alongside autism spectrum disorder, as outlined in the DSM-5-TR, so that these experiences are heard and reflected in assessment reports.

The ongoing conversation around PDA also invites us to reflect on history. Earlier editions of the DSM divided autism into subtypes such as Autistic Disorder, Asperger's Disorder, and PDD-NOS. Later research revealed these categories were often inconsistent and sometimes created obstacles to accessing support, leading to the more inclusive ASD diagnosis in the DSM-5. Since then, discussions have continued about whether a single category can fully capture the diverse support needs within the autism community.

Being neuroaffirming means supporting neurodivergent individuals and families with compassion and clinical integrity, grounded in solid evidence. As clinicians, we must listen with empathy while staying informed, so we can offer guidance that is both thoughtful and grounded, helping families navigate uncertainty with confidence. At this time, PDA remains a complex construct and currently has significant gaps in definition, assessment, and evidence. While interest in the topic continues to grow, especially among families and advocacy groups, the current research base lacks the methodological rigor needed to support formal clinical use at this time. However, given the evolving research, it will be important to continue monitoring developments in the field, ensuring that our understanding and approaches remain up to date.

## References

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