OREGON COMMISSION ON AUTISM
WHITE PAPER ON PATHOLOGICAL DEMAND AVOIDANCE
August 20, 2024

The purpose of this white paper is to provide professionals with scientifically- and legally-based information regarding the growing use of the term, Pathological Demand Avoidance (PDA, sometimes also referred to as Pervasive Drive for Autonomy), as it pertains to their work with autistic or potentially autistic individuals. This document is divided into two parts. The first summarizes the research, law, and personal and professional judgments of the Oregon Commission on Autism (OCA). The second discusses these points in greater detail and includes citations to the relevant research and law.

I. SUMMARY

The PDA label is being used with increasing frequency to describe a set of behaviors (mostly in children) related refusal or significant resistance to common, age-appropriate expectations. In some individuals this is accompanied by emotional and behavioral dysregulation that appears markedly disproportional to the nature of the expectation. However, PDA is not a separate or unique condition in the formal classification systems, laws, or practices governing health care, education, and social services. Some researchers are currently trying to determine whether it has distinct biological, social, or psychological bases, but even they acknowledge that the evidence so far is insufficient. Nor are there any evidence-based diagnostic tools or interventions specifically for extreme demand avoidance. Rather, in the clinical experience of professionals affiliated with OCA, extreme demand avoidance is better understood as a ***set of behaviors*** that may have any of a number of different causes.

OCA Position on Extreme Demand Avoidance

Because (1) reports of extreme demand avoidance and dysregulation have risen over the past the five years, (2) the reasons for behavioral or emotional dysregulation resulting from routine demands appears to be heterogeneous, (3) there are no evidence-based assessment tools or interventions specifically for individuals deemed to "have" PDA, and (4) many children and adults who display similar behaviors are not autistic, the Oregon Commission on Autism ("OCA") is urging state agencies to work together to develop more comprehensive guidance for professionals.[1] In the meantime, this paper begins to address a few topics relevant to caregivers and professionals who are faced with these behaviors in a child who has been identified as or is suspected of being autistic.

Terminology inconsistent with prevailing science, law, and practice causes confusion and delays in accessing appropriate services. Therefore, health care, education, and social service professionals should avoid using the term PDA as a diagnostic label and should clearly communicate with parents and patients/students/clients that extreme demand avoidance currently lacks a sufficient evidence base to be widely accepted in the scientific community as either a distinct stand-alone condition or a subtype of autism. They should also make clear that extreme demand avoidance by itself cannot be the basis for providing services in health care, education, or developmental disability services. Rather,

an individual will have to meet eligibility criteria for services within existing professional and legal categories, which do not include PDA or extreme demand avoidance.

By itself, extreme demand avoidance does not suggest that an individual is autistic. If there is a concern that a child or youth may be autistic and they have not been formally screened for autism, their health care provider should screen them as soon as possible using a validated autism screening tool. The individual should be promptly referred for a diagnostic evaluation if they screen positive. If they do not, other possible causes should be explored.

Educators to whom a child has been referred for a possible special education eligibility should follow their normal process for determining which type of evaluation to conduct.

Being able to handle reasonable everyday demands is an important life skill. This skill develops over time through compliance with increasingly complex demands. Extreme demand avoidance disrupts this learning process, resulting in problems for the individual and their community. Therefore, extreme demand avoidance should be investigated and addressed systematically. Professionals should not assume that parents or caregivers are the cause of the child's demand avoidance unless there is explicit evidence to suggest it. Whether or not an individual is identified as autistic, careful observation of the individual's responses in different contexts, comprehensive consideration of different areas of functioning, and a thorough developmental history may all be required to decide on the best course of action.

If traditional behavior management strategies are deployed but progress is not made within a reasonable period of time, professionals should trial nonconfrontational strategies, such as collaborative problem solving, that neither abandon important demands nor require strict adherence to all demands. If such strategies do not work, evidence-based formal interventions should be considered.

II. DISCUSSION

What Is Pathological Demand Avoidance and Why Are People Drawn to Using It?

PDA does not have a precise, widely accepted clinical definition, as acknowledged by at least some of those who are currently researching it.[2] Generally, PDA describes extreme resistance to or avoidance of everyday demands often coupled with emotional dysregulation (e.g., tantrums, meltdowns, aggression, destruction) when the demands persist. Extreme avoidance of demands occurs across ages, levels of functioning, and neurodevelopmental and psychiatric disorders, with different causes in each case.[3] In both the research literature and the clinical experience of professionals involved with OCA, these causes may include one or more of the following: (1) a response to demands placed upon the individual that exceed their developmental or biological capacity, (2) rigid adherence to traditional behavior management techniques that may work well for many, but that are either ineffective or escalate demand avoidant behaviors in others, (3) the failure to provide adequate individualized strategies, accommodations, or supports, (4) impacts of covid-era isolation on the socialization of young children, (5) the result of trauma or neglect related to caregiving, (5) the presentation of other

widely recognized mental health conditions (such as anxiety, depression, or oppositional defiant disorder), and/or (6) difficulties with attention or executive functioning.

As originally proposed by a British researcher in the 1980s, PDA was a new and unique constellation of symptoms distinct from any of the then-existing neurodevelopmental disorders. Its promoters hoped that it would be added to the major disease classification systems as a separate diagnosis.[4] However, the organizations in charge of revising these systems chose not to recognize PDA in their major revisions adopted in 1992, 1994, 2013, and 2019.[5]

Some recent conceptualizations of PDA view it as a subtype or profile within the autism spectrum, with extreme avoidance of reasonable, everyday demands caused principally by anxiety or fear responses. There are two problems with this idea. First, extreme demand avoidance appears in many individuals who are not autistic, as noted above. Second, based on the biological and psychological heterogeneity of the autism population and the failure of prior attempts at subtyping autism to produce consistent diagnoses, the organizations that establish diagnostic categories opted to reject subtyping altogether in favor of a single definition focused on the broad similarities across all autistic individuals. Under the DSM-5-TR, those similarities are: the presence of all three listed differences in social communication functioning and the presence of two out of the four listed restricted and repetitive behavior domains. The organizations that establish diagnostic categories also emphasized the necessity of understanding each autistic individual's unique array of physical and psychological characteristics. These specific characteristics, as much as any label, are critically important in determining how to care for and support an autistic individual. Building on the importance of individual differences, the neurodiversity movement advocates for respectful terminology and exploration of autistic individuals' interests and strengths, as well as their weaknesses. Autistic academics disagree about the merits of both the term PDA and its concepts.[6]

Nevertheless, some parents and affected individuals are drawn to the PDA label because it corresponds to what they experience and traditional behavior management strategies recommended by professionals in their lives haven't worked. Parents have reported that the behavior management strategies developed by advocates of the PDA construct have been helpful. They believe that the PDA label has helped then convince skeptical professionals that there is a genuine problem requiring further investigation and action. When parents go online, the information they find about PDA or extreme demand avoidance may also prompt the effort to get an autism diagnosis.

Some professionals appear to be drawn to the PDA label because traditional behavior management practices do not work in some children and they lack the training themselves or the availability of professionals who could help them determine the causes of the individual's demand avoidance.

Why the Concern About the PDA Label?

Increasingly, educators, health care providers, and disability services programs have experienced requests for autism evaluations or services for individuals who have been labeled with PDA. Many of these requests are made without an understanding of best practice and the regulations under which schools, health care services, and developmental disability services operate. This has the potential to

overburden scarce resources and delay access to the right services, not only for the given individual, but also for others seeking evaluation.[7] The goal should be to take the demand avoidant behavior seriously and follow a measured sequence of steps before referring for a diagnostic evaluation and initiating formal treatments.

Extreme demand avoidance and emotional dysregulation may indicate one out of seven core criteria for autism.[8] Therefore, extreme demand avoidance and emotional dysregulation do not automatically mean that an individual is autistic. Where autism is suspected for any reason and an individual has not been previously screened for it, their health care provider should screen them using a validated autism screening tool.[9] The individual should be promptly referred for a diagnostic evaluation if they screen positive. If they do not, other possible causes should be explored further. In school settings, educators should follow their regular processes for determining whether to evaluate a child for special education, and if so, under which disability category.

However, like the PDA label, a diagnosis or special education determination of autism does not in and of itself provide sufficient information to address extreme demand avoidance or emotional dysregulation in an individual. For this reason, professionals and parents do not have to await formal diagnoses or special education eligibility to begin to analyze the issues causing an individual's demand avoidance and emotional dysregulation.

When an individual is labeled with PDA, there is often a set of recommendations for managing their demand avoidance, sometimes by reducing demands to a minimum. Being able to handle reasonable, everyday demands is an important life skill. Therefore, it is important to determine ***why*** the individual is resisting demands, precisely ***which*** demands provoke their emotional dysregulation, and what strategies, accommodations, supports or interventions will help. This may require careful observation, a thorough developmental history, and formal assessments. It may also involve some trial and error.

Most of the recommendations for managing the behavior of children with extreme demand avoidance fall into the category of environmental accommodations or behavioral strategies. In the clinical experience of the professionals connected with OCA, some children with extreme demand avoidance and emotional dysregulation can benefit from consistent application of traditional behavior management techniques, but many do not. Most do, however, benefit from warmer and more nonconfrontational forms of interaction that neither abandon important demands nor require strict adherence to all demands.[10] In the case of autistic children, it is especially important to determine whether sensory issues are at play and whether there are nonobvious sources of anxiety. Autistic individuals, even verbally fluent and cognitively able ones who appear quite capable, may experience executive functioning issues or other co-occurring conditions that are not apparent without testing or focused consideration.

Behavior management strategies and accommodations do not rise to the level of formal interventions for which services are billed in health care or of specially designed instruction or related services that are provided in schools. If such strategies and accommodations do not lead to progress in accepting demands or regulating emotion, formal interventions should be considered.

With respect to assessments and treatments for extreme task avoidance, educators, health professionals, and disability service professionals are each subject to their own set of standards and regulatory requirements. Professionals within each system must follow them, regardless of information or concepts coming from another system or, more importantly, that do not correspond to the formal classification systems that underlie the funding and provision of their services. In Oregon, with respect to autism, health care, education, and disability services all use the definition of autism spectrum disorder set forth in the DSM-5-TR. ***PDA is not recognized as a condition for which services can be provided or billed in any of the major service systems.***[11] Instead, the individual must be assigned to a specified category to qualify for services:

(1) In the case of **health care services**, a behavioral health problem must fall under one of the conditions listed in the DSM-5-TR;

(2) In the case of **education services**, a child must meet the criteria for at least one of 12 special education eligibility categories set forth in Oregon law ***and*** require specially designed instruction in order to be eligible for special education services;

(3) In the case of **developmental disability services**, a child must either meet the criteria for developmental delay in young children or be diagnosed with one of a subset of developmental disabilities that is neurological in origin, causes significant impairment in adaptive functioning, and requires a level of training and support similar to that of people with intellectual disability.

If formal interventions are required, the health care, education, and developmental disability service systems are all subject to further regulatory standards requiring the use of validated tools and treatments that have proven to be effective. These standards require a substantial body of clinical or educational research that both follows accepted guidelines for conducting such research and demonstrates the validity of the instrument or the effectiveness of the intervention.[12] There are no assessment tools or treatments specifically for the PDA construct that meet these requirements.[13] By contrast, such tools and interventions exist for autism, anxiety, executive functioning, and some forms of emotional or behavioral dysregulation.[14]

Endorsing terms, tools, or interventions that fall outside the scientific consensus and existing regulatory frameworks for services has a number of significant negative consequences:

(1) It creates a set of expectations among parents and affected individuals that sets them up for delay, conflict, and failure when they seek services within systems that are required to use different terms and interventions. This creates mistrust, which interferes with establishing a positive therapeutic relationship in the interests of the individual receiving services.

(2) It imposes significant additional time and costs for service systems themselves to repeat evaluations and address the defeated expectations of parents or autistic individuals.

(3) It creates confusion among professionals. Most health care, education, and disability service professionals address a broad range of conditions. It is difficult for many of them to keep up with the

differences between officially accepted terms and evidence-based interventions, on the one hand, and informal terms or approaches that have not been similarly validated, on the other.

(4) To the extent that a term like pathological demand avoidance implies that demand avoidance is an inherent feature of an individual, when the cause may instead lie in the way that the affected person is being accepted, supported, and treated by those around them, there is a risk of unintentionally undermining neurodiversity-affirming practices.

(5) ***Labeling an individual with PDA does not aid in the process of determining the cause of an individual's task avoidance and emotional dysregulation***, which differs from individual to individual. ***Nor does it aid in determining the best approaches to reduce the individual's behaviors***. Sometimes demands being placed on an autistic individual are inappropriate because they exceed their biological or developmental capacities or their reasonable preferences. If not, anxiety, emotional or behavioral dysregulation, and executive functioning are all constructs that are well known in school and therapy settings. Evidence-based practices exist to address them and should be offered.

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[1] Some work of that kind is underway within the Oregon Department of Education in response to SB 819, which prohibits schools from shortening school days for special education students without the consent of their parents.

[2] This point is acknowledged both by those who are currently conducting research to explain and validate PDA and by those who believe it may turn out to be an unnecessary construct. Compare Green J. Commentary: Anxiety and behaviour in and beyond ASD; does the idea of 'PDA' really help? - a commentary on Stuart et al. (2020). Child Adolesc Ment Health. 2020 May;25(2):74-76. doi: 10.1111/camh.12379. Epub 2020 Mar 16. PMID: 32307845.
with Grahame V, Stuart L, Honey E, Freeston M. Response: Anxiety and behaviour in and beyond ASD; does the idea of 'PDA' really help? - a response to Green (2020). Child Adolesc Ment Health. 2020 May;25(2):77-78. doi: 10.1111/camh.12383. Epub 2020 Mar 27. PMID: 32307838.

A comprehensive review of research on PDA found that the studies are inconsistent, suffer from methodological weaknesses, or are largely based on anecdote or parent report. Kildahl, A. N., Helverschou, S. B., Rysstad, A. L., Wigaard, E., Hellerud, J. M., Ludvigsen, L. B., & Howlin, P. (2021). Pathological demand avoidance in children and adolescents: A systematic review. Autism, 25(8), 2162-2176. https://doi.org/10.1177/13623613211034382 .

[3] See, for example, Green, J. (2020). P.74. Intolerance of uncertainty, one of the mechanisms thought by some to be a main driver of PDA, is a transdiagnostic construct. Grahame V, Stuart L, Honey E, Freeston M. Response: Demand Avoidance Phenomena: a manifold issue? Intolerance of uncertainty and anxiety as explanatory frameworks for extreme demand avoidance in children and adolescents - a response to Woods (2020). Child Adolesc Ment Health. 2020 May;25(2):71-73. doi: 10.1111/camh.12376. Epub 2020 Mar 17. PMID: 32307840.

[4] Newson E, Le Maréchal K, David C. Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders. Arch Dis Child. 2003 Jul;88(7):595-600. doi: 10.1136/adc.88.7.595. PMID: 12818906; PMCID: PMC1763174.

[5] American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders (4th ed).* American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.) (DSM-5). World Health Organization. (1992). International Classification of diseases 10th Revision. World Health Organization. (2019). International Classification of diseases 11th Revision. https://www.who.int/standards/classifications/classification-of-diseases (2024). *Clinical descriptions and diagnostic requirements for ICD-11 mental, behavioural, and neurodevelopmental disorders.* https://iris.who.int/bitstream/handle/10665/375767/9789240077263-eng.pdf?sequence=1

[6]Moore A. (2020). Pathological demand avoidance: What and who are being pathologised and in whose interests? *Global Studies of Childhood*, 10(1), 39–52. https://doi.org/10.1177/2043610619890070. Woods R. Commentary: Demand Avoidance Phenomena, a manifold issue? Intolerance of uncertainty and anxiety as explanatory frameworks for extreme demand avoidance in children and adolescents - a commentary on Stuart et al. (2020). Child Adolesc Ment Health. 2020

May;25(2):68-70. doi: 10.1111/camh.12368. Epub 2020 Jan 16. PMID: 32307844. Milton D. E. (2013). 'Natures answer to over-conformity': Deconstructing pathological demand avoidance. *Autism Experts*. https://kar.kent.ac.uk/62694/.

[7] Wait lists for autism evaluations at major diagnostic centers vary, but can be as long as several years. A large percentage of children and youth who are referred have not been screened and many are determined not to have autism. However, almost all have some condition requiring professional attention.

[8] It is unclear which of the 7 autism criteria in the DSM-5-TR extreme demand avoidance would fit into, but there are clearly others that do not seem to match well with it. The British National Institute for Health and Care Excellence (NICE) has issued guidelines that include "Unusually negative response to the requests of others (demand avoidant behaviour)" as one of numerous social interaction "Features suggesting possible autism" in under 19s. National Institute for Health and Care Excellence. (2017). Autism Spectrum Disorder in Under 19s: recognition, referral, and diagnosis. Appendix: Features suggesting possible autism. https://www.nice.org.uk/guidance/cg128/chapter/Appendix-Features-suggesting-possible-autism . However, this is far from stating that all children with this feature have autism. Moreover, Britain uses different criteria for the identification of autism.

[9] Hyman SL, Levy SE, Myers SM; Council on Children with Disabilities, Section on Developmental and Behavioral Pediatrics. Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. Pediatrics. 2020 Jan;145(1):e20193447. doi: 10.1542/peds.2019-3447. Epub 2019 Dec 16. PMID: 31843864. https://publications.aap.org/pediatrics/article/145/1/e20193447/36917/Identification-Evaluation-and-Management-of P. 7. A list of such tools can be found at the American Academy of Pediatrics' website: https://publications.aap.org/toolkits/pages/asd-screening-tools?autologincheck=redirected.

[10] One such strategy is the Collaborative and Proactive Solutions (CPS) approach developed by Ross Greene, which is suitable for some children who are extremely task avoidant. The Oregon Health Authority provides free trainings for parents on CPS: https://www.eventbrite.com/cc/collaborative-problem-solving-for-oregon-parents-167339. It is beyond the scope of this paper to provide a complete list of strategies and supports because they will depend on the specific issues of the individual.

[11] Within health care in the United States, as noted above, the DSM-5 lists the mental health conditions recognized by the medical profession in the United States and establishes criteria for diagnosing them. Each condition corresponds to a billing code based on the ICD-10 (ICD-11's predecessor). Federal regulations require that health professionals and payers use the ICD-10 for billing. 45 CFR Part 162. (The switch to ICD-11 is expected to occur later in this decade.) Without an ICD-10 billing code, health care professionals cannot bill for autism-related services. While a recent change to Oregon's Medicaid plan requires the Oregon Health Plan to cover all "medically necessary" services, regardless of whether a child has been formally diagnosed with autism, the OHP may still require some evidence of a diagnosable condition in order to determine that the services are medically necessary.

The DSM-5 criteria for autism spectrum disorder have also been incorporated into Oregon's special education eligibility rules for this educational category. OAR 581-15-2130. Similarly, in order to qualify for developmental disability services past early to middle childhood, individuals must receive a medical or clinical diagnosis of either intellectual disability an "other developmental disability." OAR 411-320-0080(4)(a). Because state developmental disability services are funded by Medicaid, Oregon is required to use DSM-5 and CPT-10 terminology. (Young children may qualify for services under the category of "developmental delay," but there is no category for PDA.)

[12] In special education, the use of evidence-based practices is required by the Individuals with Disabilities Education Act §1414(d)(A)(IV). In health care, evidence-based treatments are the bedrock of medical necessity determinations before health care payers will pay for a service. See, for example, ORS 410-172-0630(2)(b) governing Oregon Health Plan payment for behavioral health services. Again, any health care services provided to recipients of developmental disability services must meet this requirement.

[13] The sole tool developed to assess for PDA has not been statistically validated and is acknowledged by supporters of the PDA construct to possess methodological flaws. Grahame, V. (2020). P. 71.

[14] By contrast, the Collaborative and Proactive Solutions program cited in note 10 above has a research base for effectiveness in a variety of conditions. Greene R, Winkler J. Collaborative & Proactive Solutions (CPS): A Review of Research Findings in Families, Schools, and Treatment Facilities. Clin Child Fam Psychol Rev. 2019 Dec;22(4):549-561. doi: 10.1007/s10567-019-00295-z. PMID: 31240487.