

Title:

Is Pathological Demand Avoidance a “meaningful subgroup” of autism?

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Abstract.

Pathological Demand Avoidance (PDA) is a proposed Mental Disorder, from Elizabeth Newson, in the United Kingdom. While excluded from the two main diagnostic manuals, PDA has garnered much interest and controversy. While originally viewed as a new type of syndrome, a Pervasive Developmental Coding Disorder. Presently there is much focus on PDA as an Autism Spectrum Disorder (ASD), that ignores broader discussions around how PDA should be clinically viewed. Due to arguments against doing that in favour of diagnosing PDA as an ASD. Charting the history of PDA from Newson’s research, through to how four main divergent schools of thought developed. From PDA being viewed as rebranded autism through to symptoms resulting from the interaction between autism and common co-occurring conditions. Conceptualising PDA as a common mental disorder best conforms to Newson’s opinions and research. Various empirical research supports this outlook. PDA can be diagnosed and researched independently of autism. Such an approach is needed to allow its full nature to become clear through scientific-method research.

Key Words.

Autism Spectrum Disorder; Asperger’s Syndrome; Autistic Disorder; Demand Avoidance Phenomena; Extreme demand avoidance; Pathological Demand Avoidance.

Introduction.

Proposed in 1980 as a new syndrome, Pathological Demand Avoidance (PDA) is, typically viewed as an Autism Spectrum Disorder (ASD). The defining feature of PDA is its’ titular avoidance behaviours that are frequently extremely difficult for all stakeholders to effectively regulate [1]. Image 1 shows how the Aggregated PDA Profile relates to the Diagnostic Statistical Manual of Mental Disorders, 5th Edition (DSM-5) ASD criteria. The former is composition of the four other PDA behaviour profiles in print [1; 2; 3; 4], highlighting how unstable PDA is in clinical practice [2; 5; 6].

PDA has limited social communication problems and Restricted and Repetitive Behaviours and Interests (RRBIs). PDA Surface Sociability frequently has a confused worldview and is not caused from Theory of Mind or Empathy deficits. This feature partially overlaps ASD due to 20% of autistic Child and Young persons (CYP) passing a Theory of Mind test [7]. Additional overlapping traits include Delayed Speech Development, Neurological Involvement and Passive Early History. Autistic persons often have poor coordination. Delayed speech development is common in ASD [1; 8], being a diagnostic trait of Autistic Disorder in the DSM-IV [9]. The DSM-5 added Sensory issues to ASD and this overlaps one PDA article that conceptualises PDA as neurodevelopmental in nature [4]. There are important clinical differences between PDA and autism. PDA has more RRBIs than autism as much or most of PDA behaviours are obsessive in nature [1]. These are anxiety based due to high anxiety being its central impairment [10; 11; 12]; however, Newson's work occasionally refers to panic and fear, but her article does not mention anxiety [1]. Anxiety is a recognised co-occurring problem to autism [12; 13; 14]. PDA has superficial similarities with ASD¹.

Image 1: Abbreviated DSM-5 Autism Spectrum Disorder² criteria and the Aggregated PDA Profile.

PDA is surrounded by much controversy [2; 4; 5; 10;14; 15]. Numerous factors contribute to this situation, a pivotal one is there is no consensus over how to clinically view it. The four main schools of thought on PDA are: PDA is a rebranded autism as its features are seen throughout the autistic population; an Autism Spectrum Disorder; a pseudo-syndrome resulting from interaction between autism and various co-occurring conditions; a common mental disorder. This article presents an overview of these outlooks, by situating each in the historical context of autism and PDA research.

¹ Others may disagree with this interpretation of PDA and how it relates to autism.

² Wording for the DMS-5 Spectrum Disorder criteria is from:

Evers K, Maljaars J, Carrington S, Carter A, Happé F, Steyaert J, Leekam S, Noens I (2020) How well are DSM-5 diagnostic criteria for ASD represented in standardized diagnostic instruments? *European Child & Adolescent Psychiatry*. doi: <https://doi.org/10.1007/s00787-020-01481-z>

Newson's Autism and PDA research.

Elizabeth Newson started collecting cases of PDA from her 2 clinics in Nottingham, United Kingdom (UK) in 1975 and initially presented PDA at a lecture in 1980 [1]. At a similar time, Newson and colleagues at the University of Nottingham conducted research into autistic adult experiences, as part of this participants were diagnosed utilising the Triad of Impairment of Wing and Gould. This study's participants had normal or near normal intelligence, many participants would meet criteria for Asperger's Syndrome [8]. Newson was aware of the Triad of Impairment and a broader autism spectrum that would become widely adopted throughout the 1980s. Newson created her own, new diagnostic grouping called Pervasive Developmental Coding Disorders, which she used at least from 1986 to 1996. This grouping included autism, PDA, dysphasia and dyslexia. This was done as the autism spectrum was too narrowly defined and to allow dyslexia to be included. Likewise, it makes more sense to lay people like parents. Newson worked in a specialist Coding Disorders clinic and in 1986 she questioned what the coding problems are found in persons with PDA [16; 17]. Importantly, the Pervasive Developmental Coding Disorders grouping contains non-autistic persons.

In 1988 Newson analysed 36 PDA case files to reify its behaviour profile, including coding problems in social identity, pride and shame [16; 17]. Newson spent the next 15 years researching this behaviour profile and only refines it make it easier to construct diagnostic arguments [1]. Over this time period Asperger's Syndrome is formerly accepted into the main diagnostic manuals and the autism spectrum emerges in clinical practice [8]. Simultaneously, another 84 cases of PDA are added to Newson's database to 120, indicating more than three times as many individuals with PDA per year are being seen in Newson's clinics. Considering many persons with PDA, would often be considered for a diagnosis of atypical autism or Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) [1; 11]; the sudden rise in cases of PDA appears to be caused by broadening of the autism spectrum in wider society. In 1996 Newson presented data comparing 40 autistic persons to 50 persons with PDA [16]. Newson, never systematically investigated autism features in persons with PDA [18], and excluded atypical PDA cases, often because a person presented atypical autism features. Nor collected data on their intelligence, arguing the latter is not representative of their ability due to their obsessive demand avoidance [1].

In between 1996 to 2003 Newson transitioned away from her Pervasive Developmental Coding Disorders diagnostic grouping for PDA. First produced in 1999 [19] and revised this in 2003 to “*The “family” of pervasive developmental disorders*” [1]. The later diagram displays 4 constellations of symptoms each representing a syndrome, Autistic Disorder, Asperger’s Syndrome, PDA and Specific Language Impairment. The former two syndromes are drawn overlapping each other with 3 symptoms of the Triad of Impairment of the “autistic spectrum”³ and connected to the latter 2 through genetic and other links. PDA is displayed independently of the other syndromes, with 6 core symptoms, and not based on the Triad of Impairment [1]. Supporting Newson’s outlook PDA needs to be significantly different to Autistic Disorder and Asperger’s Syndrome [1].

In the Newson et al supplementary notes⁴, the authors argue against conflating the autistic spectrum with the Pervasive Developmental Disorders. Additionally, explicitly stating PDA is a Pervasive Developmental Disorder, not an ASD, and it would be a mistake to view PDA as such. An interesting point is that each person with a Pervasive Developmental Disorder has a coding issue [1], which are not included in the diagnostic grouping descriptions in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) [9]. Newson’s definition of Pervasive Developmental Disorders is broader than what is accepted and included non-autistic persons due to including non-autism conditions. Likewise, Newson’s PDD-NOS definition is when a person does not meet clinical threshold for either autistic spectrum, PDA and Specific Language Impairments [1], thus it includes non-autistic persons. This is broader than accepted PDD-NOS definition in the DSM-IV, which is intended for persons not meeting clinical threshold for Autistic Disorder and Asperger’s Syndrome [9]. Newson’s position that PDA is not autism, does not translate well into modern diagnostic practices and this contributed towards a few opposing schools of thought on PDA.

Newson was also an autism expert and appears well versed in its UK literature from the early 1980s onwards. Over the course of her PDA research Newson espoused atypical views on PDA nosology that did not conform to

³ Newson et al refer to “Autistic Spectrum” as comprising Autistic Disorder and Asperger’s Syndrome.

⁴ Newson and colleagues’ supplementary files can be accessed below:

<https://adc.bmj.com/content/archdischild/suppl/2003/07/02/88.7.595.DC1/887595supportingmaterial.pdf>

accepted understandings; Newson's two proposed diagnostic groupings reflected the conditions she would see as part of the Coding Disorder clinical practice [1; 16; 17]. Consequently, both diagnostic groupings contained non-autism conditions and autistic persons. Newson repeatedly ignored opportunities to make PDA conform to ASD understandings, like basing PDA behaviour profile on the Triad of Impairment. Nevertheless, other contemporary autism experts disagreed with Newson, proposing it was simply variation of features within the autism spectrum, and this is detailed next.

PDA is rebranded autism.

In 2002 prominent autism clinicians Lorna Wing and Judy Gould suggested that PDA is not a distinct syndrome but features of PDA can be found throughout the autistic population. Both viewed PDA to be clinically useful [15; 20] and developed unpublished PDA Diagnostic Interview for Social and Communication Disorders (DISCO) items⁵ [2; 5; 11; 18; 21]. Wing separately argued it remains to be seen if PDA is a distinct syndrome [22]. Newson and colleagues counter in their supplementary notes, that PDA is not just Asperger's Syndrome, and there are crucial clinical differences between the two conditions. Autistic academic Damian Milton posited in 2013 that there is no characteristic specific to PDA and its features can be found in autistic persons; for instance, comfortable in role-play and pretend are displayed by successful autistic actors. Milton contests that differences between autism and PDA evaporate under scrutiny [20]. Building on Milton's deconstruction, Allison Moore argues that PDA is the pathologising of autistic persons for transgressing various cultural norms, primarily through asserting their self-agency [23]. Such viewpoints are to be expected considering there is no feature specific to either autism or PDA [11; 15; 20; 22; 24; 25]. Probably contributing to similar perspectives that PDA is an autism subtype or subgroup.

Scholars reviewing Hans Asperger's case studies for autism have found features of PDA, observing spiteful or malicious behaviours might be triggered without warning [26; 27]. Lorna Wing comparing Leo Kanner's and Asperger's respective work, note they both contain examples of behaviour problems, aggressiveness towards people and damaging objects. Relevant features of Kanner's work include a remarkable ability to mimic other people's actions, up to entire sequences of performances. This was done automatically, without understanding

⁵ Sources contradict each other if there were 17 [11], or 15 original PDA DISCO questions [2;21].

the meaning of the copied behaviours. Most striking of all is an obsessive high anxiety for perseverance of sameness, when extreme behaviours, such as tantrums and conduct problems are triggered when the environment is unexpectedly changed. Such reactions can be expected from autistic persons, from every attempt to interact with them that is not on their terms [8]. When presented with this overlap between PDA and early autism clinical literature, one can empathise with why some view PDA to be inherently autism.

PDA was a Pervasive Developmental Disorder and is now an Autism Spectrum Disorder.

Drawing upon Newson's 1999 diagram, it was first argued that PDA was part of the autism spectrum in 2007. In this diagram PDA is grouped in the Pervasive Developmental Disorders, with Autistic Disorder, Asperger's Syndrome and PDA. It is worth noting that accepted Pervasive Developmental Disorders of Childhood Disintegrative Disorder and Rett's Syndrome are missing. Through the public commonly referring to Pervasive Developmental Disorders as the Autistic Spectrum, PDA is therefore an Autism Spectrum Disorder [15]. This argument is later expanded upon to argue that as our understanding of PDA evolves, its list of traits will reduce as autism has to the Triad of Impairment [11]. Due to Newson's broader definitions for Pervasive Developmental Disorders, the logic that PDA is an ASD has been used to include non-autism conditions of Attention Deficit Hyperactivity Disorder (ADHD), dyslexia and dyspraxia in the autism spectrum [12]. The two main justifications for PDA being an ASD are that PDA best explains certain behaviours. Subsequently, these individuals need different educational approaches to other autistic persons, like requiring, novel, spontaneous and humorous approaches [1; 15; 16; 17]. Hence, PDA is receiving substantial interest and support by some UK organisations.

Key articles repeatedly discuss the interest in PDA in the UK and refer to activities of organisations that support the outlook that PDA is an ASD [2; 5; 10]. Particularly, they mention the inclusion of education guidelines by the Autism Education Trust (AET) and over-subscribed annual conferences held by the National Autistic Society. However, they do not provide wider pertinent information. The Autism Education Trust director at the time of these articles is line-managed by the National Autistic Society [28]. One co-author of these articles being on various AET boards [29]. The National Autistic Society recognised PDA in 2008⁶. The information

⁶ See page 4 and 12 of Pathological Demand Avoidance Syndrome: Awareness Matters:

displayed on the charity's website about PDA was controlled by the PDA Development Group⁷, with some of its members being authors of key articles [2; 5], and the Lorna Wing Centre is represented within this group.

Despite the recognition by AET and the National Autistic Society, PDA is not diagnosed universally across the UK [30] and remains controversial.

Wing et al [31], draw upon their clinical experience, expressing it is hard to mark the boundaries between autism subtypes and other conditions, partially because of how autistic persons often transition between subtypes. They went on to note such challenges apply to all proposed subtypes, as the paper mentions PDA these issues are applicable to it. This is supported by Newson's observations that persons can transition into any condition in her diagnostic groupings, including PDA [1; 17; 19]. Empirical research suggests a range from 30% of autistic CYP developing into a different subtype [32], and up to 86% of autistic persons receive an alternative form of autism diagnosis. Considering this figure is from 2012 [33], it is unlikely to include PDA diagnosis. A study analysing diagnostic patterns for 12 autism clinics, found the best predictor of which certain subtype a person was diagnosed with was the exact clinic they attended [3; 34; 35]. Research investigating differences between High Functioning Autism and Asperger's Syndrome found either no significant differences or resulting from circular practices [35]. This body of evidence strongly suggests that if PDA is shown to be different to autism, it is not part of the autism spectrum.

A leading PDA expert suggests debating the nature of what PDA might be is a distraction from diagnosing PDA as an ASD [11; 15; 29]. Possibly explaining why O'Nions and colleagues ignore the rationale of the Neurodevelopmental Disorder Workgroup's for removing autism subtypes from the DSM-5 [2]: (1) There is no evidence for differential treatment between subgroups; (2) Negligible differences between groups of autistic persons who met the clinical threshold for Asperger's Syndrome (i.e. had no speech delay) and other subgroups; (3) to reduce the stigma for all autistic persons [34]. PDA was considered for inclusion for the DSM-5 but was

<http://www.pdaresource.com/files/pda-awareness-matters-booklet.pdf>

⁷ See PDA Development Group Terms of Reference 2016 for more information:

<https://rationaldemandavoidancecom.files.wordpress.com/2020/08/pda-development-group-tor-july-2016.pdf>

discounted due to a lack of evidence and not being well-known in the USA. This begs the question: why did O’Nions and colleagues attempt to produce a meaningful ASD subgroup?

The argument that persons with PDA require different strategies quickly falls-down when contextualised in wider discourses. Many autistic persons do not respond well to typical autism approaches [20], and so require person-centred approaches. Plausibly explaining why comparable approaches are widely practiced independently of PDA [36], and that PDA strategies are viewed as being good practice [27]. Crucially, most interventions and approaches are symptoms or issues specific, and are often used widely among mental health disorders, including autism adjustments like visual communication methods. Many clinicians do not find the disorders within the DSM-5 useful when selecting treatments and determining prognosis [37]. Still, if one accepts that PDA does exist and that it should be diagnosed; logically, all persons who meet its profile have equal rights to receive a diagnosis, support and research, irrespective of if they are autistic or not.

By adopting Newson’s early views on Pervasive Developmental Disorders, it can be argued that PDA is an ASD via the public conflating the diagnostic grouping with the autistic spectrum. Consequently, PDA needs to be accepted as an ASD as it better explains actions of some autistic CYPs, and these have different educational needs to the rest of those on the spectrum. Yet, most of the logic does not stand up to investigation. Partly because it overlooks Newson’s views and actions in how PDA relates to autism. Furthermore, because it is apparent that autism cannot be successfully divided, both scientifically and clinically. The next outlook for PDA is that it is a common mental health disorder.

PDA is a common mental health disorder.

Since Newson et al published their research; there have been consistent views that PDA might represent a variety of non-autism conditions. In 2003 Elena Garralda posited PDA features might be explained by either: ADHD, Oppositional Defiant Disorder, Social Anxiety Disorder and that persons with PDA displayed possible signs of Schizotypal Personality Disorder [24]. Later it was suggested that PDA might be a form of trauma-based constructs, either an Attachment Disorder or Personality Disorders [15]. Furthermore, PDA might

be a common disorder [38], seen in up to a few percent of certain populations [21]; specifically: Anorexia Nervosa, some behavioural phenotype syndromes, Epilepsy, Japanese construct of Hikikomori, Language Disorders, school refusal and selective mutism [38]. Other candidate PDA populations include: Anxiety Disorders; Catatonia; Conduct Disorder; depression; dyslexia; dyspraxia; Schizophrenia [27]. Generally, these predictions and supporting evidence is based on and based on Newson's behaviour profile [15; 21; 24; 38]. Moreover, low diagnostic thresholds; for instance, PDA is defined as a score of 5 or more on the original PDA DISCO questions and including the presence of socially manipulative *or* shocking behaviour to avoid demands [21]. While Newson and colleagues stated social manipulative demand avoidance was *universal* in PDA. This outlook for PDA best fits Newson's original conceptualisations.

Features of PDA make it problematic conceptualising it as an ASD. Firstly, PDA has a more balanced gender ratio than autism. Secondly, the structure and routine of traditional autism approaches contrast to PDA strategies that involve humour, spontaneity and unpredictability. Thirdly, the PDA characteristics of preoccupation for pretend/ role-play/ difficulty telling pretence from reality; regularly are either absent or delayed in autism [10]. Fourthly, the variety and frequency manipulative behaviours displayed in PDA are not associated with autism [12; 18; 21]. Fifthly, the surface sociability difficulties in PDA are attributed to deficits in social identity, shame and pride, not to Theory of Mind [1], which matters as autistic social communication difficulties are associated with the latter theory. Sixthly, PDA central impairment is high anxiety, but anxiety is a known co-occurring problem to autism [12; 13; 14]. Seventhly, PDA has a high rate of CYP not meeting the clinical threshold they develop, from 44% - 89% [2; 21]. This is higher than equivalent figures for autism, of 0% - 47% [33]. Majority of these characteristics can form differential markers between PDA and autism for purposes of diagnostic assessment.

Limited evidence exists to support PDA as a common mental health disorder. There are examples of non-autistic persons in PDA research [2; 18; 27; 39]. Moreover, a case study into PDA and Antisocial Personality Disorder is another promising candidate, with signs of attachment problems, substance abuse, diagnoses of ADHD and dyslexia⁸ [12]. The latter a possible explanation of PDA behaviours [36]. A medium sized clinical research

⁸ I have been informed the ADHD diagnosis has been removed since the article was published.

sample indicates that PDA is predicted by High anxiety, ADHD and conduct problems [3]. This association is also supported by more recent research indicating PDA is predicted by ADHD, emotional instability and antagonism. The same research replicated prior results that PDA is associated with precursors of Personality and Personality Disorders⁹, and not autism [14; 40]. This evidence supports critique that PDA might be a “double-hit” that it is not caused by autism in autistic persons [31]. Also, ADHD, conduct problems and Personality Disorders can be linked to the environment, poor early caregiving and attachments [41; 42].

Newson argued that PDA and other syndromes in her Pervasive Developmental Disorder grouping were entirely biological or genetically caused [1; 19]. The claim was later repeated in the literature [27]. This outlook is contrasted by those who suggested PDA might be a form of trauma related conditions like Attachment Disorder. Damian Milton countered that it is plausible that autistic persons can be traumatised by social interactions and this can cause some of the demand avoidance seen in PDA; that it is potentially negligent by negating such possibilities [20]. It has been noted that PDA behaviours can be explained by aversive experiences [20; 43]. More recently, Newson’s work has been contextualised in broader clinical literature that disorders in DSM-5 lack any biomarker evidence that can be used for diagnostic purposes [27]. Presently, we are moving to a transactional understanding of PDA, where an individual’s situation and environment mutually interact together [3; 20; 29; 36]. Research suggests there is no specific anxiety intrinsically related to autism, yet autistic anxiety tends to be caused by hostile experience from interacting with others [44]. Newson and others were incorrect about PDA’s aetiology instead it is likely related to trauma and aversive experiences.

Other empirical studies support the view PDA is not an autism spectrum disorder. Theory of Mind is strongly associated with autism, with some viewing it as synonymous with it [7; 11]. Ellie Bishop investigating the relation between Theory of Mind, autism and PDA, found associations between the theory and autism, while no association between PDA and Theory of Mind [45]. Accounting for this evidence it is possible that many of the “false positives” on the EDA-Q, are positive identifications of PDA, but are being misattributed due to belief

⁹ The hypothesis that CYP with PDA shows precursors for Schizotypal Personality Disorder awaits direct empirical testing.

PDA is a form of autism¹⁰. As all attempts to divide autism have failed, Newson et al [1] and O’Nions et al [2] respective research indicate PDA is not an ASD. O’Nions et al used features that are atypical of autism to try to make PDA a meaningful subgroup of autism, primarily selecting features that were seen in less than 30% of their sample [2]. If a feature is seen in less than 30% of the autistic population, it is unlikely to be related to core autism traits, represented by the Dyad of Impairment, but instead associated to common autism co-occurring conditions [27]. Hence, explaining various studies indicating PDA is not an ASD.

From its inception there has been significant debate within the PDA literature around what it might be besides autism. Originally, Newson conceptualised PDA as a new type of disorder, she did not base PDA on the Triad of Impairment that still underpins autism diagnostic criteria [9; 46]. There are clear clinical differences between PDA and autism, which is supported by a growing body of empirical literature. Particularly, modern PDA understandings focus on transactional interactions between the environment and person with PDA [3; 20; 29; 36], indicating it is possible a person can become sufficiently distressed enough to display PDA, especially on lower diagnostic thresholds. It appears erroneous to take it as an axiom PDA is an ASD.

PDA is symptoms resulting from the interaction of autism and common co-occurring conditions.

Langton and Frederickson propose that PDA is a “triple-hit” of autism, conduct problems and anxiety [6], due to small scale research finding associations between PDA and these constructs [10]. This perspective is like the suggested “double-hit” of PDA, which mirrors hypotheses PDA might be interaction of autism and anxiety, or autism and attachment problems [4]. These suggestions fall into a separate school of thought, that PDA is a pseudo-syndrome resulting from the interactions of autism and common co-occurring conditions [3]. This makes sense in autistic persons are most likely to attract a PDA diagnosis [23].

¹⁰ For example, see unpublished research here:

<https://network.autism.org.uk/sites/default/files/ckfinder/files/Differential%20diagnosis%20between%20PDA%20and%20attachment%20disorder%20-%20Dr%20Judy%20Eaton.pdf>

Autism and co-occurring conditions often simultaneously interact and affect how autism and the comorbid conditions are presented and experienced [3; 41; 43]. Consequently, co-occurring conditions frequently have slightly different characteristics inside and outside of autism. For example, co-occurring anxiety is typically associated with sensory sensitivity and cognitive misinterpreting. When this occurs in autistic CYP, it can be overwhelming, leading to intense anxiety that potentially adds to emotional dys-regulation or avoidant and controlling actions [3]. It is probable that PDA presents slightly differently in non-autistic populations when compared to autistic persons. A small-scale study produced results that led to the suggestion PDA might be a “triple-hit” of autism, conduct problems and anxiety [10]. It must be said if PDA contains features of non-autism conditions, then it cannot be an ASD.

This article has charted the historical PDA literature from Elizabeth Newson’s formative research through to the development of four distinct schools of thought over its proposed medical ontology. Newson viewed PDA as a standalone diagnostic entity and took steps to support this view, such as excluding autistic persons from her database [1]. Before Newson and colleague’s work was published in 2003, contemporary ASD clinicians in 2002 were arguing PDA is not a distinct syndrome but it reflects features common in the autistic population [11; 15; 20; 22]. Utilising Newson’s initial 1999 conceptualisation for the Pervasive Developmental Disorders it was assumed PDA is an ASD due to the public conflating the broader diagnostic grouping with the autism spectrum [11; 15]. Contradicting Newson’s later explicit opinion PDA is not an ASD and PDA should not be conflated with autism [1]. At the same time, to the debates around PDA and its relationship to autism, it has been argued that PDA is a broader mental health disorder, potentially being a form of Attachment Disorder or Personality Disorder [15]. Emerging from initial research [10], is the outlook that PDA may be symptoms that result from the interaction of autism and common co-occurring conditions [3].

A portion of PDA’s controversy arises from how PDA is used as a proxy for specific strategies and thus in the process is turning established nosology on its head, leading to confused clinical and research perspectives [24; 36]. It appears that prematurely adopting Newson’s early scholarship has contributed to the misguided notion that PDA is an ASD, in the process forming a community of practice around this as an axiom [27]. Autism clinicians and researchers are duty bound to improve entrenched low autism research standards [47; 48]. It is imperative that we abandon the erroneous view that PDA is part of autism and in the process, this means stop

diagnosing it as a dual diagnosis with autism. Just because PDA is not in the main diagnostic manuals, does not mean PDA cannot be diagnosed as a distinct diagnostic entity. Fundamentally, all disorders in the DSM-5 lack biomarker evidence to underpin diagnostic tests [27]; they are *all* social constructs, i.e. they are all human kinds and not natural kinds [28]. PDA as a proposed common mental health disorder, should be researched to investigate how it fully manifests in all its predicted populations. Next, we discuss the case for diagnosing PDA as a separate disorder.

PDA can be diagnosed independently of autism.

Currently, PDA is often diagnosed as “Autism and PDA Traits” or “ASD + EDA Traits”. Alternatively, PDA is not formally included in diagnosis, but is recorded as part of the clinical formulation that an individual presents the PDA profile [30]. Partly because PDA is not included in the two main diagnostic manuals and there is no consensus over how to diagnose it [2; 5; 6; 23]. Moreover, PDA technically cannot be diagnosed as it lacks an agreed diagnostic profile and standardised tools [23]. Consequently, it has been argued that a PDA diagnosis is not a reliable indicator of PDA or not [6]. Accounting, for the diversity of perspectives, diagnostic practice and clinical thresholds, this view is still valid.

Historically, PDA was diagnosed as a standalone diagnostic entity. The following literature establishes PDA can be diagnosed independent of autism: (1) The at least 150 cases in Newson’s and colleague’s research [1]; (2) Around 100 of 375 caregiver reported PDA diagnoses of large scale 2018 survey in the UK¹¹ [30]; (3) The EDA-Q validation study, contained 50 diagnosed CYP with PDA, it is unknown if any these individuals had an autism diagnosis [5]. As this research was conducted before widespread adoption of dual “ASD + PDA Traits” diagnosis, many of the 50 participants are unlikely to have an autism diagnosis; (4) Four out of 22 individuals with PDA in a medium scale research into CYP with PDA educational experiences had a solo PDA diagnosis [6]; (5) At least 9 PDA case studies have PDA diagnosed as a standalone entity¹² [12; 39; 49; 50; 51; 52]; (6) The Elizabeth Newson Centre diagnosed PDA as a separate condition until 2015, using the unvalidated semi

¹¹ The Being Misunderstood Report views PDA as an ASD Profile.

¹² Eaton and Banting [52], and Trundle et al [12], both diagnosed PDA as a standalone condition that is within the autism spectrum.

structured interview created by Liz O’Nions and Francesca Happé¹³. It is possible to diagnose PDA independently of autism in-line with Newson et al wishes [1].

Newson consistently did substantial acts if they benefited other stakeholders, primarily caregivers [1; 16; 17]. Newson proposed PDA as a standalone diagnosis, as it can often explain an individual’s actions better than another syndrome¹⁴ [1; 15; 16; 17]. Likewise, creating her own Pervasive Developmental Coding Disorder’s diagnostic grouping, in part as it is easier to explain to laypersons [16]. Newson suggested the best test for a syndrome, like PDA is if persons with PDA are better explained by it, than other syndromes to caregivers and teachers [17]. Furthermore, she is clear PDA is not an ASD and took steps to ensure it is different from autism. Such as, removing cases of PDA with autism features from her database [1], and never systematically investigating autism features. [18]. Diagnosing PDA as a standalone construct matches Newson’s intent with PDA.

Newson’s perspectives that PDA is significantly different to autism are supported by present autism criteria. Typically, persons referred for a PDA diagnosis are probably those who would be diagnosed with atypical autism [1; 11; 15; 16], such cases would also be covered by DSM-IV PDD-NOS definition [9]. PDA might be the relabelling of persons diagnosed with Asperger’s Syndrome [1; 18]. Comparison studies between DSM-IV and DSM-5 ASD respective ASD criteria repeatedly show a reduction in autistic persons diagnosed, especially for those who would traditionally receive either a PDD-NOS or Asperger’s Syndrome [53]. The drop-off rates are substantial, with a range of 21% to 37%, with the majority around 33% fewer autistic persons being diagnosed under the DSM-5 [54; 55; 56; 57]. Conversely, The DSM-5 ASD criteria are not impacting overall diagnosis rates and the rise in autism prevalence is likely from earlier identification of frequently overlooked

¹³ See Supplemental Table 1”, through the following link:

<https://acamh.onlinelibrary.wiley.com/action/downloadSupplement?doi=10.1111%2Fcamh.12242&file=camh12242-sup-0001-Supinfo.pdf>

¹⁴ This reason is used to justify PDA being an ASD, this begs the question why supporters of this outlook disagree with PDA being diagnosed outside of autism?

autistic populations [58]. Individuals likely to receive a PDA diagnosis are unlikely to be considered as autistic under DSM-5. Therefore, PDA should not be diagnosed as a dual ASD diagnosis.

There are myriad other rationales for diagnosing PDA separately from autism. CYP have rights to a PDA diagnosis under the Convention on the Rights of the Child [59]; such arguments are equally applicable to non-autistic persons with PDA. As established previously in this section, it is possible to research and identify PDA in non-autistic populations. There is insufficient evidence to reduce the number of PDA traits, for instance “Neurological Involvement” awaits systematic investigation to see how it relates to PDA or not [1; 15; 17]. Four case studies [39] and a small-scale population study [21], are insufficient evidence to decide if this trait is important to PDA or not with current information. O’Nions and colleagues decided to discard the “Neurological Involvement” trait in their opinion, as such features are too common in the autistic population to allow PDA to be a meaningful subgroup [2]. Again, this is inadequate rationale for removing this trait from the PDA diagnostic criteria. Vitally, using questions that assess for less PDA features¹⁵ might also miss pertinent information during assessment when formulating a clinical diagnosis and therefore appropriate support packages; undermining the core justification for PDA that is needed for a particular set of support packages.

Diagnosing PDA as a standalone entity allows for examining if PDA features measure the trait they are assigned to. Concerns have been expressed over the “Surface sociability, but apparent lack of sense of social identity, pride, or shame trait”, that its features are hard to reliably measure [24]. Some of the features associated with this trait do not directly assess deficits in pride/shame/ social identity, for example panic attacks indicate a person is highly distressed. The extreme behaviours associated with PDA, are difficult for many people to be around and so it is reasonable that caregivers are often afraid of their CYP and are afraid for them [1]. Additionally, caregivers and other adults reporting on CYP with PDA, displaying inappropriate behaviour and lacking a sense of right or wrong are highly subjective constructs; just from whose perspective are these behaviours inappropriate and what actions do we judge to be right or wrong?

¹⁵ O’Nions et al (2016) revised the number of PDA DISCO items from 15 to 11, in the process reducing PDA traits being assessed 20 times by the original 15 questions [21], to 11 [2].

Panic attacks and other features associated to “Surface sociability, but apparent lack of sense of social identity, pride, or shame” trait are more suited to PDA RRBI traits, for instance attacks should be moved to Liability of mood, impulsive, led by need to control: Another feature is fantasising in the “*Fantatising, lying, cheating, stealing.*” of the revised 11 PDA DISCO questions [2], is more appropriate to “Comfortable in role play and pretending” trait. No-one is arguing that individuals are not presenting features described by PDA but are thoroughly scrutinising its underlying axiology. There is a need to revise the clinical picture of PDA to allow it naturally to find an appropriate diagnostic grouping. Maybe mimicking Newson by creating its own diagnostic grouping [16; 17]?

The proposed nosology of PDA often affects how one interprets its features. In the previous paragraph I establish that some features of the “Surface sociability, but apparent lack of sense of social identity, pride, or shame trait” do not reflect it. Newson questioned what PDA’s Coding Issues were in 1986 [16; 17]. Newson needed PDA to have coding problems for it to fit into her Pervasive Developmental Coding Disorder diagnostic group. O’Nions et al [2] revised the wording of PDA DISCO questions while viewing PDA as an autism subgroup, such as the “*strategies of avoidance are essentially socially manipulative*” trait and an associated question “*Socially manipulative behaviour to avoid demands*” [21], were amended to “*strategies of avoidance that are essentially ‘socially manipulative’*” and “*Apparently manipulative behaviour*” and its associated trait [2]. There was no evidence to justify such changes and the literature acknowledges that manipulative aspects of PDA make it problematic fitting PDA into the autism spectrum [12; 18; 21]; the later wording is more “autism-like” than Newson’s descriptions. While some research supports this change viewing PDA social demand avoidance as “socially strategic”, this study’s interview data was with the above revised question [60]. This is circular as the “Apparently” descriptor means that social demand avoidant behaviour cannot be manipulative. Prematurely adopting a proposed ontology for PDA often leads to fallacious assumptions.

Flawed assumptions impact the methodology and axiology of PDA research. O’Nions and colleagues mention how most of the original PDA DISCO questions were not able to differentiate PDA from the autistic population. Furthermore, Newson’s descriptions were not focused on features that differentiate PDA from the autistic population, or “weighted” in terms of profile’s core features. Their research approach was to focus on differentiating PDA among the autistic population and PDA’s “core” traits [2]. This approach directly

contradicts Newson et al's perspectives, who argued PDA is not an ASD and removed persons with PDA who displayed autism features from their database. PDA is not based on the Triad of Impairment [1], and O'Nions et al do not attempt to reconceptualise PDA along such lines [2]. The fundamental point of Elizabeth Newson's work is that PDA's acceptance in clinical practice warranted because it is significantly different to autism and therefore is not autism [1; 16; 17]. To achieve an unbiased and accurate picture of how PDA presents bias, it needs to be allowed to become its own category.

Traditionally PDA has been diagnosed independently from ASD and still is in significant numbers. Predicted PDA populations and research are based on Newson's descriptions, which are clinical different to autism. Thus, there is a need to relatively maintain the integrity of PDA's original conceptualisation to investigate how it fully manifests in all its populations. In the process resolving questions, like is the "Neurological Involvement" trait a core PDA trait or not? Separating PDA from autism, prevents PDA from becoming "autism-like", while allowing for its features to be re-categorised to appropriate diagnostic traits; for example moving panic attacks to "Lability of mood, impulsive, led by need to control". There is a pressing need to move on from viewing PDA as an ASD.

Conclusion.

This article has explored the historical nature of PDA debates. Detailing how Elizabeth Newson's PDA research and views while evolving slightly, were essentially static across 3 decades, in that PDA is not an Autism Spectrum Disorder. Nonetheless, amidst the interest and controversy four school of thought have emerged, with 3 worldviews relating PDA to autism, on the other hand, the outlook most in-line with Newson's is that PDA is a common mental health disorder. Majority of PDA empirical research supports Newson's opinion that PDA is not part of the autism spectrum. Therefore, the axiom PDA is an ASD needs to be abandoned to enable PDA's full nature to become established through ongoing research. The PDA literature has established that PDA can be diagnosed independently of autism. There is an urgent need for validated diagnostic and screening tools for this purpose, potentially the O'Nion's and Happé's semi-structured interview & the EDA-Q¹⁶ are the most promising candidates. Through scientific-method research, PDA will become uncontroversial.

¹⁶ The EDA-Q is only validated for use with autistic CYP [5].

Declarations.

Funding: Not applicable.

Ethics approval: Not applicable.

Consent to participate: Not applicable.

Consent for publication: Not applicable.

Conflicts of interests: Author/s receives funds for delivering autism and PDA training.

Availability of data and material: Not applicable.

Code availability: Not applicable.

Authors' contributions: Not applicable.

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Title:

Is Pathological Demand Avoidance a “meaningful subgroup” of autism? A response to O’Nions et al (2016).

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Is Pathological Demand Avoidance a “meaningful subgroup” of autism? A response to O’Nions et al (2016).

Proposed in 1980 as a Pervasive Developmental Disorder¹⁷ (PDD), Pathological Demand Avoidance (PDA) is presently, often viewed as an Autism Spectrum Disorder (ASD). The defining feature of PDA is the titular demand avoidance that frequently presents extremely difficult behaviours for all stakeholders to effectively regulate. Several years ago Elizabeth O’Nions and others attempted to validate questions from the autism diagnostic tool, the Diagnostic Interview for Social and Communication Disorders (DISCO), by analysing archived case files. Justifying their research by how it is believed PDA has different management strategies to traditional ASD approaches [1].

O’Nions and colleague [1] set out to make PDA a “meaningful subgroup”. Nonetheless, there is lack of consideration if this is an appropriate course of action in 2015. Pertinently, there is no consensus over how to identify PDA [2], meaning O’Nions and colleagues, decision to view PDA as a “meaningful subgroup” is an arbitrary one. Yet, there are many reasons in the literature that contradicts their approach. The specificity and validity of PDA has not been

¹⁷ PDD were a diagnostic grouping in the Diagnostic and Statistical Manual of Mental Disorders, IV Edition, that included: Asperger’s Disorder, Autistic Disorder, Childhood Disintegrative Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), and Rett’s Syndrome. Due to how PDDs were replaced with a single ASD profile, it is argued that PDA is an ASD [5].

established [3]. Some viewed PDA possibly being as common in up to 5% of the human population [4], either as a form of Attachment Disorder or a Personality Disorder [5].

There are examples of persons without autism in PDA research samples [6]. It has been suggested PDA is a “double hit” in persons with autism, as PDA might not be caused by autism [4]; for example, persons with PDA display possible precursors of Schizotypal Personality Disorder [3]. Or, a “triple hit” of: autism, anxiety and conduct problems [2]. Obviously, if PDA is not caused by autism, it cannot be an ASD. Likewise, if PDA is a double or a triple hit, it literally cannot be something it is more than, like the autism spectrum.

Features of PDA make it problematic conceptualising it as an ASD. Firstly, PDA has a more balanced gender ratio than autism. Secondly, the structure and routine of traditional autism approaches contrast to PDA strategies that involve: humour, spontaneity and unpredictability. Thirdly, the PDA characteristics of preoccupation for pretend/ roleplay/ difficulty telling pretence from reality; often are either absent or delayed in autism [7]. Fourthly, the variety and frequency manipulative behaviours displayed in PDA are not associated with autism [8]. Fifthly, the surface sociability difficulties in PDA are attributed to deficits in social identity and not to Theory of Mind [9], which matters as autistic social communication difficulties, are associated to the latter theory. These characteristics can form differential markers that exclude PDA from ASD, perhaps with PDA being a new type of disorder?

Modern autism understandings and diagnostic practice are based the triad of impairment. This includes: deficits in communication, interaction and imagination (Restricted and repetitive behaviours and interests) [10]. Newson et al [9] did not base PDA on the triad of impairment, with both autism and Asperger's Syndrome being compared to PDA. Crucially, this approach was required as systematic investigation of autistic features were not conducted. Newson and colleagues [9] stated it needs to be significantly different to both Autistic Disorder and Asperger's Syndrome.

More recently a single ASD profile has replaced the PDD diagnostic grouping. Elizabeth Newson included Specific Language Impairments as part of the PDD umbrella [9]. In 2015 Phil Christie perceived Attention Deficit Hyperactivity Disorder, dyslexia and dyspraxia as ASDs [8]. None of these conditions are a form of PDD or ASD. Newson and colleagues expanded autism to wrap around PDA, instead of PDA naturally being an ASD. Despite this Newson's descriptions of indicate PDA might be a Neurodevelopmental Disorder.

O'Nions et al [1] utilised an arbitrary cut-off of 30% to produce features that might be more specific to PDA. Though more research is needed to establish clinical cut-offs, as such, the eleven DISCO questions are essentially unvalidated. Due to the conflicting nature of PDA, the 30% threshold is meaningless, especially as diagnostic questions are arbitrarily added due to their importance in clinical understandings; for instance, "Lack of co-operation" was over the 30% threshold [1]. Logically, the question for "Anxiety" would also be added to the list, as high anxiety driven demand avoidance is believed to be the central impairment of PDA [4; 7; 8].

Pertinently, O’Nions and colleagues ignore the rationale of the Neurodevelopmental Disorder Workgroup¹⁸’s for removing autism subgroups from the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) [1]: (1) There is no evidence for differential treatment between subgroups; (2) Negligible differences between groups of persons with autism who met the clinical threshold for Asperger’s Syndrome (i.e. had no speech delay) and other subgroups; (3) to reduce the stigma for all persons with autism [6]. This begs the question: why did O’Nions and colleagues attempt to produce a meaningful ASD subgroup?

Overall, it appears premature in 2015, to assume PDA was an ASD. Since then limited evidence has emerged supporting PDA is seen persons without autism [6]. Child and young persons have rights to a PDA diagnosis under the Convention on the Rights of the Child [11]; such arguments are equally applicable to non-autistic persons with PDA. It is possible to research and identify PDA in non-autistic populations. Elizabeth O’Nions and Francesca Happé developed an unvalidated semi-structured interview that assesses PDA as an independent construct for the former’s doctoral research¹⁹ [12]. It has been utilised by the

¹⁸ Francesca Happé was a member of the Neurodevelopmental Disorders Workgroup [6].

¹⁹ O’Nions and Happé’s semi-structured interview is open access and can be accessed as “Supplemental Table 1”, through the following link:

<https://acamh.onlinelibrary.wiley.com/action/downloadSupplement?doi=10.1111%2Fcamh.12242&file=camh12242-sup-0001-Supinfo.pdf>

21st of June 2020.

Dear.

The letter article “*Is Pathological Demand Avoidance a “meaningful subgroup” of autism? A response to O’Nions et al (2016).*” Is a reply to the ““*Identifying features of ‘pathological demand avoidance’ using the Diagnostic Interview for Social and Communication Disorders (DISCO)*” by Elizabeth O’Nions and colleagues; Utilising information available from 2015, I set out to establish that O’Nions and colleagues did not contextualise their work in broader PDA debates of the time. Consequently, there central axiom of O’Nions et al (2016) article, that PDA is an autism subgroup is highly problematic and needs substantially more justification. The metrics for O’Nions et al (2016) are 24’000 views and an altmetric score of 38 (top 5% of all research). Since this article the PDA community has formed a community of practice around the assumption PDA is an autism subgroup (Woods, 2019). Thus, O’Nions and colleagues article is important research and it is ethical that it is rigorously challenged in this situation.

The submission is slightly over the 10 references limit in the author guidelines, but this is a deliberate choice to show the thoroughness of the points being made in the submission. I have used information that was available in 2015 and is often produced by authors of O’Nions et al (2016), primarily as individuals in other PDA scholarship; such as citing many of their referenced scholarship from their article. In a few cases I have citing later scholarship as citing published works over unpublished works is standard practice, as advised in the author guidelines. An example, Elizabeth O’Nions and others have previously mentioned that the manipulative behaviours aspect of PDA differentiates it from autism, but this is stated in the unpublished research “*An examination of the behavioural features associated with PDA using a semi-structured interview*”, which is available here:

<http://www.pdaresource.com/files/An%20examination%20of%20the%20behavioural%20features%20associated%20with%20PDA%20using%20a%20semi-structured%20interview%20-%20Dr%20E%20O’Nions.pdf>

However, this point is later mentioned in print in the article by Trundle et al (2017), which is the article I cite in the submission. The O’Nions and Happé semi-structured interview is first mentioned in the previously mentioned unpublished research, but is now open access through the O’Nions et al (2018) paper cited in the submission. I think that each article cited in the submission is justified.

A potential point of concern is that I have a conflict of interest in receiving payment for training in autism and PDA. This is noted on the manuscript.

The address I provide is a private address and the journal does not have permission to publish that address due to privacy reasons. Subsequently, I have reflected this in the address on the title page.

Overall, the submission "*Is Pathological Demand Avoidance a "meaningful subgroup" of autism? A response to O'Nions et al (2016).*" is a robust critique of O'Nions et al (2016) research.

Thank you for your time and I look forward to receiving your reply.

Yours faithfully,

Mr. Richard Woods.

10th of November 2020.

Dear.

I have tried to act on the reviewer's comments as best as possible, however I think the reviewer has neither appropriately engaged with the original essay or is familiar with the recent work of Elizabeth O'Nions and others. I have significantly expanded the original essay to detail the four main schools of thought around PDA's medical ontology and how these perspectives have evolved over time. In the process the basic assumption that PDA is an ASD subgroup/ subtype is inaccurate and cannot be made when considering Elizabeth Newson's views and work. Subsequently, this is an important article in correcting the PDA literature. I set out my response to the reviewer's comments below in Table 1.

1. Table 1: Reviewer's comments, with my response and actions.

Number.

Reviewer Comment.

My response and actions.

1

O'Nions et al did suggest in 2015 that PDA "could be" seen as a sub-group with in ASD, but later on in 2018 and further they have said that PDA features are seen in individuals without ASD, so hence the whole critique in this article becomes dated. Had the author submitted this in 2016 it would be appropriate / held sway but not so much now.

The reviewer misses the point of the original essay. I am clear in that essay that the article is addressing gaps in the literature review made by O'Nions et al (2016), stating:

"O'Nions and colleague [1] set out to make PDA a "meaningful subgroup". Nonetheless, there is lack of consideration if this is an appropriate course of action in 2015."

The entire point of the commentary essay is to highlight that if O'Nions et al (2016) properly represented the literature, they could not adopt the axiology and methodology they did in revising the PDA DISCO questions. I.e. O'Nions et al (2016) are doing exactly what the reviewer accuses me of doing, selecting articles to make a point. I specifically cover this in the revised essay stating:

"O'Nions and colleagues mention how most of the original PDA DISCO questions were not able to differentiate PDA from the autistic population. Furthermore, Newson's descriptions were not focused on features that

differentiate PDA from the autistic population, or “weighted” in terms of profile’s core features. Their research approach was to focus on differentiating PDA among the autistic population and PDA’s “core” traits [2]. This approach directly contradicts Newson et al’s perspectives, who argued PDA is not an ASD and removed persons with PDA who displayed autism features from their database. PDA is not based on the Triad of Impairment [1], and O’Nions et al do not attempt to reconceptualise PDA along such lines [2]. The fundamental point of Elizabeth Newson’s work is that PDA’s acceptance in clinical practice warranted because it is significantly different to autism and therefore is not autism [1; 16; 17].”

I would also contest that the original essay holds no sway, the reviewer acknowledges the validity of comments further down, expressing:

“The author does have some valid and interesting point such as PDA is not equal to ASD and vice-versa”

The reviewer appears not to be familiar with recent scholarship from Elizabeth O’Nions and others on PDA. Typically articles from Elizabeth O’Nions and other persons connected to the article, all view PDA to be part of the autism spectrum. This is mentioned in the revised essay. Examples of specific work, since 2018 where such individuals claim PDA is part of the autism spectrum include:

<https://link.springer.com/article/10.1007/s41252-020-00167-6>

&

<https://www.pdasociety.org.uk/wp-content/uploads/2019/08/BeingMisunderstood.pdf>

&

<https://linkinghub.elsevier.com/retrieve/pii/S1751722220301566>

&

<https://network.autism.org.uk/sites/default/files/ckfinder/files/Differential%20diagnosis%20between%20PDA%20and%20attachment%20disorder%20-%20Dr%20Judy%20Eaton.pdf>

I have compiled a document outlining how O’Nions and others systematically view PDA to be an ASD. I have not included it as I do not wish to be published, but I can share it with the editor upon request. The reviewer is mistaken to make these comment that O’Nions et al have changed their views.

2

The author's other point about PDA being diagnosed as a condition is actually still very controversial and PDA is not a diagnose-able condition in ICD-10 / ICD-11 or DSM-5 (the main classification systems in this field). Furthermore the larger body of experts from the UK who have written a major opinion on this do not consider PDA as a syndrome or disorder (including Prof Jonathan Green, Emily Siminoff, Gillian Baird, Ann Le Couteur and others - Ref: Green J, Absoud M, Grahame V, et al. Pathological Demand Avoidance: symptoms but not a syndrome. *Lancet Child Adolesc Health*. 2018;2(6):455-464. doi:10.1016/S2352-4642(18)30044-0) and the author has not referenced this work or point from it - this article argues that PDA is not a separate syndrome but a phenotype presentation.

I acknowledge that PDA being diagnosed is controversial and discuss this throughout the article, including devoting an entire section to it, called "*PDA can be diagnosed independently of autism*". Specific comments include:

"Moreover, PDA technically cannot be diagnosed as it lacks an agreed diagnostic profile and standardised tools"

And

"Still, if one accepts that PDA does exist and that it should be diagnosed; logically, all persons who meet its profile have equal rights to receive a diagnosis, support and research, irrespective of if they are autistic or not."

The editor can read the appropriate section for more details, but I have wrote around 1700 discussing how and why PDA should be diagnosed independently from autism.

I have referenced both Green et al 2018a and 2018b articles. The former is reference 3 and the latter is reference 36. I discuss their work in relation to the four main schools of thought relating to PDA's medical ontology.

3

Interestingly in other countries such as USA or Canada PDA is not even discussed as such - but it is a UK issue. So the range of references author has selected are biased towards proving his point.

I have referenced and drawn upon the work on non-UK based authors where relevant. Including Falk 2019 [26] and 2 articles from Christopher Gillberg. The problem is that PDA is mainly centred in the UK and its literature

acknowledges this. Subsequently, there is very little non-UK literature to reference. There are 2 articles from Northern Europe which are not available in English except for in Google translate, but I have not referenced these due to possible errors in translation.

The reviewer is being harsh with these comments.

4

Also on Page 5 (line 6 - 11) when the author writes that " Child and young persons have rights to a PDA diagnosis under the Convention on the Rights of the Child [11]" - this seems a bit unusual and extreme as medical condition that is not yet seen by the larger body of doctors or clinicians as a condition can't become a human right issue or this type of argument may be done in a philosophy or ethics journal.

I detail the case for diagnosing PDA a standalone diagnosis, primarily in the 1700 word long "*PDA can be diagnosed independently of autism*" section.

There are various justifications for this, including scientific and clinical in nature. A pertinent one, is that Elizabeth Newson never intended for PDA to be diagnosed as part of the autism spectrum, expressing in her article supplementary notes:

"It is useful to describe Asperger syndrome and classic autism together as forming the autistic spectrum; but in our view it is not useful to use 'autistic spectrum disorders' as synonymous with 'pervasive developmental disorders', as has become more prevalent lately in the UK. 'Pervasive developmental disorders' is the entirely satisfactory term of DSM-IV, in which each word has a relevant meaning to describe the nature of this 'family'; it is acceptable to parent groups in the United States and Canada, and it is easily understandable when explained to parents in the UK, where lately it has been increasingly used by such groups. PDA is a pervasive developmental disorder but not an autistic spectrum disorder: to describe it as such would be like describing every person in a family by the name of one of its members." Link to supplementary files:

<https://adc.bmj.com/content/archdischild/suppl/2003/07/02/88.7.595.DC1/887595supportingmaterial.pdf>

I do not see how the comments about this essay being suitable for an ethics or philosophy journal are relevant anymore.

5

The author does have some valid and interesting point such as PDA is not equal to ASD and vice-versa, the fact that gender ratio is nearly same and that PDA type features can exist in individuals other than ASD - ie they are transdiagnostic features (although he does not quite go into them). My opinion is that if the author sticks to the argument that PDA is beyond the diagnosis of ASD ie it can exist with in and outside ASD and hence is not a subgroup of ASD then this is a useful and helpful article.

Please see comments to the points about PDA being a valid diagnosis in my response to the reviewer's first comment.

I simply do not have room to go into full clinical details about how PDA overlaps autism and other conditions in the essay I have written. It is already over the page limit suggested for authors. I will add another section detailing how PDA features overlap autism and other conditions, if requested by the editor?

I will add, I do briefly discuss how PDA overlaps other conditions, including autism throughout the essay. Examples include:

“PDA has limited social communication problems and Restricted and Repetitive Behaviours and Interests (RRBIs). PDA Surface Sociability frequently has a confused worldview and is not caused from Theory of Mind or Empathy deficits. This feature partially overlaps ASD due to 20% of autistic Child and Young persons (CYP) passing a Theory of Mind test [7]. Additional overlapping traits include Delayed Speech Development, Neurological Involvement and Passive Early History. Autistic persons often have poor coordination. Delayed speech development is common in ASD [1; 8], being a diagnostic trait of Autistic Disorder in the DSM-IV [9]. The DSM-5 added Sensory issues to ASD and this overlaps one PDA article that conceptualises PDA as neurodevelopmental in nature [4]. There are important clinical differences between PDA and autism. PDA has more RRBIs than autism as much or most of PDA behaviours are obsessive in nature [1]. These are anxiety based due to high anxiety being its central impairment [10; 11; 12]; however, Newson's work occasionally refers to panic and fear, but her article does not mention anxiety [1]. Anxiety is a recognised co-occurring problem to autism [12; 13; 14]. PDA has superficial similarities with ASD.”

And

“Some of the features associated with this trait do not directly assess deficits in pride/shame/ social identity, for example panic attacks indicate a person is highly distressed.”

I will add another section detailing how PDA features overlap autism and other conditions, if requested by the editor?

6

But he is at the same time trying to demonstrate that PDA is a valid diagnosis then there is no way near enough arguments here to support that conclusion and the scope of that goes well beyond commentary on O'nions and the length of this. So if the author edits out the statements of PDA being a separate diagnosis and keeps to argument that it is not a subgroup of ASD only then I feel it is publishable and also perhaps make the title broader than just O'nion commentary because they have really expanded on their views from 2015-2016.

Please see comments to the points about PDA being a valid diagnosis and how the reviewer is not reflecting O'Nions and others recent opinion on PDA, in my response to the reviewer's first comment.

I have addressed the critique of O'Nions et al (2016) by contextualising their work in broader PDA literature, both historically and the 4 main schools of thought on PDA's medical ontology. I am clear that the axiology and methodology adopted by O'Nions et al (2016) is inappropriate when fully contextualised in historic PDA literature. Please see my response to the first reviewer comment for more information.

I have also changed the title of the submission to reflect it is no longer a commentary article:

"Is Pathological Demand Avoidance a "meaningful subgroup" of autism?"

7

If these changes are not possible then this is not publishable. The author may chose to write a much longer separate article to demonstrate that PDA should be accepted as new diagnostic entity but this is not possible to do it in a short commentary.

I have acted on the suggestion to write a longer piece, the essay is around 6500 words, excluding references.

I repeat the point, that I think the reviewer is being harsh and a significant amount of their comments are not valid. Thus, where I have highlighted, the reviewer's comments should be discarded when making an editor decision around publication.

Comments for the editor.

I have included the file for Image 1: Aggregated DSM-5 Autism Spectrum Disorder criteria and the Aggregated PDA Profile.

I am over the page limit suggested for authors, but the submission guidelines state this is open to negotiation with the editor. I am over the word limit to adequately cover all the topics relevant to the essay, that details how clinical opinions on PDA have evolved over time from Elizabeth Newson's original unpublished research. It is clear upon engaging with Newson's scholarship, that she did not intend for PDA to be conceptualised as an ASD, in fact she explicitly argues against such an approach. The assumption that PDA is an ASD has had important ramifications to PDA clinical practice and research, which I discuss in the article. I am open to certain aspects of the article being amended upon feedback from editor's and or reviewers. I would like submission to accepted over the word limit. What are the editor's thoughts?

I have referenced unpublished research due to how many are cited and often they are cited. This literature forms a fundamental component of the essay, such as how one cannot assume PDA is an ASD from Newson's scholarship. It is clear Newson never made PDA conform to autism understandings, if anything she went out of her way to make PDA not an ASD. For instance, excluding persons with PDA from her research sample, stating PDA is not ASD and creating her own diagnostic grouping for PDA. Largely speaking these unpublished materials have been referenced elsewhere, like in Trundle et al 2017 [12]. Additionally, the EDA-Q is based on Newson's unpublished research, as are the original PDA DISCO questions. Newson's unpublished research are an essential element to story of how the four main PDA schools of thought developed. It is appropriate for me to fully reference this literature.

I have the version of the O'Nions and Happé unvalidated semi-structured interview that was used by the Elizabeth Newson Centre, I have not obtained permission to re-publish it from the ENC. I think I need their permission to do so, as they made changes to tool by adding scoring rules and diagnostic descriptions to the 22 questions. I can send a copy of this tool to the editor, if requested?

Since I submitted the original essay, I have started a PhD at London South Bank University and so I have updated my author details. London South Bank University has a deal with Springer to publish articles open access. If the submission is accepted for publication, I would like to exercise this option to publish it open access. How would I be able to do this?

The journal has permission to publish the address provided in the updated first author details.

The submission "*Is Pathological Demand Avoidance a "meaningful subgroup" of autism*" is a robust critique of O'Nions et al (2016) research. Overall, I acted on the reviewer's comments where appropriate and I have substantially improved the submission. Nonetheless there are a few suggestions by the reviewer that simply nonsense and so I cannot implement.

Thank you for your time and I look forward to receiving your reply.

Yours faithfully.

Mr. Richard Woods.

13th of February 2021.

Dear.

Please see my formal rebuttal to the reviewer's second round peer review comments.

Table 1: Reviewer comments and author's response.

Number.

Reviewer comment.

Author's Response.

1

A Reviewer has now commented on your work; however, the comments were sent to the Editor only, because some of the comments might allow you as the Author to identify the Reviewer.

From the lengthy comment I received I can include the following without compromising the Reviewer:

I have submitted a subject access request under UK law and EU data management guidelines. Considering the nature of some of the reviewer's comments, it is appropriate for the journal to inform of the reviewer's identity irrespective of the subject access request.

Comment:

"however, the comments were sent to the Editor only, because some of the comments might allow you as the Author to identify the Reviewer."

I would argue supports another comment by the reviewer: *"It is clear the author has very good knowledge of PDA and related issues"*. As it the reviewer seems aware that my knowledge of the literature can potentially identify them, due to my very good knowledge of PDA.

2

The author is clearly passionate about his view albeit there is an equally passionate argument against the diagnosis of PDA as a separate condition (perhaps 2 head-to-head articles in a special issue written by invitation may be better). The risks of propagating the validity of PDA as a separate condition (without empirical evidence) is that there is a risk of harm coming to children and families; if they feel this is a completely novel / different condition then they seek different treatments for the very challenging behaviours in the form of PDA specific strategies, which tend to work in the short term but cause huge problems in the long term.

First, I will point out the positives of the reviewer's comments:

"The author is clearly passionate about his view"

The reviewer acknowledges my passion on the topic.

And

"albeit there is an equally passionate argument against the diagnosis of PDA as a separate condition (perhaps 2 head-to-head articles in a special issue written by invitation may be better)."

The part I draw your attention to is the part, where the reviewer acknowledges that it is suitable for the journal to publish an article on the topic of PDA as a standalone diagnosis.

I would point out this quote from the first round of peer review by the reviewer:

"The author may choose to write a much longer separate article to demonstrate that PDA should be accepted as a new diagnostic entity but this is not possible to do it in a short commentary."

I did exactly as the reviewer requested in the first round of peer review, now the reviewer is suggesting such an article should be published by multiple other authors. This seems like gatekeeping to me, just because there are “equally passionate” arguments against my view, I do not see how that matters. The “other” side of this debate is supported by various autism charities, caregiver advocacy groups etc, that side of the argument already receives sufficient coverage anyway. For example, see the PDA Society:

<https://www.pdasociety.org.uk/>

Simply because there are equally passionate sides, does not mean that both sides are equally valid, or equally strong, or even if that the other side should be platformed. In a later comment the reviewer acknowledges the strength of perspective stating “*challenging whether PDA should just be seen as a subcategory of ASD as to a behavioural profile that can be seen in children who do not ASD". There are strong arguments for this*”. Can the reviewer claim the other side is as comparably strong as my own position?

The logical extension of PDA being seen in non-autistic persons is that PDA should be diagnosed as a standalone entity. What are the other alternatives? We do not diagnose and thus do not often support such non-autistic persons with PDA? Or we diagnose such non-autistic persons with PDA, with ASD + PDA traits dual diagnosis? I think both these alternative options are more controversial than diagnosing PDA as a standalone construct. I would mention this quote by leading PDA advocate Phil Christie on the topic:

“... both ICD and DSM focus more on the reliability than the validity of the disorders they describe...no iteration of either DSM or ICD has acknowledged the fundamental distinction between researchers and practioners...who uses diagnostic classifications and for what purpose?” (Christie, 2016, p19).

While I dislike the above quote, it is applicable to this debate as it basically means stakeholders can diagnose any mental disorder construct in any persons, if they think it will help the individual. I dislike the quote, as it is basically being used to justify diagnosing PDA in autistic persons as it is

meant to be help some autistic persons; thus, disregards autistic perspectives that we do not want autism to subdivided (See, Kapp and Ne'eman, 2019):

https://researchportal.port.ac.uk/portal/files/16798548/Lobbying_Autism_s_Diagnostic_Revision_Chapter_13.pdf

Now this part of the reviewer's comment:

“condition (perhaps 2 head-to-head articles in a special issue written by invitation may be better).”

I do not see how this relevant or appropriate. ECAP has a letter section. This submission was originally around a 1000-word letter essay, and I expanded it to its current size on the suggestion of the reviewer. The point is that it the typical practice in these matters is that my submission would be published then others, like the reviewer could challenge it with a letter article. Presumably, the chief editor who made the decision is aware of the standard option.

Another important point is that I am leading PDA expert (the reviewer later acknowledges my expertise), I teach PDA at postgraduate level, have authored many pieces and spoken, both nationally and internationally on the topic. Surely, my own expertise is sufficient to warrant this piece published.

It is for these reasons that it seems to be gatekeeping to suggest that this submission is not published.

This comment by reviewer:

“The risks of propagating the validity of PDA as a separate condition (without empirical evidence) is that there is a risk of harm coming to children and families; if they feel this is a completely novel / different condition then they seek different treatments for the very challenging behaviours in the from

PDA specific strategies, which tend to work in the short term but cause huge problems in the long term.”

Where is the evidence for this being potentially harmful from the reviewer?

This part of the comment: *“The risks of propagating the validity of PDA as a separate condition (without empirical evidence)”*. First point there obviously is some form of empirical evidence to support it, as by the reviewer’s own admission there is a strong case that PDA is seen in non-autistic persons, to quote them; *“challenging whether PDA should just be seen as a subcategory of ASD as to a behavioural profile that can be seen in children who do not ASD”. There are strong arguments for this”*.

I would also add there is limited empirical evidence to support this PDA being seen in non-autistic persons, as I state in this article, and various PDA experts are stating PDA is seen inside and outside of autism:

“In addition some argue PDA is also found in non-autistic people and is not confined to autistic persons (Egan, 2019; Gillberg, 2014; Malik and Baird, 2018; McElroy, 2016). This is supported by individual cases of non-autistic persons in PDA research samples (O’Nions et al, 2015; O’Nions et al, 2016; Reilly et al, 2014), in addition to other empirical evidence set out in my initial article (Woods, 2019b).)” (Woods, 2020, p74). From:

https://www.researchgate.net/publication/339240845_Pathological_Demand_Avoidance_and_the_DS_M-5_a_rebuttal_to_Judy_Eaton

And:

“Pathological (or extreme) demand avoidance is a term sometimes applied to complex behaviours in children within—

or beyond—autism spectrum disorder.” (Green et al, 2018a, p445).

The simple counter argument, to if there is a lack of evidence that PDA is seen in non-autistic persons, then surely, we need to gather research from clinical based populations from diagnosing PDA as a standalone entity?

If the reviewer is that genuinely concerned about PDA being lacking evidence for it being a distinct thing (as PDA still awaits direct empirical evidence), then surely the reviewer would also be advocating for PDA to *not* be diagnosed at all, even for autistic persons?

This appears to be an example of the reviewer being harsh and talking nonsense again.

I would point out that PDA was originally diagnosed as a standalone diagnosis, and has been diagnosed as a standalone diagnosis in substantial numbers as I point out in the submission:

“Historically, PDA was diagnosed as a standalone diagnostic entity. The following literature establishes PDA can be diagnosed independent of autism: (1) The at least 150 cases in Newson’s and colleague’s research [1]; (2) Around 100 of 375 caregiver reported PDA diagnoses of large scale 2018 survey in the UK [30]; (3) The EDA-Q validation study, contained 50 diagnosed CYP with PDA, it is unknown if any these individuals had an autism diagnosis [5]. As this research was conducted before widespread adoption of dual “ASD + PDA Traits” diagnosis, many of the 50 participants are unlikely to have an autism diagnosis; (4) Four out of 22 individuals with PDA in a medium scale research into CYP with PDA educational experiences had a solo PDA diagnosis [6]; (5) At least 9 PDA case studies have PDA diagnosed as a standalone entity [12; 39; 49; 50; 51; 52]; (6) The Elizabeth Newson Centre diagnosed PDA as a separate condition until 2015, using the unvalidated semi structured interview created by Liz O’Nions and Francesca Happé . It is possible to diagnose PDA independently of autism in-line with Newson et al wishes [1].”

As I set out in the submission, PDA should still be diagnosed as a standalone construct.

I would contest that persons with PDA should be receiving appropriate irrespective of a PDA diagnosis or not. Especially in the UK as the Special Educational Needs and Disability systems is

needs based. Furthermore, that strategies/ approaches are issues/ symptoms specific, not diagnoses specific. To quote Green et al (2018b):

“We make clear in our paper that interventions of the kind that O’Nions and colleagues advocate are already widely used in the autism field, independent of any pathological demand avoidance label.”

From:

<https://linkinghub.elsevier.com/retrieve/pii/S2352464218302219>

I set out how comparable approaches are widespread in mental health and SEND practice here:

“DAP strategies in wider discourses

A list of DAP strategies can be found in the Autism

Education Trust’s resources (Woods, 2019b):

A specific keyworker to build a trusted relationship

Being flexible and adaptable

Indirect praise

Letting things go

Negotiating by providing choices to pupils

Positive relations

Thinking aloud

Tone of voice

Treating anger as communication

Use humour

Use of role play, novelty and variety of lesson material

Visual communication methods

Green et al (2018b) suggested a review of treatments or autism may be beneficial. Accordingly, I provide a

current list of comparable approaches and pedagogies to DAP strategies:

Autism catatonia strategies (Eaton 2017)

Autistic preferred approaches (Laurent 2019; Milton 2018)

Capabilities approach (Woods, 2019b)

Dialectical Behaviour Therapy (Eaton, 2017; Eaton, 2018a; Fieldman, 2018)

Evidence based practices (Green et al 2018b)

Inquiries based learning

Low Arousal Approach (McDonnell, 2019)

SPELL – Structure, Positive (approaches and expectations), Empathy, Low Arousal and Links Framework developed by the NAS (Milton 2017)

Universal Design for Learning (Woods, 2019b)

Eaton has noticed the similarities between Borderline Personality Disorder (BPD) and DAP, noting those individuals diagnosed with both constructs display demand avoidance or escape behaviours (Eaton, 2017). Subsequently, she used BPD's strategies of Dialectical Behaviour Therapy (DBT) with her DAPers and says it can be effective (Eaton, 2017; Eaton, 2018a). The current approach to DAP nosology is that it has strategies that are different to non DAPers; this is an atypical nosology (Green et al, 2018b). Following the logic for DAP nosology through, due to its strategies overlapping those for catatonia and BPD, DAP can be seen as either a form of catatonia or personality disorder. I will next explore how DAP strategies are generic good practice.

It is often mentioned that DAPers do not benefit from routines, compared to autistic persons. However, a more thorough investigation of the literature contradicts this. Elizabeth Newson noted in her research that 60 per cent of DAPers adhered to routines (Newson and Le Merechal, 1998). Moreover, recent resource books state DAPers can benefit from routines the DAPers themselves choose (Dura-Vila and Levi, 2018; Fidler and Christie, 2018). For general autism strategies, the

SPELL Framework is comparable to DAP strategies; for instance, the structure aspect is about removing structures that are barriers to inclusion, for instance removing any routines that increase autistic persons' stress (anxiety). Structures that promote autonomy should be included (Milton 2017). One can conclude that both DAPers and individuals with autism gain from routines of their choosing.

Autistic authors argue that DAP approaches are suitable for many persons (Milton, 2017; Woods, 2019a). Similar evidenced based strategies have been used for years with autism independent of the DAP construct (Green et al, 2018b). In his guide to a Low Arousal Approach, Andy McDonnell describes how around two thirds of distress behaviour (challenging behaviour) is triggered by requests or demands by other persons and how all persons benefit from having a sense of control (McDonnell, 2019). This can explain why Oralie Loong anecdotally observed that declarative language

is beneficial to all persons (Loong, 2019), depersonalising requests to appear as not a demand. Gore and colleagues (2019) in a series of interviews with 12 autism carers found that when parents take a rigid approach, placing many demands when an autistic person is displaying distress behaviours, this escalates such behaviours and decreases the chance of positive practices.

O'Hare (2019) writing on behalf of the British Psychological Society' Division of Educational and Child Psychology notes that simplistic and reactive approaches are stressful to teachers and do not adequately teach children why their behaviours should change. The latter point is essential when working with a demographic known for experiencing social problems, such as autistic persons and DAPers. Furthermore, O'Hare also states:

“Warm supportive relationships with adults, a sense of belonging, high expectations, teaching social-emotional skills and autonomy are the key ‘ingredients’ to positive behaviour change for children and young people.” (O'Hare, 2019).

This is reflective of the DAP strategies, for instance utilising humour. Autistic people frequently have a vibrant sense of humour (Bertilsdotter-Rosqvist, 2012). Qualitative research indicates that autistic

pupils become more 'functional' when working with their (special/intense) interests (Wood, 2019). Building trusting relations is an attachment disorder approach (Pearce, 2017). Leeds City has reduced childhood obesity, partly by using an approach where carers provide the child with a choice of food options (Boseley, 2019).

It is clear that placing any human in a position of control is probably beneficial to them. Thus, underlying the points made by Andy McDonnell (2019), and illustrating how the DAP strategies replicate good practice. Additionally, this point is underlined by the Positive (Approach and Expectations) aspect of the SPELL Framework, which mirrors the part of the Special educational needs and disability (SEND) Code of Practice, where SEND persons are to be encouraged to reach their potential and to be independent. This is a deciding factor in why some view DAP as a redundant clinical construct (Green et al, 2018b). An additional diagnostic label that exists to access approaches that replicate good practice requires substantial ethical justification.” (Woods, 2019, pages 34 -36).

https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-_a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference

How exactly is the reviewer's above comment relevant to this submission, or even valid?

3

The topic of the article is "challenging whether PDA should just be seen as a subcategory of ASD as to a behavioural profile that can be seen in children who do not ASD". There are strong arguments for this but the article goes beyond this discussion and argues that PDA is a stand alone / distinct diagnosis. I had suggested at the first review that it was best to stick to the topic only i.e. describing that PDA type behaviours are overlapping / transdiagnostic and not just ASD specific.

I will restate the positive aspect of the reviewer's comment:

“challenging whether PDA should just be seen as a subcategory of ASD as to a behavioural profile that can be seen in children who do not ASD". There are strong arguments for this”

This is supported by this comment from first round of peer review “*The author does have some valid and interesting point such as PDA is not equal to ASD and vice-versa*”

This comment by the reviewer:

“The topic of the article is "challenging whether PDA should just be seen as a subcategory of ASD as to a behavioural profile that can be seen in children who do not ASD". There are strong arguments for this”

I would argue that this shows that the reviewer is again not properly engaging with the submission. The topic of the article is how should be seen, when compared to its historic literature and evidence base. I explain the four main schools of thought on PDA, how developed, and their respective cases. I then finally argue for PDA to be viewed as a standalone diagnosis, on the reviewer’s first round of peer review advise. Again, to quote it: “*The author may chose to write a much longer separate article to demonstrate that PDA should be accepted as new diagnostic entity*” It is because I acted on this advise is why I discuss PDA as a standalone diagnosis. Which then makes the below comment by the reviewer seem absurd and harsh:

“but the article goes beyond this discussion and argues that PDA is a stand alone / distinct diagnosis. I had suggested at the first review that it was best to stick to the topic only i.e. describing that PDA type behaviours are overlapping / transdiagnostic and not just ASD specific.”

I will restate the response to the suggestion of describing the overlap of PDA with other conditions, from the revisions cover letter:

“Please see comments to the points about PDA being a valid diagnosis in my response to the reviewer’s first comment.

I simply do not have room to go into full clinical details about how PDA overlaps autism and other conditions in the essay I have written. It is already over the page limit suggested for authors. I will add another section detailing how PDA features overlap autism and other conditions, if requested by the editor?

I will add, I do briefly discuss how PDA overlaps other conditions, including autism throughout the essay. Examples include:

“PDA has limited social communication problems and Restricted and Repetitive Behaviours and Interests (RRBIs). PDA Surface Sociability frequently has a confused worldview and is not caused from Theory of Mind or Empathy deficits. This feature partially overlaps ASD due to 20% of autistic Child and Young persons (CYP) passing a Theory of Mind test [7]. Additional overlapping traits include Delayed Speech Development, Neurological Involvement and Passive Early History. Autistic persons often have poor coordination. Delayed speech development is common in ASD [1; 8], being a diagnostic trait of Autistic Disorder in the DSM-IV [9]. The DSM-5 added Sensory issues to ASD and this overlaps one PDA article that conceptualises PDA as neurodevelopmental in nature [4]. There are important clinical differences between PDA and autism. PDA has more RRBIs than autism as much or most of PDA behaviours are obsessive in nature [1]. These are anxiety based due to high anxiety being its central impairment [10; 11; 12]; however, Newson’s work occasionally refers to panic and fear, but her article does not mention anxiety [1]. Anxiety is a recognised co-occurring problem to autism [12; 13; 14]. PDA has superficial similarities with ASD.”

And

“Some of the features associated with this trait do not directly assess deficits in pride/shame/ social identity, for example panic attacks indicate a person is highly distressed.”

I will add another section detailing how PDA features overlap autism and other conditions, if requested by the editor?”

While I do not have room to copy and paste over the entire revised submission, the point here is that I do discuss the clinical overlap between PDA and other constructs throughout the submission, there is simply no dedicated section to this, which I offered to write if the editor requested it.

The point the reviewer makes about me discussing PDA as a standalone diagnosis, is because the reviewer invited me to write a larger submission on it, in the first-round peer review, so it is an unfair critique, and thus should be ignored.

I will restate my point from the revisions cover letter, that the reviewer has not properly engaged with the submission, and their comments are being harsh.

4

The author has addressed some of the comments but where he disagrees, he has simply made comments about reviewers such as "the reviewer is not familiar with O'nions work".

The Reviewer continues to extensively elaborate on his/her past personal contacts with O'nion. Without doubt I as the Editor find the respective section absolutely convincing. The Reviewer is definitely familiar with O'nions work.

This comment by the reviewer:

“The author has addressed some of the comments but where he disagrees, he has simply made comments about reviewers such as "the reviewer is not familiar with O'nions work".”

This is factually inaccurate, as I set show above in my response in the Response Number three, I gave full reasons as to why I disagreed with the reviewer. Another example from the first-round peer review, reviewer comment:

“Interestingly in other countries such as USA or Canada PDA is not even discussed as such - but it is a UK issue. So the range of references author has selected are biased towards proving his point.”

My response in the revisions cover letter:

“I have referenced and drawn upon the work on non-UK based authors where relevant. Including Falk 2019 [26] and 2 articles from Christopher Gillberg. The problem is that PDA is mainly centred in the UK and its literature acknowledges this. Subsequently, there is very little non-UK literature to reference. There are 2 articles from Northern Europe which are not available in English except for in Google translate, but I have not referenced these due to possible errors in translation.

The reviewer is being harsh with these comments.”

To provide quotes from the literature, where it is acknowledged that PDA is a UK based entity:

“Since interest in the concept of PDA largely centres on the UK, it is at present a culture-bound concept” From O’Nions et al (2019), here:

<https://link.springer.com/article/10.1007/s10803-019-04219-2>

And:

“construct has achieved increasingly wide attention, particularly in the UK (but also in some parts of continental Europe), because of advocacy work done by the Pathological Demand Avoidance Society, recognition by the National Autistic Society, research publications, and dissemination in social media.” (Green et al, 2018, p455).

Based on the reviewer's previous comments in the first round of peer review about Green et al:

“Furthermore the larger body of experts from the UK who have written a major opinion on this do not consider PDA as a syndrome or disorder (including Prof Jonathan Green, Emily Siminoff, Gillian Baird, Ann Le Couteur and others - Ref: Green J, Absoud M, Grahame V, et al. Pathological Demand Avoidance: symptoms but not a syndrome. Lancet Child Adolesc Health. 2018;2(6):455-464. doi:10.1016/S2352-4642(18)30044-0) and the author has not referenced this work or point from it - this article argues that PDA is not a separate syndrome but a phenotype presentation.”

And the later comment in this round of peer review about being a colleague of O’Nions, the reviewer is almost certainly aware that PDA is a UK based construct, especially as they probably have co-authored articles with O’Nions; that they are making an unrealistic request of me to discuss PDA in non-UK countries.

I can give other examples of how I responded to the reviewer’s comments, justifying why the reviewer’s comments were harsh to me, which feed into my response to the next part of the reviewer’s comments.

This comment by the reviewer:

“The Reviewer continues to extensively elaborate on his/her past personal contacts with O'nion. Without doubt I as the Editor find the respective section absolutely convincing. The Reviewer is definitely familiar with O'nions work.”

Just co-working with O’Nions is substantive evidence that the O’Nions has changed their opinion on PDA. It is merely the reviewer’s word. Considering the reviewer is a colleague of O’Nions, there appears to be a conflict of interest in the reviewer, conducting peer review of this submission. Considering how O’Nions has consistently viewed PDA as a form of autism, it is reasonable to infer that the reviewer also views PDA as a form of autism. In which case ECAP should have the revision

reviewed by someone less partisan. These are comments since 2018, where O’Nions views PDA as a form of autism, or should only be viewed as part of the autistic population:

“Some individuals appear more reactive to routine demands (e.g., to wash or get dressed), and others to demands in socially challenging or novel situations (e.g., when visiting friends) (Chowdhury et al. 2016). The former ‘demand-specific’ profile resembles accounts of extreme/‘pathological’ demand avoidance (‘PDA’), which describe avoidance of and reactivity to routine demands in children with ASD (Newson et al. 2003). Some accounts of PDA explicitly attribute these behaviours to elevated anxiety and distress in the context of demands (Newson et al. 2003). In contrast, the latter ‘socially inflexible’ profile, may particularly reflect intolerance of uncertainty: the tendency to “react negatively on an emotional, cognitive, and behavioural level to uncertain situations and events” (Buhr and Dugas 2009, p. 216), which characterizes some children with ASD (Boulter et al. 2014; Larson 2006)”. (O’Nions et al, 2019, pages 386-387). From here:

<https://link.springer.com/article/10.1007/s10803-019-04219-2>

And:

“We argue that using the PDA profile, or describing relevant behaviours, as part of a clinical formulation can be helpful in alerting caregivers and educational professionals to particular challenges surrounding compliance with everyday requests in some children with ASD.” (O’Nions and Eaton, 2020). From here:

<https://doi.org/10.1016/j.paed.2020.09.002>

Other places, where O’Nions has viewed PDA as an ASD include:

“Their apparently intact awareness of how to ‘push people’s buttons’ suggests a level of social insight that is unusual in children with ASD.” (O’Nions et al, 2014, p758).

And:

“These data were used to determine which of the 17 PDA-relevant DISCO items were not widely endorsed in general in an autism spectrum sample, since features typical of ASD in general are unlikely to be useful in identifying a meaningful subgroup.” (O’Nions et al, 2016a, p410).

Bear in mind even the reviewer acknowledged that O’Nions et al, 2016 were attempting to make PDA a meaningful subgroup, to quote from the first round of peer review: *“O’Nions et al did suggest in 2015 that PDA “could be” seen as a sub-group with in ASD”*. That the research approach adopted by O’Nions and others, which potentially includes the reviewer, was to:

“It should be noted that, so far, we have approached this profile from the starting point of our expertise in ASD.” (O’Nions et al, 2016b, side 2), from:

<http://repository.tavistockandportman.ac.uk/2165/>

The point I am making here is that O’Nions has consistently viewed PDA as a form of autism over an almost a decade’s worth of scholarship. That the reviewer, has probably co-authored at least one, if not many of such pieces in which O’Nions did express the view PDA is an ASD.

It does appear that the either the reviewer is mistaken, and/ or the editor is also mistaken on the topic. That these parts of the reviewer’s comments should be discarded. It does raise the question are the reviewer, and/ or the editor are being entirely truthful?

5

The Reviewer then continues:

Overall, as I said above, the author is going well beyond the topic of this article. I am not saying one should not write an article to argue that PDA should be a diagnosis but that should come from several prominent people writing the article together (as it is controversial) e.g. several authors writing that as an invited article in a PDA issue makes much more sense. It is clear the author has very good knowledge of PDA and related issues but the article is long / beyond its scope and too strongly making arguments supporting his view.

I will point out the positives the reviewer made:

“It is clear the author has very good knowledge of PDA and related issues”

The reviewer acknowledges my expertise on PDA, and the knowledge of the literature, which begs the question why the editor is currently not siding with my interpretation of things?

“I am not saying one should not write an article to argue that PDA should be a diagnosis but that should come from several prominent people writing the article together (as it is controversial) e.g. several authors writing that as an invited article in a PDA issue makes much more sense.”

The reviewer is acknowledging again, that ECAP can publish an article on the topic of PDA being a separate diagnosis.

I discuss elsewhere, mainly in my response Number one, elaborating how there is no need for such an article to be authored by many persons.

Yes, PDA is controversial. I am one of its leading advocates about *why* PDA is so controversial, such as here:

https://www.researchgate.net/publication/339240845_Pathological_Demand_Avoidance_and_the_DS_M-5_a_rebuttal_to_Judy_Eaton

And here:

https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference

The submission acknowledges that PDA is controversial. Here is my response on the topic from the revisions cover letter:

“I acknowledge that PDA being diagnosed in controversial and discuss this throughout the article, including devoting an entire section to it, called “PDA can be diagnosed independently of autism”. Specific comments include:

“Moreover, PDA technically cannot be diagnosed as it lacks an agreed diagnostic profile and standardised tools”

And

“Still, if one accepts that PDA does exist and that it should be diagnosed; logically, all persons who meet its profile have equal rights to receive a diagnosis, support and research, irrespective of if they are autistic or not.”

The editor can read the appropriate section for more details, but I have wrote around 1700 discussing how and why PDA should be diagnosed independently from autism.

I have referenced both Green et al 2018a and 2018b articles. The former is reference 3 and the latter is reference 36. I discuss their work in relation to the four main schools of thought relating to PDA’s medical ontology.”

I would point that ECAP published allowed O’Nions et al (2016) to be published with it pursuing the controversial perspective it is an autism subgroup, this is despite the reviewer’s own admission on the strong case PDA is seen in non-autistic persons: *“The topic of the article is "challenging whether PDA should just be seen as a subcategory of ASD as to a behavioural profile that can be seen in children who do not ASD". There are strong arguments for this”*. It seems inherently unreasonable and unfair

of the reviewer to suggest this submission should not be published, considering they suggested I submit it in the first place; while O’Nions and others can have their controversial and an apparently weak perspective published.

This comment of the reviewer:

“but the article is long / beyond its scope and too strongly making arguments supporting his view.”

What exactly am I meant to do, not argue for PDA being a distinct entity? If I did that it would undermine the central premise of the submission that should have always been viewed as a separate entity since 1980.

Surely, if the argument is made so strong, as the reviewer implies, then that is a reason for the submission to be diagnosed.

The simple response to this point of the reviewer is in the revisions cover letter:

“I am over the page limit suggested for authors, but the submission guidelines state this is open to negotiation with the editor. I am over the word limit to adequately cover all the topics relevant to the essay, that details how clinical opinions on PDA have evolved over time from Elizabeth Newson’s original unpublished research. It is clear upon engaging with Newson’s scholarship, that she did not intend for PDA to be conceptualised as an ASD, in fact she explicitly argues against such an approach. The assumption that PDA is an ASD has had important ramifications to PDA clinical practice and research, which I discuss in the article. I am open to certain aspects of the article being amended upon feedback from editor’s and or reviewers. I would like submission to accepted over the word limit. What are the editor’s thoughts?”

I will state this, as with the first round of peer review, the reviewer is being harsh, and much of their comments should be ignored when deciding to publish this submission.

Concluding comments.

There are many reasons, to view the reviewer as not properly engaging with the submission, and that they are being harsh. In places the reviewer is contradicting themselves. The reviewer making statements that are demonstrably untrue. There simple seems to be no valid reason for this submission to be rejected.

I would point out in the very least, ECAP should find me a more balanced peer reviewer to conduct peer review for the revisions. In my view as the reviewer:

- Did not argue against the points made in the submission.
- Acknowledged my passion on the topic.
- Acknowledged my expertise on PDA.
- The strength of the case that PDA is seen in non-autistic persons.
- That something on this topic can be published in ECAP.

And the other factors I mention in my rebuttal to the reviewer in Table 1, such as my own background on PDA; that this submission should be accepted for publication in ECAP.

I due to all these factors, I have set a deadline of the Friday the 26th of February 2021, for this submission to be accepted for publication in ECAP. If this has not been done by that date, my intent is submitting a complaint into the deciding editor's institution. Later, when I have the peer reviewer's name, a complaint against them in their institution. I will also publish this submission in Autism Policy and Practice, along with the required anonymised documents to substantiate my perspectives, such as peer reviews, cover letters, original submission, and the table containing the evidence there is an agenda to get PDA recognised as part of the autism spectrum.

Thank you for your time and I look forward to receiving your reply.

Yours faithfully.

Elizabeth Newson Centre to identify PDA. Going forward there is a need to separate PDA from ASD.

Declarations.

Funding: Not applicable.

Ethics approval: Not applicable.

Consent to participate: Not applicable.

Consent for publication: Not applicable.

Conflicts of interests: Author/s receives funds for delivering autism and PDA training.

Availability of data and material: Not applicable.

Code availability: Not applicable.

Authors' contributions: Not applicable.

Mr Richard Woods.

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