Richard Woods

Rational (Pathological) Demand Avoidance

6

Rational (Pathological) Demand Avoidance

As a mental disorder and an evolving social construct

Richard Woods

Pathological Demand Avoidance and Critical Autism Studies - context

There are different interpretations and definitions to Pathological Demand Avoidance (PDA) and Critical Autism Studies¹ (CAS). I need to be clear which definition of each I will be using throughout this chapter. While I will detail divergent PDA interpretations and how they

evolved, the CAS definition I use to do this is:

the "criticality" comes from investigating power dynamics that operate in Discourses

around autism, questioning deficit-based definitions of autism, and being willing to

consider the ways in which biology and culture intersect to produce "disability".

(Waltz, 2014, p. 1337)

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This chapter discusses how PDA is a social construct, thus as a concept, and how it has evolved

over time, in the process considering how culture and biology intersect to create PDA. This

builds on my original article (Woods, 2017); in the process the essay is representative of my

thinking in February 2021.² While I will be using a medical model of disability to discuss

autism³ and PDA, both in practice are social constructs that interact upon and with prevailing

culture. Before I explain how I define PDA and how it is quickly evolving, I will explain why

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autism, PDA, and other mental disorders are social constructs, using autism and PDA as examples. I then discuss how PDA is different and thus is not autism but is best described as a form of Obsessive-Compulsive Disorder and Related Disorders. This raises the question of why autism is viewed as part of the autism spectrum. I describe historical PDA literature and actions of certain stakeholders to control the evolution of PDA to be viewed as a form of autism. Finally, I analyse various PDA behaviour profiles to explain *how* traits of PDA have been amended for PDA to become autism-like.

Mental Disorders as social constructs

Mental disorders, like autism, PDA, Obsessive-Compulsive Disorder (OCD) are highly contentious. There is a continuum of outlooks on their respective utility, with one extreme driven by a scientific-method approach, the other that mental disorders are required as they assist many persons, through providing a model to describe a person and inform suitable support strategies. The central cause of this polarisation of perspectives is that mental disorders are social constructs; when a mental disorder is diagnosed, it is based on observable behaviours and either caregiver or service-user reports. Mental disorders are not diagnosed based on identifiable biological characteristics (Fletcher-Watson and Happé, 2019), and we should not expect this to change for the foreseeable future. Despite substantial effort and resources spent researching biomarkers for it (Pellicano et al., 2014), autism does not have a biomarker and many now accept that it is unlikely to ever gain such evidence (Woods et al., 2019). Hence, mental disorders officially lack features of fixed qualities that are rooted in nature; instead their definitions are based on human understandings and are thus fluid, evolving over time.

This dynamic intangible aspect of mental disorders affects the nature of knowledge surrounding mental disorders, as they can be controlled by human actions and decisions.

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Clinicians when assessing for features which might be attributed to a disorder, are not seeking concrete information. Instead, they are seeking information they can reliably measure, i.e. information that they can repeatedly measure consistently. Hence, mental disorders are based on reliability and not validity (Christie, 2019, Fletcher-Watson and Happé, 2019). The information a clinician uses to diagnose a mental disorder does not have to be valid, i.e. the characteristic does not have to represent what is being purported. A crucial example of this is how autism is reported to have deficits in Theory of Mind and Empathy (Bishop, 2018, Christie et al., 2012, Baron-Cohen et al., 1985), despite 20% of autistic persons passing Theory of Mind tests (Baron-Cohen et al., 1985). Social communication issues are solely located in autistic persons in the medical model. However, a growing body of empirical research supports the Double Empathy Problem, which posits that social communication problems in autism are related to breakdowns in interactions between autistic persons and those around them (Milton et al., 2020, Milton, 2017).

These challenges around generating deficits to measure, stem from how they are created as a researcher collects data on features in their sample. Statistically, each feature should produce a bell-shaped curve, a Gaussian Curve, and the line under its peak is the average of this characteristic in this population. Under the medical model of disability, the average is referred to as normal, and the extremes at the lower edge of the bell-curve are pathologised with deficits. Anyone who is attributed a deficit should receive intervention to correct the deficit. A problem is that individuals and entire populations can be cured and pathologised based on the definitions used: for example, during the 1970s, when thousands of people of Borderline Mental Retardation were cured by changing how IQ scores are used (Goodley, 2011). Pertinently, just because some persons might fall within the pathologised extreme, it does not mean that the associated features are actually 'deficits', nor that the 'deficits' can be 'repaired' with

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interventions, or pills. Frequently, there are more complicated processes occurring between the

pathologised persons and their environment, which produce the 'deficits'. Mental disorders

need to be treated for what they are: abstract representations of a collection of features.

For a mental disorder to be diagnosed reliably it needs to have validated tools and a

standardised behaviour profile, and PDA is partly controversial as there is no consensus over

what it is, or how to assess for it (Woods, 2020b, O'Nions et al. 2016a, O'Nions et al., 2014a).

Lacking both a standardised behaviour profile and validated tools, some argue PDA is best

described as a label given to a person (Moore, 2020). However, despite this, the reliability rates

for mental disorders are decreasing with each iteration of the DSM (Kinderman, 2019) and

many clinicians do not find mental disorders useful for prognosis or treatment planning (First

et al., 2019).

A critique of PDA is that much of its behaviour profile is difficult to reliably measure, like

Surface Sociability, with deficits in social identity, pride, and shame (Garralda, 2003). Some

features associated with this trait, like very inappropriate behaviour, and not knowing the

difference between right and wrong, are highly subjective and one could question from whose

perspective they are being defined. An issue with assessing features that only need to be reliable

in nature, is that one can accidentally allow for fallacious assumptions to adversely impact on

how one interprets the feature. For PDA, some of the features proposed to indicate deficits in

social identity, pride, and shame, include panic attacks and aggression towards others (Newson

et al., 2003). When a person is angry, it indicates the person is highly distressed and is highly

aroused (Woods, 2019a). The characteristics proposed by Newson et al. (2003) for PDA's

social communication issues highlight the potential problems that can occur when one reifies

them into a mental disorder.

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There are credible arguments for abandoning mental disorders (see, for example, Kinderman 2019). Nonetheless, some mental disorders do seem to be aligned to natural ways of being human. While autism lacks any biomarker evidence (Woods et al., 2019), some argue for discarding the construct (Runswick-Cole et al., 2016). There is a case to be made that autism is associated with autistic features that are valid. First, autistic perspectives are often stronger and more accurate than those of non-autistic stakeholders (Woods and Waltz, 2019). Second, autistic people are forming our own distinct culture (Woods et al., 2018). Third, autistic people frequently also possess co-occurring difficulties, such as anxiety (Woods, 2019a). How such co-occurring mental disorders present in autistic people, is often different to how they present outside of autism (Green et al., 2018a), because autism and co-occurring conditions simultaneously interact with each other (Green et al., 2018a, Brede et al., 2017, Flackhill et al. 2017). Irrespective of whether PDA and other mental disorders are social constructs, it is vital we validate the lived experience and difficulties expressed by those bestowed with a mental disorder.

Features of mental disorders can be arbitrarily chosen for political reasons. For example, when revising the autism criteria for the *Diagnostic and Statistical Manual of Mental Disorders*, *Fifth Edition (DSM-5)*, a group of autistic persons lobbied (unsuccessfully) for the reduction of number of social communication traits a person needed for a diagnosis (Kapp and Ne'eman, 2019). It means that aspects of mental disorders can be rebranded based on the outlook that is in vogue at any given moment. We can create a mental disorder from a collection of features observed in a particular population. Elizabeth Newson, for instance, reified PDA when she created its first behaviour profile in 1988 (Newson, 1989), making abstract features from her case files suddenly tangible. Additionally, the classification of mental disorders is arbitrary, and it is possible to invent new diagnostic groupings. Newson created her own Pervasive

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Developmental Coding Disorders group for autism, PDA, dyslexia, and dysphasia (Newson, 1996, 1989). Indeed, leading PDA proponents highlight how clinicians can assign a mental disorder to a specific population, expressing:

No iteration of either DSM or ICD has acknowledged the fundamental distinction between researchers and practitioners ... who uses diagnostic classifications and for what purpose?

(Christie, 2019)

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The crux of this quote is that, if a mental disorder benefits certain stakeholder groups, the diagnostic entity should be accepted and used. The purpose of a definition of a mental disorder should be to describe a constellation of features that adversely affect the diagnosed individual, and/or those around them. Consequently, each mental disorder should represent a discrete set of difficulties and correspond to a particular set of approaches. One of the main justifications for PDA is that it has different strategies⁵ to autism and traditional autism approaches do not work with PDA (O'Nions and Eaton, 2020, Eaton and Weaver, 2020, Christie, 2007, Newson et al., 2003). However, this is strongly countered by the number of traditional autism approaches that do not work with many autistic people (Milton, 2017). PDA approaches can be viewed as good practice (Woods, 2019a), replicating strategies that have been practiced with autistic persons, independently of a PDA diagnosis (Green et al., 2018b), such as the Low Arousal Approach. This matters, as it is typical practice for strategies and approaches to be associated with problems, not to be associated with a particular diagnosis.

A primary cause as to why strategies and approaches are not diagnosis specific is that all humans have spiky skills profiles; no-human conforms to all statistical averages, no human can This is the accepted version of the following book chapter: Woods, R. (2022). Woods, R. (2022). Rational (Pathological) Demand Avoidance: As a mental disorder and an evolving social construct. In: Milton, D., & Ryan, S. (Eds), *The Routledge International Handbook of Critical Autism Studies* (20 pages), Abingdon-on-Thames, UK, Routledge Publishing. DOI: https://www.taylorfrancis.com/chapters/edit/10.4324/9781003056577-7/rational-pathological-

 $\underline{demand\text{-}avoidance\text{-}richard\text{-}woods?context\text{-}ubx\&refId\text{-}eb1fb124\text{-}3497\text{-}47a3\text{-}932b\text{-}0f7419486c7a}$

be described as normal (Goodley, 2011). This results from how human features, including psychological features, exist along a continuum within the human population (Kinderman, 2019). We do not fit neatly into boxes. The professional bodies that produce manuals to diagnose mental disorders accept this intrinsic aspect of humanity, and so they create residual mental disorders for each diagnostic grouping for persons who do not meet the clinical threshold for a particular diagnosis (First et al., 2019). When autism subtypes were used in the DSM-4, autism was represented by three mental disorders: Asperger's Syndrome; Autistic Disorder; and Pervasive Developmental – Not Otherwise Specified (PDD-NOS) (Christie et al., 2012; Green et al., 2018a); the last one being the residual category for anyone not meeting clinical threshold for either Autistic Disorder and Asperger's Syndrome. Together, these three mental disorders were within the Pervasive Developmental Disorder diagnostic grouping, alongside Childhood Disintegrative Disorder and Rett's Disorder (American Psychiatric Association, 1994). Presently, the consensus is that autism subtypes are unhelpful as it is clinically and scientifically impossible to successfully divide autism (Woods et al., 2019). Yet, some argue that if individuals prefer the name of particular an autism subtype, they should be retained for those who wish to use them (Wing et al., 2011, Frith 1991).

Using autism and PDA as case studies, this section has discussed how mental disorders are social constructs and demonstrated that they do not need to be scientific in nature, they only need to benefit certain stakeholders of a particular population. In the process, mental disorders are not diagnosed on valid features, but on characteristics that can be reliably measured. This can lead to features interpreted based on observer's bias. For instance, panic attacks were assigned to the Surface Sociability trait when it is a sign of distress; more appropriately it should be assigned to the Lability of Mood trait. Due to being social constructs, politics and subjectivity affect how mental disorders are conceptualised and categorised. PDA is known for

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avoidance of the demands of everyday life (Green et al., 2018a, Christie, 2007, Newson et al., 2003), but these demands vary with each person's situation, cultural background, and lived experience. Later in the chapter I detail how PDA's evolution has been controlled to become more 'autism-like', adopting characteristics that fit this outlook. Before then, I critically evaluate PDA literature, and detail how I conceptualise PDA as a mental disorder.

PDA as a mental disorder

First, I will define what I consider PDA to be, and this can be tricky as PDA means different things to different people. Consequently, there are several different behaviour profiles for PDA, I have amalgamated these to create an Aggregated Profile, as shown in Figure 6.1. I take a medical model of disability approach to describing PDA throughout this chapter, displaying its nature as a social construct and how it interacts with cultural practices.

There are areas of overlap and difference between PDA and autism. The main similarity is that both have Restricted and Repetitive Behaviours and Interests (RRBIs) (Eaton 2018a, Christie et al., 2012, Christie 2007). PDA's RRBIs are clinically different to autism as they are described as obsessive in nature (Newson et al., 2003), and caused by high anxiety (Eaton and Weaver, 2020, Christie et al., 2012, Christie, 2007). Moreover, PDA has five RRBIs whereas autism has three. An essential point of divergence between PDA and autism is the early age of onset of traits, yet some view PDA as being neurodevelopmental in nature (Eaton and Weaver, 2020, Newson et al., 2003).

For social communication issues, the situation is inverted, with autism having three, whereas PDA has an optional one. Akin to RRBIs, PDA's surface sociability is viewed as having a different cause than autism, which is attributed to deficits in Theory of Mind and Empathy. PDA does not have these deficits, but social communication issues in PDA do overlap in some

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autistic persons, as 20% of autistic persons lack deficits in Theory of Mind (Baron-Cohen et al., 1985). Research suggests that PDA traits have no association with Theory of Mind deficits (Bishop, 2018, O'Nions, 2013). However, PDA developmental aspects were made optional several years ago (Fidler, 2019, Russell, 2018, Green et al., 2018a, O'Nions et al., 2016a). While these differences are present, PDA's behaviour profile is unstable (Eaton, 2018a); its features may in the future become more aligned with autism.

There are many other factors that prohibit PDA being part of the autism spectrum. Key clinical differences between PDA and autism include PDA's use of humour, spontaneity, and novelty, as a PDA strategy which contradicts traditional autism strategies. The fantasy and roleplay characteristics of PDA are typically delayed or absent in autism. PDA's initial gender was one male to one female, which is more balanced than male-biased autism gender ratios (O'Nions et al., 2015, O'Nions et al. 2014b). PDA's socially manipulative demand avoidance behaviours are too frequent and varied when compared to autism, as they preclude a person receiving an autism diagnosis (Trundle et al., 2017, Gillberg et al. 2015, O'Nions et al., 2015, Christie et al., 2012). PDA's surface sociability problems are associated with deficits in social identity, pride, and shame (Newson et al., 2003), unlike autism. The reduction in persons meeting the clinical threshold for PDA, of 44% to 89% is higher than that found in autism; these and other results indicate that features of PDA are developmentally unstable (Woods, 2020), and thus not pervasive.

Certain PDA characteristics could be criminal in nature, such as harassment (O'Nions et al., 2016a, Gillberg et al., 2015), and could risk individuals becoming involved in the Criminal Justice System (CJS). Early PDA research identified a few features, such as stalking and violence (Newson et al., 2003), that increase risk of engagement with the CJS (Egan et al.,

2019). Egan and colleagues (2019) found in their first study that around one fifth of their This is the accepted version of the following book chapter: Woods, R. (2022). Woods, R. (2022). Rational (Pathological) Demand Avoidance: As a mental disorder and an evolving social construct. In: Milton, D., & Ryan, S. (Eds), *The Routledge International Handbook of Critical Autism Studies* (20 pages), Abingdon-on-Thames, UK, Routledge Publishing. DOI:

sample had been arrested and about a tenth had a prior conviction. Slightly over 10% of participants in the second study were involved with the CJS (ibid.). Furthermore, Lorna Wing (2002) noted that persons with PDA gain reward from upsetting other individuals and PDA behaviours are found in all autism subtypes. The rates of involvement of PDA in the criminal justice system are higher than those found for autism, with autistic persons no more likely to engage in CJS than their peers (Yu et al., 2021). There is increasing recognition of the adverse impact stigma has for autistic persons, which the criminal conduct aspects of PDA may contribute towards. This raises the question of whether we wish to associate such features with autism, by viewing PDA as a form of autism.

PDA behaviours may not be caused by autism, i.e. a "double-hit" (Wing et al. 2011), and it may be a "triple-hit" of autism, conduct problems, and anxiety (Langton and Frederickson, 2016). Research indicates that PDA is not predicted by autism, but by ADHD, anxiety, and conduct problems (Egan et al., 2020, Green et al., 2018a). Some experts think PDA is seen outside of autism (, Green et al. 2018a; Woods 2020b) and has limited supporting evidence (Woods 2020b, Woods 2019a). These, and the previously mentioned factors, support the consistent views of the clinician who first observed PDA: that it is not part of the autism spectrum (Newson et al., 2003, Newson 1996, 1989, 1983).

PDA is commonly portrayed as part of the autism spectrum (O'Nions and Eaton, 2020, Eaton et al., 2018, Russell, 2018, O'Nions et al., 2016, Christie et al., 2012; Christie, 2007). Yet its central impairment is high-anxiety—driven demand avoidance, and anxiety is recognised as a co-occurring difficulty to autism (Woods 2020a, Egan et al., 2019, Gould and Ashton-Smith, 2011). Newson et al. (2003) conceptualised the demand avoidance as being obsessive in nature, and Christopher Gillberg questions if it is a new type of mental disorder (2014). In OCD, there

is a simplified cycle of thoughts and actions (OCD-UK, 2020), which matches what happens This is the accepted version of the following book chapter: Woods, R. (2022). Woods, R. (2022). Rational (Pathological) Demand Avoidance: As a mental disorder and an evolving social construct. In: Milton, D., & Ryan, S. (Eds), *The Routledge International Handbook of Critical Autism Studies* (20 pages), Abingdon-on-Thames, UK, Routledge Publishing. DOI:

in PDA. The OCD cycle starts with an obsession (demand), which then causes anxiety or

distress to an individual. The individual then responds to the obsession with a compulsion,

which is an act or thought that attempts to resist, ignore, and remove the obsessive thought.

Subsequently, the individual experiences temporary relief from their anxiety and distress, even

only for a few moments, until the next obsessive thought.

Some would argue that a person with PDA has atypical ways of socially interacting and they

struggle to maintain social relationships (Eaton and Weaver, 2020, Christie et al., 2012,

Newson et al., 2003). Social communication issues and issues maintaining relationships are

common in mental disorders (Wilkinson, 2017), for example Attachment Disorders (Flackhill

et al., 2017), and Borderline Personality Disorder (Eaton, 2018a). O'Nions et al. (2016a)

removed PDA's developmental traits their PDA behaviour profile, as they were too common

among autistic persons to be useful in identifying PDA as an autism subgroup. Due to how

common social communication issues are outside of autism, we can likewise make the Surface

Sociability trait optional.

A logical extension is that if one is primarily diagnosing PDA in autistic persons, the social

communications issues are covered by an autism diagnosis and so the Surface Sociability is

redundant, as those difficulties are pathologised in an autism diagnosis (Fletcher-Watson and

Happé, 2019, Eaton, 2018a). Placing the Surface Sociability trait as optional is in line with the

prediction that the diagnostic traits will be reduced as understandings of PDA are refined

(Christie et al., 2012). Exclusively utilising traits that are RRBIs reduces PDA's traits down to

those that are essential for a diagnosis and reflect the demand avoidance descriptors in its name.

Many of the features of this trait – for instance, panic attacks and violence when angry – suggest

the person is highly aroused. This can be viewed as compulsive responses to anxiety from

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demands; therefore, they are instead attributed to Lability of Mood trait, a RRBI. O'Nions (2019) argues that the demand avoidance behaviours in PDA are developed through a negative reinforcement cycle, where anxiety is temporarily relieved due to the expression of demand avoidance behaviours, which forces other humans away and thus removes the aversive demand. Ergo, these demand avoidance behaviours are viewed as scripted in nature.

In contrast, PDA's demand avoidance behaviours are viewed as manipulative in nature due to how much time and effort a person with PDA expends upon displaying them; it is viewed as their greatest asset (Christie et al., 2012, Newson, 1983). The impact of the demand avoidance behaviours is to change the dynamics of social interaction, often by terminating it, thus removing aversive demands. If a person is frequently expressing such demand-avoidant behaviours, it may lead to the person frequently experiencing chaotic and unpredictable social interactions. This highlights how PDA's obsessive-compulsive aspects interfere with a person's social and occupational functioning (OCD-UK, 2020). Traits of adopting roles and being comfortable with roleplay is viewed as an RRBI due to the obsessive and compulsive nature of these behaviours; for instance, escaping into roles as a coping strategy (Newson et al., 2003, Newson, 1983). PDA's Surface Sociability trait does not necessitate it being a form of autism.

There is substantial overlap between PDA and OCD. Empirical research investigating PDA from caregiver reports of autistic children indicates PDA has a similar cycle to OCD (O'Nions, 2019). Where an individual experiences a demand, which causes distress or anxiety, they respond with avoidant behaviour, which relieves the anxiety and distress until the next demand (O'Nions, 2019). Modern PDA perspectives adopt a transactional approach between individuals and their environment (Fidler and Christie, 2019, Green et al., 2018a, Milton,

2017). Around two thirds of distress (challenging) behaviour is caused by a demand or request This is the accepted version of the following book chapter: Woods, R. (2022). Woods, R. (2022). Rational (Pathological) Demand Avoidance: As a mental disorder and an evolving social construct. In: Milton, D., & Ryan, S. (Eds), The Routledge International Handbook of Critical Autism Studies (20 pages), Abingdon-on-Thames, UK, Routledge Publishing. DOI:

by other persons (Woods, 2019a). The compulsive behaviours in PDA include avoiding persons and situations, through behaviours people use to assert their agency, such as pretending to be ill or incapacitating themselves, attempting to negotiate better terms, and running away or hiding (Moore, 2020, Woods, 2019b).

These can be extreme behaviours and difficult for anyone to manage, including the person expressing them. Avoidance, including of certain places, objects, and persons are recognised compulsive acts in OCD (OCD-UK, 2020). PDA's compulsive, avoidant behaviour is a response to a demand, which is an anxiety or distressing thought, typically triggered from their environment, in particular other persons. PDA compulsion behaviours are so extreme that they may cause other persons to remove the demand they are placing on the individual, providing temporary relief to persons with PDA (O'Nions, 2019). Frequently, these compulsive acts impact a person's social relationships. This is reflected in questions in PDA measures, such as "I am good at getting round others and making them do as I want" (Egan et al., 2019, p. 485), and "Would you describe A as good at getting round others and making them do as s/he wants, or playing people off against each other?" Therefore, PDA social demand-avoidance behaviour is pathologising efforts of a person expressing their self-agency (Milton, 2017,; Woods, 2017). PDA is a threat to an individual's self-agency as others can ignore a person's legitimate concerns and efforts for self-advocacy, as the person being manipulative (Woods, 2017).

Researchers have found a group of autistic persons who started displaying PDA from around ages 5 to 7, and this usually triggered by aversive school experiences (Eaton and Weaver, 2020, Eaton, 2019). The researchers call this group "Rational Demand Avoidance" as they report these PDA behaviours present less frequently than "Extreme Demand Avoidance" and are not

necessarily pervasive (Eaton and Weaver, 2020). However, many of these autistic children and This is the accepted version of the following book chapter: Woods, R. (2022). Woods, R. (2022). Rational (Pathological) Demand Avoidance: As a mental disorder and an evolving social construct. In: Milton, D., & Ryan, S. (Eds), *The Routledge International Handbook of Critical Autism Studies* (20 pages), Abingdon-on-Thames, UK, Routledge Publishing. DOI:

young people (CYP) would not be able to process the reasons behind their demand avoidance behaviour. Many of these 5–7-year-old CYP may have any combination of issues with Theory of Mind, alexithymia, and interoception. They may have difficulty understanding their own mental state, their own emotions, and what their internal bodily signals mean. Consequently, these CYP would not be able to rationalise their demand avoidance. Hence, there cannot be a "Rational Demand Avoidance" group, if many of its members cannot rationalise their demand avoidance and such a distinction between "Rational" and "Extreme" demand avoidance is arbitrary.

The research team themselves consider demand avoidance in their "Rational Demand Avoidance" group to be rational from a non-autistic perspective. Autistic persons, such as Damian Milton and I, argue that PDA should be called Rational Demand Avoidance, as autistic persons will frequently avoid situations we find aversive (Woods, 2019a, Milton, 2017). In our conceptualisation of PDA, there are no distinctions between PDA and Rational Demand Avoidance. This makes sense: when autistic persons live in a world unsuited to our needs, autistic anxiety results from hostile experiences (Pellicano, 2020). This is reflected in high prevalence rates for anxiety-based difficulties, anxiety (42–56%) (Woods, 2019a), Anxiety Disorders (20%), and OCD (9%) (Lai et al., 2019). Anxiety and OCD are associated with trauma and childhood aversive experiences (Allsopp et al., 2019). PDA behaviours can be explained by trauma (Brede et al., 2017, Milton, 2017, McElroy, 2016). When accounting for the psycho-emotional disabling effects non-autistic—led culture has on autistic persons, avoiding demands resulting from said culture would be intrinsically rational.

For OCD, whether or not obsessions and compulsions are understood by those experiencing them is ignored, as children are not necessarily expected to know or express the aims of their

actions or mental acts. Additionally, a person meets a threshold when their This is the accepted version of the following book chapter: Woods, R. (2022). Woods, R. (2022). Rational (Pathological) Demand Avoidance: As a mental disorder and an evolving social construct. In: Milton, D., & Ryan, S. (Eds), The Routledge International Handbook of Critical Autism Studies (20 pages), Abingdon-on-Thames, UK, Routledge Publishing. DOI:

obsessions/compulsions take up at least an hour a day or when they adversely affect some important areas of functioning, such as social or occupational ones (OCD-UK, 2020). This approach accepts how psychological features present in a continuum and can manifest differently in persons as it does not differentiate between which is more severe between compulsions or obsessions, instead focusing on the universality of the underlying psychological process.⁷ A broad conceptualisation of PDA is inherently inclusive as it acknowledges the universal rights to a PDA diagnosis (Summerhill and Collett, 2018).

Modifying the OCD cycle for PDA allows for demands often triggered from external sources, but the obsessional demand is the individual's own thought. With a transactional approach taken in modern PDA understandings (Fidler and Christie, 2019, Green et al., 2018a, Milton, 2017), a demand management⁸ cycle is produced, as seen in Figure 6.2.

The following is an example of the Demand Management Cycle describing demand avoidance in PDA. A young autistic child has the demand to attend school. The child becomes anxious from the prospect of facing sensory overload during class and bullying at break times. The child avoids the demand to attend school through school refusal and in the process gains relief from the anxiety of facing a known distressing situation, until the next time they are faced with that demand. It can be more complicated than this in real life, with the caregivers attempting multiple times for the child to attend school each day, initially for at least two weeks, and in response the child escalates their behaviours to the aversive demand. The child might start with attempting to negotiate with the adult; as this attempt fails, they might try to incapacitate themselves. Finally, the child becomes violent with the caregiver, and at this point the demand to attend school is withdrawn for that day. When this scenario occurs over several months, it it conforms to understandings of OCD, as the distressing thoughts are inherently the child's perspective.

The compulsive school refusal and violence towards the caregiver would cause clinically This is the accepted version of the following book chapter: Woods, R. (2022). Woods, R. (2022). Rational (Pathological) Demand Avoidance: As a mental disorder and an evolving social construct. In: Milton, D., & Ryan, S. (Eds), The Routledge International Handbook of Critical Autism Studies (20 pages), Abingdon-on-Thames, UK, Routledge Publishing. DOI:

significant distress and impairment in social situations and areas of functioning and education (OCD-UK, 2020)9.

The Demand Management Cycle for PDA is partly derived from the OCD cycle, and it shares similar properties. Firstly, it should be present in most forms of PDA, but it is only a simple model and does not represent all the complex psychological processes that can occur with demand avoidance. PDA is primarily diagnosed in autistic persons (Eaton and Weaver, 2020, O'Nions and Eaton, 2020, Russell, 2018), though this is not universally the case (Woods, 2020b, Green et al., 2018a, O'Nions, 2013, Newson et al., 2003). Anecdotally, many autistic adults report that when demand avoidance forces them to miss an activity they wish to do, they subsequently experience guilt. This extra emotional baggage surrounding demand avoidance behaviours can amplify the reinforcement effects of demand avoidance. Consequently, demand avoidance can become habits and/or negatively impact a person's mental well-being (O'Nions and Eaton, 2020). It is vital that the Demand Management Cycle is not over-reified, to the detriment of the entire psychological processes present in persons with PDA.

The lack of consensus over what PDA is, makes it difficult to directly compare PDA to autism. Yet, there are many factors emerging that indicate PDA is not autism, from it being primarily an anxiety-based condition, to how it appears that PDA is neither necessarily developmental nor pervasive in nature. Furthermore, in my view, PDA is best viewed as a new type of mental disorder that fits within the OCD and Related Disorders diagnostic grouping. Each person with PDA will generally follow the same Demand Management Cycle, in which they receive a demand, which causes the person anxiety or distress. Subsequently, a person with PDA will express avoidance behaviour until the demand is removed and they experience temporary relief. It is appropriate to conceptualise PDA as "Rational Demand Avoidance", supporting the

views of Critical Autism Studies scholars (Milton, 2017, Moore, 2020, Woods, 2019a). Such This is the accepted version of the following book chapter: Woods, R. (2022). Woods, R. (2022). Rational (Pathological) Demand Avoidance: As a mental disorder and an evolving social construct. In: Milton, D., & Ryan, S. (Eds), The Routledge International Handbook of Critical Autism Studies (20 pages), Abingdon-on-Thames, UK, Routledge Publishing. DOI:

an outlook is intrinsically inclusive, by adopting a low diagnostic threshold and a broad definition, supporting the universal rights of a CYP with PDA (Summerhill and Collett, 2018). However, this outlook does not consider how PDA is mainly diagnosed in autistic persons, and the story of how the present situation occurred is provided in the next section.

PDA and its relationship to the autism spectrum

PDA's traditional diagnostic status is linked to the historic status of autism. Infantile Autism, as proposed by Leo Kanner, was originally viewed as a form of Schizophrenia (Woods, 2019a, Frith, 1991). Autism has since changed diagnostic categories to Pervasive Developmental Disorders with the use of subtypes (American Psychiatric Association, 1994). Presently, autism is viewed as an undividable continuum disorder (Woods, 2020b, Fletcher-Watson and Happé, 2019; Green et al., 2018a). Elizabeth Newson's opinions on PDA's diagnostic identity were consistent over three decades. Newson researched PDA from 1975 to 2003 (Newson et al., 2003), initially creating a new diagnostic grouping into which to place PDA in 1986, two years before the behaviour profile (Newson, 1989). This grouping, used between 1986 to 1996, is the Pervasive Developmental Coding Disorders and was composed of Infantile autism, Asperger's Syndrome, PDA, dyslexia, and dysphasia (Newson, 1996, 1989). Newson later revised this diagnostic grouping into her own version of the Pervasive Developmental Disorders, containing Autistic Disorder, Asperger's Syndrome, PDA, and Specific Language Impairment (SLIs). SLIs contain conditions such as dyslexia and dysphasia. Despite the name change Newson still required all four syndromes to have coding issues (Newson et al., 2003, Newson, 1999).¹⁰

Newson and colleagues spent 15 years refining the PDA behaviour profile, while fundamentally keeping it the same. Individuals with PDA who displayed autism features were

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removed from their database. Newson did not base PDA on the Triad of Impairment (Newson et al., 2003) that underpins modern autism diagnostic criteria (Milton, 2017). Vitally, Newson et al. (2003) expressed PDA needs as being distinct and different to Autistic Disorder and Asperger's Syndrome; PDA is not an autism spectrum disorder, and it would be a mistake to envision it as such¹¹ as early as 1983 (Newson, 1983). The purpose of Newson's PDA research is to demonstrate that PDA is different to Autistic Disorder and Asperger's Syndrome; it is not an ASD and therefore PDA needs to be recognised as a distinct diagnostic entity (Newson et al., 2003). Contrary to Newson's consistent views, PDA is primarily viewed as a form of autism. So how did this occur?

PDA is viewed as a form of autism through two pathways. In 2002, Lorna Wing and Judy Gould argued that Newson's research does not show PDA as a separate syndrome from autism (Milton, 2017, Christie, 2007, Wing, 2002), and that the features of PDA are present throughout the entire autistic population (Milton, 2017, Christie et al., 2012, Christie, 2007). Others have noted that Newson's research does not establish the specificity or validity of PDA (Green et al., 2018a, Garralda, 2003), and that there are not features specific to PDA (Eaton and Weaver, 2020, Woods, 2019a, Garralda, 2003). Later, Gould, with Ashton-Smith (2011), suggested that PDA could be a female form of autism. Wing and Gould's comments have some merit, but seem problematic as their comments came before Newson et al. (2003) article was published. Their critique was premature. Furthermore, I also question whether Wing and Gould have the clinical experience to say exactly what PDA is and how it presents in the general public, considering their history in highly specialised autism settings.

Phil Christie builds on the arguments of Wing and Gould and later discusses how controversy around PDA focuses on whether PDA is a discrete syndrome within broader Pervasive

Developmental Disorders or a syndrome in the narrower Autism Spectrum. While referring to This is the accepted version of the following book chapter: Woods, R. (2022). Woods, R. (2022). Rational (Pathological) Demand Avoidance: As a mental disorder and an evolving social construct. In: Milton, D., & Ryan, S. (Eds), The Routledge International Handbook of Critical Autism Studies (20 pages), Abingdon-on-Thames, UK, Routledge Publishing. DOI:

conventional autism and acknowledging that Pervasive Developmental Disorders diagnostic grouping is not the same as the autism spectrum, he attempts to resolve the debate by arguing that PDA should be viewed as an autism subtype, as the public often conflates the Pervasive Developmental Disorders with autism spectrum. He suggests that a prolonged debate on the topic is a distraction from focusing on the true purpose of a diagnosis (Christie, 2007). Essentially, Christie replaced the Triad of Impairment, as the underpinning of autism social construct, with the three descriptors of Pervasive, Developmental, and Disorder. 12

Christie cites a 1999 diagram by Newson that displays a version of her Pervasive Developmental Disorders diagnostic grouping (Christie, 2007). The 1999 iteration of this diagram is different to the 2003 "The 'family' of pervasive developmental disorders". The earlier version omits Specific Language Impairments (Newson, 1999, Newson et al., 2003). This is a crucial point of divergence when adopting Newson's Pervasive Developmental Disorders as the autism spectrum. Newson's version of Pervasive Developmental Disorders lacks Childhood Disintegrative Disorder and Rett's Disorder of the *DSM-4* (American Psychiatry Association, 1994), adding PDA and SLIs (Newson et al., 2003).

In the *DSM-4*, Pervaisve Developmental Disorder- Not Otherwise Specified was the residual category for Autistic Disorder and Asperger's Syndrome; these together with PDD-NOS were autism subtypes (Green et al., 2018a, Christie et al., 2012). Newson had her own definition of PDD-NOS, which is when a person does not meet the threshold for either Autistic Disorder, Asperger's Syndrome, PDA, or SLIs. Newson's definition is clinically broader than the accepted PDD-NOS definition as it includes non-autism constructs of PDA and SLIs. It therefore covers non-autistic persons. Using Christie's logic, one would also be adding SLIs to the Autism Spectrum. The prevalence rate for SLIs is 3% to 7% (Bishop et al., 2017). This

would mean using Newson's views on Pervasive Developmental Disorders to add disorders to This is the accepted version of the following book chapter: Woods, R. (2022). Woods, R. (2022). Rational (Pathological) Demand Avoidance: As a mental disorder and an evolving social construct. In: Milton, D., & Ryan, S. (Eds), The Routledge International Handbook of Critical Autism Studies (20 pages), Abingdon-on-Thames, UK, Routledge Publishing. DOI:

the spectrum and would add millions of non-autistic persons with SLIs to the autism spectrum.

Needless to say, Christie's conceptualisation of PDA as a form of autism contradicts Newson's

consistent views on this topic. Controversially, it is through Christie's logic that PDA is

commonly viewed as a form of autism (Christie et al., 2012).

Attention on PDA is primarily centred in the UK (Green et al., 2018a), with a major charity

adopting the outlook that PDA is part of the autism spectrum (Eaton et al., 2018, Green et al.,

2018, Russell, 2018, O'Nions et al., 2016, O'Nions et al., 2014a, O'Nions et al., 2014b) and

the inclusion of guidelines for PDA in national autism educational guidelines (O'Nions et al.,

2016a, O'Nions et al., 2014a). Furthermore, hundreds and thousands of caregivers partake in

surveys (Russell, 2018), petitions that view PDA as an ASD, and annual PDA conferences are

oversubscribed (Trundle et al., 2017, O'Nions et al., 2016, O'Nions et al., 2014a, O'Nions et

al., 2014b). These awareness-raising activities can lead people to be on the look-out for PDA,

potentially biasing PDA diagnoses and research (O'Nions et al., 2016). Outside of clinical

settings research heavily relies upon highly motivated caregiver's (O'Nions et al., 2016b), and

is noted as being open to bias (Eaton and Weaver, 2020). Caregivers regularly use PDA as a

proxy to gain different support strategies (Green et al., 2018b).

There are examples of CYP internalising the outlook that PDA is an ASD (O'Connor and

McNicholas, 2020, Finley, 2019), and similarly for autistic adults (Thompson, 2019, Cat,

2018). There are numerous PDA-related activities that support a community of practice around

the axiom that PDA is part of autism (Woods, 2019a). As anthropologist Roy Grinker suggests:

once a diagnosis takes hold and serves as the hub around which so much wealth, so

many people, and activities coalesce, it takes on a life of its own as an authentic,

naturalized classification (Hacking 2000). This category, in turn, provides an incentive

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for manufacturing people with the diagnosis of autism whose presence and needs support this financial infrastructure.

(Grinker, 2020, p. 62)

noindent

As a result, researchers often primarily portray PDA as being part of the autism spectrum, as an autism subtype, autism subgroup, or an autism profile (Doyle et al., 2020, Bishop, 2018, Russell, 2018, O'Nions et al., 2014a, Eaton and Banting, 2012). In 2011, a research agenda was put forward to get PDA accepted as a form of autism; it included developing new diagnostic screening tools and investigating PDA's cognitive profile in relation to autism theory, such as Theory of Mind. This research was needed to support clinical-based understandings of PDA that it is a form of autism (Christie et al., 2012). Prominent PDA researchers have approached PDA from their understandings of autism (O'Nions et al., 2016b). Subsequently, research into it is dominated by entirely (and suspect) autistic population samples (Doyle et al., 2020, O'Nions and Eaton, 2020; Russell, 2018, O'Nions et al., 2018, Brede et al., 2017, O'Nions et al., 2016a, O'Nions et al., 2014a), or only autistic persons are diagnosed with PDA (Eaton and Weaver, 2020, Gillberg et al., 2015). One could challenge the ethics of such an approach as being unscientific in nature (Woods, 2019a).

For the last few years there has been a concerted research project in PDA between a private clinic and prominent PDA researchers (Eaton, 2019, 2018b). The project involved two research projects operating in tandem, one based on cases from the private clinic (Eaton and Weaver, 2020), the other investigating PDA parenting strategies (O'Nions, 2019). PDA was only diagnosed in autistic persons (Eaton and Weaver, 2020), and PDA parenting strategies were investigated from an entirely autism-caregiver sample (O'Nions, 2019). Researchers involved

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in this project view PDA as a form of autism (O'Nions, 2019, Eaton et al. 2018, Eaton et al., 2018a). Collectively, they presented findings where they portray PDA as an autism subgroup

(O'Nions and Eaton, 2020).

Recently, a PDA charity has publicly said it will campaign for PDA's recognition as part of

the autism spectrum. The context to this statement is that the charity collaborates with the lead

clinician of the private clinic on their position and campaigning on PDA. ¹³ They do not discuss

that PDA is not based on accepted autism understandings. There appears to be a concerted

agenda to have PDA accepted as a form of autism. In the next section PDA's other behaviour

profiles are analysed to highlight how PDA has taken on 'autism-like' characteristics.

How has PDA evolved as a mental disorder?

I have discussed the nature of mental disorders, how PDA is viewed as a mental disorder, and

the history behind PDA viewed as an autism subtype. Image 1 displays all the PDA diagnostic

traits in print across four behaviour profiles, in the Aggregated PDA behaviour profile, and

compared to the DSM-5 autism criteria. Newson did not require all features of PDA to be

present for a person to meet clinical threshold for a diagnosis (Newson et al., 2003). Some

diagnostic traits of Newson are optional, as in they were discarded; these are the developmental

traits of neurological involvement, passive early history, and speech delay (Fidler, 2019;

Russell, 2018, Green et al., 2018a; O'Nions et al., 2016a).

O'Nions et al. (2016a) removed these diagnostic traits as they viewed PDA as an autism

subgroup and developmental traits are too common in the autistic population to be useful to

identify PDA as a meaningful subgroup. This outlook on PDA is reflected in main diagnostic

and screening tools for PDA, which between them only have one question to assess for Passive

Early History (Egan et al., 2019, O'Nions et al., 2016a, O'Nions et al., 2014a), which is

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Question 26 on the EDA-Q (O'Nions et al., 2014a). Hence, it is easy to conceptualise it as an

anxiety-based disorder in practice and research.

There are other signs that PDA has become more autism-like in its behaviour profiles. Image

1 highlights that sensory issues are part of the *DSM-5* autism criteria; the "Sensory Differences

trait was included in Eaton et al. (2018), which views PDA as a form of autism. A key point of

divergence is with Newson et al.'s (2003) Obsessive Behaviour trait, which was described as

such and most of PDA's behaviours are obsessive in nature. This trait evolved into "Obsessive

behaviour (often social in nature)" (O'Nions et al., 2016a), and then "Displays obsessive

behaviour that is often focused on other people" (Green et al., 2018a). There is a clear

progression to the emphasis on this trait having an autism-like special interest, specifically

focused on people, instead of special interests on objects, or mundane topics. This is in line

with interpretations of a female form of autism (Gould and Ashton-Smith, 2011, Christie,

2007).

The social aspects of PDA seem to have been reinterpreted. The Surface sociability, but lack

of sense of identity, pride, or shame (Newson et al., 2003), reflects Newson's assumptions as

to the cause of PDA's social interaction issues. They went onto to argue that the obsessive

demand avoidance seen in their cases is due to CYP knowing no boundaries to their avoidance.

O'Nions et al. (2016a) amended the wording to state that PDA had deficits in social identity,

pride, or shame. This allows the wording to change to stating there is a lack of understanding

- "Appears sociable, but lacks understanding" (Green et al., 2018) - which removes the

connotation from deficits not associated with autism.

Predicted PDA populations are largely based on Newson's descriptions (Woods, 2019a,

Milton. 2017, McElory, 2016, Gillberg, 2014, Christie, 2007), while these changes derive from

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autistic population samples (Eaton et al., 2018, O'Nions et al., 2016a), or by organisations that view PDA as a form of autism (Green et al., 2018a, O'Nions et al., 2016a). These revisions to PDA traits matter as they affect how PDA is interpreted. Autism interacts with its co-occurring conditions simultaneously (Green et al., 2018a, Brede et al., 2017, Flackhill et al., 2017), and so these conditions often present differently outside of autism. Thus, these changes to the PDA behaviour cannot be generalised onto other PDA populations.

Beyond the autism-like changes limiting the generalisability of the PDA behaviour profile, they have led to differences to features being assessed by diagnostic and screening tools and their corresponding trait. The trait of "Lability of mood, impulsive, led by need to control" (Newson et al., 2003), has the same wording in O'Nions and colleagues research with the revised PDA Diagnostic Interview for Social and Communication Disorder (DISCO) questions (2016a). Yet, the wording has been changed by the UK-based National Autistic Society to "Experiences excessive mood swings and impulsivity" (Green et al., 2018a). The DISCO question, "Using age peers as mechanical aids, bossy and domineering" (O'Nions et al., 2016, p. 415), has as its sub-question: "Does A use age peers solely as aids in own activities, e.g. to collect materials, to assist in building some construction, to take a specified part in a scenario created by A?" This matters, as such discrepancies between behaviour profiles and screening and diagnostic tools undermines the validity of PDA diagnoses and research.

The most notable change to the PDA behaviour profile is to its social demand-avoidance behaviours trait. Initially, a sub-trait to "Continues to avoid demands of everyday life" was worded as "Strategies of avoidance are socially manipulative" (Newson et al., 2003). Recently, it has adopted autism-like characteristics, first as "Strategies of avoidance that are essentially 'socially manipulative'" (O'Nions et al., 2016a), and "Uses social strategies as part of

avoidance, e.g. distracting, giving excuses" (Green et al., 2018a). The first change was made This is the accepted version of the following book chapter: Woods, R. (2022). Woods, R. (2022). Rational (Pathological) Demand Avoidance: As a mental disorder and an evolving social construct. In: Milton, D., & Ryan, S. (Eds), The Routledge International Handbook of Critical Autism Studies (20 pages), Abingdon-on-Thames, UK, Routledge Publishing. DOI:

by O'Nions et al. (2016a) who were attempting to make PDA an autism subgroup. Most of its authors had previously written that it is partly problematic fitting PDA into the autism of the manipulative behaviours associated with the profile (Trundle et al., 2017, Gillberg et al., 2015, O'Nions et al., 2015, Christie et al., 2012).

As part of the revising of the wording for strategies of avoidance that are essentially "socially manipulative", quotation marks had been added to suggest that social demand avoidance is not actually manipulative; the associated DISCO question was amended to "Apparently manipulative behaviour" (O'Nions et al., 2016a). The original wording was "Socially manipulative behaviour to avoid demands" (Gillberg et al., 2015). These changes were made based on the opinions of O'Nions et al.'s (2016a) authors. There is some evidence that views PDA social demand avoidance as "socially strategic"; however, this was conducted on an entirely autistic sample and the interview data were coded with the 11 revised PDA DISCO questions (O'Nions et al., 2018). Due to the "apparently" descriptor in the question, coded behaviours in this research could not be manipulative. There is no evidence to suggest that PDA's social demand avoidance is "socially strategic".

There is significant debate around social demand avoidance being manipulative or strategic. It is more empathetic to use "socially strategic", expressing that these behaviours are unsubtle and not like the complex manipulation of those with callous-unemotional traits. It is more compassionate to view social demand avoidance behaviours as strategic rather than manipulative (O'Nions and Eaton, 2020). This stance is from research with entirely autistic population samples (Eaton and Weaver, 2020, O'Nions et al., 2018, 2019). Yet, O'Nions et al. (2015) originally viewed social demand avoidance as manipulative. Most social demand avoidance involves taking advantage of social norms.

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Newson et al. (2003) reported that manipulative demand avoidance was universal in PDA. PDA does not have deficits in Theory of Mind and Empathy yet is purported to have deficits in social identity, pride, and shame (Christie et al., 2012, Newson et al., 2003, Newson, 1983, 1989,1996). Social demand avoidance was described as manipulative due to the empathy required behind the acts (Newson, 1983), and that it is often the greatest skill of CYP with PDA (Christie et al., 2012). Persons with PDA have awareness to "push people's buttons" (O'Nions et al., 2014a), and appear to gain reward from distressing others (Wing, 2002).

Some have argued it is paradoxical to possess sufficient empathy for targeted manipulation while lacking understanding of social hierarchies. Conversely, this research also observed that many social demand avoidance behaviours are astute, relying on social norms and manipulative intent (O'Nions et al., 2015). This replicates the results of Newson et al. (2003). The EDA-Q was designed to assesses for manipulative behaviours (O'Nions et al., 2014a), and this would be reflected in the derived self-report version, EDA-QA (Egan et al., 2019). Accounting for how manipulative behaviours that require intent are found in PDA diagnostic and screening tools, its social demand avoidance is manipulative (see Table 6.1 for examples). Acts such as harassment require intent on the part of the perpetrator, which is something that many autistic persons lack. The fact that PDA contains behaviours that require intent and that persons with PDA pursue what it is they want, strongly suggests PDA social demand avoidance behaviours are manipulative.

Considerable effort has been invested in changing PDA's behaviour profile to become autism-like, demonstrating how mental disorders can evolve over time. This is despite some amendments lacking sufficient evidence to necessarily warrant this approach; for instance the Neurological Involvement trait awaits systematic research into how it relates to PDA (Newson

et al., 2003 Newson, 1996, 1989). Such revisions to the behaviour profile have real-life This is the accepted version of the following book chapter: Woods, R. (2022). Woods, R. (2022). Rational (Pathological) Demand Avoidance: As a mental disorder and an evolving social construct. In: Milton, D., & Ryan, S. (Eds), *The Routledge International Handbook of Critical Autism Studies* (20 pages), Abingdon-on-Thames, UK, Routledge Publishing. DOI:

consequences when one is attempting to get PDA accepted by educational, local, medical, and

national authorities. The changes outlined above, when added to concerted campaigning efforts

on PDA present PDA as a form of autism, regardless of the reasons and evidence to the

contrary. This highlights the power clinicians and researchers have over mental disorders as

social constructs, and the power disability charities possess to set narratives on mental

disorders.

The language of several PDA diagnostic traits has changed in recent years, away from

Newson's outlook on PDA being a new type of mental disorder. An important change is in

trying to amend how social demand avoidance behaviours are viewed as "strategic" rather than

"manipulative", in line with autism understandings. Such changes seem to ignore how PDA

diagnostic tools include questions that pathologise a person expressing their wishes. Crucially,

the revised interpretations of PDA traits cannot be applied to non-autistic PDA populations, as

these predictions are based on Newson's research. These amendments to PDA highlight the

power of key stakeholders to control the evolution of mental disorders and how they are treated

by broader society. There are important lessons to be learnt from those of PDAs, and future

research is required to fully reveal them.

Conclusion

PDA is a new type of mental disorder and is not part of the autism spectrum. As a social

construct it represents the pathologising of behaviours that people often express to alleviate

anxiety or to simply assert their self-agency. Aspects of PDA diagnostic traits are unstable and

are impacted by the politics surrounding the construct. Some features, such as panic attacks,

are mistakenly viewed as social communication issues when, in fact, they relate to anxiety-

driven RRBIs. Originally, Newson proposed PDA as a new type of mental disorder that was

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not part of the autism spectrum. However, a few high-profile autism experts reinterpreted PDA to be as such, and in the last decade various autism stakeholders have been lobbying hard for it to be accepted as part of the autism spectrum. Consequently, the features associated with PDA have taken on more autism-like characteristics, such as changing social demand avoidance behaviours to be "strategic", instead of "manipulative", while discounting how PDA tools assess behaviours that persons typically use to exert their self-agency. As a novel social construct, PDA provides the chance to explore how such phenomena shape both society and those attributed a label of PDA.

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Figure 6.1 Abbreviated DSM-5 Autism Spectrum Disorder criteria and the Aggregated PDA Profile.

The wording for the DSM-5 autism spectrum disorder criteria is taken from Evers et al. (2020)

Figure 6.2: The Demand Management Cycle for PDA

Table 6.1 Questions and sub-questions from PDA diagnostic and screening tools that contain manipulative behaviours and denote intent

Question or sub-question.	Tool and reference.
Good at getting round others and making them do as s/he wants.	EDA-Q (O'Nions et al., 2014a).
I blame or target a particular person/persons.	EDA-QA (Egan et al., 2019).
Does A harass other people? (e.g. writing threatening letters, making	Revised PDA DISCO questions
verbal threats, stalking, untrue accusations of sexual abuse).	(O'Nions et al., 2016).
Does A frequently tease, bully, refuse to take turns, make trouble.	Revised PDA DISCO questions
	(O'Nions et al., 2016).
Socially shocking behaviour with deliberate intent	Original PDA DISCO questions
	(Gillberg et al., 2015).
Lies, cheats, steals, fantasises, causing distress to others.	Original PDA DISCO questions
	(Gillberg et al., 2015).
Would you describe A as good at getting round others and making them	O'Nions and Happé semi-
do as s/he wants, or playing people off against each other?	structured interview (O'Nions et
	al., 2015, 2018).

This is the accepted version of the following book chapter: Woods, R. (2022). Woods, R. (2022). Rational (Pathological) Demand Avoidance: As a mental disorder and an evolving social construct. In: Milton, D., & Ryan, S. (Eds), The Routledge International Handbook of Critical Autism Studies (20 pages), Abingdon-on-Thames, UK, Routledge Publishing. DOI:

What strategies does A use to get out of things? Are these strategies	O'Nions and Happé semi-
targeted at a particular person?	structured interview (O'Nions et
o Distracting (e.g. asking questions)	al., 2015, 2018).
o Apologising and making excuses	
o Withdrawing into role play or toy play	
o Charm	
o Passively (e.g. selective mutism)	
o Other	
Does A ever threaten to hurt him/herself, or do things to hurt him/herself?	O'Nions and Happé semi-
Is this behaviour impulsive, or does A do it on purpose to show s/he is in	structured interview (O'Nions et
control, cause distress or get attention?	al., 2015, 2018).

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¹ For more details, please see Woods et al. (2018).

During 2021, the dichotomous debate on PDA has become more entrenched since this chapter was drafted. Three reputable independent parties reviewed the evidence for PDA, concluding there is no good quality evidence to suggest what PDA is and equally respecting divergent opinion. These parties included a systematic review, the British Psychological Society, and National Institute for Health and Care Excellence. While "PDA Profile of ASD" supporters would highlight that PDA has been included in the recent England Autism Strategy. Although, PDA seems not to be mentioned in the England Autism Strategy's document.

³ This chapter discusses different autism conceptualisations over the last 40 years, and in that time-period what has been called autism has expanded significantly. When I refer to Asperger's Syndrome, Autistic Disorder, Infantile Autism, PDD-NOS, these are autism subtypes. Infantile Autism evolved into Autistic Disorder. I use the terms autism and autism spectrum disorder interchangeably.

- ⁴ A technical term for describing mental disorders is that they are human-kinds, and they evolve through looping effects. For more information, see Woods (2017).
- ⁵ Please see Woods (2019) for a discussion on PDA and comparable approaches.
- ⁶ This is Question 2, Sub-question 1, from a semi-structured interview from O'Nions et al. (2018) and can be accessed through this link:

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

- ⁷ DSM-5 does require specifiers in relation to recognition of the nature of a person's understanding of their obsessions (OCD-UK, 2020).
- ⁸ Prof Peter Kinderman suggested that it is preferential to focus on management of demands, rather than on their avoidance.
- 9 My present view is that demand-avoidance features need to be expressed consistently over, at least 12 months to be pathologised as a Disorder. As many Disorders in DSM-5 require features to be expressed at least several months period. Additionally, when demand-avoidance which is impairing, is expressed for at least a year, it meets the threshold for being disabled under UK's The Equality Act.
- ¹⁰ Coding issues is when a person cannot process or make sense of certain aspects of communication.
- ¹¹ The latter statement is found in Newson et al.'s (2003) supplementary files and can be accessed through this link:

https://adc.bmj.com/content/archdischild/88/7/595.full.pdf?with-ds=yes

- ¹² This approach contradicts modern approaches to PDA that do not view it as being developmental or pervasive in nature.
- ¹³ For example, see Russell (2018).
- ¹⁴ Wording for the sub-question can be accessed at:

https://static-content.springer.com/esm/art%3A10.1007%2Fs00787-015-0740-

2/MediaObjects/787_2015_740_MOESM1_ESM.pdf