Demand avoidance phenomena: circularity, integrity and validity – a commentary on the 2018 National Autistic Society PDA Conference

Richard Woods, Nottingham, UK

Address for correspondence
E-mail:
richardwoodsautism@gmail.com

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Editorial comment

There has been much discussion and debate on Pathological Demand Avoidance (PDA) since it was first described by Professor Elizabeth Newson in the UK in the 1980s. Is it part of the autism spectrum or a separate condition or can the features of PDA be found in other developmental conditions? If PDA can be separately defined, do the origins or underlying causes of PDA differ from other conditions and, if so, what are the implications?

The main consensus at present is that some autistic children and adults also have PDA and that where this is true, different strategies are needed (Christie et al, 2011). But PDA profiles have been found in people with other conditions too (Egan et al, 2019; Kaushik et al, 2015). There are some who assert that, as yet, there is insufficient evidence to determine the criteria for PDA and its classification.

Some autistic individuals have referred to PDA as rational demand avoidance where demands which are perceived to be aversive or illogical are avoided. Given that many autistic individuals show demand avoidant behaviour, there is a concern that without clear criteria for PDA, parents and professionals alike might assume that a person has both autism and PDA and then seek further assessment or follow recommended strategies for PDA which might not be useful or needed. So an ethical debate on PDA is needed. In this paper, Richard Woods, an autistic academic, presents his views on PDA or, in his words, the Demand Avoidance Phenomena.

What is Demand Avoidance Phenomena?

Demand Avoidance Phenomena (DAP), otherwise known as Pathological Demand Avoidance (PDA) was first suggested in 1980 in the United Kingdom (UK) by Professor Elizabeth Newson, a Consultant Child Psychologist (Newson et al, 2003). She ran assessment clinics for children thought to be autistic. Among the children referred, she felt that some had features in common with autism but had other features that were not.

DAP, in short, is characterised by obsessive noncompliance, distress and florid challenging and socially inappropriate behaviour in children, adolescents and adults (Egan et al, 2019). Some have proposed a change in terminology from 'pathological' to 'extreme' demand avoidance. This is to reflect the idea that, from the individual's perspective, avoidance of everyday requests may seem appropriate and not 'pathological', even though it is deemed disproportionate to others (Gillberg, 2014). For others, the severity and extent of the problem justifies the term 'pathological'.

Autistic authors have expressed that DAPers' (those identified with its profile) actions are inherently rational from their lived experience and it should be called Rational Demand Avoidance. This name would be applicable to all persons diagnosed with DAP (Milton, 2017; Woods, 2019b). For example, DAPer Harry Thompson frequently responded to dares or acted outrageously to gain other people's attention, as this was the only way he could reliably predict how others would react to him (Thompson, 2019). Such behaviour is also seen in other diagnosed DAPers.

The extreme behaviours found in Oppositional Defiant Disorder are due to individuals attempting to maintain social relations or social status (Stuart et al, 2019). Moreover, individuals with Attachment Disorders may find negative behaviour gains more attention than positive behaviour, and so expressing the former reduces anxiety from their chaotic and unpredictable worldview, so they engage in behaviours viewed challenging by others (Pearce, 2017). One can then view DAPers actions as belonging to either of these two conditions.

For a myriad of reasons I transitioned to utilising DAP. A pivotal factor is the substantial number of possible explanations for DAP which will be discussed later in the paper. There is no compelling empirical evidence base to favour any proposed ontology over another (Green et al, 2018a; Milton, 2017). Additionally, autistic persons and DAPers are prone to internalising (Eaton, 2017; Woods 2018a). DAP is promoted on social media, mainly aimed at DAP carers (Green et al, 2018a).

I accept the case put forward that DAPers and their carers need appropriate support (Russell, 2018). Unpublished research indicates DAP carers have higher anxiety levels compared to carers of autism and Conduct Disorder (Durà-Vilà and Levi, 2018), thus DAP carers are a vulnerable group. Ethically, researchers should take a balanced perspective on a topic (Brooks et al, 2014). There is little ethical justification for referring to DAP with a term that reifies it, like Pathological Demand Avoidance.

DAP behaviour profile

Over the last few years Newson's original behaviour profile has been joined by two new DAP profiles that have been put forward by the National Autistic Society and the PDA Society respectively. Aggregating the criteria, DAP has ten diagnostic criteria, with six essential for a diagnosis. These are:

- comfortable in role play and pretend
- continues to resist and avoid ordinary demands of life
- demand avoidance can use social strategies
- lability of mood and impulsive
- obsessive behaviour that is often focused on other people
- surface sociability, but apparent lack of sense of social identity, pride, or shame (Green et al 2018a; Thompson, 2019; Woods, 2019a)

The four optional traits include:

- delayed speech development
- neurological involvement
- passive early history (Newson et al 2003)
- sensory differences (Eaton et al 2018)

There is much continuing debate and controversy over the medical nature of DAP, the dominant ontology of DAP being an autism subtype (Woods, 2019a). Recently, traits of DAP have been observed in the early case studies written by Hans Asperger, who described

some unexpected impulsive acts that were extremely challenging for others to control (Falk, 2019; Sanchez, 2018). For example, Asperger noted of Fritz, V:

> *"the conduct disorders were particularly gross when demands were made on him … when one tried to give him something to do or to teach something … it required great skill to make him join some PE or work even for a short while … it was particularly in these situations that he would start jumping, hitting, climbing … or some stereotyped sing-song." (Sanchez, 2018).*

This suggests that there is no specificity to DAP. Despite substantial debates occurring, this paper draws attention to multiple facets that are not reflected in the main DAP discourse.

Current interest in DAP in the UK

There is a growing interest in the UK in DAP, and much lobbying by DAP supporters on social media (Green et al, 2018). A number of professionals and parents have also identified children who seem significantly more demand avoidant than autistic children and who do not respond to the strategies usually recommended. As a result of this increased interest, the National Autistic Society now convenes an annual conference on the subject. At the latest event in 2018, Phil Christie, a Clinical Psychologist and close colleague of the late Elizabeth Newson, and an advocate of DAP, said the aim of the conference was:

> *"to build on developments, insights and increasing recognition of PDA but maintain the integrity of how the condition is understood and the nature of support that is needed by individuals." (Christie, 2018).*

The nature and understanding that Christie is referring to above is that DAP is an autism subtype and that DAPers require strategies different from other conditions. This raises the question: is there validity or merit to this statement?

The ontology of DAP

There is much continuing debate and controversy over the medical nature of DAP, the dominant ontology being an autism subtype (Woods, 2019a). In their conclusions on a commentary paper on DAP in 2018, Malik and Baird stated that there are many features described in DAP which overlap with those found in other classified mental and behavioural disorders (Autism, Oppositional Defiant Disorder, Conduct, Anxiety/Mood Disorders) but that these may have a different underlying basis. They maintained that more descriptive research of traits across many disorders is needed to clarify the criteria and distinctiveness of other conditions, including DAP. Most, if not all, rely on subjective judgements which lead to a lack of consensus and diagnostic confusion. Agreement on constructs such as noncompliance; demand avoidance; oppositionality; social manipulation; emotional dysregulation would be needed for this work.

Should DAP be viewed as part of the autism spectrum?

Notable stakeholders, including those organising and supporting the PDA conference hold this perspective, ie parents, clinicians and charities (Green et al, 2018a). However, as *Table 1* highlights, DAP has numerous competing claims for its medical ontology. Just under three quarters (70 per cent) of autistic people have at least one co-occurring psychiatric condition (Lai et al, 2014) and 41 per cent have multiple, additional comorbid conditions (Green et al, 2018a). Some disorders, such as anxiety and depression, are prevalent in autism, and so on the balance of probability, DAP is likely to be among these co-occurring conditions (Green et al, 2018b). It is possible that DAP is frequently diagnosed in autistic people because it is invariably interpreted as a form of autism, as part of diagnostic overshadowing (Fletcher-Watson and Happé, 2019).

A population study of DAP reported in 2015 suggests that it may occur in one in five of those with autism (Gillberg et al, 2015). This prevalence rate is higher than that observed by Elizabeth Newson and raises concerns as to whether it is the same underlying condition being observed (Woods, 2019a). However, this research was conducted with an unvalidated Diagnostic Interview

for Social and Communication Disorders (DISCO); see O'Nions et al (2016) for the validated version. Happé and her colleagues have explored DAP features in autism and have identified these features also in children with a wider range of neurodevelopmental and behaviour problems (O'Nions et al, 2014; O'Nions et al, 2016). So DAP features do not appear to be confined to autism. These studies indicate DAP has a high drop off rate in persons meeting the clinical threshold for a diagnosis into adulthood, between 44 to 89 per cent (Gillberg et al, 2015; O'Nions et al, 2016). This is higher than that found in autism. However, the studies discussed in this paragraph have substantial limitations including being circular in nature.

Table 1: Demand Avoidance Phenomena: possible medical ontologies

Possible medical ontology	Comorbid prevalence rates (%)
Autism	Unable to source data
Autism subtype/ of form Pervasive Developmental Disorder	Unable to source data
Autistic trauma	Unable to source data
Female form of autism	Unable to source data
Form of Attachment Disorder	Unable to source data
Form of catatonia	12 –18% (Eaton, 2017)
Form of personality disorder	0 – 32% (Lai et al, 2014)
Heterogeneous Spectrum Condition	Unable to source data
Symptoms of autism and Attention Deficit Hyperactivity Disorder (ADHD)	28% (Green et al 2018a)
Symptoms of autism and eating disorders	4 – 5% (Lai et al, 2014)
Symptoms of autism and anxiety	42 – 56% (Lai et al, 2014)
Symptoms of autism and anxiety disorders	About 40% (Belardinelli et al, 2016; Francisca et al, 2017)
Symptoms of autism and Depression	12 – 70% (Lai et al, 2014)
Symptoms of autism and Dyslexia	Unable to source data
Symptoms of autism and Dyspraxia	Unable to source data
Symptoms of Autism and Oppositional Defiant Disorder (ODD)	28% (Green et al 2018a)
Symptom of Autism and Schizophrenia	0 – 6% (Chaplin 2017)

This table has been adapted from Woods (2018b), with the addition of dyslexia and dyspraxia from the National Autistic Society webpage on DAP (National Autistic Society 2018). Jonathan Green and colleagues note that DAP behaviours can be explained by an unrecognised learning impairment (2018b). The Gillberg et al (2015) 1 in 5 prevalence rates for DAP have not been included due to questions over their validity.

Should DAP be regarded as a separate entity?
Describing a DAP behavioural profile is not evidence that it exists as a separate entity (Woods, 2019a). Various DAP behaviours might be explained using the 'Vicious Flower' analogy often used in treating anxiety and depression (Moorey, 2010). The centre of the flower contains the distressing emotion or an unhelpful belief, and the surrounding petals are the vicious cycles which maintain the central problem. The Vicious Flower contains a cycle for demand avoidance as a part of depression, including maintaining the condition (Moorey, 2010). Two studies that take an inductive approach to DAP indicate that the construct behaviours are likely to be caused by general psychopathy (Egan et al, 2019; Green et al, 2018), with larger scale study indicating many DAPers do not meet the case for autism (Kay, 2019). Therefore, providing tentative support for the view that DAP extends beyond an autism subtype. This is not surprising as most psychopathology conditions have a significant amount of overlap (Pickles and Rutter, 2016).

Some clinicians have observed that DAP is a broad condition found in many clinical populations outside of autism, such as Christopher Gillberg (2014). A small scale study indicates DAP is found in those with Conduct Disorder and ADHD (Kaushik et al, 2015). DAP has no behavioural or cognitive trait unique to it, it has no specificity (Christie et al, 2011; Garralda, 2003; Malik and Baird, 2018; Wing, 2002). The pluripotential nature of the DAP profile and the subjective symptoms means that at present, many conditions might be identified as DAP if one is looking for it (Woods, 2018a). It is challenging to draw hard boundaries between DAP and other conditions, so diagnosing DAP can easily lead to confusion (Garralda, 2003; Green et al, 2018b).

Is DAP the result of a combination of autism and other comorbidities?
A transactional approach has been offered to view DAP as a mixture of autism and comorbidities (Fidler and Christie, 2018; Green et al, 2018a; Milton, 2017). Nonetheless, a prevailing outlook appears to be forming among both DAP's proponents and its critics, that it may be an expression of autistic trauma (Eaton, 2018b; Milton, 2017), opposite to DAP originating from exclusively biological and genetic factors (Christie, 2018). Instead of viewing that DAPers anxiety is intrinsically caused, many think DAPers anxiety is extrinsically caused. The opinion that DAP is entirely caused by genetic factors is found in the DAP literature (Harvey, 2012). Rutter and Pickles (2016) also highlight that diagnostic classification systems are not designed along biological lines and that there is no evidence to justify adopting such an approach. They went on to note that biomarker research is unlikely to make any major breakthrough. Therefore, DAP being entirely biological in nature cannot be tested and can be viewed as pseudoscience. There is no consensus on how DAP is understood (Eaton, 2017; Stuart et al, 2019; Woods, 2019a). Subsequently, there are numerous interpretations of how DAP is conceptualised.

The Autism Spectrum Disorder diagnosis has construct validity (Green et al, 2018a). As a neurodiversity supporter, I wish there to be good quality autism research as recommended by Fletcher-Watson, (2019), Milton (2017) and Waltz (2007). I contest the fact that DAP is being diagnosed as an autism subtype. For it to be accepted as an autism subtype, DAP requires an evidence base that exceeds that Asperger syndrome's in both quality and quantity. Furthermore, understanding of DAP is argued to be 30 years behind autism (Christie et al, 2011). Autism used to be viewed as a form of schizophrenia (Loong, 2019). Long term, there is nothing to prevent DAP's nosology classification changing like autism's has done.

No consensus over DAP's clinical profile

There are contradictions on precisely the criteria needed for a DAP diagnosis, with three different behavioural profiles proposed (Newson et al, 2003; Eaton et al, 2018; Green et al, 2018a). At the PDA conference, many speakers claimed that all eight criteria from Newson's diagnostic profile are compulsory for DAP identification. However, since at least 2016, the developmental components of delayed speech development, neurological involvement and passive history have not been seen as essential when making a DAP diagnosis (Green et al, 2018a; National Autistic Society, 2018; Sanchez, 2018).

One influential study shows the best predictor for what subtype a person is diagnosed with, is the clinic they attended (Fletcher-Watson and Happé, 2019; Green et

al 2018a) and autistic persons often transition between subtypes (Wing, 2002; Wing et al, 2011; Woods, 2018a). In addition, it is often impossible to mark the boundaries between subtypes, with many autistic persons having features of multiple subtypes. The challenges faced in dividing autism subgroups is faced by all proposed subtypes (Fletcher-Watson and Happé, 2019; Wing, 2002; Wing et al, 2011), including DAP. Any behaviours or traits that identify DAP as distinct from other conditions, including non-DAPer autistics; would contradict our current understandings of autism and indicate that DAP is not a form of autism.

A study by Eaton and her colleagues to explore the DAP profile in clinic referrals

Eaton and her colleagues made detailed assessments of 351 children (aged from under 5 to over 17 years) who were referred to their clinic over a two year period (Eaton et al, 2018). From their data, they grouped the children into three categories (see *Table 2*).

Table 2: Three diagnostic groups within the sample referred

Diagnostic group	Number	Percentage of sample
Autism	145	41
Autism and DAP	111	32
Neither Autism or DAP	95	27
Total	**351**	**100**

Of the children 73 per cent were diagnosed with autism and, of those, 43 per cent also had a DAP profile. All those with DAP had autism and they concluded that the children in the first two groups had more in common with each other than the third group. Qualitative and quantitative differences were found between the three groups (Eaton, 2018b). Demand avoidant behaviours as measured on the EDA-Q (Extreme Demand Avoidance Questionnaire, O'Nions et al, 2014) were found in all three groups. The EDA-Q detected DAP behaviours in all three groups, supported wider research of Egan et al (2018), Green et al (2018a) and Kaushik et al (2015).

Not much at present can be taken from findings such as these as the clinic specialised in autism and so it is likely that a narrower group of children would be assessed than children seen in a generic child development centre. For these results to carry weight they would need to be replicated across at least several sites and steps taken to ensure DAP diagnosis has over 80 per cent reliability with the ADOS (Autism Diagnostic Observation Schedule) across participating clinics, showing construct validity that autism subtypes currently lack (Green et al 2018a). The methodology has numerous flaws, including being circular as DAPers were only identified if they first matched autism diagnostic criteria in *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM5)*. Afterwards potential DAPers were assessed against the original Newson profile as this clinic only offers the Autism + DAP Traits diagnosis. Their results can be explained by diagnostic overshadowing (Fletcher-Watson and Happé, 2019).

Eaton's clinic published a DAP diagnostic profile based on information from the PDA Society, with added notes from their clinical observations (Eaton et al, 2018). Nonetheless, the author has had confirmation that Eaton and her clinic currently use a reduced Newson DAP profile as found on the National Autistic Society's website. This profile lacks: delayed speech development, passive early history and neurological involvement, from Elizabeth Newson's original profile (Green et al, 2018a; National Autistic Society, 2018; Thompson, 2019); over the PDA Society's profile. Eaton's clinic appears to have switched from utilising the full Newson profile to its reduced version after they finished collecting participants for this research. This matters as there is no consensus on how to diagnose DAP and the favoured relaxed behaviour profile means more

persons are eligible for a DAP diagnosis than the participants in this research. Therefore, this research lacks external validity. Future validation studies investigating general population and non autistic groups are required to provide meaningful information on the construct.

Non-medical explanations of DAP

DAP is a behaviourist approach to autism (Milton, 2017). Lorna Wing in her critique of DAP, noted that DAPers appear to gain reward from upsetting others (2002). O'Nions et al (2018) argue DAPers can be conditioned into the profile by finding demands aversive, indicating DAPers can be conditioned. The DAP strategies are to be practised all the time (Christie et al, 2011; Fidler and Christie, 2018; Woods 2018a); comparable to the amount of time suggested for behaviourist interventions. There are examples of DAPers receiving bribes and significant rewards after displaying demand avoidance behaviour (Woods 2018a).

Unpublished research by Sarah Potts investigating DAP and personality disorders, indicates there are differences between DAP and personality disorders, although this study appears to suffer from significant limitations. Applicable results from Sarah Potts' study, that contribute to the debate about DAPers being conditioned into the profile include: first, being inclined to break rules for personal profit; secondly, that they are motivated by material gain. Collectively, these factors lend credence that DAPers are conditioned into aspects of the profile.

It is acknowledged DAP can be explained by an Interest Based Account of autism – monotropism theory (Eaton, 2018). Nevertheless, the theory views demand avoidance as inherently rational (Woods, 2018b). Also, DAP behaviours can largely be explained as a result of stigma (Woods, 2018a). Signifying, Christie's statement is an arbitrary line in the sand (Milton, 2017).

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 for 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 DAPer's 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.

DAP citation survey

A lack of debate

There are concerns over silencing divergent opinion to the main on DAP (Woods, 2018a). Discourse maintains that it is an autism subtype and has its own unique strategies. Its leading proponents frequently argue that debating DAP is a distraction from diagnosing it (Christie, 2007; Christie et al, 2011; Fidler and Christie, 2018). Elizabeth Newson and colleagues argued in their original paper that DAP is needed to benefit parents (2003). The 'lightbulb moment' is when a person (typically a carer) has strong resonance (recognition) upon initially encountering information of the DAP profile. More recently, the lightbulb moment is a vital justification to support the dominant discourse (Christie et al, 2011; Fidler and Christie, 2018; Russell, 2018).

This central tenet to the main DAP discourse, that it is required for the benefit of parents, is pivotal to the bias to maintaining the integrity of the DAP discourse. It means that the supporters of DAP's main discourse appear closed to the DAP construct evolving away from being an autism subtype (PDA Society, 2018). It must be noted that much DAP research is coordinated by the PDA Development Group that is headed by Phil Christie. Researchers are required to be open minded, to avoid research "designed to support a preconceived notion or belief" (Chown et al, 2019, p1). Ethically, researchers need to attempt falsification of their hypothesis as part of the scientific method that is involved in most research (Milton, 2016; Rutter and Pickles, 2016). Therefore, it appears that the main DAP discourse is self validating pseudoscience.

Citation survey results

Investigating these concerns, I conducted a citation survey to explore whether the literature conforming to the dominant DAP discourse is forming a community of practice (the methodology, results and discussion are available from the author).

The results show:

- the primary DAP discourse is being challenged
- key literature is being accessed thousands of times
- key literature rarely references critical literature, except to support its case or disagree with critique
- a lack of autistic perspectives referenced
- a community of practice forming

There are various reasons why these matter to practice, particularly the implication it is a community of practice. Firstly, the main DAP discourse lacks the evidence to justify its claims. Community of practices form their own ideology (Milton, 2017). For DAP's main discourse it is that DAP is an autism subtype with its own unique strategies. This means the lack of supporting evidence for their claims is not being sufficiently challenged internally within the main discourse, as DAP is reified as Pathological Demand Avoidance. Most concerning, are the potentially negligent assumptions forming within the main DAP discourse; for instance, it is argued that the DAPers' behaviours are not caused by their parents (Durà-Vilà, and Levi, 2018). However, there is inadequate evidence to justify this (Milton, 2017).

Resulting from its individual ideology, the main DAP literature is creating its own terminology, such as 'more straight forward autism' (Fidler and Christie, 2018) and 'atypical autism' (Durà-Vilà and Levi, 2018; Thompson, 2018). Such terms are problematic for various reasons. 'Atypical autism' is nonsense as we know that autism subtypes do not hold up clinically (Sanchez, 2018); such differences between autism subtypes are basically subjective and do not stand up to empirical testing. 'More straight forward autism' ignores the large body of evidence indicating that autistic persons are systematically failed by society. This is acknowledged within DAP scholarship as all autistic pupils appear to be struggling to access appropriate educational support (Kay, 2019). Other examples can be found in Woods (2017b). A significant report by the All Party

Parliamentary Group on Autism shows many indicators of quality of service are decreasing and also notes the lack of funds available to local government (2019). Some carers are using DAP as a proxy to access better support strategies (Green et al, 2018b). This demand for the construct is partly driven by austerity measures (Woods, 2018a). Stepping into this gap in support, some private clinics have emerged diagnosing DAP and this is contributing to the commodification of autism through DAP (Woods 2017a).

Within the DAP literature it acknowledges that all autistic persons should be treated as individuals to receive bespoke approaches (Christie, 2007). There is no one size fits all approach to autism because there are no straightforward autistic persons for such an approach to be effective with. The language around the main DAP discourse leads to sources of possible confirmation bias. O'Nions et al (2016) note that the ongoing campaigning can lead people to be "on the lookout" for features of DAP. Consequently, along with omitting autistic perspectives, these undermine the ethical and epistemic integrity of the main DAP literature and its supporting research (Milton, 2017). It is worth noting that the DAP literature base is tiny and with the current UK climate of participatory research, there is no excuse for excluding autistic scholarship from the DAP literature, especially if one perceives DAP as a form of autism.

Concluding comments

This paper provides an array of provocations to stimulate debate on DAP. Initially detailing how DAP has no specificity and a large number of possible medical explanations to the profile. Compellingly, there are a significant number of common autism comorbidities which can explain the DAP through interacting with autism. I critically engage with ongoing research from Eaton's clinic, indicating it lacks external validity as its sample is not representative. I contextualise DAP strategies in wider discourses, drawing attention to how they replicate good practice found elsewhere. Finally, I explain the key findings from a citation survey and its implications for the DAP debate. DAP literature needs to be situated in wider discourses; in the process underlining why the circularity surrounding the DAP construct needs to stop and so move away from the agenda of recognising it as an autism subtype. An ethical debate on DAP is required to establish a consensus on how to approach the construct.

To conclude, there is little or no validity to justify Christie's conference statement to maintain the dominant perspective's integrity and understanding of DAP. Attempting to do so, in itself, could cause confusion over the conflicted nature of DAP (Garralda, 2003; Green et al, 2018a). Future research, taking a scientific, non circular method based approach to DAP is required for DAP to meet evidence thresholds for its acceptance. Pertinently, policy and practice require such evidence (Fletcher-Watson and Happé, 2019). Finally, in everyday practice, all stakeholders should follow the recommendations of Green et al (2018a), or treat DAP as an undefined, non-autism comorbid.

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