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Pathological demand avoidance: What and who are being pathologised and in whose interests?

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Abstract

The term 'pathological demand avoidance' was first coined in 1983. In recent years, diagnostic tools have emerged to enable practitioners to identify, name and treat pathological demand avoidance and, at least in the United Kingdom, there is an increasing number of children who attract this label. In addition to what are defined as the core 'deficits' of autism, including assumed difficulties in social communication, difficulties in social interaction and restrictive interests, children with pathological demand avoidance are thought to have an extreme anxiety-driven need to control their environment and control the demands and expectations of others. This article will argue that we must exercise extreme caution in accepting the validity of pathological demand avoidance and will suggest that it can be seen as an attempt to psychiatarise autistic children's resistance, which, in so doing, restricts their agency. First, it will draw on the arguments put forward by some autistic scholars who have claimed that pathological demand avoidance is better understood as rational demand avoidance – an understandable and rational response to the circumstances that one finds oneself in. Second, it will consider the intersection between autism and childhood. When one of the defining characteristics of pathological demand avoidance is an inability to recognise and, presumably, respect social hierarchy, children's competencies as social actors and active meaning makers of their world can easily become pathologised as defiance. Finally, the article will address the intersections of autism, childhood and gender. Girls are much less likely to be diagnosed as having an autism spectrum condition than boys are, with a ratio traditionally estimated at approximately 1:4. However, pathological demand avoidance diagnoses are fairly evenly spread between boys and girls. It will be argued that it is girls' resistance to the ordinary and everyday demands of her as a girl and her subsequent rejection or transgression of those expectations that is being pathologised.

Keywords

autism, developmentalism, gender, pathological demand avoidance

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Introduction

Pathological demand avoidance (PDA), a term coined in the 1980s by Elizabeth Newson, refers to behaviour exhibited by individuals (although the focus of interest is largely children) that is characterised as an extreme resistance to the ordinary demands of everyday life. PDA is considered to be part of the autism spectrum and has received validation by the National Autistic Society's recognition of it as a behaviour profile within the spectrum. In addition to what are defined as the core 'deficits' of autism, including assumed difficulties in social communication, difficulties in social interaction and restrictive interests, children with PDA are thought to have an extreme anxiety-driven need to control their environment and control the demands and expectations of others. This, purportedly, results in lability of mood, obsessive behaviour and an apparent sociality which, while lacking a concomitant sense of social identity, pride or shame (Newson et al., 2003), does allow the development of 'social manipulation' (Newson et al., 2003: 596) as a means of controlling one's situation. In recent years, diagnostic tools have emerged to enable practitioners to identify, name and treat PDA and, at least in the United Kingdom, there is an increasing number of children who attract this label.

This article will argue that we must exercise extreme caution in accepting the validity of PDA and will suggest that it can be seen as an attempt to psychiatarise autistic children's resistance which, in so doing, restricts their agency. First, it will draw on the arguments put forward by some autistic scholars who have claimed that PDA is better understood as rational demand avoidance (RDA) – an understandable and rational response to the circumstances that one finds oneself in (Milton, 2013; Woods, 2018). This is particularly the case for autistic people trying to navigate their way through a neurotypical world that is not designed to acknowledge, let alone meet, their needs.

Second, it will consider the intersection between autism and childhood, since children with PDA seem to be the main focus of concern for practitioners. Childhood and adulthood are constructed as oppositional and hierarchical categories and children lack control over many aspects of their everyday lives, simply because they belong to the social category of childhood and resultant assumptions about members of that social category. There is evidence that children experience that lack of control as a hardship (Waksler, 1991) or as oppressive (Hester and Moore, 2018) and that they use a range of complex strategies to avoid the demands that adults make of them, which reflects children's competence as active meaning makers of their worlds. However, when one of the defining characteristics of PDA is an inability to recognise and, presumably, respect social hierarchy, children's competencies can easily become pathologised as defiance.

Finally, the article will address the intersections of autism, childhood and gender. Girls are much less likely to be diagnosed as having an autism spectrum condition than boys are, with a ratio traditionally estimated at approximately 1:4, albeit this is slowly changing to reflect the reality of autism and gender and the different ways that autism manifests in boys and girls. However, PDA diagnoses are fairly evenly spread between boys and girls. If, as it is claimed, the fundamental difference between PDA and 'typical' autism is the anxiety-driven need to control one's environment and resist the demands of others, then it could be argued that it is girls' resistance to the ordinary and everyday demands of her as a girl, demands that are profoundly gendered, and her subsequent rejection or transgression of those expectations, that is being pathologised.

It is important to acknowledge that many of the critiques about PDA contained herein reflect arguments that could be, and indeed have been, made about autism itself (see, for example, Runswick-Cole et al., 2016) – arguments that are located within the field of critical autism studies (CAS). However, CAS is not a homogeneous movement and there is considerable disagreement over the ontological status of autism. There are those, such as Runswick-Cole et al. (2016), for

whom CAS is fairly narrowly defined as a critical discussion of whether the diagnosis of autism is scientifically valid and if such a label is meaningful to those labelled as autistic. This article is positioned within the field of CAS but it is not informed by this definition. Instead, it draws on the broader definition proposed by Davidson and Orsini (2013), which comprises 'exploring power relationships that construct autism; enabling narratives that challenge the dominant negative medical autism discourses; and creation of theoretical and methodological approaches that are emancipatory and value the highly individual nature of autism and its nascent culture' (Woods et al., 2018: 975). It also views the criticality of CAS in line with Waltz's (2014) view that it 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"' (p. 1337).

PDA: a contested terrain

Although initially proposed as a separate and distinct pervasive developmental disorder,[1] PDA is now understood, by some, to be part of the autism spectrum. The characteristics associated with PDA were first described by Elizabeth Newson who, during the course of her work at the Child Development Research Unit at the University of Nottingham, identified a number of children who had been referred to them because they '"reminded" their medical referrers of autism, but were clearly not typical of autism' (Newson et al., 2003: 595), in particular with respect to their ability to engage in role play and imaginative play, which are assumed to be areas that autistic children experience difficulties. Such children were formally diagnosed as having 'atypical autism', but, over time, Newson and her colleagues recognised similarities between them which, they felt, raised questions over the validity of that diagnosis. The most notable trait displayed by all of the children 'was an obsessional avoidance of the ordinary demands of life coupled with a degree of sociability that allowed social manipulation as a major skill' (Newson et al., 2003: 596) and which made them 'strikingly difficult' for the adults around them. They argued that the collection of shared behavioural traits represented something different from autism and proposed the term pathological demand avoidance to reflect the extent to which their resistance was of a 'truly pathological degree' (Newson et al., 2003: 596).

Based on a cohort of 150 children seen between 1975 and 2000, Newson devised a set of defining criteria, which still form the basis of diagnosis today. In addition to their 'pathological resistance' to the ordinary demands of everyday life and their 'socially manipulative strategies' to avoid them, children with PDA are characterised as having surface sociability but with a lack of inhibition or sense of responsibility, extreme mood swings driven by their need to be in control and obsessive behaviour usually focused on their demand avoidance and/or directed at people which can manifest in an 'overpowering' like of some and 'harass[ment]' (Newson et al., 2003: 597) of those they do not like. In terms of development, Newson claimed that their early childhood was one of passivity and language delay, although most children catch up with 'typically' developing children by the age of 6 (Newson et al., 2003). At the same time, children with PDA are comfortable in role play and pretend play to the extent that '[S]ome appear to lose touch with reality' (Newson et al., 2003: 597).

There is now a growing body of academic literature on PDA and increasing numbers of children are being given this label. Diagnostic screening tools have been developed, such as the Extreme Demand Avoidance Questionnaire (EDA-Q) and others are being modified to incorporate PDA (see, for example, the Coventry Grid Interview[2] and the Diagnostic Interview for Social and Communication Disorders[3]). In the United Kingdom, the Department of Education,[4] the Autism Education Trust[5] and the National Autistic Society[6] all recognise PDA as a legitimate

behaviour profile on the autism spectrum and provide guidance on how best to support children with this label.

However, PDA is not uncontroversial and has been the subject of considerable debate. Despite its acceptance by some clinicians and an increasing number of 'diagnoses', PDA is not recognised in either the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition[7] (*DSM*-V) or the *International Statistical Classification of Diseases and Related Health Problems*, 11th Revision[8] (ICD-11), the two main manuals used by clinicians worldwide in order to standardise diagnoses. As a result of its exclusion from these diagnostic manuals, PDA *cannot* be diagnosed because there is no standard definition of what it is, what the criteria for diagnosis are and how it should be assessed. Rather than a diagnosis, PDA is best understood as a label attributed to some children because of the way their behaviour is interpreted by parents, carers and professionals. Notwithstanding the critiques of diagnostic manuals, such as the *DSM*-V and ICD-11, the exclusion of PDA from them means that, at a national and regional level, the National Health Service (NHS), the publicly funded national health system in the United Kingdom, does not have a specific diagnostic pathway and each NHS Trust[9] is likely to have a different policy on PDA, if, indeed, they have a policy at all. In order to plug this diagnostic gap, a growing number of private providers have emerged who are willing to offer a diagnosis of autism with a PDA profile but that can cost anywhere between £1000 and £3500[10] – an example of the commodification of autism and the growth of the autism industry, which like all industries function to 'create [. . .] new product[s] to sell' (Woods, 2017: 755; see also, Runswick-Cole and Mallett, 2014). Therefore, diagnoses of PDA are highly variable, according to where one lives, the clinician one encounters and the financial means one has access to.

The variability of diagnosis is further compounded by the fact that screening questionnaires are usually completed by parents/carers; it is their observation and interpretation of their child's behaviour that forms the basis of assessment. In addition to the completion of one or more screening questionnaires, parents/carers will also be asked to give a detailed history of their child and the child's play will usually be observed and assessed against what are considered to be age-appropriate standards of development. In other words, a label of pathological demand avoidance is adult centric and based on developmental assumptions about who children are and how they should behave. Of course, this is true of all childhood diagnoses and children have limited opportunities to be active participants in the diagnostic process because of the dominance of developmentalism which positions children as incapable and incompetent. However, what marks PDA out as requiring greater scrutiny is the fact that because it is not recognised in either the *DSM*-V or ICD-11 there is no clinical consensus on what it is and how it is diagnosed. The imprecision of the diagnostic screening tools and developmentally driven assessment has a profound and, potentially, life-altering impact on all children, but there are some groups of children who are particularly vulnerable to attracting a label of PDA.

Autism and the pathologisation of self-advocacy

If conceptualised as a behaviour profile within the autism spectrum, individuals who already have a diagnosis of autism are at an increased risk of attracting the label PDA. This is due, in large part, to the fact that autism continues to be understood from 'cognitivist/functionalist/behaviourist' (Milton, 2018a) perspectives, which adopt exterior, rather than interior, standpoints. Autistic expertise and knowledge production are situated in the hands of the, usually, neurotypical professional, clinician and researcher, with autistic subjectivity being marginalised or dismissed (Milton, 2014; Milton and Bracher, 2013). Still dominated by a medical model, autistic behaviour is frequently interpreted, from an outside perspective, as the result of the assumed 'deficits' and 'impairments'

associated with autism. The failure to see autistic behaviour from an autistic perspective means that behaviour can be misinterpreted as PDA or, more worryingly, attributed to PDA in the wider context of what Milton has called the 'normalisation agenda' (Milton, 2012; Milton and Moon, 2012) – treatments and interventions designed to support or, in some cases, force autistic individuals to 'adapt' to the neurotypical world around them.

As already stated, the behaviours categorised as pathological under PDA are those motivated by the avoidance of the 'ordinary demands of life'. However, when the demands of everyday life produce considerable and debilitating anxieties, their avoidance is best understood not as pathological but as entirely reasonable and, indeed, rational (Woods, 2018). Research shows that autistic people see, feel and make sense of the world around them differently to neurotypical people and, because autism affects individuals in ways that are unique to them, differently from each other (Bogdashina, 2013). These differences can result in differences in communication, social interaction and sensitivities, with many autistic people experiencing hyper and/or hyposensitivity to their environment. Sensitivities can manifest in relation to light, sounds, smells, taste and touch. For example, for some autistic people with hypersensitivity issues, their encounter with a particular colour or the feel of certain fabrics against their skin is so intense that is it physically painful. In cases such as this, it is understandable that an individual would go to great lengths to avoid coming into contact with things that produce distress. Yet, this rational avoidance behaviour, motivated by a desire to minimise anxiety, can easily be labelled as 'demand avoidance' and categorised as pathological.

The 'difficulties' that autistic people experience in social communication and interaction do not arise *because* of their autism. Communication is a two-way process (Hacking, 2009; Milton, 2012) and a breakdown in communication is the result of *both* parties' failure to understand *each other* and interpret *each other's* intentions. Damian Milton calls this the double empathy problem: 'a disjuncture between two differently disposed social actors which becomes more marked the wider the disjuncture in dispositional perceptions of the lifeworld' (Milton, 2012: 884; see also Milton, 2018b). The asymmetrical dynamics that exist in social relations between autistic and neurotypical people create the conditions for misunderstanding and misinterpretation. However, the assumption that autism necessarily results in 'deficits' in social interaction, as stated in both the *DSM*-V and ICD-11,[11] means that any breakdown in communication is seen as the responsibility of the autistic person. All communication is socially situated and context specific. So, when autistic people resist the demands of everyday life because they are overwhelming, confusing or anxiety inducing, their behaviour has to be understood as 'interactional in nature, and much like a lack of social reciprocity cannot be located solely in the mind of any one individual' (Milton, 2013).[12] To misinterpret their actions as evidence of PDA demonstrates a lack of insight in the mind and experiences of the autistic individual.

It can be further argued that autistic behaviour is seen as intrinsically pathological, simply because it is not neurotypical. From the beginning of its usage to describe a particular set of behaviours, autism has been associated with disorder and 'pathologised deviancy from normative cognitive functionality' (Milton, 2013), where normative cognitive functionality is equated with neurotypical cognitive functioning. From the outset, researchers and practitioners have sought to develop interventions designed to reduce deviancy from the neurotypical norm and increase the functionality of the autistic person (Milton and Moon, 2012). Functionality is underpinned by the 'normative liberal democratic ideal of the self-governing modern subject' (Gruson-Wood, 2016: 39) and the extent to which the autistic person achieves 'functionality' 'produces an idea of [their] use and value' (Murray, 2010).[13]

The most common forms of contemporary 'treatment' to increase functionality are behaviour modification techniques, based on the behavioural psychology of John Watson (1913), Skinner

(1991 [1938]) and, later, Ole Ivar Løvaas, whose name is synonymous with applied behavioural analysis (ABA), an increasingly popular method of 'treating' autistic children, which is underpinned by the principles of behaviourism. Behaviourism assumes that behaviours can be changed through conditioning and focuses on the response behaviours to external stimuli. In seeking to modify behaviour, it uses a system of rewards and punishments. Behaviour that is deemed 'problematic' is punished, while desirable behaviour is rewarded. Such an approach is an example of psychocentrism: 'the view that all human problems are individually rooted rather than socially constituted' (Gruson-Wood, 2016: 39). Psychocentrism reflects the dominance of the psy disciplines (Rose, 1998) in modern neoliberal societies, what Foucault (1977) referred to as the psy-complex whereby everyday life becomes dominated by the language and practices of the disciplines of medicine, psychology and psychiatry to produce self-governing subjects.

Psychocentrism's focus on the individual as the locus of behavioural 'problems' masks the fact that what is considered desirable behaviour is 'inherently subjective to the moral evaluations of the rewarder, and effective only as a means of control downward along power gradations' (Williams, 2018: 62). In other words, the use of behaviour modification techniques can be seen as an attempt to reduce or eliminate autistic behaviour and impose compulsory neurotypicality. Indeed, Ivar Løvaas, the founder of contemporary Applied Behavioural Analysis (ABA), said that the aim of ABA was to make autistic children 'indistinguishable from their peers' (cited in Milton and Moon, 2012: 4). It is also worth noting that Løvaas' work has been utilised in the development of interventions aimed at sexual and gender non-conforming young people in the 1970s. Although this is lesser known than his work on autism, it illustrates how the application of behaviourism in the form of ABA reinforces the idea of 'particular kinds of humans (i.e., non-autistic and gender conforming) as normal and others as in need of containment and/or improvement' (Gibson and Douglas, 2018: 3).

In the context of autism, desirable behaviours are those categorised as such by the, usually neurotypical, rewarder and the receipt of a reward is dependent on the autistic person's ability to perform these desirable behaviours. This form of intervention simply encourages compliance from the autistic person – a dangerous method that leaves autistics vulnerable to abuse by those individuals who would seek to exploit that compliance for their own ends. Gruson-Wood (2016) summarises the relationship of power and compliance in behaviour modification techniques like ABA as one where 'both the "good" autistic person and the "good" behavioural therapist emerge through training exercises of discipline and compliance' (pp. 44–45). Because current autism interventions are, largely, based on behaviour modification techniques which require compliance from the autistic person, the notion of autistic agency becomes oxymoronic. As a result, when autistic people do exercise agency and engage in self-advocacy, they are at risk of being labelled demand avoidant. This is a risk for all autistic individuals, but autistic children who attempt to engage in independent decision-making that may resist or challenge neurotypical norms are especially vulnerable to attracting the label of PDA, simply because they are children.

Childhood and the pathologisation of competence

In, what Egan and Hawkes (2009) call, the 'Anglophone West', childhood is understood as a period of immaturity, irrationality and impulsivity, and it is only through their movement to adulthood that children are thought to develop incremental capacities and competencies. These assumptions are underpinned and legitimated by developmentalism – a developmental lens through which children are observed, assessed and evaluated against pre-determined 'Ages and Stages' standards of development (Burman, 1994, 2017; Walkerdine, 1988). Through theories of child development, children are constructed as ontologically different from adults. Quite simply, 'children are what adults are

not' (Jenks, 1996: 3). However, children are not just seen as ontologically different, they are positioned as opposite to and lesser than adults. Developmentalism naturalises adults' power and dominance over children because it perpetuates a hierarchical model of development, where adulthood is the pinnacle of human development and, consequently, children are seen as 'human becomings' or in a state of transition to humanity (Burman, 1994, 2017; O'Dell et al., 2018; Runswick-Cole et al., 2017).

From this perspective, it can be argued that the very status of childhood is pathologised. Synonyms for the word 'pathological' include 'compulsive', 'uncontrolled', 'unreasoning', 'irrational' and 'illogical'. These are the same words that are used to describe children and their competencies or, more precisely, their assumed lack of competencies. These ideas are so engrained and so powerful that the word 'child' can be and has been used to pathologise and 'other' certain groups by characterising them as childlike (Mills and Lefrançois, 2018). Child has been used as a metaphor to justify welfarist practices that infantalise disabled people and older people, for example (Mills and Lefrançois, 2018; Thompson, 2006). Furthermore, it could also be argued that the term 'demand' in the label pathological demand avoidance reflects the unequal power dynamics between adults and children. To demand something from another and expect your demand to be granted does not imply a relationship of mutuality; it suggests that an order, command or directive is being given. We do not make demands of people with whom we have reciprocity; demands are made by those with authority to issue them.

Theories of child development form the framework within which children are given a whole range of labels and diagnoses, from the 'gifted and talented' child whose abilities exceed expectations of them for their age through to notions of 'developmental delay' applied to children who do not meet pre-determined and prescribed stages of development at the age expected. It also forms the basis of the PDA profile's criteria of passivity in early childhood with 'delayed "developmental milestones"' (Newson et al., 2003: 597), language delay and speech content that is 'usually odd or bizarre' (Newson et al., 2003: 597). Developmentalism and the disciplines that reproduce it, notably, medicine and psychology, are other manifestations of pscyhocentrism whereby individual children are observed and assessed with limited, if any, recognition that behaviour is socially mediated and takes place within a network of pre-existing relationships. When a different lens is used to make sense of children's behaviour, a lens that recognises children as active meaning makers of and actors in their social worlds and contextualises their actions within the hierarchical dynamics of the adult–child dyad, it is possible to interpret their behaviour in very different ways and come to different conclusions about their motivations.

In her classic study, 'The hard times of childhood and children's strategies for dealing with them', Waksler (1991) reports on her findings from a project in which she elicited stories from her undergraduate students comprising memories of their own childhood. What she was interested in was the 'hard times' of being a child; not hard times as adults might understand them and certainly not experiences of, for example, trauma, bereavement and abuse. Instead, she focused on the ordinary and everyday difficulties associated with being a child in an adult-centric world. She concluded that the recurrent theme in these memories was lack of control over one's life as a child. In her analysis of the students' stories, she identified that children lack control over their physical world, including over their bodies, what they wore and what they ate; lack of control of their emotions and feelings where children's feelings would routinely be dismissed because of adult assumptions that they were incapable of experiencing complex emotions and; lack of control over the moral world and children's realisation that there are different moral coda for children and adults. She also examined the strategies that children developed in order to cope with their lack of control and to gain some control over elements of their lives. In doing this, Waksler highlights the power dynamics that exist between adults and children and demonstrates that, contrary to developmental

assumptions of deficits and incapacities, children have complex strategies for dealing with their hard times and for gaining control over them.

Many of the questions that appear on the EDA-Questionnaire, designed to measure behaviours considered extreme or pathological, relate to many of the areas that Waksler identified as constituting hard times for children and their strategies for dealing with them. For example, it requires parents and/or teachers to consider whether the child '[R]esists and avoids ordinary demands and requests', '[C]omplains about illness or physical incapacity when avoiding a request or demand', '[A]ttempts to negotiate better terms with adults' and is '[G]ood at getting round others and making them do as s/he wants'.[14] O'Nions et al'.s (2018) recent research on parental reports of features of PDA behaviours in children with a diagnosis of autism found that, according to the parents, children employed 'a wide range of strategic behaviours to subvert requests' (p. 222). This included feigning illness, making up excuses and trying to 'outmanoeuvre parents' (O'Nions et al., 2018: 223). These are all strategies that children employ to exercise some control over their lives in situations where they have little. The findings from Waksler's study (and replicated in Hester and Moore, 2016, 2018) demonstrate that children 'throw tantrums' or pretend to be sick to avoid doing something that causes them distress. Of course, adults, in the main, do not want to cause distress to children but the fact that this behaviour might be characterised as PDA reflects 'the habitual and unconscious dispositions of adults as well as taken for granted assumptions about children and their capabilities' (Hester and Moore, 2018: 15). Their behaviour cannot be interpreted as agentic or as a reflection of the complex ways in which children engage with and shape the world around them. At best, it is framed as typical of children's development in, for example, phrases like 'the terrible twos' or adolescent 'storm and stress' and, at worst, it is understood as 'wilful', 'stubborn', 'naughty' or 'pathological'.

One of the themes that emerged from the O'Nions et al. (2018) study was that children categorised as demand avoidant had a *'[L]ack of constraint by social norms or sense of hierarchy*' (p. 224, italics in original). One of the ways that this manifested was through '*Behaving as though they had adult status*' (O'Nions et al., 2018: 224, italics in original), considering themselves as equal to adults, lacking respect of authority figures and 'lack[ing] any concept of age or hierarchy' (O'Nions et al., 2018: 224). It has already been argued that childhood is constructed as the opposite of adulthood and is imbued with a lower status and concomitant set of rights. As a result, deep-rooted beliefs about who children are, how they should behave and how they should interact with adults have become institutionalised and taken for granted. Furthermore, as Hester and Moore (2018) suggest, '[A]dults, usually unconsciously, are heavily invested in the adult/child dichotomy and the power relations that arise from it'. They are, therefore, reluctant to challenge dominant constructions of childhood and relinquish power over children.

Perhaps it is children's behaviour that seems to blur and disrupt the adult/child dichotomy that appear to be most problematic for those wishing to establish PDA as a separate diagnosis or a legitimate behaviour profile with the autism spectrum. One of the themes that O'Nions et al. identified from their research illustrates the anxieties that this can provoke in adults. One of the 'maladaptive behaviours' to emerge from the research data was an 'Insistence that others comply with their wishes/attempts to control others' activities' (O'Nions et al., 2018: 222), evidenced in 'a tendency to monopolise conversations' (O'Nions et al., 2018: 222). One parent reported that their son had done this: 'He did this at a school meeting with three adults present. They kept calm and had a logical discussion, but he shouts you down and takes over' (O'Nions et al., 2018: 222). In this example, it is not clear whether the child's 'maladaptive behaviour' is the result of his monopolisation of conversations or because he 'shouts you down and takes over' or because he engaged in a conversation with adults and did not occupy the role expected of him as a child. In another classic sociological study, Matthew Speier (1976) suggested that children have restricted conversation rights in

comparison with adults and that adults 'own' conversations that involve children. This can be seen in the way that adults can enforce silence on children, terminate conversations and remove children from conversations. Another technique used by adults that is pertinent to the example provided by the parent above is the protection of conversations and is often utilised when children have engaged in '*interrruptional behaviour*' (Speier, 1976: 102) which threatens to disrupt 'adult talk'.

There are other 'maladaptive behaviours' listed on the EDA-Questionnaire and cited as criteria for PDA, which reflect children's relative powerlessness in relation to adults. These behaviours include throwing tantrums in public and not being embarrassed, having 'meltdowns' if 'pressurised to do something', where examples of a 'meltdown' are, for example, a 'scream, tantrum, hit or kick', or using 'outrageous or shocking behaviour to get out of doing something'.[15] Waksler's research demonstrates that, very often, children's attempts to communicate 'hardships' to adults to tell them what they do not like or do not enjoy doing are frequently not heard. When children have tried to tell adults that they do not like something and adults do not listen *and* when the development of complex strategies to try and avoid the things they do not like has not worked, children are left with very few options for communication. These particular 'maladaptive behaviours' identified in the EDA-Questionnaire are focused on children's bodies, which are frequently the focus of adult interventions aimed at socialising and civilising children. From an adult-centric perspective, children's bodies are malleable objects that can, through careful instruction, be transformed from the unruly and undisciplined bodies of children into the docile and disciplined bodies of adults. However, as Waksler's research shows, it would be a gross oversimplification to view children's behaviour as either obedient or disobedient.

Drawing on the work of Michel De Certeau (1984) and the practices of everyday life, Kallio (2007, 2008) suggests that because children are not afforded political rights in the same way that adults are and what rights they do have are granted by adults on a conditional basis, '[C]hildren's politics is based on the autonomy they hold over their bodies [. . .], the right and ability to control and command one's own body belongs to them [. . .]' (Kallio, 2007: 126). Children's behaviour, then, can be understood as corporeal political agency and all their behaviour, regardless of whether it is conforming to or challenging expectations of dominant notions of who children are and who they should become is political since 'they are *forced* either to conform or oppose' (Kallio, 2008: 286, italics added). Within the web of disciplinary institutions that children encounter – the family, school, medicine, psychology – 'they may retain their *unruly bodies*, which are free from exterior powers' (Kallio, 2007: 127) in an attempt to 'attain a "political identity"' (Kallio, 2007: 127). Denied representation in formal political institutions, corporeal performance provides children with opportunities to maintain control over their bodies and exercise a degree of agency, albeit agency that is bounded by the pre-existing power dynamics of the adult–child dyad. While many may be reluctant to seen children's 'unruly' behaviour as political, it is deeply problematic to see it simply as wilful disobedience or PDA.

Gender and the pathologisation of transgression

Developmental discourses are not limited to assumptions about what competencies children should be able to exhibit at particular ages, developmentalism is also highly gendered. Cognitive perspectives on gender development posit that children are active in the formation of their gender identity and that from as young as 2 years of age, children recognise their membership of the male or female gender category and begin to show preferences for same-sex activities, evidenced through the organisation of play and the formation of friendships.

As with all developmental theories, the acquisition of gender-related knowledge and the construction of a gender identity is incremental. For example, Kohlberg's (1966 cited in Martin and

Ruble, 2004) cognitive-developmental theory assumes three stages of gender development and is based on a Piagetian theory of development. The first stage is the emergence of 'gender identity', which occurs at around the age of 2 years of age. This is followed by 'gender stability' at approximately 4 years of age when children develop an understanding that their gender is fixed and permanent and the process is completed with 'gender constancy' between 5 and 7 years. In this final stage, children recognise that their gender remains the same regardless of cosmetic changes to their appearance or situational factors, such as engagement in gender typical or atypical activities. For Kohlberg, it is at this final stage that children begin to learn about gender 'appropriate' behaviour. Notwithstanding the fact that these theories conflate biological sex with socially constituted gender, or that there is an uncritical acceptance and perpetuation of the sex-gender binary, they continue to shape professionals' understandings of how children develop and perform their gender identity which can prove problematic for autistic children and, especially, autistic girls.

Research indicates that, rather than following the linear and incremental model of gender development, some autistic children disidentify with their gender and consider themselves gender neutral (Bumiller, 2008). Where normative models of gender development assume that children have a clear sense of being a boy or a girl from around the age of 2 and actively seek out cues as to how to perform their gender identity, some autistic people see gender as irrelevant, 'incomprehensible and inapplicable' (Jack, 2012: 5) to their lived experiences. Bumiller (2008) suggests that autistic children 'often develop likes or dislikes for possessions without attributing relevance to gender demarcations' (p. 977). A boy may enjoy dressing up in a princess outfit because the feel of the fabric produces pleasurable or relaxing sensations or a girl may play with a toy tool box because she finds the rhythmic and persistent beat of the hammer on a wooden block alleviates her anxiety. While gender disidentification is experienced by male and female autistic people, female autists are more likely than their male counterparts *and* neurotypical people to report disidentification and 'not strictly identify as female' (Dewinter et al., 2017: 2932; see also, Dewinter et al., 2013; Pecora et al., 2016).

Even before a baby is born, its gender identity is being actively constructed by adults. Ultrasound scanning can determine the sex of a foetus, which shapes how parents and carers prepare for a baby's arrival through the way they decorate their nurseries and choose clothes and toys. This illustrates that while 'sex' is considered a biological and natural category, sexed bodies 'cannot be said to have a signifiable existence prior to the mark of gender' (Butler, 1990: 8); the sexed body does not exist a priori to the gendered discourses with which it is made meaningful (Butler, 1990, 1993).

From the moment a baby is born, parents and carers have different expectations of girls and boys, which are subtly (and sometimes, not so subtly) enforced and communicated with boys and girls differently. Paechter (2007) refers to this as the 'hegemonic naturalization of difference' and argues that it is engrained, taken for granted and self-perpetuating (p. 44). Girls and boys are believed to occupy fundamentally different and oppositional categories, so adults treat them differently and, as a result, they begin to behave differently (Paechter, 2007: 44; see also, Browne, 2004; Renold, 2004), or at least they are expected to. As already stated, there are a range of behaviour modification techniques designed to 'teach' autistic children how to behave in a neurotypical world and this extends to the recognition of gender appropriateness. In effect, this means that some 'children are forced to conform to conventions that are irrelevant to them' (Bumiller, 2008: 977). Demands to wear a dress or play dolls with other girls may seem like fairly ordinary requests to adults given the hegemonic nature of the sex-gender binary and resistance to these requests might well appear 'extreme'. However, faced with demands, to comply with arbitrary and socially constructed expectations of gender-appropriate behaviour with which one does not identify and finds 'incomprehensible and inapplicable' (Jack, 2012: 5), once again, it would not seem unreasonable to avoid or resist these demands. Female children who resist the demands of adults, who speak out

or who act out are transgressing normative constructions of femininity, which raises the question as to whether it is this transgression that is being pathologised through PDA.

Conclusion

While there are reports from adults that a diagnosis of PDA was both welcomed and enabled them to make more sense of their lives (Thompson, 2019) and there are reports from parents who have found PDA to be a reassuring diagnosis for their child (Fidler, 2019), there is less research into how children, who are the vast majority of the recipients of a PDA label, react to being categorised as having PDA. As this article has argued, there is nothing inherently pathological about the behaviours classified as such under PDA. It is simply behaviour interpreted as extreme or pathological by parents, carers and professionals based on developmental, adult-centric and neurotypical assumptions of how children should behave. All children who do not conform to or actively challenge these socially sanctioned and institutionalised behaviours are vulnerable to attracting the label of PDA. However, normative expectations of children's behaviour are not only developmentalist and not all children are equally vulnerable to professional intervention. The intersection of developmental models of childhood, the normalisation of sex/gender differences and compulsory neurotypicality places female autistic children at particular risk simply because they do not, or cannot, conform to what others expect of them.

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Notes

1. The term pervasive developmental disorder was used to refer to 'disorders' where there is delayed development in social interaction and communication skills. The term has been replaced by autism spectrum disorder in the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (*DSM*-V).
2. See Flackhill et al. (2017).
3. See O'Nions et al. (2016).
4. See PDA Society (2016).
5. See PDA Society (2016).
6. https://www.autism.org.uk/about/what-is/pda.aspx
7. The *DSM* is published by the American Psychological Association and provides a standard set of criteria for the classification of mental disorders.
8. The *International Statistical Classification of Diseases and Related Health Problems* (ICD) is a medical classification published by the World Health Organization. It is a broader classification system than the *DSM* in so far as it is not exclusively focused on mental health.
9. The National Health Service (NHS) is divided into a number of NHS Trusts, which serve a particular geographical area or have a particular function.
10. https://www.pdasociety.org.uk/families/diagnosing-pda (accessed 29 May 2019).
11. The *DSM*-V states that autism is characterised by 'Persistent deficits in social communication and social interaction across multiple contexts' (https://www.cdc.gov/ncbddd/autism/hcp-dsm.html (accessed 17 October 2019). The ICD-11 defines it in a similar way: 'Autism spectrum disorder is characterized by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication' (http://www.researchautism.net/conditions/7/autism-(autism-spectrum-disorder)/Diagnosis) (accessed 17 October 2019).

12. https://kar.kent.ac.uk/62694/431/Natures%20answer%20to%20over%20conformity.pdf (accessed 15 July 2019).
13. http://dsq-sds.org/article/view/1048/1229 (accessed 15 July 2019).
14. https://www.pdasociety.org.uk/resources/extreme-demand-avoidance-questionnaire (accessed 16 July 2019).
15. https://www.pdasociety.org.uk/resources/extreme-demand-avoidance-questionnaire (accessed 16 July 2019).

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