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‘Natures answer to over-conformity’: deconstructing Pathological Demand Avoidance.

This essay was first published on the ‘Autism Experts’ website in 2013.

By Damian E M Milton

Abstract

Throughout its history autism has been primarily defined in terms of a pathologised deviancy from normative cognitive functionality, despite protestations to the contrary from autistic writers (Sinclair, 1993, Arnold, 2010, Milton, 2011). More recently however, we have witnessed the wider acceptance of a construction concerning a perceived pervasive developmental disorder known as Pathological Demand Avoidance syndrome (PDA). This conceptualisation was first formulated by Elizabeth Newson in the 1980’s (PDA Contact Centre, 2012), yet more recently has been recognised by the National Autistic Society as a variant of an autistic spectrum disorder (ASD). This paper deconstructs the psychologisation of autistic agency inherent in the theory supporting PDA, through a personal reflection of an autistic activist and academic who according to such a perspective may well have met the criteria for PDA when a child. This paper concludes by arguing that the label of PDA represents the medicalising and pathologising of behaviours that from an outsider perspective seem to be differentiated from what is deemed capable by autistic people, but could be seen as the behaviours of an autistic person who has gained a modicum of normative social skills and is simply asserting their agency. By pathologising such behaviour, one could unduly be blunting attempts at autistic self-advocacy.

Me

A withered boy who was so afraid, hiding from society in the shade, His solitary cries no-one did hear, his confused mind full of fear. His tortured soul locked inside, with his faded dreams that had died. (Milton, 1989).

My own journey through the world of psychiatry and psychology

As a young child I remember various GPs and teaching professionals being concerned with the question: “What is wrong with that boy?” Early on though, my oddball quirks were put down to shyness and eccentricity, and I was diagnosed with Asthma and Hayfever. My first encounter with psychiatric professionals came following a road traffic accident and a court case my mother had started to claim damages through, not only for herself as she had suffered significant permanent physical injuries, but on behalf of the mental and emotional damage sustained by me and my brother, with particular attention paid to me as I seemed to have been particularly adversely affected (and I had been!). I was eleven years old at the time. During this process I was assessed by a variety of psychiatrists and psychologists, each one having a different theory as to: ‘what is wrong with that boy?’ These explanations ran from ‘psychologically disturbed’, to personality disorder and catatonic schizophrenia, with some suggesting that I had not been affected by the trauma of the accident, but had an underlying condition. Following unsuccessful encounters with various counselling services I decided to avoid such professionals at all costs, with a growing fear that the ‘men in white coats would come to get me’. Indeed, one could say that throughout my childhood I

perfected ways of ‘coping’ with the imposed will of others, usually through a form of passive defiance (although not always quite so passive in my teens). Several later after some years studying sociology and philosophy in an attempt to reason with the ‘insanity’ of the social world that I found myself in, I became a father. At the age of two my son was diagnosed with autism and severe learning difficulties. By researching this diagnosis I realised that I myself was on the autism spectrum, and was later diagnosed at the age of thirty-six with Asperger syndrome. Since then I went on to claim a distinction in Psychology (conversion diploma) from the Open University and set about deconstructing the social construction of autism. I am now studying for my doctorate at the University of Birmingham researching the tensions between various stakeholders in the narratives regarding the education of autistic people.

Pathological Demand Avoidance (PDA)

Throughout its history autism has been primarily defined in terms of a pathologised deviancy from normative cognitive functionality, despite protestations to the contrary from autistic writers (Sinclair, 1993, Arnold, 2010, Milton, 2011).

“...right from the start, from the time someone came up with the word ‘autism’, the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced.” (Williams, 1996: 14).

More recently however, we have witnessed the construction of a categorisation concerning a perceived pervasive developmental disorder known as Pathological Demand Avoidance syndrome (PDA). This conceptualisation was first formulated by Elizabeth Newson in the 1980’s (PDA Contact Centre, 2012), yet more recently has been recognised by the National Autistic Society as a variant of an autistic spectrum disorder (ASD). Many of the children being diagnosed initially by the Elizabeth Newson clinic were said to display traits and characteristics of autism, yet did not show a typical presentation of ‘classic’ autism or Asperger Syndrome, and so were often labelled with ‘Atypical autism’ or PDD-NOS (pervasive developmental disorder – not otherwise specified). These labels were felt to be unhelpful to the families of these children, thus spurring Newson and her followers to attempt to identify PDA as a separate syndrome.

Children characterised with PDA are believed to ‘resist the ordinary demands of life’ to a degree deemed pathological by clinicians (Newson 2003). Children seen as having PDA are often described as ‘Jekyll and Hyde’ personalities, involving sharp mood swings and deemed to display severe ‘challenging behaviour’. As with the psychological construction of autism more generally, PDA has increasingly been identified as being produced by a combination of genetic and environmental factors which alter early brain development. Children characterised as having PDA are said to have an anxiety-led need to control their environments, possess superficial social skills, and often engage in manipulative and domineering behaviour. The criteria for PDA as devised by Newson (2003) includes:

1. Passivity in early childhood, resisting demands and missing developmental milestones.
2. Continuing to resist demands, distraction techniques, resorting to meltdowns (panic attacks) if demands are enforced.
3. Surface sociability, but apparent lack of sense of social identity, pride or shame.

4. Comfortable in role play and pretending.
5. Language delay, seemingly the result of passivity.
6. Obsessive behaviour.
7. Neurological signs – such as awkwardness, similar to autism spectrum disorders.

If one had assessed me as a child against these criteria (or for that matter as I generally present today), especially within particular contexts, I would have met them all except perhaps that of being comfortable in role play or pretending. This difference would not be enough to separate those diagnosed with Asperger syndrome however from those deemed to display traits of PDA when one considers successful performers or actors on the spectrum such as Paddy Consadine.

PDA is not currently recognised by either the DSM-IV or the ICD-10 nor is it under consideration for inclusion in the proposals for the new DSM-V. Resistance to the inclusion of PDA into the DSM being predicated on it being a false identification of a form of attachment disorder rather than having a neurological basis (PDA Contact Centre, 2012).

Despite these conceptual issues regarding the causes of the behavioural manifestations of PDA, the label has in recent times caught the attention of many psychologists and practitioners working in the field of autism studies.

The drive behind this label to become accepted in the psychology lexicon has primarily come from Newson (2003) herself and her successor as a clinician at the Elizabeth Newson centre: Phil Christie (2007). For Newson (2003) the main difference between those identified as having PDA rather than autism or Asperger's is that children displayed 'superficial social skills' and are 'socially manipulative'. The children often could also maintain eye contact. Other factors associated with PDA included a 'lack of self-identity', with an understanding of how others should behave, but being unable to include themselves in these expectations, often imitative of 'inappropriate behaviour' (with a recommendation to provide a 'normal' peer group to model behaviour on), and an obsessive need to dominate social interactions and for others to follow their terms, often coming across as overbearing. According to the PDA Contact Centre (2012) there are two main types of PDA: 'actively passive' and 'actively disruptive', yet with children moving between these reactions. These behaviours are seen as not involving choice or agency, but as a manifestation of not being able to cope with the 'stress of everyday demands' due to 'cognitive deficit and pathology'.

In contrast to the normative functionalist models of mind and behaviour that are demonstrated in the vast majority of literature regarding autism and related pervasive developmental disorders, autistic self-advocates often remark on how autism can be better understood as a cognitive difference or diversity, and that the breakdown in communication and empathy impacts of both parties (Sinclair, 1993, Milton, 2012a). Taking an interactionist or post-structural approach to social relations, it is quite bizarre to speak of someone being able to possess definable social 'skills' which are not dependent on a multitude of social influences, simply not attended to by the individualising approach of cognitive functionalism. Thus, in this conceptualisation, what can be deemed appropriate, challenging, overbearing and so on are negotiated positionalities. The labelling of the expressions of autistic agency as pathological is in itself disempowering.

According to research quoted By the PDA Contact Centre (2012) there are statistically significant differences between PDA and autism/asperger syndrome, in that PDA children are less likely to:

- Have caused anxiety to parents before 18 months of age
- Show stereotypical motor mannerisms
- Show (or have shown) echolalia or pronoun reversal
- Show speech anomalies in terms of pragmatics
- Show (or have shown) tiptoe walking
- Show compulsive adherence to routines

This list includes a contradiction however, in that children who are meant to show 'soft' neurological signs of awkwardness or clumsiness are also statistically significantly less likely to walk on tiptoes. As someone who often paces or walks on tiptoes in order to gain feedback of where they are in their environment, this seems to be highly unlikely to be such a significant difference between those potentially characterised as having PDA or Asperger syndrome. Along with this list, there is also one regarding attributes found to be statistically significant in terms of regularity within the group of children thus characterised:

- Resist demands obsessively.
- Be socially manipulative.
- Show normal eye contact
- Show excessive lability of mood and impulsivity.
- Show social mimicry (includes gestures and personal style).
- Show role play (more extended and complete than mimicry).
- Show other types of symbolic play.
- Be female (50%).

If one were to apply these criteria to me, it would be hard to characterise my actions as 'manipulative', and I am certainly not good at, or motivated by, social mimicry or role play. Newson (2003) and Christie (2007) would suggest that these differences are definably different to the traits found in autistic people, yet as said earlier, there are successful performers and actors that are on the spectrum who do display these skills. When considering such a distinction, Christie (2007) suggests that it is an important sub-type to distinguish, due to the idea that children with PDA do not respond well to traditional behavioural techniques deemed successful with those on the autism spectrum. The obvious weakness with this argument is that such techniques are not 'successful' according to many autistic people either (Dawson, 2004, Milton, 2012b).

It is also suggested that children displaying PDA are more likely to become obsessed with particular individuals or relationships and as utilising bizarre content in language use, conceived as to be more common than in autism, due to an interest in fantasy. Similar attributes however have been made regarding women on the autism spectrum (Simone, 2010) and it is interesting to note that PDA is considered to be affecting an equal number of males and females. Could it just be the case that PDA is an unnecessary extra arbitrary line in the sand?

‘Extremes of any combination come to be seen as 'psychiatric deviance'. In the argument presented here, where disorder begins is entirely down to social convention, and where one decides to draw the line across the spectrum.’ (Milton, 1999 - spectrum referring to the 'human spectrum of dispositional diversity').

The major reason for the growing interest in PDA, has according to Christie (2007) been in the sense of recognition expressed by both parents and professionals of the behavioural profile as described by Newson (2003) and how different it is conceived to be from conventional understandings of ASD. It is argued here that such statements are based on flawed misguided theories regarding what autism is (Milton, 2012c), and thus the supposed differences between these categories begin to evaporate under closer inspection. Wing and Gould (2002) contend that PDA is not a separate syndrome and that the behavioural features portrayed in the PDA children can be found within individuals with a diagnosis of ASD, having said this, they also consider PDA research to be ‘innovative’ and clinically useful.

“Individuals with PDA tend to have over-active imagination as opposed to under-active, and this clearly sets them apart from Wing's description of the autistic Triad of Impairments.” (PDA Contact Centre, 2012).

The above statement reifies the idea that autistic people lack imagination, and that someone displaying imagination in some external sense could not possibly be autistic and thus PDA would be a more accurate descriptor. This is a misinterpretation in my view of the autistic mind-set however, where the apparent rigidity of many on the spectrum can be due to a number of factors, from monotropic focus (Murray et al. 2005) to stress and overload (Milton, 2012c) or a need to control one’s external environment (which is exactly the same reasons purported to be creating an avoidance of demands in descriptions of PDA). A major difficulty in suggesting that a behavioural manifestation is not autistic, is that to make such a statement one would have to have a good idea of what autism is, and this should be anything but a presumed given, considering the lack of clarity and explanatory value the dominant psychological theories contain (Milton, 2011).

“It is important to remember that PDA is not caused by a person's upbringing or their social circumstances and it is not the fault of the parents or the individual with the condition.” (Christie and Duncan, 2012).

There is simply not enough evidence to support a claim such as this, especially when there are similar traits associated with both developmental and attachment disorders. It is more than possible that autistic people can be traumatised by social relationships and by negating such factors as ever having a causative association with avoidance behaviours could be potentially negligent. Unfortunately current theories regarding attachment and trauma are not much more coherent than that regarding PDA.

Educational discourse regarding PDA children

“...many parents describe their child as working harder to avoid the demand than she would have done by accepting it. Whatever the child’s intellectual level…educational support will need to be

geared to helping the child to tolerate 'being educated' to the greatest degree possible, in order at least to approach her potential." (PDA Contact Centre, 2012).

In this statement, the PDA Contact Centre (2012) equates 'being educated' with conformity to non-autistic hegemonic practices. The notion that a child on the autism spectrum would have to work less to comply with demands than to reject them displays a total lack of empathy with many an autistic perspective. As a case in point, I was once asked to summarise autism in three words, the answer I gave was:

"Natures answer to over-conformity…".

According to the PDA Contact Centre (2012) there are three main educational needs that practitioners working with such children need to consider:

- Keeping the child on task for a substantial period of the day.
- Ensuring that what she appears to be learning is actually absorbed and retained.
- Ensuring that a minimal degree of disruption to other children takes place, and trying to create positive peer relationships despite the resentment such disruption can cause in other children. Sometimes this will include the need to keep other children physically safe.

Such an educational agenda applied to any child, I would consider woefully teacher-led, as it does not highlight at any point the building of a relationship or an attempt to understand the educational context from the position of the learner. The learner's role in this context is simply to stay on the task as envisaged by the non-autistic adult.

"However, a mainstream school is appropriate wherever possible, as PDA children are socially imitative and therefore good normative models are important." (PDA Contact, 2012).

The above quote belies a damaging ideology that has been embedded within behaviourist models of autism since the writings of Lovaas (1987) in that the company of other autistic or neuro-divergent individuals would be a negative influence on one another by modelling inappropriate behaviours. In the mind of this autistic person however, nothing has been more disabling than being isolated from those with similar dispositions (Milton, 2012b).

Christie (2007) suggests that diagnosis of PDA should help to better understand an individual and to use that understanding to help 'formulate more effective forms of intervention and provision'. As with most literature regarding autism, the emphasis is thus on intervening with the perceived deviant disorder in a remedial effort to normalise behaviour.

"...many of the generally accepted strategies that are advocated for working for children with autism and Asperger's syndrome were not proving successful for children with PDA; an altogether different emphasis was required...The use of structure, routine and behavioural principles of reward that are usually effective for children with autism or Asperger's syndrome are rarely so for children with PDA." (Christie, 2007).

Although somewhat redeeming this account by reminding readers that no one set of guidelines is applicable to all on the autism spectrum, Christie (2007) falls foul of assuming that behaviourist principles as applied to autistic people are effective in the first place, ignoring the discourse of autistic writers which are often quite to the contrary (Dawson, 2004, Milton 2012b). Despite recommending the building up of trust and mutual relationships with key workers and the 'Circles of Friends' technique, the advice offered by Christie (2007) holds conformity to appropriate normative behaviour as the ultimate outcome to work toward, conformity and adaptation to the demands of the non-autistic world rather than a truly mutual exchange.

"People with PDA tend to respond much better to a more indirect and negotiative style that allows them to feel in control." (Christie and Duncan, 2012).

Such an approach would also be recommended with autistic people more generally (Milton, 2012c), yet the manner of such negotiation would be dependent on each person and context, although sometimes it is beneficial to actually give children (autistic or not) the power and control to make their own autonomous decisions from time to time. This begs the question: exactly who has a 'pathological' need to control whom?

The construction of PDA can thus be seen as an emblem of contemporary biopower in action (Foucault, 1973, Finkelstein, 1997), based upon the construction of self in terms of the discourses of cognitive and developmental psychology reproduced in educational ideology and practice, with those so labelled subjected to a pathologising gaze and modified to meet idealised standards. Such a construction can be seen in its contemporary social nexus as a reaction to individuals seen as a risk to productivity and conformity to normative standards, in need of 'discipline and control', a not-so 'docile body' to be transformed and modified so it becomes as such.

Conclusion

In the eyes of many psychologist, educational practitioner, and parent, there are many people who would fit the criteria for PDA, however that does not mean the conceptualisation of what is causing such behaviours is at all well understood. The PDA narrative presents what is perfectly rational behaviour from the viewpoint of the autistic person displaying it when faced with highly stressful situations, as not as a consequence of 'choice' (whatever that may be) but as a pathological response. It is deemed pathological due the distaste of those doing the perceiving and their idealisation of cultural and psychological norms.

The PDA narrative suggests that those who gain some social interaction skills and assert their needs through avoidance of imposed demands are pathological. In essence, such protests are perceived as the fault of pathology inherent in the individual mind rather than a conflicting interaction (much like 'theory of mind'). It will no doubt lead to treatments that try and stop such behaviours (which could be read as a form of self-advocacy and the gaining of skills). Such behaviours arise from any number of transactions between the individual and environment. The avoidance of demands is interactional in nature, and much like a lack of social reciprocity cannot be located solely in the mind of any one individual (Milton, 2012a).

The label of PDA represents the medicalising and pathologising of behaviours that from an outsider perspective seem to be differentiated from what is deemed capable by autistic people, but could be seen as the behaviours of an autistic person who has gained a modicum of normative social skills and is simply asserting their agency. By pathogising such behaviour, one could unduly be blunting attempts at autistic self-advocacy. Part of this misperception is due to the application of a deficit model of autism that considers autistic people as incapable of displaying social agency. As with other labels in the psychologisation of human social life, it is a descriptive construction from a medicalised pathologising functionalist discourse, yet even less than other labels it does not signpost practitioners to the needs of the person, but to the needs of those around them. One could even argue that there is a struggle for power embedded in the discourse, in which one could question who it is who needs to control whom, an incidence of biopower in action.

Distortion

As the final door begins to close, we make do with what our leaders impose. What are they implying, what is the message that is underlying? We are polluted by this infestation, I need an outlet for my frustration. I don't want to comply, and I have no need to justify. (Milton, 1989).

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