Briefing for the Public Petitions Committee

Petition Number: PE1625

Main Petitioner: Patricia Hewitt and Mary Black

Subject: Wider awareness, acceptance and recognition of Pathological Demand Avoidance Syndrome

Calls on the Parliament to urge the Scottish Government to promote a wider awareness and acceptance of Pathological Demand Avoidance Syndrome among health, education and social care and social work practitioners, and, via the appropriate agencies and bodies, to institute and facilitate training in the diagnosis of the condition, to promote the development of therapeutic programmes for those with the syndrome and to provide support for their families and carers.

Background

The petitioners have provided comprehensive background material in support of their petition.

As the petitioners state, the presence of the condition as distinctive from, but with features of, autistic spectrum disorders was first suggested by a developmental psychologist based in the University of Nottingham, Elizabeth Newson. She became known for her work on autism, and for her innovative approach in assessing children with autism spectrum disorders.

According to the National Autistic Society:

‘Pathological Demand Avoidance (PDA) is now considered to be part of the autism spectrum. Individuals with PDA share difficulties with others on the autism spectrum in social aspects of interaction, communication and imagination. However, the central difficulty for people with PDA is the way they are driven to avoid demands and expectations. This is because they have an anxiety based need to be in control.

People with PDA seem to have a better social understanding and communication skills than others on the spectrum and are able to use this to their advantage.

The main features of PDA are:

- resists and avoids the ordinary demands of life
- appearing sociable, but lacking depth in understanding
- excessive mood swings and impulsivity
- comfortable in role play and pretend, sometimes to an extreme extent
- language delay, often with good degree of catch-up
- obsessive behaviour, often focused on people.’

In a paper in 2003, *Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders*, Professor Newson outlines the main features of PDA as expressed by a cohort of 150 children diagnosed between 1975 and 2000, and how it differs from autism and Aspergers.

According to a short article on the British Psychological Society website, ‘PDA – is there another explanation? a researcher who reviewed the current evidence in the light of increased public discussion of the condition states:

“services are under increasing pressure to consider PDA as a diagnosis. Whilst PDA currently falls under the umbrella diagnosis of autism spectrum disorders (ASD) (DSM-5)\(^1\), individual services/clinicians can choose to use PDA as a descriptive diagnosis alongside a clinical diagnosis of ASD”.

She suggests that there is a mirroring in symptoms with attachment disorders:

“However, these exact same characteristics could equally be used to describe a child with disordered attachment (NICE, 2015). Furthermore, research has shown that children with a diagnosed attachment disorder may be as impaired as autistic children in their social relatedness and language skills (Sadiq, et al., 2012), and one study found that the symptoms of ASD and attachment disorder can be comorbid (Giltaij, et al., 2015)”.

**The International Classification of Diseases, tenth edition (ICD-10)**

The ICD-10 is the most commonly used diagnostic manual in the UK. It presents a number of possible autism profiles, such as Asperger syndrome. A revised edition (ICD-11) is expected in 2018 and is likely to closely align with the latest edition of the American Diagnostic and Statistical Manual (DSM). It does not list PDA as a specific profile. It would be classified under one of the two ‘unspecified’ categories:

---

\(^1\) DSM-5 stands for Diagnostic and Statistical Manual of Mental Disorders, Edition 5. DSM is the manual used by clinicians and researchers to diagnose and classify mental disorders. The American Psychiatric Association (APA) published DSM-5 in 2013, culminating a 14-year revision process. Under the Fourth edition, DSM-IV, patients could be diagnosed with four separate disorders: autistic disorder, Asperger's disorder, childhood disintegrative disorder, or the catch-all diagnosis of pervasive developmental disorder not otherwise specified. In DSM-5,
- Other pervasive developmental disorders
- Pervasive developmental disorder, unspecified

**Diagnostic and Statistical Manual, fifth edition (DSM-5)**

Although not the most commonly used manual in the UK, DSM-5 is likely to have a significant influence on the next edition of the ICD. This manual has recently been updated and is also used by diagnosticians. The diagnostic criteria are clearer and simpler than in the previous version of the DSM, and sensory behaviours are now included. The manual defines autism spectrum disorder as “persistent difficulties with social communication and social interaction” and “restricted and repetitive patterns of behaviours, activities or interests” (this includes sensory behaviour), present since early childhood, to the extent that these “limit and impair everyday functioning”.

In DSM-5, the terms ‘autistic disorder’, ‘Asperger disorder’, ‘childhood disintegrative disorder’ and ‘Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)’, have been replaced by the collective term 'autism spectrum disorder' (ASD). This means that it’s likely that ‘ASD will become the most commonly given diagnosis.

NHS Inform is already following the DSM-5 classification of a single collective term ‘autism spectrum disorder’ for people presenting with a range of recognised symptoms. The website describes the condition thus:

> Autism spectrum disorder (ASD) is a condition that affects social interaction, communication, interests and behaviour.

> In children with ASD, the symptoms are present before three years of age, although a diagnosis can sometimes be made after the age of three.

The page makes reference to NICE Guidance on the recognition, diagnosis and referral of children and young people with Autism Spectrum Disorder.

The condition (PDA) received attention following a series of Channel Four programmes broadcast in 2015, ‘Born Naughty?’

The reclassification of ‘autism spectrum disorders’ as opposed to discrete conditions, potentially makes recognition of PDA as a distinct condition moot.

The British Journal of Psychiatry published ‘Autism – an evolving concept’ in 2000 and stated the following about PDA:

> There is a risk of the diagnosis of autism being extended to include anyone whose odd and troublesome personality does not readily fit some other category; such over-inclusion is likely to devalue the diagnosis to a meaningless label. For the same reason, it is important to remain alert to the possible existence of other diagnostic groups.
Newson has identified such a group with the label of pathological demand avoidance syndrome after its predominant characteristic.

Children in this group have, at most, a mild learning disability and a high degree of social awareness, although many have enough in common with autism to attract the diagnosis (Newson & Maréchal, 1998). Pathological demand avoidance syndrome forms a long-standing and expensive disorder, persisting into adulthood and posing considerable problems in its management. The description is based on a series of 200 children but replication has been hindered by the lack of more formal publication.

Since 2000, further research has been done and papers published such as ‘Identifying features of ‘pathological demand avoidance’ using the Diagnostic Interview for Social and Communication Disorders (DISCO)’ in the journal ‘European Child and Adolescent Psychiatry’, which provides further references to more recent research.

Scottish Government Action

The Scottish Government published The Scottish Strategy for Autism in 2011. This strategy is specifically linked to other policies, legislation and frameworks such as:

- Additional Support for Learning
- Getting it Right for Every Child
- Carers Strategy (Carers (Scotland) Act 2016)
- Children and Young Peoples (Scotland) Act 2014
- Education (Additional Support for Learning) (Scotland) Act 2004 (link to summary information)
- Education (Additional Support for Learning) (Scotland) Act 2009 (link to information and legislation) (see also supporting children’s learning code of practice (Revised edition) 2010
- The Keys to Life: Improving quality of life for people with learning disabilities, 2013

The Education (Additional Support for Learning) (Scotland) Act 2004 provides the legal framework for the provision of additional support for learning. The legislation was amended by the Education (Additional Support for Learning) (Scotland) Act 2009. The Act is structured around the concept of support being needed for any reason, and for short or long term periods determined
by the individual learning needs of the child or young person. The key duties on education authorities are to identify, make provision for, and review provision for the additional support needs of children and young people for whose education they are responsible.

The Act also places duties on education authorities, (and in certain circumstances health, social work and skills development Scotland) to work to plan and make joint provision for children and young people with complex or multiple additional support needs. Where their needs are significant, require support from education and another partner agency, and will last more than one year, children and young people may have a statutory co-ordinated support plan to bring together all of the support to be provided to meet their learning needs.

The principles of all the above legislation and policy are that all children should have their health and educational needs met according to their own needs. The assumption is that these are assessed through partnership between local authorities, health boards, integration authorities, parents and the young people themselves.

**Independent Advice and Guidance for additional support for learning**

**Enquire** is an organisation, signposted by the Scottish Government, that provides independent and impartial advice for teachers, parents, local authorities and others caring for or working with children and young people with additional support needs.

Autism is a condition that is highlighted explicitly on the Scottish Government’s Education web pages. These pages link to ‘**The Autism Toolbox: an Autism Resource for Scottish Schools**’.

The **Autism Strategy has its own dedicated website** which links to other publications, resources, Autism services in Scotland, news and events.


**Anne Jepson**
**Senior Researcher**
5 December 2016

---

SPICE research specialists are not able to discuss the content of petition briefings with petitioners or other members of the public. However if you have any comments on any petition briefing you can email us at **spice@parliament.scot**

Every effort is made to ensure that the information contained in petition briefings is correct at the time of publication. Readers should be aware however that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.