Name of petitioner
Patricia Hewitt and Mary Black

Petition title
Wider awareness, acceptance and recognition of Pathological Demand Avoidance Syndrome

Petition summary
Calling on the Scottish 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.

Action taken to resolve issues of concern before submitting the petition
We have raised the issue of the recognition of Pathological Demand Avoidance syndrome with Scottish Borders Council. This has been in the context of individual cases involving our children and young people in the education system. We have also presented details to further education institutions and to parts of the NHS.

We have discussed better awareness and recognition of the syndrome with the PDA Society and among parents in the Borders and further afield in both Scotland and the UK where children and young adults have already been diagnosed with the condition.

We have raised the question of proper recognition of the syndrome with MSPs and via them the Scottish Government calling unsuccessfully for a coherent response in terms of both public policy and its implementation.

Petition background information
It is clear to us that there is a lack of familiarity with the syndrome. Furthermore we have encountered a hesitation in some official quarters to admit to its existence and even to research the literature and thereby to understand cumulative professional experience and to assess its validity.

Whilst we appreciate that the syndrome may be new to some professionals, we believe that the growing research evidence that PDA syndrome is an identifiable part of the autistic spectrum and thus requires a constructive response from the Scottish Government.

Pathological Demand Avoidance syndrome was first described by Professor Elisabeth Newson at the Child Development Research Unit of Nottingham University in the 1980s.
It was not however until 2003 that the first ever peer reviewed research paper was published by Newson, Le Marechal and David. An extensive group of papers, commentaries and case studies has developed since then, the latest of which in 2015 were O’Nions, Gould, Christie, Gillberg, Viding, Happe ‘Identifying features of Pathological Demand Avoidance using the Diagnostic Interview for Social and Communication Disorders’ in European Child and Adolescent Psychiatry 2015 and Gore-Langton and Frederickson ‘Mapping the educational experiences of children with pathological demand avoidance’ in the Journal of Research in Special Educational Needs.

PDA is now recognised as a profile within the autism spectrum and is assessed and diagnosed by many of the leading experts within the field of autism. However, the therapies and treatments for PDA are of a distinct nature in themselves and it is a recognition of this and the spread of awareness that is the pressing issue for children and young people affected and their parents.

PDA is best described in the PDA Society’s booklet ‘Pathological Demand Avoidance Syndrome – A reference Booklet for Health, Education and Social Care Practitioners’ revised edition April 2016 page 5

“Like autism or Asperger Syndrome, PDA is a lifelong disability and individuals may require differing levels of support throughout their lives, depending upon how the condition affects them.

The central difficulty for people with PDA is their avoidance of, and resistance to, the demands they are subject to and encounter. These can range from direct and explicit instructions to the more subtle everyday demands of life.

Individuals with PDA experience high levels of anxiety and there is a strong need for them to feel in control in most situations. Demands and expectations unsettle this sense of control. This in turn heightens anxiety still further and leads to compulsive and obsessive avoidance. It is this ‘can’t help it’ drive to avoid even trivial demands that earns the behaviour its pathological status.

Avoidance can be at all costs and the socially inappropriate behaviour of a panic attack driven tantrum or meltdown is common, especially in children. Some people with PDA have been described as being skilled at using interactive and social communication skills to avoid demands. They are often able to use these skills creatively and may seek to avoid demands through negotiation, manipulation or distraction.

Those with PDA share areas of difficulty with other autism spectrum disorders, but strategies and approaches found to be effective are quite different. Differential diagnosis is therefore important to signpost towards appropriate educational and handling interventions.”

Another important reference can be found on the National Autistic Society’s website at:  
http://www.autism.org.uk/about/what-is/pda.aspx

A helpful and accessible reference book is:

Reference is also made to research published by the University of Newcastle upon Tyne in which it has been found that autism is not being detected early enough in children across the UK. The average age of diagnosis at fifty five months has not decreased in more than a decade. Similarly those diagnosed “early” are still on average diagnosed at thirty months which also shows no improvement over a decade.

http://www.ncl.ac.uk/press/news/2016/04/drparautismresearch/

Earlier and more accurate diagnosis leads to early therapies and treatment by specialist services to the benefit of the recipients and their families.

Early and more accurate diagnosis must surely be a priority and along with appropriate interventions will identify those living with PDA and increase their emotional well being.
Interventions will identify those living with PDA and increase their emotional well-being and help them to achieve their full potential in life.

http://www.ncl.ac.uk/press/news/2016/10/pactautismstudy/

**Unique web address**

http://www.parliament.scot/GettingInvolved/Petitions/PE01625

**Related information for petition**

Do you wish your petition to be hosted on the Parliament’s website to collect signatures online?

YES

How many signatures have you collected so far?

0

Closing date for collecting signatures online

20 / 12 / 2016

**Comments to stimulate online discussion**

We think this is an opportunity for Scotland to lead the way in ensuring that the relevant professionals have the best awareness and training to recognise PDA syndrome, to support children, young people and their families.

Do you agree that it’s time that PDA syndrome is given proper recognition?

How do you think we can best achieve this?