

Briefing for the Public Petitions Committee

Petition Number: [PE1732](#)

Main Petitioner: Patricia Hewitt and Barbara Irvine

Subject: Toolkit for working with the Pathological Demand Avoidance profile of ASD

Calls on the Parliament to urge the Scottish Government to -

1. Draw up in co-operation with others, a toolkit for professionals to assist in diagnosing and designing therapeutic support for children, young people and adults who have Pathological Demand Avoidance, a profile within the autism spectrum
2. Offer training in the use of such a toolkit and additionally to signpost, promote and facilitate other training by those who have successfully developed therapeutic programmes
3. Provide access to appropriate education, therapies and interventions to reduce or minimise the effects of the condition for the individuals and their families and carers.

Background and update on previous petition

Pathological Demand Avoidance (PDA) has been [considered previously](#) (PE1625) by the Petitions Committee through a petition by one of this petition's main petitioners. This petition sought to raise awareness of the condition and to improve training in its diagnosis. The [SPICe Briefing for PE1625](#) provides information on the condition, relevant research and its classification under international diagnostic manuals. PDA is regarded as a condition under the classification of Autism Spectrum disorders (ASD).

The Committee considered written and oral evidence, wrote to the Scottish Government and other public bodies. It closed the petition on 9 November 2017, recognising that work was ongoing in relation to the Scottish Strategy for Autism, and that NHS National Education for Scotland had provided additional resources and support tools for the health and social care workforce. In closing the petition, the Committee agreed to write to the Scottish Government to indicate that PDA awareness should be included in the ongoing work on the Scottish Strategy for Autism. [Link to Official Report 9 November 2017](#).

The eleventh edition of the International Classification of Diseases ([ICD – 11](#)) has now been published by the World Health Organisation, but won't be fully implemented immediately, because of the variation in the sophistication of

health systems internationally. ([The EU expects member states to be adhering to it by 2022](#)). However, it continues to [classify autism spectrum disorders as one of 11 neurodevelopmental disorders](#), and does not list any sub-categories for diagnostic purposes, such as PDA.

Scottish Government Action

On 26 March 2018, the Scottish Government published a [refreshed Strategy for Autism](#), focussing on 'Outcomes and Priorities' for the period up to 2021. The document does not make specific mention of any conditions within the ASD category. This is consistent with the international classification of ASD, and with current guidance such as that relating to learning disability, additional support for learning, [Getting it Right for Every Child \(GIRFEC\)](#) and mental health policy and legislation, which highlights that the focus should be on providing necessary support according to a person's individual needs, regardless of any diagnosis.

Among the priorities and intentions, there is acknowledgement of the requests for improved training and awareness among professionals of autism in general.

The Scottish Government includes the following commitments as part of its refreshed Strategy for Autism:

- 'We will increase investment and build on the work done by NHS Education for Scotland (NES) on the autism training framework.
- We will work with NES, the Scottish Social Services Council, Health Boards, Local Authorities and Integration Authorities to analyse gaps in training across Scotland's health and social care workforce and deliver targeted training to improve the understanding of autism across the workforce.
- We will build on education resources, such as the Autism Toolbox, to ensure teachers and the education workforce have access to resources designed to help them better support autistic children.
- We will work with universities who deliver teacher education to explore how we can increase awareness of autism in teacher education.
- We will explore what needs to be done to ensure autistic parents are better supported.
- Scottish Government will work with partners to consider how autism research is translated into practice, and explore the introduction of a Scottish Autism Research Consortium.'

Some of these undertakings reflect the themes of the petition, although they apply to ASD in general, rather than PDA specifically.

Scottish Parliament Action

See above. There have also been a number of [Parliamentary Questions and a Motion](#) to raise awareness of PDA

UK Government/Parliament Action

The petitioners' highlight activity in the UK Parliament, namely the tabling of an [Early Day Motion¹ by Sir Mike Penning MP](#) in the House of Commons, as well as a [legal challenge to the UK Government over school exclusions](#) for aggressive behaviour by someone who has a disability (link is to full transcript of decision). While the legislation discussed in the judgement is the Equality Act 2010, which covers Scotland, the judgement also refers to other legislation, relating to disability and special educational needs that doesn't apply in Scotland.

However, the Equality Act was also central to a disability discrimination [claim](#) against a local authority in Scotland, concerning a child with ASD who was excluded from a primary school, was successful in the [Health and Education Chamber, First-tier Tribunal for Scotland](#). PDA is referred to once in the evidence, but is cited as pathological defiance disorder:

'In relation to Witness A's position that The child's behaviour was not necessarily due to autism, Witness A advised that she sought advice from the psychologist about pathological defiance disorder but did not feel that another label would be helpful for The child.' [p.14](#)

The school had not provided adequate support for the child, and was ordered to:

- (a) Apologise to the child and his parents for the unlawful discrimination in writing, said apology to conform to the terms of the Scottish Public Services Ombudsman's guidance on apologies, all within one calendar month of receipt of this decision.
- (b) Ensure that relevant staff at School A undertake appropriate training to improve awareness of the impact of autistic spectrum disorder on a child's behaviour and development and receive crisis and aggression limitation management (CALM) training to enable them to meet their responsibilities under the Act.
- (c) Review, develop and revise its policy on exclusion considering Scottish Government Guidance.
- (d) Review and routinely monitor exclusion rates of pupils with a disability, under the public-sector equality duty to adopt relevant policies and targets for the reduction of the exclusion gap which exists in Responsible Area for disabled pupils.'

¹ [Early day motions \(EDMs\)](#) are motions submitted for debate in the House of Commons for which no day has been fixed. As there is no specific time allocated to EDMs very few are debated. However, many attract a great deal of public interest and media coverage. EDMs are used to put on record the views of individual MPs or to draw attention to specific events or campaigns.

A search of Hansard, shows that PDA was mentioned in a [House of Lords debate in February 2019 on 'Education, Health and Care Plans'](#).

The petitioners also refer to a Lancet article, ['Pathological Demand Avoidance: symptoms but not a syndrome'](#) and associated commentary. The article cites other research on PDA.

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8 August 2019

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Published by the Scottish Parliament Information Centre (SPICe), an office of the Scottish Parliamentary Corporate Body, The Scottish Parliament, Edinburgh, EH99 1SP