



The Scottish Parliament
Pàrlamaid na h-Alba

PUBLIC PETITION NO.

PE01732

Name of petitioner

Patricia Hewitt and Barbara Irvine

Petition title

A toolkit for working with the Pathological Demand Avoidance profile of ASD

Petition summary

Calling on the Scottish 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.

Action taken to resolve issues of concern before submitting the petition

Previously submitted a petition (PE1625) on this issue
Have continued to raise this issue with various MSPs and MPs

Petition background information

Since the previous petition – [PE01625](#) – was closed in November 2017 after a detailed investigation by the Public Petitions Committee a series of significant developments have occurred. These include:

1. the tabling by Sir Mike Penning MP of an Early Day Motion 1669 in the House of Commons - "That this House commends the PDA Society and other PDA campaigners for their Call To Action campaign to raise awareness, recognition and understanding of the Pathological Demand Avoidance profile of autism; and supports their calls for Autism Boards, local authorities and clinical commissioning groups to issue a position statement to help health and education professionals provide the support so desperately needed by children and young people with PDA and their families."

2. Important articles in the Lancet by Professor Johnathan Green and others and the

2. Important articles in the Lancet by Professor Jonathan Green and others and the [commentary thereon](#) by Elizabeth O’Nions and others entitled ‘Demand avoidance is not necessarily defiance’.

3. The PDA Society’s recent survey entitled [‘Being Misunderstood’](#) , which showed that seven out of ten children or young people with the PDA profile were unable to access school and one in ten had been permanently excluded from school

4. The legal challenge to the UK Government on the way in which exclusions from school had hitherto been conducted. Part of the judgement is quoted below:

“In my judgment the Secretary of State has failed to justify maintaining in force a provision which excludes from the ambit of the protection of the Equality Act children whose behaviour in school is a manifestation of the very condition which calls for special educational provision to be made for them. In that context, to my mind it is repugnant to define as ‘criminal or anti-social’ the effect of the behaviour of children whose condition (through no fault of their own) manifests itself in particular ways so as to justify treating them differently from children whose condition has other manifestations.”

We consider that this adds weight to the information in previous petition PE1625 and demonstrates that more can and needs to be done.

Early and accurate diagnosis must surely be a priority and along with appropriate interventions will identify those living with PDA and increase their emotional wellbeing and help them to achieve their full potential in life. It will also provide relief to their families, friends and carers and reduce costs to the NHS. We believe that the Scottish Government is in danger of falling well behind developments which can be accommodated while still adhering to international standards and guidelines.

Unique web address

<https://www.parliament.scot/GettingInvolved/Petitions/PE01732>

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

21 / 08 / 2019

Comments to stimulate online discussion

Have you experienced a lack of awareness and education among health and education care and learning teams, or other professionals on providing support people with PDA?

What positive results do you think could be delivered by the development of a PDA toolkit?

Who do you think should be involved in developing the toolkit?