

PE1625/K

Petitioners submission of 2 June 2017

As the petitioners we would like to comment briefly on the four latest submissions G - J to the Committee. We were disappointed that there were not more. Our comments are below.

Our conclusion from reading all the submissions and evidence is that our petition remains entirely valid.

We have called for “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.”

We believe that any objective and impartial reader of the evidence would agree that PDA is either a stand lone diagnosis or is located on the autism spectrum. In either eventuality there is undoubtedly a need for Guidance from the Scottish Government to promote awareness and enhance training and to provide support to families affected.

We have encountered examples of ignorance among professionals of not only PDA but other conditions as well and a widespread lack of understanding of the requirements of the Additional Support for Learning Act and other legislation. That is surely the impression gained on reading comments on the website too.

We have not had an opportunity to analyse international comparisons. Anecdotally a friend of one of us mentioned a grandchild's difficulties. A PDA leaflet went to the child's parents in New Zealand. The grandchild now has an ASD with PDA diagnosis. We believe the Scottish Government could investigate practice overseas to ensure best practice is put in place at home.

We hope that the Committee agrees with us that the Scottish Government must take action and in our view, given the weight of evidence, the Government would be negligent if it did not do so.

We express our appreciation of the courtesy, help and co-operation of Committee members and the clerks in handling our petition and listening so sympathetically to our concerns.

Falkirk Health and Social Care Partnership submission of 25 April 2017

Falkirk Council's submission helpfully says that there “are a range of professionals in Falkirk Children’s Services with an awareness of Pathological Demand Avoidance Syndrome and the development of its

status as a differentiated disorder from that of the recognised Autistic Spectrum Disorder.”

It is interesting that the submission concludes that “there appears to be a need for greater research and practitioner debate” before recognition of the PDA as a standalone disorder or as part of the autism spectrum can fully take place.

That is partly what we, the petitioners are calling for. We are asking that the Scottish Government actually carries out the studies deemed desirable and thereafter clarifies the position for professionals across Scotland.

NHS Western Isles submission of 27 April 2017

The NHS Western Isles submission also calls for more research. Clearly the petitioners would dissent from some of the conclusions in this response. According to the submission, PDA is not a standalone diagnosis yet Western Isles CAMHS clinicians view PDA “patterns of behaviour” as part of an Autistic Spectrum Disorder (ASD) rather than a differential diagnosis.

Herein lies a contradiction that occurs in many responses to PDA. PDA doesn't exist yet what the petitioners and many others experience and call PDA is purportedly part of the autistic spectrum. The layman might be forgiven for thinking that some professionals are contradicting themselves saying no it doesn't exist but yes on the other hand it does exist.

It is of course important as the submission says to avoid misdiagnosis and we recognise that the symptoms of PDA might co-exist with another mental health condition. However it remains the case that this submission together with others does recognise that there is cause for further work to be undertaken to attempt to clarify and expand on current understanding.

North Ayrshire Health & Social Care Partnership submission of 28 April 2017

North Ayrshire Health & Social Care Partnership repeats the gist of the Western Isles response. A key sentence which amplifies our main point is

“PDA provides a behavioural profile which fits with exaggerated presentation of ASD in relation to difficulties associated with everyday demands and expectations.”

If PDA doesn't exist how does it do this?

The point made about “the need to be child, young person or adult centred when thinking of diagnosis and intervention” is entirely right and the petitioners would not wish anything that they have said or claimed to be construed as disputing that point.

East Ayrshire Health and Social Care Partnership submission of 4 May 2017

We were heartened by this submission. The extract below was particularly encouraging.

“Social Work Services in East Ayrshire, in collaboration with professionals in Ayrshire and Arran NHS Child and Adolescent Mental Health Services (CAMHS) recognise PDA as a developmental disorder. PDA is not considered a disability in isolation and in order to have a PDA diagnosis there requires, in the first instance to be a diagnosis of Autistic Spectrum Disorder (ASD) “

Here is a clear expression of current best practice. Whilst we would say that we believe that PDA does stand on its own, the fact that the East Ayrshire Partnership understands the condition and is prepared to countenance responses to it as part of the autistic spectrum is most welcome.

Scottish Parliament Information Centre Briefing

The SPICe briefing is a very helpful general overview of the current state of understanding of PDA. It also underlines the necessity of further research. We are grateful for the care and attention taken in its preparation.