

## PE1625/F

Petitioners' submission of 19 March 2017

The Scottish Government's response to the petition sets out the current official position as regards Pathological Demand Avoidance syndrome. The response in effect says that the syndrome is considered if not to exist, then not to have been proven to exist. The relevant and highly significant paragraph is:

"There are currently two major diagnostic classification systems in use: the International Classification of Diseases, version 10 (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5). These systems are the 'gold standard' for autism diagnosis and neither of them recognises PDA. Since Scotland is committed to standards of best practice, and as stated in SIGN 145, *Assessment, diagnosis and interventions for autism spectrum disorders: A national clinical guideline*, all professionals involved in diagnosing Autism Spectrum Disorder in children, young people or adults should consider using either one of the current versions of these classification systems. Neither SIGN nor NICE guidance recognises PDA as a distinct category for diagnosis."

Whilst it is true that "neither SIGN nor NICE guidance recognises PDA as a distinct category for diagnosis" the statement fails to recognise on-going developments such as 'The Distinctive Clinical and Educational Needs of Children with Pathological Demand Avoidance Syndrome: Guidelines for Good Practice' in the 'National Autism Standards' set out by the Autism Education Trust. The tenor of the Scottish Government's response seems to be one of wanting to turn a blind eye to progress. Is there no appreciation that SIGN and NICE guidance should be subject to revision and development in the light of better understanding of autism?

The consequences that flow from current Scottish Government thinking as expressed in the extract from its response are that practitioners are discouraged from responding to those presenting with the syndrome, however it may be described, in ways that can address their difficulties. Further it allows the avoidance of the allocation of resources by public bodies and can prevent access to types of assistance for sufferers. There appears unfortunately to be occasional hostility to those who raise the issue of PDA from some quarters.

The response to the petition from Enquire underlines what is happening. Please note the second bullet point in particular:-

"Children in Scotland have run two workshops in the past year with 58 attendees in total, 8 of these were parents or carers. Feedback included:

- attending the same course as parents enables delegates to have shared reference points to facilitate joint working
- PDA is not widely acknowledged by professionals which causes needless and unnecessary anxiety not just for children but also their families."

It is recognised that the Scottish Government will not wish to promote wider awareness of PDA syndrome if it does not believe that the syndrome exists. The other actions requested in the petition will also clearly not be undertaken by a sceptical government.

However the Committee will wish to note that the Scottish Government's response contains a fundamental contradiction. The Scottish Government says that PDA or at least its "symptoms" do actually occur as part of the autistic spectrum. Please note the pejorative use of speech marks around the word "symptoms". The muddle is expressed in the last two sentences in this extract from the Scottish Government's response.

"The Scottish Government's commitment to autistic people is and will continue to be framed within clinical guidelines and the international standards cited above. The "symptoms" of PDA are described in ASD. The behaviours described as PDA are all compatible with the ASD diagnosis and we do not recommend further diagnostic assessment. A PDA diagnosis would not be competent diagnostic practice, as it would have no official recognition."

This seems to suggest whilst the "symptoms" do indeed exist, they cannot be called PDA. However if the "symptoms" exist in ASD why then not say that the diagnosis is ASD but the range in the spectrum or sub set is PDA? It would even be better than at present if the rubric ran that the diagnosis is ASD but the part of the spectrum involved is what is sometimes called PDA.

Indeed this is just about what is said in the addendum to the Scottish Government's submission being NHS Lothian and the City of Edinburgh drafted guidance for professionals.

"What if I think PDA describes different behaviours that staff or parents notice in a child?"

Although it is not a recognised or advised diagnostic term, Health and Education staff with knowledge of ASD, are very happy to discuss PDA advice and strategies in relation to child. Parents or professionals with queries can contact their local team. The behaviours described as PDA are all compatible with the ASD diagnosis and we do not recommend further diagnostic assessment – our focus will be on individualised assessment and planning."

Would that this practical approach be the common experience of parents. The headline denial of the existence of PDA is colouring the responses which many encounter. The frustration is that in reality PDA is actually recognised even if only as a colloquialism to describe a part of ASD.

Reference is again made to the first hand experiences of parents in particular as described in Enquire's response to the Committee.

"Parents cited problems with the identification of their child's needs and in particular the identification of PDA. Differences of opinion were referred to between the professionals involved with some parents stating that the school

did not accept a diagnosis of PDA, the CAHMS team not accepting it or the Educational Psychologist not accepting it.”

This is part of what we said in the submission accompanying the text of the petition:

“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.”

The Scottish Government should understand that new national Guidance would help to remove confusion. What appears to be happening is that when PDA is mentioned the response of some professionals is to deny its existence and thereby also to deny the identity or space on the autistic spectrum. If we could all move on from the issue of terminology we could then at least consider what type of responses or therapies “ASD-PDA” requires. The concern is that ways of handling or responding to some parts of the autistic spectrum and the application of certain therapies from these parts can actually be counter-productive for “ASD-PDA” sufferers.

A flavour of the difficulties can be found in the following extract from the NHS Lothian and the City of Edinburgh addendum to the Scottish Government's response.

“Are there any risks to avoiding placing demands?”

With PDA, there is a recommendation to avoid placing demands on a child or young person. This is a debatable recommendation and this could present risks for the following reasons. Whilst it is very important to support children with ASD through adaptations to reduce anxiety, it might be problematic to avoid demands altogether. In avoiding demands there is a risk that children and young people learn to ‘opt out’ to avoid situations that make them anxious. This can lead to increased anxiety and regression because there is limited opportunity to build resilience. We know that avoiding sensory stresses can lead to an increase in sensory sensitivity. For example, regularly wearing headphones to avoid sound sensitivity can lead to an increased sensitivity to sound. It is important to gradually provide supported opportunities to experience “demand” or “challenge”.

The purpose of the petition was to explore exactly these areas.

- How can professionals be helped to navigate in these difficult waters?
- How and when should “ASD-PDA” children and young people be introduced to demands?
- Are there methods of determining the depth of “ASD-PDA” in individuals? If not could they be developed?
- Once assessed are there interventions and therapies to alleviate “ASD-PDA” and how and when should they be applied?

The concept that underpins public policy for children and young people is to act in their best interests whether this be for example in education or fostering or adoption, the Children's Panels or other arenas. It is also the culture of the courts in Scotland.

There is pretty much a complete acceptance of the public policy GIRFEC – Getting It Right For Every Child. Current attitudes and responses to ASD-PDA often appear to contradict GIRFEC and breach the Additional Support for Learning (Scotland) Act 2004.

The current deficiencies in advice to practitioners as regards terminology as set out above are leading to contradictions and contraventions of public policy. It is also obstructing the development of methods or therapies that can be applied coherently in the field.

Meanwhile people suffer, as shown in this extract of an email to Mrs Hewitt from the mother of children with PDA:

“I am a mum with two teenage daughters wrongly diagnosed. Both present with blatant PDA but it's not recognised here. Night after night they verbally and physically abuse me. Because the school and CAMHS won't recognise PDA, the correct strategies are not being used. They have destroyed so many precious things in rages. Medication makes them worse. The bruises and horrible things they say, blatant lies. I am terrified of my children. I can't find anyone to help or who understands. I can't tell anyone or they will take my children into care. I will be accused of abuse. They totally control their lives and mine. I rarely leave the house. I get no support, no respite. I fight a system that totally has failed my children and my family. The Children's Panel are involved, the Social Worker ridicules me. The option is I leave my children and they will be taken into care. I have prayed and prayed but no help comes. I just want all this to end.”

Accordingly would it have been too much to hope that some thought might have been given to revisiting these issues in conjunction with other organisations, bodies and professionals given the concerns of sufferers and parents? Will the Scottish Government not at the least investigate parents' concerns and perhaps even convene a discussion forum rather than leaving such initiatives to Children in Scotland and others? Could it not research other European countries' responses in this area?

Would it not be consonant with best practice to take an active interest in this complicated area and to recognise that the practical experiences set out by respondents to and supporters of the petition deserve fuller and better attention?

We live in hope.