

## **PE1625/R**

Petitioners' submission of 10 September 2017

1.1 We the petitioners would like to comment on the latest submissions to the Committee.

1.2 We are of course deeply disappointed by the further response of the Scottish Government to the Committee dated 21<sup>st</sup> July. There appears to be no recognition of the difficulties faced by children with the PDA Profile of the Autism Spectrum, no willingness to address new developments, no desire to take a lead but only an unimaginative resolution to wait until others break new ground and then follow their lead.

1.3 This will in consequence mean that the current varied handling of PDA by professionals across Scotland will continue. Those who are aware of the condition will respond to people presenting the symptoms whilst others will remain unaware of their existence or worse reject them and promote therapies which are of little or no use or even entirely counter productive.

1.4 It would have been helpful even if the Scottish Government whilst maintaining its position which it says rests on international experience, had at least recognised that some well qualified professionals claim to have identified Pathological Demand Avoidance syndrome and its symptoms. (See 2.5 below)

1.5 We maintain our belief that any objective and impartial reader of the evidence would agree that PDA is an ASD. We still maintain that there is a need for Guidance from the Scottish Government to promote awareness and enhance training and to provide support to families affected.

1.6 We also wish to emphasise as we say in 1.3 that in our view there are responses to those presenting the types of behaviour which actually are counter productive and make matters worse. Accordingly one of our motivations is, and has always been, to ensure that this type of situation can be much reduced for the benefit of all concerned. The Scottish Government would also appear to be in breach of the GIRFEC and SHANARRI principles if it allows a situation where the wrong therapies are applied.

## Responses

2.1 The responses from Health Boards and Health and Social Care Partnerships have a common theme which is that as there is no present recognition of PDA nationally and that therefore, there is no intention to act differently locally. The paragraph below from the Argyll and Bute response is very much to the point

*“There is significantly more work to be done to establish whether PDA does in fact have clinical validity and utility. On the one hand there are those who would like PDA to be regarded as a separate diagnostic entity amongst the pervasive developmental disorders. Others point out*

*that amongst children with an ASD diagnosis there will often be co-morbidities with other conditions such as anxiety, ODD, or attachment issues, all of which may be associated with a tendency to avoid demands. In this way of thinking it is not necessary to give it a separate label but just to describe the particular additional difficulties that go alongside the ASD diagnosis.”*

2.2 Our hope was that the Scottish Government would initiate that research and publish the conclusions for peer review and debate.

2.3 We commend the approach taken in Shetland which seems sensitive and understanding. The following from the response from Aberdeenshire says a lot about the position regarding PDA in many parts of Scotland:-

*“This is not a condition that we are aware of, we feel there is currently no training around this and it is not a work-stream the IJB currently works on. We welcome them highlighting the issue. Further guidance would be required.”*

2.4 We would wish to point out the following comment which we received by e-mail from the PDA Society:-

*“There are currently hundreds of children and young people in England and Wales that have already been diagnosed with the PDA Profile of ASD. Qualified and experienced paediatricians, psychiatrists and psychologists within England and Wales can not be incorrectly diagnosing hundreds of children. One Consultant Psychologist in England who Specialises in all Autism Spectrum Disorders and conducts Multi-Disciplinary Assessments, has diagnosed 57 under 18's within the last 3 years!”*

2.5 As PDA was only identified in the 1980s in England by psychologist Professor Elizabeth Newson and most of the research has been accomplished in England (with some professionals in other countries having been trained by English professionals), it is not surprising that England has the most expertise in the world. There are professionals in many countries including Australia, America, Denmark and New Zealand who are diagnosing individuals with the PDA Profile of ASD.

### Proposals

3.1 We suggest that the Committee may wish to consider the following steps:-

- to point out again to the Scottish Government the variety of responses to the symptoms described as PDA which children, young people and their parents receive across Scotland
- to propose that the Scottish Government forms a ‘Review Group’ made up of professionals with knowledge and interest in Autism Spectrum Disorders from health, education and social care, who will meet regularly to discuss the ‘PDA Profile of ASD’ and other profiles

such as Asperger's, in order to review research, publicise results and new understanding and to liaise with other diagnosticians within the UK.

3.2 Assuming that there is at least general agreement that there is a PDA Profile of ASD perhaps the Committee might call on the Scottish Government to:-

- design new or amend existing training for diagnostic professionals to recognise all the ASD Profiles including Asperger's, PDA and Autism
- encourage local authorities to provide training to those in education and social care in the PDA Profile of ASD, so that they can provide educational support for the best strategies for those children and young people who present with the PDA Profile
- design and provide workshops and courses for parents on the PDA Profile of ASD, so that they can be helped to parent these complex and challenging children.

3.3 We re-iterate our thanks for the sympathy, courtesy, and assistance of Committee members in dealing with our petition and hearing our concerns. The petition and the publicity surrounding it and the work of the Committee have helped to highlight Pathological Demand Avoidance syndrome.

3.4 Finally, perhaps the Committee would be so good as to publish a report with the evidence collected in appendices to inform further debate and research to help improve the lives of the vulnerable young people and their parents who are struggling to cope with this condition.