Enquire Letter of 15 February 2017

This response is based on enquiries from parents to the Enquire helpline in 2016 and some feedback to a training course delivered in 2016 by Children in Scotland on Pathological Demand Avoidance Syndrome.

We assure people contacting Enquire that calls to the Enquire service are confidential to the team unless a child is considered to be at risk and therefore it is not possible to make some details of the enquiries known if it is felt this will identify the family involved.

In 2016 12 enquiries to the Enquire helpline concern either children and young people with PDA or children and young people considered to have PDA. The children involved in the enquiries ranged from 5 to 15 years old with the majority of enquiries involving boys. In 11 out of the 12 enquiries school placement was a significant issue with children either not attending school or struggling to attend school. 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. A few parents said that the school their child attends did not appreciate the complexity of their child’s needs, as their behaviour at home was markedly different to behaviour in school.

Parents reported severe anxiety being an issue for their children and concerns and worries about the next school placement (the high school placement) or what would happen post school. Parents described their child’s distressed behaviour at home that was at times violent and difficult for the family to manage. Parents described the difficulties the family and the school have in terms of coming up with successful strategies to support children and young people with PDA.

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.

As reported to the Enquire helpline, delegates commented on needing knowledge and strategies to support children with PDA and said they would take back approaches to discuss and share with colleagues and senior management.

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1 There were 1,453 enquiries in total in 2016
On this basis we support the call to promote a wider awareness and acceptance of Pathological Demand Avoidance syndrome among all practitioners, and 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.

One of Children in Scotland’s aims is to ensure the voice of the child and young person is always sought and heard. It is our view that the term Pathological Demand Avoidance Syndrome is a term that urgently needs to be reviewed, as it sounds very negative and stigmatising for the children and young people concerned.