



Call to Action Autism Boards, Local Authorities & Clinical Commissioning Groups

Recent new work on the Pathological Demand Avoidance (PDA) profile of ASD has been published* and in the light of this the PDA Society are calling on Authorities with responsibility for providing services to those with Autism to issue a '**position statement**' on the topic for service providers and professionals in their area.

This is a complex and uncommon presentation of Autism, and many professionals are unfamiliar with the specific needs and the way in which management strategies should be adapted for this group. The difference in management strategies makes it essential that a clear signpost to the specific impairments and needs is provided in both health and education services.

A [recent survey](#) by the PDA Society found that outcomes were generally extremely poor with hundreds of children unable to attend schools because their needs were not being accommodated. In addition, mental health services were often unable to provide support.

It appears that some professionals feel that they don't have authority to acknowledge the demand avoidance trait or the constellation of impairments that can accompany it because the exact nature of the condition and its relationship to other conditions is debated. The debate should not influence practice but it currently does in some places, and this is in contradiction to the NICE Guidelines for autism in children and adolescents which lists demand avoidance as a possible sign or symptom of Autism and expects all impairments to be assessed so that needs can be met and outcomes focussed upon.

Following a Westminster petition, Ministers at the Department of Health and Social Care have reviewed current evidence and [written to campaigners](#) to say they support this call to action and will be working with their partners to see change.

Authorities such as Sheffield City Council and Surrey County Council have already published position statements. Surrey reports that outcomes are improved as a result.

Next steps:

We would like to support you to do the following:

1. Acknowledge that confusion can lead to poor outcomes;
2. Find out more about the issues from those who have experience of working with those with a PDA profile of ASD;
3. Set out a process for producing a 'position statement';
4. Publish the statement;
5. Identify and fill any staff development needs.

**The most recent publications expand on the issues:*

- 1) A [report by the PDA Society](#) of the experiences of close to 1,500 people showed that there were significant difficulties in services across the country caused by traits not being assessed and supported. This was leading to extremely poor outcomes. The use of descriptive terminology such as 'PDA profile' was being widely used in preference to alternatives and found to be a helpful signpost to strategies.
- 2) A '[Viewpoint](#)' paper published in the Lancet in March by leading Autism academics makes it clear that this constellation of traits should be assessed under the existing NICE Guidelines.