

Understanding and recognising Pathological Demand Avoidance

SNAP PCF, the parent carer forum in Central Bedfordshire, were concerned about increasing numbers of parents reporting that they were struggling to get recognition and support for their children who have [Pathological Demand Avoidance \(PDA\)](#).

PDA is widely acknowledged as a pattern of behaviour where children go to extremes to ignore or avoid anything they perceive as a demand and is most often experienced by autistic people. However, many aspects of PDA, including its clinical definition and how it is identified, are currently contested by health care professionals who have different views about identifying and how to manage PDA. As a result, parents told the forum they were having issues getting the local authority, education and health services to recognise PDA as a diagnosis and included in Education, Health and Care Plans so their child had the right support put in place. Families were having to fight for PDA recognition and were rarely successful.

The forum felt that having a publicly available PDA position statement from the local authority would mean parent carers would be able signpost health and other practitioners to it and consistent and clear information about PDA. They approached the PDA society and the local authority to see what could be done and worked with professionals across the health and education sector to coproduce a position statement to provide reassurance to families and recognise the need for extra support to children and families affected by PDA.

[The PDA position statement](#) is now available for all families and professionals to look at and is available on the local authority's local offer webpage.

"I used the position statement to include PDA in my child's diagnosis so that strategies to support could be included in his EHCP." Parent Carer

As a result of the forum's work and development of the PDA position statement, clinicians within CAMHS (Child and Adolescent Mental Health Services) are able to work with parents, carers and other professionals to try and understand the individual child's needs and tailor a package of care and personalised support. PDA training is now mandatory for any professional in a SEND role. Bespoke e-learning training was co-produced with parent carers whose children had PDA and SNAP PCF are championing the training to schools and health services.

Having the PDA position statement and training in place has also increased the skills, knowledge and confidence of parent carers that took part in the work to sit on further strategic working groups as well as helping to raise the profile of SNAP PCF.

SNAP PCF continue to support and challenge the Local Authority's education, health, and social care to promote and recognise the position statement to ensure it becomes embedded.

Kirsty Green, Director of SNAP winning Championing SEND Award at BAPS (SEND Blogs Awards) 2021.

