

PE1732/E

Anonymous submission of 20 August 2019

I have attached a link to a piece of writing that I was encouraged to write for the "Autism Ideas Midlothian" (part of The Two Trumpets/Midlothian Autism Strategy) website, after getting in touch with a person from the strategy public involvement team dealing with liaison with families regarding input with the strategy. My piece was posted on the website earlier this year:

<https://autismideasinmidlothian.com/2019/04/02/our-asd-journey-in-midlothian-a-parents-experience-and-thoughts-on-pda/>

Petition question 1 and 2: Have you noticed a lack of awareness and education amongst health and education care and learning teams? What positive results do you think could be delivered by the development of a PDA toolkit ?

I have noticed a lack of awareness and education about "PDA" type ASD presentation and useful strategies amongst many of my colleagues (the vast majority, I would say). As a result, many affected individuals with demand avoidant traits and their families are left without appropriate support. Whilst the jury is still out on diagnosing the profile clinically, families should not be denied vital help and development of a toolkit would go some way towards helping both families and health, social care and education professionals to familiarise themselves and use or recommend appropriate strategies.

To back up the and looking at the wider Scottish picture, the petitions committee might find it interesting to read the results from a survey that was conducted in 2018" (Being Misunderstood Scotland Report: Experiences of the Pathological Demand Avoidance Profile of ASD" that was carried out by the PDA society : [file:///C:/Users/mcres/AppData/Local/Packages/Microsoft.MicrosoftEdge_8wekyb3d8bbwe/TempState/Downloads/Being%20Misunderstood%20-%20Scotland%20\(1\).pdf](file:///C:/Users/mcres/AppData/Local/Packages/Microsoft.MicrosoftEdge_8wekyb3d8bbwe/TempState/Downloads/Being%20Misunderstood%20-%20Scotland%20(1).pdf)

To further argue for the usefulness and need of a PDA toolkit, I would like to make reference to the current Scottish Inclusion agenda for individuals with ASD and the recently set up "Improving understanding of autism in Scotland fund" - a new initiative that is supported jointly by Inspiring Scotland and the Scottish Government. In the absence of a PDA toolkit being developed or training for health, Social Care and Education professionals being prioritised, the inclusion policy would only be paying lip service to being fully inclusive of *all individuals on the autistic spectrum*—this needs to include addressing the needs of individuals with PDA-ASD (regardless of diagnostic status) too! so that these individuals can have meaningful roles and valuable lives within Scottish society.

Contrasting the Scottish and English situations (this might have some relevance to the petition):

In England, the DHSC has over the past year taken significant steps in addressing the needs of the PDA-ASD population, however, by contrast, the Scottish picture currently looks bleak. As a health professional, I strongly feel that this is an area where Scotland could and should lead by example.

As the petitions committee will know, across the NHS, clinicians like myself will diagnose in line with guidance such as the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the American Psychiatric Association's classification and diagnostic tool, or the International Statistical Classification of Diseases and Related Health Problems (ICD-10), a medical classification list by the World Health Organization.

There is a discrepancy with clinicians who are working in England who are guided by the NICE guidelines on ASD and clinicians who are working in Scotland who are guided by SIGN 145 Assessment, diagnosis and interventions for autism spectrum disorders:

The English government has worked closely with PDA Action over the past year. This has resulted in a ministerial statement that says that individuals with features of behaviour that are seen in the autism spectrum but do not reach the ICD-10 or DSM-5 diagnostic criteria for definitive diagnosis, should be assessed using NICE's clinical guideline, "Autism spectrum disorder in under 19s: recognition, referral and diagnosis." This guideline sets out the recommended procedure for the diagnosis of complex autism and the appendix to the guideline describes a range of signs and symptoms of autism which includes demand avoidant behaviour. This guideline also states that as part of every autism diagnostic assessment a profile of the child's or young person's strengths, skills, impairments and needs should be developed so that it can be used to create a needs-based management plan, taking into account the family and educational context. (this has relevance for Scottish PDA toolkit resource)

The situation in Scotland is that clinicians like myself are restricted to using SIGN 145. There is currently no description of demand avoidant traits in SIGN 145 on Autism. They need to be urgently updated, so that diagnosticians in Scotland can diagnose more complex ASD conditions, or give descriptions thereof, too. Hopefully this will change in the near future as more peer reviewed research has come to light and it would be crucial to have representatives from PDA action to sit on future review panel.

Petition Question 3: Who should be involved in the development of the toolkit and training ?

The DHSC in England recently launched a review of the English autism strategy (to cover children as well as adults). It has consulted with families, services and professionals and the results are expected to be published in the autumn 2019. One area the review is looking at is focussing on is follows:

- "Improving our understanding of autism and all its profiles, including recently identified forms such as Pathological demand avoidance".

May I suggest that the Scottish Government folios suit - with regards to outcomes from Petition PE0132, they should involve representatives from **PDA action** with the development of the toolkit and appropriate training.