

PE1732/A

Petitioner submission of 11 August 2019

My family has been failed by numerous professionals over the years including CAMHS, Education and those within the NHS. The list is extensive of blatant red flag issues that were missed over the years. The lack of understanding of the autism spectrum is shocking in the Scottish Borders. It was only seeing newspaper articles from parents highlighting their horror stories in the Borders and Highlands that gave me my "lightbulb", PDA moment. Family members were first diagnosed with Aspergers at seventeen and eighteen years of age. So much for early intervention. The Scottish Autism Strategy is not worth the paper it's written on. The refreshed version is also in the dark ages and not fit for purpose. The GTCS (General Teaching Council for Scotland) dismissed both my complaints. What's the point of having education laws if no one will take responsibility and uphold them? So much for GIRFEC.

As for PDA, it's like mentioning Voldemort in a Harry Potter book. Shock and horror. It's an absolute explicit word among many professionals. I was refused an out-of-area referral citing PDA was a controversial subject and there was no evidence. A family member recently agreed to a Private Diagnostic Assessment at one of the two recommended independent assessment centres now in Scotland. We now have an ASD-PDA diagnosis, with evidence since infancy; scored high on the EDAQ. As far as we are aware no one has achieved an out of area referral from the Borders. We are unable to access MH support locally as PDA is not recognised or diagnosed. We are aware of one young person who was given a diagnosis in the Borders, the clinician was reprimanded for doing so. Another family member hasn't agreed as yet but we do have PDA noted on their medical records.

Our case includes one family member being handcuffed by Police on a number of occasions; illegal restraint and seclusions within education; failure to refer; no CSP, and no transitions; the list is extensive. The infamous parenting classes offered. As soon as I suggested sitting around a table and discussing what we had all missed, ranks closed including major safeguarding issues that were swept under the table.

As for the ongoing conversation, it's been like a sponsored silence!! As far as I can tell nothing whatsoever has changed since our last Petition.

Who I suggest is involved is Jeremy Balfour MSP who is on both the Disability and Autism Committees at Holyrood. Cllr Euan Robson who has followed numerous cases through in the Borders, he has previous experience as an Education Minister. Monica Lennon MSP has had vast experience with MH Services. The Children's Care Commissioner is ESSENTIAL. LEADScotland, Yvonne Newbold and Beth Morrison have vast experience with managing challenging behaviour. These children are not naughty but facing numerous challenges fitting into a one system that fits all. Their anxiety levels are off the scale and specific strategies must be used. We need alternative education settings. As far as I am concerned children's Human Rights don't exist in Scotland. I am absolutely past the point of no return listening to the same old story of the Children's Reporter being dragged in; children removed due to ignorance and arrogance.

Areas where all support networks work well together, for example, D&G, Highlands and Hamilton where Michelle Graham has extensive experience. Residential Schools who have years of experience teaching PDA children and the Home Education Networks should be included. Instead of those in ivory towers we need those dealing first hand with PDA'ers. Both of the Independent Assessment Centres should be included. Education experts dealing with PDA. Most importantly at the forefront should be PDA'ers themselves and their families. SW advocates like Maggie Mellon and Duncan Macgillivray who himself is Petitioning Parliament. Laura Kerbey from PAST who has facilitated 14 PDA training sessions so far and is about to start more in Scotland from the Highlands to the Borders. The evidence is there, what we are lacking is neurological evidence; this needs addressing and most importantly, PDA MUST be included within the SIGN framework.

If Ministers instead of having numerous petitions in front of them, have yet more consultations to go round the inevitable hamster wheel, getting us nowhere. It's just delaying the inevitable. You can't ignore what's happening, PDA is real and it does exist. For once, listen and follow through this Petition. You threw the chance away last time, England's ahead just.

A PDA toolkit should be used for the rest of the world following Scotland's lead. We need long-term planning. For too many of us it's too late, family members have been left in crisis and beyond. Please, please listen this time around and follow our petition through.

A PDA toolkit would be a huge benefit to both families and professionals alike. It's desperately required worldwide, not just in Scotland, and gives all concerned the right type of support promptly and effectively. Just read the submissions from so many families left abandoned and without hope. The PDA toolkit would give a pathway forward.