

PE1837/I

Patricia Hewitt submission of 10 January 2021

I have experience of caring for people in their early twenties on the autistic spectrum who have been failed by numerous professionals including CAMHS, educational psychologists, education and the NHS.

The lack of understanding of the autism spectrum in Scotland and beyond is jaw dropping. My experience of a first significant diagnosis of Asperger's was at seventeen and eighteen years of age so much for early intervention yet numerous "red flag" pointers were missed over years. They have been denied a childhood and an education suitable for their needs . They have been left with mental health issues that were totally preventable, humiliated, degraded including one being handcuffed by the police, and discriminated against over the years due to lack of recognition.

They fit the profile of pathological demand avoidance. I was refused an out of area referral and I have had to pay thousands of pounds for a number of private assessments. We can't access the type of support required because PDA is not recognised in the Scottish Borders which surely breaches human rights . One of them was expected to attend a first class University. Tragically they will spend their life on benefits due to the lack of early intervention and recognition of PDA. Not one person will accept any responsibility. Being fobbed off to Enquire and Govan Law Centre after the event isn't an acceptable response from Cabinet Ministers.

The other person was written off as "lazy and winging it " and never referred which happens to be a legal requirement. Due to an inspirational tutor and ongoing support from Lead Scotland against all the odds they have zig zagged through college and completed a degree . I have had to fight for years for support. Without the in depth knowledge from Lead Scotland one of them would have dropped out at the first hurdle. We have never had one transition yet! They have had illegal 5 month exclusions and numerous education laws breached over the years with no accountability whatsoever. GIRFEC is a joke.

We need alternative education settings as many can't cope with mainstreaming which leads to school refusal and a downward spiral of issues many lasting a lifetime. Although one has a PTSD diagnosis we all fit the diagnostic criteria after years of battling the system. If it wasn't for my GP believing it wasn't me at fault I believe one would be in prison and one in a homeless unit.

I have petitioned Scottish Ministers twice with the support of the Lib Dem's and the PDA Society to spread the awareness of the PDA Profile. I hear on a daily basis families in total crisis and beyond desperation who are passed from pillar to post. I am now a member of the Disability, Dyslexia and Autism Cross Party Groups. The first Scottish PDA case was recognised in 1998 and from my research first discussed in a public petition in 2006. NAS in recent years has recognised PDA. Even with a diagnosis getting appropriate support is really challenging. Can anyone enlighten me why something wasn't done years ago and this was left to

parents to campaign? It was press articles that led me to PDA and my “lightbulb moment“.

We have education laws not worth the paper they are written on and a Autism Strategy to match. Neither are fit for purpose. “Refreshed“ isn’t good enough it’s shameful .

I would take Mr Leighton’s submission further by suggesting autism spectrum assessments are removed from CAMHS and adult mental health, it is not a mental health issue, and specific ASD Multi-Disciplinary Teams set up to assess and diagnosis ASD including the PDA Profile with ongoing support from childhood right through to adulthood. I am quite aware how challenging it is to get an accurate diagnosis as a child and as an adult yet this is essential for the correct support. These teams could also be utilised for in-house training of other Professionals and families.

Mental health services were at crisis point before the pandemic and will be for many years to come. Through FOI requests for my last petition we found out there are no statistics for PDA therefore no long term planning. That would be a starting point plus a specific working party to follow through.

I believe the only effective system that works in Scotland is the system to cover up the truth. I found that out the hard way after I dared to complain. We don’t want political spin and broken promises we need a cost effective efficient support system that will benefit ALL not just a few.

The Scottish Government is in total denial and needs to wake up. You just need to look at the Public Petitions website how many petitions are relevant to the autism spectrum. As far as I am concerned the autistic community have been sold down the river for years and it’s about time there was accountability with the added proposal of an Autism Care Commissioner. The only answer the Scottish Government has is consultation after consultation and nothing ever changes. We don’t need any more consultations it’s a delaying strategy on their behalf we need a completely new approach that works not tinkering at the edges.

I include a link to a support statement released by South Lanarkshire Council which I feel is a real step forward that other local authorities certainly need to take onboard:

https://www.southlanarkshire.gov.uk/downloads/file/14113/extreme_demand_avoidance