

PE1732/G

Rhoda Grant MSP submission of 19 February 2020

I apologise that I cannot attend the Committee to speak directly in support of this petition, but appreciate you accepting this letter in my absence.

Two years ago, I met a group of parents who explained that their children had PDA and recounted their experiences of the lack of educational and social support.

That opened my eyes to the reality of families coping with PDA.

The core issue was the lack of diagnosis and lack of support as the condition was not recognised in diagnostic manuals, which the parents argued this led to serious problems with the way their children were treated.

The parents were supported by Friends of Autism Highland.

It was stressed that while people with autism benefit from order and routine, those with PDA benefit from suggestion and control of their own situations. Also, there was a need for flexibility and choice as, when too many demands were placed on a child with PDA, they had the overwhelming need to control their environment.

It was a distressing to hear the mothers' experiences, including children being placed in handcuffs by the police and to hear of other violent situations.

Parents complained that there was no consistency when the children went to school and families found that children's stress was coming out at home.

All the parents highlighted that children had missed school due to the condition and that their own characters as mothers had been put in question.

It was stated that every child should have their 'needs met' but this was not happening in Highland and some children were being excluded and isolated.

I support the need for the Scottish Government, Highland Council and NHS Highland to have this condition on diagnostic manuals alongside ASD and also the recognition that PDA needs different methods to manage the condition than those needed for autism.

A PDA toolkit is greatly needed so that a child or young person, either with or with suspected PDA, are supported within any setting to help them reach their potential and therefore lessen the detrimental damage that using the wrong strategies have on their wellbeing and also that of family members or carers.

I am supporting the parents who have contacted me – that there is a need for a Toolkit and strategies.