

PE1732/B

Scottish Government submission of 23 October 2019

The Scottish Government is committed to ensuring that, in Scotland, autistic people have healthy lives, choice and control in relation to services, can live independently and are able to participate in all aspects of community and society. In 2017, a National Dialogue was held to develop priorities for the final phase of the 10 year Scottish Strategy for Autism (2011-21).

An analysis of the engagement was published and a list of priorities was developed. Autistic people were involved in the development of both the original strategy and the final phase, including the online engagement process.

Priorities going forward include improving public awareness of autism and improving diagnostic pathways and providing post-diagnostic support. Priorities also include the continuation of raising awareness of autism among professionals and public services, and supporting autistic people in employment and in transitions.

You state that PDA is associated with autism but requires an entirely different strategy and toolkit, which is not being implemented or recognised by most as being separate from autism. However, the group we have consulted do not agree that PDA requires an entirely different strategy but rather that each person requires an individualised approach to understanding their needs and relevant support strategies.

Within the NHS in Scotland, practitioners are guided by the Scottish Intercollegiate Guidelines Network (SIGN) to ensure practice is safe and evidence based. Based on SIGN guidance, diagnosis of neurodevelopmental or mental health conditions is made following adherence to international diagnostic criteria (DSM 5 or ICD 10). Neither of these diagnostic manuals refer to PDA.

Recent diagnostic criteria now include a much broader group of people fitting the diagnosis of ASD. Historically, the 'PDA' profile described in the 1980s referred to a group not explicitly included in previous diagnostic manuals. The new criteria have moved away from subgroups (e.g. Asperger's syndrome, PDDNOS, Semantic Pragmatic Disorder) towards a conceptualisation of autism which takes account of the profile some describe as PDA, without the need for other diagnoses.

Essentially all 'PDA' characteristics are explained by ASD in the context of an individual whose need for predictability has not been met/ is not met. Establishing full understanding of the social impairment, sensory differences and inflexible thinking that lead to extreme anxiety in autism would be a better way forward. Importantly, professionals would always wish to offer families an opportunity to discuss what has led them to feel that PDA is an appropriate way to describe their child's presentation and should seek to support an individualised approach to supporting them that takes account of their individual circumstances.

The only published research with groups of children (O'Nions et al 2013) studied 25 children thought to have PDA and all of them had comparable levels of 'autistic traits and peer problems' – i.e. they were all autistic. This small group did have more

'behavioural problems' than the ASD only group – which suggests professionals are using this to describe autism where there are such problems.

We believe that 'behaviour' arises from anxiety, as a result of the interaction between the child and the environment and that what is being described is autism where the environment or expectations of the child have not been/ are not currently predictable enough or adapted enough. Our interpretation of this is that there is therefore no need for a separate diagnosis of PDA.

Education Scotland, NHS Education for Scotland, the Scottish Government and partners are undertaking a range of work to address the implementation of good practice to support better experiences for children with neurodevelopmental disorders and additional support needs and their families.

In regards to a toolkit for professionals to assist in diagnosing and designing therapeutic support for children, young people and adults who have PDA, it would not seem sensible to make a toolkit for something that is ill-defined and unsupported by evidence.

Experts consulted do not recommend the development of a Scottish PDA Toolkit at present. It is suggested that instead a toolkit on reducing anxiety in autism might be more appropriate.

We recommend that service providers pursue appropriate individualised, needs based staged intervention (as per GIRFEC, ASL legislation and policy) and make accessible specialist advice and support for complex situations where young people are not attending school and engaged in the avoidance of social or daily routines.

If it was deemed appropriate to take this idea forward, the Scottish Autism Strategy Team could develop a costed proposal which could address the needs raised, whilst taking account of current and ongoing work still being embedded.