

PE1625/L

Scottish Government submission of 21 July 2017

Calling on the Scottish Parliament to urge the Scottish Government to promote a wider awareness and acceptance of Pathological Demand Avoidance syndrome among health, education and social care and social work practitioners, and, via the appropriate agencies and bodies, to institute and facilitate training in the diagnosis of the condition, to promote the development of therapeutic programmes for those with the syndrome and to provide support for their families and carers.

Thank you for your letter of 3 July to the Scottish Government in relation to the above Petition. The Committee further asked the Scottish Government whether it will look at policies elsewhere or identify any research on what happens in other parts of the world in relation to Pathological Demand Avoidance syndrome, and whether it plans to explore how consistency in diagnosis and support from local authorities can be delivered.

The Scottish Government has no plans to explore research or practice in other parts of the world in relation to PDA. As stated in our previous response, we are already committed to international standards of best practice and the usage of the two major classification systems currently in use: the International Classification of Diseases, version 10 (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5). These remain the 'gold standard' for autism diagnosis and neither recognises PDA as a distinct category for diagnosis.

Our national guidance on assessment, diagnosis and interventions for autism spectrum disorders, SIGN 145 states that all professions involved in diagnosing ASD should considering using one of the above-mentioned international standards. Furthermore, the recommends that specialist assessments of ASD should involve a history-taking element, a clinical observation/assessment element, and the obtaining of wider contextual and functional information.

Like those standards, SIGN 145 does not recognise PDA as a distinct category for diagnosis. SIGN 145 was published in 2016 and updated the previous guidance, SIGN 98, to reflect the most recent evidence covering children and young people and to provide recommendations for best practice in the screening, surveillance, diagnosis, assessment and clinical interventions for children and young people with ASD. It also incorporates evidence and recommendations on assessment, diagnosis and interventions for adults with ASD.

SIGN guidelines are developed and updated using a rigorous process involving multidisciplinary working groups with representation from across Scotland and a systematic review and critical appraisal of the current scientific literature which includes international publications. A detailed description of SIGN's methodology is given in *SIGN 50: A guideline developer's handbook*, which can be accessed here http://www.sign.ac.uk/assets/sign50_2015.pdf.

This handbook is updated regularly to take account of any changes in methodology. This means, in turn, that the evidence base for the guideline is identified, selected,

and evaluated according to a defined methodology. In this way, potential sources of bias in the guidelines are minimised and the likely validity of the recommendations is maximised. Guideline recommendations are explicitly linked to the supporting evidence. This provides groups of practitioners working in NHS Scotland with information to help select and prioritise recommendations for local implementation, depending on local needs, priorities, and resources.

The Committee also asked the Scottish Government has any plans to explore how consistency in diagnosis and support from local authorities can be delivered. As we said in our earlier response, we are committed to improving the lives of autistic people through our *Scottish Strategy for Autism*. This includes access to timely diagnosis and person-centred interventions.

The Scottish Government is committed to ensuring diagnostic and post-diagnostic support is consistent throughout the country. As we informed the committee in our previous reply, we have been working with NHS Education Scotland (NES) to rollout our Autism Training Framework across the health and social care workforce and wider. NES has made available other support tools including an ASD online learning space which includes a learning resource in **Differential Diagnosis and Co-morbidity in ASD. The learning space is available at:** <http://www.knowledge.scot.nhs.uk/home/learning-and-cpd/learning-spaces/autism-spectrum-disorder.aspx>

NES have also recently published a document entitled *Key considerations in promoting positive practice for Autism Spectrum Disorders*. This guide serves as a resource for staff working in health and social care. It hopes to serve as a basis from which staff, teams and services can consider their approach to autistic individuals who access their service. The guide is available at: http://www.knowledge.scot.nhs.uk/media/12413447/nesc0565%20autismguide_web.pdf

We are also investing in an Improvement Programme to reduce waiting times for assessment by improving diagnostic services and increasing diagnostic capacity across child and adult services.

In terms of consistency in support from local authorities, as a requirement of our *Scottish Strategy for Autism* each locality has a published Autism Strategy and autism plan. We expect each local area to have multi-agency steering groups responsible for monitoring the implementation of local autism plans.

Further strategy key documents aimed at ensuring consistency of autism services across Scotland are available at: <http://www.autismstrategyscotland.org.uk/strategy/key-documents.html>

While we believe much progress has been made in improving diagnostic services and creating consistent service standards, we are under no illusions that much more work remains to be done.

I hope this information will be of assistance to the Committee in its consideration of the Petition.