Department of Health and Social Care

Statement on Pathological Demand Avoidance

The PDA profile of Autism Spectrum Disorder has been identified relatively recently and we are aware that a professional consensus on its status is still required. The NHS is clinically led, and the Government should not and does not influence individual clinical judgement.

In the NHS, clinicians will diagnose in line with guidance such as the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the American Psychiatric Association's classification and diagnostic tool, or the International Statistical Classification of Diseases and Related Health Problems (ICD-10), a medical classification list by the World Health Organization.

The National Institute for Health and Care Excellence (NICE) is responsible for creating guidelines on identifying, treating and managing illnesses. It publishes a number of guidelines that provide evidence-based recommendations for the diagnosis and management of autism in children, young people and adults, and for the prevention, interventions and service delivery for people with learning disabilities and behaviour that challenges. These can be found at www.nice.org.uk, by searching for 'autism guidance'.

Individuals with features of behaviour that are seen in the autism spectrum but do not reach the ICD-10 or DSM-5 diagnostic criteria for definitive diagnosis, should be assessed using NICE's clinical guideline, "Autism spectrum disorder in under 19s: recognition, referral and diagnosis." This guideline sets out the recommended procedure for the diagnosis of complex autism and the appendix to the guideline describes a range of signs and symptoms of autism which includes demand avoidant behaviour. The guideline also states that as part of every autism diagnostic assessment a profile of the child's or young person's strengths, skills, impairments and needs should be developed so that it can be used to create a needs-based management plan, taking into account the family and educational context.

The autism strategy, *Think Autism*, was published in 2014 and recommends that every clinical commissioning group commission a diagnostic care pathway for autism in its area. People considered to have a PDA profile should also be able to get support from their GP and a referral for a diagnosis if appropriate.

Reforms under the Children and Families Act 2014 ensure that there is a focus on identifying the specific needs of children with special educational needs and disabilities, with the full involvement of their families. Where their needs are

significant, and require support from education, health and social care, children and young people may have an education, health and care plan, which brings together all the support to be provided. When assessing how best to meet these needs, professionals should do so without needing a diagnostic label. The lack of consensus on the status of the PDA profile should not be a reason to fail to identify and consider how best to meet the support needs of an individual. It is essential that health, education and social care providers work together to recognise that as young people's needs vary, there must be effective and responsive support for those needs.

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