

Pathological Demand Avoidance

Request

I am writing to you under the terms of the Freedom of Information act to ask some questions regarding your policy and procedures around Pathological Demand Avoidance (PDA). This condition is sometimes identified simply as “demand avoidance” or as “Autism Spectrum Disorder with demand avoidance”. For the purposes of this request, I am happy for you to consider all three descriptions as the same disorder. I will refer to the condition as PDA for brevity. PDA was first described in the 1990s but does not yet enjoy an entry in the ICD or DSM manuals and is only briefly referred to in NICE guidance.

1 – Does your trust have any specific policy regarding the diagnosis of PDA? If so, please enclose a copy of the relevant policy.

2 – Does your trust have any policy that would discourage or restrict clinicians from diagnosing conditions not described in the ICD, DSM, NICE guidance or other similar documents? If so, please enclose a copy of the relevant policy.

3 – Please identify the team (or teams) that fulfill the role of the “autism team” as described in section 1.1 of the NICE guidance on autism diagnosis in children and young people (CG128). Please give the name of the team and their main postal address. If you have multiple teams that fulfill this role please indicate how the case load is apportioned between the teams (for instance by geographical coverage or age ranges).

4 – Please state the total number of clinical staff in your autism team(s). Please include in this figure all clinicians that are contracted to provide a regular service as well as those directly employed by the trust.

5 – For the staff included in your answer to Q4 above please list any attendances at seminars, conferences and/or training sessions about PDA in the last five years that you have recorded. I do not need you to identify the individuals that attended; just the number of clinical staff that attended each PDA event will be sufficient.

Our Response

- 1 The Trust does not have a specific policy, however, the Trust has a multi-agency agreed pathway on ASD which has recently been updated and is attached.
- 2 The Trust supports clinicians making a reasoned clinical approach to diagnoses as described in the classification and diagnostic systems. The Trust also appreciates that Clinicians may consider diagnoses outside the classificatory system, based on their specialist skills and training (for example DISCO (Diagnostic Interview for Social & Communication Disorders) training provides clinicians with skills required to diagnose conditions included within the Autistic Spectrum Disorders. There would be an expectation that the clinical approach to such diagnoses would be structured and based on the use of appropriate validated tools.
- 3 The Families Young People and Childrens Division works with children and young people with autism across the range from Universal Services through to Specialist Services. Whilst there are specific highly specialist individuals within the division, we describe our autism service rather than

a specific team. We have a Lead Consultant Psychiatrist, Paediatrician, Specialist Nurses, Psychologists, SALT (Speech & Language Therapist) and Occupational Therapists who focus more on this group. Running alongside this is the wider team of therapists, nurses, health visitors, school nurses and medical staff all of whom may work with ASD and associated conditions as a whole integrated pathway approach and with other agencies including the voluntary sector.

- 4 Please see answer to Q3 above.
- 5 We are unable to collate this information as these training courses are so specialist they would be externally run (as opposed to our in-house training), and as such medical staff wishing to attend would need to go through the Study Leave process.