

Your ref:
Our ref:

Swandean
Arundel Road
Worthing
West Sussex
BN13 3EP

25 September 2014

Laura Fisher
Caseworker
Parliamentary & Health Service Ombudsman
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Millbank
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Dear Laura

has complained about the Trust's failure to 'accept' her private diagnoses of Asperger's syndrome in 2013, that took place after her two previous NHS assessments in 2009, and the PHSO considers that this represents a substantively new complaint

The Trust do not believe they are in a position to comment on a private diagnosis of an individual and are mindful to point out that some centres and private operators do not offer comprehensive multi-disciplinary assessments as recommended by NICE and as a consequence run the risk of offering a sub-optimal assessment and inappropriate diagnosis. The Neurobehavioural Clinic works in accordance with NICE guidelines and believe that the time, depth and quality of the clinic assessments are more than is typically available and at a level that could not be easily sourced in the private sector and the recommendations and pathways offered are very much based on symptoms and need rather than nominal diagnosis, with care plans offered within the trust and also signposting to third sector autism support groups for advice with specific relevant issues. The Neurobehavioural clinic reiterates that had two comprehensive multi-disciplinary assessments by a specialist team skilled and trained to provide an excellent standard of care with the aid of formal assessment tools. Following both of these assessments the outcome was the same that she does not fulfil criteria for a diagnosis of ASD.

When was assessed on both occasions she was offered recommendation by the assessing clinicians and was referred to the local mental health services to address presenting anxiety and on both occasions she did not engage with services that were offered.

Since has received her private diagnosis she has not been referred to the neurobehavioural clinic, but if she were the clinic would not offer her another assessment and therefore would not be making care pathway recommendations.

Please see relevant NICE guidelines below:

Chair: John Bacon CB

Chief Executive: Colm Donaghy

Head office: Sussex Partnership NHS Foundation Trust, Swandean, Arundel Road, Worthing, West Sussex, BN13 3EP

www.sussexpartnership.nhs.uk

1.1.14 The specialist autism team should have a key role in the delivery and coordination of:

specialist diagnostic and assessment services specialist care and interventions advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for adults with autism (as not all may be in the care of a specialist team) support in accessing, and maintaining contact with, housing, educational and employment services support to families, partners and carers where appropriate care and interventions for adults with autism living in specialist residential accommodation training, support and consultation for staff who care for adults with autism in residential and community settings.

1.2.5 A comprehensive assessment should:

be undertaken by professionals who are trained and competent be team-based and draw on a range of professions and skills where possible involve a family member, partner, carer or other informant or use documentary evidence (such as school reports) of current and past behaviour and early development.

1.2.7 During a comprehensive assessment, enquire about and assess the following: core autism signs and symptoms (difficulties in social interaction and communication and the presence of stereotypic behaviour, resistance to change or restricted interests) that have been present in childhood and continuing into adulthood early developmental history, where possible behavioural problems functioning at home, in education or in employment past and current physical and mental disorders other neurodevelopmental conditions hyper- and/or hypo-sensory sensitivities and attention to detail.

Carry out direct observation of core autism signs and symptoms especially in social situations.

1.2.8 To aid more complex diagnosis and assessment for adults, consider using a formal assessment tool, such as:

The following tools for people who do not have a learning disability:

The Adult Asperger Assessment (AAA; includes the Autism-Spectrum Quotient [AQ] and the Empathy Quotient [EQ])[6] the Autism Diagnostic Interview – Revised (ADI-R)[7] the Autism Diagnostic Observation Schedule – Generic (ADOS-G)[8] the Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI)[9] the Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R)[10]

1.2.9 To organise and structure the process of a more complex assessment, consider using a formal assessment tool, such as the Diagnostic Interview for Social and Communication Disorders (DISCO)[11], the ADOS-G or the ADI-R.

Yours sincerely

Simon Street
Complaints & PALS Manager