

Private / Independent Neurodevelopmental Assessments

What is neurodiversity?

People experience and interact with the world in different ways and there is no one right way of thinking, learning and behaving. Neurodiversity is a word used to describe the different thinking styles that may affect how people communicate with the world around them.

It reflects normal variations in brain function and behaviour. Neurodiversity can affect someone's behaviour, memory, or ability to learn but this is not always the case. It is an umbrella term - a word that sums up lots of different things. Neurodiversity includes autism, attention deficit hyperactivity disorder (ADHD), dyslexia, dyspraxia, dyscalculia, and Tourette's

If you have questions or concerns about your child or young person's thinking, learning or behaviour and would like to understand how you can support them, it is worthwhile talking to any professional who has regular contact with your child, about your concerns to see what help may be available. For school age children and young people, concerns and observations should be discussed in the first instance with the young person's teacher or SENCo as there are lots of things that you and the school can do to help your young person without further assessment.

Every local Council will have a 'Local Offer', which is available online. The local offer details all the help and services available for young people with additional needs in that area. The Norfolk Local offer can be found [here](#). For Waveney Families, the Suffolk Local offer can be found [here](#).

Support for neurodivergent children and young people should be coordinated across education, health and care and support needs will be different for each individual and their families.

For some children and families, it may be necessary to seek further help through an assessment of possible neurodiversity.

Advice for Families Considering Private/Independent Assessments

Think carefully about why an assessment and diagnosis will be helpful for your child and your family. Support for neurodivergent children and young people should be coordinated across education, health and care and support needs will be different for each individual and their families

For some children and families, it may be necessary to seek further help through an assessment of possible neurodiversity.

Before selecting a private / independent its important that families research their providers and check the provider is appropriately qualified.

It's useful to check whether a provider is registered on:

- Companies House <https://www.gov.uk/getinformation-about-a-company>
- With a registered body such as the HealthCare Professional Council (HCPC): www.hcpc-uk.org/check-the-register
- And when the provider was last inspected via the CQC website: www.cqc.org.uk

Costs

If you're thinking about getting a private or independent assessment, these are paid for by the family and not by the NHS. Costs can vary, so make sure you fully understand what's included.

Expect all costs upfront and check you understand what these include. Assessment and support might look different, here is what families can look for what is included:

- Pre-assessment screening – this will help decide if a full assessment is required. You or your child may be asked to complete a strengths and difficulties questionnaire.
- Pre-diagnosis support – some providers offer tailored support for you and your caregivers.
- Full assessment with a feedback meeting – this may include screening for other conditions and the meeting will describe the result of the assessment.
- A follow up meeting, ideally within six weeks of the assessment where you can ask questions about the assessment, outcome, or next steps. If medication is recommended, ask about what alternatives are available.
- Post diagnostic support – some providers offer tailored support for you. This will impact the overall cost of the service.

Reports

When the assessment is complete, you should receive an outcomes report. This report can be helpful in describing what reasonable adjustments need to be made in education or employment or how professionals can best support a young person with strategies or communication.

It is up to you whether this report is shared and how much information is included, but we recommend that as a minimum, your GP practice and school receives a copy.

The report should also describe:

- Any safeguarding/identified risks.
- Any ongoing referrals made to local agencies.
- Relevant signposting to local agencies following assessment outcome.

Medication

Medication is not a first line of treatment for children. If you decide to see a private / independent provider the parent/ carer should be aware that they are expected to pay the full costs of this. Any medicine prescribed or treatment provided during, or following a private consultation, will be at their expense. For ADHD this could include paying privately for the assessment, medication, medication reviews and annual reviews with the private provider.

Disagreement / request for second opinion

If there is any uncertainty/disagreement about the outcome of the assessment, you should liaise with the independent provider within six weeks. Requests for a second opinion will mean joining the NHS waiting list in your local area.

Suggested Questions to Ask Providers

1. Ask whether your child will be observed face to face, usually in their school or other setting. Your child's school should be asked to contribute information for the assessment.
2. You should expect an assessment to include more than one professional (see guidance: www.nice.org.uk/guidance/cg128/) so ask who is involved in the multi-disciplinary team, such as a
 - a. paediatrician and/or child and adolescent psychiatrist
 - b. speech and language therapist
 - c. psychologist with training and experience in working with autistic children and young people.
3. Ask if the clinical team include or have regular access to the following professionals if they are not already in the team:
 - a. paediatrician or paediatric neurologist
 - b. child and adolescent psychiatrist
 - c. psychologist with training and experience complementary to the psychologist in the core team
 - d. occupational therapist.
4. Ask if a child is screened for possible co-occurring conditions. An example is screening for ADHD during an Autism assessment.
5. For patient choice / right to choose referrals, the provider must have an NHS contract for Neurodiversity/Autism/ADHD assessments for children and young people 0-18. You can ask the provider if they hold such a contract with an Integrated Care Board
6. Request what information the assessor collects about your child and how they will store this information. This includes Consent.

Supporting Young People's Needs

If you, your young person's teacher/SEND/CO or GP have decided that an assessment may be required, it does not mean that you need to wait to access support.

It is important to note that confirmation of neurodiversity is not required to access support for your child at school or pre-school so you should talk to the school staff to ask what they can do to help.

There are other services, charities and support groups who will also be happy to help without a formal confirmation that your child or young person is neurodivergent. Details of local organisations can be found here: [Quick Guide to Neurodevelopmental Support \(justonenorfolk.nhs.uk\)](http://justonenorfolk.nhs.uk)

NHS Norfolk and Waveney have also published a Supporting your Neurodiverse Child information pack to support families in their journey, which details lots of links to local organisations. This pack is available [here](#).