

Advice for parents

Neurodevelopmental assessments – Independent assessments

What is neurodiversity?

Neurodiversity is a word used to describe the different thinking styles that affect how people communicate with the world around them.

Neurodiversity can affect someone's behaviour, memory, or ability to learn.

It is an umbrella term - a word that sums up lots of different things. It includes conditions like autism, ADHD, dyslexia, dyspraxia, dyscalculia, and Tourette's.

Think carefully about why an assessment and diagnosis will be helpful for your child and your family. Support should be needs led across education, health and care and it may be worthwhile talking to someone about your concerns to see what other help is available to you and your child.

- Do your research.
- Check the provider is appropriately qualified.

It's useful to check whether

- they are registered on Company House <https://www.gov.uk/get-information-about-a-company> , or
- with a registered body such as the HealthCare Professional Council (HCPC). <https://www.hcpc-uk.org/check-the-register/>
- Check the CQC website for when provider was last inspected <https://www.cqc.org.uk/>

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Costs will vary. Expect all costs upfront and check you understand what these include. Assessment and support might look different. What to look for:

- 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.

When the assessment is complete, you will 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 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 is not a first line of treatment for children. Where medication is recommended, speak to your child's GP first about ongoing prescription charges and your responsibilities for payment. This includes costs for medication reviews.

<https://www.england.nhs.uk/publication/shared-care-protocols/>

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.

QUESTIONS TO ASK

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 so ask who is involved in the multi-disciplinary team. <https://www.nice.org.uk/guidance/cg128/>
 - 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. You should 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 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.