

PRIVATE ASSESSMENTS & NHS RIGHT TO CHOOSE

This fact sheet has been written by parent carers for parent carers



If you feel your child or young person needs an assessment, it is frustrating to find there are barriers to getting it done. For example, there are long waiting times for NHS assessments for autism and ADHD and schools only have a limited number of educational psychologist's appointments available. It may be hard to get others to listen to your concerns, or you may be told that your child does not meet the threshold to be seen. So some parents will think about seeking a private assessment or diagnosis. This can be expensive, so it is not an option for all families. If you are thinking about a private assessment, there are some important things to consider.

Checking your options

It's important to research your options carefully. Don't make a decision based on hearsay as services and waiting times change. Find out more about the pathway or type of assessment you think you need. Speak to your child's GP and early years setting, school or college. You could also ask the SENDIASS advice line for information – see our contact details at the bottom of this fact sheet.

Try to get your child on the right waiting list even if you are considering alternatives. Sometimes, you may be turned down for a service because school or health practitioners don't see what you see. Your child may behave differently at home and school for example, so persist and gather evidence. If your child needs an NHS service and there are long waits locally, see if using the Right to Choose will help.

NHS Right to Choose

The national **NHS Right to Choose (RTC) Framework** allows NHS patients to choose a hospital or service when getting a referral from a GP for their initial or first appointment. This means you can choose to go somewhere other than the local NHS provider and this includes for initial assessments for neurodevelopmental differences such as autism and ADHD.

With RTC, you cannot self-refer. Your GP needs to agree that a referral is needed for a 'clinically appropriate physical or mental health service.' In simple terms, this means they agree your child needs to be referred, and the referral is to an NHS service in another part of the country, or to a private or independent provider commissioned by the NHS in England to provide the service you need. RTC is not an option in some circumstances, for example for urgent or emergency treatment or if treatment is already underway. The NHS website covers the exclusions in detail (see the Right to Choose link in Further information below). If your child is on a waiting list that is excessively long, you may be able to ask to be moved to a different provider.

You and your child's GP can look at options together, but you may want to do a bit of research beforehand. You could ask other parents, look at NHS websites or ask organisations for your child's suspected condition. You may find that some providers you hear about from other families now have waiting lists or are no longer taking referrals. Also, bear in mind the cost of travel if the provider is not local, as the NHS does not pay for this.

Ask your GP if a shared care agreement is in place. This is a formal agreement that allows the transfer of care from a specialist to your GP, so that they can oversee treatment and the prescribing of medication. This is particularly important for things like ADHD assessment. The NHS Sussex website has more information about this.





Private assessments and therapies

Families may decide to go for a private assessment if they can't get what they feel their child needs through education services or the NHS. Waiting times are just one reason. Another might be because you want more say in what is looked at or more ideas you can follow up to help your child. For example, a local authority educational psychologist's report will be professional and expert but may not give you all the detail you want to plan further ahead for your child.

Your child might have coordination difficulties that are not severe enough to be seen by an NHS occupational therapist (OT) but a session with a private OT may give you ideas, which you and your child's school can use to help them. If you decide to go ahead with seeing a private practitioner these tips will help you:

Get clear information about the cost and what will be included, in advance. Shop around and get recommendations from other parents. This can be an expensive route and it is hard to get any help with the costs. Contact has a tool you can use to search for grants, but many charitable funds will not give a grant for something that should be provided by a local authority or the NHS. If you are not yet getting Disability Living Allowance (DLA) for your child, look at whether they might be eligible for this as you can spend it in any way you choose to support your child.

Tell your child's school and GP what you are doing. You want them to be in the loop as you may be coming back to them later with the outcome or for follow up. For some assessments, the private provider should contact your child's education setting for information.

Keep your child on any NHS waiting list even if you are getting a private assessment, as this may be helpful later. For example, if your child is diagnosed privately for ADHD and medication is suggested, you will have to pay for private prescriptions but may eventually be able to move this to NHS care if they are on the CAMHS waiting list.

Make sure the person you use is appropriately qualified to carry out this particular assessment or diagnosis or therapy. Also check that they are registered with the right regulatory body. Apart from doctors and nurses, who have their own professional registers, this will usually be the Health and Care Professions Council (HCPC). For example, speech and language therapists, occupational therapists, psychologists, physiotherapists and dieticians all fall under the HCPC. Some people advertise themselves with titles like 'autism expert' without having qualifications that others will recognise. They may be useful and supportive but not carry weight with others.

For some types of private assessment, you will also need to check that the practitioner or service you use will be following National Institute for Health and Care Excellence (NICE) guidelines. For example, there is NICE guidance about autism and ADHD, including recognised tools and approaches for an assessment process.

Check if the report or diagnosis will be recognised by the services you want. Using a properly qualified and registered person who complies with NICE guidance (where this applies) is a protection for your child and you, but will also be something your child's school, local authority and NHS professionals will need to know when they look at whether to recognise any diagnosis or report. Generally, they should recognise the validity of a diagnosis or assessment if so. They will also look at whether the practitioner spoke to other professionals involved with the child, for example asking for information from the school. And, if they are making recommendations about support, care or provision, that these are proportionate with the child's needs and in line with evidence-based good practice.





Is this a report that can contribute to an Education Health and Care needs assessment (the EHCP process)? The SEND Regulations 2014 say that the local authority must seek, 'advice and information from any person the child's parent or young person reasonably requests that the local authority seek advice from.'

The regulations also state that any professional that the local authority seeks advice and information from during statutory assessment is expected to: report on a child or young person's special educational needs, the special educational provision to meet those needs and the outcomes that can be expected. Reports should only recommend a type of provision not name a specific education setting. Reports by a suitably qualified person that fulfil these requirements should be included in the pack of professional advices and contribute to the content of the relevant sections of the EHC Plan. Reports that don't meet these requirements can still be considered and can be included as part of your parental advice.

If you need a report for an Education, Health and Care needs assessment, ask the professional if it is 'compliant with the SEN Tribunal's expert witness guidance' so you can use it if you need to appeal.

Ask about

- **Amaze - Special Educational Needs and Disability Information, Advice and Support Service (SENDIASS)** offers impartial, confidential advice on anything to do with special educational needs and disabilities for 0 to 25 year olds. Parents, carers, children and young people under 25 with SEND living in Brighton & Hove or East Sussex can use the service. Visit our website at <https://amazesussex.org.uk/sendias>. Email sendias@amazesussex.org.uk or call 01273 772289.
- **Amaze - ND Family Support Service** offers information and advice for parent carers about neurodevelopmental differences, how the local assessment routes work and how to support your child. There is advice through navigation calls and access to workshops and courses. Find out more and refer yourself <https://amazesussex.org.uk/nd-family-support>
- **Amaze - help with claiming Disability Living Allowance (DLA) and Personal Independence Payment (PIP).** We can give you telephone advice, targeted resources and sometimes practical support with completing DLA and PIP claim forms. Visit <https://amazesussex.org.uk/benefits-advice> or contact our SENDIASS advice line to find out more.

Further reading and useful links

- **Amaze website advice on diagnosis** at <https://amazesussex.org.uk/health/getting-a-diagnosis/>
- **NHS website:** holds a lot of information to help you make choices, including directories of NHS services across England. There is a search function on the NHS website for consultants and procedures. <https://www.nhs.uk/service-search/other-services/hospital/LocationSearch/7/Consultants>
- **Right to Choose** information on the NHS website <https://www.nhs.uk/using-the-nhs/about-the-nhs/your-choices-in-the-nhs/>
- **NHS Choices Framework** sets out patients' rights to choice in healthcare, where to find information to help choose, and how to complain if choice isn't offered. <https://www.gov.uk/government/publications/the-nhs-choice-framework>



PRIVATE ASSESSMENTS



- **NHS Sussex** has local information about Right to Choose and autism and ADHD assessments <https://tinyurl.com/y53c48kx>
- You can **check a practitioner** is registered here: <https://www.professionalstandards.org.uk/check-practitioners> or specifically for healthcare professionals here <https://www.hcpc-uk.org/>
- **NICE (National Institute for Health & Care Excellence) Guidelines** <https://www.nice.org.uk/guidance> including autism (<https://www.nice.org.uk/guidance/qs51>) and ADHD (<https://www.nice.org.uk/guidance/ng87>)
- **Contact** publish an online search tool to help you find grants <https://contact.org.uk/help-for-families/information-advice-services/money-debt/grants-loans-welfare-schemes/online-grants-search/>

