



Helpful questions you could consider asking Diagnostic Teams

These questions are some suggestions that you could ask a diagnostic team to help you decide if a particular provider is right for you.

Please only ask the questions that are relevant to your situation. You may be able to find many of these answers on a provider's website.

Do you diagnose in line with the NICE Guidelines?

Which professionals are on your multidisciplinary assessment team? Are they members of any professional bodies?

The assessment should be conducted by a multidisciplinary team with age-appropriate expertise.

For children:

Nice Quality Standard for Autism states the following:

<https://www.nice.org.uk/guidance/qs51/chapter/quality-statement-1-diagnostic-assessment-by-an-autism-team>

The *core staff* of the autism team for children and young people should include:

- paediatricians and/or child and adolescent psychiatrists
- speech and language therapists
- clinical and/or educational psychologists.

The autism team should either include or have regular access to:

- paediatricians or paediatric neurologists
- child and adolescent psychiatrists
- clinical and educational psychologists
- occupational therapists
- other professionals who may assist with the assessment, for example specialist health visitors or nurses, specialist teachers or social workers.

[Adapted from [NICE's guideline on autism spectrum disorder in under 19s](#), recommendations 1.1.3 and 1.1.4]

For adults:

Nice Quality Standards for Autism states the following:

<https://www.nice.org.uk/guidance/cg142>

In each area a specialist community-based multidisciplinary team for autistic adults (the specialist autism team) should be established. The membership should include:

- psychologists with training and experience in working with autistic adults
- nurses
- occupational therapists
- psychiatrists
- social workers
- speech and language therapists
- support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills).

Do you assess for a PDA profile of autism within your autism assessments?

A PDA profile can, and should, be taken into consideration when undertaking autism assessments. This is in accordance with NICE Guidelines, which list demand avoidance as a 'feature of possible autism'. Autism assessments should consider all the presenting strengths and challenges, including **demand avoidance**. The extent of, and reasons for, demand avoidance should be determined in collaboration with the individual and, in children's services, their parents. Demand avoidance can occur for different reasons, so it is important to understand that a PDA profile may not always be the best explanation.

<https://www.pdasociety.org.uk/what-is-pda-menu/what-is-demand-avoidance/>

Have you read the PDA Society's Practice Guidance – identifying and assessing a PDA profile?

PDA Society **[practice guidance for identifying and assessing a PDA profile](#)** collates the professional practice and experience of a multidisciplinary group of NHS and independent professionals and aims to aid assessment of a PDA profile and to distinguish PDA from other presentations of marked demand avoidance. Here's a **[letter/email template](#)** which can be used to inform clinicians and autism teams about the practice guidance.

<https://www.pdasociety.org.uk/what-is-pda-menu/identifying-assessing-pda/>

<https://www.pdasociety.org.uk/resources/letter-email-template-identifying-assessing-pda-practice-guidance/>

What terminology do you use to refer to a PDA Profile of Autism, either in the diagnosis or within the assessment report?

PDA Society [practice guidance for identifying and assessing a PDA profile](#) 'Section 4.4 considers formulation and terminology'

<https://www.pdasociety.org.uk/what-is-pda-menu/identifying-assessing-pda/>

Do you have experience of having to adapt assessments for some children, young people or adults , and can you give me some examples of what that might mean?

What does a 'child-centred assessment' tend to look like with a PDA child?

What does a 'person centred assessment' tend to look like for a PDA adult?

Professional bodies may provide their own guidelines for best practice. However, as PDA is not universally recognised and understood, this may not always be suitable for PDA people. Whatever the case, it is always okay to ask a professional to adapt their practice to your child's needs or direct them to PDA resources.

Professionals working with PDA people should try to:

- Be person centred and focus their work with your child around their needs and preferences where possible.
- Communicate in a non-directive way.
- Be flexible around your child's changing needs.
- Take account of your child's sensory needs.
- Offer creative and playful ways to approach things that must be done.
- Be aware that many PDA people have co-occurring conditions and adjust around these too.
- The clearer you can be about what adjustments are helpful for your child, the easier it will be for professionals to meet their needs.

Do you have a/how long is your waiting list?

Do you have a 'cancellation list' where I can be invited at short notice for an assessment?

Unfortunately, many providers do have a waiting list, but these can vary in their length, and it can change, so it always worth asking this question.

Some organisations do keep a list where you have the option to have an assessment sooner, if another person cancels their appointment.

If I/my child are diagnosed, how long does it take to receive a written report following the assessment?

Can I review any follow up report before it is finalised?

Some organisations are happy for you to check their reports for any factual errors that can be corrected, however this will not alter the decision, or any professional recommendations made by the assessment team.

Do you provide any follow up services after assessment and diagnosis?

Nice Guidelines state:

<https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/assessment-and-diagnosis-of-autism-what-to-expect>

The autism team and your case coordinator should meet with you and your family as soon as possible after the assessment to explain whether they think you are autistic and why.

They should give you a written report saying what they found in the assessment and send a copy to your GP. If you agree, they should also send a copy to other adults who work with you, such as your teacher or social worker.

If the team don't think you are autistic, they should explain how they reached this decision and talk to you about any other services that might help, that they could refer you on to for support.

If you are autistic, the team should also:

- give you information about what autism is and what it might mean for you, now and in the future
- talk to you about plans for providing you and your family with support
- tell you when they will meet with you next. This should be within 6 weeks of the assessment ending.

Can I see a copy of your safeguarding policy?

Do you have a DBS (Disclosure & Barring Service) check (or Scottish/Welsh equivalent) and insurance and registration with the ICO (Information Commissioners Office) where relevant.

Professionals should have a safeguarding policy they can share with you

Please also see our page about Safer PDA: <https://www.pdasociety.org.uk/working-with-pda-menu/safeguarding/>

We believe that our community should be able to access support that helps us and doesn't harm us. It is our hope that these resources (Guidance for adults and for parents) will help our community to identify safe practice and know what to do if services seem unsafe.

What age range of people do you diagnose?

How much do your services cost and what will I get for my money. Do you need a deposit?

Can you carry out assessments online?

Do you obtain information from schools, including the person who works most closely with my child?

Do you need to obtain information from family members to complete the assessment?

How should I prepare myself/my child for the assessment?

Does your assessment include only an assessment for autism (with a PDA profile) or could it be more holistic and assess for ADHD, sensory sensitivities, alexithymia etc

(For independent providers – have your reports previously being accepted by Local Authorities for providing support)

What experience do you have of diagnosing a PDA profile?

Which assessment tools do you use? (eg ADOS, DISCO, ADI-R, 3Di)

Does the provider talk about PDA in a way that leads you to believe they'll be helpful? How does the provider describe PDA?

What are their terms and conditions, including cancellation policies.

Ask about practical information like location and timings.

A well trained, experienced, and trustworthy diagnostic team might not meet all of these criteria. However, anyone who has your best interests at heart will be happy to answer any of these questions to the best of their ability.