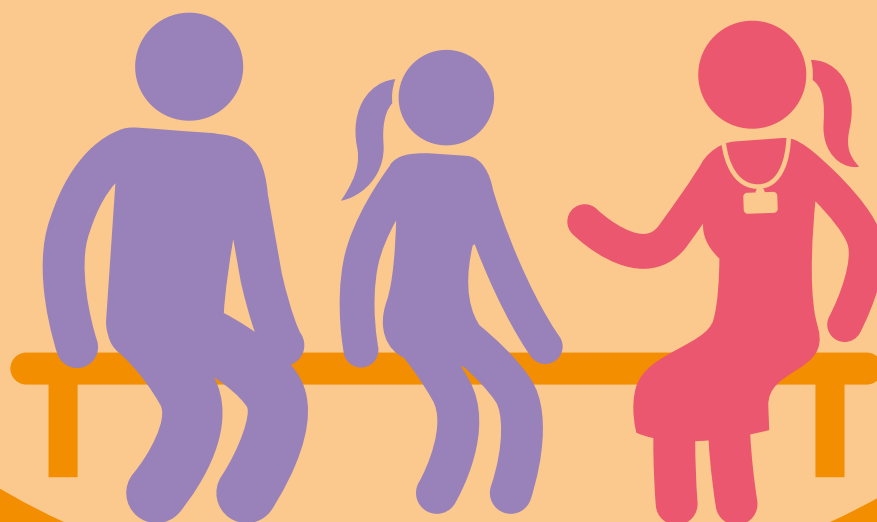


Assessment and diagnosis of autism: what to expect

A quick guide for young people and their families



*"I was so relieved when I got my
diagnosis, it felt like recognition"*
(Fran, a person with autism)

More than 1 in 100 people are autistic. Being autistic affects people in different ways. It can bring strengths but also some challenges that can impact on how comfortable, healthy and happy you feel. Getting the right diagnosis and support is important.

This guide is for young people, who are of secondary school age, and their families or adults with parental responsibility.

Why have I been offered an assessment for autism?

You might be offered an assessment if you or people in your life think that you may have some of the signs of autism. These signs may include:

finding it difficult talking to and being with other people


having unusual or intense interests

finding some situations and experiences difficult to cope with

sometimes finding noise, touch, taste and texture, lights or smells difficult to deal with

strongly preferring your usual routine

developing more easily in some areas than others



Having an assessment means you can talk about these things and find out possible reasons for them.

You may want to discuss what you find difficult more informally with someone before having an assessment, to help you decide if now is the right time for you.

You may also find it helpful to talk about this with your school, doctor or social worker, if you have one.

Arranging an autism assessment

If you are referred for an assessment, it should start within 3 months and be done by a team of people who are specialists in autism. One person in this team should be your case coordinator – this means they are in charge of:

- making sure you and your family know what will happen and when
- answering your questions
- getting information or support for you and your family
- collecting information to help the assessment (e.g. from your school, doctor or social worker if you have one)
- talking to you about how information about you and your family is shared.



Case coordinator

During the assessment

In your assessment, the autism team will talk to you and your family about different parts of your life to help them get to know you. They will ask questions about:

- what you are good at and what you find difficult
- any worries you or your parents have
- how you get on at home, at school and in other situations
- how you talk to and get on with other people.

They will think about:

- any other physical or mental health problems you might have, including doing some health checks
- anything else that might be making things harder for you, or affected how you have grown and developed.

The autism team might also need to:

- come and see how you get on at school or at home
- arrange other assessments.

This information will help them to work out how best to help you and plan what support you and your family need.



After an assessment

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.

Information and support

If you are autistic, you should be offered a named key-worker who will help you to develop a personalised plan which focuses on your strengths. You and your family should also be given information about other support in your local area, which might include:



Support groups that you or your family could contact that can help you to meet other autistic young people, or learn more about what autism is.



Activities that can help in your day-to-day life (for example improving social skills, leisure activities or supporting your learning at school).



Help to prepare for the future so you can still do the things you choose.



Where to get advice about money and benefits.

Further information

[Autism spectrum disorder in under 19's: recognition, referral and diagnosis \(CG128\)](#) – NICE guideline

[Autistic spectrum disorder in under 19's: support and management \(CG170\)](#) – NICE guideline

[Autism \(QS51\)](#) – NICE quality standard

[National Autistic Society](#) – website offering information and advice about autism, including all about [diagnosis](#)

[Ambitious About Autism](#) – information and support for autistic young people and their families, including an online community, shared experiences and stories and opportunities to get involved in

This content has been co-produced by NICE and SCIE and is based on NICE's guideline on autistic spectrum disorder in under 19's: recognition, referral and diagnosis and quality standard on autism

National Institute for Health and Care Excellence
www.nice.org.uk

© NICE 2019. All rights reserved. See [Notice of Rights](#)

Social Care Institute for Excellence
www.scie.org.uk