



Understanding Autism: A Guide to Diagnosis and Beyond

RANi Need to Know Guides | Diagnosis Advisory sheet 1

Updated: April 2025

For Parents, Carers, and Young People

What is Autism?

Autism (also known as Autism Spectrum Disorder or ASD) is a **neurodevelopmental condition** that affects how a person communicates, interacts with others, processes information, and experiences the world. Autism is a **spectrum**, which means people are affected in different ways and to varying degrees.

Common traits may include:

- Differences in social interaction and communication
- Repetitive behaviours or routines
- Intense interests
- Sensory sensitivities (to noise, light, textures, etc.)

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- Differences in play or learning styles

Autism is **not a mental health condition** or an illness. It is a form of neurodiversity. Many autistic people have strengths such as deep focus, strong memory, creativity, or unique problem-solving abilities.

When to Consider an Autism Assessment

You may consider seeking an autism assessment if your child or young person shows differences in:

- Communication (spoken or non-verbal)
- Understanding social rules or cues
- Emotional regulation or flexibility
- Play and imagination
- Coping with changes or transitions
- Sensory processing (e.g. overwhelmed by noise, picky eating, clothing issues)
- Repetitive actions (e.g. flapping, spinning, lining things up)
- Intense interests in specific topics

Other signs may include **meltdowns**, **shutdowns**, **delayed speech**, or **masking** (hiding traits in public, then 'exploding' at home due to exhaustion).

How to Request an Autism Assessment

You can usually request an autism assessment via:

1. Your GP

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Ask for a referral to the local **Neurodevelopmental Team** or **Community Paediatrics**.

2. School or Nursery

Speak to the SENCO (Special Educational Needs Coordinator) or pastoral lead. They can often refer directly or support your request.

3. Health Visitor

For younger children, your health visitor can raise developmental concerns and help refer you.

You do not need a diagnosis to access support, but a diagnosis can help you:

- Understand your child's needs
 - Access health or social care support
 - Apply for reasonable adjustments
 - Request an EHC needs assessment
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The Autism Assessment Process

This can vary by local area, but typically includes:

1. Initial Screening

- Questionnaires for parents/carers and school
- Review of medical, developmental, and family history
- Observation of behaviour in different settings

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2. Multidisciplinary Assessment

A team may include:

- Paediatrician or child psychiatrist
- Speech and Language Therapist (SALT)
- Educational Psychologist or Clinical Psychologist
- Occupational Therapist (for sensory or motor needs)

Standardised tools might be used, such as:

- ADOS (Autism Diagnostic Observation Schedule)
- ADI-R (Autism Diagnostic Interview – Revised)

3. Feedback and Diagnosis

You'll receive a written report with:

- Diagnosis (if given)
- Description of needs and traits
- Recommendations for support at home, school, and in the community
- Sometimes, follow-up support or referrals

You may hear the terms:

- Autism Spectrum Condition (ASC)
- Autism Spectrum Disorder (ASD)
- Atypical autism or social communication disorder

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Some girls and young people may be diagnosed later due to **masking**, internalising behaviours, or being misdiagnosed (e.g. with anxiety or eating disorders).

After a Diagnosis – What Next?

Getting a diagnosis is a **starting point**. Here's what you can do next:

1. Learn About Autism

Explore books, online guides, and autistic-led organisations to gain understanding.

2. Inform School or College

Share the report with the SENCO. This can help them:

- Create an SEN Support Plan
- Make reasonable adjustments
- Apply for extra support or interventions

3. Apply for an EHC Needs Assessment

If your child has significant barriers to learning or needs extra help beyond what the school can provide, you can apply for an **Education, Health and Care (EHC) plan**.

4. Support at Home

Ask for:

- Parenting courses (e.g. EarlyBird, Cygnets, Triple P)
- Local support groups
- OT, SALT, or clinical psychology if needed
- Help with behaviour, sleep, anxiety, or sensory needs

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5. Benefits and Financial Support

You may be entitled to:

- Disability Living Allowance (DLA)
 - Carer's Allowance
 - Disabled Person's Bus Pass
 - Family Fund grants
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Common Questions

Can I get support while waiting for a diagnosis?

Yes. Diagnosis is not required to get:

- SEN support in school
- Mental health services
- Some NHS therapies
- Local authority help (e.g. short breaks)

What if I don't agree with the outcome?

You can:

- Ask for a second opinion
- Request a review
- Seek a private assessment (note: may not always be accepted by the NHS or local authority)

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Is autism ever “mild” or “severe”?

Autism affects each person differently. Labels like “high-functioning” or “mild” can be misleading and don’t reflect the challenges someone might face.

Resources and Support

- **National Autistic Society** – www.autism.org.uk
 - **Ambitious About Autism** – www.ambitiousaboutautism.org.uk
 - **RANi** - For help with understanding your rights and the process
 - **IPSEA** – Free legal advice on SEND rights
 - **Your Local Offer** – Find local support groups, courses, and services
 - **SENDIASS** – Local advice service on education and disability rights
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Summary

Step	What to Do
1. Concerns arise	Keep notes, speak to school or GP
2. Ask for assessment	Via GP, school, or HV
3. Undergo assessment	Questionnaires, observations, multidisciplinary input

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4. Receive diagnosis Report, recommendations, follow-up

5. Access support At home, in school, and from local services

Remember:

Always keep a copy of all correspondence you send, along with proof of postage or delivery. If you send documents by post, we recommend using a **signed-for** service. If sending by email, request a **read receipt** if possible.

Get in Touch

If you need more information or have a question, we're here to help.

Email us: info@rani.org.uk

Please include:

- Your name
- Your child's name
- Your child's date of birth
- Your query

Or, if you prefer, you can fill out our online **contact form** and we'll get back to you as soon as possible.

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