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NICE Guidelines: Understanding Autism Support in the NHS

A practical guide for parents and carers

Updated March 2025

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1. Introduction

Understanding the NICE Guidelines and Why They Matter

When a child or young person shows signs of autism, it can feel overwhelming knowing where to turn or what to expect. That's where the NICE Guidelines come in. These are national recommendations developed by the National Institute for Health and Care Excellence to help professionals provide clear, consistent and effective care.

The guidelines are designed to ensure that children and young people under 19 with suspected or diagnosed autism receive the right support at the right time. They apply to all professionals working in the NHS, education, and social care and outline how assessments, diagnoses, and ongoing support should be carried out.

This booklet breaks the NICE Guidelines down into straightforward, family-friendly information. Whether you're just starting your journey or have already begun the assessment process, this guide explains:

- What signs to look out for
- Who to talk to and how to raise concerns
- What the autism assessment involves
- What support and services should be offered
- What to expect as your child grows up
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It also highlights your rights as a parent or carer and what you can do if things don't go as planned.

Remember: these guidelines exist to support you. Understanding them can help you feel more confident in navigating the system and making sure your child gets the care they deserve.

2. Recognising the Signs of Autism

Understanding early indicators and what to look for

Autism is a neurodevelopmental condition that affects how a person sees the world, interacts with others, and processes information. Signs of autism can appear at any age but often become noticeable in early childhood.

Every child is different, and no two people with autism are the same. However, there are some common signs that might suggest a child could be on the autism spectrum.

Common differences to look out for:

Communication differences

- Delayed or limited speech
- Repeating phrases or words (echolalia)
- Speaking in a flat tone or with unusual patterns
- Difficulty starting or holding conversations

Social interaction difficulties

- Avoiding eye contact
- Not responding to their name
- Seeming uninterested in playing or talking with others
- Difficulty understanding social rules or emotions

Sensory sensitivities

- Over- or under-reacting to sounds, lights, textures or smells
- Discomfort with certain clothing, food textures, or noisy places

Repetitive behaviours and routines

- Repeating the same actions, such as hand-flapping or spinning
- Rigid routines and resistance to change
- Intense interests in specific topics or objects

These signs might appear in different ways at different ages. Some children may show many signs, while others show only a few. It's also important to know that not all unusual behaviour is a cause for concern — but if you're unsure, it's always worth seeking advice.

3. Speaking to a Professional

What to expect when raising concerns about your child

If you've noticed behaviours or developmental signs that worry you, your first step is to speak with a professional. This is often your GP, health visitor, or someone at your child's nursery or school.

It's natural to feel anxious or unsure — but remember, you're not alone. These professionals are there to listen, support, and guide you.

What you can do:

Write things down

- Keep a diary of your child's behaviours, communication, and routines. Note anything that concerns you or that seems different compared to other children of a similar age.

Bring examples

- Share specific situations where your child has struggled with communication, social interaction, or change. This helps professionals understand your concerns clearly.

Ask questions

- You have every right to understand what's happening. You might ask:
- Could this be autism?
- Is there anything else this might be?
- What happens next?

Trust your knowledge of your child

Even if professionals haven't noticed the same signs, your observations as a parent or carer are valid and important. NICE Guidelines say concerns from families should always be taken seriously.

What professionals should do:

- Listen without judgement
- Explore your concerns thoroughly
- Avoid dismissing signs without consideration
- Offer information about what autism is and what support is available
- Explain the referral process clearly if one is needed

You don't need a diagnosis to get help — and raising concerns early means your child can get support sooner if needed.

4. The Referral Process

What happens after you raise concerns
Once you've shared your concerns with a professional, the next step may be a referral for further assessment. This helps determine whether your child might be autistic and what support they may need.

Who can make a referral?

Referrals to an autism assessment team can be made by:

- Your GP
- A health visitor
- Your child's school or nursery SENCO (Special Educational Needs Coordinator)
- Other health professionals, such as a paediatrician or speech and language therapist

In some areas, you may be referred to a paediatrician first, who then decides whether to refer on to the autism team.

When is a referral made?

A referral is usually made when:

- There are clear signs of social, communication or behavioural differences
- Concerns are present across different settings (e.g., at home and at school)
- The child's development isn't progressing as expected
- There's a family history or other risk factors linked to autism

If a child under 3 shows regression in language or social skills, they should be referred straight away.

What is included in a referral?

The professional making the referral should provide:

- A summary of your concerns and their own observations
- Your child's developmental history and milestones
- Any reports from nursery, school, or previous professionals
- Relevant medical history, including pregnancy and birth details

What if a referral isn't made?

Sometimes, a professional may suggest "watchful waiting", especially if signs are unclear. In this case:

- You should be offered follow-up appointments to monitor progress
- You can request a second opinion or ask for the referral to be reconsidered if concerns continue
- You're still entitled to support — even without a diagnosis
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A clear, timely referral can make a big difference. If you're unsure what's happening, ask for clarity — and don't be afraid to speak up if you're not being heard.

5. The Autism Assessment Pathway

What to expect during the diagnostic process

Once your child has been referred, they will usually be seen by a specialist autism assessment team — a group of professionals trained in identifying and diagnosing autism in children and young people.

Who might be involved?

The assessment team may include:

- A paediatrician or child psychiatrist
- A speech and language therapist
- A clinical or educational psychologist
- Sometimes an occupational therapist, neurologist, or specialst teacher

This multi-disciplinary approach ensures a broad and balanced view of your child's development and behaviour.

What does the assessment involve?

An autism diagnostic assessment isn't just one test — it's a detailed process combining information from several sources to understand your child's development and how they experience the world.

The process may include:

- Observations
- Watching how your child communicates, plays and interacts in different settings.
- Parental interview
- Discussing your child's development, behaviour, early milestones, and any concerns. You'll often be asked about:
  - Language development
  - Social behaviour
  - Play skills
  - Routines and repetitive behaviours
- Developmental history
- A structured review of your child's early development. This may be guided by a standardised tool (see below).
- Reports from other settings
- Input from nursery, school, or other professionals involved in your child's care.

Assessment tools commonly used in the UK

Assessment teams may use one or more of the following tools to support their clinical judgment:

- **ADOS-2 (Autism Diagnostic Observation Schedule – Second Edition)**

A widely used tool involving structured and semi-structured activities to observe communication, social interaction, and play. It is adapted based on the child's age and verbal ability.

- **ADI-R (Autism Diagnostic Interview – Revised)**

A detailed interview with parents/carers focusing on the child's development, language, communication, social behaviour, and interests.

- **DISCO (Diagnostic Interview for Social and Communication Disorders)**

Another in-depth parental interview, especially useful in complex or unclear cases.

- **3Di (Developmental, Dimensional and Diagnostic Interview)**

A computer-assisted parental interview used in some NHS trusts, designed to be quicker but still thorough.

- **Other screening tools**

These may include the Social Communication Questionnaire (SCQ) or Childhood Autism Spectrum Test (CAST), which can help flag potential signs of autism prior to a full assessment.

Note: These tools support, but do not replace, the clinical judgment of the assessment team. A diagnosis is based on the overall picture, not on a single test result.

How long does the process take?

NICE Guidelines recommend that the assessment begins within three months of referral. However, waiting times can vary significantly depending on your local area. The full assessment may take place over several appointments.

Possible outcomes

After all the information is reviewed, the team may:

- Confirm a diagnosis of autism
- Decide that your child does not meet criteria for a diagnosis
- Recommend further observation or referrals to explore other possibilities
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Whatever the result, you should:

- Receive a written report
- Be offered a follow-up appointment to discuss the findings
- Be signposted to relevant support services

6. After the Diagnosis

Understanding what happens next

Receiving a diagnosis of autism can bring a range of emotions — relief, worry, questions, or even confusion. Whatever you're feeling, it's important to remember: you are not alone, and support is available.
A diagnosis doesn't change who your child is, but it can open the door to better understanding, targeted support, and the right adjustments in health, education, and daily life.

What should happen next?

According to the NICE Guidelines, you should be:

- Offered a follow-up appointment within 6 weeks of the diagnostic conclusion

- This gives you a chance to ask questions, understand the findings, and discuss next steps.

- Given a full written report

This should explain:

  - The basis of the diagnosis
  - Your child's developmental profile
  - Recommendations for support and interventions
  - Any co-occurring difficulties that may have been identified

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- Signposted to support services

- You should receive clear information about:
  - Local autism support groups
  - Educational support services
  - Welfare benefits and entitlements
  - Emotional and practical support for your family

What support might be offered?

Depending on your child's needs, you might be referred to:

- Speech and Language Therapy
- Occupational Therapy (for motor or sensory needs)
- Educational Psychology (to support learning at school)
- Child and Adolescent Mental Health Services (CAMHS) (for emotional wellbeing)
- Autism-specific parenting courses or support programmes

You should also be offered advice on how to support your child at home and in school, as well as help to plan for future needs.

What if the diagnosis is unclear or not given?

Sometimes, a child may show traits of autism but not meet full diagnostic criteria. In these cases:

- Further observation or follow-up may be recommended
- The team may explore other possible explanations (such as developmental delay or anxiety)
- You may still be offered support, even without a formal diagnosis

If you disagree with the outcome, you have the right to:

- Request a second opinion
- Discuss concerns with the lead clinician
- Ask for a referral to a specialist or tertiary diagnostic service

A diagnosis is not the end of the journey — it's the beginning of understanding and support. With the right help in place, children and families can thrive.

Support and Services You Might Be Offered

Getting the right help in place for your child and family

After a diagnosis of autism — or even while waiting for one — your child and your family may be entitled to a range of support. This can come from the NHS, local authorities, schools, and voluntary organisations. Support should be tailored to your child's individual needs. It might focus on communication, behaviour, learning, or helping them manage daily life.

Healthcare support

Depending on the outcome of the assessment, referrals may be made to:

- **Speech and Language Therapy** – to support understanding, expression, and interaction
- **Occupational Therapy** – for help with motor skills or sensory challenges
- **Physiotherapy** – if movement or posture needs support
- **CAMHS (Child and Adolescent Mental Health Services)** – for anxiety, emotional regulation, or mental health concerns
- **Community paediatrics or neurodevelopmental services** – for long-term care and monitoring

You may also be offered a case coordinator or key worker to help manage appointments and ensure your child's needs are met across services.

Educational support

Schools and nurseries must make reasonable adjustments to support children with additional needs. This might include:

- A SEN Support Plan or Education, Health and Care Plan (EHCP)
- Access to a Special Educational Needs Coordinator (SENCO)
- 1:1 support, visual schedules, or sensory-friendly spaces
- Flexible routines or adaptations to the curriculum

Professionals may visit your child's setting to offer advice, carry out assessments, or help create support strategies.

Social care and family support

You may be entitled to a social care assessment for your child and a carer's assessment for yourself. Support may include:

- Short breaks (respite)
- Help with personal care or behaviour support
- Parenting programmes tailored for autism
- Help navigating benefits or accessing services

Voluntary and community support

Local autism organisations — such as ASD Helping Hands — often provide:

- Peer support groups
- Family events and drop-ins
- Advocacy and form-filling help
- Workshops and courses for parents and carers
- Advice about EHCPs, PIP, DLA, or transition planning

Even without a diagnosis, many of these services may still be available based on need.

8. Challenging Behaviour and Additional Needs

Understanding and responding to what's really going on

Many children and young people with autism experience behaviours that others might find difficult — such as meltdowns, aggression, running off, self-injury, or extreme distress. These are often referred to as "behaviours that challenge," but it's important to understand that such behaviour is usually a form of communication. Children may act out because they are overwhelmed, anxious, in pain, unable to express their needs, or facing sudden change.

What the NICE Guidelines recommend

Rather than focusing on the behaviour itself, professionals should look at why it is happening. This includes:

- Identifying triggers and unmet needs
- Assessing for co-occurring conditions like ADHD, anxiety, or sensory processing difficulties
- Understanding the child's communication style and emotional regulation

You should be offered a functional behaviour assessment — a structured look at what happens before, during and after behaviours — to help find practical strategies for support.

Common causes of challenging behaviour

- Sensory overload (e.g. bright lights, loud noise)
- Transitions and changes in routine
- Pain or discomfort that the child can't describe
- Misunderstanding social expectations
- Demands that feel overwhelming or unpredictable
- Mental health difficulties, such as anxiety or low mood

Support and interventions

Based on the assessment, your child may be offered:

- Environmental changes – e.g. visual timetables, quiet spaces, clear routines
- Therapeutic support – such as emotion regulation coaching, CBT, or mental health input
- Parent/carer training – to help understand behaviour and use consistent approaches
- Multi-agency planning – working together across school, home, and health settings

In some cases, medication (e.g. antipsychotics) may be considered only if behaviour is very severe and other strategies haven't helped — and should always be closely monitored**.**

Co-occurring conditions

Children with autism may also experience other conditions that need support, including:

- ADHD
- Anxiety disorders or phobias
- Learning disabilities
- Obsessive Compulsive Disorder (OCD)
- Sleep problems
- Sensory processing difficulties
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NICE guidelines stress that all needs should be identified and addressed together, not in isolation.

Behaviour is a form of communication — understanding what's underneath it is key to finding the right support. With the right strategies and joined-up care, things can improve for your child and your family.

9. Interventions to Avoid

What NICE says should not be used to treat autism

While families are often eager to explore every option to help their child, it's important to know that not all interventions are safe, helpful or supported by evidence. The NICE Guidelines clearly set out which treatments should not be used for autism in children and young people.
These recommendations are based on research and expert review — not because these options are unkind, but because they are either ineffective, potentially harmful, or not appropriate for the core features of autism.

Not recommended for treating the core features of autism:

- **Antipsychotic medication**

Should not be used to treat autism itself (though it may be considered for severe behaviour if all other options fail).

- **Antidepressants**

Not suitable for treating core autistic traits. They may be used carefully for diagnosed anxiety or depression, under medical supervision.

- **Anticonvulsants**

These are for epilepsy, not autism, and should not be used unless your child has seizures.

- **Special diets (e.g. gluten-free, casein-free)**

There is no strong evidence these improve autism symptoms and they can lead to nutritional deficiencies if not managed properly.

- **Chelation therapy**

A dangerous procedure used to remove "heavy metals" from the body — not supported by any credible research and can cause serious harm.

- **Hyperbaric oxygen therapy**

Often marketed for autism online, but NICE advises against it entirely.

- **Secretin injections**

Shown to have no benefit for autism and not recommended.

- **Omega-3 fatty acid supplements**

These are not harmful, but there's no strong evidence they help with autism symptoms.

- **Auditory Integration Training and Neurofeedback**

These are not advised for managing speech, language or sleep issues in autistic children.

- **Medication for sleep problems unless absolutely necessary**

A sleep plan and behavioural strategies should be tried first. If medication is used, it must be prescribed by a specialist and closely monitored.

Be cautious of…

- Treatments that promise a "cure" for autism — autism is not an illness to be cured.
- Unregulated online therapies, miracle diets, or expensive private programmes with no evidence base.
- Professionals who dismiss your concerns about safety, side effects, or lack of improvement.

10. Transition to Adulthood

Planning ahead for the teenage years and beyond

Transition refers to the time when a young person begins to move from children's services to adult services — in health, education, and social care. For autistic young people, this can be a time of uncertainty, but with the right planning and support, it can also be a chance to build independence and confidence.
The NICE Guidelines stress the importance of early planning and clear communication to make this process as smooth as possible.

What you can do:

Health care

- If your child is under paediatric care or CAMHS, there should be a handover to adult services where needed.
- Any co-existing health conditions should be reviewed and updated.
- A comprehensive health assessment should be offered.

Education and employment

- Support for college, apprenticeships, or training
- Planning for reasonable adjustments in further education
- Support into employment if needed (e.g. through Supported Internships or Access to Work)

Social care

- At age 18, young people are entitled to a statutory adult social care assessment.
- If eligible, they may receive support for independent living, personal care, or community access.

Mental health and emotional wellbeing

- Risk of anxiety, depression, and stress can increase during big life changes.
- If CAMHS are involved, a referral to adult mental health services should be planned.

Involving the young person

Young people should be supported to make decisions about their future as much as possible. Professionals should:

- Use accessible language
- Offer information in visual or easy-read formats
- Respect the young person's preferences and pace

Parents and carers should also be involved, especially where the young person lacks capacity to make decisions independently.

Key tips for families

- Start early – don't wait until the last minute
- Keep all reports and assessments safe — they may be needed for college or benefits
- Ask questions — if you're not sure what services are available, request a transition coordinator or social worker
- Remember that your child is entitled to support whether they remain in education or not

Transition is a journey — not a single event. With the right support, autistic young people can move confidently into adulthood with opportunities that reflect their strengths, interests and needs.

11. Your Rights and Involvement

Making sure your voice — and your child's — is heard

As a parent or carer, you have an important role in your child's care. The NICE Guidelines emphasise the principle of person-centred care — meaning that decisions should be made with you, not for you.
You and your child have the right to be listened to, informed, and involved every step of the way — from initial concerns to diagnosis, support planning, and beyond.

Your rights under the NICE Guidelines

- **To have your concerns taken seriously**

Professionals must listen to you — even if others (like school staff) haven't raised concerns.

- **To be involved in decisions about care and treatment**

You should be given all the information you need to make informed choices — and your child should be included wherever possible.

- **To access assessments and support in a timely way**

The autism assessment should begin within 3 months of referral. Unreasonable delays can and should be challenged.

- **To receive clear, written reports and outcomes**

These should explain what has been assessed, what was found, and what happens next.

- **To be treated with respect and sensitivity**

The assessment process and support should be adapted to your child's needs, including sensory and communication adjustments.

The rights of your child or young person

- To express their views and preferences in a way that works for them
- To be supported through changes in school, services or routines
- To receive the same level of healthcare and education as any other child
- To have reasonable adjustments made so they can access services and education fairly

Making your voice heard

If you feel your child's rights — or your own — are not being respected:

- Speak to the service manager or SEND lead
- Request a second opinion
- Use local complaints procedures or ask for advocacy support
- Contact SENDIASS (Special Educational Needs and Disabilities Information, Advice and Support Service)
- Contact your local authority or Integrated Care Board (ICB) if services are not being provided as expected

You can also request a Carer's Assessment to explore any support you may need in your caring role.

Working in partnership

When services, families and professionals work together, outcomes are better. You bring expert knowledge about your child; professionals bring knowledge of services and strategies. Both are essential.

Don't be afraid to ask questions, challenge decisions, or request support — you are your child's biggest advocate, and your input matters.

ASD Helping Hands

Our Mission

“Empowering autistic individuals and those around them, ASD Helping Hands is dedicated to fostering confidence, independence, and inclusion at every stage of life. We provide guidance, education, and resources to help individuals, families, and professionals navigate autism with knowledge and empowerment.

We champion the rights of autistic people, striving to create a more inclusive society while ensuring our services remain accessible, reliable, and built on trust.”

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Updated May 2025