

# Right from the Start

a guide to autism in the early years



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# Right from the Start

Welcome to our Right from the Start toolkit – a resource designed to help parents and carers of young children with autism to navigate their journey in the early years.

These days there is a staggering amount of information about autism available online, in books or through word of mouth. Much is reliable, some less so – but the sheer volume of information can feel overwhelming, difficult to sift through and hard to verify.

This is why Ambitious about Autism has created this toolkit – to provide practical and straightforward information in one place that will guide families with young children through their autism journey.

The guide is designed to support parents through the earliest years of their children's lives up to the age they start school at four or five.

We have condensed lengthy documents, created practical tips and checklists, and have provided signposts to sources of support or additional information.

These signposts will direct you to our 'Right from the Start resources library', where you can visit recommended websites or download suggested resources.



This toolkit will take you on a step-by-step journey through autism in the early years.

Although every effort has been made to describe this journey accurately, we know that, at times, your own 'journey' may be very different. This toolkit should therefore be considered a 'guide book' rather than a timetable – one that has been designed to be helpful and relevant for your travels, whatever stage you are at.

We use the word 'parent' throughout the toolkit but we understand that the range of people caring for a young child is much broader than that. By 'parent' we mean any primary carer of a young child, including adoptive or foster parents.



**The autism  
journey is one  
that lasts a lifetime.  
Getting it right from  
the start can make an  
enormous difference.**



## **Why is early identification and early intervention important?**

The sooner you understand your child's needs, the sooner they will have the support they need. Early identification of your child's needs and early intervention (therapies and support strategies) can provide:

- a better understanding of your child and how best to help them
- access to the correct services and supportive educational settings
- knowledge of the skills needed to enhance your child's education, friendships and quality of life
- a chance to prepare yourself emotionally and mentally for the future
- the opportunity to take advantage of early brain development, maximising the potential impact of interventions
- an opportunity to get the support your child needs to help them learn and develop to be ready for school and adult life.

The Right from the Start toolkit is divided into six sections:



## What is autism?

This section provides information about how autism is commonly described in medical manuals, what the common features of autism are and how they can vary in complexity.



## You, your family and autism

This section covers important topics such as looking after yourself and involving your family in the autism journey.



## Does my child have autism?

This section will help you if you think that your child may be displaying some of the features of autism.



## Supporting your child

This section looks at the things you can do to support your child's development, including their communication and play skills. It also looks at how you can help your child with some of the challenges they may face when it comes to things like sleep, toileting and behaviour.



## The autism pathway for children under five years old

From the time you find yourself asking 'does my child have autism?' through to having a formal assessment of your child's needs is often referred to as a 'pathway'. This section looks at each stage of a typical pathway from taking the first step through to a potential diagnosis.



## Practical support

In this section you will find all the information and resources that you will need when it comes to the practical things like finding childcare; applying for a school place; accessing funding or support from your local council and health services; or finding national and local sources of support.



**'If you've met one person with autism,  
you've met one person with autism.'**

# What is autism?



**Around 1 in 100 people in the UK have autism, so it's likely that most of us will have met someone with autism. Autism is not a disease. It is a neurological condition that affects the way a person communicates and how they experience the world around them.**

It is also a developmental disorder – something a person is born with and which impacts them across their whole life. Together, these categories mean that autism is often referred to as a neurodevelopmental condition. It is something you can't change and there is no cure for autism.

Autism is also a spectrum condition, meaning that people with autism share certain characteristics but are also highly individual in their needs and preferences.

As a parent, it's important to understand not only what autism is defined as, but what being autistic means for your child.

Healthcare professionals use diagnostic manuals to make medical assessments. The UK uses the DSM-V, the fifth edition of the Diagnostic and Statistical Manual, which outlines the criteria diagnostic professionals use to decide if autism is the right description of the difficulties the person is experiencing.



The DSM-V describes autism as a disorder that affects a person's communication skills and social interactions, including repetitive behaviours and activities. In addition, the DSM-V says that there should be evidence of 'persistent' difficulties across more than one of these categories:

#### **Communication**

**differences:** difficulties using and interpreting speech, written words and non-verbal language such as gestures.

#### **Social interaction**

**differences:** difficulties expressing emotion and recognising or understanding the feelings and intentions of others ('reading' other people).

#### **Repetitive behaviours and activities:**

being highly focused on particular subjects, objects, routines and rituals.

It is also common for people with autism to have difficulty dealing with and processing sensory information – the information their senses send to their brain. If a sense is ‘turned up’ (hypersensitivity) in a child with autism, they might become overstimulated by situations and environments that can cause sensory overload. In situations like this, if the child is made to remain in the overwhelming environment, this could lead to a ‘meltdown’.

The National Autistic Society defines a meltdown as ‘an intense response to overwhelming situations’. A meltdown happens when someone becomes completely overwhelmed by their current situation and temporarily loses behavioural control. This loss of control can be expressed verbally through shouting, screaming or crying; physically by kicking, lashing out or biting; or in both ways.

If their senses are ‘turned down’ (hyposensitivity), they may not react to their sensory environment or seem unaffected by sometimes quite dangerous environments. Some autistic children can also be ‘sensory seeking’, which means they seek out sensory stimulation because they like the sensation of particular sensory inputs.

Repetitive behaviours are also a common feature of autism in children and young people. They can be an essential way of regulating emotion, providing someone with a source of comfort or enjoyment, and enabling them to carry on with their day.

The common name for repetitive behaviours in autistic people is **stimming** – short for ‘self-stimulatory behaviour’. Some forms of stimming are barely noticeable, and some are very visible. They vary in frequency and appearance, depending on the person. Stimming helps autistic people regulate their emotions and process their sensory environment.

Stimming is often an autistic person’s way of managing a situation and reducing stress; as such, it shouldn’t be stopped or reduced. However, stimming can sometimes cause self-injury, for example through head-banging or scratching.

Some forms of repetitive behaviours are often linked to the senses, for example:

**Visual:** staring at spinning objects; staring at lights: doing things to make the vision flicker such as repetitive blinking or shaking fingers in front of eyes.

**Auditory:** listening to the same song or noise on repeat or making vocal sounds; tapping ears and snapping fingers.

**Tactile:** rubbing the skin with hands or with another object; scratching.

**Taste/smell:** sniffing objects or people; licking or chewing on things that often aren’t edible.

**Proprioception:** this is the body’s ability to feel where it is and what it’s doing. This could present in behaviour such as rocking, swinging, jumping, pacing, running, tiptoeing or spinning – all of which give the body’s sense of balance and position a boost. Some autistic children enjoy the sensation of pressure.

Autism is many things but, put simply, it is a different way of viewing and experiencing the world. It is important to understand how autism applies to your child, including their skills and talents. It’s also important to encourage and nurture your child in the things they are good at, as well as supporting them with any difficulties they face. As a parent you may automatically do this, but it may be good to emphasise your praise and support with an autistic child.

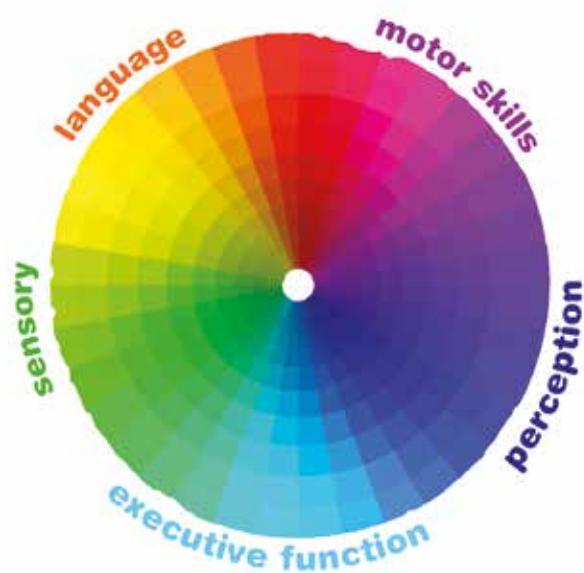
## Autism as a ‘spectrum’

Because there are different levels of complexity, autism is often described as a spectrum. The term ‘autistic spectrum disorder’ (ASD) is, in fact, often used. But this suggests that ASD is a simple sliding scale like this:

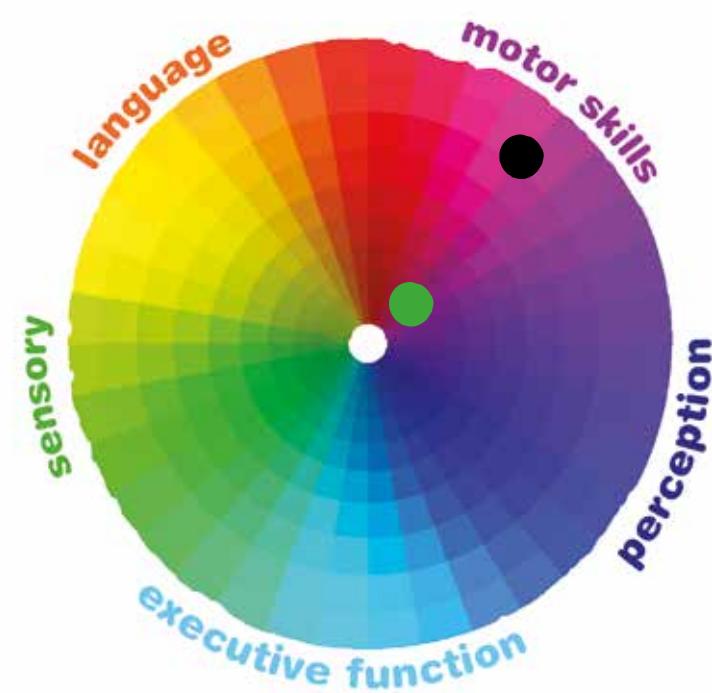
**Not autistic** **Very autistic**

This is misleading. Autism is not a linear scale like this, and we shouldn’t place autistic people on a scale based on our assumptions about their abilities. It is more accurate to say that autism might influence some areas of the brain while other areas will be no different from an average, or ‘neurotypical’, person.

To visualise this more clearly, the spectrum can be thought of as a colour wheel, where characteristics like motor skills and language blend together like the colours of a rainbow:

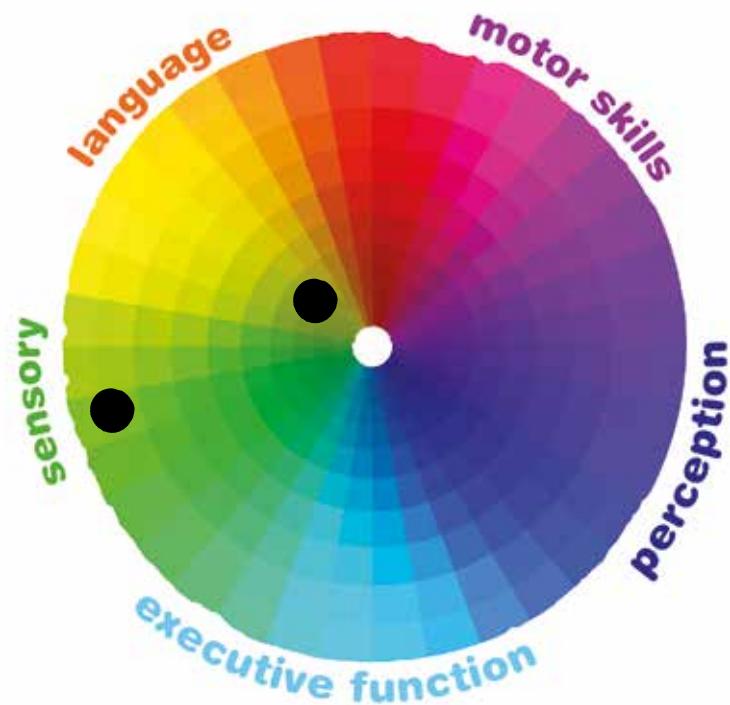


Everyone is different. Some people have highly developed skills in certain areas, while other people find those same things challenging. In the case of motor skills for instance, there are people who can assemble the fine parts of a watch while others may struggle to thread a needle. But let’s assume on our wheel, the watchmaker is shown with the green dot and the person who struggles to thread a needle would be the black dot.

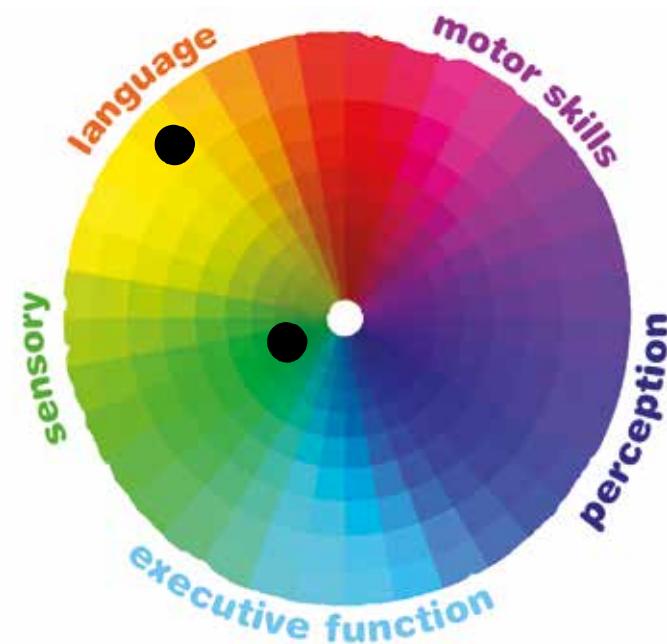




Everyone will have different abilities and skills in different areas of the wheel. For example, one person may be very good at making conversation (language) but may experience sensory overload in loud and crowded spaces. It may be that they function no differently in all other areas. If this was mapped out, it would look like the spots in this wheel:



Another person might be happy in loud crowds but find conversation hard, which would look like this:



Seeing the spectrum in this way illustrates that difficulties in one area don't define a person's skills in all areas. For example, someone who is not good at communicating verbally may just need a different way to communicate. This approach also shows how some people with autism might have highly developed skills in certain areas, such as memory, observing fine detail or knowledge of a particular subject, even though their autism may lead to difficulties in other areas.

So, seeing the spectrum in this way shows that an autistic person is not simply a 'little bit' or 'very' autistic. People with autism can have significant strengths while feeling challenged in other areas. Remember that the DSM-V says that a criteria for diagnosing autism is 'persistent difficulties' across more than one area.

## Autism and girls

Research suggests that four times as many boys are diagnosed with autism than girls. But many think the actual number of girls with autism is likely to be much higher.

The ways in which autism manifests in girls remains under-researched, but we know that girls often display autistic traits in subtler ways than boys.

For example, girls are more likely to take part in imaginative or pretend play, such as playing tea parties with dolls, which is a type of play that children with autism often find difficult. However, in girls with autism, this type of play is often learnt by watching other children and they tend not to go on to develop their own play sequences.

Girls with autism also often have better language skills than boys with autism and their restricted interests may be less obvious (for example, animals or people such as TV characters, rather than objects).

Girls are less likely than boys to show sensory-seeking, repetitive behaviours. There is also research that suggests, perhaps because of greater societal expectations, that many girls try to mask their difficulties, for example by copying the behaviour and appearance of other girls.

Young girls with autism can need a lot of downtime to recover after socialising, as masking and compensating can be very tiring.

All of these aspects can make it harder to identify autistic traits in girls, especially if they don't have additional challenges such as a language delay. It is often said that assessment and diagnostic tools are biased towards boys, in part because most research into autism and how to diagnose it has focused on boys. When a GP, teacher or health worker sees a girl who is socially different, they may be less inclined to wonder whether it could be

autism than in the case of a boy. Other difficulties, such as eating disorders or anxiety, may be diagnosed, while autism is overlooked. This has meant that, in many cases, girls do not receive assessments, diagnosis or support until they are much older.

There is increasing awareness about autism in girls and women but, if you have a daughter with suspected or confirmed autism, you may have to work a little harder at making sure your daughter's difficulties are recognised and supported by you, your family, friends and others in her childcare or educational environment.



To find out more about autism, use the Ambitious About Autism website in the 'Right from the Start resources library' at the end of the toolkit (page 101).





**Does my child  
have autism?**

# Understanding your child

Your child's speech, language and social skills are a useful indicator of their developmental progress. Speech and communication development is not just about using more and more words. It is also about understanding how words are used, for example that 'where is teddy?' is a question requiring a response. It is also about how children interact with the people around them; such as asking for things, telling you what they want and forming relationships with other children and adults.

By the time they are two years old most children will have begun to understand and use simple words that they hear often, such as 'Mummy', 'Daddy', 'ball' and 'teddy'. They will start to take an interest in naming or understanding parts of the body, such as the eyes, head and toes. They will begin to understand that words are linked to activities – for instance, that 'yummy' and 'lunch' are linked to eating, or that 'bedtime' and 'tired' are linked to sleeping. They will have probably started to use gestures such as pointing or shaking their head to mean 'no'.

Between two and three years old they will start to take an interest in what other children are doing. They may want to join in and will be aware of ideas such as 'sharing' and 'playing together'.

If your child does not do these things, it does not necessarily mean that they have autism, but it may suggest that they need a little help and support in these areas. Understanding where they might need extra support will make it easier to provide it yourself or to seek professional help.

All children develop and grow in their own time and in their own way, but there are common developmental 'milestones' such as crawling, walking and talking that generally occur at particular ages. Some children may take longer to reach these milestones, and some may need help getting there.

Use our **Understanding Your Child Checklist** on page 14 to help you understand your child's development. The checklist includes a range of statements relating to speech and communication milestones in children aged two years or older. If you find yourself answering 'no' to most of the statements, you should talk to a speech and language therapist, your GP or health visitor. Regardless of how old your child is, it could indicate autism but may also suggest other forms of speech delay.



For more information about your child's speech development, visit [talkingpoint.org.uk](http://talkingpoint.org.uk). This website includes a detailed progress checker for 0 to 11 years.



To find out more about your child's general development, use the NHS Birth to Five Timeline, in the 'Right from the Start resources library' at the end of the toolkit (page 101).

# Understanding your child checklist

This checklist is based on a range of statements relating to speech and communication in children between 24 and 36 months and is designed as a guide only.



**My child uses about 50 words or more**

yes

no

**My child uses lots of consonant sounds when they talk, like p, b, m, w, k, g, t and d**

yes

no

**My child follows simple instructions like 'show Daddy' or 'find your teddy' or 'put your toys in the box'**

yes

no

**My child understands simple action words such as 'sleep', 'eat', 'run' or 'fall'**

yes

no

**My child has started putting short sentences of two to four words together, like 'more juice' or 'Mummy sit down'**

yes

no

**People understand what my child is saying most of the time**

yes

no

**My child asks lots of questions like 'what's that?' or 'who's that?'**

yes

no

**My child will sit and listen to me reading from simple story and picture books**

yes

no

**My child clearly communicates their need for potty or toilet**

yes

no

**My child enjoys pretend play (making a box into a car or a boat) or pretending to do things like cooking, driving a bus or feeding lunch to teddy**

	yes	no
<b>My child talks about themselves, for example what they like or don't like</b>	<input type="radio"/>	<input type="radio"/>
<b>My child understands simple facial expressions such as when I'm cross or happy</b>	<input type="radio"/>	<input type="radio"/>
<b>My child listens carefully and concentrates when someone is talking to them</b>	<input type="radio"/>	<input type="radio"/>
<b>My child recognises danger and seeks the support of an adult for help</b>	<input type="radio"/>	<input type="radio"/>
<b>My child likes to talk to me or have a conversation</b>	<input type="radio"/>	<input type="radio"/>
<b>My child joins in other children's games</b>	<input type="radio"/>	<input type="radio"/>
<b>My child shows concern if another child is hurt or sad</b>	<input type="radio"/>	<input type="radio"/>
<b>My child enjoys getting attention and wants to show me what they can do</b>	<input type="radio"/>	<input type="radio"/>
<b>My child enjoys playing with a range of toys</b>	<input type="radio"/>	<input type="radio"/>
<b>My child likes imaginative play such as feeding or dressing dolls or cuddly toys</b>	<input type="radio"/>	<input type="radio"/>
<b>My child likes to copy what other children or adults are doing</b>	<input type="radio"/>	<input type="radio"/>
<b>My child enjoys playing with new toys</b>	<input type="radio"/>	<input type="radio"/>
<b>My child turns to me and responds when I say their name.</b>	<input type="radio"/>	<input type="radio"/>





# The autism pathway for children under five years old

# The autism 'pathway' for children under five years old

In most cases the pathway begins by having a conversation in which you raise your concerns about your child's development with your GP, health visitor or a member of staff at your child's nursery, which leads to them making a referral to a team of autism specialists who will carry out the assessments and diagnosis.

What happens after your GP or health visitor has made a referral depends on where you live. In some areas you will be invited for an initial assessment to decide if more information is needed before a diagnosis can be made.

There are different types of assessment processes depending on where you live. Some areas might have a 'screening playgroup' run by a speech and language therapist, and some may involve a health or early years professional visiting you at home or your child at nursery. These assessments are designed to gather information about your child that will help identify their needs.

Depending on where you live, the journey from first suspecting that your child may have autism to reaching a diagnosis can be very long – over a year in some cases. The stages and steps along the journey are often referred to as a 'pathway'.



In some areas you might be referred directly for a diagnosis appointment, normally at a clinic, health centre or child development centre.

In England, the National Institute for Health and Care Excellence (NICE) provides advice and quality standards to health and social care services. Its autism diagnosis guidelines say that every local area should have a multidisciplinary team who will carry out the diagnostic assessment.

This team might include a paediatrician, an educational psychologist, a child psychiatrist or a speech and language therapist. You can find a helpful Who's Who list in the 'Right from the Start resources library' at the end of the toolkit to understand more about these people and what they do.



## How can an autism assessment be important?

An autism assessment can be important for several reasons, regardless of whether or not it leads to a formal diagnosis of autism. It can give you key information about your child's development and behaviour. It can identify your child's strengths and areas where they may have difficulties. It can also help you to access support for your child's development before they start school and throughout their education.

Assessment during the early years can be beneficial because early support is linked to better outcomes in youth and adult years. An assessment will enable your child to access specific support, including therapy or extra help in school or nursery. An assessment can qualify you and your child to access support such as respite and short breaks, and financial help.

It will also provide evidence to support an assessment for an Education, Health and Care (EHC) plan. An EHC plan is a legal document that describes a child or young person's special educational needs, the support they need and the outcomes they would like to achieve. See page 67 for more information about EHC plans.

If your child is not diagnosed with autism, they may have specific difficulties that suggest other conditions such as attention deficit hyperactivity disorder (ADHD), anxiety, attachment disorder, epilepsy, dyslexia, dyspraxia and a wide range of physical health issues. Autism is under an umbrella of wider neurodevelopmental, developmental and learning differences/disabilities. Your child may require further assessments and diagnoses, so this information will still be helpful, as you:

- may be entitled to other forms of support
- can better cater to your child's needs if you know what they are.

What happens following a diagnosis also depends on where you live. Local health trusts and local authorities offer different types and amounts of support. There is no standard model, so it is important to find out as much as you can about the autism pathway and the processes in your local area.

The best way to find out what your area offers is through the Local Offer. This is a source of local information and a directory of local services for children and young people with special needs or disabilities that every local authority must publish by law. In most cases, you should be able to find your council's Local Offer on their website. If you are having trouble finding the Local Offer in your area, you should contact your local Family Information Service.

There is more information about diagnosis on pages 31–32.



To find out more on how to search for your local Family Information Service, use the Coram Family and Childcare Trust website in the 'Right from the Start resources library' at the end of the toolkit (page 101).

## Taking the first step

If you have a concern that your child has autism, the first step is a conversation with your GP, health visitor or a member of staff at your child's nursery.

The professional you speak to will have a few questions about why you think your child has autism, or your concerns that your child is not meeting the developmental milestones. At this stage, you might feel that, by highlighting your child's struggles, you are being overly negative and ignoring their achievements.

Remember that while your child has a wide range of achievements, big and small, the focus of assessments and medical appointments is generally: 'What is wrong and how can I help?'

In order to refer your child for an autism diagnosis, the professional you speak to needs to understand the cause of your concerns so that they can evaluate whether your child needs an assessment.

To do this, they may ask you what you have observed in terms of your child's behaviour or accomplishments. Since this can be a stressful conversation, and your observations may have happened over a long period of time, it is best to write down all the relevant details in advance. This information will help the professional get a clear picture of how your child is developing.

## How to prepare for that first appointment

Since people with autism process things differently, a GP or health visitor's questions will mainly focus on any signs your child is displaying in relation to:

- verbal and non-verbal communication (including understanding the meaning of common words and phrases, facial expressions or tone of voice)
- relationships and interactions with others, such as making eye contact and knowing how to share
- playing with others and imaginative play – their range of imaginative activities and whether they prefer to play alone or with others.

The GP or health visitor will want to find out how these compare with the milestones children would commonly be meeting at their age. The 'Understanding your child checklist' on page 14 can help you with this, so take it with you to the appointment. The GP or health visitor may also ask about the pregnancy, your health and whether there is a history of autism in the family.

To help you collect your thoughts and summarise the information that has led to your concerns, we have created an 'Appointment checklist' on page 21. It is based on questions a GP or health visitor should ask you during an appointment to discuss possible signs of autism. Complete the form before the appointment and use it to help answer the questions. You could always offer to leave a copy for their files; this might help your GP or health visitor when it comes to making a referral.



There are a few things you can do to help yourself at this meeting:

- Remember your child relies on you to be their advocate.
- Remember that you have your child's best interest at heart.
- Collect all the relevant information that explains why you have concerns, in writing or by recording videos.
- Take your partner, a family member or a friend with you for support.

What to bring to the appointment:

- completed 'Appointment checklist' on page 21
- completed 'Understanding your child checklist' on page 14
- any videos you've recorded
- any medical records or documents from previous appointments.

GP appointments are usually only 10 minutes long and there is probably a lot you will want to discuss. It might be useful to book a double appointment, if possible, to make sure you have enough time to talk about your concerns.

Whoever you speak to may say that you should wait and see; that your child is still growing and developing and may grow out of things you've noticed. They could be right, as all children develop differently. As a parent, however, trust your instincts. If you don't think that sounds right, speak to someone else who knows your child or knows about autism.



**Use the 'Understanding your child checklist' on page 14 and the 'Appointment checklist' on page 21 to help if you need to speak to someone else.**

### How to use this checklist

- Use the 'Understanding your child checklist' on page 14 to help you fill this checklist in.
- Use the boxes to make further notes.
- Write down everything you can think of that applies, even if there isn't a question about the topic.



# Appointment checklist

Your child's name

Child's date of birth

 / 

Child's age Years

 Months 

Date of appointment

 / 

with

Your name

Phone number

email address

## “Tell me about your concerns”

**How would you describe your concerns? What are the five key words or phrases you would use?**

1.

2.

3.

4.

5.

**Use this space for other notes and reminders. If someone else has raised a concern, use this space to summarise who it was and what they said.**

**How old was your child when you first started to notice things that concerned you?**

Years

Months

**Looking back from the birth of your child until now, is there anything about their development that stands out in your memory? Think about milestones such as crawling, walking and eating solid foods. Think also about things that might have stood out about their sleep or weaning.**

## “Tell me about your child’s sleep”

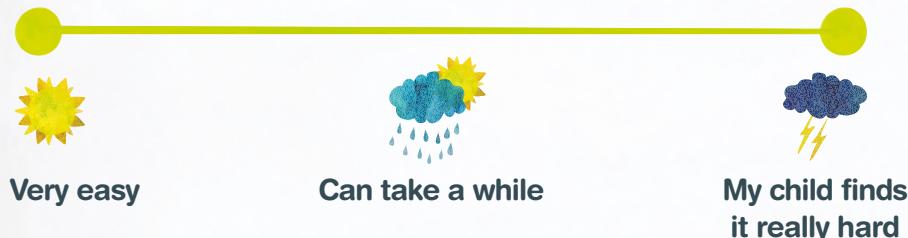
What time does your child normally go to sleep at night and wake up in the morning?

88:88	88:88	_____
Sleep	Wake up	Total hours

If your child sleeps during the day, what time do they sleep?

88:88	88:88	_____
Sleep	Wake up	Total hours

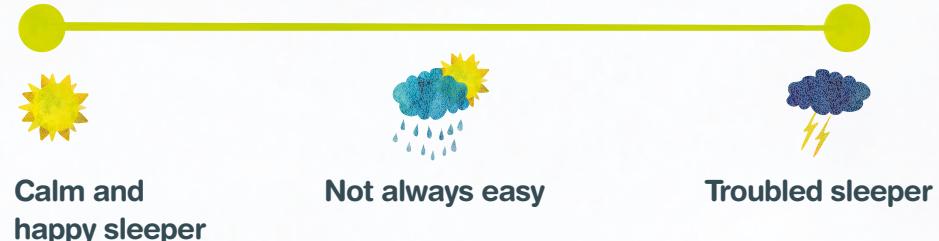
How easy is it for your child to go to sleep?



How often does your child wake in the night?



How has sleep been in general since they were a baby?



Use this space for any other notes about your child’s sleep.

## “Tell me about how your child talks and communicates”

Are there things you think your child should be saying or doing by now? How would you describe your main concerns:

1.

2.

3.

4.

5.

Has anyone – a member of nursery staff or a childminder, perhaps – commented on your child’s speech? If so, what did they say?

Does your child gaze into your eyes and are they comfortable holding eye contact?



Never



All the time

Use this space for any other notes about your child’s communication.

## “Tell me about how your child plays”

How would you describe the way your child plays? What are the top five words or phrases you would use:

1.

2.

3.

4.

5.

‘Imaginative play’ is when a child uses their imagination to pretend to be an astronaut or a bus driver, or to pretend to do things like cook or clean for example. How often would you say your child’s play was ‘imaginative’ in this way?



Hardly ever



Sometimes



All the time

Does your child prefer to play on their own? Will they watch other people and join in with them, such as other children, other adults or family members?



Prefer playing  
on their own



Watches others but  
doesn’t join in



Joins in with others

## “Tell me about how your child plays”

What are the main games, toys, topics or objects that your child is most interested in?

1.

2.

3.

4.

5.

Use this space for any other notes about how your child plays.

## “Tell me about your child’s likes and dislikes”

How much does your child like routine?



Hates routines



Describe their routines.

Your child might regularly do things like clicking their fingers, flapping their hands or doing repetitive movements. Have you noticed anything like this?

If your child is angry or upset, is there anything that they do to soothe themselves?

Our senses include sight, sound and touch. Does your child react negatively/strongly to things such as loud noises, bright lights or sensations like something being wet? Or do they ever seem not to notice or react to these things when others do? Describe how they respond to sensory input.

## “How well does your child eat?”



**The foods they like**

**The foods they don't like**

### What they like to eat for breakfast

### What they like to eat for lunch

### What they like to eat for dinner

### What snacks they eat throughout the day

## “Tell me about you, your child and your family”

How long did the pregnancy last?      Months       Days

Did the mother take any medication  
during pregnancy?      Yes       No

Where was your child born?

Were there any complications or difficulties during pregnancy  
or birth?

Use this space for any further notes about your pregnancy  
and the birth.

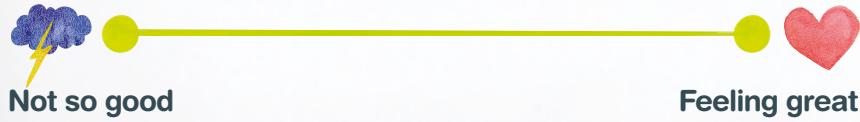
## Your health

How has your health been since your child's birth?



Do you have any ongoing health problems? If so, what are they and are you taking any regular medication?

How would you describe your mood?



Use this space to add some notes or more detail about what you'd like to say about your health. You can also use this space to talk about your partner's health if you think it is appropriate.



## “Has your child had any health problems?”

This isn't about the usual coughs and colds. Think about things like fevers, infections, bowel problems or any other conditions.

### Family history

Think in particular about anyone in your family (uncles, aunts, grandparents, your child's brothers and sisters) who has or may have autism spectrum disorders or other developmental, mental or physical health problems, such as ADHD, a learning disability or epilepsy.

Relationship to your child

Health issue

Use this space for any other thoughts, observations or questions.

## Assessment and diagnostic appointments

A referral may lead to an assessment and, eventually, an appointment for a formal diagnosis. Receiving a formal diagnosis can bring with it a variety of feelings, from relief to anxiety and everything in between. The most important thing is to remind yourself that these appointments are a step forward.

An assessment appointment may be the first time your child will have been required to be present. There are things you can do to help them prepare for the day. Read our section on 'Visual support' on page 54 for tips on how to help them understand what will happen.

The team of professionals doing the assessment will probably have allowed a set amount of time for the appointment and it is likely that there will be another family coming in after you. But don't be rushed. Make sure you say everything you want to say and ask the questions you want to ask.

### What to bring to the appointment:

- the completed 'Understanding your child checklist' on page 14
- a copy of the completed 'Appointment checklist' on page 21 – your child may be older now, so you may want to have an updated version
- any videos you've recorded – the autism team may prefer to observe your child directly but it may be helpful to have videos to illustrate some of your concerns or observations.

You may be referred for further assessments, including blood tests where there may be other health concerns, but it is likely that you will be notified of the outcome of the diagnosis at the end of your appointment.

## Types of diagnostic assessment

The diagnostic process for autism varies depending on where you live in the UK but all processes must follow the National Institute for Health & Care Excellence (NICE) guidelines. To read about the NICE guidelines, use the NICE website in the 'Right from the Start resources library' at the end of the toolkit (page 101).

There are multiple tools that might be used during a diagnostic assessment. These generally collect two kinds of information:

- your description of your child's development
- the professional's observation of your child's behaviour.

Diagnostic tools help professionals to collect information in a consistent way. Current tools include rating scales with questions the professional uses to score your child, based on their observations, discussions with you and other evidence, such as information provided by your child's nursery.

Some rating scales also include **section** for you, or others who know your child well, to complete.

Other tools include: a form of a 'structured' or 'semi-structured' interview (see page 32), in which the professional asks you prepared questions; and tools that look at how your child engages in specific tasks.

Whichever tool is used, the professional conducting the assessment will have received specific training in its use.

Since different diagnostic tools are used in different areas, try to find other parents who have had a diagnostic assessment in your area. They will be able to tell you what to expect during the appointment.



## Commonly used diagnostic tools include:

### 1 Autism Diagnosis Interview Revised (ADI-R)

The ADI-R is a semi-structured interview that looks at social interaction, communication and language, and restricted and repetitive interests and behaviours.

### 2 Autism Diagnostic Observation Schedule (ADOS)

The ADOS is a semi-structured tool assessing social interaction, communication, play and imaginative use of materials. It consists of a number of tasks in which the professional will seek to engage your child and then to observe how they respond and interact.

### 3 Childhood Autism Rating Scale-2 (CARS-2)

The CARS-2 consists of 15 categories that assess a wide range of areas, including relationships, emotions, play, communication and the senses.

### 4 Diagnostic Interview for Social and Communication Disorders (DISCO)

The DISCO is a semi-structured interview that assesses social interaction, social communication and imagination, and repetitive behaviours associated with autism.

### 5 Gilliam Autism Rating Scale-3 (GARS-3)

The GARS-3 assesses restricted and repetitive behaviours, social interaction, social communication, emotional responses, cognitive style (the way your child thinks and how they process and experience the world) and speech.

A single tool is not enough in itself to provide a diagnosis of autism. Rather, it is used along with information from other sources, such as discussions with you, to help the professional come to a conclusion about your child's diagnosis.

## Types of therapy

You may be offered therapeutic support for your child during the wait for an assessment as well as after a diagnosis. The two therapies you are most likely to encounter are speech and language therapy and occupational therapy.

## Speech and language therapy

Children with autism interact and communicate differently. They may find it difficult to communicate using words or to listen to and understand what people say. They may have difficulties understanding the non-verbal rules of communication. They may find it difficult to read emotions or understand when to speak and when to listen.

Speech and language therapists work with you to:

- plan practical ways to make communication easier for you and your child
- identify and plan strategies to support your child to communicate their thoughts, needs and feelings
- help you to implement techniques and strategies to develop your child's attention, interaction and play skills.



## Occupational therapy

Because children with autism experience the world in a unique way, they may use their body in a variety of ways to understand how different things feel: they may spin around, rock back and forth, touch things, smell objects or place lots of things in their mouths. They may also get easily overwhelmed by busy environments and run away or hide to escape unfamiliar places that to them seem scary.

These reactions could mean that your child may be trying to communicate something to you, or they might be trying their best to cope with a situation or difficult environment.

Occupational therapists work with you to identify these traits and develop solutions to make daily life easier for you and your child. This might include:

- helping you to plan and implement routine
- helping you develop and implement strategies to make transitions easier, so that your child can cope with moving from one activity to another
- improving your child's independence and participation in everyday activities
- recommending appropriate calming activities that you can easily do at home.

## Other therapeutic support

Whether you are provided with support by your NHS health trust, local You might receive support from your NHS health trust, local authority special educational needs and disability service, private health provider or a local charity. Whoever provides the therapy or intervention, it should be approved by the NHS or the National Institute for Health and Care Excellence (NICE),

the regulatory body that approves medicines and treatments in the UK. NICE will not approve any treatments unless there is strong evidence of their effectiveness.

If you use a local charity or private health provider, it is important to make sure that their services are approved and delivered by suitably qualified practitioners. Some people choose to use private therapists and charities because they are frustrated by long waiting lists or because they want a service not provided in their area. Either way, it is sensible to let your NHS provider know that you are accessing alternative provision, as it avoids duplication and allows the provider to adjust the interventions planned for your child, if required.

The Research Autism website (page 101) provides information about therapies and interventions, including research findings on their effectiveness. This information will help you to understand the therapy you have been offered and to seek out additional interventions should you think they are necessary. On the website you will find:

- information about interventions
- key principles to consider when choosing an intervention
- independent and impartial evaluations of autism interventions, treatments, and therapies
- questions to ask, such as the aims, costs and risks of an intervention
- 'red flags' and warning signs to look out for – remember, there is no cure for autism, so claims about cures are false and some of the products and activities that you might find could be harmful to your child.



To find out more about the pages above, use the Research Autism website in the 'Right from the Start resources library' at the end of the toolkit (page 101).