Ambitious about Autism

Right from the Start

a guide to autism in the early years

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.

Does my child have autism?

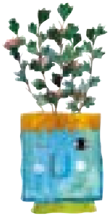
This section will help you if you think that your child may be displaying some of the features of autism.

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.

You, your family and autism

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



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.

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?

Autism is not a disease. It is a neurological condition.

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.

Around 1 in 100 people in the UK have autism. It is not a disease, but a neurological condition that affects the way a person communicates and how they experience the world around them.

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.

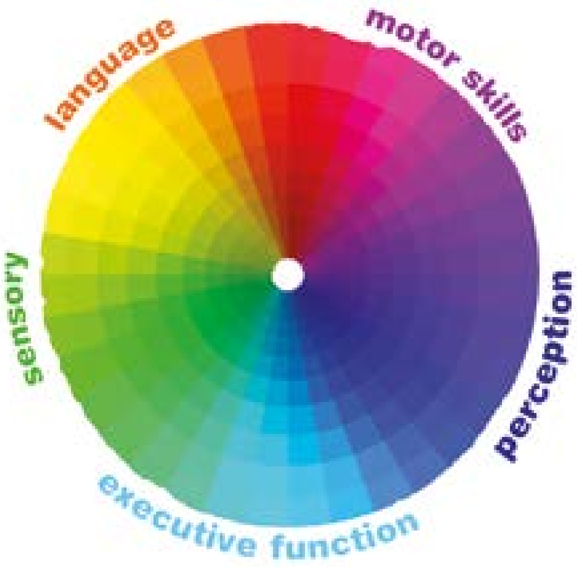
Autism is many things but, put simply, it is a different way of viewing and experiencing the world. It is important to understand how autism applies to your child, including their skills and talents. It's also important to encourage and nurture your child in the things they are good at, as well as supporting 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'

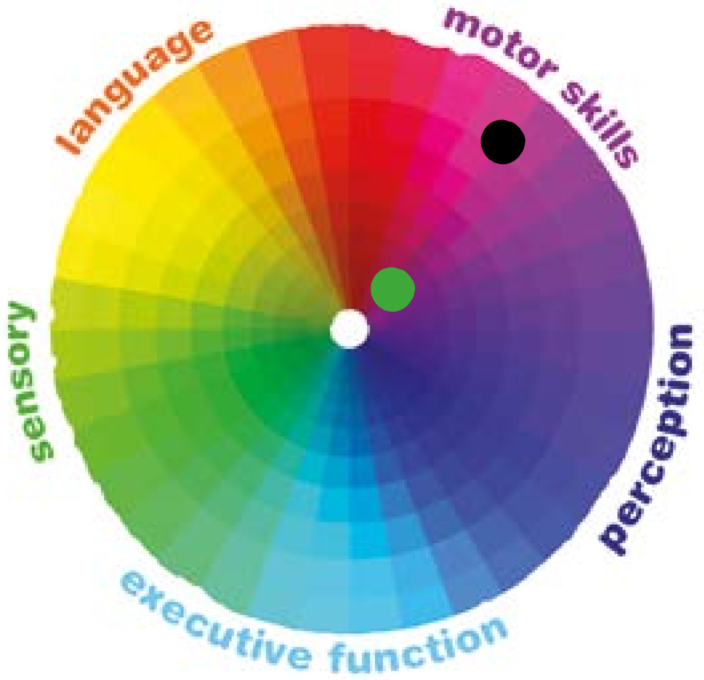
Because there are different levels of complexity, autism is often described as a spectrum. The term 'autistic spectrum disorder' (ASD) is, in fact, often used. But this suggests that ASD is a simple sliding scale like this:

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.

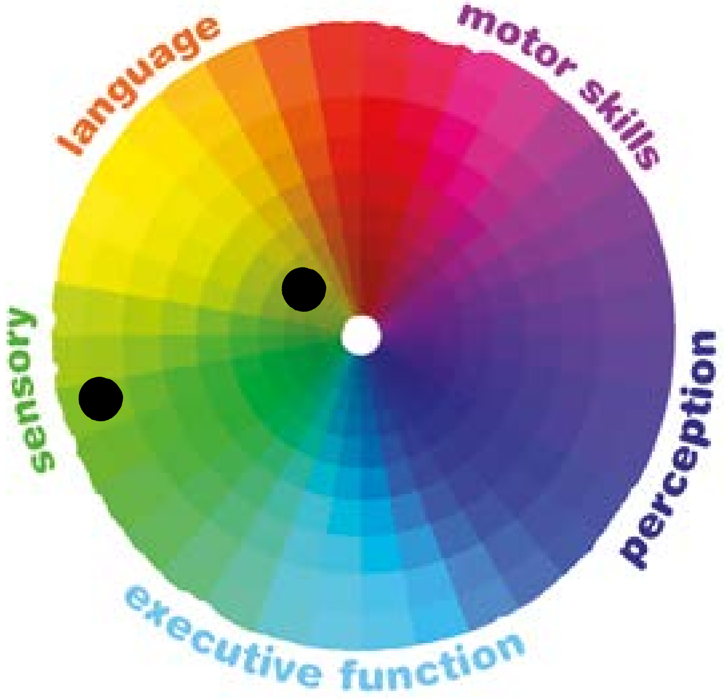
To visualise this more clearly, the spectrum can be thought of as a colour wheel, where characteristics like motor skills and language blend together like the colours of a rainbow:



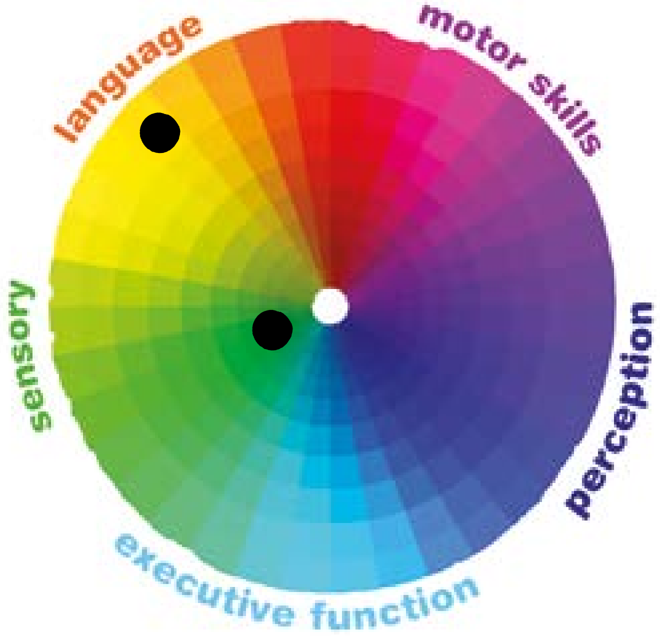
Everyone is different. Some people have highly developed skills in certain areas, while other people find those same things challenging. In the case of motor skills for instance, there are people who can assemble the fine parts of a watch while others may struggle to thread a needle. But let's assume 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 as 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 ican.org.uk/i-cans-talking-point. 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).

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.

Download   Editable

Understanding your child checklist

	yes	no
My child uses about 50 words or more	○	○
My child uses lots of consonant sounds when they talk, like p, b, m, w, k, g, t and d	○	○
My child follows simple instructions like ‘show Daddy’ or ‘find your teddy’ or ‘put your toys in the box’	○	○
My child understands simple action words such as ‘sleep’, ‘eat’, ‘run’ or ‘fall’	○	○
My child has started putting short sentences of two to four words together, like ‘more juice’ or ‘Mummy sit down’	○	○
People understand what my child is saying most of the time	○	○
My child asks lots of questions like ‘what’s that?’ or ‘who’s that?’	○	○
My child will sit and listen to me reading from simple story and picture books	○	○
My child clearly communicates their need for potty or toilet	○	○
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**
My child talks about themselves, for example what they like or don't like	○	○
My child understands simple facial expressions such as when I'm cross or happy	○	○
My child listens carefully and concentrates when someone is talking to them	○	○
My child recognises danger and seeks the support of an adult for help	○	○
My child likes to talk to me or have a conversation	○	○
My child joins in other children's games	○	○
My child shows concern if another child is hurt or sad	○	○
My child enjoys getting attention and wants to show me what they can do	○	○
My child enjoys playing with a range of toys	○	○
My child likes imaginative play such as feeding or dressing dolls or cuddly toys	○	○
My child likes to copy what other children or adults are doing	○	○
My child enjoys playing with new toys	○	○
My child turns to me and responds when I say their name.	○	○

Download **Editable**

The autism pathway for children under five years old

How the autism pathway begins

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 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.

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 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.

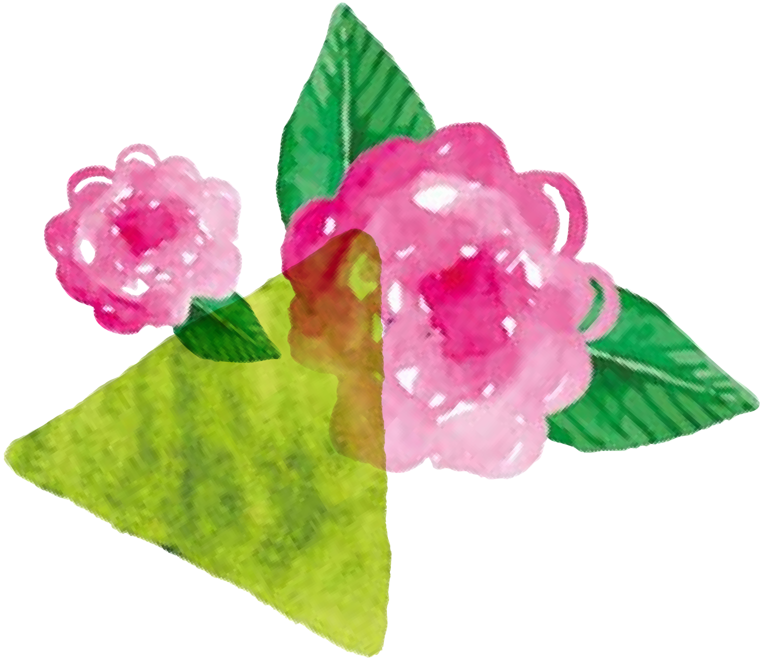
Whoever you speak to may say that you should wait and see; that your child is still growing and developing and may grow out of things you've noticed. They could be right, as all children develop differently. As a parent, however, trust your instincts. If you don't think that sounds right, speak to someone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

Download Editable



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.

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

Years ☐ **Months** ☐

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.

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.

Download Editable

“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 Sleep	88:88 Wake up	________ Total hours

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

88:88 Sleep	88:88 Wake up	________ Total hours

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

Very easy

Can take a while

My child finds it really hard

How often does your child wake in the night?

Rarely

Occasionally

Every night

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

Calm and happy sleeper

Not always easy

Troubled sleeper

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

Download

Editable

“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.

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

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

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

Download Editable

“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.

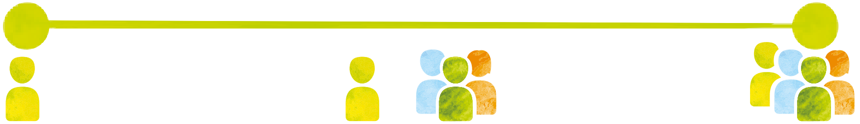
5.

‘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

Download **Editable**

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

Loves 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.

Download **Editable**

“How well does your child eat?”

Very fussy eater

Enjoys eating

Mainly prefers
one food

Enjoys lots of
different foods

The foods they like

The foods they don’t like

Download

Editable

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 the pregnancy and the birth.

Download

Editable

Your health

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

Not so good ○————————○ Feeling great

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?

Not so good ○————————○ Feeling great

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.

Download

Editable

“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

Download

Editable

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 and 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 sections for you, or others who know you 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

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).

You, your family and autism

Living with autism

When professionals talk about children with autism, developmental delay or special educational needs, they often refer to them as having 'additional needs'.

In many ways, as a parent of a child with autism, you also have additional needs. As well as bringing up a family, you have to learn about the condition, navigate a 'system', be an advocate for your child, and deal with your emotions and those of the people close to you. There is a lot to do and a lot to think about.

In this section of the toolkit we cover areas such as looking after yourself, dealing with autism in the family and looking at ways in which you can be the best help for your child whatever stage you are at – whether you are waiting for an assessment or have had a formal diagnosis.

Find our list of '10 tips for parents' on page 36 to get you started.

10 tips for parents

1. **Be informed about autism,** but focus on your child's need and not the label. There is a lot of information out there and it's easy to become overwhelmed. But, every child with autism is different. So, focus on what you need to do to support your child and their needs at each stage of their journey, and take it one step at a time.

2. **Your child has their own unique personality** just like every other child. Love your child for who he or she is. And don't think that they don't love you, even though they may not say it or ask for cuddles. You are the centre of their universe.

3. **Don't push your feelings away.** Talk about them. You may feel angry or overwhelmed. You may find yourself worrying about a future that is still years away. These thoughts are normal and it's okay to tell people that this is how you feel. No one is judging you – and people around you probably understand more than you think.

4. **If you feel angry,** be angry with the situation or the challenges you and your child face. It doesn't help to be angry with your loved ones. If you find yourself arguing with your family over an autism-related issue, remember that the issue might be a difficult one for them too.

5. **Remember that you have a life too.** Don't let autism consume every waking hour. Make time for yourself. Spend quality time with your other loved ones and try not to be constantly talking about autism. Everyone in your family – including you – deserves to be valued, noticed and happy, despite the challenges you may be facing.

6. **Appreciate all your child's victories, no matter how small.** Focus on what they can do. Work with your child's strengths and accept their special interests. Try not to make comparisons with other children.

7. **You're not alone.** Make friends with other parents who have children with autism and who understand your day-to-day challenges and the feelings you experience. Try to build a community of supportive and understanding people.

8. **Take advantage of all the services and activities** for autistic children available to you and your child. Accessing autism-friendly services is an easy way to surround you and your child with people going through similar things, and those who are more understanding of your situation.

9. **Consider integrating** your child early on by attending 'mainstream' services and activities. Don't be put off if your child is the only autistic child there. It is not up to your child to 'fit in'; it should be up to the activity to accommodate your child.

10. **Get involved.** Being a champion for autism can be empowering and productive. You may feel frustrated by a lack of support or other people's attitudes. Use that energy to bring about the change you want to see.

Download

Looking after yourself

Your journey on the pathway is likely to be a long one and the build-up to a child's diagnosis is something you have most likely been anticipating for quite a while. Nevertheless, it is a momentous event. Over the course of the journey there will be times when you need to take stock of your emotions and adjust to the possibility, or the confirmation, that your child has a lifelong condition.

Some people might very quickly see the positives about a diagnosis and will feel positive and hopeful. Some people may take longer to get there. In the next section, Clinical Psychologist Giulia Maccarini reflects on dealing with difficult emotions.

Some thoughts on resilience and self-care

by Giulia Maccarini BA Psychology, MSc Neuroscience, Autism Specialist

Every stage of the journey can feel hard. All the steps from referral to diagnosis can be full of doubts. You may experience periods of uncertainty and anxiety. And getting an official diagnosis can be extremely hard; learning your child has autism will affect not just them but your entire family and those close to you. Right from the beginning your role as a parent/carer will change and that can lead to a range of emotions and reactions. However you are feeling right now, it can help to remember that getting an early assessment will enable your child to receive early intervention.

To some parents the prospect of autism is a shock. To others it is the confirmation they needed, while still others experience denial. It is important to understand that all of these feelings – including denial – are normal.

Parents-to-be often idealise their child from the moment they find out they are having a baby, some even before that. They imagine what they will look like, what characteristics they will inherit, what their likes and dislikes will be, whether they will have friends, learn other languages, or travel the world.

Some parents of autistic children have described feeling as though everything they had hoped for and imagined for their child had been taken away. For some parents, the process might trigger a sense of grief; a feeling that they have lost the child they dreamed of and that another child has been given to them. This sense of grief can come with a range of other feelings.

You might feel sad. And feeling sad is normal. Allowing yourself to feel sad can help you to grow and understand. You might also feel angry, and anger is also a natural part of the process. Expressing those feelings is a healthy way to better understand yourself and how autism impacts you as an individual and as a parent.

The journey through autism in the early years can also feel very lonely, especially since parents can have different reactions. A couple raising a child together can have different views and feelings around the diagnosis. Having different perspectives can make you feel isolated from one another and overwhelmed. Don't deny or ignore your feelings. Anger, sadness and loneliness are all part of the path to acceptance and part of what will make you more resilient.

Build your resilience

Resilience is defined as 'the capacity to recover quickly from difficulties'. The act of building resilience comes from focusing on your feelings, practising acceptance and learning to get up when you fall. It's important to shift your focus from thinking to doing. In times of adversity there is nothing to be gained by feelings of blame or regret. Focus instead on what you have to do; having a purpose can motivate you to persevere through the process before and after diagnosis.

Build a network

Having a network of people who understand and support you will help increase your resilience. Knowing that you are not alone, and being brave enough to ask those around you for help, is a more efficient use of your energies and can motivate you to persevere despite the hardships.

Take care of yourself

Caring for a child with autism can be both emotionally and physically draining. Finding space to care for your own personal needs is not easy, and might take time, but is vital for your health. If you've ever travelled by plane, you will have heard the safety instructions at least once: 'Put on your own oxygen mask first, before helping others.' You need to follow the same principle; you can't help anyone else without helping yourself first. It often doesn't take much – sometimes just going for a walk will give you the space to breathe so you can begin to feel like yourself again.

Focus on the positive

When difficult days happen, we tend to focus solely on what made it hard and we rarely reflect on the positive things we've achieved or that also happened during the day. Today might not have been the best but make a point of identifying the good things and celebrating the positives. Write a short list of what was good that day. You'll be surprised by what you find.

Give yourself time

You don't need to strive for acceptance straight away. It's OK to have negative feelings towards a possible or confirmed diagnosis. Difficult emotions can't, and shouldn't, be buried. These thoughts will always try to get in and they are likely to be persistent. But, in the same way we can choose not to answer a ringing phone, we can – with practice – choose not to let certain thoughts take hold.

Be realistic

There's no perfect mother or father, but every parent is doing what they can to help their child.

Explore interests outside of the autism world

Keep in mind that you are more than just a parent of a child with autism or special needs. Exercise, go out for a meal, read a book, watch a movie or take up a hobby. Look after yourself so that you can look after your child.

Ask for help

If you have trouble working through your feelings and emotions, seek the help of your partner, your parents, your friends, your GP, a support group, a psychologist or a professional in counselling. There is no shame in asking for help to cope.

A final thought. There is a popular folktale in which a group of a wise advisers tell a king that, whatever problems or triumphs he faces, he should always remember that ‘this too shall pass’. It’s true. Bad moments will pass, and good moments will too. The uncertainty, the difficult moments, the much-celebrated victories – all will come and go. Events and emotions are like waves. We can’t stop them from coming, but they always roll over us and, just as in the king’s story, they too shall pass.

Talking to your family and friends about your child’s needs

Telling your family and friends that your child may be autistic can be difficult. Some family members might dismiss your concerns, suggesting ‘they’ll just grow out of it’, or that your child’s behaviours and actions are something to do with the way you parent. Some family and friends will be incredibly supportive and will want to know what they can do to help. Reactions can vary widely, but it’s important to share. Autism doesn’t only affect the child – it affects the entire family and even your close friends.

It might help to keep people informed about where you are on the journey. You could start by explaining that although your child may not have had an assessment or diagnosis yet, you and the professionals that you have spoken to are concerned about your child’s development and feel it’s important to check things out. It can be helpful to explain what you have been through – how you (or someone else) became concerned, that you spoke about it with your GP or another professional, and that they suggested a referral for an assessment.

Talking about a possible diagnosis of autism might help your family and friends to understand that there is a reason for some of your child’s behaviours. They may even have noticed some of these behaviours already; for instance, that your child only likes to play with one thing, doesn’t speak or doesn’t like certain textures or sensations.

Educate your family and friends. Tell them about what you've learned:

- Autism is a spectrum with varying degrees of complexity.
- Children with autism often have difficulties with their communication and their ability to interact with others, and may have restricted or repetitive patterns of behaviour.
- Children with autism experience the world differently and can be under- or oversensitive to sensory information.
- Children with autism can have highly developed skills and abilities.
- You are seeking an assessment to provide you with important information about your child's behaviour and development.

If those around you understand why your child displays these behaviours, they might stop worrying about them, or having unhelpful opinions about them, and begin to accept and work with them.

You should be prepared for people who won't, or can't, understand or accept what is happening. Some friends and family members may say that you are being overcautious or that your child's development is just a bit delayed. This may simply be the view of someone who doesn't live with your child on a day-to-day basis. It may take them longer to come to terms with what you are telling them about your child.

If someone from a health team or your child's nursery has suggested some tips or strategies to support your child's development, consider sharing these with your family and friends. You can achieve more if everyone is working towards the same goals.

Involving your family and friends

Everyone around you can help you to suppport your child with autism. Encourage your friends and family members to learn about autism and keep believing in what you are doing. Despite any differences you may have, try to focus on the love you all share for your child.

To help you to start a conversation with your family and friends and suggest ways in which they can help and support you, we have produced '10 tips for grandparents and other family members' on page 41.

If your child has siblings, it is important that they feel involved and informed. We have produced 'Tips for brothers and sisters' on page 42 to help them understand their own journey as the sibling of a child with autism.

These were written with older children in mind. If your child's siblings are very young, use the tips to start your conversation with them about their sibling with autism.

10 tips for grandparents and other family members

1. **Ask how you can help your family as they support your loved one with autism.** Every family member has something to offer and your efforts are bound to be appreciated. Showing support can come in many ways, whether it's looking after the child for an hour so that their parents can have some free time, helping to find local support services, or even helping to fundraise for your loved one's school or nursery.

2. **Learn more about autism and how it impacts your loved one.** Around one in 100 people are autistic and it affects every one of them differently. It may be a lifelong condition but it isn't a life sentence. A young child with autism has a rich and promising life and, as they grow, you will learn their likes and dislikes, their talents and their challenges – just like any child. Share that sense of hope with your family.

3. **Look for support for yourself.** If you find it difficult accepting and dealing with the fact that your loved one has autism, seek out your own support. Your family are dealing with their own emotions, so they may not be able to provide you with support. Find a trusted person outside of your family to talk to.

4. **Be open and honest about autism.** It may be hard to talk about it at first but, as time goes on and as you learn more about autism and your feelings about it, it will be easier.

5. **Put judgement aside.** Consider your family's feelings and be supportive. Respect the decisions they make for their child with autism. They are working very hard to explore all options and reach well-researched conclusions.

6. **Try not to compare your loved one to other children.** All children develop at their own rate and each child has their own strengths and gifts.

7. **Make special time for every child in the family.** You can enjoy special moments with family members who develop typically and those with autism. They all enjoy spending time with you.

8. **Children with autism thrive on routines.** Find something that you can do together that is regular and structured, or is linked to something the child is particularly interested in. Even if it's just watching the trains in the station or doing a jigsaw.

9. **Focus on your loved one's needs and not the label.** There is a lot of information out there about autism and it's easy to become overwhelmed with it all. Every child with autism is different. Focus on what you need to do to help support the autistic child in your life at each stage of their journey, and take it one step at a time.

10. **Learn how to be an advocate for your loved one with autism.** Learn how to stand up for them, how to educate other people, and how to love them for who they are. Understand that people are often fearful of things they don't know or don't understand, and that judgement comes from ignorance. You have the opportunity to share your knowledge and to help others feel more understanding of, and more comfortable with, all people with autism.

Download

Tips for brothers and sisters

1. **Be proud of your brother or sister.** There's no reason not to be open when you're talking to your friends about autism. If you are embarrassed by your brother or sister, your friends will sense this. It will make it awkward for them and could make it harder for you.

2. **Love your brother or sister for who they are.** You would want them to do the same for you. Try to highlight what your sibling is good at; we all want to be recognised for our strengths.

3. **Even though you love your brother or sister, sometimes you may feel as though you do not like them.** That's okay – all brothers and sisters feel like that at times.

4. **If you're finding it too much, make sure you tell someone.** Don't bottle up your feelings. If you feel you can't talk to your parents about it, try finding someone else who will listen. There are other people you can talk to who care about you, like your teacher or other family members.

5. **Remember your parents may be struggling too.** Try not to take it out on them. Everyone finds it difficult and everyone is trying to do their best.

6. **You are not alone!** Almost everyone has something to face in their families. Ask your friends – they'll all have a story to tell. And lots of families have children with autism.

7. **Do things together as a family but also spend some time with your family members without your brother or sister.** You need to feel important too. Speak to your family if you feel left out. They'll understand. They probably won't realise until you mention it.

8. **It's okay for you to want time alone.** Having a brother or sister with autism can be tiring and frustrating. Sometimes it helps just to have a bit of space.

9. **Find something that you and your brother or sister enjoy doing together.** You will find it rewarding to connect with them, even if it's just a simple thing like doing a jigsaw puzzle. What's boring to you might be really exciting to your brother or sister. So, just join in. They'll be so happy they can share that with you.

Download

Notes

Supporting your child

Whether you are at the referral stage or have a diagnosis, you are still your child’s primary carer and their first teacher.

Many of the challenges that parents or carers of young children face, such as weaning or getting a child into a sleep routine, are often more challenging when your child has additional needs or a disability. A survey of parents of children with autism conducted by the University of Warwick for Ambitious about Autism revealed that the areas parents most want help with are:

Sleep **Eating** **Toileting** **Behaviour**

There are people and services who can help with these challenges and there are training courses that cover many of these topics. However, they are not always available. Check your council’s Local Offer pages for information about local support services and courses, or ask your health visitor or local children’s centre. Many children’s centres run parenting groups or have access to specialists who may be able to help and advise you.

Contact, the national charity supporting families of children with special needs and disabilities, has a comprehensive range of information and resources for families of children with special educational needs and disabilities.

Contact has worked with a wide range of specialists and professionals to produce the following helpful guides, which cover the four topics highlighted in the Ambitious about Autism survey. The guides are not specific to autism but contain helpful information that applies to all children for whom sleep, eating, toileting and behaviour can be challenging, whatever the reason.

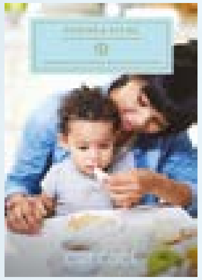
Click on the pictures to download each **Contact guide**:

Helping your child sleep
(36 pages)
contact.org.uk/parent-guide-sleep

Includes:
- Why sleep can be a problem
- Bedtime routine
- The sleep cycle
- Avoiding bad habits
- Melatonin
- Getting support

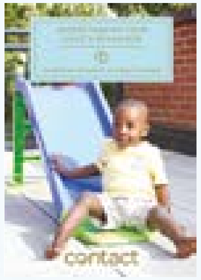
Potty/toilet training
(12 pages)
contact.org.uk/parent-guide-toilet-training

Includes:
- What do we mean by toilet training
- When should you start toilet training
- Once you start
- Children who find it hard to communicate
- If your child takes longer to use the toilet
- Useful contacts



Feeding and eating
(12 pages)
contact.org.uk/parent-guide-feeding

Includes:
- Physical problems that affect eating/feeding
- Eating independently
- Equipment and utensils
- Diet
- Hints/tips around mealtimes
- Useful contacts



Understanding your child’s behaviour
(76 pages)
contact.org.uk/parent-guide-behaviour

Includes:
- Why children behave in certain ways
- Setting the scene for good behaviour
- Managing specific issues
- Responding to behaviour that challenges
- Looking after yourself
- Who can help

What you can do to help your child's communication

Many of the characteristics of autism relate to communication difficulties, so it is important to support your child's communication development. Here are 10 tips to help you.

Follow their lead

Follow your child's lead, rather than directing them. They will be more likely to pay attention to the activity and focus on the same thing as you if they are interested and motivated to begin with.

Be face to face

Face your child and get down to their eye level when communicating so that they can see the variety of facial expressions used in communication.

Copying

Copy your child's actions and sounds. If they use a sound like 'vroom' instead of 'car', don't correct them – just go with 'vroom', because you both know what they mean. If they bang the spoon on the table, and you do the same, it is likely that they will pay attention to you. This can help your child begin to understand the power of communication.

Get involved

For example, if your child is lining up their cars in a row, join in by handing them cars one by one. If they are only interested in throwing the toys on the floor, you could use a basket to collect them before giving them back. Show your child that you're interested in the same things as them and that interaction can be rewarding and interesting too.

'High-interest' objects

Blowing up a balloon and then letting it go so that it flies up in the air usually gets a child's attention. Blowing bubbles often has the same effect. If things like balloons and bubbles get your child's attention, then use them to encourage two-way communication. Blow up the balloon part-way and wait for a response before blowing it up to its full capacity. Blow a few bubbles, then close the container and wait for a response from your child before you blow any more. Don't continue if your child reacts badly, just try a different 'high-interest' object that will get their attention in a positive way.

Encourage requests

Place favourite toys or foods somewhere slightly out of reach, on a shelf, for example, where your child can see it but is unable to reach it. Alternatively, place the favourite object in a container that is difficult to open, such as a plastic container. This will encourage your child to ask for help and result in an interaction.

Give them things gradually

For example, if your child wants a biscuit, you could break it into small pieces. Start by giving them one piece and then gradually give them more once they have communicated a request for it.

The words you use – 'less is more'

If your child does not yet talk much or at all, then build up the use of words gradually. For example, if your child just uses the name of a toy they reach for, just add one more piece of information to what they say. For example, if they say 'car', you can reply 'yes, blue car'.

Use gestures and visual supports

When offering a drink, mime the action of drinking. Nod or shake your head for 'yes' and 'no'. Wave your hand for 'hello' and 'goodbye'. When talking about people – for example, 'Grandma is staying' – show a photo of who is being spoken about. When you go out, show a photo of where you are going.

Most of all – have fun playing together!
Don't force any of these things. If they're causing distress then stop. Use these tips as a starting point to find what works for you and your child.

Supporting your child's play

All young children enjoy and benefit from play. Children with autism are no different. But play is more than just fun. It is very important developmentally. It is the way in which every child explores the world and makes sense of it as they grow and learn. Play also helps children to develop important physical and social skills.

Sometimes, play can look different in young children with autism. They may be interested in only a very small range of toys – possibly only one or two – or they might do the same thing over and over. Your child might not use toys in the way you would expect them to. For example, they may be interested only in spinning the wheels on a toy car rather than pushing it along the floor.

Autism affects the development of social skills and communication skills. Play provides a useful opportunity to help nurture and develop some of these skills. By helping your child to play, you can also help them to develop their imaginations, and social and communication skills. For example, they can learn about taking turns, asking for help and making choices.

Below are the six main types of play, with specific suggestions for helping your child:

- ✓ **Exploratory play:** learning about the world and your body by exploring different textures, shapes and sizes.

  You can help your child's exploratory play by joining in and encouraging them to explore a wide range of shapes, textures and sensations, including water, sand or foam.

- ✓ **Interactive play:** playing with toys that require your child to do something such as press a button, to make something happen.

  Your child may work out how to use the toy themselves or you may need to help by showing them. Either way, be sure to praise your child when they get it right, and encourage them to explore other toys that use the same cause-and-effect principle. This will help them to understand that their actions have effects and give them a sense of control in their play.

  Cause-and-effect toys are also a good way to teach your child how to ask for help and to play by taking turns. For example, you could take turns pressing a button to make something pop up and then take turns pushing it back down again. To help communicate these ideas, say simple things like 'Mummy help' or 'Daddy's turn'.

✓ **Toy play:** playing with toys as they were designed to be used, for example throwing a ball or pushing a toy car.

Try not to overwhelm your child with too many choices. Offer two or three toys at a time and let them choose which one to play with.

Join in with your child. Sit in front of them so that you can watch each other use the toy. Join in the play, rather than instructing your child. Begin by copying what they do with the toy, then ask for your turn and introduce a new action. If your child likes squeezing a ball, do the same but throw it in the air or roll it towards you before squeezing it.

If your child doesn't copy you, encourage them by saying, 'Your turn to roll the ball.' Or guide your child's hand in the rolling action.

Use frequent praise in clear language. For example, say, 'Good throw. The ball went a long way!' You can use rewards such as blowing bubbles or something else that your child enjoys.

Look out for signs that you child is losing interest or getting frustrated. Before this happens, try to end on a positive note, with your child having accomplished something.

✓ **Constructive play:** building or making things – such as building a tower out of bricks, drawing a picture or completing a jigsaw puzzle.

Start by showing your child what to do. If your child struggles with a task, break it down into smaller tasks. For example, if your child is struggling to complete a jigsaw, you could encourage them just to do the final piece, before gradually introducing more pieces to complete the jigsaw. That way, things stay more positive because your child always succeeds.

Start with simpler tasks and make them more challenging as your child's skills develop, such as jigsaws with more pieces, or using smaller bricks for a tower.

✓ **Physical play:** physical activities such as running, jumping or dancing that use the whole body help your child build muscle and improve coordination.

Physical play gives children the experience of interacting with other people and objects in their surroundings. Playing outside gives your child the chance to explore the natural environment, have adventures, discover their physical limits and build self-confidence.

When your child is outside, they probably have more space and freedom for big movements, like running, jumping, kicking and throwing. Such activities are good for your child's health, fitness and physical development. Outdoor play can also mean more mess – and more mess often means more fun.

- ✓ **Pretend play:** pretending and using your imagination during play. Examples include dressing up or pretending to have a picnic with dolls and teddy bears.

  Using their imagination during play helps your child develop language, communication and social skills. This type of play is often delayed in children with autism, but many children can and ultimately do develop pretend play.

Social play skills for children with autism

Social play skills usually develop and evolve gradually from playing alone (solitary play) through to playing and cooperating with others. The ability to play with others can be particularly challenging for children with autism.

The four key stages of social play were developed by American sociologist Mildred Parton Newhall in the 1920s and are still widely used to describe children's progression through different and more complex types of play. Whatever stage your child is at, there are things you can do to help them move on to the next stage:

- ✓ **Solitary play:** when your child is alone and is playing independently. Whatever stage your child is at, they're likely to want to spend time playing by themselves. It's OK if your child wants to play alone some of the time.

- ✓ **Parallel play:** when children play alongside each other, often separately from other children but perhaps watching them or mimicking their actions. This type of play is seen as a transition stage to more social and cooperative play. You can help to promote parallel play by encouraging your child to play alongside other children, including siblings and cousins, or through 'play dates'.

- ✓ **Associative play (playing and sharing with others):** the stage at which children begin to interact with other children, often through sharing, taking turns or coming up with ideas or suggestions. Encourage your child to begin incorporating these things – for example by encouraging them to swap toys or do something similar to another child, such as ride a bike if the other child is using a scooter.

- ✓ **Cooperative play:** involves games and activities such as hide-and-seek where there might be rules or when you need to work together to make something like a den or a sandcastle.

  Cooperative play can be complicated and usually involves communication skills. The social rules involved in this type of play can be difficult for children with autism. You can help your child by using clear and simple instructions. For example, you could say something like: 'First, you hide somewhere in the garden. Then Jo counts to 10. Then Jo comes to find you. When Jo finds you, it will be your turn to count to 10 while Jo hides. Then you have to find Jo.'

  It can also help to explain the rules of the game using visual support such as pictures or 'social stories' (see pages 54 and 58). Making games more visual can also help. If you are organising a game of tag, for example, you can mark the person who is to be chased with a scarf or a piece of cloth.

Making the most of play

Play is a useful tool to help you build skills in other areas. For example, you might focus on communication skills by asking your child to describe what is going on in the game or encouraging them to choose what to do next. You can use play to develop social skills such as taking turns by offering praise and simple rewards.

Here are some tips for using play in this way:

✓ Talk about what's happening while your child plays. Use the names of objects, like 'car', 'ball' and 'paint brush'. Gradually add single words such as 'blue' to 'car' and 'big' to 'ball'. You can also give words to the things your child is doing, for example 'feed teddy'. Over time, you can build longer sentences.

✓ Use play to help your child settle into new environments. For example, if your child likes building towers with blocks, encourage them to build a tower with other children at a friend's house.

✓ Use play to support everyday routines such as bath time.

✓ Opportunities for play happen all the time. If your child is interested in an object that they see, use it to create a game, for example 'find the hairbrush'.

✓ Use play to help your child cope with social rules or situations that they might find challenging. For example, hold a birthday party with teddy bears and dolls to explain what will happen when your child is preparing to go to a friend's birthday party.

✓ Use play to help your child develop everyday skills. For example, dressing a doll or changing in and out of dressing-up costumes can help your child learn to dress themselves.

✓ Use play as an opportunity for you and your child to have fun together.

Going out and about with your child

There is often still a lack of awareness about autism in society. This can lead to uninformed people misjudging autism as 'naughty behaviour'. This in turn can have a big impact on your emotions if your child begins to struggle in a public place.

As a parent, you may feel a range of difficult emotions such as shame, guilt, anger and helplessness, if you're out in public with your child and they are struggling to cope. It can be difficult to feel like a good parent if your child is having a meltdown due to sensory overload, or 'stimming' (see page 8) to self-regulate and soothe themselves. It's harder still if you feel like others are judging you.

People may be better able to understand your child, and how they can help, if you share information about them. We have created a simple 'My one-page profile' (see pages 52–53) to help you to describe your child's needs and preferences to others when you're visiting community settings such as playgroups.

You can use the 'My one-page profile' when your child starts nursery or if you want to attend activities such as a Stay & Play or music and dance sessions. Give a copy to the group leader so that they understand your child's needs and preferences.

Your child has the right to be integrated into the community and to experience life outside the house, even if their actions and behaviours look different.

One-page profile

How to use 'My one-page profile'

My diagnoses
Use this space if your child has a formal diagnosis. Briefly describe the outcome of the diagnosis. List all the conditions, such as epilepsy, speech disorder, and so on. If you don't have a diagnosis yet, use this space to describe your situation, for example: 'I have been referred for an assessment' or 'I am receiving speech and language therapy'.

My medication
Describe what medicines your child needs and when and how they are administered, for example: only by you, when needed or by agreement with you. Leave blank or write 'none' if your child does not need any medication.

My allergies
Leave blank or write 'none' if your child does not have any allergies. If there are foods they really don't like or react badly to, use the 'Things I don't like' box to describe them.

How I like to play
Use simple phrases, for example: 'I like to play on my own', 'I like to play in small groups' or 'I like toy cars/cuddly toys', and so on. Also use this space to describe how your child likes to be with other children. Be honest but be positive, for example: 'I like to play with other children but find it hard to share sometimes'.

How I talk and communicate
Describe your child's language. For example: 'I don't use many words' or 'I understand instructions better if you point or use pictures'.

Things I like
This could include special interests, friends, certain clothes, being cuddled or being left alone, or actions such as flapping, dancing, running, humming, and so on.

Things I don't like
This could include sensory stimuli such as bright lights and loud noises. It could also relate to communication-related issues such as direct eye contact.

Things that help when I'm upset
Use this space to describe the things your child might need in order to be soothed or the things they do to soothe themselves. This may be things like having a favourite toy or comforter, or getting a cuddle.

Things that show I'm upset
Use this space to describe the kinds of behaviour your child starts to display if they get agitated or upset. These might include covering their ears, making noises or repetitive movements.

Things I'm good at
Use this space to describe your child's strengths, talents and abilities. Ask your child what they'd like to say in this box.

Download Editable

My one-page profile

My name is

My date of birth is / /

My parent/ carer is

Their phone number is

Their email address is

My diagnoses

My medication

My allergies

In the boxes below I have listed the things I like and don’t like so that you can understand me a bit better.

How I like to play

Things I like

Things that help when I’m upset

Things I’m good at

How I talk and communicate

Things I don’t like

Things that show I’m upset

Preparing for situations outside the home

While it’s true that certain locations or events might prove challenging for your child, there are things that can help both of you to prepare for these situations and to conquer life outside the home. These include:

- ✓ **Physical prompts.** Going to visit a new location – such as a doctor’s surgery or hairdressers – before an event so your child is physically familiar with the environment.
- ✓ **Make back-up plans.** Sometimes you may have to consider additional planning for special events such as birthday parties or when you’re in large public spaces, for example a football stadium or busy swimming pool, where things might change unexpectedly. Having a back-up plan can be really helpful. Is there a quick exit if your child becomes distressed? Will it be loud? Would ear defenders help? Does your child have a favourite toy, game or book to occupy them during any unexpected, unstructured time?
- ✓ **Look out for patterns to help you work out the cause of your child’s behaviour.** For example, a parent we spoke to told us that her son would resist going into some new places but would happily go into others. Eventually, she worked out that he didn’t like going through a closed door. So, some shops were OK, as their doors were always open or would open automatically, but he would get anxious if the door was closed. Going ahead of him and opening the door helped solve the problem.

Your child might feel more secure and less anxious if they already know what to expect at a new event or in an unfamiliar setting. A simple and useful technique to prepare your child for what will happen, and who will be involved, is to use visual support. The next section covers what visual support is and how to use it.

Visual support

Consistency and routine are important to autistic children. The world can be a very unpredictable place for young children with autism and this can be frightening and can create anxiety. Knowing what is going to happen, and when, can help young children to manage this anxiety.

Visual support is about using pictures or real objects to help your child understand what is happening or anticipate what is going to happen. At its simplest, you can use real objects, for example: show your child a cup when asking if they’d like a drink; or photographs, pictures on your phone, line drawings or symbols if you’re talking about going to a shop or someone visiting your home.

Using visual support gives your child another way to communicate while their speech is developing. Visual support can help your child understand:

- what is going to happen
- the past and the future
- their feelings and the feelings of others
- how to do things independently
- what they need to know about difficult situations
- the choices available to them.

There are several methods of using visual support, including Now and Next boards, Time Timers, visual timetables and ‘social stories.’

Now and Next boards

Now and Next boards are a simple visual support to help a child move from one activity to another. There are two columns – one for 'Now' and one for 'Next', with space for you to draw a simple picture or symbol or stick a photo or image under each.

How does it work?

- Place a symbol, drawing, photograph or image on each side of the board.
- Show your child the board, point to each symbol and reinforce the message with simple instructions. Don't use a lot of words. For example, say 'brush teeth now … put pyjamas on next'.
- When your child has finished with the activity, you should inform them by saying 'brushing finished, pyjamas now' while pointing to the next picture.
- One thing to bear in mind is that you can use the 'Next' side of the board to place an activity that really motivates your child to act. This can work as a reward, something your child can aim for.

You can use our simple 'Now and Next' template on page 56.

Now	Next

Download

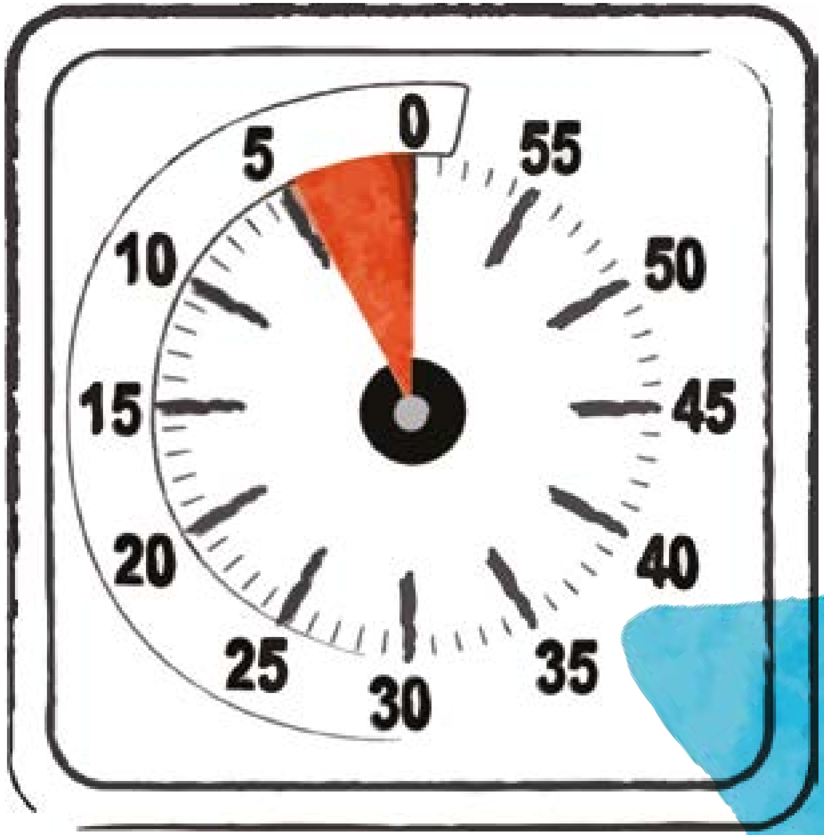
Time Timers

The concept of time can be very difficult for any child to understand. When you say ‘five more minutes’, a child has no way of knowing what that really means. A Time Timer is a commercially available type of clock designed to show the passage of time. As the time ticks down and the red disk gradually disappears, your child can clearly see the passing of time, have a better idea of how much time they have left and know clearly when something has finished.

For example, if you use the Time Timer to tell your child they can watch TV for 10 minutes, you could say, ‘So, when the red stops moving and the beep sounds, TV time is finished.’ This provides both a clear instruction and a way to help your child ‘visualise’ the amount of time they have and when the activity is meant to finish. It helps them anticipate that the activity is coming to an end and provides them with a concrete ‘finish time’.

Time Timers can be used in a variety of situations, including to support your child when they are brushing their teeth, having a bath or playing with a particular toy.

This can be helpful in supporting your child to transition from one activity to the next. Using a Time Timer also promotes positive routines and can help your child’s self-regulation skills, as they are less likely to be upset if an activity suddenly has to stop.



Visual timetables

These work a little like a Now and Next board, but cover longer sequences of activities. A timetable can be created for the day, for the week or even the year if you have a particular event, like a holiday, that you need to prepare your child for. A visual schedule, using pictures and symbols, helps your child to know what is going to happen and can help with the transition from one activity to another: 'Today we are going to drive to the supermarket to buy food. We will then drive to Grandma's. We will then have lunch. We will then drive home. You can then play. We will have our tea …' – and so on.

Be guided by your child's needs and preferences; some children find it reassuring to see the whole day at once, while others find that overwhelming. At first, it may be helpful to 'start small', with a few activities at a time, and then to gradually extend the length of the sequence you use as you and your child become familiar with the system.

If you are using a visual timetable:

- Have a dedicated space for it where your child can see it easily and often (on the fridge door perhaps, at your child's eye level).
- Take the timetable or a copy with you when you are out for the day. Use it to remind your child what they have just done and what will happen next.
- Actively show that an activity has finished by ticking or removing the symbol or picture.
- Review the timetable at the start and end of each day if your child finds this helpful.

Social Stories

Social Stories™ are another form of visual support. They were created in the 1980s by Carol Gray, a teacher in the USA working with children with special needs. Carol had observed that many of her pupils struggled with unpredictability. She began sketching out story-boards for her students with autism that broke down a complex chain of events into simple steps that could be explained and rehearsed.

To find out more about Carol Gray and Social Stories, use the Carol Gray Social Stories website in the 'Right from the Start resources library' at the end of the toolkit (page 101).

A parent's experience

The best way to describe how visual support works, how these techniques are used and how they may benefit you is through a parent's experience. On the next page, a parent shares her experience of using visual support with her autistic child.

What’s the big deal about social stories?

by Manaz Pimple, parent

Our story started when our son was two years old and we began to suspect that something was not right. After all the usual appointments and waiting lists, he got his diagnosis of autism at the age of five.

The period between knowing that something is not right and then receiving the formal diagnosis is a very difficult period for us parents, as we don’t receive much support or information on how to interact with and help our child. For the child this is a very critical period as well because, at this age, they are beginning to learn to build trust, establish relationships and develop a sense of the complicated social aspects of our human behaviour that we take for granted.

My son was three years old when I was introduced to the concept of ‘social stories’ by a speech and language therapist. My first reaction was to laugh it off. I remember telling her: “He barely has any speech, he can’t sit in one place for more than two minutes, I don’t know what his language comprehension skills are, and you want me to show him images and tell him stories. How is that going to help with his meltdowns? How is it going to help me manage his behaviour once we are out of the house?”

Her explanation has stuck in my mind forever: “When you leave the house to go shopping, you know in your head when you are going, which shop you will go to, how you get there, what exactly you want to buy and what time you are coming back home. An autistic mind needs this confirmation 10 times more than your mind. They need to know the ‘what next’ at all times. If they don’t, then the sensation of anxiety begins to build: ‘What is going to happen next? Am I going to fall in a black hole!’ This heightened anxiety then puts their nervous system into the ‘fight or flight’ mode and that’s when you have meltdowns, sensory overload and other behaviour problems.”

Then came my next concern – I don’t have the tools or time to create social stories for every situation. I don’t have easy access to a computer or a printer, or the time to search for images. To these concerns, she replied: “Can you draw? I am sure you can draw stick figures. All you need is a pencil and a notebook.” I had no more excuses then! So began my first experience of creating ‘social stories’ and experiencing the magic that followed.

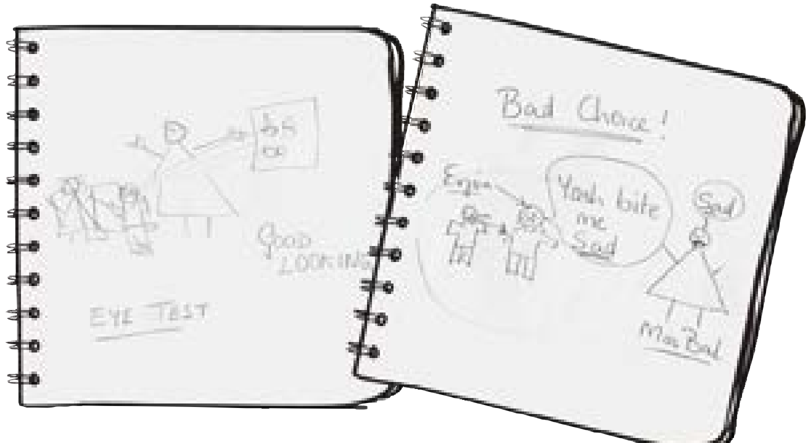
The first time I put it to the test was when I was travelling with my son all by myself. Airports were particularly tricky. He did not like waiting in the queues, he would have a meltdown when they would take his favourite toy and put it on the scanning belt, and he would refuse to sit down in the waiting area. On the plane he would keep standing on the seat, saying “home, home” every half an hour and crying. I would just wait for him to fall asleep. So, on this particular journey I tried using a ‘social story’ to explain to him what was going to happen and what was expected of him.

I took him through the story a couple of times before we left. Then, as the situations unfolded, I took him through it again so that he could anticipate what was happening next. It was magic! He waited patiently in the queue and did not cry. Instead he counted up to 10 with me while his toy went through the scanner and sat in the plane seat and was much calmer throughout the journey.

From then on ‘social stories’ became my son’s crutch. I use the comparison of a crutch because, as a sceptical mum, I quickly began to question what would happen if my son got so used to ‘social stories’ that he refused to function without them. My speech and language therapist had the answer: “When you break a leg, you use a walking stick or a crutch until your leg heals and you gain the strength and confidence to start walking. It will be the same for your son. Once he gains trust and understanding, and develops his speech, his reliance on ‘social stories’ will automatically fade away or you will be able to use them in a more casual way.”

I was no longer worried about taking my son out or going to social events. All I had to do was to know what would happen while we were out or at an event, and draw a simple ‘social story’ to explain the steps and take him through it before the event.

We survived so many tricky situations with the help of ‘social stories’: eye tests at the hospital, his first haircut, weekly shopping trips and his first day at school. I also started to use ‘social stories’ to prompt appropriate behaviour.



The things I find important to remember when using visual support are:

- Match the language and vocabulary levels of the child.
- Present it when the child is relaxed and distraction free.
- Use ‘social stories’ frequently prior to the actual event.
- If possible, ask the child to repeat the story and share it with others.
- Present the story in a simple format, Black ink on white paper works well but some children find coloured paper easier to use.
- Stress the steps that you know are going to be the tricky ones. For example: ‘There will be a long queue and [use your child’s name] will need to wait.’
- Use rewards at the end of the event. For example: ‘If you sit in the supermarket trolley so that Mum can buy five things, then Mum and [your child’s name] will go to the toys section to see and touch toys.’ Don’t be afraid not to give the reward if the steps are not followed. I had to do this only a couple of times for my son to realise that I was serious when I said that the reward would only be given if the steps were followed.

The beauty of using visual support was that it helped us work towards building trust. It made my son feel so much more in control. As a result, he was calmer and became more receptive to things changing unexpectedly. All I had to do was say “oops”, change the drawing quickly and show him. Gradually, I moved to just verbally explaining to him what would happen and then, if there was a sudden change, he would just shout out: “Oops, the swimming pool is shut – we will now go to the park.” There were no meltdowns!

I know it is not easy but it is all about trial and error. ‘Social stories’ worked for me and I hope they work for you as well. As parents we need to plan a little better and to anticipate things in advance so that we can help our child feel more in control. It is possible.

‘Social story’ products and systems

It is easy to create simple DIY ‘social stories’ such as those described by Manaz. There is also a wide range of commercially available ‘social story’ products and apps. Some use cards or plastic picture holders that you can carry with you and some use images and symbols you can download onto a phone or tablet. You may have to experiment, mix and match or get creative and adapt these products to meet your requirements and your child’s needs. See also our 10 tips below:

10 tips for creating and using ‘social stories’

1. **Know your goal.** Be clear and specific about what you want to achieve and focus your story on that goal. It could be as simple as ‘now’ and ‘next’: ‘Now we brush our teeth. Next we get into our pyjamas.’

2. **The beginning, the middle and the end.** A successful ‘social story’ just needs three things: a title and introduction that clearly identifies the topic; a body that adds detail; and a conclusion that reinforces and summarises the information. One or two stick figure sketches will help illustrate what you are talking about and can be used as a visual reminder while the event or activity is going on.

3. **Keep it brief, keep it simple.** Try to tailor the story you have drawn and are describing to match the language skills, attention span and interests of your child.

4. **Sound positive.** Describe everything in a positive and patient tone.

5. **Who is in the story?** You might want to use either second- or third-person language, for example: ‘You will then go to the shop’ or ‘Suzi will go to the shop’. You might need to experiment to find out which one your child responds to best.

6. **When does the story happen?** Be consistent when using past, present and/or future tenses. Don’t jump from one to the other in the same story. For example, try not to say: ‘The last time we went to the pool the water was cold. When we go tomorrow, it will still be cold.’ Instead, create a story that helps your child to remember the last visit to the swimming pool, or assume that you’ve never been before and describe how it will be. Once again, experiment to see what works best.

7. **Who, what, when, why, where and how?** Try to incorporate the full range of ‘who, what, when, why, where and how?’ You don’t need to draw these; just explain them as you go, pointing at the pictures you have drawn. When it comes to ‘why’, you should think about explaining the basic rationale behind the event or activity.

8. **Describe rather than direct.** A ‘social story’ is based on descriptions rather than direction: ‘the music at the party will be loud’ rather than ‘there will be loud music at the party so find a quiet space to go to’. You might want to use ‘coaching sentences’ at this point, such as: ‘The music will be loud. That’s because some children like that and it makes them want to dance. It’s OK if you don’t want to dance.’

9. **Practice makes perfect.** The old proverb, ‘if at first you don’t succeed, try again’, applies perfectly to ‘social stories’. This may be new to you and your child and it might take a few attempts for you to both feel comfortable with it. If it doesn’t work first time, that doesn’t mean it won’t work at all.

10. **Praise your child.** When you praise your child at the end of the event or activity, remind them about the ‘social story’ you used and how everything you talked about happened and how much better things were because you had both been able to ‘rehearse’ what was going to happen. This will build your child’s confidence and trust in you.

Practical support

Support for children and young people with SEND – the legal framework

The Children and Families Act 2014 requires all organisations that work with or support children and young people with special educational needs or disabilities (SEND) to comply with a standard set of principles and policies.

The statutory guidance that sets out these principles and policies is known as the SEND Code of Practice. The guidance sets out the procedures and legislation that local authorities, health trusts, schools and childcare providers must follow. The SEND Code of Practice is a lengthy but important document that contains information that will help you understand your rights and entitlements as a parent of a child with SEND. The SEND Code of Practice outlines what local authorities should do. In practice, some parents report that the system can feel very bureaucratic and that there are often delays and frustrations.

The key elements from the Code of Practice are summarised here.

The Local Offer

Your local authority must identify the education, health and social care services that it provides for children, young people and families with SEND, and list them in a directory called the Local Offer. The Local Offer must also list services provided outside your local area but which local people are likely to use. The Local Offer is usually located on the local authority's website.

SEND Support

If a child attending registered childcare has SEND, they should be able to access help to meet their needs. The planning and delivery of this is known as SEND Support.

The four stages of SEND Support are described by the Department for Education as:

1

Assess: Your child's difficulties must be assessed so that the right support can be provided. This should involve the setting talking to you and to the professionals who work with your child and looking at records and other information. It might also mean getting advice and further assessment from someone like an educational psychologist, a specialist teacher or a healthcare professional. The assessment needs to be reviewed regularly so that the support provided continues to meet your child's needs.

2

Plan: With your involvement, your child's school or early years setting needs to agree the outcomes that the SEND Support is intended to achieve; in other words, how your child will benefit from any support they get. All those involved will need to have a say in deciding what kind of support will be provided. They should also collectively decide a date by which the support will be reviewed to check how well the support is working and whether the outcomes have been, or are being, achieved.

3

Do: The school or setting will put the planned support in place. Your child's teacher or key worker remains responsible for working with them on a daily basis. The special educational needs coordinator (SENCO) and any support staff or specialist teaching staff involved in providing the agreed support should work closely with them. This team should track your child's progress and check that the support is effective.

4

Review: The support your child receives should be reviewed at the time agreed in the plan. You can then decide together if the support is having a positive impact, whether the outcomes have been, or are being, achieved and if – or how – any changes should be made.

You should be kept directly involved and updated during this process, with your views, and those of your child, sought throughout.

The school or early years setting may contact you if they think your child needs SEND Support, or you can contact them to request it.

Education, Health and Care (EHC) needs assessments and plans

If your child has SEND and needs a more intensive level of specialist help than can be provided through SEND Support, you – or your child's setting – should ask your local authority for an EHC needs assessment. This assessment could lead to your child getting an EHC plan, which "brings your child's education, health and social care needs into a single, legal document". For children and young people whose needs mean they clearly require an EHC needs assessment and plan, the local authority should start this process without delay. See page 67 for more information about EHC assessments and plans.

Support for under-fives

All Ofsted-registered early years settings follow the Early Years Foundation Stage (EYFS), which states that arrangements must be in place to support children with SEND. See page 72 for more information about the EYFS. The Department for Education states: "Early years settings must not discriminate, harass, or victimise disabled children. They must also make reasonable adjustments for disabled children – such as providing auxiliary aids (for example, tactile signs) – so that these children are not disadvantaged when compared with other children."

Personal Budgets

The support needs set out in an EHC plan are funded by the local authority or by the NHS. However, you are entitled to request a Personal Budget if your child has an EHC plan, or has been assessed as needing a plan, and you want to be involved in "choosing and arranging a part of the provision to meet your child's needs". A Personal Budget is an amount of money your local authority has identified to meet some of the needs in your child's EHC plan. A Personal Budget can only be used for support that has been agreed and set out in the EHC plan.

There are four ways that you can use a Personal Budget:

- **Direct payments:** You receive money to buy and manage services yourself.
- **Notional arrangements:** Your local authority or education provider holds the money and commissions the included services as according to your directions.
- **Third-party arrangements:** You choose someone to manage the money on your behalf.
- A combination of the three scenarios listed above.

Challenging or disagreeing with decisions

If you disagree with a decision your child's school or early years setting has made about their support, you should discuss this with them in the first instance. If you can't reach agreement, your local authority must provide independent disagreement resolution and mediation services.

Details of disagreement resolution and mediation arrangements can be found in the Local Offer.

Mediation

Mediation is a voluntary process that is available if you can't reach an agreement with your local authority or the NHS on some aspect of your child's EHC plan. Your local authority provides access to an independent service if there are disagreements relating to their decision:

- not to carry out an EHC needs assessment or reassessment
- not to draw up an EHC plan, once they have done an assessment
- not to amend the EHC plan after an annual review or
- to cease to maintain the EHC plan.

Details of local mediation information and services can be found in the Local Offer.

SEND Tribunal

Mediation must be available if you disagree with the details in an EHC plan that describe your child's special educational needs or the support that will be provided to them.

You will need mediation if you are thinking about appealing to the SEND Tribunal, an independent, legal tribunal that hears parents' and young people's appeals against local authority decisions about the special educational needs of children and young people.

A SEND Tribunal has the power to order local authorities to carry out EHC needs assessments, issue EHC plans, and amend existing EHC plans. It also hears claims of disability discrimination against schools.

You can appeal to a SEND Tribunal if you're unhappy with a decision made in relation to an EHC needs assessment or an EHC plan. There are no fees for parents or young people to pay, but you may need to pay for legal support.

The information we have provided about support for children and young people with SEND consists of short extracts from the Code of Practice. To read the full version of the SEND Code of Practice Guide for parents and carers, use the link in the 'Right from the Start resources library' at the end of the toolkit (page 101).

To find free and independent legally based information, advice and support about mediation and all your legal rights under the SEND Code of Practice, use the Independent Provider of Special Education Advice (IPSEA) website in the 'Right from the Start resources library' at the end of the toolkit (page 101).

Education, Health and Care (EHC) plan

On page 64 we described SEND Support, which is the help a child with SEND receives in a childcare setting or school. If you, or the setting, believe that your child's needs cannot be met through SEND Support, then a request can be made to your local authority for an EHC needs assessment.

This is an assessment of a child or young person's education, health and care needs; it is the first step to getting an EHC plan. An EHC plan is important, as it is a legal document describing a child's special education needs, the support they need, and the outcomes they and/or their parents would like to achieve. An EHC plan can result in additional support and funding for a child or young person with SEND.

The special educational provision described in an EHC plan must be provided by the child's local authority. This means that having an EHC plan should ensure that your child receives the support they need. It also gives parents the opportunity to choose the school or other setting that they want their child to attend.

An EHC plan can only be issued after a child or young person has gone through the process of an EHC needs assessment.

How to request an EHC needs assessment

You can request an EHC needs assessment at any time. You should start the process as soon as possible if you or the setting believe your child will need extra help when they start school.

You are able to request an EHC needs assessment by writing to your local authority, but if your child is in an early years setting it is important to speak to the SENCO beforehand (see page 64). If you prefer, the setting can make the request for an EHC needs assessment.

Your local authority's website should set out clearly how a request can be made. If not, write to your local authority's most senior person, usually the Director of Children's Services. Contact details should be on their website.

Your letter requesting an EHC needs assessment must set out why you believe your child has SEND and what is required to meet those needs. A typical reason given by local authorities for refusing an ECH needs assessment request is 'insufficient evidence'. So it's important to clearly outline the evidence that supports these points.

The Independent Provider of Special Education Advice (known as IPSEA) is a registered charity that provides free independent legally based information, advice and support for children and young people with SEND. IPSEA have created a letter template to help parents request an EHC needs assessment.

To fill out an EHC assessment request letter, use the template by IPSEA in the 'Right from the Start resources library' at the end of the toolkit (page 101).

To find more model letters, use the IPSEA website in the 'Right from the Start resources library' at the end of the toolkit (page 101).

The local authority's initial decision

Once it has received a request for an EHC assessment, your local authority has six weeks to decide whether to carry out an assessment and to get back to you with their decision.

If the local authority decides not to carry out an assessment, you have the right to appeal to the SEND Tribunal. If this is the case, you should immediately contact your local SEND Independent Advice and Support Service (IASS or SENDIASS). Details of this service will be on your council's website under their Local Offer. They will be able to advise you on your rights of appeal.

Assessment

If the local authority decides to carry out an assessment, it will gather as much information as it can about your child's needs, as part of this process.

It may ask for information from:

- you
- your child's setting
- healthcare professionals
- an educational psychologist
- family support practitioners
- any person you ask them to contact, as long as they agree it's a reasonable suggestion
- anyone else the local authority thinks is necessary.

Once it has all this information, your local authority then holds a meeting to decide whether it needs to make provision for special education needs (SEN) in an EHC Plan. It is a good idea to consult your area's Local Offer for information on how this process is managed locally.

If the local authority decides an EHC plan is not necessary, it must inform you within 16 weeks of the original request for assessment. It should also tell you that you have the right to appeal to the SEND Tribunal if you don't agree with its decision.

If it does decide an EHC plan is necessary, the next stage is drafting it.

Drafting the EHC plan

Once it's agreed that an EHC plan should be drafted, there will be a second meeting with you and the local authority in which, together, you will begin to write the plan. Decisions should be made in partnership with you. This can be a major opportunity to influence things, so it's a good idea to have researched schools and local service providers in the local authority's Local Offer beforehand.

What is in an EHC plan?

An EHC plan does not have a fixed format – each local authority can develop its own ‘style’ – but, legally, it must contain a number of separate sections:

Section A: You and your child’s interests, aspirations and basic view of the situation

Section B: Your child’s special education needs

Section C: Any health needs that are related to your child’s SEN

Section D: Your child’s social care needs

Section E: What outcomes you’re hoping to achieve, including your long-term hopes for your child’s adult life

Section F: What special educational provision your child requires

Sections G & H: What provision(s) you need health or social care services to make

Section I: The name of your child’s school or other placement, and the type of setting it is

Section J: The Personal Budget. See page 65 for information about Personal Budgets

Section K: The advice and information that was gathered when EHC needs were being assessed

The EHC plan must also discuss what are known as ‘outcomes’. This is simply the formal way of describing where you want to be at the end of the process – what you hope your child can achieve, and how you want their education to support that.

Outcomes are about the effects of your child or young person’s education, not just the content. The SEND Code of Practice describes this distinction as follows: “The provision of three hours of speech and language therapy is not an outcome. In this case, the outcome is what it is intended that the speech and language therapy will help the individual to do that they cannot do now, and by when this will be achieved.”

Agreeing the EHC plan

After the meeting, the local authority will write up everything that was discussed into a draft EHC plan. Once it’s complete, it will then send it to you for comments. You have 15 days to respond, though if circumstances make that difficult, you can apply for an extension.

If you have identified a particular school or college for your child, this is the moment to bring forward your preference. The first draft EHC plan can’t include any references to preferred schools: the 15-day comment period is when you get to make the request. The local authority should mention this to you when it sends you the draft EHC plan. The draft EHC plan is sent to the preferred school and will not be named on the EHC plan until that school has confirmed they can meet the child’s needs.

If the local authority refuses to include your preferred school, the SEND Tribunal is the place to go to appeal. You will have to wait until after the final EHC plan has been issued to make such an appeal.

Finalising the EHC plan

Once everything has been agreed, the local authority will send you the final EHC plan. You should receive it a maximum of 20 weeks after the first request for assessment.

Once you have an EHC plan it establishes your child or young person within the system and is the main authority you can refer to when attempting to get his or her needs met. An EHC plan makes life easier in several very important ways:

- If your child is in mainstream education, it allows the school to apply for extra funding. This could, for example, make it possible for them to arrange a teaching assistant to support your child in class, visits from speech and language therapists, extra equipment, or other things that they previously couldn't access.
- If you want your child or young person to go to a special school or an autism resource based within a mainstream school, an EHC plan can make it possible for you to apply for a place.

When does an EHC plan come to an end?

An EHC plan should be reviewed every three to six months for children under five (annually after that), as your child's needs may have changed, and the support offered should reflect those changes.

A local authority can only end an EHC plan under two circumstances:

- If it decides that the child/young person no longer needs the support the EHC plan laid out.
- If it is no longer responsible for the child. This may be because you have moved house and are now under a different local authority, or because your child is now a young adult and is in employment or has entered university.

Do you need a diagnosis to have an EHC plan?

The good news is that an EHC plan is not reliant on a diagnosis – it is reliant on your child's educational needs. You need to show that your child has special education needs and is accessing help already but needs more support than is currently available to them.

Challenging or disagreeing with decisions

If you are refused an EHC plan or you want to challenge or disagree with any decision, you should use your local authority's mediation process. See pages 65–66 for information on challenging or disagreeing with decisions.

Finding national and local sources of support

Support and information networks vary depending on where you live. Many local areas have established and effective parent forums, some of which are specifically about autism and some of which have a wider scope. In some areas this may just take the form of an online forum, which can still be a valuable source of information and support, as it is often the ‘lived experience’ of other parents that provides the ‘real’ detail.

While it is important to seek support, it is also important to keep in mind that a lot of misinformation exists, particularly online. You may come across things that scare or mislead you, such as suggestions of ‘cures’ for autism. Always think about how reputable the information source is and what other agenda they may have for what they are telling you or trying to sell you.

When considering sources of national and local support, you may want to start with reliable sources such as the NHS or your local council, children’s centre or specialist school. Quite often these sources will lead you to trusted local services and networks. These should include local networks that will help you to connect with other families in your area, such as:

- **Parent forums and parent support groups**
  These groups often provide training and advice or will sometimes advocate on your behalf. They also challenge local service providers, lobbying for more or better services. They often organise social events such as family fun days, where you can meet other families and enjoy a safe, fun day with your children.
- **Online internet forums**
  These platforms can help you find parents and connect with others who are facing or sharing the same challenges and opportunities as you. They may reduce feelings of isolation and be a safe space to express your feelings. Be careful, always check what you are being told and be aware that, like most social media platforms, there are risks relating to privacy and disclosing information.

Ambitious about Autism has partnered with Talk Talk to create Talk about Autism, the UK’s largest supportive, friendly online autism community where you can discuss anything related to autism. You can find a link to Talk about Autism in the ‘Right from the Start resources library’ at the end of the toolkit (see page 101).

Contact, the national charity supporting families of children with special needs and disabilities, runs a range of parent support groups and online forums across the UK. To find local support groups, use the Contact website in the ‘Right from the Start resources library’ at the end of the toolkit (see page 101).

Contact also supports the National Network of Parent Carer Forums (NNPCF). The NNPCF is a membership-led organisation made up of over 150 local parent carer forums across England. To find local parent carer forums near you, use the NNPCF website in the ‘Right from the Start resources library’ at the end of the toolkit (see page 101).

Early education and childcare

Looking for childcare can feel daunting, as you may be preparing to leave your autistic child in someone else's care for the first time. However, good quality childcare is beneficial for all children and will support your child's development, independence and social skills.

Registered childcare

There are many different types of registered childcare available, including private nurseries, childminders, maintained nurseries and nurseries attached to primary schools.

'Registered childcare' means that the childcare provider is officially registered with Ofsted (the national body responsible for inspecting education and children's services providers in the UK). To be registered, a provider must meet certain standards. Ofsted also awards each provider a grade (as part of a short inspection report), which shows how well the provider meets children's needs. Ofsted's website (**ofsted.gov.uk**) lists all registered childcare providers with grades and reports.

Early Years Foundation Stage (EYFS)

All Ofsted-registered early years education and childcare providers must follow the EYFS. This set of standards includes requirements on how providers should care for children with special educational needs and disability (SEND). The EYFS states that providers should:

- have plans in place to support children with SEND, and that parents are informed of these plans
- have a staff member who acts as special educational needs coordinator (SENCO), with primary responsibility for SEN in the setting
- discuss concerns about a child's development with their parents, agree how best to support them, and consider if specialist input is needed
- carry out ongoing assessment and keep parents informed about their child's development
- provide a written summary of a child's progress when they are between two and three years old
- respond quickly to any difficulties that come up by trying new approaches, consulting with the child's parents and developing a plan.

Looking for childcare

There is a range of different types of childcare. Some are for children of all abilities, and some are specialist services for children with additional needs. Think about the type of childcare environment that would suit you and your child. For example, would you like your child to be cared for in a group setting, like a nursery, or in a home environment, with a childminder? You will also need to consider how well the childcare setting can accommodate any additional needs your child has.

Most local authorities have a Family Information Service that will be able to give you details of all the registered childcare providers in your area. The service will also be able to advise you about childcare funding, including your free early education funding entitlements.

To search for your local Family Information Service, use the Coram Family and Childcare Trust online Family Information Service finder in the 'Right from the Start resources library' at the end of the toolkit (see page 101).

Look at the childcare provider's website, read their policies and Ofsted reports, and consider feedback from other parents. Most local authority early years services will have an Area SENCO who advises and supports childcare providers, to enable them to care for children with SEND. Your Area SENCOs will have good local knowledge and will be able to provide further support and advice. Your local authority Early Years team will be able to advise you on how to contact the Area SENCO.

Remember that providers rated 'Good' or 'Outstanding' often have a waiting list for vacancies, so give yourself plenty of time to find the right setting for your child, especially if you have work commitments.

You can use all these different sources of information to create a shortlist of those providers that look most suitable for you and your child. Once you have your shortlist, visit as many of these settings as possible and talk to staff and to parents whose children are in the setting.

Some nurseries allow you to just drop in (if not, then you could book an appointment to visit) and some hold 'open days'. If you attend an open day, you may also want to visit on a 'normal' day too, to see how the setting usually runs.

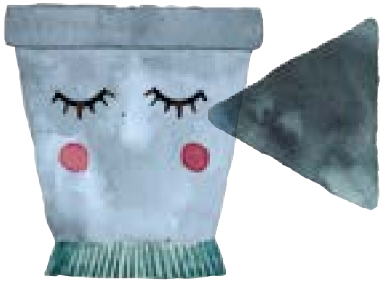
Ask about how the setting will support your child's needs

It is important to think about how well the childcare setting can accommodate any additional needs your child has. Every child's needs are different, so it's important to talk to someone about your own specific requirements. Try to speak to the manager or the SENCO to find out what experience the setting has of working with autistic children.

Take our completed 'Choosing childcare checklist' on page 76 with you when you visit each setting, as a reminder of things to ask, look out for and make a note of. This will help you in making your final choice.

What if I cannot find any suitable childcare?

It can be very difficult and time consuming finding the childcare that feels right for you and your child. If you are unable to find a setting that can, or will, accommodate your child's needs, you should contact your local authority Family Information Service. Many Family Information Services provide a 'brokerage' service that actively supports families by contacting childcare providers, arranging visits, and discussing any adaptations or training that settings and service providers might need in order to support your child.



Funding for early education and childcare

All three- and four-year-olds in England are eligible for 15 hours' free early education and childcare per week, paid for by the government. Some three- and four-year-olds with working parents are eligible for 30 hours free early education and childcare per week. Two-year-old children can also get free early education and childcare if you live in England and receive certain income-related benefits (for example Income Support, Universal Credit or Tax Credits) or if they get Disability Living Allowance (DLA) or have an EHC plan.

Any early education and childcare for children under the age of two, or additional hours on top of the free entitlement, are subject to fees charged by the early education and childcare provider. Some charge per day, and others per hour, and some providers may also charge for items within their fees, for example nappies, milk or food.

To find out more about what free early education and childcare is available in your area and the 15 hours, 30 hours and funding for two year olds, use the free early education and childcare search function on the Gov.uk website in the 'Right from the Start resources library' at the end of the toolkit (see page 101).

A comprehensive guide to childcare for children with special educational needs and disabilities in England has been created by the Coram Family and Childcare Trust. The Coram Family and Childcare Trust Guide includes an important reminder: "You should not be charged additional fees if your child has additional needs." The SEND Code of Practice states that your child should not be discriminated against because of their special needs or disability.

To find out more about the guide, use the Coram Family and Childcare Trust website in the 'Right from the Start resources library' at the end of the toolkit (see page 101).

All local authorities are required to establish an Inclusion Fund for three- and four-year-olds with SEND with lower or emerging needs (it can also be used for two-year-olds at the local authority's discretion). This fund is designed to enable childcare providers to meet the needs of individual children with SEND. The funding amounts available under this scheme are determined locally and are paid directly to the childcare provider.

To enable children and young people aged 0–25 years with more complex needs to access education, all local authorities and some schools are allocated High Needs Funding from the government. High Needs Funding is used to provide appropriate support packages for children and young people. The school or setting will apply for the funding to enable them to accommodate a child's needs. It is paid directly to the school or setting. It is up to the local authority to decide which children will qualify for High Needs Funding, and the High Needs Funding process varies in each local authority.

Contact your local authority SEND team for more information about the Inclusion Fund and High Needs Funding or speak to your child's setting. Note that regardless of where you live, there are considerable demands placed on these budgets and it can be a very challenging and time-consuming business trying to access this funding.

Disability Access Fund (DAF)

The DAF is funding provided by the government to early education and childcare providers to support children with SEND by "removing barriers which prevent children from accessing their free early education entitlement".

Three- and four-year-olds are eligible for the DAF if the child:

- is in receipt of child Disability Living Allowance (page 92) and
- attends an early years provider for the funded 15 hours' or 30 hours' entitlement.

The DAF currently awards £615 per child per year to early education and childcare providers. The funding is paid directly to your early education and childcare provider.

Your childcare provider can claim the funding once you have demonstrated that your child is in receipt of Disability Living Allowance. If you think you are eligible for DAF, speak to your early education or childcare provider. They will advise you about the application process in your area.

Note: Four-year-olds in primary and infant school Reception classes are NOT eligible for Disability Access Fund.

Helping your child to make the most of their early education

Providers should suggest a settling in period and work with you to ensure this is appropriate for your child and their needs.

This allows time for you and your child to get used to the setting and for the key person (the member of staff with key responsibility for your child's care) at the setting to get to know your child. Most parents find that, with time, care and support, their child adapts to and enjoys childcare. Keep in regular contact with your childcare provider regarding your child's progress and discuss any concerns as they arise. You will know whether your child is happy.

Choosing childcare checklist

Download Editable

Use this form to take notes when you visit each setting or childcare provider.

Name of setting

Date of visit / /

Whom did I speak to?

Name	Role/job title

Additional notes

Download Editable

Things to look out for

- Is the setting welcoming and are the staff happy to show you around?
- Are you able to speak to the special educational needs coordinator (SENCO)?
- Does the setting have a SEN policy?
- Are the staff comfortable around your child and sensitive to their needs?
- Does the setting appear busy, but relaxed, with children who seem happy?
- How do the staff interact with the children?
- What activities are the children engaged in?
- Are the premises safe and clean?
- Are the premises welcoming and friendly?
- Do they have outside play space?
- Are there quieter areas that children can access freely?
- Is it inclusive? (Can children of all abilities move around easily? Are the toys appropriate? Are things clearly labelled with signs and symbols that children can understand?)
- Are there fun activities planned each day? Childminders and nurseries all need to plan their days with children’s interests and enthusiasms in mind.

Notes

Download Editable

Questions to ask

- How many children do they care for?
- What is the ratio of staff to children?
- What support do they offer children with disabilities or SEN?
- Are there children with similar needs already at the setting?
- What relevant training have staff had? Would they need more training?
- What adaptations would the setting need to make for your child? Are they willing to make relevant adaptations?
- How would they ensure that your child has inclusive play and learning opportunities?
- How would they nurture your child’s development?
- If other parents had questions about your child, how would they handle this?
- How will they keep you updated on your child’s progress?
- Do they know about, or currently work with, any of the health and educational services your child may be known to?
- What are their policies on discipline and how do they manage children's behaviour?
- What alternative communication systems (such as picture-based or signs) do they use?
- Do they provide meals, snacks, nappies, and so on, or will you need to provide them?

Notes

Ready for school

The average age at the time of diagnosis in pre-school children is three years and four months. This means it's likely that, by now, you are beginning to think about your child starting school and about all the planning that requires.

This section of the Right from the Start toolkit is designed to help you navigate this last stage of the early years journey.

Applying for a school place

Every child – including those with autism – has the right to mainstream education (that is all the local maintained schools and academies in your area). Some children with more complex SEN and disabilities attend special schools designed specifically to meet their needs.

The process of applying for a mainstream school place is broadly the same for all children in England. Getting a place in a special school requires an EHC plan. If your child has been issued with an EHC plan at pre-school age, the normal application procedure may not apply. Instead, the most appropriate school for the child may be selected in consultation with you and the professionals working with your child, and named in the EHC plan.

The information in this guide mainly deals with the process of applying for a mainstream school.

It is important to remember that **school admissions and applying for an EHC plan are two separate processes, even though they may run in parallel.** Depending on when you start, an EHC Plan may not be finalised by the time you start applying for a school place. So, it is important to apply for a mainstream school place if you don't already have an agreed EHC plan in place.

Schools are designed to meet the needs of most of the children, most of the time. If your child has autism, or SEND, a mainstream school should make all reasonable adjustments to help ensure that your child gets the most out of their time there.

The allocation of school places is managed by your local authority – you still apply through your local council, even if you're applying for schools in another council area. The application form will ask if your child has special educational needs, and you may be asked to provide more information to be taken into account when allocating places.

Most children start school the September after they turn four. It is worth noting, however, that if you do not think your child is ready to start school by then, you can delay the start date. They can start part-way through the year or start part-time, as long as they are in full-time education by the time they reach 'compulsory school age' – this is on 31 December, 31 March or 31 August following their fifth birthday, whichever comes first.

You can also choose to defer for a year. In this case, your child would enter school according to their age – in Year 1 instead of Reception.

If you want to delay or defer your child's starting date, you'll need to apply for a school place for them to start at the normal time, i.e. the September after their fourth birthday, but should submit your request for delayed or deferred entry at the same time. Your local authority admissions team should tell you how to make your request.

Applications for a school place must be made to the local authority where the child is living. Applications for maintained schools are almost always online. You will probably be required to pre-register on your local authority website before submitting an application. Independent and private fee-paying schools will all have their own application processes, so you will need to check with each school's own website for details.

If your child is attending an early years setting, such as a nursery, you may receive a reminder letter from the local authority when it is time to submit applications. If your child is not attending an early years setting, it will not affect the process but you will need to keep an eye on the calendar to make sure you apply at the right time via the local authority's website.

Applications can begin as early as September and the deadline for submitting completed applications is in the following January. The deadline is usually the same for all local authorities so that they can coordinate school admissions.

You will be informed of which school your child has been allocated to on the 'National Offer Day' in mid-April when all families are notified of the outcome of their application for a primary school place.

If you are happy with the place you have been offered, make sure you officially accept it. If you don't accept on time, the offer might be withdrawn.

If you are unhappy with the outcome of your application, you are entitled to appeal to the local authority admissions team, but successful primary school application appeals are very rare and usually only succeed if the local authority is at fault and has made a mistake when assessing an application.

Long journeys or having siblings at a different school are not considered grounds for an appeal. However, it's worth getting good advice if you want to challenge the decision.

If your child has, or is being assessed for, an EHC plan, your local Independent Advice and Support Service (IASS or SENDIASS) will be able to advise and support you through the process of identifying and securing a school place for your child. You can find details of your SENDIASS in the Local Offer on your council's website.

There's a lot to think about. We have created a school place and EHC planner (see page 91) so that you know what to do and when, to help you navigate this complex and busy period.

Choosing a school

Step one

Do your research. Remember, the application process is not a case of you choosing a mainstream school but rather a case of you listing your preferences. The school place you will be offered is decided by the local authority based on their attempt to satisfy everyone's preferences. Most local authorities ask parents to list up to six schools in order of preference. So, it is important to visit and decide upon a number of schools so that you can at least have a list of acceptable options.

Be realistic – don't just put your favourite school on the list and hope for the best. Include at least one school for which you are confident that you might be offered a place, even if it isn't your first choice. Otherwise, you risk being offered an unsuitable school some distance away. This also applies if your child has an EHC plan. It would be good practice to identify at least two schools when you are agreeing your child's EHC plan.

Look at each school's website, especially their special educational needs and disabilities (SEND) section; read their Ofsted reports; and see what they say in their entry in the Local Offer on the council's website. Also consider journey times, siblings and your own work commitments.

Step two

Visit. Most schools have open days, usually in the autumn term. Check the local authority schools admission web pages for open day information or contact the schools directly to ask about their open days. Draw up a list of schools to visit and go to as many as you can (you may need to book, so check first). This is your chance to get a feel for the school, speak to students and staff, and see the classrooms, playground and facilities.

Use our 'Open day checklist' on page 82 when you visit local schools, as a reminder of things to look out for.

Step three

Meet the SENCO or headteacher. You might not get a chance to discuss your child's needs in-depth at an open day. But, after attending open days, you will know which schools you want to consider further. If possible, contact all your preferred schools to ask for a meeting with the SENCO or a member of the leadership team, such as the headteacher. Use this meeting to tell them about your child's needs and to ask about the support they can offer.

You can find a list of questions you might want to ask in our 'SENCO meeting checklist' on page 86.

Step four

Complete and submit your School Admissions Application form.

Open day checklist

Download Editable

Use this form to take notes when you visit each school.

Name of school		**Date of visit**	/ /

Whom did I speak to?

Name	**Role/job title**

Things to look out for (✓)

School grounds

- ○ Are gates and doors secure to prevent children leaving the site?
- ○ Is there parking for families close to the gate or inside the perimeter?
- ○ Are the building and play areas accessible? Is there a lift or ramps?
- ○ Are different areas clearly identified to help children's independence in finding their own way around?

Communal areas

- ○ Are the toilets close to the classrooms and play areas?
- ○ Are there private changing facilities for children who are not yet toilet trained?
- ○ Is there plenty of room to prevent children knocking into each other in the cloakrooms?
- ○ Are cloakrooms tidy and next to the classroom? This is important for independence.
- ○ Is the school hall used for lunch as well as for PE and assemblies? Has the school accounted for possible sensory issues relating to smell if the hall is used for meals?

Download Editable

Classroom

○ Do several classes come together in a big open-plan learning space? If so, how do staff ensure that children are meaningfully engaged during play-based learning sessions?

○ Is the classroom mainly lit by artificial light? Are there possible sensory issues relating to lights?

○ Is the classroom tidy and distraction free? Are there possible sensory issues relating to overload?

○ Does the classroom have soft furnishings to absorb some of the sound, i.e. to minimise possible sensory issues relating to noise?

○ Is there evidence of visual support for learning and independence, such as a visual timetable, clearly defined learning areas, or sand timers?

○ Does the class have access to areas for individual or small group sessions?

○ Is there a sensory room or a quiet room?

Outdoor areas and play times

○ Do the children have regular access to a secure outside play area?

○ Do younger children have their own play area or outdoor play time?

○ How many staff are in the playground at break and lunch times?

○ Do adults support children's play at lunch times, for example by organising playground games or special interest clubs?

Food

○ Can children bring their own snack rather than having one provided by the school? Are there rules as to what is allowed?

○ Can children bring their own lunch? Are there rules as to what is allowed in lunch boxes?

Additional notes

Learning

○ Is there a balance between 'taught' sessions and learning through play?

Notes

○ Are children taught to be independent in their llearning, through visual prompts, clear instructions, and clearly labelled learning areas?

Notes

○ Do the children learn basic life skills, such as finding their own coat and getting changed for PE?

Notes

○ Are there social skills groups for learning to share and take turns?

Notes

○ Are children helped to make friends?

Notes

○ Can homework be done at school?

Notes

○ Are reward systems used and can they be adapted for individual children?

Notes

○ What is the school's behaviour policy and what strategies and sanctions are used?

Notes

Other

○ Are there breakfast and after-school clubs that anyone can join?

Notes

○ School community: what events are organised for parents and families?

Notes

○ Is there a uniform?

Notes

SENCO meeting checklist

Download Editable

Use this form to take notes when you visit each school.

Name of school ☐

Date of visit / /

Whom did I speak to?

Name	**Role/job title**

Things to look out for (✓)

Support

○ Will your child have a designated support assistant? Can you be involved in choosing the right candidate? Will they be able to offer support at break and lunch times?

Notes

○ How does the school implement the Assess—Plan—Do—Review system to support children, as set out in the SEND Code of Practice?

Notes

○ How much support can the SENCO offer? (Are they full time in the role?)

Notes

○ What is the school's Behaviour Management policy?

Notes

○ Does the school have a designated speech and language therapist and can your child have access to them?

Notes

○ Does the school have a designated educational psychologist and can your child have access to them?

Notes

○ Does the school take advice from the local Autism Advice service (if available), and can your child have access to it?

Notes

○ Will the school support your child's sensory diet (the system of exercises set by an occupational therapist)?

Notes

Download Editable

○ Will the school accommodate any external support your child is already receiving, such as a specialist tutor, for example?

Notes

○ Does the school use home/school communication books?

Notes

Home/school communication

○ How often will you be able to have face-to-face meetings with the SENCO or class teacher to discuss progress and concerns?

Notes

○ Do they use support strategies you can use at home and vice versa?

Notes

○ Will the school hold a Team Around the Child (TAC) meeting before the child starts school to discuss strengths, needs and support?

Notes

○ Can your child start part time and build up to full days over the first term?

Notes

○ Does the school have a family support adviser who can support parents?

Notes

Download Editable

○ Can the child attend several settling in/transition visits in the summer term?

Notes

○ Can the school provide a photo book of the school for the family to share with the child during the summer holidays?

Notes

Your requirements

○ Ask about changes your child may need to the environment (such as fewer distractions, alternative toileting arrangements or a special diet).

Notes

○ Raise any questions or concerns that arose from your open day visit.

Notes

School place and EHC planner

August	September	October	November	December	January	February
Start to research your local schools.	Book your school open day visits.	Attend the school open days. Make a shortlist of your preferred schools.	Meet with the SENCO or headteacher of your preferred schools.		Submit your mainstream school admission application setting out your preferred choices.	

March	April	May	June	July	August	September
	School places are allocated. Confirm that you accept the place that has been offered to you.	Attend any transition meetings arranged by your early years setting and the school your child will be attending.			Start introducing your child to the school uniform (if there is one). Practise the journey to school. Use visual support to start the 'countdown' to starting school.	Your child starts school.

EHC plan process = 20 weeks (or approximately 5 months)

Week 1
EHC plan assessment application received.

Weeks 2 to 6
Further reports and evidence requested and gathered.

Weeks 7 to 12
Further reports and evidence requested and gathered.

Weeks 13 to 16
- draft plan written
- consultation with family
- consultation with school before it is named on the final plan
- plan sent to the local authority for final agreement.

By week 20
Final plan.

Mark the date you started – or plan to start – the EHC needs assessment process on the school place planner above. By counting along five months you will get a rough idea of the point you will be at in the school application process when your child's EHC plan should be finalised.

If, for example, you wish to have the EHC plan finalised by the time you submit your mainstream application in January, you would need to make a request for an EHC assessment in the August of the year before your child is due to start school.

Financial support for young children with SEND

The main source of financial support if your child has autism and/or SEND is Disability Living Allowance (DLA). You do not need a diagnosis to be able to apply for DLA as long as your child meets the criteria.

DLA is financial support provided by the government to help with the extra costs of looking after a child (under 16 years old) who:

- has difficulties walking or
- needs much more looking after than a child of the same age who does not have a disability.

They must have had these difficulties for at least three months and it must be expected that they will continue to last for at least six months. You don't need a diagnosis to prove this but will need medical evidence that this is the case.

The DLA rate is currently between £23.20 and £148.85 a week and depends on the level of help the child needs.

Usually, to qualify for DLA for children, the child must:

- be resident in Great Britain (there are some exceptions, such as family of members of the Armed Forces)
- have lived in Great Britain for two of the last three years, if the child is over three years old; a child under six months must have lived in Great Britain for at least 13 weeks; and a child aged between six months and three years must have lived in Great Britain for at least 26 of the last 156 weeks
- be habitually resident in the UK, Ireland, Isle of Man or the Channel Islands and not be subject to immigration control.

You can claim DLA for children if you're in or out of work.

To claim DLA, use the DLA claim form in the 'Right from the Start resources library' at the end of the toolkit (see page 101).

For further information, contact the DLA helpline
Telephone: 0800 121 4600 Textphone: 0800 121 4523

Telephone helplines and support services

The **National Autistic Society** Autism Helpline provides confidential expert advice and support on autism for autistic people, their families and friends.

The Autism Helpline number is 0808 800 4104
autism.org.uk/get-involved/about-us/contact-us.aspx

SOS!SEN is a national charity aiming to empower parents and carers of children with **SEND** to tackle successfully themselves the difficulties they face when battling for their children's rights.

SOS!SEN provides a free service including:

- a telephone Helpline five days per week during term time
- monthly drop-in advice centres in some areas during term time
- information sheets on many topics.

For more information, contact the SOS!SEN national helpline on 0300 302 3731 or 0208 538 3731
sossen.org.uk

Navigate is an emotional support service for parents of children with SEND provided by SCOPE.

✓ Navigate is a national mentoring service that is open to any parent or carer who:

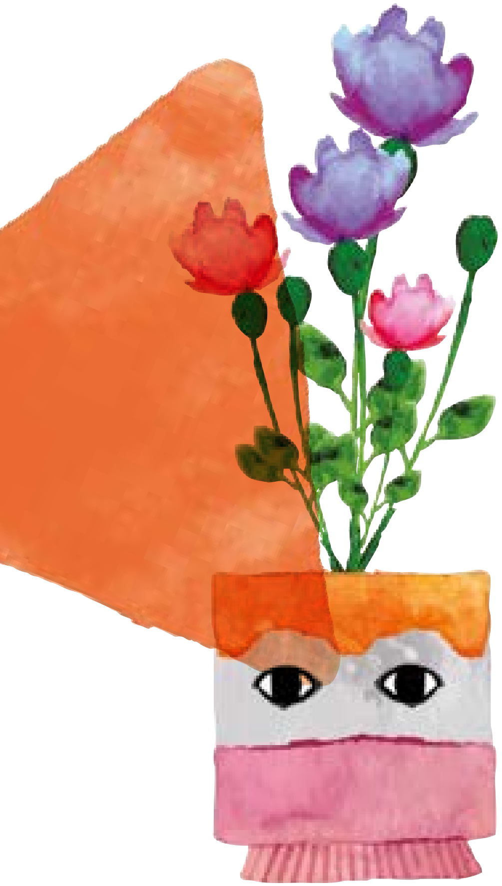
- lives in England or Wales
- has a child under 18 years of age who is going through or has received a diagnosis in the last year.

✓ Navigate is a six-week programme that provides you with a personal adviser who will help you to talk about your feelings and concerns. The personal adviser will work with you to:

- explore your needs and personal goals
- agree a six-week action plan, and
- provide you with support, if you need it.

You can apply for a Navigate personal adviser online or get a referral from the helpline. Contact with your adviser will be online or by phone.

For more information, contact SCOPE on 0808 801 0510
scope.org.uk/family-services/navigate



Right from the Start resources library

Who's who

A

Audiologist or ear, nose and throat (ENT) specialist

A healthcare professional who specialises in identifying and treating hearing and balance disorders.

B

Behavioural optometrist

There is some research evidence that coloured overlays could be useful for some autistic people. A behavioural optometrist can carry out an assessment to find the appropriate colours for overlays or lenses.

C

Child and adolescent mental health services (CAMHS)

These services assess and treat children and young people with emotional, behavioural and/or mental health difficulties.

Child psychiatrist

A medically qualified doctor who specialises in the diagnosis, treatment and prevention of mental health conditions in children.

Clinical commissioning group (CCG)

CCGs are part of the structure of the NHS and are responsible for commissioning – that is, planning and arranging the delivery of – the healthcare provision in the local areas for which they are responsible. This includes GP services, hospitals and community NHS services.

Clinical psychologist

Psychologists, unlike psychiatrists, do not undertake full medical training but are trained purely in psychology (the study of the mind and behaviour). The other difference is that a psychologist can't prescribe medication. In the case of children with autism, they often help with specific problems like managing behaviour difficulties. Clinical psychologists are able to make the initial diagnosis of an autism spectrum disorder. They can make an assessment with regard to behavioural and emotional issues, and may implement a behaviour management plan.

Contact

A registered charity operating in England. Contact supports families with the best possible guidance and information, brings families together to support each other, and helps families to campaign, volunteer and fundraise to improve life for themselves and others.

Counsellor or psychotherapist

Counsellors and psychotherapists offer support via 'talking therapies' to individuals and families experiencing stressful or challenging circumstances, including anxiety, depression, family breakdown, relationship difficulties, grief and loss, or the emotional impact of receiving an autism diagnosis. You can access counselling on the NHS through a GP referral. There are also many counsellors working in private practice.

D

Dietitian

Dietitians are qualified health professionals who assess, diagnose and treat dietary and nutritional problems. Your GP, paediatrician or hospital consultant can make a referral to a dietitian. You should consult a dietitian before introducing any dietary intervention.

E

Early years advisor

Generally employed by a local authority, early years advisors are early education experts who support childcare settings to improve the quality and standards of early education. They also work closely with settings and special educational needs co-ordinators (SENCOs) to develop inclusive early learning environments and to help meet the needs of individual children.

Educational psychologist

Educational psychologists carry out psychological assessments, usually in educational settings. They offer consultation, advice and support to teachers and parents, as well as to the child or young person concerned. They may be involved in the process of diagnosis as part of a multi-disciplinary team. Educational psychologists are usually employed by local authorities, but some work in private practice.

F

Family support worker

Family support workers provide practical support and advice to families who may be experiencing difficulties. Family support workers may be employed by schools, children's centres, local authorities or charities. The range and scope of their work will be influenced by who they work for. Some family support workers may work for specialist agencies relating to housing, health, mental health or immigration, for example.

G

General practitioner (GP)

Although responsible for the general health of their patients, GPs do not usually offer specialist advice or treatment. Your GP or family doctor can make referrals to relevant, specialist professionals.

H

Health visitor

Health visitors are trained nurses or midwives who have undergone extra training to specialise in the health and development of pre-school children. Concerns about development may be raised with or by a health visitor during routine appointments or developmental assessments.

Higher level teaching assistant

Higher level teaching assistants are teaching assistants with an increased level of responsibility, including teaching classes on their own, covering planned absences and allowing teachers time to plan and mark.

I

Independent Provider of Special Education Advice (IPSEA)

A registered charity operating in England. IPSEA offers free and independent legally based information, advice and support to help get the right education for children and young people with all kinds of special educational needs and disabilities (SEND). They also provide training on the SEND legal framework for parents and carers, professionals and other organisations.

K

Key worker

Key worker is the term that is often applied to a named professional who is the relevant contact in relation to a child in a nursery or other setting. Where there is a team of professionals working together to support a child, the term key worker may be applied to identify the lead professional who is the primary contact for any queries about the child.

L

Learning support assistant (LSA)

A commonly used term for an assistant providing in-school support for pupils with special educational needs. An LSA will normally work with an individual child or a small group of pupils, providing close support and assisting the class teacher. This person is also sometimes known as a teaching assistant (TA).

M

Music therapist

Music therapy can be very helpful for those with a diagnosis on the autistic spectrum. Involvement in making music can both stimulate and relax a person. Music therapists are qualified ‘allied health professionals’ (AHPs) and will hold a Masters degree in music therapy.

N

Named local authority officer

The person from a local authority who liaises with parents regarding education, health and care plan assessments and plans.

Nutritionist

Nutritionists are qualified to provide information and advice about food and healthy eating. They are not qualified to assess, diagnose and treat dietary and nutritional problems.

O

Occupational therapist (OT)

Occupational therapists provide practical support to help people overcome the effects of disability on everyday tasks. They are trained and qualified to assess and support children and adults with sensory issues. Children with autism may have problems with their fine motor skills, and an occupational therapist will work with them to manage activities such as eating with a knife and fork. Occupational therapists work in a variety of settings, including health organisations, social care services, housing, education, voluntary organisations or as independent practitioners.

P

Paediatrician

A doctor who specialises in children’s health and development. It is often a paediatrician who makes a diagnosis of autism.

Phlebotomist

Phlebotomists are specialists in gathering blood from a patient (for example, for clinical or medical testing or for blood transfusions).

Play therapist

Play therapists use a range of play and creative arts techniques to alleviate chronic, mild and moderate psychological and emotional conditions in children that are causing behavioural problems and/or are preventing them realising their potential. Play therapists can help children with autism improve their social and emotional skills, think in different ways, increase their language or communication skills, and expand the ways in which they play with toys and relate to other people.

Portage worker

Portage workers provide a home-visiting service for pre-school children (under five years old) who have special educational needs (SEN), and their families. The portage interventions involve a programme of play, communication, relationships and learning. The model is named after the town of Portage in Canada where it was developed.

S

Schools autism advice service

These services are different things in different areas. They provide support, advice and guidance to individuals, families and professionals. They can advise on local services and signpost to other support agencies.

SEN team in local authority

Local authorities have a statutory duty to identify and assess the special educational needs (SEN) of children and young people for whom they are responsible. The SEN team is responsible for the processes regarding Education, Health and Care (EHC) needs assessments, the issuing of EHC plans and the transfer of Statements of SEN to EHC plans.

SENDIASS (Independent Advice and Support Services)

Local authorities have a statutory duty to commission a Special Educational Needs and Disabilities Information Advice and Support Service or SENDIASS. This is a free, confidential and impartial service for parents and carers, children and young people up to 25 years.

Social worker (disabled children's team)

Qualified social workers are a key component of a local authority's disabled children's social care service and are responsible for assessing the needs of, and providing social care support and care management for, disabled children and young people up to the age of 18.

Special educational needs coordinator (SENCO)

A teacher or nominated person in a mainstream nursery or school who arranges the extra help for pupils with special educational needs (SEN) and/or disabilities.

Specialist health visitor

Specialist health visitors provide guidance and support to children and young people with additional needs and their families. This may include supporting parents and carers through the process of diagnosis, discussing developmental concerns, and helping with issues relating to sleep, hygiene, diet and toileting.

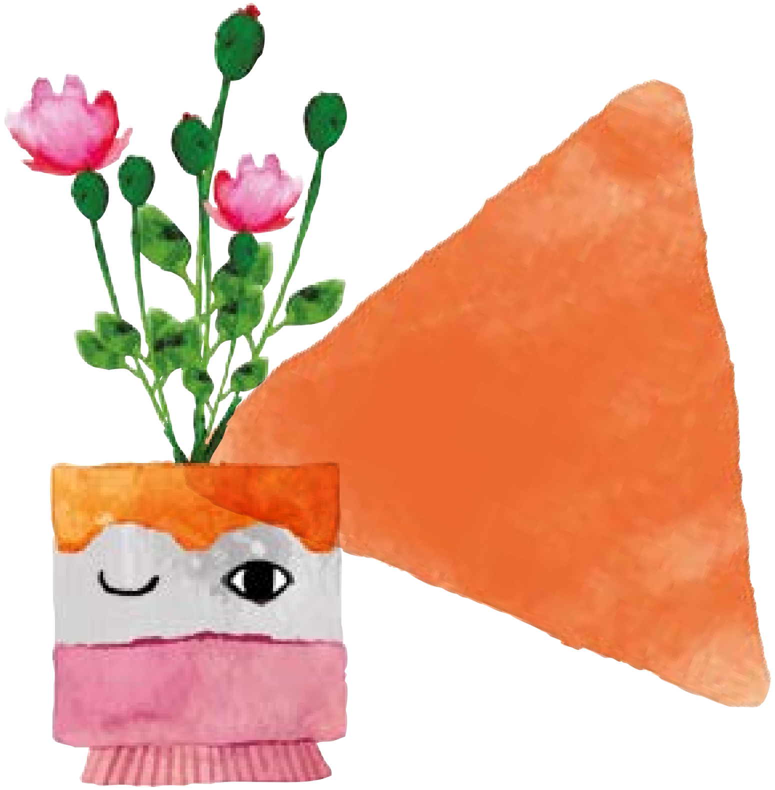
Speech and language therapist (SLT or SaLT)

SaLTs provide assessment, intervention and support for people with communication difficulties, or with difficulties eating, drinking and swallowing. Because speech and communication issues are one of the defining indicators of autism, SaLTs are often part of the multidisciplinary teams assessing, diagnosing and supporting children with autism.

T

Teaching assistant (TA)

A teaching assistant (TA) assists qualified teachers in carrying out their role. They are often involved in developing resources, as well as supporting pupils as required by the teacher.



Glossary of terms

A

Advocacy

Helping to ensure that a person is listened to, and that their rights, concerns and needs are acted upon. An advocate is someone who acts in a person's best interests.

Applied Behavioural Analysis (ABA)

A behavioural treatment programme used with children with autism, aimed at improving social skills. Behaviours are taught through an intensive skill training system of rewards and consequences.

C

Children's centre

A children's centre is a place, or group of places, where local families with children aged 0-5 can go to receive support they need in relation to child development, parenting skills and child and family health.

Clinical assessment

An assessment carried out by one or more professionals from specialisms including, but not limited to, speech and language therapy, occupational therapy, Applied Behavioural Analysis, psychology and psychiatry.

Code of Practice (SEND)

A national guide for schools and local authorities in England, issued by the Department for Education. It details the help schools and local authorities must give to children and young people with special educational needs or disabilities (SEND). Schools, local authorities and health services must have regard to the Code when they are involved with a child with special educational needs or disability.

D

Developmental disorder

A disorder resulting from abnormal or delayed mental or physical development.

Developmental milestones

Behaviours or physical skills most infants or children can do by a certain age.

Diagnostic manuals

Specific handbooks used by healthcare professionals as authoritative guides to the diagnosis of particular disorders.

Diagnostic tool

Processes, such as checklists and interviews, that are used to help a healthcare professional to diagnose autism. Diagnostic tools usually rely on two main sources of information – parents' or caregivers' descriptions of their child's development, and professionals' observations of the child's behaviour.

DSM-V

The fifth edition of the 'Diagnostic and Statistical Manual of Mental Disorders' (DSM-V) is a diagnostic manual published by the American Psychiatric Association. It provides the standard criteria for the classification of disorders and can be used in diagnosis.

E

EarlyBird and EarlyBird Plus

Support programmes for parents and carers, offering advice and guidance on strategies and approaches for dealing with young autistic children. Both programmes work on understanding autism, building confidence to encourage interaction and communication, and analysing and managing behaviour.

Echolalia

The uncontrollable repetition or imitation of sounds, words and phrases. When someone asks, for example, 'How are you today?', a person who uses echolalia will respond with 'How are you today?', rather than 'I'm fine'.

Education, Health and Care (EHC) needs assessment

A formal assessment carried out by a local authority to decide how much extra support a child or young person needs.

Education, Health and Care (EHC) plan

A legal document issued by the local authority describing a child or young person's education, health and social care needs and the support that will be given to them.

F

Fine motor skills

The ability to handle small objects with dexterity; for example, to use scissors, hold a pencil appropriately, or exercise control in writing and drawing.

G

Gross motor skills

The ability to control where your body is in space and time; for example, the ability to walk, run, jump or climb with agility.

I

Idiosyncratic language

Idiosyncratic language occurs when the child uses standard words or phrases in an unusual but meaningful way.

Intervention

An action, such as a treatment, therapy or the provision of a service, that is intended to help someone on the autism spectrum.

L

Local authority

An administrative body in government that is responsible for all the public services and facilities within a geographical area.

M

Mediation

Intervention in a dispute in order to resolve it. This usually takes the form of a third party using specialised communication and negotiating techniques.

Meltdown

An intense response which happens when an autistic person becomes completely overwhelmed by their current situation and temporarily loses behavioural control. This loss of control can be expressed verbally (shouting, screaming or crying) or physically (kicking, lashing out or biting).

Multidisciplinary team

A team that combines or involves professionals from several different disciplines or specialisations.

N

Neurological

Relating to the nerves and the nervous system.

Neurotypical

A term sometimes used to describe people whose neurodevelopment has been typical; people who are not autistic and not neuro-atypical.

O

Ofsted

Office for Standards in Education, Children's Services and Skills. This body inspects and regulates services that care for children and young people and those providing education and skills for learners of all ages.

P

Portage

A home-based educational support for pre-school children with SEND and their families.

Positive behaviour support (PBS)

A framework or process for developing an understanding of challenging behaviour, from which effective support can be put in place.

Pragmatics

Social rules for using functional spoken language in a meaningful context or conversation.

Prosody

The rhythm and melody of spoken language expressed through rate, pitch, stress, inflection or intonation.

R

Referral

The process of formally requesting a consultation, review or further action, such as directing a patient to a medical specialist by a GP.

Regression

When a child appears to develop normal language and social skills but then loses them.

Repetitive behaviour

An abnormally intense preoccupation with one subject or activity; distress over change; insistence on routines or rituals with no purpose; or repetitive movements, such as hand-flapping.

S

Sensory diet

A sensory diet is a personal activity plan designed by an occupational therapist that provides the sensory input a child or person needs to help tolerate sensations, regulate emotions, reduce unwanted sensory seeking and handle transitions with less stress.

Setting

The law refers to 'early years settings' or 'providers'. This term includes the range of childminders, day nurseries, pre-schools, holiday playschemes and childcare in your own home.

Shutdowns

A response to extreme overload or stress when an autistic person may become completely silent or unable to move.

Special interest

Something a person with autism is particularly interested in that brings them joy/pleasure. Common special interests include transport/trains, Doctor Who, Harry Potter, statistics, chess and music. Special interests are different to obsessions, which can be distressing/detrimental.

Statutory assessment

A very detailed assessment of a child's special educational needs that may lead to an Education Health and Care (EHC) plan.

Stimming

Short for 'self-stimulatory behaviour' and sometimes also called 'stereotypic' behaviour. In a person with autism, stimming usually refers to specific behaviours that include hand-flapping, rocking, spinning or repetition of particular words and phrases.

T

Theory of Mind

A theory that describes a person's ability to understand things/situations from the point of view of someone else.

Tribunal hearing

The meeting at which a tribunal appeal against a school or local authority is considered.

Tribunal (SEND)

A legal body, independent from schools and local authorities, responsible for assessing appeals against decisions made by a local authority relating to an Education Health and Care (EHC) plan. The Tribunal is also responsible for assessing claims of disability discrimination made against schools. In these cases, the tribunal examines the claim and related evidence, and the school's response and evidence, and decides whether the school has acted unlawfully.

W

Weaning

Commonly used to describe the process of mothers gradually introducing babies to solid food.

Resources library

Page 11

Ambitious About Autism website – Understanding Autism
ambitiousaboutautism.org.uk/understanding-autism/about-autism/what-is-autism

Page 13

NHS Birth to Five Timeline
nhs.uk/tools/documents/timelines_js/index.mob.html?project=birth_to_five

Page 18 and page 73

Coram Family and Childcare Trust – Family Information Service finder
finder.familyandchildcaretrust.org/kb5/fct/childcarefinder/home.page

Page 31

NICE website
nice.org.uk/guidance/cg128

Page 33

Research Autism website

About:
researchautism.net/autism-interventions/introduction-autism-interventions

Key principles:
researchautism.net/autism-interventions/making-the-decision/principles

Evaluations of autism interventions:
researchautism.net/autism-interventions/our-evaluations-interventions

Questions:
researchautism.net/autism-interventions/making-the-decision/intervention-questions

Red flags:
autism.org.uk/about/strategies/before-choosing.aspx##flags

Page 45

Contact guides

Helping your child sleep
contact.org.uk/parent-guide-sleep

Potty/toilet training
contact.org.uk/parent-guide-toilet-training

Understanding your child’s behaviour
contact.org.uk/parent-guide-behaviour

Feeding and eating
contact.org.uk/parent-guide-feeding

Page 58

Carol Gray Social Stories
carolgraysocialstories.com/social-stories/

Page 66

IPSEA website
ipsea.org.uk

Page 66

SEND Code of Practice Guide for parents and carers
gov.uk/government/publications/send-guide-for-parents-and-carers

Page 67

IPSEA website – EHC assessment request letter
ipsea.org.uk/making-a-request-for-an-ehc-needs-assessment

IPSEA website – model letters
ipsea.org.uk/model-letters

gov.uk/government/publications/send-code-of-practice-0-to-25

Page 71

Talk about Autism
ambitiousaboutautism.org.uk/talk-about-autism

Page 71

NNPCF website
nnpcf.org.uk/about-the-nnpcf/find-your-local-forum

Page 74

Gov.uk website – free early education and childcare search function
gov.uk/find-free-early-education

Page 74

Coram Family and Childcare Trust. – Guide to Childcare for Children with Special Educational Needs and Disabilities in England
familyandchildcaretrust.org/guide-childcare-children-special-educational-needs-and-disabilities-england#05---support-in-early-years

Page 92

DLA claim form
gov.uk/government/publications/disability-living-allowance-for-children-claim-form

Other useful websites

The Challenging Behaviour Foundation
challengingbehaviour.org.uk

Autism Education Trust – early years resources
autismeducationtrust.org.uk/resources/early-years-resources

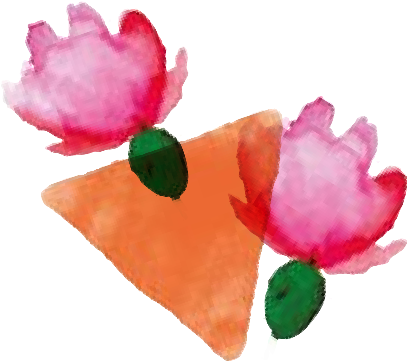
Autistica
autistica.org.uk

Centre for Research in Autism and Education
ucl.ac.uk/ioe/departments-and-centres/centres/centre-research-autism-and-education

Contact website
contact.org.uk/advice-and-support/local-support

Ambitious about Autism is the national charity for children and young people with autism. We provide services, raise awareness and understanding, and campaign for change. Through TreeHouse School, The Rise School and Ambitious College we offer specialist education and support. Our ambition is to make the ordinary possible for more children and young people with autism. We hope that the information and resources in the Right from the Start toolkit will help you to realise your ambitions for your child.

The Right from the Start toolkit was designed and created with the help and contributions of a wide range of parents, practitioners and organisations. We would particularly like to thank Sarah Yamani, whose generosity and commitment made the Right from the Start toolkit possible.



We would like to thank the following individuals and organisations for their knowledge, expertise and generous support:

Kari Askey, Area SENCO, Ronald Openshaw Nursery Education Centre
Emily Bishop, Speech and Language Therapist, East London Foundation NHS Trust
Wendy Boorman, Kent Autistic Trust
Dr Carole Buckley, GP
Rebecca Burgess, artist and illustrator
Elisavet Vlachaki, Right from the Start toolkit designer and illustrator
Eunice Costello, Area SENCO, Ronald Openshaw Nursery Education Centre
Julia Cox, Early Years SEND Inclusion Trainer and Consultant
Professor Richard Hastings, Cerebra Chair of Family Research, University of Warwick
Professor Francesca Happe, Director MRC Social, Genetic and Developmental Psychiatry Centre, Kings College London
Giulia Maccarini, Clinical Psychologist, Therapy Lane
Hannah Mace, Parent
Catherine McLeod MBE, Chief Executive, Dingley's Promise
Manaz Pimple, Parent
Suzi Scott, PhD Student, University of Warwick
Catherine Stanford, Research Assistant, University of Warwick
Maggie Stovold, Early Years SEND Inclusion Trainer and Consultant
Dr Vaso Totsika, Associate Professor in Intellectual Developmental Disability, University College London
Ren Wilson, Occupational Therapist, Whittington Health NHS Trust
Autism Speaks
Contact
IPSEA
London Borough of Islington School Admissions Team

Ambitious about Autism would also like to thank the following organisations for their support and guidance as members of the Right from the Start Reference Group:

British Academy of Childhood Disability
Centre for Research in Autism and Education
Contact
Coram Family and Childcare Trust
Council for Disabled Children
Dingley's Promise
MENCAP
National Autistic Society
NASEN
Ofsted
Royal College of General Practitioners
Royal College of Paediatrics and Child Health
Special Needs Jungle
Whittington Health NHS Trust

Notes

We are Ambitious about Autism

Ambitious about Autism is the national charity for children and young people with autism.

We provide services, raise awareness and understanding, and campaign for social and policy change. Through TreeHouse School, The Rise School and Ambitious College, we offer specialist education and support.

Our ambition is to make the ordinary possible for more children and young people with autism.

Ambitious about Autism

Contact us

The Pears National Centre for Autism Education
Woodside Avenue, London N10 3JA

020 8815 5444
info@ambitiousaboutautism.org.uk
ambitiousaboutautism.org.uk

Follow us
@ambitiousautism
ambitiousaboutautism
ambitiousaboutautism

Charity number 1063184 Registered company 3375255

Published – January 2020