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.

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

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

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.

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

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

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

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

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

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

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

Repetitive behaviours and activities: being highly focused on particular subjects, objects, routines and rituals.

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

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

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

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

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

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

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

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

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

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

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

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

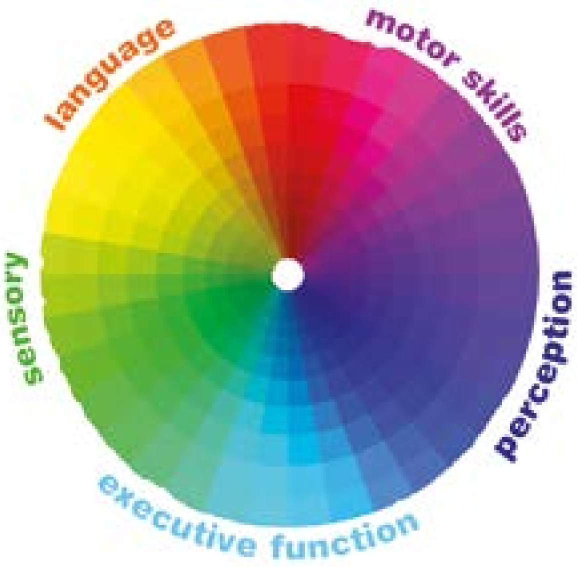
Autism is many things but, put simply, it is a different way of viewing and experiencing the world. It is important to understand how autism applies to your child, including their skills and talents. It’s also important to encourage and nurture your child in the things they are good at, as well as supporting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

Autism as a ‘spectrum’

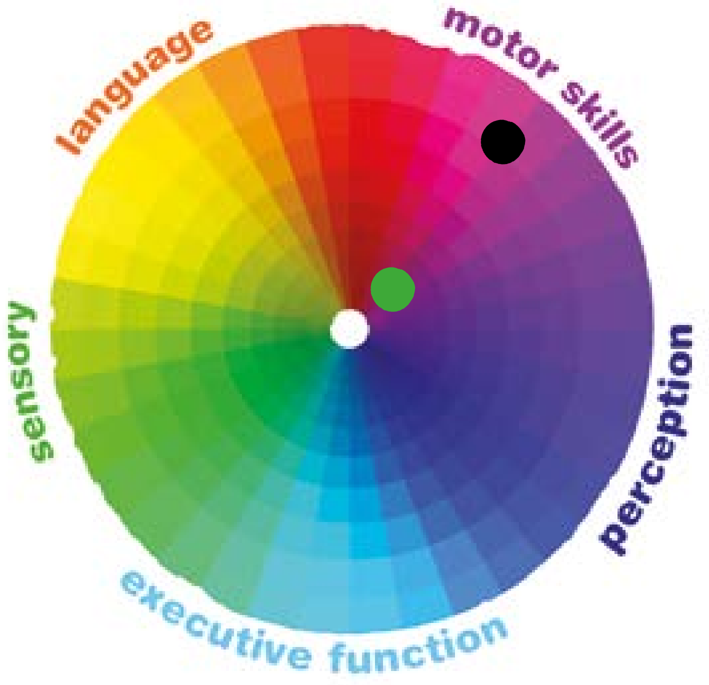
Because there are different levels of complexity, autism is often described as a spectrum. The term ‘autistic spectrum disorder’ (ASD) is, in fact, often used. But this suggests that ASD is a simple sliding scale like this:

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.

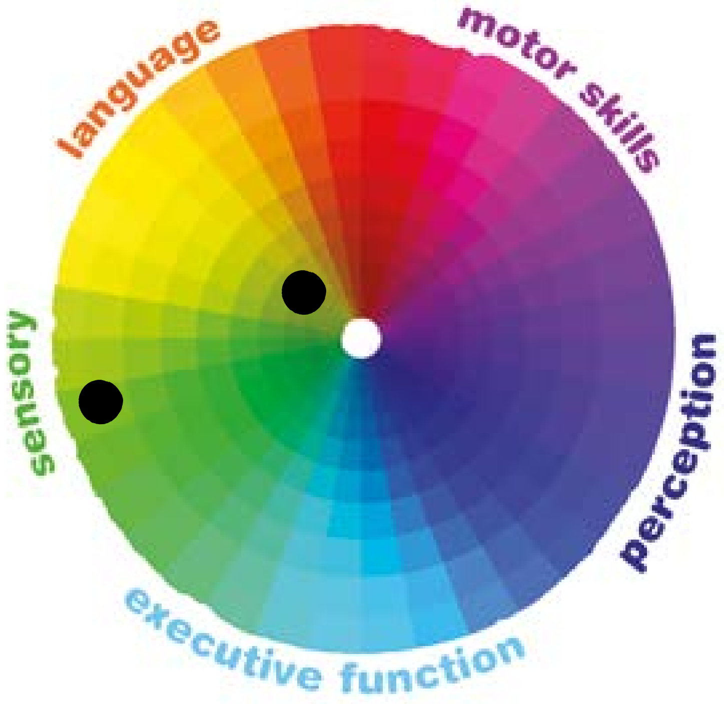
To visualise this more clearly, the spectrum can be thought of as a colour wheel, where characteristics like motor skills and language blend together like the colours of a rainbow:



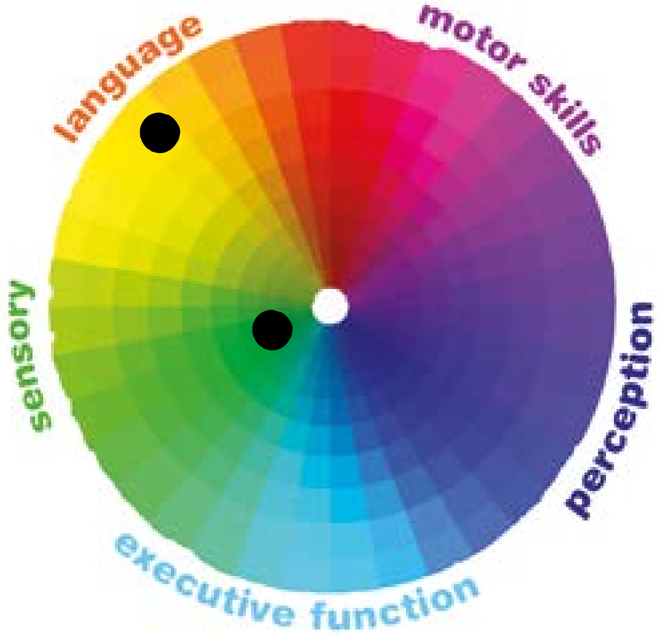
Everyone is different. Some people have highly developed skills in certain areas, while other people find those same things challenging. In the case of motor skills for instance, there are people who can assemble the fine parts of a watch while others may struggle to thread a needle. But let’s assume 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.

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.

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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.	○	○

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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).

“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.

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“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?

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

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

“How well does your child eat?”

Very fussy eater

Enjoys eating

Mainly prefers
one food

Enjoys lots of
different foods

The foods they like

The foods they don’t like

What they like to eat for breakfast

What they like to eat for lunch

What they like to eat for dinner

What snacks they eat throughout the day

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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).

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.

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

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

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.

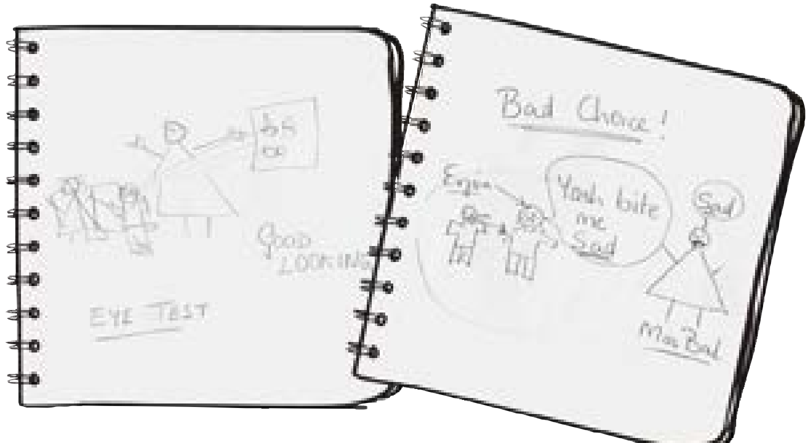
The first time I put it to the test was when I was travelling with my son all by myself. Airports were particularly tricky. He did not like waiting in the queues, he would have a meltdown when they would take his favourite toy and put it on the scanning belt, and he would refuse to sit down in the waiting 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.

Resources library

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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

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NICE website
nice.org.uk/guidance/cg128

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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

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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

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

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IPSEA website
ipsea.org.uk

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

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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

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

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

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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