

Early Support

for children, young people and families

Information about autism spectrum disorders



About this resource

This is an information resource for those who want to know more about **autism spectrum disorders**.

In this resource you will find information on:

- autism spectrum disorders
- getting a diagnosis
- what happens after diagnosis
- the effect of autism spectrum disorder on the family
- where to go for further support and information

You may not want to read this guide all at once; you may find it more useful to refer to different sections over time.

This resource was developed by **The National Autistic Society** for Early Support, in consultation with families. It uses the term 'autism spectrum disorder' to cover a range of developmental disorders, including **Kanner autism** and **Asperger's syndrome**.

The National Autistic Society would like to thank all the parent carers who helped to produce this guide. Most of the quotations are from parents, but some are taken from *Love, hope and autism* by Joanna Edgar (1999) and Early Years Equality Early Support focus groups (2012).

Early Support

Early Support is a way of working, underpinned by 10 principles that aim to improve the delivery of services for disabled children, young people and their families. It enables services to coordinate their activity better and provide families with a single point of contact and continuity through key working.

Early Support is a core partner supporting the implementation of the strategy detailed in *Support and aspiration: A new approach to special educational needs and disability*, the Government's 2011 Green Paper. This identified Early Support as a key approach to meeting the needs of disabled children, young people and their families.

Early Support helps local areas implement the Government's strategy to bring together the services families need into a single assessment and planning process covering education, health and care. Early Support provides a wide range of resources and training to support children, young people, families and service deliverers.

To find out more about **Early Support**, please visit www.ncb.org.uk/earllysupport.

Where a word or phrase appears in colour, like this, it means you can either: look them up in the [Glossary](#) at the back of the resource; or find contact details for the organisation or agency highlighted in the [Useful contacts and organisations](#) section.

Explanation of the term parent carer

Throughout this resource the term 'parent carer' is used. This means any person with parental responsibility for a child or young person with special educational needs or disability. It is intended as an inclusive term that can cover foster carers, adoptive parents and other family members.

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Autism spectrum disorders

An **autism spectrum disorder** is a lifelong developmental impairment that affects the way a person communicates and relates to people around them.

“It’s as if your child’s brain has been wired up in a different way to usual. This doesn’t change, but the ways in which it shows itself, and the extent to which it shows itself, do change.”

“It’s really easy to think that the autism is like a shell around your normal child and that if you try hard enough you’ll get that outer shell off, and your child will be free to get on. But you have to realise that it’s not something in the way of them being normal, it’s part of them.”

Children and young people with autism spectrum disorders are affected in a huge variety of ways and to very different degrees. This is why it’s called the ‘autism spectrum’.

Autism spectrum disorders can affect children and young people with any level of intellectual ability, from those who are profoundly learning disabled, to those with average or high intelligence. At one end of the spectrum, children may have learning difficulties and require high levels of support. At the other end of the spectrum, some people with **Asperger’s syndrome** or ‘high-functioning autism’ are very intelligent academically. They can excel in their chosen field of study or work. However, they still experience significant social and communication difficulties.

Some children have other conditions that are not directly related to their autism, such as **developmental coordination disorder** (sometimes referred to as dyspraxia), **dyslexia** or **attention deficit hyperactivity disorder (ADHD)**. It’s important to seek an assessment of any other conditions, as they will affect the sort of support that best meets your child’s needs.

What are the signs and characteristics of autism spectrum disorders?

Children and young people with autism spectrum disorders have significant difficulties relating to other people in a meaningful way. They can find it hard to develop relationships, and to understand other people’s feelings and the ‘social rules’ of communication.

Everyone with an autism spectrum disorder has difficulties in three main areas. These are known as the **triad of impairments**:

- **Social interaction** – When there is difficulty understanding social rules, behaviour and relationships. For example, they appear indifferent to other people or don’t understand how to take turns.

- **Social communication** – When there is difficulty with verbal and non-verbal communication. For example, they don't fully understand the meaning of common gestures, facial expressions or tone of voice.
- **Rigidity of thinking and difficulties with social imagination** – When there is difficulty in the development of interpersonal play and imagination. For example, they have a limited range of imaginative activities, possibly copied and pursued rigidly and repetitively.

The way in which these impairments present themselves can vary enormously. These variations are described in more detail on the following pages.

Note: this section draws on *Autism: how to help your child* and *Autism in the early years – a practical guide*. For full publisher details go to the [Resources](#) section.

Social interaction

Most babies seem ready to become sociable and develop communication skills from birth. Young children just seem to **know** that other people are important to turn to for comfort, to share moments of pleasure with, to look to for guidance and to learn from.

Children with autism spectrum disorders find this very difficult. They may seem less interested in people and find it hard to see things from another person's point of view. They often seem trapped in a world of their own. Some may like being sociable and tactile, but are not always sure how to go about this. A young child with an autism spectrum disorder can't make sense of people and may find them frighteningly unpredictable. They may:

- seem to relate better to objects than people
- only tolerate approaches from very familiar people
- not want to be comforted when they are distressed
- seem to use people as a means to an end, for example, they might take someone's hand but only to get an object that is out of their reach
- seem to be unaware of social rules

Social communication

Children and young people with an autism spectrum disorder can have difficulty with verbal and non-verbal communication. They can often find it hard to understand communication that is not literal. Expressions like 'I laughed so much I nearly died,' or 'If you eat any more you'll burst,' can be very frightening for them. They may also have difficulty understanding that stories are not real.

Non-verbal messages include things like facial expressions and gestures. If a child struggles to 'read' these messages, they may not understand what is expected of them, or

recognise when someone is happy or upset and what that means. A child or young person with an autism spectrum disorder may:

- develop speech in a way that is slow, disrupted or disordered – or may not develop speech at all
- often use words out of context and without trying to communicate
- not respond when spoken to
- use language correctly but not really understand what they are saying
- echo words other people say, straight away or later (this is called echolalia)
- use words and then ‘lose’ them (not use them again)
- not use eye contact as a natural part of communication
- rarely understand or use gestures
- point at things, but only to indicate need rather than to share an experience

Rigidity of thinking and difficulties with social imagination

‘Social imagination’ helps us understand the world, see other people’s perspectives and predict their behaviour. Children with an autism spectrum disorder are unable to do this to any great extent. This makes the world appear a very uncertain place, so children will often find reassurance in routines that they can control.

Difficulties with social imagination do not mean that children with an autism spectrum disorder are unimaginative. However, the development of pretend or imaginative play may be different.

Some children never seem interested in what a toy is for or what it represents. They may focus on the features of a toy, such as the wheels of a car or the packaging a toy came in. Other children may run a toy car in and out of a garage, but won’t act out more complex stories – or they may insist upon acting out the same story in the same way every time. Sometimes the story turns out to be an imitation of a video or a book. Other patterns in behaviour might be apparent. A child:

- may not easily make sense of sequences and events
- may become distressed if a familiar routine changes or may resist change
- may impose their routines on others
- may engage in stereotypical body movements (for example, some children flap their hands, some rock back and forth)
- may find it hard to work out what other people are going to do, or why
- will only develop symbolic (pretend) play slowly, if at all

Other common challenges

Children with an autism spectrum disorder may also experience some of the following challenges. The challenges that children face, and the things that they are good at, can change over time. You can call [The National Autistic Society Autism Helpline](#) to ask for information sheets on many of these issues.

“There may be improvements in one area and then issues become more apparent in another. You look back and see what was a problem then is no longer one and vice versa.”

Here are some common challenges children with autism spectrum disorder may face:

- **Sensory difficulties** – For further information on this, see the [Making sense of the world](#) sections.
- **Difficulties with motor skills** – Children may have difficulties with ‘fine’ or ‘gross’ motor skills. Fine motor skills include things such as holding a pencil, while gross motor skills include standing and walking.
- **Obsessions or special interests** – Thomas the Tank Engine and dinosaurs are common obsessions, as are various types of electrical equipment.
- **An unusual focus on detail** – A child may focus on minor details and ignore the main situation, for example, looking at a spot of dirt on the floor when they are in the middle of a chasing game.

Ask the [paediatrician](#) and other practitioners you are working with to write down information about your child’s diagnosis, so that you have a written record of your child’s needs and difficulties. This can be important when you are asking for services to help your family. (Note that you may be able to access some services without a diagnosis.)

As with all children, the full picture of a child’s abilities, impairments and difficulties will only become apparent over time and it’s important that you review their progress regularly with all the practitioners involved.

In the beginning

Diagnosis

An autism spectrum disorder cannot be diagnosed by a blood test or brain scan. Instead, a detailed developmental history will be sought from parent carers and any other significant people in a child's life, such as nursery staff. Practitioners will observe your child's behaviour carefully to see if it fits the diagnostic criteria for an autism spectrum disorder. They may do this in a clinic, but they may also visit you at home or observe your child at nursery or school, which allows them to see how your child interacts with other children.

A **paediatrician** or **clinical psychologist** can make a diagnosis of autism or Asperger's syndrome, but the most thorough form of assessment is a multi-disciplinary one where several different practitioners are involved, such as a **paediatrician**, a **speech and language therapist** and a **clinical psychologist**.

Feelings

Waiting for a diagnosis

If your child has not yet had a diagnosis, the uncertainty can be very worrying and stressful. It can sometimes take a long time to get a diagnosis, and for some parent carers, 'not knowing' is the hardest thing to deal with.

"The stress is not knowing. If you know a bit and you're actually doing something, even though there are a hundred things you could be doing, you feel better about it."

If the process of diagnosis is taking a long time, it may be that practitioners suspect a child has an autism spectrum disorder, or a related condition, but want to be certain that their diagnosis is correct. This is important because if a child has an accurate diagnosis, they **should** be able to access support that will effectively address their needs. Unfortunately, there are sometimes delays in accessing support simply because of the high demand for services for children with additional needs.

"Some health specialists may be reluctant and say 'We don't like to label children'. Well, we as parents don't like to label them either, but we have to. Getting that label is the first step to getting some help and you want to know what it is you are dealing with."

Getting appropriate education and/or therapy at the earliest possible stage is important for children with an autism spectrum disorder. It gives them a chance to develop their abilities and potential. The sooner you get a diagnosis, the sooner you can begin to get help – but remember that you can access some services before you get a diagnosis.

After diagnosis

If you are a parent carer whose child has recently had a diagnosis, you may be experiencing a number of different emotions, including shock, fear, anger or grief. All of these are completely normal reactions; many families experience significant emotional upheaval around the time of diagnosis.

A diagnosis, even if not unexpected, can still come as a big shock. Some families feel they need to grieve for the loss of the child they thought they had. Feeling angry is also a common reaction. It is part of the process of accepting your child's diagnosis, which can take time.

"It's really hard, and often you deal with it on your own. It's a sense of bereavement really – and devastating."

"I said, 'I want to know now, I've come all this way. I've been waiting a year, I need to know now.' They said, 'He's autistic.' I sat there, thinking, 'Do I really want to know this?' I was really angry with my husband because he hadn't come."

Some family members may find it easier than others to adapt to the family's new situation and this can add to the strain.

"There's no way of knowing how to deal with each other – how to deal with members of your family who say the most stupid things, like, 'Oh, he'll grow out of it.'"

Many parent carers say they initially felt a sense of shock and an inability to do anything, but then moved beyond that to a point where they began to accept the situation.

"I think the most important thing is for someone to tell you that you need to accept he's got this thing. Once you accept, you can help. I think what we tend to do is feel sorry for our children and then you can't do anything."

"It's nothing that you've done. A child doesn't become autistic. It's in them already. They don't learn to be autistic."

Some parent carers say it's helpful to think in terms of setting out on a journey. It won't be the journey you expected or wanted to go on, but it may turn out to be fulfilling nonetheless.

"I read something that I thought was very powerful. It starts off: 'I thought I was going to Paris. All my friends were going to Paris and I thought that's where I was going, too. But I suddenly found I wasn't in Paris. I was in Amsterdam. I didn't want to go to Amsterdam. That wasn't where I'd set out to go. But now I'm in Amsterdam and I'm looking around, and Amsterdam is different to Paris. But actually it's quite beautiful in its own right.' And why that was very powerful for me was because it was about stopping comparing. It was about stopping wishing you were in Paris and starting to look at Amsterdam and to think about what you can do there."

It can be stressful to have a child with an autism spectrum disorder and there is no denying that families experience low points. Some parent carers feel very alone and unsure of how to cope with social situations.

“Sometimes you have negative thoughts about your child, but when you talk to other parents you realise that it’s quite common and that it doesn’t mean that you’re a dreadful person or a bad parent.”

“You feel so isolated. I tried to take my little boy to the park but he would run off and hit other children. So sometimes you’re just stuck indoors and you do start to get a bit depressed.”

However, it’s important to emphasise that being the parent carer of a child with an autism spectrum disorder can also be rewarding – and that there is help and support out there.

Visit **The National Autistic Society’s** website, www.autism.org.uk, to find information about autism spectrum disorders, life after diagnosis, services, support groups and helplines.

Above all, **the important thing to remember is that it is not your fault**. The fact that your child has an autism spectrum disorder has nothing to do with the way you have looked after them. The causes of autism spectrum disorder are still not fully understood, but we know for certain that it is not caused by parenting. The condition affects children from all walks of life in all countries and cultures. You’re not alone.

Telling others about your child’s impairments and differences

Telling other people about your child’s impairments and differences is a personal decision; it’s something to do as and when you feel ready.

Autism spectrum disorders affect more than one in 100 people in the UK. Many of us will know someone with the condition and public awareness and understanding is improving gradually.

Each child with an autism spectrum disorder is an individual with their own unique personality. When explaining the condition, you can point out your child’s strengths as well as some of the things they find difficult. For example, your child may have an excellent memory or great attention to detail.

Telling family members can be very hard. They may themselves be going through a period of bereavement now that the diagnosis is confirmed. Explaining to siblings that their brother or sister is different can also be difficult. However, there are some fantastic books available that can help. For more information see the **Books for siblings** in the **Resources** section.

It can be particularly difficult to deal with people’s lack of understanding, but over time you will develop ways to handle other people’s reactions.

“Give him a slap,’ growled the young workman sitting with his cup of tea reading his Sun. The unfamiliar surroundings were making Davis anxious and he was whining. This time I was ready. There was an awkward silence from the other people in the café. Into it, to no one in particular, I said, in as neutral a way as I could manage, ‘He has a disability,’ and left it at that. The workman retreated into his paper. The others relaxed and returned to what they were doing. We had created some space for ourselves. It had worked.”

The National Autistic Society produces cards that state ‘This child has autism/Asperger’s syndrome, please show some understanding’. These can be very useful when you’re out and about. For more information see the [Resources](#) section.

Looking after yourself

Having a child with an autism spectrum disorder is not without its rewards but there are times when it can be very demanding and hard work. You need to look after yourself so that you can look after your child. Ask for help and support from family and friends if and when you need it, and accept any offers of help you get, as long as you feel comfortable with them.

“It’s very easy to feel guilty, to feel you should be doing more for your child. Every time you sit back and let them watch a video for hours on end you feel you’ve failed. But you have to conserve your energy and look after yourself because if you’re not happy, your child won’t be happy, and having a child with an ASD is long-term – it’s a marathon not a sprint.”

Make sure you are getting all the support you are entitled to:

- Ask for an assessment from your local social services child disability team. This can lead to some respite care if it is assessed as a need for you or your child.
- Check that you are claiming all the benefits you are entitled to. You can use the money to pay for equipment your child may need or to pay for travel costs, for example, to appointments. Some benefits also act as a ‘gateway’ to other services. The benefits system is changing, so for further information see www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Disabledpeople/DG_10011925 or contact The National Autistic Society Welfare Rights Service.
- Contact your local parent carer or family support group to find out what help is available in your area, contact [The National Autistic Society](#), or see the [Meeting others](#) sections.

Early years

Getting started

Understanding your child's behaviour

Some children behave in ways that parent carers find very difficult to manage and that cause considerable stress for the whole family.

It's always useful to start by trying to identify the reason for the behaviour from your child's perspective and considering what purpose the behaviour serves. For example, is your child trying to communicate something? It might be a reaction to a circumstance or situation that can be dealt with, such as bullying.

While every child with an autism spectrum disorder is different, it is quite common for certain behaviour to be directly linked to difficulties a child has with communicating. Other common 'triggers' include social situations that a child finds stressful, unstructured time, sensory difficulties, medical reasons and change.

Behaviour diary

You may find it helpful to track your child's behaviour in a diary, so you can begin to see patterns. You'll notice small, positive changes as you develop strategies to deal with the behaviour. Here is an example of a behaviour diary.

Date and time Location	What happened immediately beforehand	The behaviour	What happened afterwards
23 November In supermarket	Shop was busy and there was an announcement over the tannoy system	Harry started to bite and kick me	We left the shop
12 December Soft play centre	Centre became busy and loud. Other children came into the ball pit area where Harry was	Harry hit another child in the area	We left the centre

In the examples above, we can see that Harry may have sensory issues that mean he is averse to loud noise (perhaps especially if the noise is unexpected) and possibly to being touched or brushed against by other children.

Understanding your child's behaviour and the reasons behind it will help you develop strategies to deal with it, where necessary. Try to be consistent when dealing with difficult behaviour and don't expect it to change overnight.

Exercise, such as trampolining or swimming, can be a good way of relieving stress and working off frustration. Introducing structure, using visual supports or addressing sensory issues may also be helpful. We explore these strategies in more depth later on in the resource.

Consider carefully whether a behaviour that seems quite 'cute' in a four-year-old will be acceptable in a teenager or grown adult.

“Jonathan always wanted to tickle ladies' hands. He would shout 'Tickle,' and run over to them to do this. No one minded him doing this as a child, but as a 16-year-old it caused enormous problems. Eventually, we taught Jonathan that if he wanted to greet someone he should shake their hand and tickling was reserved for family members. We wish we had taught him this earlier.”

If there is a sudden change in behaviour it is always worth checking if there is a physical (medical) cause. Your child could have earache, for example, but be unable to tell you, even if they have a good vocabulary. This is what other parent carers say about behaviour:

“Whilst appreciating that many children have tempers, [everyone who has] witnessed these in Dan remarks at the ferocity and regularity of his. We are sure that many tempers are caused by his frustration at his inability to communicate his feelings and needs.”

“You need to make sure that everyone who comes into contact with your child gets to know him or her and the triggers that set off difficult behaviour, because each and every child with autism has different triggers.”

“You've got to learn to think differently. Supposing he's ripping wallpaper off the wall. Try and look at that destructive behaviour and turn it into something constructive, like, 'Yes, you can rip something up, but rip this catalogue up.' Then you get a bin bag, you put the rubbish in there, and then you do some papier mâché.”

Sometimes a practitioner with experience of autism spectrum disorders can give advice, or it might help to talk to other parent carers who have experienced similar problems and developed ways to help their child. All the advisers on [The National Autistic Society's Autism Helpline](#) can advise on behavioural issues. There are also some helpful books giving advice on strategies for difficult behaviours. For more information see [Books for family members](#) in the [Resources](#) section.

Using visual supports

Children with autism spectrum disorders often have strong visual skills, so visual supports can be a very effective way of making the world an easier place to understand. They can also help to reduce anxiety and challenging behaviour. Some examples of visual supports include:

- real objects
- photos
- line drawings
- symbols
- written words

Visual timetables or schedules are a good way to illustrate clearly what is happening next. You can stick several pictures on to a Velcro strip. Your child can then remove the relevant picture once an activity has finished so they know it is over and it is time to move on to the next thing.

Visual supports can also help to explain sequences, for example, the stages involved in getting dressed in the morning.

For more information about visual supports visit www.autism.org.uk/visualsupports or call [The National Autistic Society Autism Helpline](https://www.autism.org.uk/about-us/the-national-autistic-society).

Interacting and communication

Communication is a particular challenge for children with an autism spectrum disorder. Difficulty in this area leads to frustration and sometimes very challenging behaviour. Helping children to communicate can lead to reduced anxiety and improved behaviour. Here are some tips for communicating and interacting with your child:

- Use your child's name so they know you are addressing them.
- Keep background noise to a minimum when communicating with your child (switch the TV off, for example).
- Keep language simple.
- Speak slowly and clearly with pauses between words.
- Accompany what you say with simple gestures.
- Allow extra time for your child to process what you have said.

- Encourage requests from your child. For example, have a favourite toy within vision but out of reach, so your child has to communicate in some way that they would like it.

Speech and language therapy

Speech and language therapists assess, diagnose and then develop programmes to help people who have difficulty communicating. They may work on things like listening and attention skills, play, social skills and understanding. They may also use methods such as signing or picture symbols, rather than focusing on speech alone.

There are a number of ways to get a referral to a speech and language therapist. For an NHS appointment you can either contact your local speech and language therapy department yourself or your GP can refer you. If you would like to contact a speech and language therapist without going through your GP, speak to [The Royal College of Speech and Language Therapists](#). For a private appointment that you pay for, contact the [Association of Speech and Language Therapists in Independent Practice](#), which can send you details of therapists working in your area.

Picture symbols

Some children who have not developed speech, or even those who already have a vocabulary, find picture symbols helpful. Symbols help them to communicate more effectively, for example, by allowing them to ask for things. Many people with an autism spectrum disorder find it easier to learn visually and for this reason symbol use is often encouraged. See also [Visual supports](#) section.

For some, the [Picture Exchange Communication System \(PECS\)](#) will be a precursor to learning spoken language. The PECS approach is based on the idea that greater understanding between adult and child can be achieved when spoken words are supported by the use of a symbol or icon. Symbols can be used to construct visual timetables that help a child to see what is going to happen and when. Symbols can also be used as prompts when skills like brushing your teeth are being taught in a step-by-step way. Picture symbols are often used in combination with other interventions. It is important that any communication system is relevant to your child. You may wish to check that there are symbols and icons included in these packs that are reflective of your child's ordinary life and inclusive of your home culture so that your child can relate to the symbols and utilise them successfully. You could customise them if required.

For further information, contact [Pyramid Educational Consultants UK](#). Useful resources can also be found at www.do2learn.com.

Signing

Signing can be used alongside communication systems such as PECS and with other interventions. **Makaton** and **Signalong** are two examples of signing. Signing is not usually intended as a replacement for speech, but helps a child to develop spoken language and communicate their intentions.

Signing may be especially suitable for children who have difficulty discriminating between visual symbols, or for those who do not have the fine motor skills or motivation to use picture cards. For further information, contact **The Makaton Charity** or **Signalong**.

Parent training

EarlyBird is a free, three-month course for families with a preschool child who has a diagnosis of an autism spectrum disorder. The course supports parent carers to develop their child's communication and behaviour at home.

EarlyBird is offered in most areas of the UK by licensed teams. To find out if there is a team in your area call 01226 779218 or visit www.autism.org.uk/earlybirdteams.

General information

Everyday life

Day-to-day life with a child with an autism spectrum disorder varies. Your child may like to follow specific routines and rituals in order to feel safe and these can be time-consuming and have an impact on the rest of the family. For example your child may:

- have a lengthy morning routine, with lots of rituals they feel the need to do
- insist that people sit in the same places at mealtimes
- insist that you always drive the same route to places, such as to school or the shops
- have a lengthy bedtime routine

It will not always be possible to stick to set routines or ways of doing things. However, you can create an autism-friendly home environment where things feel predictable and manageable for your child.

Making sense of the world

People with an autism spectrum disorder often describe the world as a very confusing, unpredictable or frightening place. Children may not learn from experience, or apply what they learn in one situation to another in the same way as their peers.

Children with an autism spectrum disorder are generally happier when they understand what is happening next and have some routine and structure. Home life doesn't need to become completely rigid, but having some structure to your day can really help. The structure becomes easier to understand (and adapt) if presented visually to a child.

Social stories can also help to make the world more understandable. Visit www.autism.org.uk/socialstories for more information.

Developing the senses

Many people with an autism spectrum disorder have sensory differences. Some senses are overstimulated (hypersensitive) and others are under stimulated (hyposensitive). A child may, for example, have a heightened sensitivity to sound but lack sensory awareness of temperature or pain. Some children shift between hypersensitivity and hyposensitivity.

As well as the five main senses (touch, taste, smell, hearing and vision), there are two others.

Vestibular – This sense is based in the inner ear. It tells us where our body is in space and its speed, direction and movement. It helps us to keep our balance and posture.

Proprioception – This sense is situated in our muscles and joints, and is our body's awareness system. It tells us where our bodies are and how different parts are moving.

Sensory difficulties and impairments can have a significant impact on behaviour and communication.

“We thought it was the cabinets (at the delicatessen counter in the supermarket) but it ended up being the little lights that tell you the numbers. Every time they flicked over, that bothered her. She could hear them buzzing. It was so loud for her and it wasn't until she was a lot older that she could tell us that. We've only really known in the last 18 months. We just could never understand why she used to scream at the top of her voice whenever we were in a place like that.”

Here are some examples of sensory differences:

Sense	Hypersensitive response	Hyposensitive response
Smell	Strong reaction to certain smells, such as perfume	May lick things to get a better sense of what they are
Taste	May only eat foods with certain tastes or textures	May seek out strong tastes, or add lots of seasoning or sauce to foods
Touch	Finds touch uncomfortable and may try to avoid it. May not be able to tolerate certain fabrics, or find clothes labels or seams irritating, and refuse to wear some items of clothing	Enjoys deep-pressure touch and may seek this out, for example, by hugging people tightly or wearing very tight-fitting clothes. May have a high pain threshold
Vision	May find lots of incoming visual information hard to cope with and look away or focus on something else	May be clumsy and have problems with throwing and catching
Hearing	May find noisy environments difficult and certain noises, such as Hoovers or lawnmowers, painful. May hold hands over ears or try to avoid these situations altogether	May not acknowledge certain sounds. May enjoy noise and bang objects or doors
Vestibular	Difficulties with stopping quickly; with activities where their head is not upright; or where their feet are off the ground	May seek out experiences that involve rocking, spinning or swinging. Sitting still can be a challenge
Proprioception	May move whole body to look at something. May have difficulties with fine motor skills, such as doing up buttons	May stand too close to people, or bang into people or objects

For further information about sensory issues and strategies that may help, visit www.autism.org.uk/sensory or contact [The National Autistic Society Autism Helpline](#).

Playing

All children learn through play but children with an autism spectrum disorder play differently to other children. Generally, they do not engage in imaginative play. A child with an autism spectrum disorder may line cars up but they are unlikely to play a game involving cars in an imaginary situation, such as driving over the sofa, picking up some petrol then having a crash. Sometimes basic imaginative play can be observed but this is generally copied and repetitive.

Children with an autism spectrum disorder also lack the ability to imagine an object as something else for the purpose of play, so they won't, for example, pick up a banana and pretend that it is a telephone.

There are plenty of play opportunities that you can offer your child, though. The more play experiences children are exposed to, the more opportunities they have to learn.

Children with an autism spectrum disorder may particularly benefit from messy play as it helps to stimulate underactive senses and possibly manage oversensitivity in a safe way. There is no pressure to produce an end product, such as a picture. Here are some messy play ideas:

- **Water** – Your child may enjoy pouring water from one container to another or watching it spin a water tower.
- **Sand** – Provide buckets and spades for digging, or hide items in the sand for your child to discover.
- **Cornflour gloop** – Mix cornflour or custard powder with water until it reaches a paste consistency. Let your child place their hands in it or mix it with utensils. Children often enjoy making marks in the mixture. Mark-making is a precursor to writing.
- **Playdough** – You can buy playdough or make it at home (you'll find recipes on the internet). If you make your own, try adding another sensory dimension: peppermint essence or herbs for their smell; glitter for extra sparkle; or uncooked rice for texture. Your child may enjoy stretching, pinching, rolling and squashing the dough. This helps to strengthen hands ready for fine motor skills such as doing up buttons and using cutlery.
- **Ice cubes** – Have a tray of ice cubes for your child to touch and feel. It may be the first time they experience a cold sensation.
- **Shaving foam** – Your child may enjoy the feel of foam between their hands. Show them how clapping with foam on your hands makes little bubbles fly into the air. If

the sensation of touching the foam is too much, provide spoons or spatulas to move the foam around.

If your child is hypersensitive to touch, try playing with dry or less intimidating items at first, then move on to wetter items.

More information about messy play will be available from your local Children's Centre. See [Books for family members](#) in the [Resources](#) section for details of a book on messy play.

Toy ideas

Children with an autism spectrum disorder usually enjoy games that are visually interesting and involve visual-spatial skills, such as jigsaws and construction. Some popular toy ideas, suggested by parent carers are:

- bubbles
- rolling a ball
- torches
- dark dens with lights in
- Duplo and Lego
- marble runs
- trains (especially Thomas the Tank Engine)
- physical activities such as swinging, bouncing, climbing and slides

There are a number of places locally where you can get help and advice with play. These include:

- toy libraries, which allow you to borrow toys for free
- toddler groups, which give an opportunity for your child to play with different toys as well as socialise
- your local Child Development Centre (CDC) or Sure Start Children's Centre
- sensory rooms, which are available at some services – ask at your local Child Development Centre, Sure Start Children's Centre or library

Sleep

Children with an autism spectrum disorder may have problems getting to sleep or may wake periodically throughout the night. Your child may catch up on sleep during the day or simply seem to require much less sleep than the rest of the family. Some children may not be able to sleep until they know that everyone else is also in their own beds and asleep. Sleep problems can be a huge strain on a family. Here are some ideas that may help:

- Decide what time you would like your child to be in bed and stick to it.

- Make sure you have a consistent bedtime routine, for example bath, story, cuddle, sleep. You could present the routine as a visual schedule.
- Read a set number of stories and have a set time that cuddles last for.
- When putting them to bed, say the same phrase each time you leave your child's room ('Sleep time now,' for example).
- Make sure your child has plenty of exercise during the day, but keep things calm during the hour or so before bed.
- If your child repeatedly gets out of bed to come downstairs, make sure your whole family responds in the same way, for example, by gently putting your child back to bed and not engaging in conversation. Then leave their bedroom, repeating your standard phrase (as above). Try the same strategy if your child wakes during the night.
- Wake your child at the same time each morning. This helps their bodies to get in to a routine.

If sleep-related problems persist or get worse, keep a sleep diary. Record what times your child wakes, what he or she does and what you do. This may help to identify a pattern. Contact your health visitor or GP for help with sleep issues. In some areas specialist sleep clinics are also available. You can also find more information on this area in the Early Support information resource on [Sleep](#) – available to download from www.ncb.org.uk/early-support/resources.

Eating and drinking

Children with an autism spectrum disorder may only eat certain foods, or foods of one consistency or colour. Others have rituals, such as insisting that different foods never touch each other on the plate. This is not necessarily a problem, as long as your child is eating a varied diet.

If you feel that your child has a limited diet, seek advice from a dietician or a feeding clinic. Your GP or local Child Development Centre should be able to refer you. Further information about eating issues is available at www.autism.org.uk/dietmanagement.

Personal care: toilet-training

Toilet-training is often delayed in children with an autism spectrum disorder and it is important to wait until they are physically ready. Trying to potty-train a child who is not ready can cause a lot of anxiety.

First, decide whether you will use a potty or go straight to using the toilet. Make sure your child is familiar with the potty or the toilet. About half an hour after they have a drink, try sitting your child on the toilet or potty. If they use it, reward your child gently with something that they find motivating, for example a cuddle or a sticker. Do not go over the top, but make it clear that you are pleased and why.

If your child does not do anything after sitting on the toilet for a while, do not worry, just try again later.

There are lots of things about toilets that children with an autism spectrum disorder can find difficult, including the noise of the flush and having their legs dangling. Try to position a step under your child's feet while they sit on the toilet (if your toilet is not a squat-style toilet) and leave the flush until later if it is a big issue.

Make sure your child always washes their hands after they have used the potty or toilet and see if they can pull their clothes up by themselves. Some children with an autism spectrum disorder appear to 'hold on' and can suffer from constipation. Your GP can prescribe medication to help with this.

Your health visitor should be able to offer support with toilet-training and help you to decide when it's the right time to start. Further information about toileting is available at www.autism.org.uk/toilet-training or from [The National Autistic Society Autism Helpline](#) or [ERIC](#).

Home environment

Your home is never going to be as structured as a nursery or preschool, but it does help children with an autism spectrum disorder if there is some organisation and possibly some adaptations to the environment. Tips include:

- having a clear home for everything
- clearly defining different rooms – for example, having a different carpet in each room
- avoiding harsh lighting, such as strip lighting
- using carpet or soft flooring as it is quieter than laminate flooring for those who are sensitive to noise
- using low-arousal colours (such as cream) for walls and soft furnishings
- using non-patterned carpets and wallpapers
- keeping furniture to the edge of rooms; this makes them easier to navigate

Equipment and aids

Some children with an autism spectrum disorder may need their home environment modified because of specific health or behavioural difficulties. Others can have a very poor awareness of danger and some may seek out sensory experiences that could be unsafe, such as climbing. Depending on your child's individual needs, you may need to take some extra safety measures at home, such as installing:

- locks or high handles on cupboards containing items that could be unsafe (cleaning products, etc.)

- plug locks
- strengthened glass on windows
- window locks
- an alarm mat, for children who run out of the house
- high fences in the garden
- a lockable garden gate or a high handle

The gov.uk website has information on how you can access home adaptations and equipment at www.gov.uk/help-for-disabled-child/home-adaptations. The National Autistic Society's website also has a list of companies that make equipment and aids for the home at www.autism.org.uk/environment.

Funding for home adaptations

A child displaying behaviour that is challenging can have a big impact on your household expenses. For example, you may need to replace furniture and bedding more often if your child repeatedly damages them. Speak to your local Citizens Advice Bureau or The National Autistic Society Welfare Rights Service to check that you are receiving all the benefits you're entitled to. If you use a room in your house solely for a learning programme for your child, you can apply for a council tax reduction.

If large adaptations are needed, contact your local social services' occupational therapy department. They can carry out an assessment to see what is required and how it may be funded. Help with funds for home adaptations may be available from a number of sources, for example, the Family Fund.

Meeting others

Parent carers often say that it really helps to talk to other parents of children with an autism spectrum disorder.

“It’s important to be able to share a problem with somebody who knows exactly what you’re going through. You haven’t got to go through the rigmarole of explaining it all – because that’s the depressing factor, I think. But when somebody else has got it as a normality in their life as well, you can laugh about some of the weird things that happen.”

Parent

Parent and toddler, and play and share groups

For younger children, attending local parent and toddler, and play and share groups can be a really useful way for them to socialise and become familiar with other children. Some groups can be large and noisy, and children with an autism spectrum disorder can find them quite difficult. Your local Children’s Centre and local community childcare centres will also run groups and these may be smaller. Many of these centres also offer toy libraries and family support, so it is worth getting in touch with them.

Support groups

Local autism groups can be a real source of information and support. You will be able to meet families going through the same experiences as you, and who know what support is available in your local area. Some local groups are able to offer more in-depth services, such as outreach support, activities, courses and resource libraries.

“Nobody tells you what’s going to happen, but when you go to support groups and other parents say, ‘Yes, he’s putting toothpaste all over the walls,’ you think, ‘OK, right. It’s normal.’”

You can find out about support groups by asking your library for a list of local voluntary organisations, calling [The National Autistic Society Autism Helpline](https://www.autism.org.uk/helpline) or searching the Autism Services Directory at www.autism.org.uk/directory.

Going out with your child

Going out with a child with an autism spectrum disorder is not always easy. They can easily become overstimulated, or may get anxious about where they are going and when they are coming back.

However, there are strategies you can use, such as visual supports, to explain where you are going and that you will be coming home afterwards. Start off with short visits to places and try to end on a positive note (for example, leaving before your child starts to become anxious).

[The National Autistic Society](https://www.autism.org.uk) has a series of information sheets providing advice on going to different places, such as the hairdresser, the shops, the dentist and the hospital. You

can download these from www.autism.org.uk/outandabout or call **The National Autistic Society Autism Helpline**.

Choosing a preschool

There is a variety of childcare options available for younger children, including preschools, day nurseries and childminders. Contact your **Family Information Service** for a list of local providers. Here are some tips for choosing an early years childcare setting:

- Visit lots of different settings. Do the children seem happy? Is there a lot of interaction between staff and children?
- Is there an outdoor space suitable for your child's needs?
- Is there a quiet area available if your child is becoming overstimulated?
- How much one-to-one attention will your child have?
- Will the adult(s) have the skills to build up your child's desire and ability to interact and communicate?
- How will your child's time be structured?
- Are activities adapted to meet the particular needs of individual children?
- Have the staff had previous experience of children with autism spectrum disorders?
- Have the staff had training in autism spectrum disorders? If not, would they be prepared to attend?
- Does it feel safe and secure? For example, if your child likes to climb are you confident that they would be safe?
- Can they meet the sensory needs of your child?
- Can they support your child's behaviour?
- Are they flexible? For example, would they use visual supports with your child?
- How do they work in partnership with parents and other practitioners who are involved with your child?
- Do they offer a communication book? This is a way of making sure that things are consistent between home and the preschool setting, and that there is clear communication between the two.
- Ask other parents/carers if they would they recommend the setting?
- Do they have an equality named coordinator (ENCO)?
- Have staff had equalities training? How are staff attitudes and values assessed in regard to disability equality and other forms of equality?
- How do they deal with bullying or discrimination?
- Look at the most recent Ofsted report. This can be found at www.ofsted.gov.uk/inspection-reports/find-inspection-report or you can ask the setting for a copy.

- Ask to see a copy of the special education needs (SEN) or inclusion policy, and equalities policy if they have these.
- Do they offer taster sessions?
- Do the hours available and location suit you?

Most children with an autism spectrum disorder attend a mainstream nursery or preschool setting when they're young. However, some require more specialist provision. There may be a local 'opportunities' playgroup, specialist childminders or a specialist school with a preschool unit. Another option is **Portage**, a home visiting educational service.

Access to specialist provision is usually funded by your local authority and is agreed after an assessment of your child's needs is carried out. The process for this is currently changing. For up-to-date information visit www.direct.gov.uk/en/DisabledPeople/EducationAndTraining/Schools/index.htm or contact **The National Autistic Society Autism Helpline**.

Starting an Early Years setting

'Early years setting' is the general name for nurseries, playgroups, day nurseries and other childcare facilities for children under five. Every early years setting will have its own policy on helping new children to settle in. However, it will need to be flexible for a child with an autism spectrum disorder. Different approaches will work for different children, but options could include shorter initial sessions, or the parent carer staying for part or all of the sessions. For some children it may be best to start as you mean to go on and leave them with staff for short periods from the outset. This way your child will not associate you with the setting and not always expect you to stay.

More early years settings now have equality named coordinators (ENCOs), whose aim is to build good relations and to support individual equality and setting needs to meet requirements. The ENCO works closely with the special educational needs coordinator (SENCO) to meet disabled children's holistic equality needs. You can assist with this by identifying, for example, any cultural, language, religious or belief considerations they should give due regard to when planning for and supporting your child.

A visual book with pictures of the preschool, detailing for example, where the toilets are, who the staff are and where to put coats, can be useful for children to look at before they visit.

Sometimes children with an autism spectrum disorder develop close relationships with particular members of staff. It can be useful to have a picture board outside the setting illustrating which staff are present for the day so your child knows who they will see and can be prepared in advance if their favourite member of staff is not there.

It can also be useful to have a communication book so that you know how your child is getting on every day. Use the book to highlight any issues, rather than having a lengthy

discussion in front of your child. It also helps as a means of passing on information about important events in a child and family's life, and on events that are ongoing in the setting, such as culturally specific visits, activities, celebrations etc.

Choosing a school

Choosing a school for your child is a big decision and you would be right to explore your options and ask lots of questions. There are several different types of school:

- **Mainstream school** – Some children with autism spectrum disorders do very well at their local mainstream school, with or without additional support.
- **Specialist unit within a mainstream school** – Children are based in a specialist unit but can access the rest of the school as appropriate.
- **Special school** – Special schools may cater for children with variety of additional needs, or could be specifically for children with an autism spectrum disorder.
- **Residential school** – Children stay at the school on a weekly or termly basis. These can be mainstream or specialist schools.
- **Independent or non-maintained school** – Schools that are not maintained by the local authority. Payment is either made privately or, if agreed, by the local authority.

Although each child with an autism spectrum disorder is unique, there are some features that are common to all good autism education provision. These include:

- access to practitioners who understand autism spectrum disorders
- a willingness and ability to present information in a way that addresses a child's communication difficulties
- a willingness and ability to adapt some 'normal/ordinary' routines for a child, according to their needs

Try to visit several different schools. Observe the children in the classroom and also the playground if possible. Ask to see a school's most recent Ofsted reports or look it up at www.ofsted.gov.uk/inspection-reports/find-inspection-report.

Here are some questions you may want to ask:

- Will the curriculum be adapted to meet my child's needs?
- Can you provide an appropriate environment for my child – for example, structure, consistency, specific communication approaches?
- Will my child get the level of one-to-one support from an appropriately skilled adult that they need?
- How willing are you to work with parent carers?
- How will you help my child to participate in whole-school activities they will benefit from?
- What training have staff had in autism spectrum disorders?

- What training do staff have in equalities and how are staff attitudes assessed for disability equality and other forms of equalities too?
- Does the school have an ENCO?
- What experience have you had of supporting pupils with autism spectrum disorders?
- Are you accredited by Autism Accreditation? (This usually applies to specialist schools.)
- Have you been awarded a local autism certificate or quality standard? For example, some local authorities run their own schemes such as the Autism Mark in Lincolnshire, and the Autism Aware Award in West Sussex. (This usually applies to non-specialist schools.)
- Do you have knowledge of creating 'circles of friends' or other systems of social support that might help my child?
- Do you teach social skills and understanding as part of the curriculum?
- Are alternative communication methods used by members of staff, for example, the **Picture Exchange Communication System (PECS)**, or pictures and photos?
- If my child can't cope with unstructured time, what support will be put in place during breaks and lunchtime?
- Are there clear expectations and rules of behaviour for children? But equally, is there flexibility to deal with children who struggle to conform?
- Are there designated areas available for children to use for quiet time or as their special learning space?

Ask to see a copy of each school's special education needs (SEN) or inclusion policies, and their equalities policy and cohesion policy, too. It is also a good idea, if you can, to talk to other parents who have children at the schools you are visiting.

Process

When choosing a school your options will depend, in part, upon your child's specific needs. Children can get extra help in mainstream schools with or without a statement of special educational needs. In order to attend a special school a child needs, at the time of writing, a statement of special educational needs (in England and Wales). This process is changing. For updated information visit

www.direct.gov.uk/en/Parents/Schoolslearninganddevelopment/SpecialEducationalNeeds/index.htm.

"A lot depends on where you live. When I started to ask about education for my son, we hit a brick wall. But we moved into the neighbouring local authority and they could not have been more helpful. They really listened [and] understood where we were coming from."

“ We wanted our child to be in a school that was reflective of our local multi-racial community and which was inclusive. The local authority took both the disability needs and our son’s minority ethnic needs into consideration when helping us find the suitable school, which was really helpful to us.”

You can find details of schools that cater for children with an autism spectrum disorder on the Autism Services Directory at www.autism.org.uk/directory.

Your local **Parent Partnership Service** can provide advice to parent carers who have children with additional needs. Help is also available from **The National Autistic Society Education Rights Service** or **IPSEA**.

Starting school

Schools will have a settling-in plan for all children, but you should discuss an individual transition plan for your child if you think it is needed. This may involve:

- more frequent visits before starting school, perhaps including some visits before other children return
- a chance to meet the **special education needs coordinator (SENCO)**, equality named coordinator (ENCO) teacher and classroom assistant
- a home visit
- you and your child highlighting your equalities identities and needs so that these can be given due regard in the transition plan and its implementation
- a transition book for your child with pictures of the school and their classroom, a map of the school, photos of where they will put their coat and lunch box, where the toilets are, etc. You child can then familiarise themselves with their new school before they start.
- short taster sessions, for example, only staying until lunchtime initially

Home-school communication

Strong communication between home and school is vital for children with an autism spectrum disorder. There needs to be consistency at home and school for a child to be able to make sense of things. For example, behaviour strategies you use at home should also be used at school and vice versa.

A home-school communication book can be very useful, as can regular meetings with school staff. You should feel that you can approach staff at any time if you need to discuss your child’s needs.

Working with professionals

A number of practitioners may be involved with your child, so clear communication between all parties is important. Meetings where everybody is present can be hugely beneficial. The **Common Assessment Framework (CAF)** is a way of making sure that all practitioners working with a child know what each other are doing. There is usually a lead professional who organises meetings and reviews progress. Further information about the CAF is available at

www.education.gov.uk/childrenandyoungpeople/strategy/integratedworking/caf/a0068957/the-caf-process.

In addition, many areas will be using Early Support approaches, working in an integrated way around the child, young person and family. You may have a team of practitioners working together with you and your family at the centre, possibly with some key working support. For more information about such approaches, see www.ncb.org.uk/early-support/key-working.

School years

Getting started

Many children are not diagnosed with an autism spectrum disorder until after they start school; some are only diagnosed when they are in secondary school. This is a time when a child's differences may become more apparent.

If your child is of school age, the diagnostic process is the same as with younger children, but the school will be involved. Practitioners involved in assessing your child may wish to observe them in the school environment.

General information

Everyday life

Day-to-day life with a school child with an autism spectrum disorder can be similar to that experienced with an early years child. However, your child may find that the pressures of school mean that they need a release when they get home.

Many families say that their child behaves differently at school to how they behave at home. Often it seems that behaviour is worse at home, but it can happen the other way round. There may be many reasons for this. It could be that your child has spent the day working really hard in situations they find difficult and they need some sort of release when they get home, a place where they feel safe and secure.

If you are in this situation there are a couple of strategies you could try. One is having a physical transition activity between school and home, where your child uses up some energy and gets rid of anxieties before they get home. This could be a long walk, a run round the park or a bounce on a trampoline. Alternatively, your child may like to listen to some calming music for 20 minutes when they first get home. It will depend on the individual.

School holidays can also be a difficult time for children with an autism spectrum disorder because their routine changes and there is less structured time.

Making sense of the world

Your child may be starting to make more sense of the world, but there will still be lots of things they find challenging. Try to use strategies to make the world a more predictable place for your child, such as visual supports that explain situations or events. You can also try things like **social stories** to help your child cope when there is an unexpected change.

Older children may experience significant problems with anxiety. Again, there are some strategies that can help with this, detailed below:

- Regular medical check-ups can help to make sure there are no physical problems that could explain sudden changes in mood or behaviour.
- Research suggests a link between food and mood; a good diet is important for health and well-being.
- Exercise is beneficial for both physical and emotional health.
- Finding ways to relax is important. These may not be traditional methods of relaxation, as your child may find different ways to relax from other children. Suggestions might include: time alone; time linked to an obsession or special interest; calming music; yoga; or deep breathing.
- Give your child ways to communicate when they are becoming anxious. For example, they could hold up a red card to tell you or their teacher that they need a quiet place to retreat to.
- Present each day's activities in a visual format so that your child knows what is happening next and when an activity has finished. You can also prepare your child for any expected changes by using visual supports (such as marking a date clearly on a calendar).
- Identify what triggers anxiety in your child. The easiest way to do this is to record their behaviour and see if a pattern emerges.

You can also help your child to understand and manage their emotions. There are several books that cover this topic, including *Understanding and managing anger* by Andrew Powell (see the [Books for family members](#) in the [Resources](#) section).

If you are concerned about your child's anxiety or are worried about any other mental health issues contact [The National Autistic Society Autism Helpline](#) or [YoungMinds](#).

Developing the senses

The sensory issues your child may have experienced when younger are likely to remain, although he or she may be learning how to cope with them. It is important to remain aware of these issues. If they are having a big impact on your child's ability to function, and concentrate on what they need to do in their day-to-day life, then it may be useful to request a sensory profile assessment. This is usually carried out by an [occupational therapist](#), often based in a Child Development Centre. You can be referred through your local centre or GP.

Playing

Play is a very important activity for all children. Children with an autism spectrum disorder usually continue to enjoy visual-spatial toys and you could also try toys that encourage waiting and turn-taking skills. Board games can introduce the concept of winning and losing. Good toys for school-age children with an autism spectrum disorder include:

- jigsaws
- Lego or any other construction toy
- marble runs
- snap
- snakes and ladders
- Guess Who?
- chess (some children with Asperger's syndrome can be excellent at this)

Computer games can also be very popular, but be aware that they can sometimes become an obsession. You may wish to set a limit to the amount of time your child spends on the computer.

Sleep

Sleep problems might still occur during the school years. You may find that your child is more tired from school but that anxiety can keep them from falling asleep or wakes them during the night. You should try to use the same strategies as for a younger child (see the [Early Years](#) section), and if necessary seek specialist support through your GP. In some cases medication is prescribed.

You can also find out more information in the Early Support information resource on [Sleep](#) – see www.ncb.org.uk/early-support/resources.

Eating and drinking

Some children with an autism spectrum disorder have a very restricted diet; they may only eat foods of certain textures or colours, or from particular packaging. Continue to offer a variety of food, on separate plates if necessary. You may find that your child will eat different foods in different places.

“Emma would never ever eat bread at home but eats it happily at school each day.”

Some children with an autism spectrum disorder may eat excessively, possibly because they don't recognise the feeling of being full. They will need guidance from you or practitioners about healthy eating. This may include setting clear limits about the amounts of food they should consume. Getting plenty of exercise will also be important. If you are concerned about your child's diet, speak to your GP about a referral to a dietician or feeding clinic.

Personal care

Some children with an autism spectrum disorder may still need support with going to the toilet when they go to school, whereas others will be able to go independently. If your child still has continence issues, day or night, ask for support from the school nurse. In some areas specialist continence nurses are available. Your child can usually be referred to a specialist nurse via their school nurse or GP.

It might be that in your home you have a squat-style toilet and your child might need to become accustomed to sit-down toilets. This should be introduced gradually from a young age so that your child becomes less alarmed at the differences and more adept with using both. Likewise, your child may be from the faith background that requires compliance with Islamic toilet etiquette, also known as Qadaa' al-Haajah, and you may need to speak with staff in the school about supporting your child with chirality, for example. Initially, the ENCO and/or your child's SENCO may be the best people to approach in this regard.

It is helpful to encourage as many independent personal care skills as possible. Encourage your child to wash and dress themselves. Here are some tips to help with this.

- Break tasks down into small steps.
- Allow your child to achieve the last step of a task. So, for example, if teaching your child how to put tights on, you get the tights ready and round the right way, and put your child's feet in, but get them to complete the final step of pulling them up. Once this is mastered, work backwards through the steps. This is known as 'backwards chaining' and gives the child a sense of achievement for completing the task.
- Praise your child whenever they achieve a new skill, however small. Be specific in your praise, for example, 'Well done for washing your hands,' so they know exactly what you are pleased about.
- If your child does not achieve a skill you are working on, don't worry, just try again another time. Try not to comment too much when they don't achieve something.
- Use visual supports to illustrate the sequence of events for particular skills.

Choices and challenges

Friendships

Some children with an autism spectrum disorder are able to form friendships. Others want to but find this very difficult. They may need some guidance on understanding what makes a good friend and what friendship actually means.

If you feel your child needs extra support with making friends, try talking to their school about how they can help. One approach is something called 'a circle of friends'. This does not lead to instant friendships, but can help to build relationships between your child and some of their peers. Approximately six children volunteer, or are selected, to support a child at playtime (volunteering being the best option) and they meet regularly with school staff to discuss how to do this.

Further information about the circle of friends is available at www.autism.org.uk/circleoffriends or from [The National Autistic Society Autism Helpline](#).

Coping with differences

As they get older some children and young people start to become more aware of their differences. You may decide that it is time to tell your child that they have an autism spectrum disorder. There are lots of useful books available to help you to do this. For more information see the [Resources](#) section.

It is important to emphasise the positives of autism spectrum disorders as well as discussing the challenges. For example, many children with an autism spectrum disorder have a fantastic attention to detail; they are punctual, rule-abiding, honest and reliable. There are also examples of successful historical figures who were probably somewhere on the autism spectrum.

Sadly bullying and discrimination still happen in schools, and some children with an autism spectrum disorder can be a target for bullies. One useful strategy can be for schools to set a zero acceptance position on bullying and discrimination, and to run lessons on autism spectrum disorders, talk about people's different abilities and skills, and raise pupils' awareness of the condition. Lesson plans for primary and secondary schools are available from [The National Autistic Society](#) website: www.autism.org.uk/teacherpack.

If you think your child is being bullied, speak to their school immediately. Further support is available from [The National Autistic Society Autism Helpline](#) or [Kidscape](#).

Developing independence

Continue to support your child to be as independent as possible, using strategies such as backwards chaining for self-help skills like dressing and washing. Also have a think about your child's ability to everyday things, such as make a sandwich, use cutlery (if this is one

of your cultural traditions) and so on. Involve them in daily tasks like this as much as possible. You can use visual supports as prompts if these are helpful.

Everything can be viewed as a learning opportunity for a child with an autism spectrum disorder. Try not to be tempted to do everything for them, even if it is quicker!

What if things aren't working?

If things aren't going as well at school for your child as you would have hoped, talk to their school. Communication is essential. If things still don't improve contact [The National Autistic Society Autism Helpline](#) or [IPSEA](#).

Choosing a secondary school

Choosing a secondary school is a big decision for any parent carer and the transition for a young person with an autism spectrum disorder needs to be carefully managed. Here are some tips:

- Visit the schools and ask to look at their Ofsted reports.
- Speak to head teachers or **special education needs co-ordinators (SENCOs)** and equality named coordinators (ENCOs). Speak to other parents, too.
- Ask what experience schools have of other pupils with an autism spectrum disorder, and what training staff have in autism spectrum disorders.
- Ask what equalities training all staff have had, and how staff are assessed for their values and attitudes on disability equality and other forms of equality, too?
- Ask how schools keep parents informed of their child's progress. Are there additional opportunities for you to communicate with the school about your son or daughter? Who will be your main contact?
- How does the school deal with bullying and discrimination?
- Will schools be able to support your child's sensory and/or behavioural needs? How will they do this?
- How do schools promote positive behaviour?
- What arrangements are in place for break times? Children with an autism spectrum disorder can find break times the most difficult time of day as they are not structured. Are alternatives to the playground available? Do schools use a circle of friends or buddy system?
- How will your child be informed of any changes to their school routine?

Further tips are available at www.autism.org.uk/choosingaschool.

Preparing for the transfer (transition planning)

Secondary schools will have transition plans for all pupils but it is important to identify your child's specific needs and create an individual transition plan for them.

It can be useful if staff from the secondary school visit your child while they are still at primary school and to gauge from you the aspects of your child's ordinary life that is important to you and your child. For example, any cultural, home language or religious considerations etc. This in turn will add richness and reality to the transition plan too.

It is also a good idea to arrange visits to the new school during the summer holidays or during the previous term. This could be with other pupils, but individual visits with a parent carer may be useful too. Your child will become familiar with the buildings, some of the staff there, and their route to and from school. Here are some other ways to prepare:

- Create a transition book with photographs of the classrooms, teachers and other key people, the dining hall, toilets, coat hooks, etc.
- Provide a map of the school, with key places highlighted.
- Provide the new timetable in advance so your child can plan their route between classes.
- Get a copy of the school or class rules in writing, backed up with visual supports if required.
- Prepare a diary with checklists of simple instructions, including what your child needs to take to school each day. The diary can also be used to warn them of any changes or special events.
- See if your child can have a transition buddy, someone who is already familiar with them and can meet them at the start of each day, walk with them between lessons, etc.
- If possible, arrange a quiet refuge at playtime, or a buddy or circle of friends system.

Meeting others

Parent carer groups

Local autism groups can be a real source of information and support. You will be able to meet families going through the same experiences, who know what support is available in your local area. Some groups are able to offer more in-depth services, such as outreach support, activities, courses and resource libraries.

Many families stress how important parent carer support groups have been to them. These groups provide early support, advice, information and, to some extent, a social life.

“There are lots of parents who have been in the same place as you. They’ve been in your shoes. You don’t have to reinvent the wheel.”

“Having our daughter, Chenguang, here in the UK meant that we were isolated from our families back home in China. So being able to go to a parent and carers support group helped us not only to learn from the experience of other families, but to make community links and to find Chinese families too, who understood our culture and our cultural concerns about Chenguang’s autism impairments and opportunities for the future.”

You can find out about parent carer groups by asking your library for a list of local voluntary organisations, calling [The National Autistic Society Autism Helpline](tel:0800111155) or searching the Autism Services Directory at www.autism.org.uk/directory.

Going out with a child or young person with an autism spectrum disorder

Going out with a child or young person with an autism spectrum disorder is not always easy. They can become overstimulated, or may get anxious about where they are going and when they are coming back.

However, there are strategies you can use, such as visual supports to explain where you are going and that you will be coming home afterwards. Start off with short visits to places, and try to end on a positive note (for example, leaving before your child starts to become anxious).

[The National Autistic Society](http://www.autism.org.uk/outandabout) has a series of information sheets providing advice on going to different places, such as the hairdresser, the shops, the dentist and the hospital. You can download these from www.autism.org.uk/outandabout or call [The National Autistic Society Autism Helpline](tel:0800111155).

Short breaks

There are several ways to access short breaks or respite. To find out what is available in your area contact [The National Autistic Society Autism Helpline](tel:0800111155) or visit www.autism.org.uk/directory.

Most short break and respite services will have certain criteria, the most common being that your child should be receiving specific rates of benefits (for example, middle-rate care component of Disability Living Allowance), or have had an assessment from social services. For further information on this please contact [The National Autistic Society Autism Helpline](#).

Into adulthood

Getting started

Many people are not diagnosed with an autism spectrum disorder until they are in their teenage or adult years. Diagnosis can still be extremely useful at this age. It can help a young person and their family to understand their difficulties and strengths, and to access specialist support if it is needed. [The National Autistic Society](#) has information for adults at www.autism.org.uk/adults.

Think about the future

Helping young people choose what they want out of life

Young people with an autism spectrum disorder should be involved in planning for their future. Formal transition planning for adulthood usually takes place in year nine (around the age of 14). The young person, their family and any practitioners involved with them should discuss future plans and how these can be achieved.

Some young people may have very clear ideas about their future, but for many people with an autism spectrum disorder the future can be a difficult and sometimes frightening concept. Their options need to be introduced carefully and clearly. Sometimes it is useful to have an independent [advocate](#) to help speak on the young person's behalf. More information about advocacy is available at www.autism.org.uk/advocacyandautism or from [Advocacy Resource Exchange](#).

Person-centred planning

Person-centred planning is an approach adopted by local authorities and supported by legislation. It has five key features:

- The young person or adult is at the centre of the planning process.
- Family and friends are partners in the planning.
- The plan shows what is important to the person now and for the future, and what support is needed.
- The plan helps the person to be part of their chosen community and helps the community to welcome them.
- The plan puts into action what the person wants for their life and keeps 'listening'; it remains live as a working document that can be amended and changed as required.

Person-centred plans are owned by the person and must be meaningful to them and understood by them. Lots of different styles are available. Visit www.autism.org.uk/pcp for further information or contact [The National Autistic Society Autism Helpline](#). The Early

Support resources to support information sharing and planning take a person centred approach. For more information see www.ncb.org.uk/early-support/resources.

School and college options

Some young people with an autism spectrum disorder do very well at mainstream colleges. Others achieve well at a specialist college. A list of specialist colleges is available at www.autism.org.uk/colleges or by calling [The National Autistic Society Autism Helpline](tel:08000111111).

Some young people with an autism spectrum disorder go on to study at undergraduate level or above. Some find studying at home, for example, through the Open University, works for them. Others are able to study and live away from home.

Support, including financial support, is available for disabled students. Every university in the UK has a disability or inclusion officer or similar who you can discuss support with. [Disability Rights UK](http://www.disabilityrightsuk.org) also offers information about further and higher education for students with disabilities. Visit www.disabilityrightsuk.org/disabledstudents.htm.

Work options

Some people with an autism spectrum disorder move in to the workplace. Very able people can have successful careers in fields such as engineering or IT; others enjoy and thrive in jobs that are repetitive and predictable, such as shelf-stacking.

Supported employment services are available in different parts of the country, including Prospects, [The National Autistic Society](http://www.autism.org.uk)'s specialist employment scheme. Details of different schemes are available on the Autism Services Directory www.autism.org.uk/directory or from [The National Autistic Society Autism Helpline](tel:08000111111). You could also talk to your local Jobcentre Plus about support available in your area.

Adults with an autism spectrum disorder are protected under the Equality Act 2010. This act aims to protect disabled people and prevent discrimination. In terms of employment this means that:

- it is unlawful for employers to discriminate against disabled people, including at the application and interview stage, and in terms of employment, training and promotion
- disabled employees must not be treated less favourably
- employers should make 'reasonable adjustments' to the workplace so that disabled people are not disadvantaged

Further information about employment and the Equality Act 2010 can be found at:

www.direct.gov.uk/en/DisabledPeople/Employmentsupport/YourEmploymentRights/DG_4001071.

Further information about employment is available at www.autism.org.uk/employment or from [The National Autistic Society Autism Helpline](tel:08000111111).

Living options

Some people with an autism spectrum disorder can live independently, others may need support with certain tasks, or, in some cases, 24-hour specialist care.

At the time of writing, if your child has a statement of special educational needs then transition planning at the age of 14 should include a discussion of their future housing needs. If your child does not have a statement, their housing needs are unlikely to be discussed formally at school. However, you can still start to think about them at this stage and discuss options with a social worker, if your child has one. There are various housing options available.

Independent living

Some people with an autism spectrum disorder are able to live independently without any support from external agencies. Here are the main options:

- **Home ownership** – A person who owns their own home and pays for it through earnings or benefits. Alternatively, they may inherit a property or be its joint owner, perhaps by combining resources with parent carers
- **Shared home ownership** – You buy a share of the property and pay rent on the rest to the housing provider. Rent payments may be covered by benefits.
- **Renting private property** – Rent is paid to a private landlord or letting agent.
- **Renting from local housing authorities or associations** – If you think this is a suitable option for your child, add their name to the appropriate waiting list as soon as possible.

If your child lives independently without formal support, they may still rely heavily on you for help, for example, with managing finances, cooking and shopping. If you provide this sort of support, you may be entitled to a carer's assessment. Your child may be also entitled to a community care assessment. Both these assessments are carried out by social services departments.

Supported living

Some people with an autism spectrum disorder live semi-independently and get support with some tasks. This is generally known as supported living. The main options are:

- home ownership with support
- part or shared ownership with support
- renting private accommodation with support
- housing authority/association accommodation with support

- cluster housing. These are small blocks of self-contained flats with a bedroom, bathroom and kitchen. A manager, warden or support worker is usually on-site or available for 24-hour support.
- community support networks. This is a self-contained house or flat, which is close to similar homes occupied by people with disabilities. A community living worker (CLW) lives nearby and supports residents. Network managers support tenants with specific issues, such as benefits.

Living with others

Your child may share a house with others and receive some support from social services. A community care assessment will help to identify your child's needs. Options for living with others include the following:

- **Supported lodgings** – The person lives in someone else's home as a lodger, but has extra support with things like personal care.
- **Homeshare** – The person shares a house or flat with a second person who has different needs. Both people will have something to offer each other.
- **Group homes and shared housing** – This is where three or four people share a home. Residents can do their own shopping and cooking with support from staff.
- **Further education colleges or residential colleges** – These are for people in further or higher education. Any additional support would depend on an assessment of individual needs and aspirations.

High support needs

Some people with an autism spectrum disorder require specialist 24-hour support. Here are the main options:

- **Parental/caregivers home** – A person who lives in the family home with support from social services. In this situation, parent carers should ask for a carer's assessment.
- **Home ownership with full support** – A person who owns their own property and gets full-time support from social services.
- **Renting with full support** – A person who rents a property from a private landlord or a housing authority with full-time support provided by social services.
- **Shared ownership with full support** – A person who part-owns a property and gets full-time support from social services.
- **Residential homes** – Some residential homes cater for people with a range of impairments and other additional needs, while others are autism-specific. The number of people in a residential home can vary from as few as three to more than 20. There is usually 24-hour care and this may include personal care.

- **Group homes** – These homes are usually smaller than residential homes and shared by three or four people.

Further information about housing options and funding can be found at www.autism.org.uk/housingoptions or contact **The National Autistic Society Autism Helpline**.

Find out what services are available in your local area by visiting www.autismdirectory.org.uk or calling **The National Autistic Society Autism Helpline**. If the service you require does not exist in your borough or county, you may be able to get a placement elsewhere, depending on the social services assessment.

Developing independence

Everyday life

Many young people and adults with an autism spectrum disorder will need to be accompanied when travelling, but some are able to travel independently. In fact, bus and train timetables can be a popular interest for many people with an autism spectrum disorder. Travel training should be discussed with college staff or others involved with your child. A risk assessment may need to be completed to see if it is safe for them to travel alone, and if so, what measures need to be put into place.

Some adults with an autism spectrum disorder are able to learn to drive. However, it is important to make sure that they have a clear plan of what to do if they experience a problem, such as having an accident, and whom they need to contact for help. Perhaps, provide this in a visual or written form and keep it handy in the glove box of the car.

Further information about learning to drive is available at www.autism.org.uk/driving or from [The National Autistic Society Autism Helpline](#).

Social activities

There are an increasing number of social groups for adults with an autism spectrum disorder. Details can be found on the Autism Services Directory at www.autism.org.uk/directory.

Social activities don't have to be restricted to specialist groups, though. Adults with an autism spectrum disorder can benefit from the same activities that the rest of us enjoy. Some find swimming relaxing, whereas others find the sensory environment of a swimming pool overwhelming. Some enjoy going for country walks, whereas others may not understand the point of a walk unless it has a clear purpose, such as posting a letter or having a picnic. Participation in cultural events or attending evening classes related to a special interest can be popular.

In some areas befriending schemes exist. This person who befriends the adult with autism spectrum disorder can accompany them to activities of their choice and provide valuable social contact. Further details of befriending schemes can be found on the Autism Services Directory www.autism.org.uk/directory or by contacting [The National Autistic Society Autism Helpline](#).

Eating and drinking

Some young people and adults with an autism spectrum disorder may continue to have a restricted diet, or seek out certain strong-tasting foods. Others may not recognise the feeling of being full and continue to need guidance on healthy eating, or have their diet monitored for them and boundaries set around food.

Young people with an autism spectrum disorder can be involved in cooking from an early age. They may follow a visual recipe, or help someone else to cook. People with an autism spectrum disorder should have a say in the menu that is on offer where they are living, and be involved in shopping for food.

Personal care

Some adults with an autism spectrum disorder may still need support with their personal care needs. Women may require particular support with the use of sanitary wear when menstruating. Particular cultural and religious or belief requirements around menstruation care may also need to be considered and supported in order to meet a woman's equalities needs. Practitioners may need to approach you as the parent carer to seek clarity on this, or alternatively go to a cultural or religious advisor if you feel you are not the best person to give this information. Independence should be encouraged as much as possible and visual supports may, again, prove very useful.

Strategies such as backwards chaining (see [Personal care](#) in the [School Years](#) section), can still be used with young people and adults with an autism spectrum disorder. Visual supports also continue to be useful, so a visual schedule showing the order in which to wash or dress can be helpful still. There are other ways of making things more visual and understandable as well.

“Jason was able to shower by himself but as he could not read [he] used to get very confused by which bottle to use for shower gel, shampoo or conditioner. He recognises numbers 1 to 5 so we decided to number the bottles ‘1 = shower gel’, ‘2 = shampoo’ and ‘3 = conditioner’. Now he is able to shower independently in privacy, and we know the right bottle is being used for the right thing!”

Home environment

It helps a young person with an autism spectrum disorder if their home is autism-friendly, with some organisation and possibly some adaptations to the environment. Some tips for creating an autism-friendly environment include:

- having a clear home for everything
- clearly defining different rooms – for example have a different carpet in each room
- avoiding harsh lighting, such as strip lighting
- using carpet or soft flooring as it is quieter than laminate flooring for those who are sensitive to noise
- using low-arousal colours (such as cream) for walls and soft furnishings
- using non-patterned carpets and wallpapers
- keeping furniture to the edge of rooms; this makes them easier to navigate

Equipment and aids

Some young people with an autism spectrum disorder have a very poor awareness of danger and some, due to their sensory issues, may seek out sensory experiences that could be unsafe. Depending on your child's individual needs, you may need to take some additional safety measures at home, such as installing:

- locks or high handles on cupboards containing items that could be unsafe (cleaning products, etc.)
- plug locks
- strengthened glass on windows
- window locks
- an alarm mat for young people who run out of the house
- high fences in the garden
- a lockable garden gate or a high handle

The National Autistic Society's website has a list of companies that make equipment and aids for the home. Visit www.autism.org.uk/environment.

If you think that your home needs to be modified in some way, you may want to seek advice. The gov.uk website has information on home adaptations and equipment at www.gov.uk/help-for-disabled-child/home-adaptations. Alternatively, you can telephone The National Autistic Society Autism Helpline.

If large adaptations are needed, contact your local social services' occupational therapy department. It can carry out an assessment to see what is required and how it may be funded.

Letting go

Supporting choice and autonomy

People with an autism spectrum disorder should be involved in decisions affecting their care and life. This ranges from choosing what to wear and eat, to wider decisions.

Choice and autonomy can be promoted and supported by well-trained staff, understanding family members and skilled advocates with a knowledge of autism spectrum disorders.

Making choices can be difficult for people with an autism spectrum disorder, but it shouldn't be assumed that they are unable to make decisions. You can try presenting only two choices at a time at first and using visual supports. For example, in the morning you can help your child to choose between two items of clothing to wear.

In order to support decision-making and choice, anyone working with your child needs to know them well. You could make a 'life story book' where their preferences and habits are listed – get your child to help you make the book if they would like to.

Developing self-awareness

Young people and adults with an autism spectrum disorder may become increasingly aware of their condition. If it wasn't explained to them as a child they may need to be made aware of what an autism spectrum disorder is and how it affects them. For some adults, this can be a revelation. Suddenly they have an explanation for the things they may have found difficult. They realise that they weren't 'stupid' or 'naughty', or any of the other things they were mislabelled as, but in fact they had an autism spectrum disorder. Some go on to become experts in their condition and can have great insight in to their own difficulties and strengths.

Adults may find it useful to read some of the personal accounts written by other people with an autism spectrum disorder. See [Books by people with an autism spectrum disorder](#) in the [Resources](#) section.

Supporting positive risk-taking

New opportunities and experiences involve a certain amount of risk for everyone. However, in order to lead an interesting and productive life we all need to try new things and this is the same for adults with an autism spectrum disorder. They will learn from new experiences and opportunities, but may need additional support and preparation in order to benefit from them. If you feel something involves too much risk for your child, you should discuss it carefully with the practitioners involved with them to see if you can come up with a solution together.

Meeting others

Parent groups

There are some groups that are specifically for parent carers of an adult child with an autism spectrum disorder. For details see www.autism.org.uk/directory or contact [The National Autistic Society Autism Helpline](#).

Short breaks

If you are still caring for your adult child you may be entitled to short breaks or respite. Details of short break and respite services in your area can be found at www.autism.org.uk/directory or contact [The National Autistic Society Autism Helpline](#).

To access short breaks you will often need to have been assessed by your local social services department. It will look at your child's needs but also what you require as their carer. Further information about social services assessments is available from [The National Autistic Society Autism Helpline](#) or [Carers UK](#).

Top tips

These top tips have been provided by The National Autistic Society's Parent to Parent Service volunteers (all parent carers of children or young people with an autism spectrum disorder):

- Expect yourself to feel a mixture of emotions when you get a diagnosis. Don't put yourself under pressure to be on top of things. It is OK to feel upset.
- Information is power, so learn what you can but don't overwhelm yourself, feeling you have to read every text book.
- Pace yourself. You may feel that you have a thousand things to find out about, but limit the time you spend on this every day. You have the rest of your life to live as well.
- If you have a partner, divide up calls and tasks. Try to attend support groups together.
- Look after yourself. Sleep and relax when you can and accept any offers of help.
- You are not alone. Contact [The National Autistic Society](#) and attend a local support group, so you can talk to others in the same situation. There is a big community of fellow parents who are happy to help.
- Seek help and make use of services. Apply for benefits and help from social services. Find out about extra support at school for your child.
- If you are refused services ask for an explanation in writing and don't be afraid to challenge the decision.
- Attend [EarlyBird](#) training if it is available in your area.
- Autism is a lifelong condition and you may come across people who are passionate about, or are selling, a 'cure'. Talk to professionals or [The National Autistic Society](#) about the evidence base for their claims. Research Autism is an independent charity that rates therapies linked to autism spectrum disorders using all available research. You can look up any therapy and its rating at www.researchautism.net. A list of questions to ask before starting a particular therapy is available to download from www.autism.org.uk/approaches/choosing or call [The National Autistic Society Autism Helpline](#) for a copy.

Resources

General resources

- **Autism Alert card** – Developed by **The National Autistic Society** in consultation with people with an autism spectrum disorder and their families, this mini information pack is designed for adults to use in situations where communication may be difficult. It includes a key facts leaflet about autism and a credit-card style insert for emergency contacts.
- **‘I’m not naughty, I’ve got autism’ children’s T-shirts** – These are available in a range of sizes and can be useful for tricky moments when out in public.
- **‘This person has autism’ cards** – This business-size card is suitable for use by all ages and asks people to show understanding. It can be handed out to members of the public when difficult situations arise. A version is also available for people with Asperger’s syndrome.

The resources above are available to buy from **The National Autistic Society**’s online shop at www.autism.org.uk/shop. Alternatively, call Central Books on 0845 4589911.

Books by people with an autism spectrum disorder

Grandin, T., (1996). *Thinking in pictures*. New York: Vintage

Jackson, L., (2002). *Freaks, geeks and Asperger syndrome*. London: Jessica Kingsley Publishers

Lawson, W., (2000). *Life behind glass*. London: Jessica Kingsley Publishers

Williams, D., (1993). *Nobody nowhere*. London: Corgi

The National Autistic Society has an area of its website aimed at young people and adults with a diagnosis of autism spectrum disorder, visit www.autism.org.uk/adults.

Books for family members

Attwood, T., (2008) *The complete guide to Asperger’s syndrome*. London: Jessica Kingsley Publishers

Beckerleg, T., (2008) *Fun with messy play: ideas and activities for children with special educational needs*. London: Jessica Kingsley Publishers. This is packed full of messy play ideas to try at home.

Bogdashina, O., (2003) *Sensory perceptual issues in autism: different sensory experiences, different perceptual worlds*. London: Jessica Kingsley Publishers

Christie, P., et al., (2009) *First steps in intervention with your child with autism – frameworks for communication*. London: Jessica Kingsley Publishers

Clements, J., (2004) *Behavioural concerns and ASD: explanations and strategies for change*. London: Jessica Kingsley Publishers

Dickinson, P., and Hannah, L., (1998) *It can get better: dealing with common behaviour problems in young autistic children*. London: The National Autistic Society

Doherty, K., McNally, P., and Sherrard, E., (2000) *I have autism... what's that?* London: The National Autistic Society. This is visual guide to autism spectrum disorders for young children.

Dunn Buron, K. and Curtis, M., (2008) *The incredible 5-point scale*. London: The National Autistic Society. This book, for children with an autism spectrum disorder, aims to help them manage their behaviour.

Edgar, J., (1999) *Love, hope and autism*. London: The National Autistic Society

Gray, C., (2001) *My social stories book*. London: Jessica Kingsley Publishers. This contains examples of how to write social stories.

Hannah, L., (2001) *Teaching young children with autistic spectrum disorders to learn*. London: The National Autistic Society. This is a practical, straightforward book for parent carers and staff in mainstream schools and nurseries who are supporting children aged three to seven.

Hodgdon, L., (2004) *Visual strategies for improving communication*. Troy, MI: Quirk Roberts Publishing

Ives, M. and Munro, N., (2002) *Caring for a child with autism*. London: Jessica Kingsley Publishers. This is broad-ranging book that aims to answer all the questions that parents of newly diagnosed children ask. It contains numerous useful contacts.

Lawson, W., (2001) *Understanding and working with the spectrum of autism*. London: Jessica Kingsley Publishers

Legge, B., (2002) *Can't eat, won't eat: dietary difficulties and autistic spectrum disorders*. London: Jessica Kingsley Publishers

Leicestershire County Council and Fosse Health Trust, (1998) *Autism: how to help your young child*. London: The National Autistic Society

Moor, J., (2008) *Playing, laughing and learning with children on the autistic spectrum*. London: Jessica Kingsley Publishers. This is practical guide to play activities. It is useful for toddlers and primary school children who are struggling to learn how to play.

Morrell, M. F. and Palmer, A., (2006) *Parenting across the autism spectrum: unexpected lessons we have learned*. London: Jessica Kingsley Publishers

Myles, B. S. and Dunn Buron, K., (2004) *When my autism gets too big: a relaxation book for children with ASD*. Overland Park, Kansas: Autism Asperger Publishing Company

Pike, R., (2008) *Talking together about an autism diagnosis*. London: The National Autistic Society. This is aimed at primary school-age children.

Powell, A., (2011) *Autism: understanding and managing anger*. London: The National Autistic Society

South Gloucestershire Council, (2005) *Guidelines for working with children with autistic spectrum disorders at foundation stage and key stage 1*. London: The National Autistic Society

Stock Kranowitz, C., (2005) *The out-of-sync child*. New York: Perigee

Thomas, M. and Elder, J., (2005) *Different like me: my book of autism heroes*. London: Jessica Kingsley Publishers. This is a book detailing different historical figures who probably had an autism spectrum disorder.

Whitaker, P., (2001) *Challenging behaviour and autism: making sense – making progress*. London: The National Autistic Society. This is a step-by-step practical guide for parent carers and teachers of youngsters with an autism spectrum disorder, looking at prevention and management of common behavioural difficulties.

Books for siblings

Bleach, F., (2001) *Everybody is different: a book for young people who have brothers and sisters with autism*. London: The National Autistic Society. This is aimed at children aged eight to 13.

Brock, C., (2010) *I'm a teenager.....get me out of here!* London: The National Autistic Society. This is aimed at teenage siblings.

Gorrod, L., (1997) *My brother is different: a book for young children who have brothers and sisters with autism*. London: The National Autistic Society. This is aimed at children aged four to seven.

Hunter, S., (2006) *My sister is different*. London: The National Autistic Society. This is about life with a sister who has autism, written by a 10-year-old who also has an autism spectrum disorder.

The National Autistic Society has an area of its website especially for siblings. Visit www.autism.org.uk/siblingsinfo

Useful organisations and websites

Action for Advocacy

An advocacy organisation that is able to provide details of local advocacy services

www.actionforadvocacy.org.uk

020 79214395

Advocacy Resource Exchange

An advocacy organisation that is able to provide details of local advocacy services

www.advocacyresourceexchange.org.uk

02380 234904

Association of Speech and Language Therapists in Independent Practice

Offers details of speech and language therapists in the UK who are in independent (private) practice

www.helpwithtalking.com

Carers UK

A leading charity for carers in the UK

www.carersuk.org.uk

0808 8087777

Citizens Advice Bureau

Able to assist with a variety of issues, including rights and entitlements, such as benefits, and debt

www.citizensadvice.org.uk

Wales : 08444 772020

England: 08444 111444

Citizens Advice Scotland

Able to assist with variety of issues, including rights and entitlements, such as benefits, and debts

www.cas.org.uk

0808 8009060

Contact a Family

A charity for families of children with any disability

www.cafamily.org.uk

0808 8083555

Disability Rights UK

An organisation that offers information and advice to students with disabilities

www.disabilityrightsuk.org/disabledstudents.htm

0800 3285050

EarlyBird

A free, three-month course for families with a preschool child who has a diagnosis of an autism spectrum disorder. The course supports parent carers to develop their child's communication and behaviour at home. EarlyBird is offered in most areas of the UK by licensed teams. To find out if there is a team in your area call 01226 779218 or visit

www.autism.org.uk/earlybirdteams

Early Years Equality

Provides disability equality and other protected characteristic equality support, guidance, advice, discrimination casework and training to children, families, organisations, providers and policy makers across the UK.

0114 2700214

enquiries@earlyyearequality.org.uk

www.earlyyearequality.org.uk

ERIC

A charity providing advice, support and resources relating to continence

www.eric.org.uk

0845 3708008

Family Fund

Financial help and grants for families with children with additional needs

www.familyfund.org.uk

0845 130 4542

Family Information Service (FIS)

Provides a range of information to parents, including up-to-date details of local childcare and early years provision. Services are usually located in local authorities or councils. The Daycare Trust website allows you to search for your local FIS.

www.daycaretrust.org.uk/findyourFIS

IPSEA

A charity providing advice and support on all aspects of educational issues, including tribunal support

www.ipsea.org.uk

0800 0184016

Kidscape

A charity providing advice and services relating to bullying

www.kidscape.org.uk

08451 205204

The Makaton Charity

A charity providing information and training on the use of Makaton sign language

www.makaton.org

01276 606760

The National Autistic Society

Leading autism charity, providing services, information, advice and support on all issues relating to autism spectrum disorders

www.autism.org.uk

Helpline: 0808 800 4104 (this number can also be used to access the Welfare Rights and Community Care advice services)

Education Rights Service: 0808 8004102

Parent to Parent Service: 0808 8004106

Parent Partnership Service

Impartial support for families with children with additional needs, particularly relating to educational issues

www.parentpartnership.org.uk

020 78436058

Pyramid Educational Consultants UK

An organisation providing training in the use of PECS

www.pecs.org.uk

01273 609555

The Royal College of Speech and Language Therapists

Offers information about speech and language services in the UK

www.rcslt.org.uk

020 73781200

SALT independent practice

Provides details of private speech and language therapists

www.helpwithtalking.com

01494 488306 (answerphone)

Scottish Independent Advocacy Alliance

Provides details of advocacy groups in Scotland

www.siaa.org.uk

0131 260 5380

The Signalong Group

Offers information about the use of signing

www.signalong.org.uk

0845 4508422

YoungMinds

A charity providing information and support on issues relating to mental health and well-being in children and young people

www.youngminds.org.uk

0808 802 5544

Glossary

Advocacy – Support to help people who find it difficult to communicate their views, especially in relation to statutory and legal services.

Advocate – A person who helps people to communicate their views.

Asperger's syndrome – An autism spectrum disorder. People with Asperger's syndrome usually have fewer difficulties with language than people with autism, and do not have the accompanying learning disabilities that some people with autism have. They are likely to be of average or above average intelligence.

Attention deficit hyperactivity disorder (ADHD) – A developmental disorder that can cause overactive behaviour (hyperactivity), impulsive behaviour and difficulties in concentrating.

Autism spectrum disorder – A developmental disorder characterised by difficulties with social interaction, social communication and rigidity of thinking. It is an umbrella term and covers autism and Asperger's syndrome.

Clinical psychologist – A psychologist who may be involved in the assessment and diagnostic process, and who specialises in looking at behaviour.

Common Assessment Framework (CAF) – A process to ensure that a child's needs are met. The process helps to make decisions about how a child's needs can be met in terms of what families can do and what services need to be provided.

Developmental coordination disorder – A difficulty in coordinating movement, sometimes referred to as dyspraxia.

Disability Living Allowance (DLA) – A benefit for children and adults with a disability. It is made up of a care component and a mobility component.

Dyslexia – A learning difficulty that mainly affects the development of literacy and language-related skills.

Echolalia – Repeating words or phrases spoken by someone else, often with little understanding of what they mean.

Educational psychologist – A psychologist who tackles difficulties encountered by children and young people in education. They carry out a wide range of tasks with the aim of enhancing children's learning and helping teachers to become more aware of the social factors that affect teaching and learning.

Kanner autism – Also sometimes called 'classic autism'. This is an autism spectrum disorder characterised by difficulties in social communication and interaction and rigidity of thinking. People who have Kanner autism often have a delay in developing language and a learning disability.

Makaton – A form of sign language often used with people who have learning disabilities.

Occupational therapist – A person who looks at a child or adult's ability to function and do the things they need to do in everyday life, such as use cutlery or dress themselves. They also look at sensory processing issues.

Paediatrician – A doctor who specialises in treating children.

Parent Partnership Service – A local service for families of children with additional needs, which provides support and advice about getting the correct support at school.

Picture Exchange Communication System (PECS) – A way of using pictures and symbols to help children who have difficulty communicating with speech.

Portage – A home-visiting educational service for preschool children with additional needs. They work on agreed goals with a child and family.

Social stories – Short descriptions of a particular situation, event or activity, that include specific information about what to expect in that situation and why.

Special education needs coordinator (SENCO) – A member of staff in schools and early years settings who coordinates provision for children with special educational needs. They are sometimes referred to as an inclusion manager.

Special educational needs (SEN) – A legal term used to describe the needs of a child that require extra support at school.

Speech and language therapy (SALT) – A form of therapy to support people who have difficulties with communication. They may work privately or through the NHS.

Statement of special educational needs – A document provided by a local authority, which sets out a child's needs and all the extra help they should get.

Triad of impairments – the three impairments that characterise autism: social communication, social interaction and rigidity of thinking.

Early Support

for children, young people and families

www.ncb.org.uk/earllysupport

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Department
for Education

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Early Years Equality
removing racism • defying discrimination

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