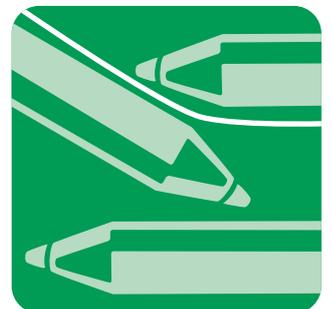
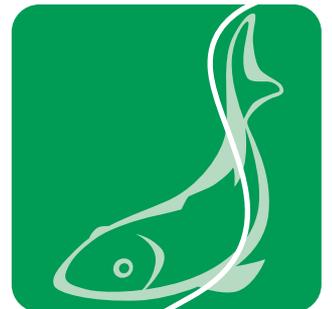


## Information for parents Autistic spectrum disorders (ASDs) and related conditions







**A guide for parents with children who have recently been diagnosed with an autistic spectrum disorder, or who are in the process of getting a diagnosis.**

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## Introduction – where you are now

If you have recently learned that your child has an [autistic spectrum disorder \(ASD\)](#), this guide is for you. It has been drawn up with the help of parents of children with autism, to:

- help you understand what autism is
- give you a picture of what you and others can do to help your child
- tell you about the support that is available
- answer the questions that many parents have at this time.

Throughout this booklet the terms [autism](#), [autistic spectrum disorders](#) and the abbreviation [ASD](#) are used to cover the range of developmental disorders, which include Kanner's autism and Asperger's syndrome. In places, we refer specifically to Asperger's syndrome.

It may be that you do not have a diagnosis yet. There may be a recognition that your child has an autistic spectrum disorder, but it's not yet clear where your child is on the spectrum. Or, there may be indications that your child has a related condition. Whether or not your child is eventually diagnosed with autism, this guide provides some information to help you contribute to the assessment process, and prepare for what happens next. You may not want to read it all at once – you may find it more helpful to refer to different sections over time.

[The National Autistic Society \(NAS\)](#) and [Parents Autism Campaign for Education \(PACE\)](#), who wrote this booklet, would like to thank all the parents of children with autism who helped us to produce it. All the quotations are from parents. Some are taken from [Love, Hope and Autism](#) by Joanna Edgar. You can find out more about this and other publications at the back of the booklet.



**First, there are two very important things for you to remember:**

**It's not your fault!**

The fact that your child has an ASD, or may have an ASD, has nothing whatsoever to do with the way that you have been looking after them. The causes of autism are as yet unknown, but we do know for certain that autism is not caused by parenting. Parents of young children with ASDs are just like everyone else. Autism affects children from all walks of life and in all countries and cultures.

**You aren't alone!**

The [National Autistic Society](#) estimates that autistic spectrum disorders touch the lives of 500,000 families throughout the UK. Many other parents are going through what you're going through and there are many who are further on in their journey.

Even if you don't feel like taking any other steps right now, we recommend that you make contact with other parents of children with autism through a local support group as soon as possible. They can help you make sense of the things you read here and can be a valuable source of information and advice on how things work in your area.

You can find out about local support groups by:

- contacting [The National Autistic Society \(NAS\) Helpline](#) on 0845 070 4004 or [autismhelpline@nas.org.uk](mailto:autismhelpline@nas.org.uk)
- asking the person who gave you this booklet, or your health visitor
- asking at your local library.

*'My message to other families of autistic children is always to think positively, follow your own instincts and never ever give up hope.'*

## Coming to terms with a diagnosis of autism or a related condition

If your child has not yet had a diagnosis, uncertainty about their situation may be very stressful for you. Sometimes the process of reaching a diagnosis seems to take a very long time, and for some parents this time is harder than the period after a problem has been identified.

*'The stress is not knowing. If you know a bit and you're actually doing something, even though there are 100 things you could be doing, you feel better about it.'*

If the process of diagnosis is taking a long time, it may be that the professionals suspect your child has autism or a related condition but want to be certain their diagnosis is correct. This is important, because it affects the type of help that will most effectively address your child's needs. Unfortunately, there are delays sometimes simply because of the high demand on services for children with disabilities.

*'Some health specialists may be reluctant and say 'We don't like to label children'. Well, we don't like to label them as parents 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 – you just want to know.'*

There is general agreement that getting appropriate education and/or therapy at the earliest possible stage maximises the chance that a child with autism will develop their abilities. The sooner you get a diagnosis, the sooner you can begin to get the help your child needs.

If you have received a diagnosis, even though you may have thought you wanted definite information, it can still be a big shock. Many families experience diagnosis as a time of great emotional upheaval.

*'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 families feel they need to grieve the loss of the child they thought they had. Feeling angry or feeling that you must be at fault are normal and common reactions. This process is an important part of accepting your child's diagnosis, and it can take time.

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

When some family members find it easier than others to adapt to the family's new situation 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".'*

Some families go through a process that starts with shock and an inability to do anything, and then moves through anger to some sort of acceptance. Different family members are likely to take a different amount of time to go through this process. But parents of children with autism emphasise that it really helps when you reach a point at which you can begin to accept the situation.

*'I think the first 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.'*

Some parents 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 and it will have low points but it will also at times bring rewarding experiences.

*'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.'*

*'Someone who also had a child with a disability told me: "You'll meet people in your life now that you would never ever had met if you weren't setting out on this journey. You will meet the most genuine, the most kind, the most imaginative people, and if you weren't entering into this world, you would never have had the opportunity to do that."'*

However, it's important not to deny how stressful it can be to have a child with an ASD.

*'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.'*

Some parents feel very alone, and unsure of how to cope with social situations.

*'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 with him, and you do start to get a bit depressed, really.'*



It can also be particularly difficult to handle other people's lack of understanding. Over time, you will develop skill in handling 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.'*

All parents say that what really helps is talking to other parents of children with autism.

*'Unless you're fortunate enough to speak to other parents who have been in the same position, you feel that you're on your own.'*

*'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.'*

This guide aims to help you to find the information and support you need so that you can move forward and feel more in control.

## What is an autistic spectrum disorder (ASD)?

Autistic spectrum disorders (ASDs) are lifelong, developmental disabilities that affect the way a person communicates and relates to people around them.

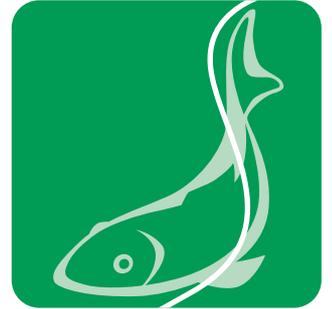
*'It's as if your child's brain has been wired up in a different way to usual. This doesn't change, but the ways in which it shows itself, and the extent to which it shows itself, do change.'*

*'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.'*

*'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.'*

Children with ASDs are affected in a huge variety of ways and to very different degrees. This is why it's called 'the autistic spectrum'. Autism can affect children with any level of intellectual ability, from those who are profoundly learning disabled, to those with average or high intelligence. So, having an ASD doesn't necessarily mean that you have learning difficulties. The more seriously affected children at one end of the spectrum have learning difficulties as well 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 may go on to be successful in their chosen field. However, they still experience significant social and communication difficulties.

Some children have other difficulties which are not directly related to their ASD, such as hypermobility, dyspraxia, dyslexia or attention deficit hyperactivity disorder (ADHD). It's important to seek an assessment of any other conditions, as this affects the sort of support that will best meet your child's needs.



## What are the signs and characteristics of autistic spectrum disorders?

Children with ASDs have significant difficulties relating to other people in a meaningful way. Their ability to develop relationships is impaired, as is their capacity to understand other people's feelings and the social rules of communication.

Everyone with an ASD has difficulties in three main areas. These are known as 'the triad of impairments', or 'the three impairments':

- social understanding and social behaviour
- social communication (verbal and non-verbal)
- rigidity of thinking and difficulties with social imagination.

All children with autism have impairments in all three of these areas. However, the ways in which these three impairments manifest themselves vary enormously.

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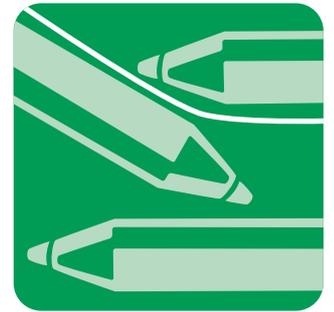
This section draws on *Autism: How to help your child* (1998) and *Autism in the early years – a practical guide* (2000).

Read more about this in **Books and further sources of information**

## Social understanding and social behaviour

When they are born, most babies seem ready to become sociable and develop communication skills. 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 ASDs find this all very difficult. They may seem less interested in people. They 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 don't seem to understand how to do these things. A young child with an ASD 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
- only be receptive to approaches from people they know well
- not want to be comforted in distress
- seem to use people as a means to an end – for example, by taking someone's hand to obtain something out of their own reach
- seem to be unaware of social rules and conventions.



## Social communication (verbal and non-verbal communication)

Children with ASDs may not be eager to communicate. They may not be ready to learn things that other children learn naturally and therefore don't have the chance to tune into language in the same way. They find it very hard to make sense of the things that happen around them. Words may mean very little to them and they may be unable to link what they see with the things being said to them.

Young children with ASDs not only have difficulty making sense of words but also with reading non-verbal messages in facial expressions and gestures. This makes it difficult for them to learn what is expected of them, and to recognise when someone is happy or upset and what that means. A young child with an ASD 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 communicative intent
- use language correctly but not really understand what they are saying
- echo words other people say – straight away, or later (this is sometimes called echolalia)
- use words and then 'lose' them
- not use eye contact as a natural part of communication
- rarely understand or use gesture
- develop a pointing gesture, but use it to indicate need rather than to share an experience.

*'The concepts of physical and mental impairment are fairly easy for people to grasp, but the idea of social impairment is much more difficult to understand (and to explain).'*

## Rigidity of thinking and difficulties with social imagination

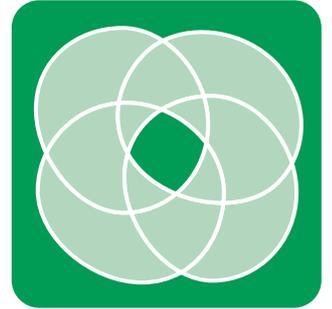
Imagination helps us understand the world and predict and see the perspective of other people. Children with an ASD are unable to do this to any great extent. When pretend play begins to appear in children who don't have an ASD, it's a sign that imagination is beginning to develop. In children with ASDs this process occurs very slowly, in unusual ways, or not at all.

Problems of imagination show themselves in different ways. Some children never seem interested in what a toy is or what it represents. They may focus on the features of the toy such as the wheels of the car or the box the toy came in. Other children may run the toy car in and out of a garage, but don't act out more complex stories. Some children seem to act out stories or take on particular characters, but the story turns out to be an imitation of a video or book. This doesn't mean that children with autistic spectrum disorders don't have any imagination, it just means they tend to have less ability in this area and they tend to be less interested in sharing their imaginative ideas than other children.

Some children with ASDs learn to talk easily, but 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 have difficulties understanding that a story is not real.

Problems with imagination make the world a very uncertain place, so children with ASDs find reassurance in setting up routines and patterns that they can control. Repetitive behaviours and routines are a common feature of ASDs. A young child with an ASD:

- cannot easily make sense of sequences and events
- may become distressed if a familiar routine changes
- may impose routines on others



- will often engage in stereotypical body movements (for example, some children will flap their hands, some may rock back and forth)
- will often resist new experiences, for example trying different foods or wearing new clothes
- may find it hard to work out what other people are going to do, and cannot make sense of why other people do what they do – they are unable to take someone else’s perspective
- will only develop symbolic play slowly – if at all (symbolic play is play which involves being in a particular role and using imagination)
- will often pay particular attention to unusual details and struggle to see the bigger picture.

## Other common challenges for children who have an ASD

This section may look daunting, so it’s important to remember that strengths and challenges change over time and that not all of the following will be relevant for your child.

*‘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.’*

- **Sensory difficulties**

A significant number of children with an ASD are very sensitive (hypersensitive) or under-sensitive (hyposensitive) in one or more of their senses. They may have heightened sensitivity to certain types of sound, touch, texture, taste of food, light, colour or smell. Something like a clothes label, for example, might cause a child extreme discomfort. Other children lack sensory awareness of temperature or pain. Some children shift between hypersensitivity and hyposensitivity. Sensory difficulties 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, you know, the little lights that tell you the numbers. Every time they flicked over that bothered her. She could hear them buzzing and we thought it was the actual light that was on, like you would, the neon type, but it wasn't and we couldn't understand why she could look at them but then she'd run away. 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 that 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.'*

- **Sleeping difficulties**

Children may have problems getting to sleep or may wake periodically throughout the night. The child may catch up on sleep during the day or may seem to require much less sleep than the rest of the family.

- **Eating difficulties**

Children may only eat certain foods, or foods of one consistency or one colour. Others have rituals, such as insisting different foods never touch on the same plate.

- **Difficulties with toileting**

As with eating difficulties, it may be advisable to look into whether there are other medical reasons for your child's difficulty, such as constipation.

- **Bowel problems, which may cause pain**

Some children may be prone to constipation or diarrhoea and some benefit from a special diet. They may experience both, at different times, or at the same time (if the bowel is blocked, then only liquid matter can pass the blockage).

- **Difficulties developing independence and personal care skills**

- **Difficulties with motor skills**

For instance, they may have unusual difficulty holding a pencil (a fine motor skill). Some children may be clumsy or have an odd way of standing or walking (gross motor skills).



- **Obsessions**

Thomas the Tank Engine is a popular one. Some children with an ASD insist on certain rituals.

- **Fears and phobias**

These can include everyday things such as certain advertisements, pictures in books, specific songs.

- **Poor spatial awareness**

Spatial awareness is the sense of knowing where you are in relation to other objects around you.

- **An unusual focus on detail**

Focusing on minor details and ignoring the main picture – for example, looking at a spot of dirt on the floor when they are in the middle of a chasing game.

- Difficulty with social relationships
- Difficulty with verbal communication
- Difficulty with non-verbal communication
- Difficulty in the development of play and imagination
- Resistance to change in routine

Labels for icons:

- Displays indifference
- Indicated needs by using an adult's hand
- Echolalic – copies words like parrot
- Inappropriate laughing or giggling
- No eye contact
- Joins in only if adult insists and assists
- Does not play with other children
- Variety is not the spice of life
- Lack of creative pretend play
- One-sided interaction
- Talks incessantly about only one topic
- Bizarre behaviour
- Handles or spins objects
- But some can do some things very well, very quickly but not tasks involving social understanding

## What are the strengths of children with an ASD?

Every child is unique, but there are particular strengths and skills that children with an ASD seem more likely to develop than other children.

All of the following are characteristic:

- An ability to focus on detail and to concentrate for long periods of time on a single activity. Some children can give their sole attention to a task and therefore achieve a high level of skill and continue to work on tasks way beyond the point at which other children of the same age would tire of them.
- A talent for learning facts and skills when they want to, and when they are presented in a way particularly suited to their learning style, for example using lots of visual material.
- A very individual way of looking at the world and figuring out how the world works. For some families, these idiosyncrasies provide a special source of delight and humour.

*'One of the positive things they do is make you look at things differently. As you get older you're conditioned to think, "You should do this, that and the other". They do things in such a refreshingly different way. It's quite nice, really. All children do this, but especially autistic children. They're so direct and frank. I think that's really nice.'*

- A powerful and unusual learning curve. Children may seem to stand still in their development for a while then take an unexpected leap forward in their abilities and skills, perhaps after trying a particular task only once. This pattern of development is usually associated with learning that requires skills other than language or communication, like using building blocks, doing jigsaws, memorising facts and figures, understanding things visually, mimicry, or using a natural musical ability. A small proportion of individuals with autism excel in one or several of these areas. Very occasionally a child's general level of ability will be in very sharp contrast with very impressive expertise or knowledge in one particular area.



## Getting exact information about your child's diagnosis

The term **autistic spectrum disorder (ASD)** is an umbrella term that encompasses the terms **autism**, **Asperger's syndrome**, **autistic disorder**, **classic autism** or **Kanner's autism**. The information in this pack is relevant for children with ASDs and related conditions, which include:

- **pervasive developmental disorder (PDD)**
- **pervasive developmental disorder not otherwise specified (PDD-NOS)** (also known as atypical autism)
- **semantic pragmatic disorder (SPD)**.

Read more about this in **What are the signs and characteristics of autistic spectrum disorders?**

The behaviours described in the '**three impairments**' discussed on page 9 might be seen individually in a non-autistic child from time to time, but an **autistic spectrum disorder** is diagnosed when a child has behaviour indicating all three impairments. The underlying causes of autism are unknown in the majority of cases (and may well be different for different individuals with ASD).

In recent years, there has been a marked increase in the number of children diagnosed with autism. It's not clear why this is the case. Some people believe it's the result of better diagnosis, others believe there has been an increase in the incidence of ASD. If you would like more information on this subject, contact the **NAS Helpline**. Contact details are given at the end of this booklet.

When you get a diagnosis for your child, it's important that the person making the diagnosis also gives you an indication of how your child, as an individual, is affected. This will give you more of an idea of their skills and needs, and the support you might want to ask for now, and in the future.

Ask the paediatrician and other professionals you are talking with to write down information about your child's diagnosis for you, so that you have a written record of your child's difficulties. This helps because you have information to read through in your own time and to refer to again as time goes by. Written information about your child and their needs and difficulties can be important when you are asking for services to help your family.

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



## Getting help

### Statutory services

Statutory services are services that your local authority or NHS Trust must provide by law. They are organised in different ways in different places but include health, education and social services.

You are entitled to receive certain forms of support from statutory services.

However, this booklet cannot tell you exactly how you should receive help, because that will depend on your child's particular needs and the way in which services are organised in your area.

At present, the different types of support available for children and families are not always well co-ordinated, and parents often report that they discover what's available in a piecemeal way, from different sources, at different times. While some parents experience support that is organised smoothly and quickly, others find getting help can be a drawn-out process taking many months.

It's Government policy to develop better joint working between professionals and departments and more integrated services. Where services are less well co-ordinated, parents often find they need to play an active role in ensuring that services and professionals work together.

### Parent groups and voluntary organisations

Many different voluntary organisations, charities and parent support groups can help. They provide a broad range of support, and can help you to find out how services work in your area. They can also help with practical things like applying for financial help and benefits.

Many families stress how important parent 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.'*

*'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, "Okay, Right. It's normal."'*

You can find out about local groups by talking to other parents, asking your library for a list of local voluntary organisations or by searching on the internet.

The [National Autistic Society \(NAS\)](#) holds a list of parent support groups and local affiliated organisations throughout the UK. It also has many branches which support families in different areas. Ring the [NAS Helpline](#) if you want to find support groups or services near you or visit the [NAS website](#). Contact details are given at the end of the booklet.

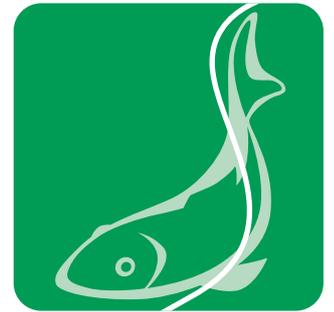
NAS runs a [Parent-to-Parent scheme](#) in some areas. This is a confidential telephone support service provided by other volunteer parents. You can ring the freephone number [0800 952 0520](#) at any time, leave a message and a contact telephone number. The next parent volunteer on duty will pick up the message and phone you back.

The [NAS Befriending Scheme](#) also operates in some areas and puts trained volunteers in contact with families to provide a friendly listening ear or company when you're out and about. For more information about this service, ring [0115 911 3369](#).

Some parent support groups operate on the internet. Email networks and chat rooms can be valuable sources of information. There are discussion groups and chat facilities for parents, siblings, people with autism, and general groups for anyone with an interest in autism.

Email discussion lists let you post questions and useful information to other members on the list, at a time that's convenient for you. Chat channels are for conversations in 'real time'.

Read more about this in [Voluntary organisations that can help in Useful organisations](#)



The NAS website has links to a range of internet groups. To reach the list of links, go to [www.nas.org.uk/external](http://www.nas.org.uk/external). A few of these links are included below for information. As these are open internet groups, this publication cannot endorse their contents, but you might find it helpful to know about them.

### **Autism networks**

A charitable body run by a group of like-minded parents, carers, professionals and people with autism. One of their aims is to make links with anyone concerned with autism.

[www.autismnetworks.org.uk](http://www.autismnetworks.org.uk)

### **AspergersUK**

For UK parents of children with Asperger's syndrome.

<http://health.groups.yahoo.com/group/AspergersUK/>

### **Autism sibs**

A list for brothers and sisters of autistic children to discuss issues about growing up with a child with ASD.

[http://groups.yahoo.com/subscribe/autism\\_sibs](http://groups.yahoo.com/subscribe/autism_sibs)

### **ASD friendly**

For everyone to share experiences of everyday life with ASD children.

[www.ASDfriendly.org](http://www.ASDfriendly.org)

### **Autism UK**

An active UK-based list which provides a forum for wide-ranging discussion on many issues related to autistic spectrum disorders.

<http://lists.autismisanotherworld.com/mailman/listinfo/autism-uk/>

### **Autistichat**

A place for people with autism and related disorders to chat online. The channel is also open to the parents, friends and family of individuals with autism.

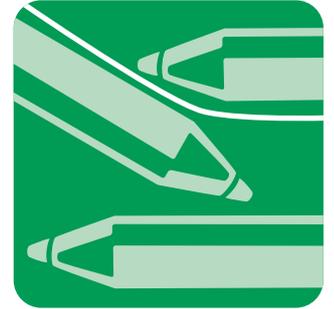
[www.autistichat.net/](http://www.autistichat.net/)

### **Jypsy's Email Penpal Registry**

Can match you with a suitable penpal if you leave your details on the website. There are separate listings for people on the autistic spectrum, and for parents and professionals.

[www.isn.net/~jypsy/penpal3.htm](http://www.isn.net/~jypsy/penpal3.htm)

*'Before I joined an e-group, I used to be dubious about them. But when you think about it, it's amazing, because instead of ringing up someone and asking them the same questions over and over again because you haven't taken it in, you can go to archives and look at the messages that you've saved. And somebody else is sure to ask a question that you're too embarrassed to ask, because they're new to the group. If there's something that you don't want to deal with now, someone will ask the question in four months' time and maybe you're ready to look at it then. So I think it's an incredible source of support and information for a parent.'*



## Early intervention

Early intervention refers to educational or therapeutic services that are delivered soon after a child has been diagnosed with a developmental disorder such as an autistic spectrum disorder. Getting appropriate education and/or therapy as soon as possible maximises the chances of a child developing their abilities.

*'Some children will always require extra help because of the disadvantages they face. The key is to ensure children receive services at the first onset of problems.'*

*Every Child Matters*  
Green Paper, 2003

## How is early intervention helpful?

Early intervention can help you:

- communicate with your child better
- encourage your child to communicate better with you
- establish routines.

Communication is a particular challenge for children with autistic spectrum disorders and difficulty in this area leads to frustration. Helping children to understand and communicate can lead to improvements in behaviour. Different approaches can be tried to help children with autism understand the world around them and to communicate better with other people.

Many children with the kind of difficulties described in this booklet are helped by having structure and routine built into their daily lives. Making the world predictable reduces anxiety and associated difficult behaviour. Structure needs to be communicated to the child in a way they can understand. For example, visual cues and schedules are helpful, because children with an ASD are often better at understanding information that is presented visually, in the form of pictures or photographs.

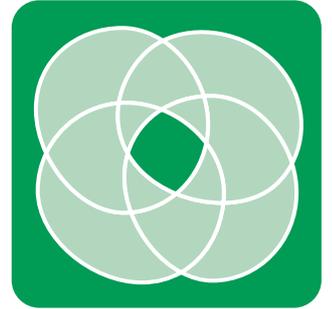
## What kind of early intervention might help?

[Augmentative communication systems](#) help some children express themselves and understand other people better. [Augmentative communication systems](#) are ways of communicating that are additional to or different from spoken language.

- The [Picture Exchange Communication System \(PECS\)](#) uses symbols to help the child express what they want to say. Symbols can be combined to form a sentence.
- Signing (such as [Makaton](#) or [Signalong](#)) helps some children develop communication skills.
- Gesture based on [British Sign Language](#) to support spoken language assists some children to express their own ideas and intentions and to understand other people better.

There are several teaching or therapeutic approaches which have been developed specifically for children with autism. Some, such as [TEACCH](#), were developed for older children, but can also be used with children of pre-school age. Others, such as the form of [applied behavioural analysis \(ABA\)](#) known as the Lovaas method, were developed specifically to support home-based early intervention for children with autism. Other forms of ABA are also used, for example [verbal behaviour](#). The professionals working with you may use some of these approaches as part of the early intervention programme being developed for your child.

Read more about this in [Early intervention programmes and approaches for children with autism](#)



## Choosing an intervention method for your child

There's a lot of debate about different types of early intervention and some parents or professionals hold strong views about what works and what doesn't. Some families feel a particular programme or intervention has really helped their child and so are keen to recommend it. Other parents, who have not experienced such good results, feel families should be warned that there are no easy solutions or magic cures for autism. It's important to remember that each child is different, and that what works for one child doesn't necessarily work for another.

There is not yet a lot of research evidence into the effectiveness of different interventions, which can also make this more confusing.

It can be hard to make an informed choice about what you think is right for your child. However, you'll be in a better position to discuss possibilities and make a plan for your child if:

- you're aware of all the options available
- you've talked to other parents about their choices
- the information you have about the effectiveness of different approaches comes from more than one source.

This booklet gives some basic information about the options available, but it cannot recommend any particular methodology.

## Access to early intervention

Most children and their families are helped and supported in the early years, but the level and type of support available in different places varies widely. For example, some children attend a nursery class daily and receive one-to-one support there; other children may only be offered one hour of input on alternate weeks. Some families supplement what their local authority is able to provide by paying for services themselves. Some parents receive funding from their local authority to help them do this, while others do not.

The types of early intervention support for children with an ASD which are normally provided by statutory services include:

- **Portage** (a pre-school home visiting special educational needs support service), which is usually accessed via your local authority's education department
- **playgroups**, including those run by the **Pre-school Learning Alliance**, where additional help is provided for your child
- **nursery classes**, which may be specially resourced by your local education authority to support children with special educational needs
- advisory services of different types, run by education departments with input from speech and language therapists, educational psychologists and teachers.

As early intervention services vary greatly in approach and intensity, it's important to clarify exactly what support is being offered to your family when you're talking with professionals about the options that are available.



## Early intervention programmes and approaches for children with autism

The following interventions and techniques are the most commonly used by statutory agencies and specialist provision. Some can be combined with one another. Different approaches are presented here in alphabetical order:

### Applied Behavioural Analysis (ABA) for example 'Lovaas'

An intensive, interactive approach designed to teach basic learning skills. Aspects of learning that the child finds hard are broken down into small steps, and are then presented in a simple and consistent way. Emphasis is placed on providing positive reinforcement so that the child feels successful and is motivated to learn more. Learning is observed and measured to help decide the sequence in which new skills should be taught. The programme assumes a heavy commitment of time and one-to-one teaching. Some families use a standard Lovaas approach involving a number of therapists working with their child on a one-to-one basis in the home for up to 40 hours a week. Other families use many of the same techniques in a less time-intensive way, and find that the underlying principles of ABA can be applied successfully to more general areas, like behaviour management, social interaction and communication.

Various centres and schools have been set up by parents to provide ongoing support for ABA programmes in the UK.

For further information, contact:

**PEACH (Parents for the Early Intervention of Autism in Children)**

The Brackens  
London Road  
Ascot  
Berkshire SL5 8BE

Tel: 01344 882 248  
Fax: 01344 882 391

Email: [info@peach.org.uk](mailto:info@peach.org.uk)  
Web: [www.peach.org.uk](http://www.peach.org.uk)

**The EarlyBird Parent Support Programme**

This programme was developed specifically for parents/carers of pre-school age children with ASD. The programme takes place once a week over a three-month period. It helps parents facilitate their child's social communication and appropriate behaviour through group sessions and home visits. Small groups of parents or other family members meet with a trained professional and learn about ASDs and helpful strategies. Families are also visited at home. Professionals who have specific expertise in working with children with ASDs run the programme and support parents in trying out new strategies. The programme also provides an opportunity to meet and make friends with other parents in similar situations.

EarlyBird uses parts of the **Hanen** approach (see next entry) to help with communication.



For further information, contact:

### **EarlyBird**

NAS EarlyBird Centre  
3 Victoria Crescent West  
Barnsley  
South Yorkshire S75 2AE

Tel: 01226 779 218

Email: [earlybird@nas.org.uk](mailto:earlybird@nas.org.uk)

Web: [www.nas.org.uk/earlybird](http://www.nas.org.uk/earlybird)

### **The Hanen programme**

A family-based training programme that helps parents facilitate their child's language development and social interaction. Speech and language therapists trained in the Hanen approach use group sessions, individual consultations and evaluation to help parents learn strategies that will encourage language development.

[The National Autistic Society](#) can direct you towards further details about the Hanen programme. The NAS helpline number is given at the back of this booklet.

The Hanen Programme  
The Hanen Center  
Ontario, Canada

Email: [info@hanen.org](mailto:info@hanen.org)

Web: [www.hanen.org](http://www.hanen.org)

## Picture Symbols (including the PECS system)

Some children who have not developed speech, or who already have a vocabulary find picture symbols helpful. Symbols enable them communicate more effectively – for example, they can learn to ask for things. Many people with an ASD find learning easier if it's presented in a visual way and it's for this reason that they're encouraged to use symbols. The 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 timetables to help explain to a child what is going to happen and when. They can also be used as prompts when skills like brushing your teeth are being taught in a step-by-step way. Picture symbols can be particularly helpful if a child can't make the eye contact that is needed to use sign language. Picture symbols are often used combined with other interventions.

For further information, contact:

### Pyramid Educational Consultants UK

Pavilion House  
6 Old Steine  
Brighton  
East Sussex BN1 1EJ

Tel: 01273 609 555  
Fax: 01273 609 556

Email: [pyramid@pecs.org.uk](mailto:pyramid@pecs.org.uk)  
Web: [www.pecs.org.uk](http://www.pecs.org.uk)

Useful resources can also be found at: [www.do2learn.com](http://www.do2learn.com)



## Signing

Signing can be used with other communication systems like PECS, and with other interventions. Makaton and Signalong are two examples of signing. Signing is not usually taught as a replacement for speech, but to assist in the development of spoken language and communication of intentions. Signing may be a more accessible and interactive communication tool for children who have difficulty discriminating between visual symbols presented to them in pictures, or for those who do not have the fine motor skills or motivation to manipulate picture cards.

For further information, contact:

### **Makaton Vocabulary Development Project (MVDP)**

31 Firwood Drive  
Camberley  
Surrey GU15 3QD

Tel: 01276 61 390  
Fax: 01276 681 368

Email: [mvdp@makaton.org](mailto:mvdp@makaton.org)  
Web: [www.makaton.org](http://www.makaton.org)

### **Signalong**

The Signalong Group  
Stratford House  
Waterside Court  
Neptune Close  
Rochester  
Kent ME4 4NZ

Tel: 0870 774 3752  
Fax: 0870 774 3758

Email: [mkenard@signalong.org.uk](mailto:mkenard@signalong.org.uk)  
Web: [www.signalong.org.uk](http://www.signalong.org.uk)

### British Sign Language

British Sign Language is used by deaf people. You can find out more about it from the British Deaf Association (BDA).

For more information, contact:

### British Deaf Association

1–3 Worship Street  
London EC2A 2AB

Helpline: 0870 770 3300

Textphone Helpline: 0800 652 2965

Fax: 020 7588 3527

Videophone: 020 7496 9539

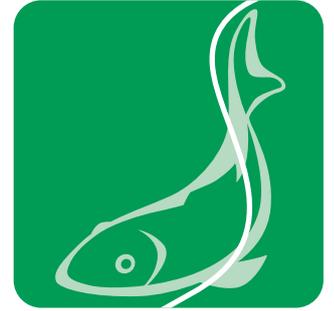
Email: [helpline@bda.org.uk](mailto:helpline@bda.org.uk)

Web: [www.bda.org.uk](http://www.bda.org.uk)

[www.british-sign.co.uk/](http://www.british-sign.co.uk/)

### The Son-Rise Program (Options)

Son-Rise is an intensive child-centred, home-based approach focusing on language, interaction, and relationships. Parents and facilitators work one to one with a child in a room designed to be an optimal learning environment. The first aim is to build the child's self-esteem and help them trust and enjoy other people and their environment; the second is to use relationships to help the child learn and manage their difficulties. The starting point is acceptance of the child's world – parents and facilitators join in with the child's chosen activities and behaviours. Unwanted behaviour is played down; interaction and positive behaviour are celebrated. Developments and challenges are closely monitored. Appropriate strategies are then chosen to encourage the child's development and learning at a rate which keeps it fun. Essentially, Son-Rise builds bridges towards the child and then back again towards the wider world.



For further information, contact:

**Autism Treatment Center of America**

2080 S Undermountain Road  
Sheffield  
MA  
USA 01257-9643

Tel: 001 413 229 2100

Email: [sonrise@option.org](mailto:sonrise@option.org)

Web: [www.son-rise.org](http://www.son-rise.org)

Visit [www.nas.org.uk](http://www.nas.org.uk) for information about Son-Rise training courses in the UK.

**Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH)**

The TEACCH programme is the most widely-used approach in the UK. It's designed to help children with autism be as independent as possible. It does this by providing children with strategies for coping and understanding their environment. The strategies help to make their world a less confusing and more predictable place. The TEACCH approach organises environments and learning situations to be consistent with what is known about how people with autism think and learn.

TEACCH is used to provide a wide range of services for toddlers, children and adolescents and their families. It's used to support individual treatment programmes, special education and social skills training. Professionals who use TEACCH focus on the whole child and tend not to specialise in the way that speech and language therapists or psychologists do. Programmes are individual, identifying emerging skills and building on them.

The TEACCH approach actively involves parents.

You can find out more about TEACCH and training in the UK from [The National Autistic Society](http://www.nas.org.uk). Contact information is given at the back of this booklet.

Read more about this in **Useful organisations**

## Dietary and bio-medical interventions

### Note:

If you wish to try interventions with diets or supplements with your child it's important that you consult your doctor for advice first. They may refer your child to a dietician.

### Casein and/or gluten-free diet

Some children on the autistic spectrum benefit from a casein-free (ie no milk products) and gluten-free (ie no wheat products) diet. The theory behind this involves the way some children process these substances in their bodies. Children who benefit most from such dietary interventions appear to be those who have problems with their bowel movements, although this may not always be apparent early on.

### Using vitamins and other food supplements

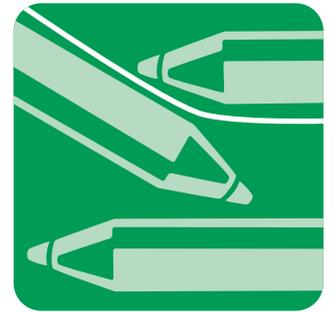
Some parents report that increasing certain substances in children's diets brings improvements in behaviour and communication. Some scientists also believe that vitamins (eg B6 or C), and certain food supplements (like essential fatty acids) can help children with autism.

For more information on dietary and bio-medical interventions, contact:

### Allergy Induced Autism

11 Larklands  
Longthorpe  
Peterborough  
Cambridgeshire PE3 6LL

Web: [www.autismmedical.com](http://www.autismmedical.com)



**The Autism Research Unit**

School of Health Sciences  
University of Sunderland  
Sunderland SE2 7EE

Tel: 0191 510 8922

Email: [autism.unit@sunderland.ac.uk](mailto:autism.unit@sunderland.ac.uk)

Web: <http://osiris.sunderland.ac.uk/autism/>

**Autism Unravelled**

3 Palmera Avenue  
Calcot  
Reading  
Berkshire RG31 7DZ

Tel: 0118 961 5967

Fax: 0118 961 5967

Email: [bluecat@autism-unravelled.org](mailto:bluecat@autism-unravelled.org)

Web: [www.autism-unravelled.org](http://www.autism-unravelled.org)

## Helping your child at home – behaviour

Some children have behaviours that parents 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 the child's perspective, and considering what the child is trying to communicate through their behaviour. Some behaviours are directly linked to difficulties the child has in communicating or making sense of the world, because of their autism. Understanding your child's particular difficulties will help you develop strategies to help with behaviour problems.

This is what other parents say:

*'Whilst appreciating that many children have tempers, all mothers (and grandmothers) who have witnessed these in Dan remark 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.'*

*'Our child cannot tell us when he's really tired, so we've learned that when he wants to go to bed, he throws his toys around.'*

*'When dealing with their difficult and challenging behaviour follow the three Cs: Calmness, Consistency and Clear messages. Again it's one of those things we all know we should do but when little 'Steve, Sally or Jane' is throwing yet another seemingly unwarranted 'paddy' in the middle of the supermarket or park or insists upon lying on your coffee table while your friends are trying to rescue their cups and looking at you with that "How do you cope with this?" look on their faces, you have to be almost super human to maintain control.'*

*'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.'*



*'I think you've got to learn to think differently. Supposing he's ripping wallpaper off the wall. You think "Oh no, is he going to stop doing that?". Then you 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.'*

*'My husband would sometimes do mashed potato, make it into a boat, and say "That's the boat on the sea", using a bit of creative thinking. Especially for something they're particularly obsessed about like say dinosaurs or something, you could make a picture of one out of food. It's amazing, but it does actually work.'*

Read more about this  
in **Books and further  
sources of information**

Sometimes a professional with practical experience of autism can give advice, or it may help to talk to other parents who have experienced similar problems who have developed creative solutions to help their child. There are several helpful books giving advice on strategies for difficult behaviours. Details are given at the end of this booklet.

# Statutory support for children with autism and their families

## Access to early intervention

Help in accessing early intervention for children with autistic spectrum disorders (ASDs) is organised by local education authorities (LEA) as part of their provision for children with special educational needs. Extra help or support in the pre-school years is provided at different levels, depending on how severe a child's need for extra help is.

Understanding of the nature and impact of ASDs is still developing. Provision for children under three is further complicated by the fact that the challenges that a child is facing may only be recognised slowly as their development begins to look different from that of other children. Diagnosis is sometimes difficult or ambiguous.

Children with the most severe and complex special educational needs are issued with a **statement of special educational needs** (also called a **statement**) by their LEA, although this is rare for children under three. Some families with children with ASDs have found they need to request an assessment and secure a statement of special educational needs in order to get their LEA to fund the special provision or intervention they think their child needs.

Some authorities are further ahead in responding to the rising number of children with identified ASDs than others. The best provide good early support for children with autism without having to write statements for children. Others are not so good.

*'A lot depends on where you live. When I started to ask about the education for my son, we hit a brick wall. But we moved into the neighbouring LEA and they could not have been more helpful. They really listened, understood where we were coming from, and provision that was funded was all that we had hoped for.'*



Read more about  
this in **Useful  
organisations**

A statement can be requested at any age. Parents may start the process themselves by requesting an assessment and they can do this as early as they feel it's appropriate (for instance, on the basis of their child's behaviour at playgroup or nursery). If you would like more information about this, contact **PACE (Parents Autism Campaign for Education)**. Contact details are at the end of this booklet.

In addition to services and support provided by statutory agencies, many areas have services run by a thriving independent sector (ie charities or commercial organisations). Sometimes these services are bought in, or funded, by local authorities. For example, your child attends a nursery run by a local voluntary organisation which has particular experience of supporting children with ASDs, with your local authority education or social services department paying for them to attend. It's important to check what your local area offers, and that you have been given information about the independent as well as the statutory agency services that are available in your area. You should also check which of the different types of intervention listed earlier in this booklet are available near you.

Read more about  
this in **Early  
intervention  
programmes and  
approaches for  
children with autism**

If you would like advice on special educational needs or if you are experiencing any problems in accessing the support you feel your child needs, you can contact the **NAS Advocacy for Education Service** on **0845 070 4002**, an autism-specific education advice service. They can also tell you about other organisations that provide educational advice for parents of children with special educational needs which you might like to know about.

## Access to short breaks and assessment of carers' needs

A child with ASD can add to the stresses and expenses of family life. Parents sometimes experience high levels of stress, exhaustion and lack of sleep. You may also find it difficult to find time to look after yourself and other family members.

There are different types of **respite care** (a break from caring) or **family support schemes** for children with disabilities. These are provided by social services departments and include play schemes, babysitting services or residential short break services. Using these schemes could help your child by providing them with new activities and experiences, and help you by giving you time to relax, spend time with the rest of your family and get your energy back.

You can request an assessment of your support needs from your social services department. If you have a child with autism or a related condition, the department is obliged to carry out this assessment. If you are assessed as needing respite care, the local authority must supply it. However, because of very high demand for these services, waiting lists for respite care or short break schemes are usually long.

Where services are available, families say that the most important consideration is whether the staff involved have experience and skill in working with children with autism. It can be hard to find suitable schemes, and it's a good idea to ask whether staff working for any service you are thinking of using have received any autism training.

## Direct Payments

Families may choose to organise support and services for their child themselves, rather than accessing the services on offer through social services. In such cases, Direct Payments can sometimes be made by social services directly to you to cover the cost of arranging services yourself. You can find out more about Direct Payments by contacting your social services department.



## Benefits and financial help

### Disability Living Allowance (DLA)

DLA is the main benefit for disabled children. Entitlement to DLA is based on walking difficulties and/or the need for personal care, which results from severe disability. Your child's medical condition is not, necessarily, the key factor. Rather it's the disablement that results from it and the effects of that disablement. You can get an application pack to claim DLA from your local Benefits Office.

DLA comprises two components; a **care component** (payable at one of three rates from birth) and a **mobility component** (payable at one of two rates – the lower rate of which is payable from the age of 5 and the higher rate from the age of 3). The effects of your child's autism may mean that you qualify for either or both of the care and mobility components of the allowance.

For the lower rate mobility component your child does not need to have physical difficulty in walking in order to qualify; hyperactivity and a lack of any sense of danger or road safety are solid grounds for a claim. If you apply for this component you may wish to give examples in your application form, such as little or no awareness of danger, or behaviour problems like your child sitting in the road or running in front of cars. However, the guidance or supervision your child requires must be substantially in excess of a child of his/her age in normal physical and mental health. To help identify particular problems you may wish to keep a diary.

## The Blue Badge scheme

Eligibility for the higher rate mobility component means that you are also eligible for a [Disabled Person's Parking Badge \(the Blue Badge scheme\)](#). You should apply for the higher rate mobility component if your child has a physical disability which means he/she is unable or virtually unable to walk. For families with a child with an autistic spectrum disorder (ASD) a Blue Badge can be extremely helpful, as it enables families to park near local amenities. Several London Boroughs are exempt from the scheme and run their own schemes – contact your council to check what happens if you are in one of these areas.

*A Parents Guide to Behavioural Phenotype* (Contact a Family 2003) is a publication which describes how behaviour can affect mobility, if you want to know more.

*'It's hard to describe autism within the questions and boundaries of the application form.'*

You may find that your child's autism is difficult to describe within the sections of standard benefit forms. This does not mean that you are not entitled to support, so don't be put off from applying. It's worth talking this through with someone who has had experience of describing a child with an ASD on application forms before. This could be another parent or a professional. Alternatively carers' centres or advice agencies, such as the Citizen's Advice Bureaux, may be able to help.

Some parents find completing a DLA form problematic, as it concentrates on the difficulties that your child has. For some parents this is a time when they realise how much help and support their child actually needs. Many families also question whether they are entitled to claim this benefit, believing that it's for needier families. It's important to remember that your child has a right to claim. It may be helpful to get the advice of others who are familiar with the forms when filling them in.

Read more about this in [Books and further sources of information](#)



It's important to note that benefits will only be paid from the date of submission of the application forms. As claims are not backdated, it's well worth making this a priority.

You can download a DLA application form from:

[www.dwp.gov.uk/lifeevent/benefits/disability\\_liv\\_allowance2.asp](http://www.dwp.gov.uk/lifeevent/benefits/disability_liv_allowance2.asp)

Or call the [Benefits Enquiry Line](tel:0800882200) on 0800 882 200.

## Help with adaptations in the home

Some children may need their home environment modified because of health or behaviour difficulties. If you use a room in your house solely for your child's learning programme, you have a right to apply for a Council Tax reduction.

A child's challenging behaviour can have a big impact on your household expenses. For example you may need to replace furniture and bedding more often, if your child repetitively damages them. If you are on Income Support or Income Based Jobseekers Allowance ask whether you can get financial support from the Social Fund.

The Family Fund may also be able to help. For more information, contact:

### The Family Fund

PO Box 50

York YO1 9ZX

Tel: 0845 130 4542

Textphone: 01904 658 085

Fax: 01904 652 625

Email: [info@familyfund.org.uk](mailto:info@familyfund.org.uk)

Web: [www.familyfund.org.uk](http://www.familyfund.org.uk)

Support for adaptations may be available in a number of ways and if you think that you are in need of changes in your home you may want to seek advice. Ring the [NAS Autism Helpline](tel:0800882200).

## Being a parent

Parents of children with ASDs often feel they have to take on the vital role of ensuring that their child gets what they need. This may seem daunting as you think about the journey ahead but many parents find that later they become impressed by their own determination, level of knowledge and sheer ability to cope.

*'What would I say to other parents? "You're the mother, you're the parent, you know best. Go with your instincts".'*

*'You find such hidden strengths in yourself. I mean I have done so many things that I would never have done otherwise. I started a psychology degree because I got fed up with people saying, "You haven't got letters behind your name" – and so I said, "Watch this space".'*

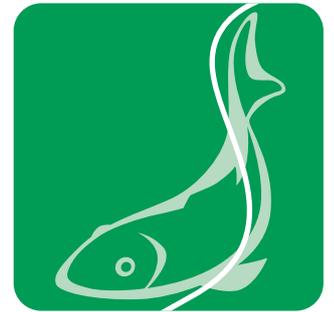
But you don't have to become a 'super mum' or 'super dad'. It's important to look after yourself too.

*'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.'*

In order to get support for your child you may have to read about the subject, ring people or follow up when things don't happen.

*'You don't have to take everything at face value and you can ask questions. You will find that, if you choose to research the subject, you will quickly become more knowledgeable than many professionals.'*

If you understand what you are entitled to and how statutory services operate, you will find it easier to ask professionals the right questions at the right time.



*'I believed that the paediatrician had a lot more power than they did. So when the paediatrician said, "I've written to the education department and told them to do a statement", I thought, "A doctor has told the education department to do a statement, that means it's going to happen". I had no idea that a doctor had no power or authority over the education department. All she was doing was asking the education department to put our name down on a list. Nothing happened.'*

*'I have had to go through two or three different professionals. Some won't refer, some will – and you just have to keep asking for a second opinion when you can. We got a referral from somebody that I would never have expected to be able to refer. It was a clinical psychologist in the end, who was basically helping us with diet. She was the one that referred us to occupational therapy when nobody else would refer us there. Mind blowing really.'*

Other parents emphasise that it's important to develop good working relationships with professionals who are supporting your child and to recognise the constraints that they work under. It also helps to work closely with the people who are supporting your child on communication, behaviour management and daily structure. If your child is treated consistently, the better the results will be and the less isolated you will feel.

In the past, understanding of autism was often inadequate. There is more knowledge and understanding than there used to be, partly because of the efforts of parents and autism charities to educate professionals about the condition. At times, however, you can still come across gaps in professionals' understanding.

*'You have to acknowledge up front that the systems aren't perfect. Then parents are less likely to get so confrontational, so disappointed, so angry, particularly if they're referred early on to other parents who have been there, and done that.'*

With pressure on services and poor co-ordination between departments, it can take a long time and be quite difficult to access the help your child needs. In some cases, parents have had to learn a lot about the system in order to access the service their child is legally entitled to.

If you're not happy about the service you're getting, it's important to keep a note of the facts, with dates, and to find a way to voice your concern. Sometimes it's effective to write a letter, and sometimes it's necessary to formalise your request into a letter of complaint, and use whatever complaints procedure is available.

If your concerns are about the service provided by the local education authority, someone from your local [Parent Partnership Service](#) may be able to help you put your complaint together in a non-aggressive way. Parent Partnership Services provide support and advice to parents whose children have special educational needs. Their job is to provide accurate, unbiased information on the full range of options available. They are there to help parents make informed decisions about their child's education. If you need help finding this agency in your area ring:

### Contact a Family

209–211 City Road  
London EC1V 1JN

National Freephone Helpline: 0808 808 3555

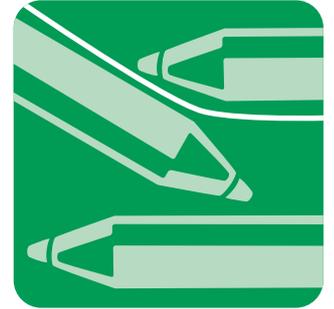
Textphone Helpline: 0808 808 3556

Email: [info@cafamily.org.uk](mailto:info@cafamily.org.uk)

Web: [www.cafamily.org.uk](http://www.cafamily.org.uk)

If you are unhappy about a health service, the NHS [Patient Advice and Liaison Service \(PALS\)](#) may be able to help. PALS should listen to your concerns and help sort out problems on your behalf. Contact details for your local PALS team should be available from your GP or health centre.

You could also call the [NAS Helpline](#) for advice on how to make a complaint or what to do if you are dissatisfied with a service.



## A final word

With all the challenges facing parents who have a child with an autistic spectrum disorder (ASD), it's a common experience to start to focus on meeting their child's needs at the expense of their own. When a child depends so much on the understanding of someone who can tune into their complex needs, it's hard for parents both to persuade others to give them a break from care and to develop confidence that others can do it.

*'When it comes to getting help for your child, it's important to keep a balance. If you're spending 24 hours of the day dealing with your child with special needs, to the exclusion of everything else that exists in your life, your marriage might break up or you might lose your other children in terms of their communication and connectedness. So I would say, keep a balance, try out different things but don't try them all at once. Have a go at some things and see.'*

Read more about this  
in **Books and further  
sources of information**

Brothers and sisters of a child with an ASD may need their own support, or they may just benefit from being with other children who share this experience. They may have this opportunity if their parents join a local group. There are a number of books for siblings that explain ASDs in a child-friendly way which you can find out about at the end of the booklet.

Finally, parents stress that by taking one step at a time they have been able to overcome what they felt were huge challenges. You may never be able to answer all the questions, but the ratio of questions to answers will change, and you will be more able to see the bigger picture.

*'You can be confident that what you feel is daunting now, you will actually look back on and find that you can deal with easily. There are always going to be challenges ahead, but, you'll be amazed at the level of expertise that you gain.'*

*'Just take a deep breath and if you can, do one thing a day. If it's one phone call that has left you with another ten to do, then still you have done something. And doing something makes you feel better.'*

## Books and further sources of information

*Autism: How to help your young child*

Leicestershire County Council & Fosse Health Trust (1998)

*Autism in the Early Years – A Practical Guide*

Cumin, Leach and Stevenson, David Fulton Publishers (2000)

*Caring for a child with autism*

Martine Ives and Nell Munro

The National Autistic Society/Jessica Kingsley Publishers (2002)

A broad ranging book which aims to answer all the questions that parents of newly diagnosed children ask and with numerous useful contacts.

*Challenging behaviour and autism: making sense – making progress*

Philip Whitaker, The National Autistic Society

A step-by-step practical guide for parents, teachers and carers of youngsters with ASD looking at prevention and management of common behaviour difficulties.

*Diagnosis: Reactions in Families*

B Nally, The National Autistic Society

*Everybody is different: a book for young people who have brothers and sisters with autism*

Fiona Bleach, The National Autistic Society (2001)

Aimed at children aged 8–13.

*Love, hope and autism*

Joanna Edgar, The National Autistic Society (1999)

*My brother is different: a book for young children who have brothers and sisters with autism*

Louise Gorrod, The National Autistic Society (1997)

Aimed at children aged 4–7.



*Siblings of children with autism: a guide for families*

Sandra L Harris, Woodbine House

*Teaching young children with autistic spectrum disorders*

Liz Hannah, The National Autistic Society

A very practical and straightforward book for parents and staff in mainstream schools and nurseries, for children from three to seven. It contains lots of ideas and exercises to address the particular needs of a child with autistic spectrum disorder (ASD).

*The autistic spectrum: a guide for parents and professionals*

Lorna Wing, Constable and Robinson (1996)

Explains how people with autism see the world, the reasons behind their behaviours and why they need a more structured and routine environment.

**For information about tackling particular problems, look at:**

*Can't eat, won't eat: dietary difficulties and autistic spectrum disorders*

Brenda Legge, Jessica Kingsley Publishers (2001)

*Toilet training for individuals with autism and related disorders: a comprehensive guide for parents and teachers*

Maria Wheeler, Jessica Kingsley Publishers (1999)

*Sleep better! A guide to improving sleep for children with special needs*

V Mark Durand, Paul H Brookes (1998)

All of the above books are available from NAS Publications. You can order them from:

**Barnardo's Despatch Services**

Paycocke Road  
Basildon  
Essex SS14 3DR

Tel: 01268 522 872

Fax: 01268 284 804

Email: [beverley.bennett@barnardos.org.uk](mailto:beverley.bennett@barnardos.org.uk)

**Parents considering educational options may wish to read the following:**

*Autistic Spectrum Disorders: Good Practice Guidance*

Department for Education and Skills

Department of Health

DfES/597/2002/REV

*Educational Interventions for Children with Autism: A Literature Review of Recent and Current Research*

Rita Jordan, Glenys Jones, Dinah Murray

The University of Birmingham School of Education

DfES1998, Ref: RR77

*Special Educational Needs: A guide for parents and carers*

Department for Education and Skills

DfES/0800/2001

These publications are available from:

**DfES Publications**

PO Box 5050

Sudbury

Suffolk CO10 6ZQ

Tel: 0845 602 2260

Fax: 0845 603 3360



The following books were also recommended by parents who helped write this guide:

*The AIA Gluten and Dairy Free Cookbook*

Compiled by Marilyn Le Breton  
Jessica Kingsley Publishers

*Autism Handbook*

Andrew Nye  
The National Autistic Society (2000)

*Children with Starving Brains*

Jaquelyn McCandless  
Bramble Books

*Diet Intervention and Autism*

Marilyn Le Breton

*Freaks, Geeks & Asperger Syndrome*

Luke Jackson  
Jessica Kingsley Publishers (2002)

*Life Behind Glass*

Wendy Lawson  
Southern Cross University Press

*My Social Stories*

Carol Gray  
Jessica Kingsley Publishers (2002)

*Nobody Nowhere*

Donna Williams  
Jessica Kingsley Publishers (1992)

*Out of Sync Child*

Carol Stock Kranowitz  
G P Putman's & Sons

*A Parents Guide to Behavioural Phenotype*

Contact a Family 2003

*Teach Me Language?*

Sabrina Freeman

SKF Books

*Thinking in Pictures*

Temple Grandin

Vintage Books

*Understanding and Working with the Spectrum of Autism*

Wendy Lawson

Jessica Kingsley Publishers

*Visual Strategies for Improving Communication*

Linda Hodgden

Quirk Roberts



## Useful organisations

### Contact a Family (CAF)

Helps families who care for children with any disability or special need. CAF is a main source of information about rare disorders and can assist affected adults as well as children.

209–211 City Road  
London EC1V 1JN

Freephone Helpline: 0808 808 3555

Textphone Helpline: 0808 808 3556

Tel: 020 7608 8700

Minicom: 020 7608 8702

Fax: 020 7608 8701

Email: [info@cafamily.org.uk](mailto:info@cafamily.org.uk)

Web: [www.cafamily.org.uk](http://www.cafamily.org.uk)

### National Autistic Society

The National Autistic Society has a Helpline for anyone in the UK whose lives are affected by autistic spectrum disorders. It answers enquiries on a wide range of topics and can direct you towards sources of help and support. The Helpline is accessible to callers whose first language is not English as it has access to interpreters, it also has a Textphone number for deaf and hard of hearing callers. The Helpline is open 10am–4pm Monday to Friday.

393 City Road  
London EC1V 1NG

Helpline: 0845 070 4004 (local call rate)

Textphone: 0845 070 4003 (local call rate)

Parent-to-Parent Support Line: 0800 952 0520

NAS Befriending Scheme: 0115 911 3369

Tel: 020 7833 2299

Email: [autismhelpline@nas.org.uk](mailto:autismhelpline@nas.org.uk)

Web: [www.nas.org.uk](http://www.nas.org.uk)

The NAS also has an [Advocacy for Education Service](#) that provides advice and support on education related issues. On ringing the number below, callers can be transferred to the [Education Advice Line](#) for general advice, or the [Tribunal Support Scheme](#) for help with appealing to the SEN and disability Tribunal.

Tel: 0845 070 4002 (local call rate)

### **PACE (Parents Autism Campaign for Education)**

PACE is a national parent-led charity that works with parents and public authorities to raise awareness of the educational needs of children with autism.

PO Box 46551  
London N1 2XT

Tel: 020 7583 9032  
Fax: 020 7583 9021

Email: [info@pace-uk.org](mailto:info@pace-uk.org)  
Web: [www.pace-uk.org](http://www.pace-uk.org)

### **Pre-school Learning Alliance**

National educational charity and umbrella body, linking 16,000 community based pre-schools and 500,000 children and their families. Supports the active involvement of parents in their children's early education and offers a range of training courses.

69 Kings Cross Road  
London WC1X 9LL

Tel: 020 7833 0991  
Fax: 020 7837 4942

Email: [pla@pre-school.org.uk](mailto:pla@pre-school.org.uk)  
Web: [www.pre-school.org.uk](http://www.pre-school.org.uk)



The **Early Support Pilot Programme (ESPP)** is a Government programme involving the Department for Education and Skills, Sure Start and the Department of Health. The purpose of the programme is to improve the delivery of services to disabled children under three and their families. ESPP promotes service development in partnership with health, education and social services, service users and organisations in the voluntary sector. For more information, visit [www.espp.org.uk](http://www.espp.org.uk)

ESPP is putting into practice the principles outlined in the Government guidance document *Together from the Start* which was published in May 2003. The guidance recognises that where children have special needs and disabilities, it is important that these are identified at an early stage and that identification leads directly to effective early intervention and support for families and children.

This booklet is one in a series produced by ESPP in response to requests from parents and voluntary organisations for better information for parents. ESPP has produced booklets about a number of disabilities or known conditions and expects to develop more as the programme progresses. The following titles are currently available:

|   |                              |
|---|------------------------------|
| Autistic spectrum disorders (12)        | Cerebral palsy (10)          |
| Learning disabilities (15)              | Down's syndrome (13)         |
| If your child has a rare condition (18) | Multi-sensory impairment (9) |
| Speech and language difficulties (14)   | Visual impairment (8)        |
| When your child has no diagnosis (16)   | Deafness (11)                |

Copies of these booklets can be obtained from:

DfES Publications  
PO Box 5050, Sherwood Park,  
Annesley, Nottingham NG15 0DJ  
Tel: 0845 602 2260 Fax: 0845 603 3360  
Textphone: 0845 605 5560 Email: [dfes@prolog.uk.com](mailto:dfes@prolog.uk.com)

Please quote the appropriate reference number.

ESPP has also produced a **Family Pack**, which supports families through the first years of their children's lives. The Pack contains background information about the services you may need, the help you are entitled to and a **Family File** designed to help co-ordinate any support being provided for your family. They are resources that other families have said would make a difference. If you and your child are receiving regular support from a professional or range of professionals, please feel free to ask them about the **Early Support Family Pack**, which may help and which is available free of charge.

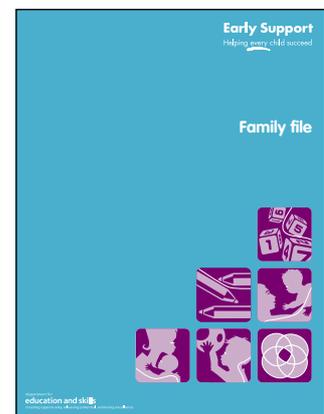
ESPP would like to thank all the parents and families involved in the production of these resources.

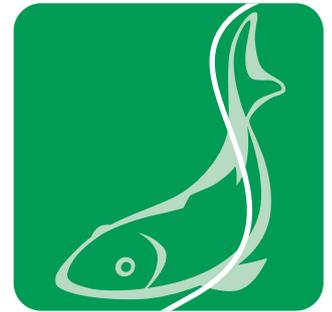
ESPP would also like to thank **The National Autistic Society (NAS)** and **Parents Autism Campaign for Education (PACE)** for their help in writing, consulting upon and producing this resource.

**The National Autistic Society (NAS)** was founded in 1962 by a group of parents and people with a professional interest in autism. Today, the Society has become the UK's foremost charity for people with autism, including Asperger syndrome, and for their parents and carers. The NAS leads national and international initiatives providing a strong voice for autism. The organisation works in many areas to help people with an autistic spectrum disorder live their lives with as much independence as possible.

#### The National Autistic Society:

- runs schools and adult centres
- supports local authorities in the development of their own specialist services
- maintains a library and publishes a range of books and leaflets
- runs the Autism Helpline for parents, carers and people with ASD
- offers specialised diagnosis and assessment services
- supports local groups and families around the country
- organises parent workshops
- encourages research into interventions in autism
- offers advice and advocacy for special educational needs





- raises awareness and creates a better understanding of autism
- organises volunteering schemes
- provides information and consultancy to professionals and organisations
- offers an accreditation programme for a wide range of autism-specific education and care services
- campaigns to improve services for autism in Westminster, the Scottish Parliament and the Welsh Assembly.

#### The National Autistic Society

393 City Road, London EC1V 1NG

Switchboard: 020 7833 2299 Helpline: 0845 070 4004

Minicom: 0845 070 4003 Fax: 020 7833 9666

Email: [nas@nas.org.uk](mailto:nas@nas.org.uk) Web: [www.nas.org.uk](http://www.nas.org.uk)

**Parents Autism Campaign for Education (PACE)** is a national charity, set up in 1998 by a group of parents and parent-led charities who were concerned at the difficulties faced by parents in accessing appropriate educational intervention for their children. PACE works with parents and public authorities to address the system failures that prevent children with autism accessing the education they need. PACE seeks to bring these issues to the attention of policy-makers and opinion-formers, and has made a significant contribution to a number of government initiatives affecting children with autism.

The contact details for PACE are:

#### **PACE (Parents Autism Campaign for Education)**

PO Box 46551, London N1 2XT

T: 020 7583 9032 F: 020 7583 9021 E: [info@pace-uk.org](mailto:info@pace-uk.org)



Copies of this booklet can be obtained from:  
DfES Publications  
PO Box 5050  
Sherwood Park  
Annesley  
Nottingham NG15 0DJ  
Tel: 0845 602 2260  
Fax: 0845 603 3360  
Textphone: 0845 605 5560  
Email: [dfes@prolog.uk.com](mailto:dfes@prolog.uk.com)

Please quote ref: ESPP12

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following organisations in the production of this resource.

