

# Information for parents

## Autistic spectrum disorders (ASDs) and related condition



## About this publication

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

This publication is based on the information for parents booklet *Autistic spectrum disorders (ASDs) and related conditions*. It has been adapted by kind permission of Early Support, a UK government initiative funded by the Department for Children Schools and Families. The original version of this booklet was developed in partnership with the National Autistic Society and TreeHouse in response to requests from families, professional agencies and voluntary organisations for better standard information and it reflects what parents who have 'been there before' say they would have liked to have known in the early days of finding out about their child's situation. This version of the publication was adjusted for the Welsh context by Autism Cymru.

To find out more about [Early Support in Wales](http://www.earlysupportwales.org.uk), visit [www.earlysupportwales.org.uk](http://www.earlysupportwales.org.uk)

### The ASD Strategic Action Plan for Wales (2008)

Wales is fortunate to have the first government led strategy in the world. This Action Plan was developed in collaboration with an All Wales External Working Group on Autism consisting of key stake holder groups both in the statutory and the voluntary sector as well as service users. It is a ten-year plan and aims to give a clear direction for the development of necessary services for individuals with ASD and those living and working with them. It will ensure that specific and measurable actions are undertaken.

It is a plan that covers services from the cradle to the grave and links into a number of other Welsh Assembly Government policies such as *The National Service Framework for Children, Young People and Maternity Services* (Welsh Assembly Government, 2005) and *Making the Connections: Delivering Beyond Boundaries* (Welsh Assembly Government, 2006).

Copies can be obtained from the Children's Health and Wellbeing Team, Welsh Assembly Government, Cathays Park, Cardiff, CF10 3NQ Tel: 02920 825660

Where words in running text appear in colour **like this**, it means they can be found in the **Glossary** or that the contact details for an organisation can be found at the back of the booklet.

Copies of this publication can be obtained from:

Welsh Assembly Government Publications

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[www.earlysupportwales.co.uk](http://www.earlysupportwales.co.uk)

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Llywodraeth Cynulliad Cymru  
Welsh Assembly Government



## Autism Cymru

**Autism Cymru** is Wales' National Charity for Autism. It has worked in collaboration with others in the public and voluntary sector to influence major policy changes. Autism Cymru has made great strides in raising the profile in Wales encouraging the Welsh Assembly Government to establish the world's first government-led strategy for autism. **Autism Cymru** has offices in Cardiff, Aberystwyth and Wrexham.

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## National Autistic Society (NAS)

Formed in the 1962, the **National Autistic Society (NAS)** is a UK based charity for people with autism, including Asperger syndrome, their parents and carers. It has a membership of 15,000, a network of 60 branches, and 90 partner organisations in the autism field. The NAS exists to champion the rights and interests of all people with autism and to ensure that they and their families receive quality services, appropriate to their needs. The NAS has a regional office in Wales

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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 a range of developmental disorders, which include **Kanner's autism** and **Asperger syndrome**. In places, we refer specifically to **Asperger 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 **TreeHouse** who wrote this booklet, and **Autism Cymru** who adapted it for the Welsh context, would like to thank all the parents of children with autism who helped us to produce it. Most of the quotations are from parents. Some are taken from **Love, Hope and Autism** by Joanna Edgar (1999).

First, there are two very important things 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

According to the Welsh Assembly Government's Strategic Action Plan for autism (2008), there are 60 per 10,000 individuals with ASD in Wales. Many other parents are going through what you're going through and there are many who are further on in their journey. Recent research suggests that one in every hundred children is affected by autism.

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)
- visiting [www.info.autism.org.uk](http://www.info.autism.org.uk), a searchable database of autism services including local support groups
- 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 - but remember that you can get access to services before you get a diagnosis

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.



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'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 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 **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 interaction** - difficulty understanding social 'rules', behaviour and relationships, for example, appearing indifferent to other people or not understanding how to take turns



- **social communication** - difficulty with verbal and non-verbal communication, for example, not fully understanding the meaning of common gestures, facial expressions or tone of voice
- **rigidity of thinking and difficulties with social imagination** - difficulty in the development of interpersonal play and imagination, for example, having a limited range of imaginative activities, possibly copied and pursued rigidly and repetitively.

All children with autism have impairments in all three of these areas. However, the ways in which the three impairments manifest themselves vary enormously. They are described in more detail in the following pages.

Note:

This section draws on [Autism: How to help your child \(1998\)](#), [Autism in the early years - a practical guide \(2000\)](#) and [Autistic Spectrum Disorders in the Early Years \(2007\)](#).

## 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
- show preference for individual activity
- only tolerate approaches from very familiar people
- are more adult orientated than peer orientated
- only be receptive to approaches from people they know well

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- 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
- have a poor understanding 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 trying to communicate
- show little desire to communicate socially
- not respond when spoken to
- develop expression before understanding
- talk at, rather than to
- echo words other people say - straight away, or later (this is sometimes called **echolalia**)
- use words and then 'lose' them (not use them again)
- not use eye contact as a natural part of communication
- not appreciate the need to communicate information
- have poor grasp of abstract concepts and feelings
- 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 phrase or 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)

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- will often resist new experiences, for example trying different foods or wearing new clothes
- cannot deviate from one way of doing things
- may be tolerant of situations and then over-react to something minor
- 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 or point of view
- will only develop symbolic play slowly - if at all (symbolic play is play which involves pretending and using imagination)
- will often pay particular attention to unusual details and struggle to see the bigger picture
- can develop extreme behaviours to avoid some things/experiences.

## 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. Information sheets on many of these issues are available from the [National Autistic Society Helpline](https://www.nas.org.uk) (Tel. 0845 070 4004 or email [autismhelpline@nas.org.uk](mailto:autismhelpline@nas.org.uk))

'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.'











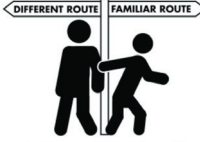




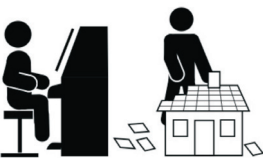
- **Sleeping difficulties**  
Children may have problems getting to sleep or may wake periodically throughout the night. The child may catch up on sleep during the day or may seem to require much less sleep than the rest of the family.
- **Eating difficulties**  
Children may only eat certain foods, or foods of one consistency or one colour. Others have rituals, such as insisting different foods never touch 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) and they may not know how hard to push or pull and cannot gauge the amount of force needed
- **Obsessions**  
Thomas the Tank Engine and dinosaurs are common obsessions, as well as various types of electric equipment. 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, buttons or clocks.
- **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**



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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.

These pin people illustrate some of the ways in which autism is displayed (Adapted from *Autism is...*, National Autistic Society, based on illustrations used by Professor J. Rendle-Short, Australia and National Society for Autistic Children USA)

		
Displays indifference	Joins in only if adult insists and assists	Indicates needs by using an adult's hand
		
One-sided interaction	Echolalic - copies words like parrot	Inappropriate laughing or giggling
		
Does not play with other children	Talks incessantly about only one topic	Variety is not the spice of life
		
Bizarre behaviour	No eye contact	Lack of creative, pretend play
		
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 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).

The behaviours described in the 'three impairments' discussed above 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. Information for parents

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 - but don't forget you may be able to access services without a diagnosis.

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

### Parent groups and voluntary organisations

Voluntary organisations, charities and parent support groups 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 or asking your library for a list of local voluntary organisations. The [PARIS online autism database](#), at [www.info.autism.org.uk](http://www.info.autism.org.uk) also holds information about local groups, services, autism events, training courses and other resources. The [National Autistic Society](#) offers a comprehensive membership scheme providing information and support, both nationally and locally, for parents and carers of those with an autistic spectrum disorder. For more details call 020 7903 3563 or visit [www.autism.org.uk/membership](http://www.autism.org.uk/membership)

### Befriending

Some local support groups provide professional and volunteer befriending schemes. 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.

#### NAS Befriending Scheme

Tel: 0115 911 3369

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

## Telephone lines and contacts

### Contact a Family Cymru

Contact a Family is a UK-wide charity providing support, advice and information for families with disabled children. Contact a Family can help give you further information about autism and other conditions, and advise you on the services available in your area. They run a helpline for family members. Contact a Family can also help you get in touch with other parents of disabled children living near you.

33-35 Cathedral Road, Cardiff, CF11 9HB

Tel: 029 2039 6624      Fax: 029 2039 6625

Helpline: 0808 808 3555

Textphone: 0808 808 3556 (Free for parents and families 10am-4pm, Mon-Fri)

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

Web: [www.cafamily.org.uk/inyourarea/wales/index.html](http://www.cafamily.org.uk/inyourarea/wales/index.html)

### SNAP Cymru

SNAP Cymru is a Charity that offers information and support to families of children and young people who have special educational needs. These may be additional learning needs or disability. SNAP Cymru provides Parent Partnership Services in Wales.

Helpline: 0845 120 3730 (Mon, Tues, Fri 10am-4pm; Weds, Thurs 10am-8pm)

Head office - 10 Coopers Yard, Curran Road, Cardiff, CF10 5NB

Telephone: 029 2038 4868      Fax: 029 2064 4477

Textphone: 029 2039 0001

Email: [cardiff@snapcymru.org](mailto:cardiff@snapcymru.org)      Web: [www.snapcymru.org/default.asp](http://www.snapcymru.org/default.asp)

### Parent to Parent Line

The Parent to Parent Line is a free, confidential telephone support service for parents of an adult or child with autism provided by other volunteer parents. You can ring the freephone number 0800 9 520 520 at any time, and leave a message and contact telephone number. The next parent volunteer on duty will pick up the message and phone you back.



## Specific Programmes

### 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 ASD and helpful strategies. Families are also visited at home. Professionals who have specific expertise in working with children with ASD 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 to help with communication.

Early Bird Plus is similar to Early Bird but is for parents and carers of children aged four to eight. Two family members can attend, along with a professional such as a keyworker or a teacher who regularly works with the child.

For information about local programmes contact Early Bird, visit [www.info.autism.org.uk](http://www.info.autism.org.uk) or contact your local authority.

### 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 help! programme

The help! programme offers information, advice and support for parents and carers of people with a recent diagnosis of ASD, including children over five. The emphasis is on clear, practical and up-to-date information and on making sure parents know about their rights and entitlements. There are two main programmes that currently run free of charge across the UK for parents and full time carers - a 20 hour programme and a one day programme.

help! 2 is a series of seminars for parents and carers who have some basic knowledge of ASD. The seminars focus on practical topics such as anger management, helping siblings, making and using visual supports, writing to Social Stories, and anti-bullying tips.

### help! team

The National Autistic Society Cymru

Glamorgan House

Monastery Road

Neath Abbey SA10 7DH

Tel: 01792 325 298

Fax: 01792 325 293

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

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

### Internet and email networks

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'. Autism Cymru's bi-lingual site has a wide range of materials and information to download. The site also hosts on line seminars and an international conference which allow participants to pose questions of leading experts in the field. [www.awares.org](http://www.awares.org)

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

**Autism Connect** - An online resource providing information about autism, news and events from around the world, and access to discussion forums and other web sites about autism.  
[www.autismconnect.org](http://www.autismconnect.org)

**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)

'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.'



# Statutory support for children and families

## Universal, statutory and independent services

Most families in an area use 'universal' or 'statutory' services, i.e. the services provided by their local authority for all families and children, including health, education and social services. Local authorities provide some services directly - for example, benefits, schools and short break schemes funded by social services. However, a thriving independent sector provided by charities or commercial organisations with a particular interest in ASD also operates in many places. Sometimes these services are bought in, or funded, by local authorities. For example, your child might attend a nursery run by a local voluntary organisation with particular experience of supporting children with ASD, but with your local education authority or social services department paying for them to attend.

It's important to find out about everything that is available in your area, and to check that you have been given information about the independent as well as the statutory agency services that are available. You should also check which of the different types of intervention listed later in this booklet are available near you.

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

It's the Welsh Assembly Government's policy to develop better joint working between professionals and departments and better-integrated services for children. Where local services are not well coordinated, parents often find they need to play a more active role in ensuring that services and professionals work together.

## What education provision is available for children and at what age?

Understanding of the nature and impact of ASD is still developing. Provision for young children 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.

For children with an ASD, education may mean learning some things that other children develop naturally. For example, specific teaching may be needed to help children learn to tolerate or interact with other children or to understand the rules and routines of situations that other children take for granted.

The education of children who have an ASD is often the main concern of parents



following diagnosis. Support for children with ASD is organised by local authorities 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 and on the approach taken by each individual local authority.

It can be time consuming and tiring to work out what's the best early years setting or school for your child. As a result of the Welsh Assembly Government's Strategic Action Plan for autism, local authorities in Wales have Steering groups- planning groups for autism. These groups are usually made up of parent representatives, the voluntary sector and professionals from health, education and social services. Each local authority in Wales has a named lead person for autism.

'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 local authority 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.'

### What should you look for?

It can be helpful to ask yourself:

- What kind of education does my child really need?
- What education provision is available in my area and at what age?
- What level of education and additional support is my child legally entitled to?

### What education does your child need?

Although each child with ASD is unique and the autism spectrum is very broad, there are some features that are common to all good autism education provision. These include:

- access to professionals who understand ASD
- willingness and ability to present information in a way that addresses a child's communication difficulties
- willingness and ability to adapt some 'normal' routines for a child with ASD, in line with their individual needs.

## Support in the early years

In addition to childcare provided by family members, most children and their families are helped and supported by professionals in early years settings. However, the level and type of support available in different local authorities varies widely. Some children attend a nursery class daily and receive one-to-one support there; other children are only offered one hour of input on alternate weeks.

Some families supplement what their local authority is able to provide by paying for services themselves - for example in private nurseries or autism-specific home programmes. 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 that are normally provided by local authorities include:

- Portage (a pre-school home visiting special educational needs support service), which is usually accessed via your local authority.
- Playgroups, including those run by the Mudiad Ysgolian Meithrin (who in partnership with Autism Cymru are training staff to be autism friendly) and the Pre-school Playgroup Association, where additional help can be provided for your child
- Nursery classes which may be attached to a local mainstream or special school and which are specially resourced to support children with **special educational need**
- Advisory services of different types provided by local authorities with input from **speech and language therapists**, educational psychologists and teachers
- Integrated Children's Centres, which provide childcare, early education and family support in one place. Some have additional facilities for children with special needs or disabilities

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, because early intervention services vary widely in their approach and intensity.

### From birth to 3 years

For the very youngest children, parents and carers normally play the most important role in deciding and funding the provision that is right for their child. However, some local authorities will fund or provide services such as those above for very young children with ASD.



### Questions to ask about services for very young children

- How much one-to-one attention from an adult will my child have?
- Will the adult(s) have the skills to build up my child's desire and ability to interact and communicate?
- How will my child's time be structured?

Families where at least one parent works 16 hours a week or more may qualify to receive the Working Tax Credit. The childcare element of the Working Tax Credit enables families to get back up to 80 per cent of costs for eligible childcare.

### 3 to 5 years

All children in Wales are entitled to receive a free, part-time early education place from the 1 September, 1 January or 1 April following their third birthday. A 'free nursery education place' means a minimum of 12.5 hours per week for 38 weeks of the year. In some areas, this is being extended to 15 hours of sessions per week. The Government has announced its intention to extend this entitlement so that, by 2010, all three and four-year-olds will have access to 15 hours of free early years provision per week for 38 weeks a year, and parents will be able to take up the entitlement more flexibly over a minimum of three days.

Free early years education is provided in various settings, including pre-school groups, Children's Centres, registered childminders, nursery and reception classes in primary schools, nursery schools and private nurseries.

### Questions to ask about early years settings

- Are activities adapted to meet the particular needs of my child?
- How will the setting provide structure and consistency?
- How much one-to-one attention from an adult will my child have?
- Do the adult(s) have the skills to address my child's specific communication, social, behavioural and sensory needs?

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### Autistic spectrum disorders

#### Looking for the right school

In Wales, children are required to attend school at the start of the term after their fifth birthday, either on 31 August, 31 December or 31 March. However, in some areas children may start earlier than this, depending on local admission arrangements.

There is no straightforward answer to the question 'What's the 'right' type of education?', because ASDs are so complex and individual. The 'right' kind of provision is the one that meets your child's individual needs.

Talk with other parents, support groups and ask questions of any schools and early years settings that you visit. It's important that you get to know the choices available and get a sense of the training, expertise, environment and ethos which is on offer to meet the needs of your child.

'I found out the best way to get my child into the school I wanted was by talking to other parents who had been through the same.'

Your child is entitled by law to attend the local mainstream school. However, because different children with autism need very different types of provision, it's a good idea to start looking at a range of schools available in your area (and in neighbouring local authorities) as early as possible. It may take some time to find the place that you feel will best meet your child's needs.

Some of the alternatives include:

- Assessment centres
- an autism-specific resource base within a mainstream school
- a mainstream school where autism-specific support is provided, tailored to the individual
- a special school with experience and expertise in autism
- home education
- a combination of the above, tailored to the child's needs

'There was always agreement between the teachers, specialists and me that, as long as he was very well supported, a mainstream school with a specialist unit would be best for Callum.'

'My son is severely autistic (no language, little understanding, few self-help skills) so a dedicated special school is the only viable option for him.'

'He started with a full-time placement in the special unit and after three years when he



was ready and expressed a wish to join the mainstream children, he was put into a non-stream class in the mornings with a lot of support.'

To find out what is available locally, you can contact your local authority and SNAP Cymru. You can also look up schools and other education services on the [www.awares.org](http://www.awares.org) or the PARIS website, [www.info.autism.org.uk](http://www.info.autism.org.uk) in your area.

### Questions to ask about schools

- Is the curriculum adapted to meet the particular needs of my child?
- Will they be able to 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 is the school to work with parents and discuss things with us?
- How will the school help my child to participate in the whole-school activities they will benefit from but protect them from other activities that will not meet their needs?

A few parents choose to educate their child at home, running autism-specific home-based interventions. If you are interested in this option, you must inform the local authority of your decision once your child is five.

### Finding out more - Parent Partnership Services

Parent partnership services (such as SNAP Cymru) provide support and advice to children have **additional learning needs**. Many local autism specific services which have been set up with the help. They should provide accurate and neutral information on the full range of options available to parents. They are there to help parents to make informed decisions about their child's education.

Where parents want an independent parental supporter, the service should provide one.

Your local authority, your child's education provider or **Contact a Family** will be able to

put you in touch with the local parent partnership service who can also give you the names of local voluntary organisations and parents' groups that might be able to help.

To find out more about SNAP Cymru or Parent Partnership Services ring [Contact a Family](#) on 029 2039 6624 .

## The SEN System

Children with [special educational needs \(SEN\)](#) are defined as have learning difficulties or disabilities that make it harder for them to learn than most children of the same age.

They may need extra or different

help from that given to other children. For children with an ASD difficulties at school with learning and school work may be associated with difficulties making friends or relating to adults, with behaviour, with organising themselves or physical or sensory difficulties that affect their life at school.

Every mainstream school and early years setting has a member of staff called a [SENCO](#) (special educational needs co-ordinator), who is there to make sure that the appropriate provision is made for children who have [special educational needs](#).

*'We had a great SENCO at mainstream nursery who gave us all the options and supported the decision we made.'*

All good early education settings and schools place importance on identifying [special educational needs](#) early so that they can help children as quickly as possible. Once it is clear that your child has SEN, your child's teachers should take a graduated approach to providing different levels of additional educational support and intervention.

This graduated approach recognises that children learn in different ways and can have different kinds or levels of SEN. So increasingly, step by step, specialist expertise can be brought in to help the school with the difficulties that a child may have.

The levels of additional support available are:

- [Early Years Action or School Action](#) - additional help and support provided for a child by the school or early years setting
- [Early Years Action Plus or School Action Plus](#) - additional help and support given to a child by the school, but with the help of other professionals brought in from outside
- [Statement of Special Educational Needs](#) - If extra resources are required to support your child that cannot be provided at [Early Years Action](#) or [Early Years Action Plus](#), then they will be assessed so that their needs can be set out in a legal



document called **a statement of special educational needs**. Some families with children with ASD find they need to request an assessment and secure a statement in order to get their local authority to fund the special provision or intervention they think their child requires. A statement can be requested at any age, although this is less common for children under three. Parents can 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). In Wales the Statutory Assessment process is currently under review in an attempt to provide a better service.

A school or early years setting must tell you when they first start giving additional or different help to your child at **Early Years Action** or **Early Years Action Plus**. The additional or different help associated with **special educational needs** could be a different way of teaching certain things, some help from an extra adult, more time working in a small group, or making changes to the learning space your child uses. In addition to the questions in the sections above, you may find some of the following questions helpful things to bear in mind when thinking about an education provision or visiting a setting:

- Does the senior member of staff (e.g. the head teacher or the playgroup manager) have an understanding of ASD?
- Do the **SENCO** and other members of staff understand ASD?
- Is staff training available on ASD?
- Has the setting understanding of setting up Circles of Friends or other systems of social support that might help your child?
- Does the setting teach social skills and understanding as part of the curriculum?
- Are alternative communication methods that might help your child used by members of staff - for example, the **Picture Exchange Communication System (PECS)**, or pictures and photos?
- If your 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 in the setting? At the same time, is there flexibility to deal with children who struggle to conform?



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- Are there designated areas available for children with ASD to use as places for quiet time or as their special learning space?

## What level of education is your child entitled to?

Children with **special educational needs** enjoy the same rights as any other child to receive educational provision that meets their individual needs. It is unlawful for education settings to discriminate against disabled children and prospective children who may be disabled, and they must make reasonable adjustments to accommodate children's disabilities.

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

You could also contact the **Advisory Centre for Education**. Their general advice line is open Monday to Friday 2-5pm on 0808 800 5793 or Autism Cymru on 01978-853841 and full contact details are given at the back of the booklet.



## Access to short breaks and financial help

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 short breaks (respite care) 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 have the right to request an assessment of your family's support needs from your social services or children's 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 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. It's a good idea to ask whether staff working for any service you are thinking of using have received any autism training. If you are having difficulties with social services, contact [Contact a Family](#) or the [Family Rights Group](#).

## Direct Payments

Some families choose to organise support and services for their child themselves, rather than using the services on offer through social services. Direct Payments can sometimes be made by social services to families to cover the cost of arranging services yourself. You can find out more about [Direct Payments](#) by contacting your social services department or visiting <http://tiny.cc/e2S9h>

## Disability Living Allowance (DLA)

DLA is the main benefit for disabled children. Entitlement to DLA is based on mobility difficulties and/or the need for personal care which results from severe disability, including behavioural and communication difficulties. 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 the Benefits Enquiry Line.

### Benefits Enquiry Line

Freephone: 0800 882 200

Text phone: 0800 243 355

Email: [BEL-Customer-Services@dwp.gsi.gov.uk](mailto:BEL-Customer-Services@dwp.gsi.gov.uk)

Web: <http://www.direct.gov.uk/disability-money>

DLA has 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 five and the higher rate from the age of three). 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 it might be useful to keep a diary. 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. Some behavioural and safety issues might be equivalent to this.

If you want to know more, **Specific Disorders and Your Child's Behaviour: A Parents Guide to Behavioural Phenotypes** (Contact a Family, 2004) is a publication which describes how behaviour can affect mobility. It is listed at the back of the booklet.

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 Bureau, may be able to help.

Some parents find completing a DLA form problematic, as it concentrates only on the difficulties that your child has and not on their strengths and positive qualities. 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.

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.

If your child receives the middle or higher rate of DLA and care for your child at least 35 hours a week you may also be entitled to claim Carer's Allowance.

You can get more information and download application forms for DLA and Carer's Allowance from:

[www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DisabilityLivingAllowance/DG\\_10011925](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DisabilityLivingAllowance/DG_10011925) and

[www.direct.gov.uk/en/CaringForSomeone/MoneyMatters/CarersAllowance/DG\\_10012547](http://www.direct.gov.uk/en/CaringForSomeone/MoneyMatters/CarersAllowance/DG_10012547) respectively.

## The Blue Badge scheme

For families with a child with ASD, a Disabled Person's Parking Badge (a 'Blue Badge') can be extremely helpful, as it enables families to park near local amenities. If your child receives the higher rate mobility component of DLA then you should automatically get a Blue Badge, but you can still apply even if your child doesn't receive DLA. Contact your council to find out about local arrangements.

## 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

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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.

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. The following Government website provides information on home adaptations and equipment:  
[www.direct.gov.uk/en/DisabledPeople/HomeAndHousingOptions/YourHome/index.htm](http://www.direct.gov.uk/en/DisabledPeople/HomeAndHousingOptions/YourHome/index.htm)

Alternatively, you may like to ring the [NAS Autism Helpline 0845 070 4004](tel:08450704004).

The Family Fund may also be able to help with funds for specific items. For more information, contact:

#### [The Family Fund](http://www.familyfund.org.uk)

Unit 4, Alpha Court

Monks Cross Drive

Huntington

York

YO32 9WN

Tel: 0845 130 4542; Textphone: 01904 658 085; Fax: 01904 652 6250

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

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



## Therapies and interventions

### How are therapies and interventions helpful?

All parents want to ensure that their children are being given the best chance to make progress. Effective early intervention can help your child:

- communicate with you and with other people
- understand more about the world around them

Effective intervention can also help you:

- interact with your child better
- understand and respond to your child's behaviour.

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 intervention might help?

There are several teaching and therapeutic approaches which have been developed specifically for children with autistic spectrum disorders. Some were developed for all ages, and in all settings, while others are specifically for pre-school children in a home setting. The professionals working with you may use some of these approaches as part of the intervention programme being developed for your child at home or in a pre-school or school setting.

## Choosing an intervention method for your child

There's a lot of debate about different types of intervention and therapies and some parents or professionals hold strong views about 'what works' and 'what doesn't'. Some families feel a particular therapy 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 helps one child might not help another, and also that children can benefit from different interventions at different stages of their progress.

**It is important to recognize that each child with autism is unique and so there is no 'one size fits all' and for many something which uses elements of lots of different approaches will be more beneficial and suit their growing needs as they mature.**

There are many interventions, with varying levels of research evidence about how effective they are. This booklet can give some basic information about some of the options available, but it cannot recommend any particular methodology. 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
- you've had a chance to observe the interventions/therapies in practice the information you have about the effectiveness of different approaches comes from more than one source.

As you consider different alternatives you may want to ask some of these questions:

- Does this approach have a track record?
- How does it work?
- Is there evidence about how many children with autism have undergone this therapy and what the outcomes are?
- Is there any evidence about whether children who have strengths and difficulties similar to my child are particularly likely to benefit from this approach?
- Is the therapy unsuitable for certain people? Who? Why?
- Are there any side effects? If yes, what are they?
- On what basis will professionals decide whether a particular approach is appropriate for my child?
- How will we judge whether the therapy is successful for my child?



Don't forget to ask questions about the therapist's training and experience (including experience of working with clients with your child's difficulties), and about the arrangements for therapy including cost, payment arrangements, transport and accommodation and whether you will have a written agreement with the therapist.

## Some options

The rest of this section lists some therapies and interventions.

### Applied Behavioural Analysis (ABA)

If you watch a child with autism being taught according to the principles of ABA, you should see an intensive, interactive approach (often one-to-one) designed first to teach basic learning skills and then to encourage motivation to learn more advanced skills. Any aspects of learning that the child finds hard are broken down into small, achievable steps, and are then presented in a simple and consistent way. This approach pays particular attention to the careful reinforcement of a child's achievements and close monitoring of each child's progress, underpinned by precise data collection and observation.

People often think that ABA programmes are only used in the home and for pre-school aged children. For example, the form of ABA known as the **Lovaas** method was developed for home-based pre-school teaching.

However, there are other applications of ABA, for example 'Verbal Behaviour', which are used both at home and in school settings, and are not just for young children with autism.

Decisions about the most appropriate type of ABA approach for a child will be based on the needs of the children and their families. A 'good' ABA approach will place a lot of emphasis on enabling children to translate their learning into new situations and providing parents with the skills to respond to their child's communication, social and behaviour needs.

For further information about ABA, contact National Autistic Society Cymru or:



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**Peach**

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)

**TreeHouse**

Woodside Avenue  
London  
N10 3JA  
Tel: 0208 815 5444  
Email: [info@treehouse.org.uk](mailto:info@treehouse.org.uk)  
Web: [www.treehouse.org.uk](http://www.treehouse.org.uk)

**The Son-Rise Program (Option therapy)**

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  
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.info.autism.org.uk](http://www.info.autism.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 is 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 Wales by contacting Autism Cymru's Cardiff office on 02920-463263.

## Dietary and bio-medical interventions

A range of bio-medical interventions are promoted and publicised for children with autism, but as yet very few have received any robust evaluation. 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 (i.e. no milk products) and gluten-free (i.e. no wheat products) diet. This is based on the theory that some children have difficulty processing these substances and that this has an impact on their ASD. Children who benefit most from such dietary interventions appear to be those who

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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:

#### The Autism Research Unit

School of Health Sciences  
University of Sunderland  
Sunderland SR1 3SD  
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/Fax: 0845 22 66 510

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

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

## Communication support

Communication is a particular challenge for children with ASD and difficulty in this area leads to frustration. Helping children to understand and communicate can lead to improvements in behaviour.

### Picture symbols (including PECS)

Some children who have not developed speech, or who already have a vocabulary find picture symbols helpful. Symbols enable them to 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. For some, the use of **PECS (the Picture Exchange Communication System)** will be a precursor to learning spoken language.

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: [mvdv@makaton.org](mailto:mvdv@makaton.org)

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

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### Signalong

The Signalong Group  
Stratford House  
Waterside Court  
Neptune Close  
Rochester  
Kent ME2 4NZ

Tel: 0870 774 3752

Fax: 0870 774 3758

Email: [mkennard@signalong.org.uk](mailto:mkennard@signalong.org.uk)

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

### British Sign Language

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

For more information, contact:

British Deaf Association

10th Floor

Coventry Point

Market Way

Coventry

CV1 1EA

Tel: 02476 550 936

Fax: 02476 221 541

Textphone: 02476 550 393

Email: [midlands@signcommunity.org.uk](mailto:midlands@signcommunity.org.uk)

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

## 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 Hanen Programme

The Hanen Center

Suite 515-1075 Bay Street, Toronto, Ontario, Canada M5S 2B1

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

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



## Speech and language therapy

Speech and Language Therapists assess, diagnose and develop a programme of care 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 some of the methods described above, such as signing or picture symbols, rather than focusing on speech alone.

There are a number of different ways to get a referral to a speech and language therapist (SALT). 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 in your area without going through your GP, contact [The Royal College of Speech and Language Therapy](#). For a private appointment that you pay for, you can contact the [Association of Speech and Language Therapists in Independent Practice](#), who will be able to supply you with contact details for Speech and Language Therapists working in your area.

### [The Royal College of Speech and Language Therapists](#)

2 White Hart Yard, London , SE1 1NX

Tel: 020 7378 1200

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

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

### [The Association of Speech and Language Therapists in Independent Practice](#)

WWS

Coleheath Bottom , Speen , Princes Risborough, Buckinghamshire HP27 0SZ

Tel: 01494 488306 (Answerphone)

Fax: 01494 488590

Email: [asltip@awdry.demon.co.uk](mailto:asltip@awdry.demon.co.uk)

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

## 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. Before you try to tackle a behaviour decide whether it really is a problem rather than just inconvenient or embarrassing. 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 communicating because of their autism. Other triggers might be social situations which they find stressful, unstructured time, sensory difficulties, medical reasons, and change which your child finds stressful. You may find it helpful to track your child's behaviour in a diary, so you can begin to see patterns in behaviour and notice small, positive changes as you develop strategies. Understanding your child's particular difficulties will help you develop strategies to help with behaviour problems. 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 really good way of relieving stress and working off frustration.

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.’

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. All the advisors on the [NAS Autism Helpline](#) have experience of working with people with autism and can advise on behavioural issues. There are several helpful books giving advice on strategies for difficult behaviours. Details are given at the end of this booklet.



## 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

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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 Cymru

33-35 Cathedral Road

Cardiff

CF11 9HB

Tel: 029 2039 6624; Fax: 029 2039 6625

Helpline: 0808 808 3555; Textphone: 0808 808 3556 (Free for parents and families 10am-4pm, Mon-Fri)

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

Web: [www.cafamily.org.uk/inyourarea/wales/index.l](http://www.cafamily.org.uk/inyourarea/wales/index.l)

#### SNAP Cymru

10 Coopers Yard, Curran Road,

Cardiff, CF10 5NB

T: 029 20 388776

F: 029 20 371876

Helpline: 0845 120 37 30



## 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.'*

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 other sources of information

**All About Autistic Spectrum Disorders-** A booklet for parents and carers  
Freely downloaded from [www.awares.org](http://www.awares.org)

### **Autism: how to help your young child**

Leicestershire County Council & Fosse Health Trust  
The National Autistic Society (1998)

### **Autistic Spectrum Disorders in the Early Years**

Lynn Plimley, Maggie Bowen and Hugh Morgan  
Sage Publications: London (2007)

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

Brenda Legge  
Jessica Kingsley Publishers (2002)

### **Caring for a child with autism**

Martine Ives and Nell Munro  
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 (2001)

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**

Brenda Nally  
The National Autistic Society (1999)

### **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.  
National Autistic Society (2005)



**Guidelines for working with children with autistic spectrum disorders at foundation stage and key stage 1**

South Gloucestershire Council

**It can get better: dealing with common behaviour problems in young autistic children**

Paul Dickinson and Liz Hannah

The National Autistic Society (1998)

**Learning to Play: Playing to Learn- An information Booklet for those living and working with young children with an ASD**

Maggie Bowen, Autism Cymru

Free to download on [www.awares.org](http://www.awares.org)

**Living with ASDs**

Hugh Morgan and Elizabeth Attfield

Sage Publications : London (2006)

**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.

**My sister is different**

Sarah Hunter

National Autistic Society (2006)

Life of a sister who has autism, written by a 10 year old who also has an ASD.

**Playing, laughing and learning with children on the autistic spectrum**

Julia Moor

Jessica Kingsley Publishers (2002)

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A practical guide to play activities. Useful for toddlers and primary school children who are struggling to learn how to play.

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

V. Mark Durand

Paul H. Brookes (1998)

#### Social Skills and ASDs

Lynn Plimley and Maggie Bowen

Sage Publication: London (2007)

#### Teaching young children with autistic spectrum disorders to learn

Liz Hannah

The National Autistic Society (2001)

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 (2002)

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

#### The autistic spectrum: a parent's guide

National Autistic Society (2001)

The NAS 'parent's pack' also contains six leaflets for parents who have just received a diagnosis for their child.

#### We can do it! Helping children who have learning disabilities with bowel and bladder management: a guide for parents

Enuresis Resource and Information Centre (2002)

All of the books listed above can be ordered from:

NAS Publications

Central Books Ltd

99 Wallis Road



London E9 5LN  
Tel: 0845 458 9911  
Fax: 0845 458 9912  
Email: nas@centralbooks.com

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

**Autistic spectrum disorders: good practice guidance**

Department for Children, Schools and Families.  
Department of Health  
DCSF/0597/2002/REV

**Special Educational Needs Code of Practice**

Department for Children, Schools and Families.  
DCSF/0581/2001

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

Department for Children, Schools and Families.  
DCSF/0800/2001

These publications are all available from:

**DCSF Publications**

PO Box 5050  
Sherwood Park  
Annesley  
Nottinghamshire  
NG15 0DJ

Tel: 0845 602 2260  
Fax: 0845 603 3360



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

**The AiA gluten and dairy free cookbook**

Marilyn Le Breton

Jessica Kingsley Publishers (2002)

**Children with starving brains**

Jaquelyn McCandless

Bramble Books (2002)

**Diet intervention and autism**

Marilyn Le Breton

Jessica Kingsley Publishers (2001)

**Freaks, geeks & Asperger syndrome**

Luke Jackson

Jessica Kingsley Publishers (2002)

**Life behind glass**

Wendy Lawson

Jessica Kingsley Publishers (2000)

**My social stories book**

Carol Gray

Jessica Kingsley Publishers (2002)

**Nobody nowhere**

Donna Williams

Corgi (1993)

**The out-of-sync child**

Carol Stock Kranowitz, G P Putman's & Sons (1998)

**Specific disorders and your child's behaviour: a parent's guide to behavioural phenotypes**

Contact a Family (2004)

**Teach me language?**

Sabrina Freeman and Lorelei Dake , SKF Books (1996)



**Thinking in pictures**

Temple Grandin

Vintage Books (1996)

**Understanding and working with the spectrum of autism**

Wendy Lawson

Jessica Kingsley Publishers (2001)

**Visual strategies for improving communication**

Linda Hodgdon

Quirk Roberts (2004)

## Useful organisations

### Advisory Centre for Education (ACE)

1c Aberdeen Studios  
22 Highbury Grove  
London N5 2DQ  
Tel: 0808 800 5793 General advice line (Mon-Fri 2-5pm)  
Web: [www.ace-ed.org.uk](http://www.ace-ed.org.uk)

### Autism Cymru

6, Great Darkgate St,  
Aberystwyth  
SY23 1DE  
Tel: 01970 625256  
Fax: 01970 639454  
[www.awares.org](http://www.awares.org)

Cardiff: 02920 463263  
Wrexham: 01978 853841

### 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.

Contact a Family Cymru  
33-35 Cathedral Road  
Cardiff  
CF11 9HB  
Tel: 029 2039 6624  
Fax: 029 2039 6625  
e-mail: [wales.office@cafamily.org.uk](mailto:wales.office@cafamily.org.uk)



### Family Rights Group

The Print House  
18 Ashwin Street  
London E8 3DL

Advice line is open: Mon to Fri: 10am-12pm and 1.30pm-3.30pm Freephone number 0800 731 1696.

Email: [advice@frg.org.uk](mailto:advice@frg.org.uk)

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

### National Autistic Society (NAS)

Formed in the 1962, the **National Autistic Society (NAS)** is the UK's leading charity for people with autism, including Asperger syndrome, their parents and carers. It has a membership of 15,000, a network of 60 branches, and 90 partner organisations in the autism field. The NAS exists to champion the rights and interests of all people with autism and to ensure that they and their families receive quality services, appropriate to their needs.

The **National Autistic Society** has an **Autism 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 and it also has a minicom number for deaf and hard of hearing callers. The Helpline is open 10am-4pm Monday to Friday. Helpline information sheets are also available online at [www.autism.org.uk/a-z](http://www.autism.org.uk/a-z)

Helpline: 0845 070 4004 (local call rate)

Minicom: 0845 070 4003 (local call rate)

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

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**National Autistic Society Cymru**

6/7 Village Way  
Green Meadow Springs Business Park  
Tongwynlais  
Cardiff  
CF15 7NE  
Telephone – 029 2062 9312  
E mail – wales@nas.org  
www.nascymru.autism.org.uk

**PARIS (Public Autism Resource and Information Service)** is a UK-wide online searchable database which holds up-to-date information on local support groups, diagnostic services, schools and early years support, training courses and a range of other services, [www.info.autism.org.uk](http://www.info.autism.org.uk)

The **NAS Advocacy for Education Service** 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)



## Glossary

**Advocacy** - support to help people who find it difficult to communicate their views, especially in relation to statutory and legal services

**ABA** - Applied Behavioural Analysis. An approach to teaching which emphasises positive reinforcement and is underpinned with observation and monitoring: interactive and child-centred

**Asperger Syndrome** - a type of autistic spectrum disorder. People with Asperger Syndrome usually have fewer difficulties with language than people with autism and do not have accompanying learning disabilities that some people with autism have. They are likely to be of average or above average intelligence

**ADHD** - attention deficit hyperactivity disorder. A developmental disorder which can cause overactive behaviour (hyperactivity), impulsive behaviour and difficulties in concentrating

**ASD** - autistic spectrum disorder, a developmental disorder characterised by difficulties with social interaction, social communication and rigidity of thinking

**Carers allowance** - a benefit available to people with care for someone with a disability

**Casein** - protein found in milk and milk products

**Direct payments** - a way of choosing and paying for services provided by Social Services which can be adapted to meet your family's needs

**Disability Living Allowance** - a benefit for children and adults with a disability. It is made up of a care component and a mobility component

**Dyspraxia** - a difficulty in co-ordinating movement

**Echolalia** - repeating words or phrases spoken by someone else **Gluten** - protein found in wheat

Information for parents

Autistic spectrum disorders

**Hanen** - a training programme for children who have a delay in developing language

**Kanner autism** - also sometimes called 'classic autism'. An autistic 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

**Lovaas** - a form of Applied Behavioural Analysis delivered in a home setting for pre-school children

**Makaton** - a form of sign language often used with people who have learning disabilities

**Paediatrician** - a doctor who specialises in treating children

**Parent Partnership Service** - a local service which provides support and advice for families of children with special educational needs

**PDD** - pervasive development disorder. A general term for disorders which affect communication and social skills and includes autistic spectrum disorders

**PDD-NOS** - pervasive development disorder not otherwise specified. Where someone has a pervasive development disorder but there is not enough information to give a more specific diagnosis

**PECS** - picture exchange communication system. A way of using pictures and symbols to help children who have difficulty communicating with speech

**Portage** - a home visiting educational services for pre-school children with additional needs such as a disability

**Respite services** - services for people who have a disability and their family to give them a rest and a break

**Semantic pragmatic disorder** - a communication disorder where people have difficulty understanding the meaning of words and may use them in the wrong context. It can be linked to autism

**Special Educational Needs (SEN)** - special educational needs

**SENCO** - special educational needs co-ordinator. A member of staff in schools and early years settings who co-ordinates provision for children with special educational needs

**Son-Rise** - a home-based, intensive, autism-specific intervention

**Speech and language therapy (SALT)** - a form of therapy to support people who have difficulties with communication. Speech and language therapists 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

**TEACCH** - an autism-specific approach which helps children cope with and understand their environment

**Triad of impairments** - the three impairments which characterise autism: social communication, social interaction and rigidity of thinking



## About Early Support

**Early Support** in Wales is the Welsh Assembly Government's mechanism for achieving better co-ordinated, family-focused services for young disabled children and their families across Wales.

Early Support builds on existing good practice. It facilitates the achievement of objectives set by broader initiatives to integrate services, in partnership with families who use services and the many agencies that provide services for young children.

To find out more about the Early Support programme and associated training opportunities and to view other materials produced by the programme, visit [www.earlysupportwales.org.uk](http://www.earlysupportwales.org.uk)

This booklet is one in a series produced in response to requests from families, professional agencies and voluntary organisations for better standard information about particular conditions or disabilities. The other titles in the series are:

Cerebral palsy

Down Syndrome

If your child has a rare condition

Learning disabilities

Deafness

Speech and language difficulties

Multi-sensory impairment

Visual impairment

When your child has no diagnosis

Other **Early Support** information about services is available separately, or as part of the Early Support **Family pack**. The Family pack helps families who come into contact with many different professionals to co-ordinate activity and share information about their child through the first few years of life, using a Family file.

These are resources that families say make a difference. If your family is receiving regular support from professionals, please feel free to ask them about the **Early Support family pack**. It may help and is available free of charge. To find out how to obtain copies of any of the **Early Support** materials mentioned here, see [www.earlysupportwales.org.uk](http://www.earlysupportwales.org.uk)

This edition of the booklet up-dates information and ensures it is appropriate to the context in Wales.

**Early Support** would like to thank the many families and professionals that have been involved in development of these resources and to thank the National Autistic Society (NAS), TreeHouse and Autism Cymru for their help in writing and more recently revising this booklet.