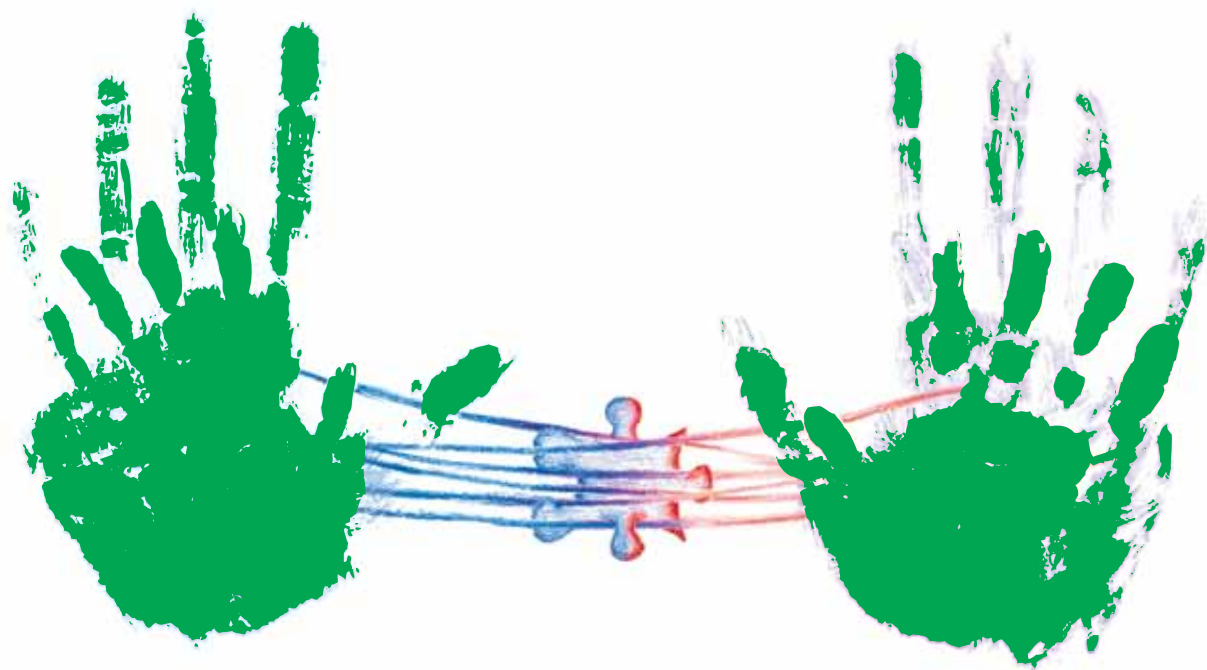


# Autism: A Guide for Parents and Carers Following Diagnosis



The background of the cover is an abstract, textured artwork. It features a mix of warm yellow and golden tones on the left side, transitioning into deep green and dark teal on the right. The textures are organic and layered, resembling marbled paper or a natural stone surface. The overall effect is vibrant and dynamic.

# Autism: A Guide for Parents and Carers Following Diagnosis

Artwork on front cover kindly supplied by Carrie Francis

# Foreword

I am pleased to present to you *Autism: A Guide for Parents and Carers Following Diagnosis* and hope that it will provide important help and support to many families of those diagnosed with an Autistic Spectrum Disorder.

The need for information at the point of and following diagnosis remains a constant message from families and something that we agreed locally should be one of our key priorities. Families told us that receiving a diagnosis often left them with questions and a need for knowledge which was not always readily available. They expressed a need for something to refer to which would be a single-resource and which would be easily accessible. It would answer their questions, provide them with information, help and support as well as signpost them to further resources should they need them.

*Autism: A Guide for Parents and Carers Following Diagnosis* helps give a greater focus on supporting our families within their local communities at as early a stage as possible. We must remain ambitious in what we want to achieve together for our families. We want to equip them with the knowledge and skills that they will require in order to provide support for their children and young people. This will enable them to achieve the very best possible outcomes at every stage of their lives.

This guide has been developed with input from staff in a variety of agencies and disciplines and, more importantly, with families of those with ASD. These families have keenly supported the development of the pack and have been wholeheartedly involved in every stage, using their experiences to inform the content of *Autism: A Guide for Parents and Carers Following Diagnosis* so that, with the value of hindsight, other families will receive the information they need at the point of and following diagnosis. We are extremely grateful for their valuable contribution which ensured that we remained focussed on developing a resource that truly meets the needs of the families it is intended for.



Allison Williams  
Chief Executive  
Cwm Taf Health Board

# A message from some of our parents

*"It is empowering for parents and carers to have their voices heard and their experience valued where ASD's are concerned and so we welcomed the opportunity to work with professionals in creating Autism: A Guide for Parents and Carers Following Diagnosis. We are proud to have been part of the process. It's our hope that what we have shared about our personal journeys will help you in your own journey and that this will prove to be a good resource for you, whenever you need information. There were times when we wished we had had something like this."*

Parent Representatives  
Rhondda Cynon Taf ASD Steering Group

# Acknowledgements

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# Introduction

If you have recently learned that your child has an autistic spectrum disorder (ASD), this guide is for you. It has been developed 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.

You may not want to read it all at once – you may find it more helpful to refer to different sections over time.

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

Being a parent/carer or family member can be both very rewarding and very stressful. Dealing with the everyday ups and downs of family life and the world around us is hard enough, but doing it as a parent of a child with Autism can at times seem near impossible.

We hope that this document gives you some useful information and points you to how and where you can access further information and help.

It has been written with and for parents / carers. We wanted this booklet to acknowledge that you are an important person in your child's life and often spend more time with your child than any other person, and therefore we hope the information enclosed will go some way in helping you. Inside we have laid out sections with some hints and tips to help you to help your child fulfil their full potential. Your life may indeed feel or be very different after your child's diagnosis, but different doesn't necessarily mean 'bad' or 'wrong', it may just mean different.

With all good wishes...

# What is an Autistic Spectrum Disorder (ASD)?

An Autistic spectrum disorder (ASD) is a developmental disorder which affects the way a person communicates with and relates to other people and the world around them. The way in which people are affected varies from one individual to another and by age and intellectual functioning.

Children with ASDs are affected in a 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.

*'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.'* — Early Support

*'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.'* — Early Support

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

Children with ASDs have significant difficulties relating to other people in a meaningful way. It is very common for ASD children to have profound sensory issues. This, combined with the triad of impairments, means that children with autism experience the world very differently. The 'triad of impairments', or 'the three impairments' are issues with:

- 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.

It is usual that all children with a diagnosis of autism have difficulties in all three of these areas. However, the ways in which they manifest themselves vary enormously. This can make autistic children very anxious. In this guide we will aim to help you understand the characteristics of autistic spectrum disorders in more detail.



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

First, there are two very important things to remember:

## 1. It's not your fault

The fact that your child has 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.

## 2. You aren't alone

According to the Welsh 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.

The way in which a diagnosis has been made will vary from one person to another. For some it will have been a relatively straightforward process but for others it may have taken months or even years.

For some parents, receiving a diagnosis is a shock as they may not have realised that their child had an ASD. For others, there may be feelings of relief following a long time of knowing that there was something different about their child.

*"[Getting a diagnosis] meant I could start to live and get the best out of life for my son." — [Parent]*

*"..we finally held the missing puzzle piece. This helped as we could now justify typical autistic behaviour and learn how to tackle and resolve arising situations." — [Sibling]*

There is no right or wrong way to feel about your child being diagnosed with an ASD. Parents experience a variety of emotions around this, and these can often change on a daily basis. It is quite normal to experience feelings such as:

Sadness  
Anger  
Relief  
Denial

Guilt  
Frustration  
Fear  
Grief

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.

Within the family, other people will also be coming to terms with the diagnosis and this may take some time with some taking longer than others to do so. Difficulties may arise when people are not experiencing the same feelings, or not experiencing the same feelings at the same time. It is important to realise that individuals will feel differently, and to try and have some understanding about this. Talking about problems will often help with family understanding, but is usually only a good idea when all those involved are ready to do so.

*"...my mum has become involved and founded a support group for parents of autistic children. As a result of this I am fortunate enough to have had multiple opportunities to attend group meetings and various seminars that have offered a lot of help, advice and information on how autistic people think, act and function." — [Sibling]*

*"If you can, find a parent support group so that you are supported and don't feel so alone." — [Parent]*

Having a child with an ASD can provide a lot of stress within the family due to the needs or behaviours of the child. This will more than likely have been the case for a long time before the diagnosis is received. This can cause tension for individuals and also tension within relationships in the family. Disagreements about the way to manage behaviours or the way to move forward can occur.

However, it is important to remember that your child is still the same child they were before they received their diagnosis; they have not changed. The only change is that now you have a diagnosis you will be better able to understand your child and their needs.

*"I am a very lucky lady to have the honour of having my son. Autism in our house stands for Always Unique, Thoughtful, Intelligent, Smart Mam's boy. I did not know so many qualities could be in one person. Autism found him; he has made me a better person." — [Parent]*

- A** Always
- U** Unique
- T** Thoughtful
- I** Intelligent
- S** Smart
- M** Mam's Boy



### Some top tips following diagnosis:

- ◆ When you feel ready, consider contacting / joining a support group
- ◆ Talk to someone you trust and feel comfortable with about how you are feeling
- ◆ Don't forget that extended family can be affected too and may need help / support
- ◆ Remember you are a very important person in your child's life and you have needs too!
- ◆ Write down any questions you may have so that you can take them with you to future appointments — there is a notes page for you to use at the end of this section
- ◆ Learn about autism — there are some books, DVD's and websites recommended in this booklet
- ◆ Just remember, you are not alone

### Where else can you get information?

- Local Authority — contact your Family Information Service and Parent Support Officers for details of support groups in your area and also ask for details of any parent support programmes they can offer
- [www.ASDInfoWales.co.uk](http://www.ASDInfoWales.co.uk) the e-resource for ASD in Wales
- Your Health Visitor may have some good advice and strategies that you can use
- Awareness Raising Packages from Welsh Government  
Website <http://wales.gov.uk/topics/health/nhswales/majorhealth/autism/?lang=en>
- The National Autistic Society (NAS) parent support helpline 0845 070 4004
- The NAS will also be able to tell you if there is an EarlyBird or EarlyBird Plus programme running in your area [www.autism.org.uk](http://www.autism.org.uk)
- Contact a Family parent support helpline 0808 808 3555 or email [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)  
website [www.cafamily.org.uk](http://www.cafamily.org.uk)
- Cerebra parent support helpline 0800 328 1159, or email [info@cerebra.org.uk](mailto:info@cerebra.org.uk)  
website [www.cerebra.org.uk](http://www.cerebra.org.uk)
- Early Support Wales offer free training for parents and have a useful free booklet on autistic spectrum disorder. Telephone 029 2034 2434 and ask to speak to the Early Support administrator  
website [www.earlysupportwales.org.uk](http://www.earlysupportwales.org.uk)

# Welcome to Holland

By Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability — to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip — to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "welcome to Holland".

"Holland?!" you say, "What do you mean, Holland?" I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to some horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy a new guidebook. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes, that's where I was supposed to go. That's what I had planned."

The pain of that will never, ever go away, because the loss of that dream is a very significant loss.

But if you spend young life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.



# Celebrating Holland — I'm Home!

By Cathy Anthony

I have been in Holland for over a decade now. It has become home. I have had time to catch my breath, to settle and adjust, to accept something different than I'd planned.

I reflect back on those years of past when I had first landed in Holland. I remember clearly my shock, my fear, my anger — the pain and uncertainty. In those first few years, I tried to get back to Italy as planned, but Holland was where I was to stay. Today, I can say how far I have come on this unexpected journey. I have learned so much more. But, this too has been a journey of time.

I worked hard. I bought new guidebooks. I learned a new language and I slowly found my way around this new land. I have met others whose plans had changed like mine, and who could share my experience. We supported one another and some have become very special friends.

Some of these fellow travellers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many have encouraged me. Many have taught me to open my eyes to the wonder and gifts to behold in this new land. I have discovered a community of caring. Holland wasn't so bad.

I think that Holland is used to wayward travellers like me and grew to become a land of hospitality, reaching out to welcome, to assist and to support newcomers like me in this new land. Over the years, I've wondered what life would have been like if I'd landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

Sure, this journey has been more challenging and at times I would (and still do) stomp my feet and cry out in frustration and protest. And, yes, Holland is slower paced than Italy and less flashy than Italy, but this too has been an unexpected gift. I have learned to slow down in ways too and look closer at things, with a new appreciation for the remarkable beauty of Holland with its' tulips, windmills and Rembrandts.

I have come to love Holland and call it Home.

I have become a world traveller and discovered that it doesn't matter where you land. What's more important is what you make of your journey and how you see and enjoy the very special, the very lovely, things that are Holland, or any land, has to offer.

Yes, over a decade ago I landed in a place I hadn't planned. Yet I am thankful, for this destination has been richer than I could have imagined!

# Notes



# Characteristics of ASD



# Characteristics of ASD

This section will try to explain the characteristics of autism in more detail:

- Social understanding and social behaviour
- Social communication
- Rigidity of thinking
- Anxiety
- Repetitive Behaviours / Stimming
- Special Interests / OCD
- Sensory issues

As we mentioned earlier in this pack, children with ASD's are affected in a variety of ways and to very different degrees, and this is why it is called a spectrum. It is important to remember that the autism spectrum is broad and therefore different individuals with ASD may display all or only some of the characteristics described in the following sections.

## 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
- 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).'* — *Early Support*

## 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)
- 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.

**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



# Our Journey

By Josh (JJ) and Carole Murphy

We're on a journey Josh and I  
It started several years ago  
We've met many people along the way  
Who've told us that they "know"

At first we listened carefully  
Waiting for answers and help to come  
Waited for the map and the directions  
But we've now learned there are none

So we are finding our own way Josh and I  
Plotting our course as we go  
We get lost, and take wrong turns  
But we are the ones that "know"

We're not sure of our destination  
But we've learned that that's OK  
We are having some great adventures  
And there's much laughter along the way.





# Notes

# Anxiety

**One of the things that many parents talk about is how anxious their child seems to be.**

High levels of anxiety in children with an ASD are often a common feature and it is this feeling of anxiety that might be causing some of the behaviours that you may see in your child.

Your child might be feeling anxious about something but is not able to tell you. In fact the way of communicating their anxiety is often through behaviour. Some of the behaviours you might see are:

- Tantrums and aggressive behaviour
- Becoming withdrawn and resisting any interaction with others
- Experiencing pain
- Become distressed

The reason anxiety is mentioned at this point in this booklet is because anxiety is not always talked about when your child is diagnosed. But being aware that your child might be anxious about something is such an important part of helping your child.

Anxiety and autism go hand in hand and it is more prevalent in children with autism because they have difficulty making sense of the world around them and understanding social rules. Causes of anxiety are numerous, which makes it very difficult for parents to know what to do or how to react.

We all experience anxiety, it is part of our everyday life and we all react to stressful situations in a way which is personal to us, but the symptoms of anxiety are often similar. Think of a time when you have felt anxious, you may have experienced feelings such as being scared, panic, increased heart rate, sweating, sickness, not knowing where to turn or what to do next, loss of confidence etc. These are unpleasant feelings and can impact our mood, energy levels and behaviour, so imagine what it must be like to feel anxious every day of your life but not understand why.

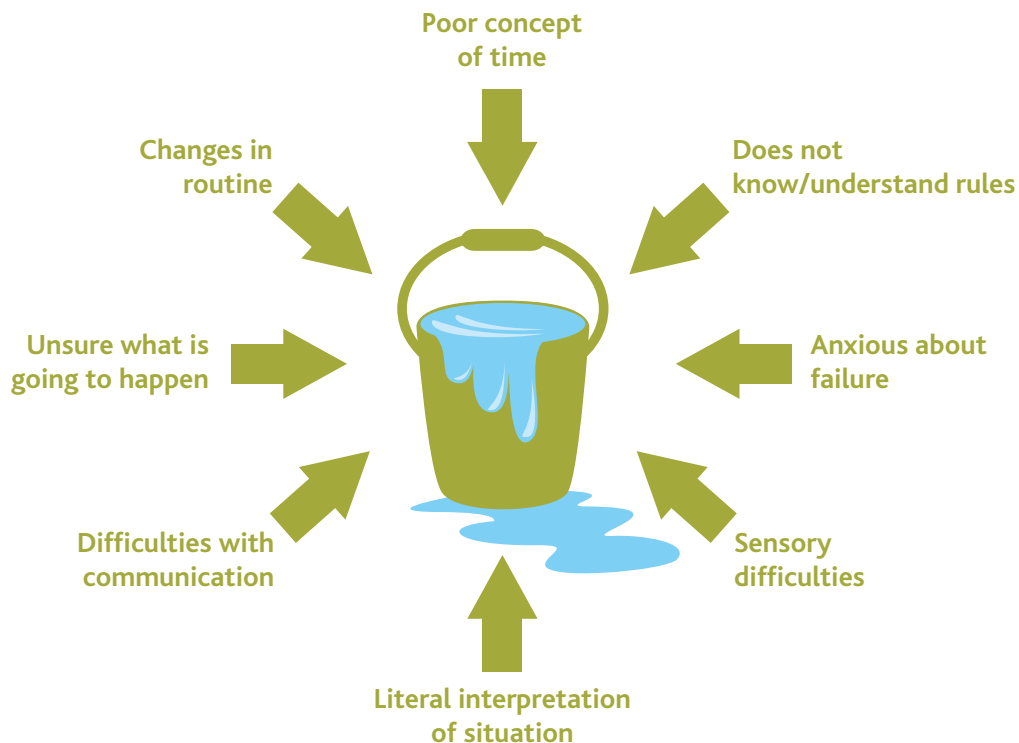
**Children with ASD experience anxiety for a variety of reasons, which can include:**

- meeting strangers
- being given too many choices
- not being able to communicate their needs
- changes in routine
- new activities or places
- experiencing unpleasant sensations, eg dog barking, flashing lights, crowded and noisy environments, overpowering smells
- transition from one activity to another — even small transitions
- trauma - remembering unpleasant events eg having a haircut, seeing the dentist or doctor, which when being asked to repeat makes them anxious

'Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seem to be no clear boundaries, order or meaning to anything. A large part of my life is spent just trying to work out the pattern behind everything. Set routines, times, particular routes, and rituals all help to get order into an unbearably chaotic life.' (Joliffe, 1992, p16)

Sometimes, children with an ASD can be anxious about more than one thing at a time causing overload, which could then lead to extreme anxiety behaviours (meltdown).

**Below is the analogy of a bucket overflowing. When levels of anxiety get too high it can result in the extreme anxiety and inappropriate behaviour.**



For all of these reasons and more, it is no wonder that children with ASD experience anxiety. Their quest in life can become one of routine and predictability. Some children may want to control situations or take part in things only on their terms. This might be because being in control reduces their anxiety levels.

**Some top tips for managing your child's anxiety:**

- ◆ Always consider anxiety levels when deciding how to manage your child's behaviour or when introducing them to change or new activities.
- ◆ Be empathetic — remember how it feels when you are anxious
- ◆ Allow for the autism - be patient and tolerant
- ◆ Maintain a neutral and calm tone of voice - your own anxiety, anger or frustration can make a child more anxious
- ◆ Keep a diary of your child's behaviour and you may be able to identify a trigger for their anxiety
- ◆ Establish routines and stick to them. If you do need to change a routine, provide your child with as much notice that is possible. Explain what is going to happen instead
- ◆ Small transitions can be a big deal to a child with an ASD eg taking a bath and then cleaning teeth straight away might cause anxiety. Allow time between activities wherever you can
- ◆ Give one instruction at a time
- ◆ Give your child time to process information
- ◆ 'Fiddle toys' such as stress balls, play dough, etc may help a child to lower their anxiety levels
- ◆ If your child is upset, distressed or behaving in a challenging way, consider whether this is being caused by sensory issues. Sometimes it may be the fear of what might happen which will make them anxious
- ◆ Identify a 'safe place' that your child can go to when they are feeling anxious, for example their bedroom. Provide your child with a time out mechanism for when things are getting too much. Use of a 'time out' or 'break' card can be useful or even coloured cards to relay how they feel eg red might mean time out now, green might mean okay for now. Alternatively, you could have a verbal code or hand gesture. If your child is older you could try teaching them an anxiety scale using numbers eg 1=calm 2= very happy 3=feeling worried 4=very anxious 5=extreme anxiety behaviours
- ◆ If your child has a way of calming themselves which you find difficult or annoying, be tolerant as your child is doing this to reduce the unpleasant feelings they are experiencing
- ◆ Help your child to understand social rules. Social stories or visual structures can be helpful
- ◆ Learn as much as you can about autism

# Repetitive Behaviours/ Stimming

The term repetitive behaviour is used to describe specific types of unusual or seemingly odd behaviours that are often seen in children with autism.

Repetitive behaviour is sometimes referred to as self-stimulating behavior or stimming. This behaviour may involve any or all of the senses in various degrees in different individuals. Several examples are listed below:

- Visual — staring at lights, blinking, gazing at fingers, lining up objects
- Auditory — tapping fingers, snapping fingers, grunting, humming
- Smell — smelling objects, sniffing people
- Taste — licking objects, placing objects in mouth
- Tactile — scratching, clapping, feeling objects, nail biting, hair twisting, toe-walking
- Vestibular — rocking, spinning, jumping, pacing
- Proprioception — teeth grinding, pacing, jumping

Some repetitive behaviours are very obvious while others are more subtle and hard to detect such as blinking or eye rolling, tapping fingers and mild hair twisting.

We all engage in some of these behaviours occasionally, especially when we are stressed. However, your child may engage in these activities excessively to the point that they interfere with learning or daily living activities.

## Why Repetitive Behaviour?

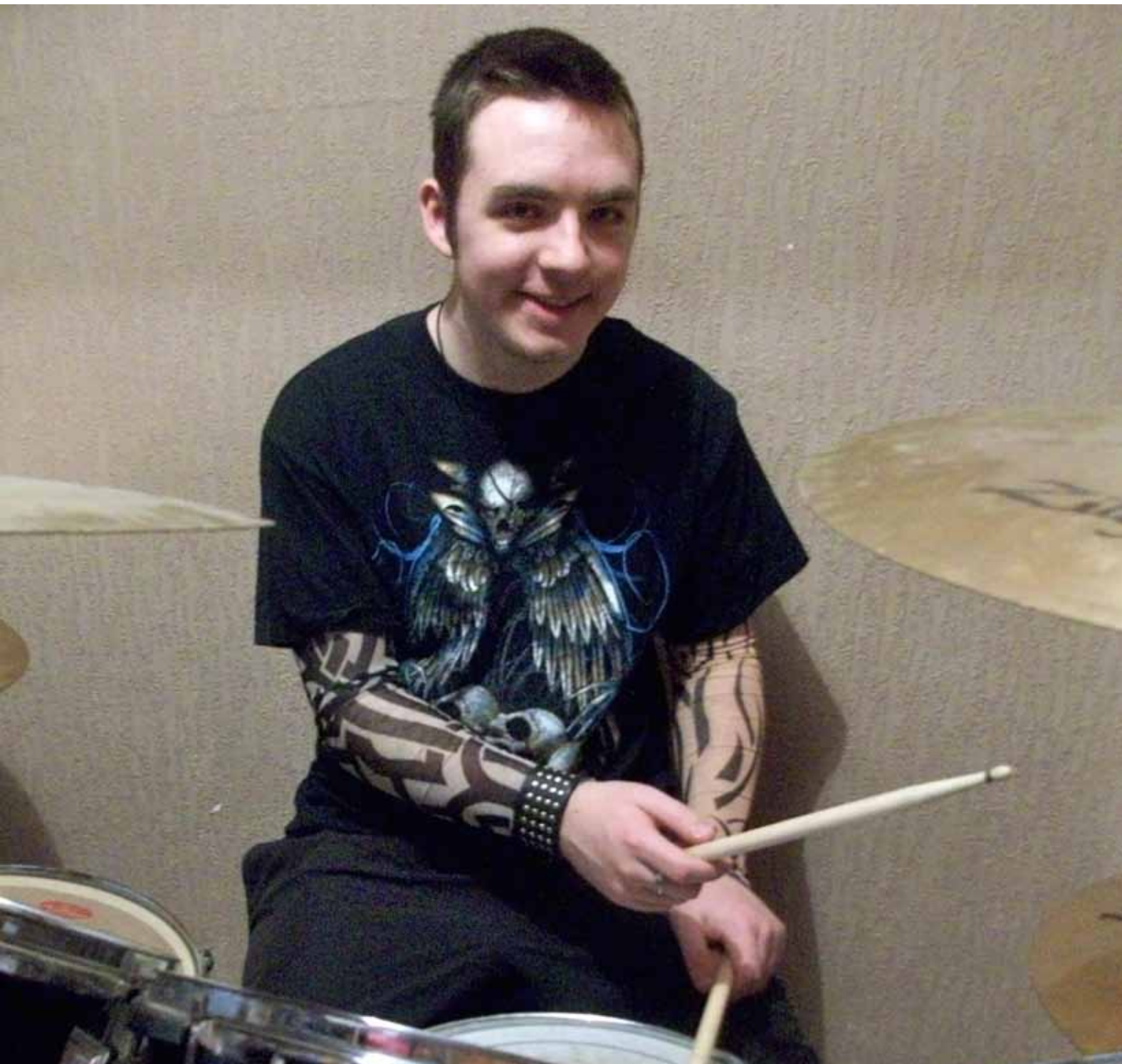
It's not completely clear why repetitive behaviour almost always goes with autism, but it is the case that children with ASD experience a lot of chaos in their world and repetitive behaviour is a way of bringing predictability to an otherwise unpredictable and frightening world. Some of the reasons children adopt repetitive behaviour are outlined below:

- Self regulation, which helps the child become calm and overcome situations of stress or upset
- Demonstrates excitement
- Provides the child with an escape route when they are overworked or wound up
- Makes the child happy. Some children find the behaviour pleasurable even if causing injury to themselves
- Provokes a reaction from others, which reinforces the behaviour
- A way of avoiding a task or activity

Some children learn to monitor their behaviours so they can engage in them in 'safe' environments (at home rather than at school or out in the community).

No matter what repetitive behaviour your child engages in, you need to understand this is something that they need to do in order to find peace in their autistic world.

*"My son taps repetitively on every surface. On the basis of 'if you can't beat them, join them' we got him a drum kit. If he gets cross, angry or frustrated he goes and plays drums which helps him calm down and he is a grade six drummer now which gives him something to be proud of." — [Parent]*





**Some top tips for managing your child's repetitive behaviours / stimming:**

- ◆ Be patient and tolerant — allow for the autism
- ◆ If the behaviour is causing or likely to cause your child harm, ask to be referred to an Occupational Therapist who might be able to help reduce or change these behaviours
- ◆ Become a detective — observe your child and try to understand the underlying causes of the behaviour, what has happened in that day, what is due to happen, has anything been different, are you wearing a new perfume, etc
- ◆ Keep a behaviour diary
- ◆ Don't reprimand your child for their behaviour — ignore the bad but always give lots of praise for good behaviour
- ◆ Read the section in this booklet about supporting your child with different behaviour
- ◆ Remember there will be a reason that the behaviour is happening. As well as the autism look out for signs of sensory or medical problems
- ◆ Learn about autism — there are some books, DVDs and websites recommended in this booklet

# Special Interests / Obsessive Compulsive Disorder

*"It is not uncommon for autistic people to become fixated on past events, animals, places and people! This can be very interesting because they may feel comfortable sharing information and facts with you, which will give you a chance to bond with them in a way that they feel comfortable." — [Sibling]*

All children have favourite things games, films, toys but most children can be distracted or engaged in another activity without too much fuss. Also most children like interaction with other people in order to get the most enjoyment from their activities.

However, some children with ASD seem to develop interests in a way that makes it seem as though they are obsessed. These interests are usually referred to as 'special interests' and to a child with ASD they might be the most important thing in their life. Children with ASD normally develop interests that do not involve anyone else, where they can retreat into their own little world for hours and hours, whereas other children might want to talk non stop about their interest, which in turn makes it difficult for them to develop friendships.

These interests are different to repetitive behaviours but some of the reasons for the special interest can overlap, such as:

- Reducing anxiety
- Maintaining a sense of calm
- Makes them happy
- A way of avoiding another task or activity

To others some of the interests of children with ASD may appear utterly pointless or mind numbingly boring but the child will be experiencing something completely unique to them. For some children their ability to focus on detail will mean that they are experiencing something completely beyond your imagination.

*"... it is important to use the interest as a means to share interest, open communication..." — [Parent]*

Special interests can be anything from weird to wonderful. Some of the more common examples of special interests in children might include:

- Lining up toys eg cars, trains etc
- Drawing
- Counting
- Watching things spin
- Dinosaurs
- Cartoon characters
- Thomas the tank engine
- Types of cars

As with repetitive behaviours children can become engaged in their special interest if they are feeling anxious or scared, but the reality is that they have an uncontrollable desire to involve themselves in these things because their interest is real and their enjoyment and satisfaction is real.

Children with an ASD will normally have one special interest at a time, but they often change as the child develops and experiences more things.



Special interests can interfere with learning or daily living activities but they can also be used to motivate and engage with your child. Some of the most famous autistic people have developed successful careers from their special interest.

*“Even though my son had great difficulties working in a group and turn taking, his keen interest in music allowed him to overcome his difficulties. We encouraged him to join in workshops and group music sessions, and this helped him to work on his social skills and team work, with like-minded people. He is now a valid member of a rock group and enjoys performing in gigs throughout the area.” — [Parent]*

**Some top tips for managing your child’s Special Interests:**

- ◆ Be patient and tolerant — allow for the autism
- ◆ Empathise with your child, show them that you know how important their interest is to them
- ◆ Don’t tease the child about (or criticise) their interest
- ◆ If the interest is interfering with learning or daily activities, try offering specific times for them to spend on their special interests and once agreed don’t waiver on this unless you have given advanced warning
- ◆ Look for ways to expand your child’s special interest
- ◆ Learn more about what they are doing and talk to your child about their interest, this might help you to engage more with your child
- ◆ If you are travelling try to take their special interest with you so that they have an instant comforter if they are feeling anxious or to stop them from becoming bored
- ◆ Remember, to you the special interest may seem pointless or silly, but to your child it might be the most precious thing in the world
- ◆ Learn about autism — there are some books, DVDs and websites recommended in this booklet



# Notes

# Sensory Issues in Autism

The seven senses are sight, hearing, touch, smell, taste, balance (vestibular) and body awareness (proprioception). In individuals with autism, the brain sometimes processes sensory information differently to those without ASD. Everybody is different and therefore individuals will experience things differently and respond in different ways.

*"... early on the OT identified proprioceptive problems, but this was not viewed by us as ASD, but now we can see it's part of the triad." — [Parent]*

Sometimes these different sensory perceptions can cause pain, distress, anxiety, fear or confusion and result in 'challenging' behaviour as the individual tries to block out what is causing the problem.

In some cases the senses may work too well and the brain receives too much information (hypersensitive) or not well enough where the brain doesn't get enough information (hyposensitive). When the senses are hyper you may find that individuals with ASD rock, flap, spin, hit their ears, etc as a way of trying to block out the overload that they can't tolerate and to help them to calm down or relieve the pain. In cases where the senses are hypo individuals may make or seek out noises, bang objects, etc as a way of causing more sensations and getting the senses to work better.

## Things to look out for:

### Hypersensitive

- Dislikes dark and bright lights
- Looks at minute particles, picks up smallest pieces of dust
- Covers ears
- Dislikes having their hair cut
- Resists touch
- Avoids people
- Runs from smells
- Moves away from people
- Craves certain foods
- Uses tip of tongue for tasting
- Places body in strange positions
- Turns whole body to look at something
- Difficulty walking on uneven surfaces
- Becomes anxious or distressed when feet leave the ground

### Hyposensitive

- Moves fingers or objects in front of the eyes
- Fascinated with reflections, brightly coloured objects
- Makes loud rhythmic noises
- Likes vibration
- Likes pressure, tight clothes
- Enjoys rough and tumble play
- Smells self, people and objects
- Seeks strong odours
- Mouths and licks objects
- Eats anything
- Rocks back and forth
- Lack of awareness of body position in space
- Spins, runs round and round
- Bumps into objects and people

*Taken from 'Sensory Issues in Autism' by the Autism and Practice Group, East Sussex County Council*

Examples of sensory issues that your child may experience include:

- The brain tries to process everything at once without filtering out unimportant things like background noise, wallpaper, people moving about, the feel of clothes on their skin, etc resulting in sensory overload.
- Sometimes there is an inability to separate foreground and background information so that everything is seen as 'a whole'. For example, when they look at a room they will see everything at once and so even when something small is changed they will notice. This will make the room look 'wrong' and can cause fear, stress and frustration.
- When there is too much information to be processed at the same time it may be difficult for children with autism to break a whole picture down into meaningful units. For example, when talking to someone we will see their whole face but some people with autism may see eyes, nose, mouth, etc as individual things which all need to be processed separately. This makes it more complicated to process information and can lead to the child focussing on only one aspect or not having enough memory to process everything.
- Sometimes it can take time to process information, particularly if there are distractions (eg background noise, scratchy clothing, etc), if there is a lot of information to process or if the context changes (eg they may learn to make a cup of tea in the kitchen but be unable to transfer that skill to a different kitchen).
- In some cases senses become distorted which may mean that the autistic child sees, hears, smells, tastes or feels something different to everyone else.

*“When my son was older he explained to me ‘When I was a baby I remember having a strange object thrust into my mouth which I found quite annoying. It had a very strange taste and an even stranger texture. Also, when I sucked on it, it made the most awful squeaking noise.’ I now realise the reason why my son got so distressed when a rubber teat on a bottle or dummy was put into his mouth!!” — [Parent]*

- At times one of the senses may appear 'shut down' as a way of the child coping with sensory overload. For example, when noises become unbearable the child may appear to be deaf because this enables them to cope and to allow their other senses to work better.
- Due to the difficulties outlined above, some children will use some senses to compensate for others. For example, they may smell, lick or touch objects, or watch their feet whilst walking, etc.

It is important to remember that when people are tired, unwell or stressed their tolerance levels are affected and this is also true of a child with ASD's ability to tolerate sensory stimuli. Therefore, try to learn what sensory issues your child may have and the ways in which they cope with these so that you can understand and support them. Below is a list of things that may be helpful and things that may challenge your child. Through observation you may be able to tell if suggestions on the list, or something similar, are relevant to your child.

*“My son can only wear certain types of socks, as he gets very agitated by the join line on the toe section. We also had to cut out the labels in clothes as this also caused sensory issues.”— [Parent]*

These things might help me	These things might challenge
Look to the side of my face or over my shoulder when you are interacting with me	Direct eye contact
Address what you are saying to the wall	Direct communication
One person talking to me at a time	More than one person talking to me, other people's conversations
Neutral odours	Perfume, aftershave or other scents
Plain clothes	Patterned clothing
Dull coloured clothing	Bright coloured clothing
Uplighters	Strip lights
Red or green bulbs	Bright or white light, bright sunshine
A quiet environment	Kettles, engines, traffic sounds, phones
Quiet personal care	The toilet flushing, running water, fans
Consistency	Different people responding to me in different ways
One thing at a time	Being bombarded by a lot of information
Knowing what is happening next	Unpredictability and chaos

*Taken from 'Sensory issues in Autism' by the Autism and Practice Group, East Sussex County Council*

#### **Some top tips relating to Sensory Issues:**

- ◆ Observe your child and try to learn which sensory issues they may have — the more you can learn and understand, the easier it will be to support your child
- ◆ If your child is upset, distressed or behaving in a challenging way, consider whether this is being caused by sensory issues. Sometimes it may be the fear of what might happen which will stress them
- ◆ Be aware that your child may only be able to utilise one sense at a time. For example, when they are looking at something they may not hear you
- ◆ When you've identified issues which trigger sensory problems, try to avoid these where possible
- ◆ Follow a routine, where possible, to try and avoid sensory overload and stressful situations
- ◆ Have a quiet time / space so that your child can relax and regain their composure





# Notes

# ASD and Other Disorders

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.

Sometimes individuals with an ASD have another disorder as well. Some conditions appear to affect individuals with ASD more frequently, although it is sometimes difficult for professionals to ascertain whether symptoms are part of the ASD or another condition. Some of these disorders are:

- Dyspraxia
- Dyslexia
- Depression
- Anxiety
- Epilepsy
- Obsessive Compulsive Disorder (OCD)
- Attention Deficit Hyperactivity Disorder (ADHD)
- Tourette's Syndrome

It is important to recognise that individuals with ASD are not excluded from other mental health and physiological conditions.





# Notes

# Communication

The background of the page is an abstract, textured composition. It features a mix of warm colors, primarily shades of orange, yellow, and red. The texture is reminiscent of thick, layered paint or perhaps marbled paper, with visible brushstrokes and irregular, vein-like patterns. The colors transition from a bright, almost white-yellow at the top left to a deep, dark red at the bottom right, creating a sense of depth and movement.

# Communication

Individuals with ASD have difficulties with both social communication and social interaction, and this can cause problems in giving information to and gaining information from your child. Being aware of these difficulties and adapting your own communication style will go some way to ensuring that your child understands what you are asking them and ensuring you get the most accurate response.

Long questions and explanations can cause confusion for someone with ASD, so try to avoid using them.

People with ASD will often have a very literal understanding of language. Idioms, metaphors and similes may be very confusing or create misunderstandings. Here are some examples of everyday sayings that can cause confusion for an individual with ASD:

## Idioms:

Make up your mind  
You're barking up the wrong tree  
Pull your socks up  
Don't make a mountain out of a molehill  
That's the pot calling the kettle black

## Metaphors:

She's an old flame  
Dad is a rock  
You are an angel  
Bill is a snake  
My head was spinning

## Similes:

He is as rich as a king  
She is as cool as a cucumber  
You are as cold as ice  
As bright as a button

When interpreted literally, these phrases are very strange and can have a totally different meaning so avoid using them. Don't be misled by the individual using metaphors, it does not necessarily mean they will understand yours, especially if they are not familiar with them.

People with ASD often have an unusual way with eye contact and some describe feeling uncomfortable with maintaining eye contact. Just because your child is not maintaining eye contact does not mean that they are not paying attention to you.

Because people with ASD may have problems interpreting social cues such as eye contact and body language, they may not realise that you are addressing them. Start by saying their name and making sure you are in their view before speaking.

If your child has sensory problems, it may be difficult for them to focus on what you are saying if the area around them is busy. Try and reduce noise, smells and bright lights before talking to them.

*"I discovered that we could have longer and deeper conversations over a cup of hot chocolate by candle light or with the dimmer switch turned down, and also by speaking 'through' glove puppets in his toy puppet theatre." — [Parent]*

*"Loud noises, including shouting, make my son just shut down and then you can't reach him. My son is always better being shown things rather than told where possible." — [Parent]*

We often use analogies to try and explain things to children in simpler terms. For example, if we are trying to explain why a child needs to eat his dinner, we might talk about it being like putting fuel in a car and explain that if the car doesn't have enough fuel it will break down. It is difficult for a child with ASD to link this sort of an explanation with the original problem you are trying to explain. Try and use facts to explain things instead of analogies.

Someone with ASD may need more time to process and understand what you are saying. Pausing frequently and allowing them to think, and allowing a longer time for a response can help.

Try not to rely on your tone of voice, facial expression or eye contact to convey a message as the individual with ASD may not be able to understand these subtle ways of communicating. Sarcasm is even more confusing and often relies on somebody reading tone of voice, facial expression and then contrasting them with the words being used. Individuals with ASD will often be unable to do this, and will assume the words used are accurate. So if your child's hair is looking messy, say this rather than saying it looks lovely and making a funny face.

*"When our son was 17, about six months after his Asperger's diagnosis, he was just beginning to make sense of what it meant for his past experiences. He told me that he'd always thought I'd been angry with him a lot of the time. Unless I was laughing, smiling or obviously happy then he'd thought that actually I was angry. I felt sad but I started to do two things: I gave clearer facial signals, including smiling much more; and if we were having a conversation about something important or difficult we agreed to tell each other 'this is how I'm feeling now...' including, if necessary, saying 'I am upset and I feel angry...'" — [Parent]*

In a similar way, a child with ASD may not support their verbal communication with body language, facial expression or changes in tone of voice. If they do use these forms of communication, they may not accurately reflect how the person is feeling so be careful not to make assumptions.

Using generalised questions may produce misleading answers, eg “How are you feeling?” may get a learned response of “very well, thank you”, but asking “have you got a sore tummy?” may get a “yes”, because it is a specific question.

*“When caught chewing gum in the school corridor, he was told ‘spit that gum out boy’. When he spat the gum onto the corridor floor [the teacher] thought he was being arrogant.” — [Parent]*

People with an ASD often do not offer any more information than they are asked for. For example, if asked “can you reach the milk out of the fridge?” they may answer “yes”, but may not offer additional information such as “but only if I stand on tip toes on top of a box”.

When giving information or teaching someone with ASD, it is often helpful to use pictures or photographs. Always check that the child has understood what you have told them by asking them to explain it to you.

**Some top tips for supporting communication:**

- ◆ Ensure you have their attention, say their name before beginning
- ◆ Minimise sensory distractions such as noise, bright lights and busy rooms
- ◆ Use a clear, calm voice
- ◆ Keep things short and simple
- ◆ Allow your child some time to process information and check that they’ve understood
- ◆ Beware of using idioms, metaphors and similes — ensure they know what you mean
- ◆ Use facts to explain things, avoid analogies and never use sarcasm
- ◆ Don’t rely on body language, gestures and tone of voice
- ◆ Ask specific questions
- ◆ Use pictures to help explain things
- ◆ Always check you have been understood

# Notes





An abstract painting with a textured, expressive style. The background is dominated by deep blue and teal tones, with prominent vertical and horizontal brushstrokes in bright yellow and green. The overall effect is one of dynamic energy and emotional depth.

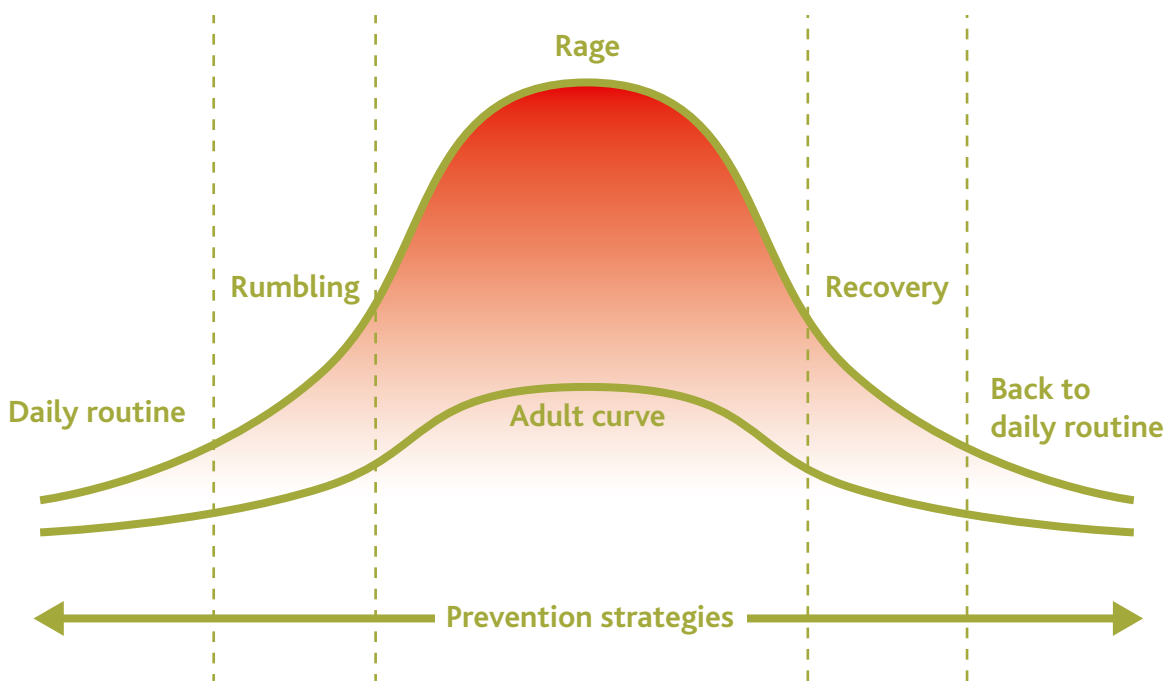
# Supporting your child with different behaviour

# Supporting your child with different behaviour

Everyone displays 'behaviour difficulties' at some time because it is a way of communicating what they are thinking or feeling. Those with autism may seem to display challenging behaviour more frequently than other children but this is because they see the world differently.

They do not always understand social rules, may have difficulty expressing themselves and may struggle to cope with changes in routine and understanding how other people may be feeling, all of which can lead to very stressful situations for them. This, together with any sensory issues they may have, can be overwhelming for them to deal with and their only way to cope and to let you know that they are struggling is through inappropriate or 'challenging' behaviour (sometimes described as tantrums, rage and meltdowns).

Tantrums, rage and meltdowns can mean different things for different individuals but they usually occur in three stages which are rumble, rage and recovery (diagram below). The rumble phase is the start of the behaviour, also known as the trigger or antecedent. It is the most important phase because this is the point where the child is building up to the rage phase and there are usually opportunities to defuse the situation. Every child is different but you may notice certain 'rumbling' behaviours such as fidgeting, making noises, foot tapping, pulling faces / grimacing, etc.



*Adapted from Curtis and Dunn 2000*

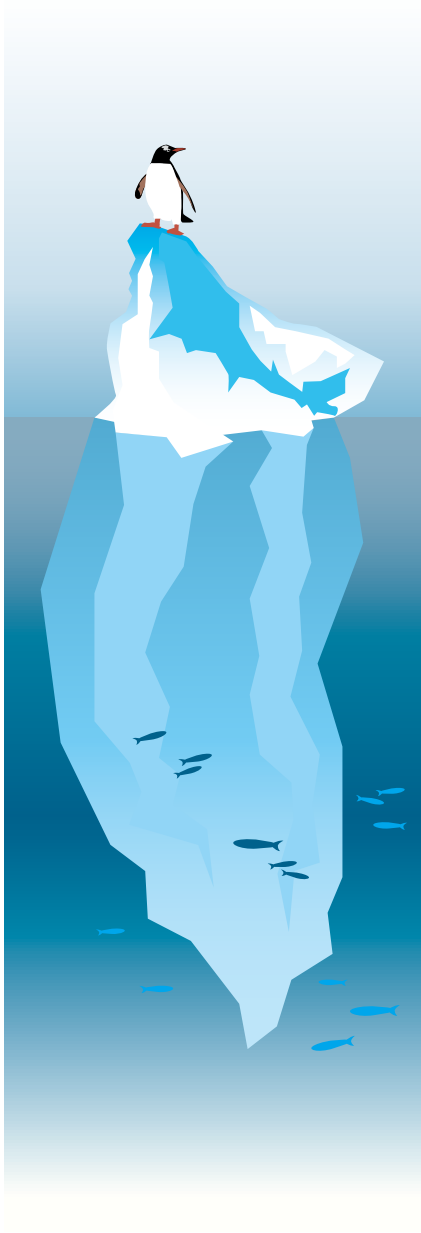
These behaviours may initially appear to be minor and unrelated to the ensuing meltdown or they may be more obvious but over time you will be able to more easily identify what your child's rumbling behaviour is. Later in this section we will describe the 'cause, behaviour, function' chart and how to use it to identify the triggers, the rumbling behaviours and the reasons behind these. This in turn will help you to identify the best way to intervene at the rumbling stage and to develop some prevention strategies to stop your child reaching the rage phase.

The rage phase is the 'acting out' behaviour or meltdown. Again, this will be individual to your child but may include externalised behaviour (eg screaming, hitting, biting, destroying property, etc) or internalised behaviour (eg becoming withdrawn). If your child reaches this stage, the main thing to do is to try to remain calm and to ensure the safety of the child and those around them.

The recovery phase is when the behaviour has passed. The child may be tired / sleepy or may apologise whilst others may deny the behaviour or even not remember what happened.

When your child misbehaves it is important to think about what may be causing the behaviour and what they are trying to communicate. The iceberg is a useful way to help people analyse and understand what is causing a certain behaviour in a child with ASD. When you see an iceberg you are only seeing a very small part of it — the 'tip of the iceberg'. The largest part of the iceberg is unseen as it lies beneath the surface of the water. The iceberg diagram helps you to think about the characteristics of ASD and how they may affect your child in a certain situation (there is a blank diagram for you to use at the end of this section).





**What we can see:**

**The Specific Behaviour:**

Shouting and screaming in a supermarket

**What we can't see:**

The possible reasons / underlying difficulties:

**Interaction**

Doesn't understand how to behave — why are people lining up? What are people doing, wandering up and down, looking at things? Why do I have to wait? Ohh, lots of nice sweets — I want one — why can't I have one?

**Communication**

Do not know how to express what they want.

Trying to communicate that they are frustrated at not being allowed to eat the sweets / they are bored / cold, etc.

**Flexibility of thought**

This is a different shop to the one we normally go to — everything is different

I don't know what to expect

**Sensory**

Lots of bright lights, very noisy, unpredictable noises, horrible smell of fish, some areas are really cold (freezer department)

Also, think about the **function** of the behaviour — what do they get from doing the behaviour?

I scream and shout → Mum / Dad gives me the sweets or they take me out of the shop

To try and find out what is causing or triggering the behaviour it can be useful to look at the cause, behaviour and function (purpose) of the behaviour.

**Cause** — This is the trigger for the behaviour. This can sometimes be clear-cut such as somebody saying 'no' to a request but in individuals with ASD it can be more difficult to identify because the cause may be related to sensory issues such as loud noises or specific sounds or related to the need for predictable routines.

**Behaviour** — It is important not to jump to conclusions about behaviour as many individuals with ASD have difficulties in expressing their feelings in an appropriate way. For example, anxiety may present as worry but could also present in repetitive behaviours or aggression.

**Function** — This is the purpose of the behaviour which may be to gain something they wanted, to avoid something or simply to communicate feelings to others.

The best way to look at this would be to monitor and record behaviours over a period of one to two weeks. Each time an undesirable behaviour occurs, write it down on a chart such as the example below (there is a blank chart for you to copy / use at the end of this section):



Date and time	What happened before?	What happened during?	What happened after?
<p>You might see a pattern emerging when behaviour occurs eg around 11 am everyday might lead you to think that they are hungry.</p>	<p>Where is the young person? Who is there? What is the young person doing? What are the adults doing?</p>	<p>What exactly does the behaviour look like? How does it start? How does it escalate?</p>	<p>What happened immediately after the behaviour? What did the young person do? What did the adult do? How did the young person feel? What did other people do?</p>
<b>Example</b>			
<p>Friday afternoon (3.30pm) after school</p>	<p><b>Where:</b> In supermarket in vegetable aisle</p> <p><b>Who:</b> John (young person with ASD), mother and two year old sister, crowded supermarket – lots of children as after school</p> <p><b>What are people doing?</b> John – walking ahead, mother looking at carrots with two year old in trolley</p>	<p>John starts looking around John starts counting the carrots (handling them) Mum tells John not to touch the carrots John starts pacing and then running across the aisles Mum shouts at John to come back and then goes after him</p> <p>John reaches the magazine aisle and grabs his favourite magazine</p> <p>Mum takes the magazine off him telling him that he can't have it and to go back to the vegetable aisle</p> <p>John starts screaming and lies on the floor</p> <p>Mum gives him the magazine</p> <p>or mum takes him home</p>	<p>John is beginning to feel anxious or bored Counting carrots helps to calm him / or keep him occupied</p> <p>Mum is worried that other people watching will be critical of John touching the carrots John goes back to feeling anxious / bored so seeks another way to entertain himself</p> <p>Mum is worried she will lose John in the crowd John has found something to make him feel better</p> <p>Mum feels cross John feels distressed as he cannot have what he wants</p> <p>John has something to help him manage his anxiety / boredom</p> <p>John's anxiety is relieved as he gets to go home and mum feels distressed and upset</p>

In the example we can see that John does not like supermarket shopping, he might find it boring or he might be anxious because of the busy environment. John's initial behaviour of counting carrots was because he was either bored or he was anxious. If mum knew this she could have averted the behaviour escalating by asking John to put five carrots in the bag and this would have kept him occupied, helping him to manage either his boredom or anxiety. However, because mum did not let him continue his behaviour John had to find another way to relieve his boredom and anxiety. Eventually John got what he wanted, either he got to go home earlier or he got his favourite comic.

At the end of the time spent monitoring, look through the chart and try and find common patterns. The 'what happened before?' sections will give clues as to the cause or trigger. The 'what happened after?' will give clues as to the function the behaviour serves.

It is always better to try and manage an individual's behaviour by avoiding it, and avoiding the trigger point, and this is particularly true when the person has ASD.

*When you have the information you need and can identify a clear pattern of behaviour, you can begin to work on it. There are two ways in which you can try to address the behaviour, either:*

- Alter the environment or
- Work on the behaviour directly

If the child's behaviour is appropriate even if it is undesirable (for example becoming anxious around a change in routine) you should not try to change the behaviour, but rather change the environment. If sensory issues are the cause of the unwanted behaviour, altering the environment will also be the way to move forward.

*"Making sure my son is not hungry stopped his challenging behaviour. It took a friend to notice and point it out to me. That was a few years ago. I did not feel bad, I just did not know, regular meals solved the problem." — [Parent]*

If however the behaviour is not appropriate or desirable you may need to start some work around changing the behaviour.



## Altering the Environment

Behaviour triggered by sensory stimuli such as noise, temperature changes	Reduce sensory stimuli, make a quiet space, avoid supermarkets at busy times etc.
Behaviour occurs around other people	Educate key people as to the needs of the individual with ASD, how to communicate, note sensitivities they may have
The response to behaviour varies from one to another	Have a clear plan around how to respond to the behaviour and ensure all key people follow the same plan
The environment is chaotic with lots of unpredictable changes	Try to develop a routine that is consistent and predictable

## Working Directly on Behaviour

If you want to change a behaviour, try working using these two behavioural principles:

- If you reward a behaviour you will see more of it
- If you ignore a behaviour you will see less of it

When trying to decrease an unwanted behaviour, it is important that you teach a new way of behaving appropriately at the same time. This will prevent other negative behaviours developing. To do this you will need to remove all rewards from the unwanted behaviour and look for ways to reward a behaviour that is wanted.

For example, ignore the individual when they interrupt you talking by asking for something, but respond immediately if they say 'excuse me'. In this situation the individual will learn that they will only get the response they are seeking by saying 'excuse me' first.

In order to help the learning of new behaviours it is important that your response is clear and consistent, you must respond in the same way each time.

Sometimes, the 'reward' for a behaviour is the attention you give to it. We can give attention to a behaviour in a number of ways including praising, giving rewards such as stickers / money, shouting, asking for explanations etc. Sometimes we do not even realise we are rewarding a behaviour because we are shouting or being negative to try and stop it.

In an individual with ASD the picture can be even more confusing, for example if the individual prefers to spend time alone, using 'time out' as a punishment could be rewarding. It is therefore important that you take the individual into consideration when deciding on how to give or remove rewards for a behaviour. When managing an individual with ASD's behaviour, it is important that you adapt your communication and this was discussed in an earlier section.

*"[Don't] push yourself for your child — one day at a time." — [Parent]*

*"...the most valuable piece of advice I have gathered is to have patience, and to try and see things from their point of view." — [Sibling]*

**Some top tips for supporting your child with different behaviour:**

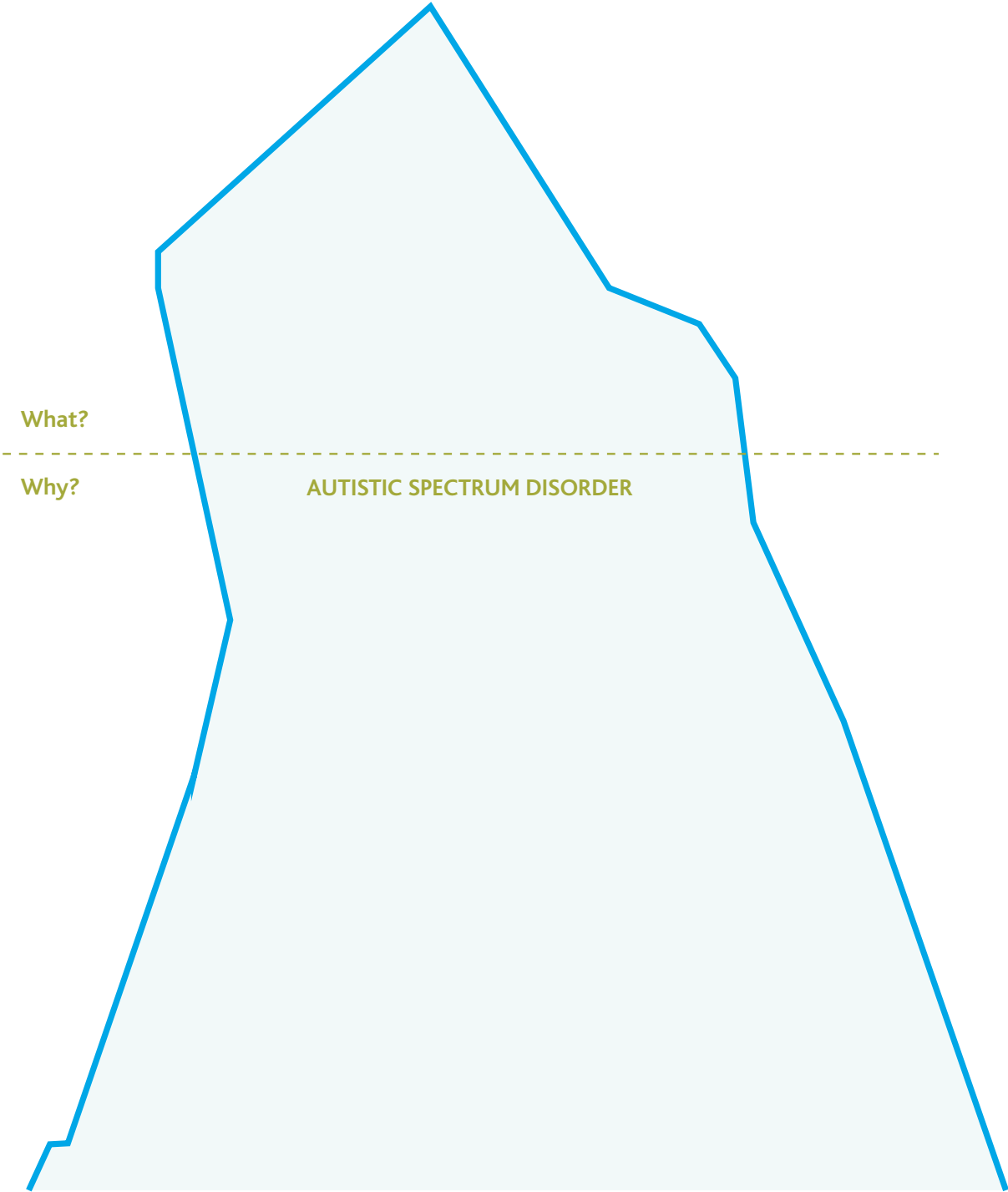
- ◆ Be positive and praise good behaviour. Make sure praise is given quickly and clearly so that your child knows what you are praising them for
- ◆ Don't try to change too much too soon. Tackle one or two things at a time and perhaps try to choose something which will be easier to change first
- ◆ Improve the way you communicate with your child (see section on Communication)
- ◆ Help your child to understand and change their behaviours through, for example, social stories and explaining about other people's thoughts and feelings
- ◆ Use calendars and other visual information to help your child understand the concept of time
- ◆ Plan ahead for activities and changes to routines (see section on managing change)
- ◆ Find out what relaxes your child so that you can help them calm down

Date and time	What happened?	What happened during?	What happened after?
<p>You might see a pattern emerging when behaviour occurs eg around 11 am everyday might lead you to think that they are hungry.</p>	<p>Where is the young person?            Who is there?            What is the young person doing?            What are the adults doing?</p>	<p>What exactly does the behaviour look like?            How does it start?            How does it escalate?</p>	<p>What happened immediately after the behaviour?            What did the young person do?            What did the adult do?            How did the young person feel?            What did other people do?</p>

### The Iceberg Metaphor Worksheet

Write down your child's behaviour in the 'tip' of the iceberg

In the bottom part of the iceberg write down what happened before the episode, an outline of your child's sensory issues, and then what happened afterwards. This should help you analyse why your child behaved the way they did.





# Top tips for Common Issues



# Top tips for Common Issues

Many parents report they need help with:

- Diet
- Sleep
- Toileting
- Play
- Body awareness

In this section we will briefly look at these and give you some top tips which may help.

## Diet

What children with ASD eat can be an area of concern for some parents. In this section we will discuss two common diet issues:

- Extreme Fussy Eating
- Using diet as a treatment for ASD

### Extreme fussy eating

It can be very exhausting when you are parent / carer, to watch your child refusing to eat or to try new foods. It is not uncommon for ASD children to be 'extreme' fussy eaters, ie only choosing to eat very specific foods, colours or textures. This is a highly complex problem to unravel and often you may need to seek expert help. What we do know is that when an individual is anxious, one of the first things that happens is their digestive system slows down (butterflies in your stomach — fight or flight). If your child is an extreme fussy eater, as well as numerous strategies you may be given, the aim is to work towards creating a calm, happy setting so they will be more willing to try new foods. You should not force them to eat.

Why ASD children are extreme fussy eaters is not clearly understood:

- Is it that they have sensory issues?
- Is it that they are using food as part of their repetitive behaviour?
- Is there some other factor that we don't understand?
- **Sensory issues** ASD children often have profound sensory issues and so food may not smell, taste or feel the same as it does to us. These issues may extend to memory anxiety — eg remembering an event / person when a particular food was eaten and that thought being so strong that it interferes with eating that food. Sometimes ASD children eat 'non-food' ie paper, fluff, etc. This is called PICA. If your child does this talk to your health professional who should be able to refer you for more specialist help.

*'Every time you ask me to try an apple I remember back to when I had a bad tummy, and I had an apple and was sick. When I have the fruit in my mouth my memory is so strong I can taste, feel, and smell the memory of the sick, and I can't taste the apple... that's why I won't try it.'* — [Individual with ASD]

- **What about the environment?** Is the environment putting them off eating? Bright lights, noisy children, sitting opposite messy eaters could be some of the reasons they are finding eating new foods difficult. The normal approaches to fussy eating may not work or apply to these kids. If you think your child is an extreme fussy eater ask your GP or health worker for help and advice. They may be able to refer you to your local dietician (or a MDT if available), who can assess your child's diet, check that it is nutritionally balanced and give you practical hints, tips and support.

*'I need to eat on my own because I can't block out the way other children eat, they eat with their mouths open, the food is falling out, they are picking their noses and it puts me off eating.'* — [Individual with ASD]

- **Is something else going on?** Sometimes children refuse to eat because of an underlying medical problem that may be making eating hard — sore mouth, painful teeth, constipation, etc. Speak to your doctor about this. They may be able to refer you to the appropriate health professional. Is your child eating a limited diet because of their strong desire for sameness giving them a sense of safety and calm?





### Some top tips to try around diet:

- ◆ Spend some time monitoring your child. Keep a food diary to see how many different foods your child is eating. You may find that they are in fact eating a wider variety of foods than you thought
- ◆ Be a 'detective' and try and guess why they are eating in a certain way. If they have language, ask them why they can't eat or if they can write, ask them to try and write it down, or draw what's wrong
- ◆ A place mat which is 'their area' to eat from can help
- ◆ If your child finds eating with others difficult, make sure they are not sitting directly opposite another person
- ◆ If eating at school is difficult, ask what the environment is like at school or even visit the school during a meal time
- ◆ Try and make meal times predictable. Serve three meals and planned snacks and try and establish a routine
- ◆ Visual / prompts timetables (pictures and or words, PECS) can be helpful
- ◆ Choice boards / choice books — These can have the foods your child eats in the front and foods they may like to try at the back, the aim being to bring the 'Today I will try' picture forward
- ◆ Try writing a Social story — see glossary — these can be used to help your child try new foods or to explain why eating a varied diet is important (your ASD professional may be able to help you with this)
- ◆ Expose your fussy eater to food at every opportunity, get them to handle food, play with food, and help in the kitchen, so food and eating becomes relaxed and fun
- ◆ Use your child's interest as motivators, eg make the food into a train, line up peas, maybe their favourite character could come to 'tea'
- ◆ Try and make eating and being around food a pleasure not a chore!
- ◆ Remember, you need to persevere. You often have to expose your child to a new food a lot (15 or more times!) before they accept it as new food and will try it
- ◆ If your child has PICA look at what they are eating. Can you offer them something 'safer' or more acceptable to give them the sensation they are seeking but in a more acceptable form
- ◆ Ask for help if you think you need it

# Diet as a treatment for ASD

At present there is a lack of clear consistent evidence to recommend any particular kind of therapeutic diet for ASD kids. Some parents report very strongly that their child has dramatically improved after following a special diet. Experts are at the moment trying to find out which of these therapeutic diets (of which there are hundreds!) may be useful, safe and have good evidence to say they help.

If you decide you want to try a special diet, there is more information on these via the National Autistic Society. It is strongly recommended that you seek impartial advice about this before embarking on this road. Many of the diets are expensive, a few can be harmful, and for children who seek routine a drastic change in what they are given to eat can be very distressing. This is especially true if your child is an extreme fussy eater. Here are two of the most popular:

- **Gluten and Casein Free diet (GFCF diet)**

This diet involves removing all gluten (a protein found primarily in wheat, barley, rye and oats) from the individual's diet, ie avoiding ordinary bread, pasta, crackers, many cereals, etc. It also removes Casein (a milk protein) so no cow's milk, ordinary cheese, yogurt, etc from the child's diet. It is based on the theory that ASD individuals have a 'leaky gut' which affects their mental function and behaviour.

- **Fish oils and supplements high in Omega 3**

Omega 3 is a type of fat which is found in number of foods (including oily fish — salmon, sardine, mackerel, herring, etc) which is important for brain function. Taking a supplement high in Omega 3 has been reported to help ASD individuals attend and concentrate better. The amount of Omega 3 a child should take is not clear, however encouraging your child to eat more oily fish is not a bad thing.

There are many, many other dietary interventions around for ASD. If you think you may like to try one of these with your child, it is highly recommended that you speak to your GP who may then be able to refer you to your local dietitian. The dietitian will be able to discuss the pros and cons with you and support you during the period of 'trying the diet'. Most importantly they can make sure your child's diet is nutritionally balanced so they are not missing essential nutrients which could affect the overall health and growth of your child, eg a Casein free diet can make a child's diet low in calcium so can affect bone growth and thickness.

## Where else can you get information?

### Books

*How to Get Your Kid to Eat But not too Much* by Ellyn Satter  
*Can't Eat Won't Eat* by Brenda Legg

### Websites

[www.autism.org.uk](http://www.autism.org.uk)  
[www.wales.change4life.com](http://www.wales.change4life.com)  
[www.thegraycenter.org](http://www.thegraycenter.org)

# Sleep

Many children with ASD will experience difficulties with sleep at some point. When a child has difficulty sleeping, it means the whole household has difficulty sleeping which can lead to a tired, irritable family. 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.

Many children display behavioural problems during the day purely because of tiredness and a lack of sleep during the night.

Often sleep problems can be rectified with behavioural interventions, sometimes even a small change can make a big difference. It is easy to 'give in' to behaviours in the night in order to settle the child for the whole house to get some sleep.

Individuals with ASD often prefer to have predictable routines. Ad hoc times and routines of going to bed can cause anxiety which will in turn cause the individual to have difficulty in sleeping. Busy environments can also cause difficulties in settling to sleep, especially if the child has sensory issues.

Children who need external pacifiers such as a dummy, TV or cuddles from a parent will be likely to wake in the night. On moving into light sleep they won't be able to re-settle without such pacifiers.

Many children become excitable during the late evening because they are overtired, if a child is not in bed early enough they will have more problems settling to sleep.

Below are some tips for managing sleep difficulties for you to try. However, if problems persist it may be a good idea to get some professional input to rule out other causes and to offer you some alternative strategies to those listed here.

### Some top tips for managing sleep difficulties:

- ◆ Set up a regular night time routine and stick to it. Try to start 'winding down' at least an hour before bed time. Baths, stories and a milky drink will all help your child to relax before bed. Avoid stimulating activities such as exciting TV, computer games and physical play.
- ◆ Create a non stimulating bedroom where possible. Switch TV off, switch off or dim lights and try to control noise.
- ◆ Encourage your child to settle alone in their own bed. If you usually cuddle your child to sleep, gradually change this. Each night withdraw yourself a little more; sit next to the bed, away from the bed, in the doorway, on the landing etc until your child can settle alone.
- ◆ Repeat these steps if your child wakes in the night
- ◆ Have clear rules and explain them to your child eg 'you must stay in your own bed', 'you are not allowed to watch TV in your room after 7pm'
- ◆ Do not allow your child to sleep in your bed because it is easier, it will only make more problems in the long term
- ◆ Encourage your child to stay in their own bed by using a reward chart
- ◆ If problems persist, speak to your GP, Health Visitor, Social Worker, etc for more help



# Toileting

Toilet training can be a difficult task whether your child has autism or not, but the process for children with ASD may take a little longer.

There are many good sources of information for toilet training such as the National Autistic Society (NAS) or Education and Resources for Improving Childhood Continence (ERIC) (contact details listed below). We have listed some top tips relating to toilet training for you to consider.

Some children with ASD 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). If difficulties persist, or you are concerned in any way, contact your GP or another health professional involved in the care of your child to provide advice and, where necessary, to consider possible medical reasons for their difficulties.

### Some top tips for toileting:

- ◆ Ensure that everyone involved with your child is aware of the approach that you have decided to follow so that you are all consistent
- ◆ Use your child's preference for routine to support the learning process
- ◆ Be aware that your child may not like change and therefore it may be easier not to toilet train using a potty as this will involve a further change from potty to toilet
- ◆ Observe your child to try and establish when they wee and poo so that you can try and establish when you are likely to need to take them to the toilet
- ◆ Have a visual sequence beside the toilet to help your child understand what to do
- ◆ Some children may find bowel movements frightening so it may be useful to explain the digestion process
- ◆ Some children may prefer the feel of a full nappy and be reluctant to change
- ◆ Consider the toilet/bathroom environment and how this will affect your child's sensory issues
- ◆ Some children enjoy the feel of smearing and therefore alternative acceptable activities need to be provided instead
- ◆ Consider what alternatives are available if your child does not like the texture of toilet paper (eg, wet wipes, etc)
- ◆ Avoid childlike terminology as it may be difficult to change language later in life
- ◆ Use the same toileting routine in the community and when visiting new places as you do at home
- ◆ If difficulties persist, contact your GP or another health professional involved in the care of your child to provide advice and, where necessary, to consider possible medical reasons for their difficulties

### Where else can you get information?

- **ERIC (Education and Resources for Improving Childhood Continence)**

**Email** [sales@webshop.org.uk](mailto:sales@webshop.org.uk)

**Website** [www.ericshop.org.uk](http://www.ericshop.org.uk) or [www.enuresis.org.uk](http://www.enuresis.org.uk)

**Helpline** 0845 370 8008 (Mon — Fri, 10am — 4pm)

- **National Autistic Society**

**Website** [www.autism.org.uk](http://www.autism.org.uk)

# Play

Children with ASD often do not develop play in the same way as other children of their age and can appear to find play difficult.

Teaching and encouraging a child to play has a number of benefits. It helps a child develop language and to understand social situations through role play and aids interaction. It can encourage questioning and answering and develops a better understanding of how others play.

Rewarding the child during and following a play session is often a good incentive to take part next time, this can be as simple as a smile or a cheer or a 'thank you so much for playing with me, I've had such fun'.

It can be useful to involve other family members in play so that the child has an opportunity to interact with other people but sometimes at first one to one is a first step.

- **Create a person friendly space**

Children with ASD find being with and interacting with others difficult so playing in a space with lots of distractions can make play more difficult. Ringing phones, blaring televisions, and electronic games can make engaging with our children much more challenging.

Only play with your child if you really want to. Five minutes of 'I want to play' will be much more useful than an hour of 'I have to play' and somehow our children just know if you are just going through the motions. If you are tired, stressed and anxious, don't play, do it at time when you feel more focused and positive. Play should be fun and easy not a struggle.

- **Should I join in their chosen activity?**

Children with ASD often play in a way which seems strange to us. One type of play encourages joining in their chosen activity or engaging with what they like to do.

When your child does a repetitive behaviour you could try doing it with them. It's a way of saying 'I want to be with you so much I want to do what you are doing more than what I am doing.'

After joining your child you can then slowly start to expand on their play aiming to make solitary play into two way play.

**Note:** Be prepared that initially your child may not want to play with you and may very strongly indicate that they want to play by themselves. This is fine. Play is difficult for our kids and you may need to persevere before you get something back and your child learns this is fun!

### Some top tips for play:

- ◆ Questioning children during play can be stressful. Try commenting or making statements about the child, the play or even how you are feeling eg 'that's a great tower you are making, I'm going to make one too'
- ◆ Turn off your phone / TV etc when playing to keep the focus on being with you
- ◆ Make yourself irresistible and get down to your child's level
- ◆ Try joining in their chosen activity. Really try and experience what they are doing. Focus on their chosen activity and if you feel your mind or your resolve dipping, stop and try again later
- ◆ Remember play is hard for our kids so do praise them at regular intervals for their efforts
- ◆ Play should be energetic and fun; if it feels laboured stop and try again another day
- ◆ Start with what your child likes to do, then free your imagination. Can you put a twist on what they like to do
- ◆ Play with toys that use your imagination. Often simple items are best ie boxes, paper, feathers, bubbles, blocks, wigs, stickers, musical instruments, mini trampolines, scarves
- ◆ Don't overload your child's play space with toys. A few toys on a high shelf (to help initiate a request) are often better than hundreds that are easily accessible







# Body Awareness (Behaviour and Boundaries)

Talking to your child about body awareness, sexual issues and relationships can seem quite daunting but it is important that all children and young people, including those with autism, are taught clearly and calmly in a way which they will understand.

People with ASD can have difficulty understanding body language, facial expression and tone of voice. They often have difficulties in reading social situations and are sometimes unaware that their behaviour is inappropriate. This can lead to confusion, misunderstandings and upset. They may also be confused or worried about changes that are happening to their bodies and their feelings.

There are many good sources of information and we have listed the relevant contact details below. We have also listed some tips for you to consider.

Earlier sections of this book about communication and behaviour may also be helpful to you.

*"It can also be hard for autistic people to express themselves, especially emotion. [My brother] doesn't like people invading his personal space. This can mean that affection (hugs) is only offered when [he] feels comfortable. However, this doesn't stand as a rule for autistic children; you may find that your sibling may be over-affectionate. At this point they need to be informed of boundaries they must abide." — [Sibling]*

## Some top tips for supporting your child with body awareness:

- ◆ Socially appropriate behaviour needs to be adopted long before puberty begins. However, if your child displays 'inappropriate' behaviour make sure that you determine the purpose of the behaviour as it may be different to your assumption!
- ◆ Comment on inappropriate behaviour when it occurs but explain what is inappropriate about it and how the matter / situation could have been handled
- ◆ Be calm, clear and consistent — repetitive messages support learning
- ◆ Ensure your child has understood — ask them to tell you in their own words
- ◆ Talk to your child's school to find out what will be covered during PSHE lessons, etc — to make sure that you are happy with what is being taught to your child and to try to ensure that you are working together
- ◆ Some Community Health Nurses have expertise in supporting parents and children on sexual matters — they can be contacted via your family GP
- ◆ Monitor television and film viewing — you may need to check their understanding of any sexual content

## Where else can I get information?

- **Websites**

The Family Planning Association website includes information about sexual health, sex and relationships

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

The National Autistic Society has a section on their website about sex education for children and young people with an ASD

[www.autism.org.uk/living-with-autism/communicating-and-interacting/sex-education](http://www.autism.org.uk/living-with-autism/communicating-and-interacting/sex-education)

The National Health Service's Livewell website has information for young people about sexual health, sex and relationships

[www.nhs.uk/Livewell/Sexandyoungpeople/Pages/Sex-and-young-people-hub.aspx](http://www.nhs.uk/Livewell/Sexandyoungpeople/Pages/Sex-and-young-people-hub.aspx)

The BBC's website includes a useful section on the human body and contains information about puberty which may be helpful

[www.bbc.co.uk/science/humanbody/body](http://www.bbc.co.uk/science/humanbody/body)

- **Books**

The family Planning Association has three books (which are not autism-specific but for children with learning disabilities) and information relating to these can be found on their website.

- **They include:**

***Talking Together About Growing Up*** \_\_\_\_\_ *Lorna Scott and Lesley Kerr-Edwards*

***Talking Together About Sex and Relationships*** \_\_\_\_\_ *Lorna Scott and Lesley Kerr-Edwards*

***Talking Together About Contraception*** \_\_\_\_\_ *Lorna Scott and Lesley Kerr-Edwards*

***Making Sense of Sex: A Forthright Guide to***

***Puberty, Sex and Relationships for People***

***with Asperger Syndrome*** \_\_\_\_\_ *Sarah Attwood*

# Notes





# **What about Family, Friends and the Child Themselves?**

# What about Family, Friends and the Child Themselves?

Once you have come to terms with your child's diagnosis, you will also want to consider how you tell your other children, members of your family, your friends and the child with ASD themselves. In this section we provide some information and top tips about:

- Siblings
- Extended Family and Friends
- How do we tell our child they have ASD?

## Siblings

*"Understandably, when a child is diagnosed the thoughts and advice flow to the parents, but people do have a tendency to forget about the siblings and how it can impact upon them too. There are many difficulties that can be encountered, however these are equally measured with the good times and memories that can be created." — [Sibling]*

Other children will often find things difficult too. They may find it difficult to understand the behaviours of their brother or sister with ASD. They may feel rejected if their sibling does not want to play with them, or does not respond to their social advances in the way they would like.

Sometimes other children can feel as if you are not giving them as much attention, or even as if you do not love them as much. Children, especially younger ones can find this difficult to explain to parents. Their feelings may be displayed in the way they behave which may not be how they would usually behave or how parents / family like. Sometimes other children start to behave differently as a means of securing parent's attention.

Providing siblings with information about autism will depend on their age and level of understanding. There are different ways to give information and this will depend on the needs of the individual child. For example, some will prefer to read a book; others would rather watch a DVD, whilst others will be happy to discuss it face-to-face with you or someone else. It may be helpful to provide them with a basic overview and then answer questions as and when they arise, giving simple and specific information.

*"Aside from what can seem as the bad part of living with an autistic sibling there can also be good times, just like living with any other person." — [Sibling]*





### Some top tips to support siblings:

- ◆ Talk about their feelings, tell them that it is okay for them to feel angry, sad, etc and that they may need some support themselves to deal with this
- ◆ Give them the opportunity to discuss their feelings with someone else they trust / feel comfortable with — sometimes young people would like to talk to someone else because they don't want to worry you
- ◆ Reassure your child(ren) that having to spend more time helping their brother or sister does not mean you love them any less
- ◆ Encourage them to interact with their sibling
- ◆ Help them to understand their sibling's behaviours and difficulties, but also explain their strengths and the things they are good at
- ◆ Acknowledge their role in the family — they are an important part of the family and whilst they are not their sibling's carers, they may want to be involved in helping and supporting you and their sibling
- ◆ Give your child(ren) the opportunity to have their own space — older siblings may appreciate privacy to do homework, have friends round, etc without interruptions.
- ◆ Allow them to have a safe place to keep important items, particularly if their sibling is prone to breaking things
- ◆ Make individual time with your child(ren), just 10 minutes a day can make a difference — explain that this is their time rather than simply excluding their ASD sibling
- ◆ Think together about activities which can be done as a family and what you can do with them on their own
- ◆ Remember to praise your other child(ren)'s positive behaviour. Look for things to praise such as sitting quietly, sharing, getting dressed without help. This will give attention and stop them seeking it in other ways.
- ◆ Explain to siblings that other people may not understand what ASD is or know their brother / sister so may react differently towards them

### Where else can you get information?

- [www.autism.org.uk/16720](http://www.autism.org.uk/16720)
- [www.sibs.org.uk](http://www.sibs.org.uk)
- The Useful **Contacts** section will have details for your Local Authority who can signpost you to support groups, etc in your area

# Extended Family and Friends

Members of your family and friends may have noticed that your child sometimes behaves differently from other children. It is important that family and others understand what an autistic disorder is so that they can help to support your child and you appropriately.

Initially you may decide to only tell those closest to you but the decision to tell family and friends will be individual to you and your personal circumstances. Provide them with some basic information about autism and explain how it specifically affects your child and their behaviour. Let them know how best they can help and support you and your child.

Different people will react in different ways to the news. When there is denial about the diagnosis, especially from wider family members who may not know the child as well, it may be an idea to provide some information about ASD. They may offer unhelpful or well-meaning but misguided comments but providing them with appropriate information may help. Reading about typical signs / behaviours can often help others to understand, as people often do not realise what an ASD is.

*“No one believed me. I just knew from an early age that he was different but the family wouldn’t have it. Even after the diagnosis it took one or two people several years to get on board. I just kept leaving books and pamphlets about autism lying around and I know that some of them were reading them in secret. Everybody ‘got it’ in the end and we could all pull together.” — [Parent]*

Family and friends may be unsure about ASD or specific aspects of your child’s behaviour so encourage them to talk to you if they want to know more or there’s something they don’t understand.

Accept help and support from family and friends when it’s offered. Sometimes people feel reluctant to offer help because they are unsure how they can help so think of some practical ways that they could help.

### Some top tips about extended family and friends:

- ◆ Explain to them about your child's diagnosis and provide them with information about autism
- ◆ Encourage them to ask if there is something they don't understand or want to know more about
- ◆ Explain how ASD impacts on your child and your child's behaviour
- ◆ Tell them how best to connect with your child, ie talk about their likes and dislikes and the best way of communicating with your child
- ◆ Acknowledge that they may struggle to come to terms with the diagnosis and may need support
- ◆ If someone makes unhelpful comments or is reluctant to accept the diagnosis, try not to take it to heart
- ◆ If family / friends offer to help, accept! If they don't offer it may be because they're not sure how they could help so ask, even if it's just to chat and listen

### Where else can you get information?

- The Useful Contacts section will have details for your Local Authority who can signpost you to support groups, etc in your area



# When do we tell our child they have ASD?

There is no hard and fast rule about when to tell your child and this will depend on personal circumstances. Their diagnosis may mean that their level of understanding or ability to process language is different to other children their age so the right time or age to discuss the diagnosis will depend on their individual abilities, needs and emotional strength and these are all factors you will want to consider. However, you are their parent and you know them best.

*"[I told my son] when he asked about going out on his own and why was I always with him; he was 11. I think you will know when the time is right and there is no set age. Always do what is right for your family."*  
— [Parent]

Some parents decide to tell their child when they are young so that they gradually become aware of their differences whilst others prefer to wait until their child is a little older so that they will understand better. If children are told about their condition and provided with the support they need it is suggested that the likelihood of problems occurring decreases. Some children may begin to ask questions and this may be a good time to talk to them. However, be aware that some children may have questions but not know how to express them.

When talking to your child about their diagnosis try and be as positive as possible. Use language and information according to their age and level of understanding. It may be a good idea to provide minimal information to begin with and add more over time. Your child may need some time to process the information and may have mixed emotions about their diagnosis. It is important to let them know that they can talk to you about how they are feeling or any questions they may have.

*"[My son] still refuses to accept he has Asperger's — probably because he was 10 when he was diagnosed (he is now 15). I have been watching programmes on ASD and Asperger's with him and gradually he is coming round to the idea."* — [Parent]

There are a range of books and DVD's that may be useful for you to use and you could speak to your doctor / health visitor / another professional or indeed other parents to help you with this.

*"It's not as if I was born with legs and then I had them taken away from me in an accident. I was born with Asperger's and I don't know any different... Maybe I'm one of the normal ones and you lot have the problem!"* — [Individual with ASD]

### Some top tips for talking to your child about their diagnosis:

- ◆ Use language and information appropriate to their level of understanding
- ◆ Try and be as positive as possible
- ◆ Give them time to process the information and encourage them to ask questions
- ◆ Reassure them
- ◆ Provide information in ways that suit them best — books, websites, DVD's, etc
- ◆ Have a question box, email or diary system if they find talking face-to-face difficult
- ◆ Ask for help from professionals and other parents

### Where else can you get information?

#### • Age 4 — 9 years

- Doherty, K., McNally, O. and Sherrard, E. (2000) *I have Autism. What's that?* Down Lisburn Trust
- Larson, EM (2006) *I am Utterly Unique: celebrating the strengths of children with Asperger's syndrome and high functioning autism* Autism Asperger's Publishing Company
- Eye Television (2006) *A Different Life: Rosie's Story* (DVD)

#### • Age 8 — 12 years

- Elder, J. (2006) *Different Like Me: My Book of Autism Heroes London:* Jessica Kingsley Publishers
- Autism Helpline (1999) *What is Asperger's Syndrome and How Will it Affect Me?*
- Vermeulen, P. (2000) *I am Special: Introducing Children and Young People to their Autistic Spectrum* London: Jessica Kingsley Publishers
- Doherty, K., McNally, P. and Sherrard, E. (2000) *I have Autism. What's that?* Down Lisburn Trust
- Gerland, G. (2000) *finding out about Asperger's Syndrome, High-Functioning Autism and PDD* London: Jessica Kingsley Publishers
- Jackson, L. (2002) *Freaks, Geeks and Asperger's Syndrome* London: Jessica Kingsley Publishers

#### • Age 12 years +

- National Autistic Society (2008) *Being Me* London: The National Autistic Society (CD-ROM and DVD set)
- Autism Helpline (1999) *What is Asperger's Syndrome and How Will it Affect Me?*





# Notes

An aerial photograph of a river delta, likely the Nile, with a semi-transparent purple overlay. The text "Services and Support" is written in white, bold, sans-serif font in the upper left quadrant.

# Services and Support



# Services and Support

In this section we consider therapies and interventions which may be available for children and families with autism, information about education and the education system and claiming benefits.

## Therapies / Interventions

Autism is a life-long condition and the causes are not yet known. Whilst it is important to recognise that autism is no-one's fault and as yet there is no known cure, we do know that there are approaches that can be helpful.

From talking to professionals and other parents or by looking at the internet you may come across a number of programmes, therapies and interventions.

However, it is important to remember that what works well for one individual may not necessarily work well for another. It may be advisable to discuss these, and / or others you may be aware of, with the professionals involved in the care of your child to find out which therapies / interventions are available locally and whether they think they may be of benefit. Please be aware that the interventions listed below may not all be available locally and you may have to pay to access them.

Examining existing research and findings for families for whom it has worked are probably the best ways to evaluate how effective an approach may be. Speak to other families who have tried the approach because, even if an approach has shown spectacular results, it may not be right for your child if you do not have the time and money to implement it in the same way. The families it has worked for may have plenty of money, large amounts of support from extended family and friends and live in an area where services are readily available. If these things don't apply to you, then it's possible that the approach won't work either. Don't despair, there is plenty you can do to help your child, even if you don't plan on remortgaging your house to pay for therapies!

We have provided an overview of some of the most common therapies / interventions below.

## PECS

The Picture Exchange Communication System (PECS) aims to improve word learning and overall communication through picture-word association, ie pictures are used instead of words to help children communicate. It uses the behavioural principle of reinforcement, where acting in a certain way (communicating with PECS) provides something the child wants thus reinforcing the required behaviour relating to that particular picture.

### For further information:

#### **Pyramid Educational Consultants UK Limited**

T 01273 609555

W [www.pecs.org.uk](http://www.pecs.org.uk)

PECS resources available from:

W [www.do2learn.com](http://www.do2learn.com)

W [www.pecs.com](http://www.pecs.com)

W [www.childrenwithspecialneeds.com](http://www.childrenwithspecialneeds.com) (click on 'downloads')

## National Autistic Society Early Bird and Early Bird Plus Programmes

The aims of the NAS Early Bird Programme are to:

- Support parents in the period between diagnosis and school placement.
- Empower parents and help them facilitate their child's social communication and appropriate behaviour within the child's natural environment.
- Help parents establish good practice in handling their child at an early age so as to pre-empt the development of inappropriate behaviours.

Early Bird plus is for parents whose child has received a later diagnosis of an Autistic Spectrum Disorder and is aged 4 – 8 and in Early Years or Key Stage One provision. Early Bird Plus uses the established Early Bird framework of teaching about autism before considering how to develop communication or manage behaviour.

### To contact the Early Bird Service to see if there is a licensed team available in your area:

Early Bird Centre, Barnsley Road, Dodworth, South Yorkshire, S75 3JT

T 01226 779218

F 01226 771014

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

## National Autistic Society Help! Programme

Help! is a series of one-day family support seminars providing information and advice to families of children and young people affected by autism. The NAS delivers parent seminars and professional seminars.

The NAS delivers Help! seminars nationally and supports families to:

- Develop an understanding of autism
- Gain awareness of sensory needs of children with autism
- Discuss experiences of getting a diagnosis
- Identify how autism can affect families
- Explore practical ideas for developing communication strategies
- Clarify support that families may be entitled to and ways to access this
- Discuss why children with autism often have challenges with anger
- Identifies a low arousal approach for support through stressful situations
- Explore the cycle of anger and possible support strategies
- Examine strategies for managing feelings
- Consider sensory systems and how effective these may be
- Examine how sensory information may be processed differently
- Discuss how people with autism may experience different senses.

Families can book two places on a one day Help! seminar for £30 which includes a full resource pack of useful information, advice and support guidelines.

**For further information the NAS website is:**

*<http://www.autism.org.uk/our-services/residential-community-and-social-support/parent-and-family-training-and-support/help-seminars.aspx>*

## SPELL

This course is usually offered to professionals although parents can and do access it on occasion.

SPELL stands for Structure, Positive (approaches and expectations), Empathy, Low arousal and Links. The SPELL framework has been developed by the National Autistic Society to understand and respond to the needs of children and adults on the autistic spectrum. The framework is also useful in identifying underlying issues; in reducing the disabling effects of the condition; and in providing a cornerstone for communication. It also forms the basis of all autism specific staff training and an ethical basis for intervention.

The SPELL framework recognises the individual and unique needs of each child and adult and emphasises that planning and intervention be organised on this basis. A number of interlinking themes are known to be of benefit to children and adults on the autism spectrum and by building on strengths and reducing the disabling effects of the condition progress can be made in personal growth and development, the promotion of opportunity and as full a life as possible.

## TEACCH

TEACCH stands for the Treatment and Education of Autistic and Communication-Handicapped Children.

The long-term goals of the TEACCH approach are both skill development and fulfilment of fundamental human need. 'Structured Teaching' was developed to achieve these goals.

**The key elements of Structured Teaching include:**

- Developing an individualised person- and family-centred plan for each client or student, rather than using a standard curriculum.
- Structuring the physical environment.
- Using visual supports to make the sequence of daily activities predictable and understandable.
- Using visual supports to make individual tasks understandable.

TEACCH courses specifically for parents are offered from time to time in Wales.

## Cognitive Behavioural Therapy (CBT)

Cognitive Behavioural Therapy (CBT) is based on the idea that how we think, how we feel, and how we act, affect each other.

CBT uses techniques to help people become more aware of how they reason, so that they can change how they think and therefore how they behave.

CBT is likely to work only for those individuals who have both the capacity and the preference for monitoring and managing their own behaviour. It is therefore more likely to work for high-functioning individuals with autism or Aspergers syndrome who are more than 8 years old.

There are also a wide range of other therapies that you may come across. Again, our suggestions would be that you discuss them with the professionals involved in the care of your child and with parents / families who may have used those therapies and can give you feedback to try and help you decide if they would be suitable for you and your child.

## Early Intensive Behavioural Intervention

Early Intensive Behavioural Intervention is a highly structured and intense intervention in which a child is taught a range of skills by a team of therapists.

The therapists break down the skills into small tasks that are considered to be achievable and which are taught in a very structured manner.

Desired behaviour, such as use of language or socialisation, is positively reinforced and accompanied by lots of praise. Negative behaviour, such as self harm or aggression towards others, is not reinforced. For example, a child who hurts himself in order to gain attention would be prevented from hurting himself and the therapists might stop talking to the child until he showed a more desirable behaviour.

## Music Therapy

Music therapy uses live music making and composition techniques to encourage children, adolescents and adults with autism spectrum disorders to engage in spontaneous and creative musical activities.

The therapist and client use a variety of percussion or tuned instruments, or voice, to develop shared and interactive musical activities.

The individual with autism does not need musical skills to benefit from music therapy but the music therapist does need a high level of musical and therapeutic skill.

Supporters of music therapy believe that it can be used to develop social engagement, joint attention, communication abilities, while also addressing emotional needs and quality of life.

## Social Groups

Social groups provide an opportunity for individuals with autism to meet each other and to improve their social skills in a safe, supportive environment.

The groups are usually facilitated by professionals or volunteers but offer flexibility in the leisure activities they provide. For example, some may focus on one activity, such as drama, whilst others may offer a wider range of activities.

Social groups differ from social skills groups in that they are less focussed on the attainment of skills and more focussed on providing opportunities for people to participate in mainstream leisure activities.

## Social Skills Groups

Social skills groups provide an opportunity for individuals with autism to practice and improve their social skills in a safe, supportive environment.

Some groups include people with and without autism, although some groups consist only of people with autism. The groups are usually facilitated by professionals.

Social skills groups differ from social groups in that they are more focussed on the attainment of skills and are therefore likely to be more structured.

## Developmental, Individual-difference, Relationship-based (DIR) / Floortime

The emphasis of this approach, developed by Greenspan and Weider (1999), is about following and imitating the child's actions, using sensorimotor techniques such as swinging the child or applying physical pressure if this increases attention to the adult. Adults also present problem-solving activities to the children, and playfully obstruct any repetitive routines and attempt to elicit communication by not responding to non-communicative actions.

## Relationship Development Intervention (RDI) Programme

RDI trains parents to foster the social communication skills of their children with autism. Parents are trained to target deficits in their child's interpersonal interaction skills (such as joint attention, gaze direction and use of facial expression) through stimulating and fun activities. Parents are trained to use indirect prompts and 'invitations' rather than directive ways of interacting. The idea is that once children with autism have discovered the value of relationships through repeated positive experience of interpersonal activity, they will be motivated to learn the verbal and non-verbal skills required to sustain these relationships.

## Social Stories

A Social Story is a description of a social situation written in the first person (as if from the perspective of the child) and in a concrete style and format. The story includes sufficient detail for the child to recognise the situation when it actually occurs and examples of the appropriate kind of response to make. Other information might include details of how the child might feel in the situation, and how his / her response might affect others. The idea is that the child rehearses the story ahead of time with an adult. When a comparable situation occurs the child can then use the story to help guide his or her behaviour.

An example of a Social Story is included at the end of the Glossary section.

For more information relating to Social Stories try the following websites:

W [www.autism.org.uk/16261](http://www.autism.org.uk/16261)

W [www.thegraycenter.org/Social\\_Stories.htm](http://www.thegraycenter.org/Social_Stories.htm)

## Applied Behavioural Analysis (ABA)

ABA involves teaching linguistic, cognitive, social and self-help skills across all settings and breaking down these skills into small tasks which are taught in a highly structured and hierarchical manner. There is a focus on rewarding, or reinforcing, desired behaviours and ignoring, re-directing or otherwise discouraging inappropriate behaviours.

How a person progresses on an ABA programme will depend on a range of factors including their particular needs and abilities and the way in which the programme is implemented.

## Lovaas

The Lovaas method is an early intensive behaviour therapy approach for children with autism and other related disorders. It is also known as:

- Applied Behavioural Analysis (Lovaas method)
- Early Intensive Behavioural Intervention
- Home Based Behavioural Intervention
- University of California Los Angeles (UCLA) Programme by Dr Lovaas
- UCLA Model of Applied Behavioural Analysis (ABA) (as developed in the Lovaas Institute for Early Intervention)

Behaviour modification is based on the fact that pleasant consequences can promote good behaviour and unpleasant consequences, such as punishments, can reduce unacceptable behaviours.

The therapy is on a one-to-one basis for six to eight hours per day, five to seven days per week for two or more years. Teaching sessions usually last two to three hours with breaks. As part of the sessions, all skills are broken down into small tasks that are achievable and taught in a very structured manner and accompanied by lots of praise and reinforcement. Examples of reinforcers are small bites of food, play with a favourite toy, social rewards such as verbal praise and hugs and tickles. Gradually food and other artificial reinforcers are replaced, if possible, by more social and everyday reinforcers. Aggressive or self-stimulatory behaviours are reduced or replaced by ignoring them or by introducing more socially acceptable forms of behaviour.



## Rebound Therapy

This therapy uses trampolines in providing therapeutic exercise and recreation for people with a wide range of special needs. Participants range from mild to severe physical disabilities and from mild to profound and multiple learning disabilities, including dual sensory impairment and autistic spectrum disorder.

Rebound Therapy is used to facilitate movement, promote balance, promote an increase or decrease in muscle tone, promote relaxation, promote sensory integration, improve fitness and exercise tolerance, and to improve communication skills.

## Drama Therapy

Drama therapy offers the opportunity for children with autism to build on their imitative strengths by learning, practising and perfecting 'lines' in a fun, supportive setting. It allows participants to work on social improvisation, practise social skills learned in other settings, work on reading and body language and develop speaking skills.

## Touch / Massage Therapy

Massage is the practice of applying pressure, tension, motion or vibration to the skin, muscles and other soft tissues of the body and is used to obtain therapeutic effects. There are many different massage techniques and practices.

Massage or 'touch' therapy may have physical and emotional benefits for children with ASD and may improve their language and social skills or help with anxiety and sleep issues.

If you are interested in the therapy there should be no potential risks of massage for children with autism. However, the evidence-base for the effectiveness of this therapy is limited and more research needs to be undertaken.

## Autism Assistance Dog (Dogs for the Disabled)

An autism assistance dog trained by Dogs for the Disabled can give parents and children independence and provide a safer environment for the child making them feel more secure. An autism assistance dog is highly trained and socialised to meet the needs of the child and their family and can help change behaviour by introducing routines, reducing bolting behaviour, interrupting repetitive behaviour and helping a child with autism cope with unfamiliar surroundings. In addition the dog can be trained to provide therapeutic support to a child.

Applications for this service can only be considered for children from 3 years of age up to their 10th birthday. The age is set due to the nature of the harness used when working and the resulting welfare of the child and dog. There are set criteria for accessing this service.

## Parents Autism Workshops and Support (PAWS)

Parents Autism Workshops and Support (PAWS) is part of the work of Dogs for the Disabled. They have found that there can be a special chemistry between the dog and the child and in some cases the dog can have a calming effect when a child with autism is angry, anxious or distressed. They can distract a child away from disruptive or dangerous behaviour and create a space for the parent / carer to take control of a situation.

There are three workshops which take the parents through a specially devised programme of activities with one workshop every month for three months. They also offer advice on identifying tasks to work with your dog and can put you in touch with local trainers.

## 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 session, individual consultations and evaluation to help parents learn strategies that will encourage language development.

## Son-Rise

Son-Rise is a home-based programme for children with autistic spectrum disorders and other developmental disabilities. The programme emphasises eye contact, accepting the child without judgment, and engaging the child in a non-coercive way, and it hypothesizes that treated children will decide to become non-autistic.

However, no published independent study has tested the efficacy of the programme. A 2003 study found that involvement with the programme led to more drawbacks than benefits for the families involved over time, and a 2006 study found that the programme is not always implemented as it is described in the literature, which means it will be difficult to evaluate its success /failure rate.

For further information about therapies and interventions:

National Autistic Society

This website contains the latest information on therapies and interventions that are available:

W [www.autism.org.uk/approaches](http://www.autism.org.uk/approaches)



# Notes

# Education

## 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 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.

## 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 Ysgolion 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.

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?

### 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.'* — [Parent]

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 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 [my son].'* — [Early Support]

*'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.'* — [Early Support]

*'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 nonstream class in the mornings with a lot of support.'* — [Early 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 who have additional learning needs and their families. Many local autism specific services 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](tel:02920396624).

## 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.'* — [Early Support]

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 (eg 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?
- 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 T: **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 T: **0808 800 5793** or Autism Cymru on T: **01978 853841** and full contact details are given at the back of the booklet.

### For further information contact:

**Contact a Family** T: **02920 396624**

**NAS Advocacy for Education Service** T: **0845 070 4002**

**Advisory Centre for Education** T: **0808 8005793**

**Autism Cymru** T: **01978 853841**

### Benefits

You may be entitled to claim certain benefits and/or apply for reduced rates with some service suppliers.

For up-to-date information about benefits which you may be entitled to and information about the benefit system we recommend that you view the DirectGov website or telephone / visit the Citizen's Advice Bureau (contact details below). Alternatively, your local council should be able to provide you with contact details for local information services and their contact details are included at the end of this booklet.

Some utility suppliers (gas, electricity, etc) may have special rates / savings for families claiming benefits so it may be worth contacting your current suppliers to find out.

**For further information contact:**

**DirectGov**

T Benefits enquiry line 0800 882 200

W [www.direct.gov.uk](http://www.direct.gov.uk)

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

**Citizen's Advice Bureau**

T 0844 477 2020

W [www.adviceguide.org.uk](http://www.adviceguide.org.uk)

**Turn2us**

T 0808 802 2000 (Freephone 8am — 8pm)

W [www.turn2us.org.uk/benefits\\_search.aspx](http://www.turn2us.org.uk/benefits_search.aspx)

**National Autistic Society**

T 0808 800 4104 (Mon — Fri, 10am — 4pm) The Helpline will take details of your query and arrange a telephone appointment for you with the NAS Welfare Rights Co-ordinator who will call you back at the agreed time to discuss your query in detail.

W [www.autism.org.uk/our-services/advice-and-information-services/welfare-rights-service.aspx](http://www.autism.org.uk/our-services/advice-and-information-services/welfare-rights-service.aspx)

[welfarerights@nas.org.uk](mailto:welfarerights@nas.org.uk)

It would be helpful if you could confirm the name of the benefit you are enquiring about and provide as much detail as possible regarding your enquiry.

**Disability Alliance**

W [www.disabilityalliance.org](http://www.disabilityalliance.org)

**Cerebra**

Cerebra offer a handbook on DLA: [www.cerebra.org.uk/parent\\_support/DLA\\_guide.htm](http://www.cerebra.org.uk/parent_support/DLA_guide.htm)

# Useful Contacts

## **Welsh Government**

Cathays Park  
Cardiff  
CF10 3NQ  
T *English 0300 060 3300 or 0845 010 3300*  
T *0300 060 4400 or 0845 010 4400*  
W [www.wales.gov.uk](http://www.wales.gov.uk)

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## **Welsh Local Government Agency**

Local Government House  
Drake Walk  
Cardiff  
CF10 4LG  
T *02920 468600*  
W [www.wlga.gov.uk](http://www.wlga.gov.uk)

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## **Aneurin Bevan Health Board**

Headquarters  
Mamhilad House  
Block A  
Mamhilad Park Estate  
Pontypool  
Torfaen  
NP4 0YP  
T *01873 732732*  
W [www.aneurinbevanhb.wales.nhs.uk](http://www.aneurinbevanhb.wales.nhs.uk)

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## **Blaenau Gwent County Borough Council**

Municipal Offices  
Civic Centre  
Ebbw Vale  
NP23 6XB  
T *01495 311556*  
W [www.blaenau-gwent.gov.uk](http://www.blaenau-gwent.gov.uk)

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## **Caerphilly County Borough Council**

Family Information Service  
Dyffryn House  
Dyffryn Business Park  
Ystrad Mynach  
Hengoed  
CF82 7RJ  
T *01443 815588 / 01495 226622*  
W [www.caerphilly.gov.uk](http://www.caerphilly.gov.uk)

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## **Cardiff and Vale University Health Board Headquarters**

Whitchurch Hospital  
Park Road  
Whitchurch  
Cardiff  
CF14 7XB  
T *02920 747747*  
W [www.cardiffandvaleuhb.wales.nhs.uk](http://www.cardiffandvaleuhb.wales.nhs.uk)

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**Cardiff Council**

County Hall  
Atlantic Wharf  
Cardiff  
CF10 4UW  
T 02920 872000  
W [www.cardiff.gov.uk](http://www.cardiff.gov.uk)

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**Cwm Taf Health Board**

Headquarters  
Ynysmeurig House  
Navigation Park  
Abercynon  
CF45 4SN  
T 01443 744800  
W [www.cwmtafwb.wales.nhs.uk](http://www.cwmtafwb.wales.nhs.uk)

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**Merthyr Tydfil County Borough Council**

Civic Centre  
Castle Street  
Merthyr Tydfil  
CF47 8AN  
T 01685 725000  
W [www.merthyr.gov.uk](http://www.merthyr.gov.uk)

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**Monmouthshire County Council**

County Hall  
Cwmbran  
NP44 2XH  
T 01633 644644  
W [www.monmouthshire.gov.uk](http://www.monmouthshire.gov.uk)

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**Newport City Council**

Civic Centre  
Newport  
NP20 4UR  
T 01633 656656  
W [www.newport.gov.uk](http://www.newport.gov.uk)

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**Rhondda Cynon Taf****One4All Centres:**

Rock Grounds  
High Street  
Aberdare  
CF44 7AE

Tŷ Sardis  
Sardis Road  
Pontypridd  
CF37 1DU

Tŷ Bronwydd  
Bronwydd Avenue  
Porth  
CF39 9DL

Treorchy Library  
Station Road

Treorchy  
CF42 6NN  
T 01443 442100  
W [www.rhondda-cynon-taf.gov.uk](http://www.rhondda-cynon-taf.gov.uk)

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**Torfaen County Borough Council**

Civic Centre  
Pontypool  
NP4 6YB  
T 01495 762200  
W [www.torfaen.gov.uk](http://www.torfaen.gov.uk)

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**Vale of Glamorgan Council**

Civic Offices  
Holton Road  
Barry  
CF63 4RU  
T 01446 700111  
W [www.valeofglamorgan.gov.uk](http://www.valeofglamorgan.gov.uk)

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### **ASD Info Wales**

This website is specific to Wales and includes information and advice for families and professionals about ASD. The site also includes a search facility which allows you to look for specific services available in your local area.

W [www.asdinfowales.co.uk](http://www.asdinfowales.co.uk)

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### **Advisory Centre for Education**

T 0808 800 5793 (Mon - Fri, 2pm - 5pm)

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### **Ambitious About Autism**

The Ambitious About Autism national charity is a campaign organisation which is working to improve the services available for children and young people with autism and to increase awareness and understanding of the condition. They provide services, raise awareness and understanding and influence policy. They also provide specialist education through the Treehouse School.

T 0208 815 5444

W [www.ambitiousaboutautism.org.uk](http://www.ambitiousaboutautism.org.uk)

E [info@ambitiousaboutautism.org.uk](mailto:info@ambitiousaboutautism.org.uk)

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

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### **ASD Friendly**

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

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

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### **AspergersUK**

For UK parents of children with Asperger Syndrome.

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

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### **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.

W [www.autismconnect.org](http://www.autismconnect.org)

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### **Autism Cymru**

Welsh national charity which aims to influence major policy change via collaborative practice, education and training, research and awareness raising.

W [www.awares.org](http://www.awares.org)

E [adam@autismcymru.org](mailto:adam@autismcymru.org)

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### **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.

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

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### **Autism Sibs**

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

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

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### **Autism UK**

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

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

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### **Autistica**

Autistica is a UK charity raising funds for medical research that will improve diagnosis, advance new treatments and discover the causes of autism.

*T 01491 412311*

*W [www.autistica.org.uk](http://www.autistica.org.uk)*

*E [info@autistic.org.uk](mailto:info@autistic.org.uk)*

Autistica

Rotherfield House

7 Fairmile

Henley-on-Thames

RG9 2JR

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### **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.

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

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### **Carers Wales**

Carers Wales is part of Carers UK which is a policy, campaigning and information organisation.

They provide information and advice to carers about their rights and how to get support.

*T 02920 811575*

*W [www.carerswales.org](http://www.carerswales.org)*

*E [info@carerswales.org](mailto:info@carerswales.org)*

Carers Wales

River House

Ynysbridge Court

Gwaelod y Garth

Cardiff

CF15 9SS

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### **Careers Wales**

Careers Wales provides free careers information and advice for young people, adults, parents, employers and professionals in Wales. There are six Careers Wales companies covering the Welsh regions and each company has its own Chief Executive and board of directors.

The Careers Wales companies work in partnership together and with a wide range of other organisations at local and national level. The Careers Wales Association has been set up to provide the Careers Wales companies with national, centralised support facilitating joint initiatives and partner liaison.

*Cardiff and Vale: 0800 100 900*

*Gwent: 0800 028 9212*

*Mid Glamorgan & Powys: 0800 183 0283*

*Careers Wales Association: 02920 854880*

*Learning and Careers Advice:*

*T 0800 100 900 — from a land line*

*T 02920 906801 — from a mobile*

*E [lca@careerswales.com](mailto:lca@careerswales.com)*

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### **Cerebra**

Cerebra is a charity set up to help improve the lives of children with brain related conditions through researching, educating and directly supporting children and their carers.

*T 0800 328 1159*

*W [www.cerebra.org.uk](http://www.cerebra.org.uk)*

*E [info@cerebra.org.uk](mailto:info@cerebra.org.uk)*

Cerebra (Parent Support)

FREEPOST SWC3360

Carmarthen

SA31 1ZY

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### **Children's Commissioner for Wales**

Keith Towler is the Children's Commissioner for Wales and his job is to stand up and speak out for children and young people. He works to make sure that children and young people are kept safe and that they know about and can access their rights.

Here are some of the things that Keith and his staff do for Wales' children and young people:

- Telling everyone, including children and young people, about the Commissioner and about children's rights
- Meeting with children and young people and listening to what they have to say about issues that affect them
- Talking to children and young people about the Commissioner's work, what else they think he should do and how he should do it
- Looking at the work of organisations like councils and health boards to see if they are thinking about children's rights
- Telling people who can make a difference what children and young people think is important and how to improve things
- Giving advice and information to children and adults who contact the Commissioner's team.

T 0808 801 1000

(children and young people's freephone)

Or text: 80 800 start your message with COM

W [www.childcom.org.uk](http://www.childcom.org.uk)

E [post@childcomwales.org.uk](mailto:post@childcomwales.org.uk)

Children's Commissioner for Wales

Oystermouth House

Phoenix Way

Llansamlet

Swansea

SA7 9FS

T 01792 765600

F 01792 765601

Children's Commissioner for Wales

Penrhos Manor

Oak Drive

Colwyn Bay

Conwy

LL29 7YW

T 01492 523333

F 01492 523336

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### **Citizen's Advice Bureau (CAB)**

The CAB provides information about people's rights including benefits, housing, employment, debt, consumer and legal issues.

T 0844 477 2020

W [www.adviceguide.org.uk](http://www.adviceguide.org.uk)

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### **Contact A Family**

Contact a Family provides support, advice and information for families with disabled children, no matter what their condition or disability.

T 0808 808 3555 (Mon - Fri, 9.30am - 5pm)

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

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

Contact a Family Cymru

33 - 35 Cathedral Road

Cardiff

CF11 9HB

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### **Crossroads Care**

Crossroads Care provides support to carers and the people they care for.

T 0845 450 0350

W [www.crossroads.org.uk](http://www.crossroads.org.uk)

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### **DirectGov**

DirectGov is the UK government's digital service for people in England and Wales. It delivers information and practical advice about public services, bringing them all together in one place.

*Benefits Enquiry Line: 0800 882 200*

*W [www.direct.gov.uk](http://www.direct.gov.uk)*

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

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### **Disability Alliance**

Disability Alliance is a national registered charity which works to relieve the poverty and improve the living standards of disabled people. They provide information on benefits, tax credits and social care to disabled people, their families, carers and professional advisers. They also have a range of publications for download including the Disability Rights Handbook.

*W [www.disabilityalliance.org](http://www.disabilityalliance.org)*

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### **EarlyBird Centre**

EarlyBird is for parents whose child has received a diagnosis of an autism spectrum disorder and is not yet of statutory school age. The programme aims to support parents in the period between diagnosis and school placement, empowering and helping them facilitate their child's social communication and appropriate behaviour in their natural environment.

EarlyBird Plus is for parents whose child has received a later diagnosis of an autism spectrum disorder and is aged 4 — 8 and in Early Years or Key Stage One provision. The programme addresses the needs of both home and school settings by training parents / carers together with a professional who is working regularly with their child, the aim being that a child will be given consistent support.

*T 01226 779218*

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

Early Bird Centre  
Barnsley Road  
Dodworth  
South Yorkshire  
S75 3JT

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### **Early Support Wales**

Early Support Wales offers free training for parents and have a useful free booklet on autistic spectrum disorder

*T 02920 342 434*

*W [www.earlysupportwales.org.uk](http://www.earlysupportwales.org.uk)*

Early Support  
c / o Children in Wales  
25 Windsor Place  
Cardiff  
CF10 3BZ

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### **Epilepsy Wales**

Epilepsy Wales is a charity which supports people with epilepsy in Wales, their family and carers by providing help, advice and information.

*T 0800 228 9016 (Mon - Fri, 9am - 5pm)*

*W [www.epilepsy-wales.org.uk](http://www.epilepsy-wales.org.uk)*

*E [weabradbury@btconnect.com](mailto:weabradbury@btconnect.com)*

Epilepsy Wales  
PO Box 4168  
Cardiff  
CF14 0WZ

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### **ERIC (Education and Resources for Improving Childhood Continence)**

ERIC is a national children's health charity dealing with bedwetting, daytime wetting, constipation, soiling and potty training in children and young people. ERIC provides information, support and resources to families and health professionals on bladder and bowel problems.

**T 0845 370 8008** (Mon - Fri, 10am - 4pm)

**W [www.enuresis.org.uk](http://www.enuresis.org.uk)**

**W [www.ericshop.org.uk](http://www.ericshop.org.uk)**

**E [info@eric.org.uk](mailto:info@eric.org.uk)**

ERIC (Education and Resources for Improving Childhood Continence)

36 Old School House

Britannia Road

Kingswood

Bristol

BS15 8DB

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### **The Family Fund**

The Family Fund is a charity which helps families with severely disabled or seriously ill children and young people aged 17 and under to have choices and the opportunity to enjoy ordinary life. They provide grants for things that make life easier and more enjoyable such as washing machines, driving lessons, computers and holidays.

**T 0845 130 4542**

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

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

The family Fund

Unit 4, Alpha Court

Monks Cross Drive

Huntington

York

YO32 9WN

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### **The Family Planning Association**

The Family Planning Association has information about sexual health, sex and relationships and has published three books which may be of use when talking to your child.

**W [www.fpa.org.uk](http://www.fpa.org.uk)**

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### **Family Rights Group**

The Family Rights Group is a charity in England and Wales which advises parents and other family members whose children are involved with or require children's social care services because of welfare needs or concerns.

They promote policies and practices that assist children to be raised safely and securely within their families, and campaign to ensure that support is available to assist grandparents and family and friends carers who are raising children who cannot live at home.

**T 0800 731 1696** (Mon - Fri, 10am - 3.30pm)

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

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

Family Rights Group

The Print House

18 Ashwin Street

London

E8 3DL

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### **Gwent Association of Voluntary Organisations (GAVO)**

Gwent Association of Voluntary Organisations is a Community Voluntary Council which is committed to strengthening the effectiveness of the Voluntary and Community Sector across Blaenau Gwent, Caerphilly, Monmouthshire and Newport. GAVO works with individuals and community groups as well as the public and private sector.

T 01633 241550

W [www.gavowales.org.uk](http://www.gavowales.org.uk)

E [chris.thomas@gavowales.org.uk](mailto:chris.thomas@gavowales.org.uk)

Ty Derwen  
Church Road  
Newport  
NP19 7EJ

### **Interlink**

Interlink is the County Voluntary Council (CVC) for Rhondda Cynon Taff, supporting individuals and organisations to work together to make a positive impact on the life of people who live and work in RCT.

T 01443 846200

W [www.interlinkrct.org.uk](http://www.interlinkrct.org.uk)

6 Melin Corrwg  
Cardiff Road  
Upper Boat  
Pontypridd  
CF37 5BE

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### **Jobcentre Plus**

Jobcentre Plus can help you with:

- What type of work you'd be suited to
- Schemes and resources to help you find work
- Retraining programmes
- Help if you are disabled or are a single parent
- Help with self-employment issues
- How to complete application forms and prepare for an interview
- Financial schemes / help while you look for work
- What vacancies there are at the Jobcentre Plus Jobs Centre

The following website will enable you to locate your local Jobcentre Plus.

W [www.jobcentreplusadvisor.co.uk/wales](http://www.jobcentreplusadvisor.co.uk/wales)

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### **National Autistic Society (NAS)**

The NAS is a UK charity for people with autism (including Asperger Syndrome) and their families. They provide information, support and services and campaign for a better world for people with autism. The NAS will also be able to tell you if there is an EarlyBird or EarlyBird Plus programme running in your area.

T 0845 070 4004 (Mon - Fri, 10am - 4pm)

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

NAS Cymru  
6/7 Village Way  
Greenmeadow Springs Business Park  
Tongwynlais  
Cardiff  
CF15 7NE

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### **NAS Advocacy for Education Service**

If you are experiencing any problems in accessing the support you feel your child needs the NAS provides a 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.

*T 0845 070 4002*

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### **Parent to Parent Line**

The Parent to Parent Line is a new, confidential telephone support service for parents of an adult or child with autism provided by other volunteer parents. You can ring the freephone number 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.

*T 0800 952 0520*

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### **Rackety's**

Rackety's is a clothing company for disabled children and adults.

*T 01538 381430*

*F 01538 370156*

*W [www.disabled-clothing.co.uk](http://www.disabled-clothing.co.uk)*

*E [info@racketys.com](mailto:info@racketys.com)*

Rackety's Ltd

Unit 16

Town Yard Business Park

Station Street

Leek

Staffordshire

ST13 8BF

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### **Sensory Smart**

*Clothing solutions for sensory-sensitive children.*

*T 01425 674712 (Answerphone)*

*W [www.sensorysmart.co.uk](http://www.sensorysmart.co.uk)*

*E [sensorysmart@googlemail.com](mailto:sensorysmart@googlemail.com)*

264 Burley Road

Bransgore

Hampshire

BH23 8DR

*Please email in first instance because the owner runs her business around the needs of her son who has autism!*

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### **Sibs**

Sibs is the UK charity for people who grow up with a brother or sister who is disabled, has a long term chronic illness or a life-limiting condition. SibS provides information and support to siblings and influences service provision for siblings throughout the UK.

*T 01535 645453*

*W [www.sibs.org.uk](http://www.sibs.org.uk)*

Sibs

Meadowfield

Oxenhope

West Yorkshire

BD22 9JD

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### **SNAP Cymru**

SNAP Cymru is a national charity which aims to advance the education of people in Wales and support their inclusion. SNAP works with families, children and young people, their parents / carers and professionals working with those who have or may have additional learning needs. These include SEN, disability and other barriers, eg exclusion, disaffection, poverty, deprivation, English or Welsh as a second language.

They provide information, advice and support for a range of issues relating to education, health and social care provision and discrimination as well as advocacy services, disagreement resolution and training for young people, parents and professionals.

T 02920 384868

W [www.snapcymru.org](http://www.snapcymru.org)

E [headoffice@snapcymru.org](mailto:headoffice@snapcymru.org)

SNAP Cymru Head Office

10 Coopers Yard

Curran Road

Cardiff

CF10 5NB

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### **Torfaen Voluntary Alliance (TVA)**

TVA is the voluntary council for the County Borough of Torfaen and their role is to support, promote, develop and represent voluntary and community groups in the county.

Pontypool Office

T 01495 756646

F 01495 740097

Portland Buildings

Commercial Street

Pontypool

Torfaen

Blaenavon Office

T 01495 793259

F 01495 792434

Ground Floor Office 5

Church View

Ivor Street

Blaenavon

W [www.torfaenvoluntaryalliance.org.uk](http://www.torfaenvoluntaryalliance.org.uk)

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### **Turn2Us**

Turn2us is a charitable service which helps people access the money available to them through welfare benefits, grants and other help.

T 0808 802 2000 (Freephone 8am — 8pm)

W [www.turn2us.org.uk](http://www.turn2us.org.uk)

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### **Vale Centre for Voluntary Services (VCVS)**

VCVS helps to improve the quality of life of individuals and communities by supporting voluntary groups.

T 01446 741706

F 01446 421442

W [www.valecvcs.org.uk](http://www.valecvcs.org.uk)

E [vcvs@valecvcs.org.uk](mailto:vcvs@valecvcs.org.uk)

Barry Community Enterprise Centre

Skomer Road

Barry

CF62 9DA

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### **Voluntary Action Cardiff**

Voluntary Action Cardiff is the County Voluntary Council which represents and promotes the voluntary sector in Cardiff.

T 02920 485722

W [www.vacardiff.org.uk](http://www.vacardiff.org.uk)

E [enquiries@vacardiff.org.uk](mailto:enquiries@vacardiff.org.uk)

Voluntary Action Cardiff

3rd Floor

Shand House

2 Fitzalan Place

Cardiff

CF24 0BE

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### **Voluntary Action Merthyr Tydfil (VAMT)**

Voluntary Action Merthyr Tydfil (VAMT) aims to support voluntary and community activity in the County Borough of Merthyr Tydfil by helping new projects, bringing groups together in forums and networks, producing regular newsletters, providing training and practical help. VAMT offers information and advice on funding, legal matters, volunteering, marketing, ICT and how your group can work effectively.

T [01685 353900](tel:01685353900)

F [01685 353909](tel:01685353909)

W [www.vamt.net](http://www.vamt.net)

E [enquiries@vamt.net](mailto:enquiries@vamt.net)

Voluntary Action Centre  
89 — 90 High Street  
Pontymorlais  
Merthyr Tydfil  
CF47 8UH

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### **Wales Autism Research Centre (WARC)**

The Wales Autism Research Centre (WARC) was initiated through a unique collaboration between Autism Cymru and Autistica, the School of Psychology, Cardiff University and the Welsh Government.

WARC researches risk factors, identification, diagnosis, cognitive development and intervention. Based in the School of Psychology they engage in multi-disciplinary research collaboration across a number of areas. They study and use research evidence in services for autism and contribute to awareness-raising. A unique goal, made possible by the ASD Strategy in Wales, is to integrate scientific research findings with policy.

W [www.psych.cf.ac.uk/warc](http://www.psych.cf.ac.uk/warc)

E [warc@cardiff.ac.uk](mailto:warc@cardiff.ac.uk)

Wales Autism Research Centre (WARC)  
School of Psychology  
Cardiff University  
Tower Building  
Park Place  
Cardiff  
CF10 3AT

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### **Youth In Mind**

Youth In Mind is a website which enables you to search for books and websites about different topics for young people, parents and teachers.

W [www.youthinmind.com](http://www.youthinmind.com)

# References

ASD Monitoring and Support Group (2010) ***Autism — ASD Parent Information Pack***  
East Sussex County Council

Available from:

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Llywodraeth Cynulliad Cymru  
Welsh Assembly Government



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



GIG  
CYMRU  
NHS  
WALES

Bwrdd Iechyd  
Cwm Taf  
Health Board



GIG  
CYMRU  
NHS  
WALES

Bwrdd Iechyd  
Aneurin Bevan  
Health Board



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NHS  
WALES

Bwrdd Iechyd Prifysgol  
Caerdydd a'r Fro  
Cardiff and Vale  
University Health Board



STRONG HERITAGE | STRONG FUTURE  
RHONDDA CYNON TAF  
TRETADAETH GADAEN | DYFODOL SICR



CARDIFF  
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BRO MORGANNWG



CAERPHILLY  
COUNTY BOROUGH COUNCIL  
CYNGOR BWRDEISTREF SIROL  
CAERFFILI



monmouthshire  
sir fynwy



Newport  
CITY COUNCIL  
CYNGOR DINAS  
Casnewydd



Cyngor Bwrdeisdref Sirol  
Blaenau Gwent  
County Borough Council



# Glossary / Index

△ — symbol used by medical / clinical staff to mean 'diagnosis'

**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

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

**Agency** — An organisation which is statutory, private or voluntary which provides and / or purchases social care, health care or other services

**ASC** — autistic spectrum condition — see ASD

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

**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

**Assessment** — The process of defining an individual's needs, deciding on the help that they require and determining their eligibility for services

**Attention Deficit Hyperactivity Disorder** — see ADHD

**Autism Cymru** — Autism Cymru is a practitioner-led charity in Wales which aims to influence major policy change via collaborative practice, education and training, research and awareness raising

**Autistic spectrum conditions** — see ASD

**Autistic spectrum disorders** — see ASD

**Benefits Advisor** — Benefits advisers usually work directly with individual / carer to make an assessment of an individual's situation, answering questions and giving advice on state benefits and tax credits and helping people to fill in forms to apply for benefits and/or tax credits. Benefits advisors may be based within employment / careers advice centres, voluntary organisations or provide advice via help-lines

**Careers Advisor** — A careers adviser provides information, advice and guidance to help people make realistic choices about education, training and work. Careers advisors work with a range of clients aged 14 to adults. Career advisors may be based in schools, colleges or employment centres

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

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

**Child and Adolescent Mental Health Services (CAMHS)** — CAMHS provide assessment, treatment and intervention for children and young people with mental health difficulties. They may be based in a hospital, community clinic or health centre. Support may be offered via clinic appointments, home visits or day hospital care. Accessing these services is usually dependant on a referral from another professional

**Child Health Services** — Child Health Services are often referred to as Paediatrics, and are the department that deal with illness in children and young people (including delayed development). They may be based in a hospital, health centre or community clinic. Accessing these services is usually dependant on a referral from another professional

**Classroom Assistant / Teaching Assistant / Learning Support Assistant (LSA)** —

Teaching assistants provide support to teachers and pupils in a school setting. They may work to support the class or a specific pupil. Their work is directed and monitored by the class teacher

**Clinical Psychologist** — Clinical psychologists work with children or adults who experience mental or physical health problems and learning disabilities. Clinical psychologists aim to reduce psychological distress and enhance and promote psychological wellbeing. They often work as part of a multidisciplinary team, including in hospitals, clinics and community teams

**Community Learning Disability Nurse** — The Community Learning Disability Nurse works as part of the Learning Disability Services (see section below) and supports individuals in a variety of areas including the management of challenging behaviour

**Community Mental Health Teams (CMHTs)** — CMHTs are usually based in community clinics or health centres. They help to support and treat adults with mental health difficulties. They offer support via clinic appointments, home visits or day hospitals. Accessing these services is usually dependant on a referral from another professional

**Community Psychiatric Nurse (CPN)** — Mental health nurses work with children or adults suffering from various types of mental health problems. The work involves helping people to recover from illness, or come to terms with it in order to maximise their life potential and sometimes providing therapeutic interventions. Mental health nurses work within a team to plan and deliver care using a multidisciplinary client-centred approach. Mental Health Nurses work in hospitals, day hospitals, clinics and in the community

**Co-morbidity** — Term used by medical / clinical professionals to describe the presence of additional conditions / disorders to the initial diagnosis

**Counsellor** — Counsellors help people to explore feelings and emotions that are often related to their experiences. This allows them to reflect on what is happening to them and consider alternative ways of doing things. Counsellors do not give advice, but help clients to make their own choices within the framework of an agreed counselling contract. Counsellors may specialise in working with young people or adults. Counsellors may be based within health centres, GP practices, schools and colleges or employing organisations

**Dietician** — Dieticians work with people who have special dietary needs, give unbiased advice, evaluate and improve treatments. They may work directly with clients or advise doctors, nurses, health professionals and community groups

**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** — A person has a disability if he or she has a physical or mental impairment which has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities

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

**DSM-IV** — Diagnostic and Statistical Manual of Mental Disorders version 4 — Manual used by clinical staff to classify and code diseases and disorder (version 5 is expected to be published in 2013)

**Dyslexia** — Dyslexia causes difficulties in learning to read, write and spell. Short-term memory, mathematics, concentration, personal organisation may also be affected

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

**Echolalia** — repeating words or phrases spoken by someone else

**Educational Psychologist** — An educational psychologist is concerned with helping children or young people who are experiencing problems within an educational setting with the aim of enhancing their learning. They work directly with young people as individuals or in groups and also advise teachers, parents, social workers and other professionals who are involved with the child

**Epilepsy** — currently defined as a tendency to have recurrent seizures (sometimes called fits)

**GFCF Diet** — Gluten and Casein Free Diet

**Gluten** — protein found in wheat

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

**Health Visitor** — Health visitors work as part of a primary health care team, assessing the health needs of individuals, families and the wider community. They aim to promote good health and prevent illness by offering practical help and advice. The health visitor works within a community setting, often visiting people in their own homes. The health visitor primarily supports new parents and pre-school children as well as elderly people and those of any age who suffer from a chronic illness or live with a disability

**ICD-10** — International Classification of Diseases version 10 — Manual used by clinical staff to classify and code diseases and disorders

**Intervention** — term for any action, such as treatment or therapy, used to improve a condition

**IQ / Intelligence Quotient** — a score from tests to measure the level of someone's intelligence

**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

**Learning Disability Services** — Learning Disability Services are a community-based, multi-disciplinary team that includes Clinical Psychologists, Occupational Therapists, Speech & Language Therapists and Clinical Nurses who can offer a range of therapeutic interventions to people who have a learning disability and ASD who may experience difficulties with behaviour, communication, epilepsy and mental health. The service is home and not clinic based, and for adults with learning disability and ASD they also have access to a specialist Consultant Psychiatrist in addition to the team listed above

**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

**MDT** — Multi-Disciplinary Team which is a team of professionals from a range of different services

**MAT** — Multi-Agency Team which is a team of professionals from a range of different services

**National Autistic Society (NAS)** — The NAS is a charity for people with ASD and their families which provides information, support and services and campaigns for a better world for people with autism. The NAS Cymru website includes everything from the UK website about autism and provides information about their services and activities in Wales

**Neurology** — The study of the brain, its diseases and disorders

**Nutritionist** — is an expert on ways of giving the body the nutrition that it needs. A nutritionist knows the relationship between diet, food and ill health and how one affects the other

**Occupational Therapist** — Occupational therapy is the assessment and treatment of physical and psychiatric conditions using specific, purposeful activity to prevent disability and promote independent function in all aspects of daily life. Occupational therapists may use a wide range of techniques and strategies to help an individual to achieve and maintain normal daily tasks. Occupational therapists work within a wide range of services, in hospitals, clinics and community teams

**Paediatrician** — A paediatrician is a doctor who specialises in diagnosing, looking after, and treating children and young people who are ill or who have delayed development

**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

**Pharmacist** — These are specialist health professionals who make and sell medicines and are often called 'chemists'. They are experts on medicines and the way they work and will make up prescriptions provided by your doctor and can give advice on treatments that can be bought over the counter

**Physiotherapist** — Physiotherapists assess and treat patients with physical difficulties resulting from illness, injury, disability or ageing. They treat children and adults in hospital and community settings

**Pica** — Eating 'non-food' such as paper, fluff, etc

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

**Prevalence** — One of the main ways to measure the frequency of a disease in a particular population. It is the total number of cases that are present at any one time covering both old and new cases

**Prognosis** — A forecast as to the probable result of an illness, particularly with regard to the prospect of recovery

**PSE** — Personal, Social Education — see PSHE

**PSHE** — Personal, Social and Health Education — Part of the school curriculum where children and young people learn about

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

**Primary Health Care Services** — Primary health care services are the health services / professionals you can access directly, without the need for a referral. These include your GP, health visitor and practice nurse. They deal with a variety of physical and mental health issues and can refer you to other services for more specialised assessment help or support

**Psychiatrist** — Psychiatrists are medically qualified doctors who look after patients with mental health problems. Psychiatrists work with individuals of all ages and usually specialise in working with children or adults. Psychiatrists work as part of a team in hospital, clinic and community settings

**Public Sector** — (or Statutory Sector) The group of bodies which is required to obtain or provide particular services such as the Local Authority and the Health Service which receives central government funding

**Regression** — To go backwards. This usually refers to the loss of skills previously acquired, especially those basic skills related to early childhood

**School Nurse** — A school nurse works in partnership with schools to create an environment that promotes healthy living, as well as responding to the needs of individual children. School nurses promote and support physical, mental and emotional wellbeing and usually work within a number of schools

**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

**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. This involved co-ordinating work with a range of agencies and parents, gathering appropriate information on children with special needs and ensuring individual education plans (IEP's) are in place

**Social Services** — Social Services Departments are based in local authorities and provide services that support, care and protect individuals of all ages. Social Services have a number of teams who work with individuals with differing needs and usually separate children's and adults' services. Examples of the teams are child protection, adoption and fostering, children with disabilities, protection of vulnerable adults, mental health and learning disability services

**Social Stories** — These were developed by Carol Gray in America. They are short stories which assist people with social understanding by teaching appropriate social skills and behaviours for specific situations. An example is provided at the end of the glossary

**Social Worker** — A social worker works with a variety of individuals including those who are socially excluded or experiencing crisis. Social workers work with children and adults. They provide support to enable individuals and their families to help themselves. They may be based within a social services team or within another team or service. Social workers work in a variety of settings including the home, schools, hospitals and other public sector and voluntary organisations

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

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

**Special Educational needs Co-Ordinator** — see SENCO

**Speech and Language Therapy (SALT)** — a form of therapy to support people of all ages who have difficulties with speech, language and communication problems. They may also work with people who have eating and swallowing problems. Speech and language therapists may work privately or through the NHS in hospital, clinic and community settings

**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

**Stimming** — Repetitive behaviours referred to as self-stimulating behaviour some of which are obvious whilst others are more subtle. Examples of stimming include hand-flapping, spinning, eye rolling, tapping fingers, etc. This repetitive behaviour is used for a number of reasons including self-regulation in times of stress, demonstration of excitement, a way of avoiding a task or activity or to provoke a reaction from others

**Support Worker / Assistant** — A support worker can be attached to a variety of teams or professionals and help to carry out the care, monitoring or treatment of an individual. The support worker carries out work under the direction and supervision of a qualified professional e.g. nurse, speech and language therapist or occupational therapist

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

**Tourette's Syndrome** — a neurological condition, the key feature of which is tics (involuntary and uncontrollable sounds and movements)

**Triad of impairments** — the three impairments which characterise autism include issues with: social communication, social interaction and rigidity of thinking

# Example of a Social Story — Going Shopping

*"Sometimes I go shopping with Dad to the supermarket. We usually go in the car to Sainsbury's. When we get there, we choose a trolley. Dad gives me the list of things we need. We walk up and down the aisles to find what we need. Sometimes Dad lets me get the things off the shelf and put them in the trolley. This is being helpful. When we find the items, I can cross them off my list. Then we go to the checkout. We usually have to wait in a queue. When it is our turn, we take the items out of the trolley and put them on the conveyor belt. The shop assistant scans the items and then Dad packs them into bags. Dad will be pleased if I try and help him. After he pays the assistant, we push the trolley back, get into the car and drive home. If I try to stay calm we will get home quicker. Dad will be pleased with me if I try to stay calm and help with the shopping."*

# Notes





# Notes