



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

www.cymru.gov.uk

A guide for families of children and young people with Autism



This booklet is an Easy Read version of:

'Autistic Spectrum Disorders: 'A Resource for Families in Wales'

Welsh Assembly Government, March 2011

Contents

Pages

| | |
|--|----|
| What is this booklet about? | 4 |
| What are Autistic Spectrum Disorders? | 5 |
| How might I behave? | 6 |
| What can you do to understand and help me? | 8 |
| Checking and confirming I have Autism | 9 |
| Effects on my family | 10 |
| Where you can get information and support | 12 |

This booklet is to help families of children and young people with Autism to:

- understand and learn about Autism
- be able to help and support the young person with Autism



- This booklet is written through the 'eyes' of a person who has Autism.
- Where 'I' and 'me' is used, it is the person with Autism speaking.
- Where 'you' is used, it is the family member.
- Where the booklet refers to 'parent', this can mean Parents and any other family carer.
- The booklet will also be useful for parents who have adult children with Autism.



What are Autistic Spectrum Disorders?

Autism is the short name given to a range of disorders known as 'Autistic Spectrum Disorder'.

Autism is a type of disability.

You cannot tell by looking at someone that they have Autism.

Autism affects 1 in 100 people in this country.

No one knows why people have Autism.

Autism lasts for a person's life.

There is no cure for Autism.

2 out of every 3 people with Autism have learning disabilities.

More than 1 person in a family can have Autism.

Genetic is when conditions can pass from parents to their children.

If your child has Autism, you are not to blame.

Behaviour, learning and needs vary a lot. There are different names used within the spectrum.

Some might have high support needs.

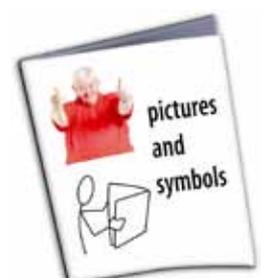
For people with high functioning autism they can live independent lives, form relationships and have children.

Asperger Syndrome is a type of autism but people with this do not have learning disabilities.



How might I behave?

- I might have problems understanding and mixing with other people.
- I might have problems taking part in everyday life.
- This makes me angry, frustrated or confused which means I behave in certain ways.
- I might:
 - find it difficult to tell people what I need, and how I feel;
 - not know when to start or end a conversation with someone or copy what other people say;
 - not understand what someone says or take what someone says the wrong way;
 - not understand someone's body language, tone of voice, or an expression on someone's face;
 - not understand other people's feelings. This means I might find it difficult to make friends;
 - find it difficult to take part in activities with other people so I choose to be alone;
 - find it difficult to cope in situations that are new to me;
 - find co-ordination difficult. This means I might find it hard to use scissors, use knives and forks or ride a bike. I might be clumsy or move in an unusual way;
 - not be able to talk and might need to use symbols or signs to communicate;



- be very good at something, such as maths, art or music;
- only talk about my favourite subject;
- have special interests that I repeat all the time;
- have special interests that I use in my job or as a life long hobby;
- like doing the same things every day such as 'carrying';
- not know what will happen next or understand danger;
- hurt myself or others. Shout, swear, or run away;
- flap my hands, rock from side to side or spin round in circles.



Autism can affect my senses

- **Sight** – I might not like bright lights and colours. Other might like them a lot.
- **Sound** – I might not like loud noises. Others might like certain noises.
- **Smell** – I might not like some smells. Others might like certain smell.
- **Touch** – I might not like being touched. Others might like being touched.
- **Taste** – I might like to eat the same food everyday. Others might like different foods.



We use our senses to understand our surroundings. Some behaviours are a result of me trying to feel comfortable where I am and to stop my senses becoming overloaded.

What can you do to understand and help me?

- Use clear language and allow me time to understand.
- If I say things that hurt you, it might be because I cannot understand your thoughts and feelings.
- Even though my activities may seem boring to you, give me time and space to do them.
- I like routine so agree times for certain things, such as mealtimes. Tell me in advance if any changes are going to be made to my routine.
- Allow me to calm down if I am angry or frustrated before you talk to me about it. Try and stay calm yourself.
- Keep a diary of my behaviour to look at what causes it. This will help you decide how things can be changed or if certain places need to be avoided.
- It may help to plan a visit to somewhere or to someone by creating a 'story' with pictures to show what will happen so I know what to expect. You may want to act this out so I can practice my response.



Remember: My behaviour is because I have Autism. It is not because you are a bad parent. All behaviour I show has a purpose and sometimes it takes time to understand.

Checking and confirming that I have Autism

If you have worries about my learning, development or behaviour, you can get an Assessment.

Some families have problems getting professionals to accept their worries, so make sure you keep trying.

It is unlikely they will confirm it is autism when I am under 2 years old.



Step 1: Family doctor, Health Visitor or Teacher

Your doctor will refer me to someone who knows a lot about autism. This person is called a Specialist.

Step 2: Assessment by a Psychiatrist or Child Specialist

I might be seen more than one person. They will look at our family history, other people's views and my behaviour.

The specialist should explain how they are going to assess me.

The assessment may take place over several visits and over a certain period of time.



Step 3: Confirming I have Autism.

This is known as a **Diagnosis**. The specialist will tell you:

- what they have found out about me during the assessment;
- what type of Autism I have;
- what services, support and help with money you can get for me.



If I have Asperger syndrome, this will often mean that I do not have learning disabilities. This may mean it can be difficult to get services because I might not qualify under the rules.

If you get a diagnosis for me as early as possible you will be able to get the right services for me and our family.

It will also help with understanding and better relationships within our family.

Effects on my family

Getting a diagnosis for me can be a sense of relief for me and our family, but it can also be a very emotional time.



It can help with your understanding on how I need to be supported.

Often you get to know a lot about autism. You will be the best person to speak up for me as I grow up.

My Mother

if my mother is my main carer, she might feel stress, sadness, anger or worry.

- She might have to give up work or work part time.
- Her health might be effected.
- She will often talk to other mothers with children with Autism to help deal with her emotions, to get and offer support to others.



My Father

- He tends to be affected by the stress felt by my mother, rather than the autism itself.
- He often hides his feelings, but might feel angry.



My Brother or Sister

They will see that I am different but won't understand why. Telling them that I have autism can be difficult, but often they accept it well. There are good books to help them understand.

My autism affects my brother or sister in different ways. They might feel:

- that life is unfair because I get special treatment or more attention;
- angry;
- that they want to care for me and protect me. My sister may want to mother me;
- embarrassed or annoyed when other people don't understand my Autism, so just think I am badly behaved;
- worried about whether they will have to look after me in the future;
- worried that their own children might have Autism.



It is important to talk about problems and find ways to keep family relationships happy. Thank and praise my brother or sister for the support they give me.

Growing up

My development towards becoming independent is not the same as other teenagers. This can be a difficult time for the family.

More teenagers with Asperger Syndrome can suffer with not feeling well in their mind. This is called Depression.

You will be the best person to speak up for me about what I need as I go through the transition to adulthood.



Out and about

Going out in public can be difficult for my family because other people can react badly to my behaviour. This is because people do not realise or understand that I behave the way I do because of my Autism.



Where you can get Information and Support

Social Services

I can have an Assessment of my needs.

As my parent, you can have Carer's Assessment of your needs.

As a result of the Assessments, it will say what help and support you and our family can get. This can include:

- things to do in the day time;
- aids and adaptations;
- home help;
- taking a short break. This is called Respite.

As part of the Welsh Assembly Government's action plan on Autism, there is now a person in charge of autism services in each local authority.

To find out who this is in your area, contact the Welsh Local Government Association (WLGA) on 029 2046 8600.

The WGLA also has 3 regional staff who can help you with information on Autism.



Health Service

Different staff can help you. You can get help with:

- help with improving my speech and language;
- physical and sensory problems;
- what I eat, sleeping and toileting problems;
- managing my behaviour;
- counselling. This is to help me or you talk about problems and deal with emotions.

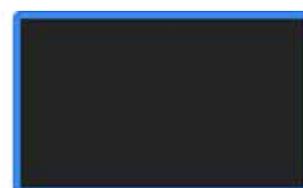


Education

I might go to a mainstream school or a special school. I can get extra help at school.

I might need an Assessment of my education needs. This is done by the education department at your local council.

It will be good if you have a close relationship with the school to help so they learn about my Autism give me the right support.



Benefits

You will be able to get benefits for me and our family.



Support Groups

Joining a support group will give you information and support. To find your nearest group contact [The National Autistic Society Helpline](#) on 0845 070 4004.



Voluntary organisations

You can find out who can help and support you. The website, doctor's surgery or library are good places to find out. [Here are some:](#)



National Autistic Society has a lot of information on their website and has free fact sheets.
www.autism.org.uk

All Wales Autism Resource tells you where to find information you need and holds events.
www.awares.org.uk

SNAP Cymru gives information and support about learning needs.
www.snapcymru.org

Contact a Family gives information and support to families of children with disabilities.
www.contactafamily.org.uk

Learning

Local authorities and voluntary organisations have training and seminars on autism that you can go to. At some, people with Autism speak about their experiences.

There is more information on where to find help and support in the main booklet. It also suggests books to read. To get copies of this booklet go to www.wales.gov.uk



Easy Read prepared by Learning Disability Wales using Photosymbols 3. December 2010