



Llywodraeth Cynulliad Cymru  
Welsh Assembly Government

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# A guide for staff who give support to people with autism and their families



This booklet is an Easy Read version of:

**'Autistic Spectrum Disorders: 'A Guide for Practitioners  
providing family support in Wales'**

Welsh Assembly Government, March 2011



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# This booklet is to help staff:

- understand and learn about Autism
- be able to support the person with Autism and their family



The booklet is for staff supporting children and young people with autism. It will also be useful for staff supporting adults.

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 member of staff.

Where the booklet refers to 'parent', this can mean parents and any other family carer.



# 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 and there is no cure.

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

More than 1 person in a family can have Autism. It can be Genetic. Genetic is when conditions can pass from parents to their children.

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

Some might have high support needs.

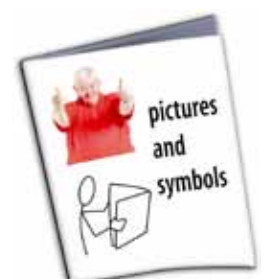
For people with high functioning autism they can live independent lives, form relationships and have children.

Asperger Syndrome is a type of autism but people with this do not have learning disabilities. Although high functioning Autism and Asperger Syndrome are different, people's needs are often met in a similar way.



# 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 a specific item or following set times to do things;
- 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 effect my senses

**Sight** – I might not like bright lights and colours. Others 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 a 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?

You should re-assure my parents that the behaviours I show are not to do with how they are as a parent.

You need to get to know me as a person, who I am, what I like and don't like, how I behave and how I live.

It is important to remember that there is a reason for my behaviour. You only need to only deal with my behaviours that are a problem.



# Effects on my family

Having autism can affect my whole family, often in different ways.

## 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 affected.
- 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 my Autism.
- He often hides his feelings, but might feel angry.





## My Brother or Sister

**My autism will affect my brother or sister in different ways. They might feel:**

- that they want to 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.



Being part of a support group with others in a similar situation can be helpful.

Where families are bigger, there is more support so they often cope better.

## Growing up

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

Over time, my parents know and understand me well so may be able to cope better.

As I get older, sometimes my behaviours don't happen so often, so life can get easier.

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



## 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.



## What can you do in times of change?

Change happens to everyone. It can be things like:

- Moving house or moving school.
- Becoming an adult.
- If parents split up.
- A death in the family.
- Small changes like a change of clothes.

You need to:

- help my family with planning for the change;
- introduce small changes in a place that is familiar to me;
- speak to me in the way I can understand. I might need pictures and symbols or Easy Read;
- visit a new place beforehand;
- use ways to make me feel calm and relaxed.



# What can you do to give me and my family a break?

A break gives my family time away from caring for me. I like to have a break too. This is called a Short Term Break or Respite Care.

## Breaks can be:

- in my home where someone comes to look after me;
- at another house;
- in the daytime or evening;
- trips and activities.

Short term breaks help my family stay well and help us all get on better together.

Often my family reaches a difficult time before a short term break is offered to us. This is not good. They need to be planned beforehand.

## Families often don't get short term breaks because

- there are not enough places;
- they might not be right for the person;
- there is not enough choice.

My parents have the right to an Assessment of need.

If they have a need for a short term break, you should make sure this happens.



# Meetings with me and my family

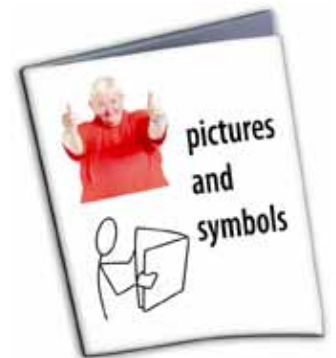
Meetings between you, me and my family can be:

- visits to my home or at your office
- to look at mine and my families' changing needs. This is called a Review.



## How you can plan a good meeting?

- Explain the reason for the meeting.
- Use language that I can understand such as plain English, Easy Read or pictures. Do not use hard words or jargon.
- See if I want to meet beforehand to prepare for the meeting.
- Ask me if I want to come to the meeting. If I don't, then get my views beforehand. I could write them down.
- Make sure the meeting goes at the right pace so I can understand and give my views.
- Make sure I can communicate at the meeting. I might need to leave. Give me a red card or some thing like that to hold up.
- Make sure the room suits me. That is how big it is, the light and what is in it. Show me the room beforehand so I feel OK about it.





•Keep to time and talk about only one topic at a time.

•Use my name if you want to ask me a question.  
You don't need to look at me in the eye as  
I might not like that.



•Don't ask questions that lead me answer in a certain way. Ask questions that give me a chance to give my views.

•Give me time to answer the question.  
It is OK if I don't want to answer.



•Even if I fidget and move about, do not assume that I am not listening.

•Sum up what has been said at the meeting.

•End the meeting by talking about the good points of the meeting so we all go away feeling positive.



•Send out an Easy Read summary of the meeting.



•Follow up the meeting with a phone call or a visit to my home.

## To help with your learning and understanding of Autism

To help you learn and understand you can go to seminars and training courses on Autism.



# Where you can get more information

## Welsh Assembly Government

The Welsh Assembly Government has an Action Plan on Autism.

## Social Services

There is someone in your local social services department that plans for services for people with Autism. You can find out who this person is by contacting your social services department or the Welsh Local Government Association on 029 2046 8600.

## Voluntary organisations

National Autistic Society has a lot of information on their website and has free fact sheets. [www.autism.org.uk](http://www.autism.org.uk)

All Wales Autism Resource tells you where to find information you need and holds events. [www.awares.org.uk](http://www.awares.org.uk)

SNAP Cymru gives information and support about learning needs. [www.snapcymru.org.uk](http://www.snapcymru.org.uk)

Contact a Family gives information and support to families of children with disabilities. [www.contactfamily.org.uk](http://www.contactfamily.org.uk)



There is more information on where to find information in the main booklet. To get copies of this booklet go to [www.wales.gov.uk](http://www.wales.gov.uk)  
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