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# Autistic Spectrum Disorders

A Guide for Practitioners Providing Family  
Support in Wales

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The information contained in this booklet is based on research evidence from a variety of sources.

## What are Autism Spectrum Disorders?

Autism is a wide 'spectrum' of disorders, which includes Asperger Syndrome<sup>1</sup>, and affects around 1 in 100 people in very different ways. Some can live typical and independent lives, form relationships and have children, while others will always need specialist support. The main differences for people with Asperger syndrome are that they may experience no delay in their development of language or intellectual ability.

All will, however, experience varying levels of difficulty in the three areas known as the 'triad of impairments':

- social communication;
- social interaction;
- social imagination.

### Difficulty with social communication

This includes verbal and non verbal language. Many people affected by autism cannot interpret body language, tone of voice or facial expression like a smile or frown. Some take words very literally: for example, interpret the phrase 'It's smashing' as meaning something is breaking rather than something is good; or not understand the intended meaning of commonly used phrases or jokes.

Others have limited language and need to use symbols or signs for communication. Some may repeat what's just been said, or talk only about one topic. Although some have good language skills, they may still not know when to start or end a conversation or will not understand the 'give and take' rules in conversation.

<sup>1</sup> Asperger syndrome can be confused with High Functioning Autism (HFA). Although these are different diagnoses, there is little clinical difference between them and no differences in terms of approach or treatment.

## Difficulty with social interaction

People with autism often don't understand other people's emotions or feelings and find them too unpredictable. This can make it hard for them to form friendships or fit in socially, even if they want to and this can cause anxiety. Some people may not understand social rules, such as how close to stand to someone, or what appropriate conversation topics are. Others may appear insensitive, or prefer to be alone, not seek comfort from others or seem to behave very strangely.

## Difficulty with social imagination

Many people with autism are extremely creative, so difficulty with social imagination must not be mistaken for lack of imagination. Some have difficulty in understanding other people's thoughts and actions, imagining alternative outcomes to situations, predicting what will happen next and may have no concept of danger. Although some do have imaginative pastimes, these are likely to be repetitive activities. Many find coping in unfamiliar situations extremely hard and need support to prepare for change or plan for the future.

## Other characteristics:

- Routines and rules - such as wanting to travel the same route to a place each time, always carrying a specific item, following set rituals.
- Sensory sensitivity - over or under-sensitive sight or sound, or sense of touch, smell or taste.
- Special interests - that can turn into a career or remain a lifelong hobby.
- Learning disabilities - around two-thirds of people with autism also have a learning disability.

# The effect of having a relative with autism in the family

## Parents

The presence of autism is likely to have an effect on the whole family and this will vary according to family circumstance. Mothers tend to be the main carers and may experience more emotional distress and health problems than fathers. This is more likely if the child has behaviour problems and if there is little family support. Mothers often have to give up work or can work only part-time and this has a significant impact on their own career hopes and the family finances.

Fathers tend to be affected more by the stress experienced by the mother than by the autism itself, and this can put pressure on relationships. Fathers often suppress their feelings, but may show anger. Mothers often rely on talking to others, especially other mothers of children with autism, to help deal with their emotions. There is some evidence to suggest that a higher rate of lone parenting exists amongst those caring for children with autism, compared to the general population.

“My husband couldn’t accept that there was something wrong and this caused friction in our family, although the grandparents have been great it has been a rollercoaster ride for all of us” (Parent).

## Siblings

The effect on siblings can be very varied. Some may become protective of their sibling with autism and others may feel resentment or embarrassment.

“...people look at us in funny ways... just because it’s a family with autism... so if he starts swearing or starts kicking, you know, it’s quite embarrassing because people might think, oh, you know, their mother or father taught him to do that, so it’s quite embarrassing to me to think that people sort of disrespecting my family and me and my brother.” (Sibling<sup>2</sup>).

<sup>2</sup> Petalas, M. A., Hastings, R. P., Nash, S., Dowey, A., & Reilly, D. (2009). “I like that he always shows who he is”: The Perceptions and Experiences of Siblings with a Brother with Autism Spectrum Disorder. *International Journal of Disability, Development and Education*, 56, 381-399.

Some may develop higher levels of social and caring skills and gain self-esteem. Sisters often assume a greater mothering role while brothers sometimes experience the burden of higher parental expectations. As they get older, siblings may worry about the role that they will have to play in their brother or sister's future.

“When [my mum's] really old, am I going to have to look after him, which I wouldn't mind doing, but is he going to be able to look after himself? That's what worries me about it,” (Adolescent Sibling<sup>3</sup>).

They may also worry about whether their own children will have autism. Better adjustment has been found in larger families where additional siblings provide more sources of support. Sibling support groups can also be beneficial. Effects can be life-long, as some studies have suggested that siblings are much less likely to marry.

### Effects over time

Effects on families can be expected to change over time. Childhood can be the most difficult due to inexperience and a lack of understanding about autism within the family, amongst relatives and the general public. Adolescence, too, can bring problems when the typical expectations of increased independence and autonomy are not met. Adolescents with Asperger syndrome can also be prone to depression and this can be hard for the whole family. As with the general population depression needs to be identified and treated and it can continue or recur from time to time. However, depression is not an inevitable result of Asperger syndrome.

<sup>3</sup>Petalas, M. A., Hastings, R. P., Nash, S., Hall, L. M., Joannidi, H., & Dowey, A. (under review) The Perceptions and Experiences of Teenage Sibling with a Brother with an Autism Spectrum Disorder.

The effects of caring into adulthood can vary: planning for the future, continued behaviour problems or severe disabilities can maintain high stress levels. However, as carers become more experienced over time they can sometimes cope better. Some autism traits like obsessions and unresponsiveness can eventually diminish with age, and this can reduce stress.

## **It's not bad parenting and this is why...**

“Most professionals support by telling you all theory or recommending more books to read. I am asking for their help because I've got the knowledge and read the ideas but am struggling to make it work. When you are shattered, physically and verbally battered, mentally and physically exhausted there is no one to help” (Parent).

Behaviour is an expression of the way a person with autism experiences and makes sense of the world and how they relate to others. It is important to reassure families that the behaviours that they see are not driven by parenting style.

A range of behaviours could be observed, such as:

- Refusing to eat, being uncooperative.
- Obsessions and ritualistic patterns.
- Physically harming self or others, lack of sense of danger.
- Inappropriate questions, shouting, swearing, running away.
- Flapping hands, rocking, spinning.
- Inappropriate or unintentional sexual behaviour.

“At the heart of understanding why difficult behaviours occur is the following assumption; all behaviour has a purpose” (Veronica Bliss 1999) stressful, tiring and embarrassing.

If a person cannot communicate their wants and needs then their feelings may be expressed through their behaviour.

Communication difficulties can lead to frustration, anxiety and confusion and create misunderstandings.



A lack of awareness of social rules and the perspectives of others may lead an individual to develop behaviour which could appear inappropriate but helps them to avoid or limit social contact they find uncomfortable.

A need for routine and predictability means that it is often important for people to understand what is happening now, for how long, when it finishes and what happens next. Without clear information some may become distressed.

### Sensory considerations

Although universally acknowledged as being a characteristic of autism, the sensory processing difficulties experienced are often overlooked. What we see, hear, feel, smell, and taste gives us information about our environment and ourselves. As well as an under or over sensitivity, many people with autism find it hard to process a range of sensory stimulation at one time.

Some behaviours are an attempt by the individual to create a comfortable environment and avoid their senses becoming overloaded.

“There’s a test if you can’t hear enough but there is no test if you hear too much, being over sensitive to noise is like having the radio turned up too loud all of the time, when people shout it hurts my son’s ears” (Parent).

Difficulties with fine or gross motor coordination and control can cause clumsiness or unusual motor responses, e.g. odd posture, walking on tip toes that can be misunderstood as attention seeking behaviour.

Positive strategies can ONLY be developed by fundamentally understanding how autism affects the individual. This will include a detailed analysis of the person’s situation, environment and sensory profile amongst other things, to investigate what function the behaviour has. It is also important to consider if the behaviour is really a problem at all.

Remember, all behaviour has a purpose although sometimes it can take time to understand.

## At times of change

Throughout life, change is unavoidable. Any change, large or small, can be a challenging experience for both those affected by autism and their families and is likely to cause anxiety and unease. Change can include a wide variety of things, including:

- moving house, school or job;
- transition from children's to adult services;
- going on holiday;
- marital breakdown;
- bereavement;
- small changes such as someone wearing a different jumper or ornaments being moved.

“Change is always difficult people don't realise how much work and preparation we have to do to prepare him for any sort of change. We have moved home twice and each time our son's behavioural problems flared up to the point of aggression” (Parent).

In order to prepare for change in the future it can be very helpful for the family to consider introducing small changes in a familiar environment. This may help the person with autism to get used to the fact that things do change. Even so, when real change is happening a person with autism will need a lot of help. It may be necessary to support carers to prepare and plan carefully to ensure that change can happen as smoothly and seamlessly as possible.

It is vital that, whatever the nature of the change, the person is prepared.

- Be proactive in finding out what is involved in a specific change.
- Make sure that the communication and plan is tailored to the person's needs and level of understanding.
- Use visual supports if necessary (in words, pictures or symbols).

During a period of change it is important help the person to reduce their levels of anxiety. Methods that can help include relaxation techniques, reassurance, visiting new places in advance, taking a familiar object with you and knowing the detail of what is going to happen.

## Respite care

Respite care allows carers to take a break from the responsibility of caring and should also provide a positive experience for the person with autism. Too often families reach crisis before respite is considered and so a proactive approach is needed.

Good quality planned respite helps sustain family health and wellbeing as carers can face serious health and social risks as a result of stress associated with continuous care giving. Carers may also wish to work, undertake training or participate in leisure activities all of which can positively impact on family circumstances.

Respite care can take many forms such as:

- Emergency respite care for unforeseen circumstances, such as illness
- Residential respite care for planned periods of time
- Domiciliary respite care which is provided in the home
- Day centre respite care
- Befrienders who spend time with the person with autism
- Clubs, activity days and play schemes
- Family aides
- Shared Care

There are a number of barriers to all families in accessing respite support, including critical short supply, inconsistent quality and suitability, little choice and carer's confidence in the service being offered.

In addition there are a number of specific barriers relating to autism such as lack of:

- Understanding of autism.
- Preparation for change of environment and care-givers.
- An individualised approach, incorporating special interests.
- Clear routines.
- Flexible approach to suit changing needs.

“Our son has never had so called respite because he doesn’t like new people so we have to rely on friends, which we cannot do very often as we don’t want to burden them” (Parent).

Respite care has been identified as a significant area of unmet need. Current legislation (Carers Equal Opportunities Act 2004) gives carers increased rights when their needs are being assessed. It is important that in supporting families effectively their need for respite care is assessed and acted upon.

## Setting up a meeting

Meetings take many forms such as appointments including home visits and reviews. They are one of the key ways in which professionals work with families and people with autism.

Before reading the following section, take a moment to think of a meeting you have attended such as your last job interview, hospital appointment or some other situation where you were uncertain and not in control. Can you remember your feelings?

You may have felt calm, but it is more likely that you felt anxious. This state of anxiety is a normal state for so many children and adults who have autism and they live with this anxiety every minute of every day. In an unfamiliar situation such as a meeting with you, their anxiety levels will rise.

Therefore, it is important that the preparation for a meeting, and the conduct of the meeting itself, are given a lot of thought, by trying to see things from the viewpoint of the individual with autism.

## Good practice checklist:

- Ensure that the person with autism and parents/carers/advocate know the reason for the meeting. You may need to put this in writing, and simplify the language used.
- Establish the best ways to communicate with the person with autism eg using words, using pictures.
- See the person informally beforehand to explain what the meeting is about and to consider if a pre-meeting is required in order for them to fully participate.
- Offer a choice to the person on whether they want to attend the meeting or not.
- If attending is too stressful ensure that their opinions are sought and brought to the meeting.
- Tailor the meeting to the person's needs to ensure that they are given every opportunity to express their opinions and wishes. Carers or an advocate may be able to help with this.
- It may be useful for the person to write down their contribution to the meeting which could be read out on their behalf.
- If the person attends, ensure that they are able to let someone know if they feel uncomfortable during the meeting. Consider the need for visual cues (e.g. they could show you a red card to indicate a need to leave).
- Arrange a time and place which is best for the person and consider the environment. Look at the room set up - people with autism can be distracted by windows, light, noise levels, temperature, posters and general office clutter.
- Show the person the room beforehand and let them choose where they would like to sit, and next to whom. They may need plenty of space or to walk around.
- Decide on a time to finish and try to be prompt.
- Take each agenda item in turn and discuss one topic at a time. It is good practice not to digress, nor interrupt each other.

- Speak clearly and concisely. Try not to use abbreviations e.g. SENCO, CDT or local sayings that may be hard to understand. It can also be useful to avoid ambiguity, metaphors and idioms.
- Bear in mind that the person may be unable to process too much verbal information, read facial expressions or understand gesture.
- When speaking to the person, it may be helpful to use their name first and wait to gain attention before speaking. Remember this needn't mean eye contact. Many people with autism find it difficult to look at the person that is talking to them.
- Allow the person time to respond but do not insist on a response.
- Do not ask leading questions such as 'but you like going there, don't you, John?'
- Don't assume that the person understands and if the person is fidgety or is fiddling, don't assume they are not listening. They may be doing this to keep calm.
- At the end of the meeting check what has been understood, give a brief summary and try not to leave unanswered questions.
- End the meeting on a positive note, emphasising good points. People with autism can have low self esteem and need reassurance.
- Send out an easy to read summary of the meeting.
- Arrange for a named person to follow up the meeting with a phone call or home visit.

## **“Keep learning” Links and Useful Resources**

There are lots of opportunities in Wales today through a variety of organisations to hear people with autism talk about their experiences, and to attend seminars, workshops and training programmes. Many local authorities and Local Health Boards in Wales run local autism training opportunities.

## Useful Resources and Links within Wales:

- In April 2008, the Welsh Assembly Government published the world's first government action plan for autism and this strategy has led to a local ASD being identified within every local authority area in Wales. You can find out who your local ASD lead is by contacting your local social services dept or by contacting the Welsh Local Government Association (tel 02920 468600). The WLGA is the home for three ASD regional support officers who will also be able to give you the information you require. Make sure you receive by email regular copies of the WLGA ASD Strategic Action Plan newsletter, which updates autism progress and practice throughout Wales, simply give you email address to the WLGA ASD Regional Support Officers ([ASDinfo@wlga.co.uk](mailto:ASDinfo@wlga.co.uk))
- Also in Wales from 2010 the Wales Autism Research Centre (WARC) located in the School of Psychology, Cardiff University. The Director of the autism research team is Professor Sue Leekam, Chair in Autism. The research centre's website is [www.cardiff.ac.uk/psych/home2/warc/](http://www.cardiff.ac.uk/psych/home2/warc/)
- [www.awares.org](http://www.awares.org) - The All Wales Autism Resource (AWARES) provides details of a wide range of useful resources for people in Wales, including events and learning opportunities. Every autumn this website also hosts the world on-line autism conference which attracts contributions from many of the world's leading 'autism' educators, researchers, clinicians, family members and individuals with an ASD.
- [www.autism.org.uk](http://www.autism.org.uk) - The National Autistic Society website includes a wealth of information about behaviour, communication and play, benefits, diagnosis, and practical tips for parents, as well as training opportunities. There are a wide range of free factsheets available for download and publications available to purchase from the National Autistic Society by visiting [www.autism.org.uk/shop](http://www.autism.org.uk/shop)

- [www.autistica.org.uk](http://www.autistica.org.uk) - is an autism research funding charity and their website includes a range of information on biomedical research to bring benefits to individuals and families affected by autism spectrum disorders.
- [www.thegraycentre.org](http://www.thegraycentre.org) - Information and resources relating to social stories and comic strip conversations.
- [www.do2learn.com](http://www.do2learn.com) - Games, songs, communication cards, print resources and information for special needs.
- [www.pecs.com](http://www.pecs.com) - Information about the widely-used Picture Exchange Communication System.
- [www.contactfamily.org.uk](http://www.contactfamily.org.uk) - Contact a Family is a UK wide charity that provides support and information for families with a disabled child.
- [www.snapcymru.org](http://www.snapcymru.org) - SNAP Cymru is a charity in Wales offering information and support to families of children with additional learning needs (ALN).

Adam Feinstein, who is a both parent of a young man with autism and is employed in Wales by Autism Cymru, is the author of “A History of Autism, Conversations with the Pioneers” which was published by Blackwells/Wiley in 2010. This includes the most accurate history to date of autism, the way it is currently viewed throughout the world and the approaches being used by governments and those working with people with autism. This book is being viewed as a ‘classic’ in the disabilities field.

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