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# Autistic Spectrum Disorders

A Guide for Practitioners Working in Advocacy  
Services in Wales

December 2010



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## What are Autism Spectrum Disorders?

Autism is a lifelong disorder which commonly affects three main areas of development:

- Social understanding; the ability to understand the thoughts, feelings and behaviour of other people.
- Social communication; the ability to understand and use many forms of communication including speech, body language, gesture, facial expression, pitch and tone of voice.
- Ability to think and act flexibly; sometimes described as impaired social imagination, this affects the ability to act spontaneously and try new experiences. It tends to mean that people with autism are highly dependent on routine and resistant to change. This can also impair the development of play.

We think of autism as a spectrum condition, because it encompasses such a wide range of strengths, skills and needs. Some people with autism may have an additional learning disability; others may have normal or above normal levels of intelligence. Some might have additional mental health conditions and anxiety is often a particular difficulty. In addition, many people on the autism spectrum have some differences of sensory perception and processing.

## Implications of ASD for Advocacy Services

A growing number of organizations are providing advocacy for people with learning disabilities or mental health issues and many autistic people access these services. However it is important to recognize that there are significant features of the autistic spectrum which require the support of an advocate with training and experience in working with people on the autism spectrum.

It might be obvious that a person with limited verbal communication could benefit from the support of an advocate, but a person with ASD and good verbal skills might appear to be

able to communicate their needs independently and thus not be offered access to advocacy. However, evidence shows that good expressive communication skills do not equate to understanding in autism. People on the autism spectrum tend to use language literally and for conveying factual information. The ability to use language to describe emotions, feelings, needs or concerns is impaired, as is the ability to gauge what other people already know, what they need to know and what to tell them. Whilst it may not be immediately obvious that autism poses real difficulties, any person with a diagnosis of autism, regardless of the level of intellectual ability, might require the support of an advocate.

## What is Advocacy?

Advocacy is taking action to help vulnerable people say what they want, secure their rights, represent their interests and obtain the services they need.

The National Autistic Society describes advocacy as:

“A process of supporting and enabling people to express their views”

An advocate is someone who listens and helps an individual to be heard, and to decide what to do, who is there just for the person concerned and is on their side. An advocate is not usually part of social services or an individual’s service provider, and does not take the place of family and friends.

## Types of Advocacy

There are different types of organisation that offer advocacy and there are different types of advocacy. It is important to approach an organisation that offers the right type of advocacy, and to remember that individuals with autism may need different types of advocacy in different situations and at different stages of life.

## Self Advocacy

Supports the individual to communicate their wishes and views themselves.

It is important to identify early in the advocacy relationship what level of capacity and interest the person has in representing themselves. To strengthen skills and reduce anxiety, friends and supporters can prepare individuals by using role play scenarios to learn about meetings, or visit venues and meeting rooms ahead of appointments. Some people with autism are able to write down their needs and views instead of having an advocate to speak for them. It is always preferable to support a person to learn how to self-advocate in the long term rather than to use an advocate but ability, age and interest may make that problematic.

Those involved in planning for and supporting a person on the autism spectrum should be prepared to help them to use music, film, pictures, symbols or any method that works for the person to enable them to make their voice heard and help them understand the decision making events that frame their lives.

## Citizen Advocacy

Is usually for adults, and involves an advocate (sometimes an unpaid volunteer) who works with an individual to find out their views and needs, and then speaks for them. In citizen advocacy, getting to know the individual with autism is essential because the advocate does not make decisions for a person. The advocate must be able to communicate with the person to find out what their views are and will probably work with the individual over a long period of time. Citizen advocates, like most other formal advocates, are usually supported and guided by an advocacy organization.

## Short term advocacy

Is also sometimes called issue-based or crisis advocacy; a paid or volunteer advocate works short term with an individual in order to resolve a particular need or issue. This type of advocacy might

be needed when a person with ASD encounters a sudden change or crisis.

## Group Advocacy

Is when people who use the same services, or who share a common interest or difficulty gather together to speak out jointly. This enables people to have a say about how their services are organised and run. Whilst well established and tested in services for people with learning disability or mental ill health, this is not always an easy model for people on the autism spectrum to use as some find it difficult to participate in group activities.

Examples in Wales include a schools council for pupils with Asperger syndrome in mainstream school and children with ASD taking part in a Junior Safeguarding Board, looking at bullying and child protection. There are also a rising number of online groups, particularly for adults. Have a look online for the Autism Hub, which promotes diversity and human rights, with ethics and diversity as the core guiding principles; aspects include empowerment, advocacy, acceptance and a positive outlook.

## Peer Advocacy

Describes an advocacy relationship between an advocate on the autism spectrum working to support another person on the spectrum to speak out or represent their wishes and views. An advantage of peer advocacy is that the advocate might have a deep understanding of the difficulties and experiences of the person they are advocating for, so trust and understanding are quickly established between the advocacy partners. A possible disadvantage is that some people on the spectrum have an impaired ability to see another person's point of view, and a tendency to assume that others want, think, believe and know the same things that they do. There is a risk that the peer advocate actually advocates for him/herself rather than the individual concerned. This can be overcome by increasing the availability of trained peer advocates within existing advocacy organizations, enabling the advocate with ASD to develop

listening and reflective skills and to leave their own agenda outside the advocacy partnership.

### Professional Advocates

Are trained and/or qualified for the service they offer and they are paid for their services. They are not usually involved in any other way in the life of the person they advocate for, but have understanding and experience of autism which enables them to work successfully with this group of children and adults, and to speak on their behalf.

### Legal Advocacy

Is carried out by trained lawyers or barristers who can represent people on the spectrum in the Criminal Justice System. The legal advocate assists the person in exercising or defending their rights, but this is not advocacy in the same sense as above. The theoretical basis in the legal arena is best interest in the law, not the best interest of the individual. For example, the law may work under guidance that cannot support the individual to pursue what they would choose, such as an independent or isolated lifestyle.

### Non-instructed Advocacy

Is the last resort in the field of advocacy and differs in that the advocate is expected to use a greater level of judgment than in instructed advocacy. Advocates will undertake non-instructed advocacy when an individual is not able to instruct another person to speak or act on their behalf and is not able to make their views or wishes clear in a specific situation. The advocate makes representations based on the perceived and theoretical preferences of the person with ASD. It is important for the advocate to get to know the person, to use observation and to reflect on what the person “tells” by their behaviour and mood, and to use information and advice from others who know them well. The quality of life measures that most people would find

acceptable, together with relevant legislation and standards in social care are used as a baseline and compared with the quality of life of the person being advocated for. A knowledge and understanding of the autism spectrum is essential, as we should not expect that people on the spectrum will necessarily want or need the usual measures of an acceptable quality of life, such as holidays, friends and employment (although many people on the spectrum do).

“The non-instructed advocate seeks to uphold the person’s rights; ensure fair and equal treatment and access to services; and make certain that decisions are taken with due consideration for their unique preferences and perspective.” (Henderson R, 2007 p.7).

### Case study:

Jim lives in a residential home with 14 other people. Jim has a few spoken words and uses a few signs, but he is not able to tell another person what he wants. Jim’s family and staff at the residential home have observed that he seems to like the rock band Aerosmith and he enjoys being underneath trees. He doesn’t like sudden loud noises or groups of other people. Jim’s family and the staff at the home agree that Jim seems happiest when out in the car: he claps his hands and sings along with the radio. Jim gets upset most mornings because there are not enough staff and not enough cars for him to go out every day. Jim’s social worker, support workers, the home manager and his family have talked about what will make Jim’s quality of life better; could he move to a place where there are less other people? Could he visit home more often? How about training more staff to use signs and pictures to communicate with Jim? Jim’s advocate spends a lot of time getting to know Jim and says the important thing is for him to have a car of his own, using the mobility element of his disability living allowance, because she concludes this will make the most positive difference to his quality of life.

have been explored and exhausted. Additionally, an individual's capacity needs to be regularly revisited as all people's skills change over time, especially if motivated. However, it may be appropriate for people on the autism spectrum who have an additional learning disability and are unable to tell another person what they want or need.

## Why people with Autism might need Advocacy

People on the autism spectrum have difficulty knowing what they need to communicate to others as they tend to assume that people know how they think and feel and, indeed think and feel the same thing. In addition, they might have difficulty understanding the link between action and consequences. They might need someone to help explain the likely consequences of their choices and explore options. An advocate can help the person to explore choice and make it clear to others how much independent choice the individual actually wants. Often, people on the autism spectrum have priorities we would not expect.

### Case study:

Will is 19 and lives in a flat in a shared house. His doors and windows are not secure and other residents come into Will's flat, borrow his belongings and use his property. The person living upstairs is a drug user and sometimes threatening people come to collect money or sell drugs. Will's family, his support worker and social worker all agree that moving to a different flat is the top priority for Will. However, Will is more focussed on saving up to buy a new digital camera so he can pursue his special interest in photography. At a meeting to review Will's situation his advocate supports him to express this in writing and is able to explain why the new camera is so important to Will. This enables Will and his friends and supporters to make a plan which addresses both the need for alternative housing and the need for a digital camera.

the range of choices available. An advocate can help to make this clear.

We know that some people with autism remain in the family home long after the age at which most people move on to a level of independence. Although they may be vulnerable people and need extra support and safeguarding, opportunity to undertake challenge, risk and autonomy is crucial to well-being and development. Some people need the support of an advocate to help them move on to more independent lives and experience the risks and personal achievements associated with adult life.

A person with ASD might need an advocate at any time of choice, change or crisis. To help families and supporters, the following are examples of times and situations when it is a good idea to ask for advocacy.

## **Why people with Autism might need Advocacy**

In education, in order to identify and access an education provision that meets the individuals' needs and to ease transition from one school to another. One in five children and young people with ASD will be excluded at some time during their school years (NAS 2000) and will need the support of an advocate in appeals, and to resolve issues around behaviour, anxiety and whether or not the provision can meet their needs. Transport to and from school can also be an issue because drivers and escorts need to understand the communication and sensory needs of the young person.

When the education provision that is most appropriate is residential, and perhaps a long way from home an advocate might be needed to help the child or young person express their wants and needs.

When a child or young person is particularly vulnerable due to their circumstances, for example when looked after by the local authority, during child protection processes (in order to obtain

adaptations to meet the needs of children and young people with ASD and to enable them to attend and participate in meetings) or to help resolve family contact issues when a child or young person is in care.

During transition from school to adult life, when moving on from the family home toward greater independence and to find suitable housing and employment (and sometimes to be supported in employment). The individual might need the support of an advocate to help negotiate the benefits system and get what they are entitled to, to obtain the support that will enable them to make friends and integrate into society or to access health, social care and voluntary services.

To access appropriate psychological support. An advocate might be needed to ensure that this is provided with understanding of the autistic perspective and sensory, communicative and cognitive style of the condition, and with awareness of underlying mental health issues.

### If the person becomes involved with the criminal justice system.

There is no evidence that people with autism are more likely to commit crime than any other group in society, but there is evidence that they encounter the police more frequently as witnesses, victims or perpetrators of crime. Children and young people are vulnerable and therefore protected in these circumstances. The diagnosis of autism confers vulnerable adult status on individual with ASD in the criminal justice system. This should trigger access to support including the presence of an Appropriate Adult during interview and other measures to protect the person and ensure they are treated fairly. To advocate effectively in these circumstances familiarity with both the criminal justice system and the autism spectrum is necessary. Issues of competency, intent, mitigating circumstance and remorse may all come into play.

Once charged with a crime, the individual with ASD might be examined by a psychiatrist in order to determine competency. Only if judged competent to assist in his or her defence can the person be tried. The concept of intent is fundamental in British law and determination of intent is often crucial when criminal proceedings are taken against a person with ASD. Indeed, because they involve detailed enquiry into a person's history and behaviour, attempts to determine intent can lead to a first diagnosis of ASD in some individual cases.

If an individual is able to give a clear factual account of their actions but shows no appearance of remorse (because the ability to describe emotion and feeling is impaired among people with ASD) this might be mistaken for intent. The advocate requires knowledge of both the individual concerned and the cognitive and communicative style of people with ASDs to act effectively for this person. Whilst autism cannot absolve or exonerate someone of criminal responsibility, an advocate might need to help protect a person with ASD from a conviction that is based solely on evidence that is linked to autism, for example when the person's description of their actions is the only evidence of the crime. Advocates need to be fair, objective and able to treat each case individually.

### Mental capacity or competency

The well being and support needs of individuals with autism can fluctuate over time and according to their situation. There might be times in an individual's life when, just like anybody else, they lack capacity to make important decisions about their life. An advocate can help a person with ASD to plan for these. For example a person who experiences periodic severe depression can make decisions in advance about the sort of treatment and support they want to receive.

There might also be certain issues or aspects of adult life about which an individual with autism is not able to make decisions. Sometimes preventative work is not possible, or an unexpected

crisis can arise. For these situations, the Mental Capacity Act (2005) introduced the statutory role of the Independent Mental Capacity Advocate (IMCA) to support people who lack capacity to make certain decisions. Local Authorities and NHS bodies have a duty to instruct an IMCA to support an individual if they meet the criteria as laid out in the Act.

### An IMCA must be instructed where:

- There is a decision to be made regarding either serious medical treatment or change of accommodation.
- The person has no close family or friends to represent their views.
- The person has been deemed by the Decision Maker not to have capacity to make that decision in accordance with the assessment of capacity as defined in the Act.

Visit [www.imcawales.org](http://www.imcawales.org) to find out which organisations in your area offer the independent mental health advocacy service.

## Successful Advocacy: potential barriers and solutions

It can take a long time to gain the trust of a person with autism and to really get to know them. It's important that the advocate has sufficient time and is prepared to ask for time frames and agendas that suit the child or adult. Unexpected changes and cancellations are not good, so try to ensure that these don't happen. In case they do, try to prepare for the unexpected and have back up plans and photos and schedules for alternate scenarios. Some advocates might find it difficult to understand and relate to the very different styles and ways of thinking and perceiving in autistic individuals. Even once a supportive rapport is established, the individual with ASD might still find it very difficult to make choices and decisions, connect up their possible actions with the likely consequences and see all the available options.

An advocate who has Asperger syndrome sums up the solution;

“Have more advocates trained to work with people on the spectrum, have more advocates who are on the spectrum, or provide autism awareness training for all advocates who might encounter a person with ASD.”

## **What the Advocate needs to know about the Autism Spectrum**

As an advocate working with and on behalf of autistic children or adults you need to know about autistic thinking and perception. People with autism are concrete thinkers and have difficulty with grey areas and uncertainty. They work best within a predictable framework which should govern the behaviour of others around them. Individuals with ASD need to know what to expect of you, what your job description is, what you can do for them and what you cannot do. You will need to set realistic time lines and achievable aims.

Be aware of bright lights, noises, smells, colours and tactile stimuli. Sometimes these get mixed up so the person may perceive a particular colour as a painful stimulus, or numbers as having texture. They might find things about other people aversive, for example strong perfume or aftershave, or a loud voice. These environmental and interpersonal issues can affect the person's stress levels and so their ability to communicate and understand. Speak clearly and say what you mean; avoid speculation, figures of speech, irony, sarcasm and implied meaning. Slow your speech and be prepared to pause to allow your advocacy partner to absorb information and respond to questions.

It might be difficult for people on the autism spectrum to share the interests of others and they often appear to be lacking in empathy. Sometimes you will need to explain things to them that you might expect to be intuitively understood. A very simple example;

You ask, “Tom, can you shut the door?” and Tom replies “Yes” but the door remains open. Say instead, “Tom, please shut the door.”

People with autism often have special interests which are all absorbing and are the main focus of their attention. You can use such interest to motivate engagement and build rapport. Plan ahead and visit rooms where meetings or interviews will take place. Use photos of the space and of who will be there. Set clear start and finish times and, if necessary use pictures of a clock face to show this. Provide the child or adult with a clear signal, sign or way of saying “I need to stop now”. When possible remove or adjust aspects of the setting the individual might find challenging. Find out what objects, rituals or movements can comfort the person and enable them to use these in stressful situations. You may need to do this without regard to whether the objects of comfort and behaviours are age or situation appropriate; it is more important that they help the person to feel calm and safe. Be reflective in your work and be adaptable to new behaviours and communication.

## Helpful Links and Further Reading

### 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 lead being appointed 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](tel:02920468600)). 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 your email address to the WLGA ASD Regional Support officers [ASDinfo@wlga.co.uk](mailto:ASDinfo@wlga.co.uk)

- As a result of the WAG ASD Strategic Action Plan there are a number of other awareness-raising materials being published for Teachers, GP surgeries, Criminal Justice System and so on.
- All-Wales Autism Resource: a bi-lingual information resource for ASD in Wales and each autumn runs the world on-line autism conference featuring many of the world's leading educators, clinicians, researchers including individuals with ASD and parents [www.awares.org](http://www.awares.org)
- Advocacy Wales is a National network of independent advocacy providers, visit <http://advocacywales.org>
- Advocacy Action Wales provides a range of advocacy services to vulnerable adults in South East Wales; [www.actionforadvocacy.org.uk](http://www.actionforadvocacy.org.uk)  
For more information about non-instructed advocacy, Rick Henderson's 2007 article, Non-Instructed Advocacy in Focus can be found in the Articles and Resources section of the Action for Advocacy website.

### Links outside of Wales

- The National Autistic Society website contains very useful guidance and advice [www.autism.org.uk](http://www.autism.org.uk)  
(Choose 'our services' from the left hand menu, followed by 'support for people with autism'.)
- 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" published by Blackwells/Wiley. 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 viewed as a modern 'classic' in the disabilities field.

The British Institute of Learning Disability is a good source of information about advocacy for people who have learning disabilities; [www.bild.org.uk](http://www.bild.org.uk)

<http://www.autism-hub.co.uk/> the autism hub promotes diversity and human rights with ethics and diversity as the core guiding principles; aspects include empowerment/advocacy, acceptance and a positive outlook.

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We are very grateful to the young people and adults on the autism spectrum who shared their personal experiences with us and helped to write this booklet.