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Autistic Spectrum Disorders

Employment and Work Related Issues in Wales

December 2010



ISBN 978 0 7504 5978 5 © Crown copyright 2011 WAG10-11196 F1141011

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What are Autism Spectrum Disorders?

First identified more than 50 years ago, Autism is a life-long condition which affects half a million people in the UK. It is one of the most common developmental disorders and is normally diagnosed in early childhood, though many people on the autism spectrum reach adulthood without a formal diagnosis. Autism affects people of all racial, ethnic and socio-economic background and tens of million of people worldwide. Current estimates suggest that boys are four times more likely to be diagnosed with autism than girls.

Autism is a spectrum disorder varying in severity and impact from individual to individual, ranging from those with no speech and severe learning disabilities to people with IQ in the average range, some of whom are able to maintain paid work, relationships, and family life. Asperger Syndrome is a form of autism in which speech development and IQ are normal, but in which social disability can be compounded by depression and mental health problems.

People with autism have difficulties communicating, forming relationships with others and making sense of the world around them. They might also have unusual patterns of language development, narrow and intense areas of special interests, and a marked preference for routine and predictability in everyday life. Anomalies of sensory perception and processing are common among people with autism, particularly hypersensitivity to bright lights, tactile stimuli, and to noise. The autism spectrum encompasses a wide range of strengths, skills, and needs.

Impact of ASD for Employment and related areas

Autism is classed as a disability under the Disability Discrimination Act (DDA) 1996, under which people with disabilities are protected at work and as customers. Although some people on the autism spectrum do not consider themselves disabled, they should still be offered this protection. Many want to work and live an ordinary, valued life in the

community, but estimates suggest that only 6% (NAS Scotland) are in full time paid employment, though they may be highly qualified. So how can we approach employment for people who are on the autism spectrum?

For some people, the impact of autism is so severe they are not likely to be able to work in any capacity. More commonly, if a person has autism with an additional learning disability, it may be necessary to look at work experience, therapeutic work, voluntary work or a supported work placement as part of a progression towards paid work. Employment can promote increased independence and self-esteem; provide learning opportunities, structure to the day and a predictable environment, all of which are beneficial to many people on the autism spectrum. Even when earning money is not the primary objective, the person should be paid a fair wage.

Careers Wales

Careers Wales can guide and support people with autism through the education system and into employment. Their work begins with supporting young people in year 9 in school to help them develop their future career plans. A careers adviser usually attends the year 9 transition review for school pupils with ASD and the review in the young person's final year at school. After school, the careers adviser will stay in touch with the young person whilst they are at college, whether residential or local. The careers adviser can help support people who wish to enter training and those who are looking for work. This can include help with application forms, completion of a CV and support with interview skills.

Case study

Patrick left school aged 16 having sat Entry Level exams and then attended a local Further Education College for 3 years. At college he studied a Life Skills Course and a Vocational Studies Course at Level 1. Both courses enabled Patrick to continue to improve his life and basic skills and gain work experience 1 day per week.

Since childhood Patrick has been keenly interested in cars and he has always wanted to to be a mechanic, so the careers adviser arranged for his work experience to be in a local garage. During this time it became apparent that Patrick did not have the communication skills required to deal directly with customers, nor the ability to retain information, or the fine motor skills necessary to work as a mechanic. However, by the time Patrick left College aged 19 he had passed his driving test and owned a car. He took a lot of pride in his car, and was passionate about keeping it spotlessly clean inside and out.

After leaving college Patrick entered a work-based training programme, which enabled him to gain a work placement in another local garage. The employer was aware that Patrick did not have the skills or ability to train as a mechanic, so initially the employer gave him routine tasks such as changing oil, changing tyres and brakes. It soon became apparent to the employer that Patrick was meticulous about the appearance and cleanliness of cars, and that he preferred to work on his own, so Patrick became more involved in the car valeting process and he thoroughly enjoyed this. The garage owner realized that he had found a 'niche' role for Patrick and offered him employment as a full-time car valet through the Work-Step initiative.

Careers advisers aim to offer a personalized and individual service and can continue working with individuals throughout education and on entry into employment, training and higher education. There is no upper age limit for people accessing services from Careers Wales. Providing careers advice and guidance to adults represents the main growth area of their work.

Careers advisers work closely with training organisations, with voluntary organisations and with the Disability Employment Advisors at Job Centre Plus and have a strong commitment to multi agency working.

Find out more about the work of Careers Wales and the location of your nearest careers centre at www.careerswales.com

Seeking employment

For people with autism but no additional learning disability, most of whom will have a diagnosis of Asperger Syndrome, paid employment is a goal. There are some key considerations for this group of people and for those supporting them to find paid employment;

Finding an employment niche which puts the individual's skills and interests to good use is very important, but can take a long time. Some people with Asperger Syndrome, particularly those comfortable within their specialist field or within academia can secure employment without help, but most will need some support to negotiate the application, interview and induction process. Likewise, once employed, some people will need ongoing mentoring to maintain secure employment.

They might need advice about what people expect of them and what the boundaries and unwritten social rules are at work. For example, what is the dress code, or how to tell when it is their turn to make the tea? When things go wrong, they might not know who to tell, or how to describe what is happening. A degree of mentoring is often all that is required to maintain a safe, productive and positive working environment for a person on the autism spectrum.

Even when able and keen to find work, it can be difficult for a person on the autism spectrum to find the right job. The application and interview process is stressful and full of uncertainties. Once in work, if the requirements overstretch the person's social or communication skills, mental health and physical well being can be affected, so maintaining the correct level of benefit whilst seeking suitable work is crucial.

Work related benefits

Job Seekers Allowance (JSA) is a benefit that involves signing on every fortnight, being available for, and actively seeking work.

Employment and Support Allowance (ESA) is designed to help people with a disability and health related conditions move into work if they are able to. It has replaced Incapacity Benefit and has two main groups. All new claimants will have to attend a work capability assessment to determine which group they will be in. Some people will go into the support group, in which you do not have to undertake work related activities, but can volunteer to do so if you wish. Others will be in the work related activity group in which you are provided with a range of support to help you find suitable work.

When going to see someone to discuss benefits, it is important that an individual with ASD is accompanied by some one who can help with communication. This should be someone who knows the individual well, and can help to describe what they are good at and explain any areas of difficulty. Clear information about the Pathways system, ESA and eligibility can be found on the Disability Alliance website.

For those people with autism on JSA, visiting the job centre once a fortnight to sign on and providing proof of ongoing consistent efforts to find work can be very stressful. Every Job Centre has a Disability Employment Advisor (DEA) and it is the DEAs responsibility to record that an individual has an ASD and what reasonable adjustments need to be made when attending the Jobcentre.

Advice for people with autism visiting the job centre:

- It is ok to take someone with you. It's best to choose some one who knows you well and can help with communication.
- You can ask for a private room.

- Tell the person to give you clear instructions. It is ok to ask them to speak slowly or to repeat things. It's their job to help you.
- Ask for help with job searches.
- Ask for help with completing forms.
- You can and should ask to see the DEA.

Remember, a disability is the only criteria necessary in order to see a DEA. It doesn't matter if you are on benefits, or in work; you can still see the DEA. Seeing a DEA is voluntary; in fact the DEA is the only person in the job centre you don't have to see. You can find out more about the role and responsibilities of the DEA on the Job Centre Plus website.

Advice for Job Centre Plus advisors

- The most important factor in making sure that attendance at a Job Centre has a good outcome for a person with an ASD is that they see the DEA rather than anyone else.
- Many people with autism find it very difficult to use a telephone.
 They have a disability under the DDA and are entitled to a face to face interview.
- You might need someone to facilitate communication: encourage the person with an ASD to bring a supporter with them.
- It will help if the person with autism can see the same advisor every time. For some people, this is essential.
- People with autism might have great difficulty coping in open plan spaces and with the different unknown people within them.
- Open plan offices or lack of privacy can cause problems about confidentiality, because people with autism might not being able to filter out other people's overheard conversations.
- Privacy will help the person relax and communicate.
- Remember this person wants a job.

Curricula Vitae, Application forms and Interviews

A CV is an optimum description of ability, in which we focus on our strengths. On an application form we enhance our skills and play down our weaknesses. In an interview, we rely on our social understanding and social communication and try to appear interesting, confident, and competent. Whilst not lying, we might not tell the literal truth either and both parties know this. We also add up the available information and mould the CV, the application form or our interview style to what we think the employer wants. This is very difficult for an individual with autism spectrum condition to achieve, as is speculating about what a job might be like and making a judgment whether he or she will be good at it.

Support to find and start work

Help finding work, negotiating the application and interview process, and mentoring during the first weeks or months of employment can be via a Supported employment scheme or a Job Broker. The individual is supported by an organisation which has specialist training in supporting job seekers who may need additional support to achieve the employers required standards in the early days of their employment. The first step is development of a detailed, holistic and person centred vocational profile, followed by a job search to match potential work opportunities to the person's skills and interests. A Job coach will support the person to enter employment via a path that suits them, including work placements and work trials leading to paid employment. The job coach will support the individual as they learn the skills needed and once this is done, will gradually withdraw.

Different organisations across Wales are linked in a consortium, the Wales Association of Supported Employment Agencies.

Access to supported employment schemes is usually via the DEA, but access to a Job Broker could be direct or via another adviser and this varies across Wales. At the time of writing,

the system is about to change, with the introduction of Flexible New Deal.

Find out about more about Flexible New Deal and about New Deal for Disabled People at the Direct.gov.uk website.

Effective Communication

Some people with autism do not learn to use speech for communication. Most do, but often the spoken word is not their preferred communication method and they may have difficulty remembering verbal information and instruction. It can help if you use written information, lists, timetables and schedules to support spoken communication. Email and text messaging are preferable to telephone calls for many autistic people.

Communication difficulties are less noticeable among those with Asperger Syndrome, who tend to have fluent speech, well developed vocabulary and precise use of grammar. However, they might have difficulty understanding and using words that describe emotions and feelings and convey information which is not fact. You should expect that they will use and interpret spoken communication literally and will miss implied meaning, sarcasm, irony, innuendo and some forms of humour. They might have naive understanding and use of lies, white lies and deception. An impaired ability to read or use facial expression, pitch and tone of voice, body language and gesture and to interpret the meaning usually carried by eye contact is also a feature of the autism spectrum.

Whether you are a JCP advisor, a DEA, a job broker, employer, colleague or a friend you can help by preparing in advance and making some adjustments to your own communicative style.

- Speak slowly and clearly.
- If you are a loud person, lower the volume of your voice.
- Say what you mean.
- Avoid unnecessary chat.
- Ask direct questions.

- Ask one question, or give one instruction at a time.
- Avoid irony, sarcasm, innuendo, ambiguity and figures of speech.
- Allow the person time to process the information you have given or the question you have asked.
- Think about supporting your spoken communication with written instructions and information.
- Check understanding, if you need to repeat a question, don't change the way you ask it (providing you are sure you meant what you said the first time).
- Don't hurry.
- Be honest when giving feedback and explanations; do not tell the person everything is fine if there are problems.
 Explain things that you might expect to be self evident.
- Don't expect the person to make eye contact until they get to know you.
- Bright lights, background noise and strong scents can cause discomfort and reduce the person's ability to concentrate and communicate.

Remember no two individuals with autism are the same; once you get to know the person it will be much easier to meet their communicative needs.

Why recruit people who have Autism?

In the field of music, consider the work of Gary Numan, electronic pop pioneer who revealed in 2001 that he has Asperger syndrome, or the remarkable pianist, Derek Paravicini. Derek cannot count to ten, has limited spoken communication and needs constant support, but he has perfect pitch, is able to remember and play any piece of music he has ever heard and has just brought out his first CD, a jazz compilation called Sounds to Be.

In science, consider the work of Temple Grandin, world famous authority on animal behaviour and cattle handling, professor of animal science at Colorado state university, advisor to commercial giants such as McDonalds and internationally acclaimed author on animal welfare. Temple says:

"People on the autistic spectrum have uneven skills; they will be very good at one thing. We need to be finding out what an Autistic child's going to be good at and develop that specialised talent into an employable skill, or a really good hobby that they can share. There are many famous scientists who have high-functioning Asperger's or Autism. Einstein had no speech until age five and would be diagnosed as Autistic today. When I was three I was completely Autistic with no speech." http://www.bbc.co.uk/ouch/interviews/autism_helps_me_understand_animals_an_interview_with_temple_grandin.shtml

The artist Stephen Wiltshire first came to public attention as a child in a BBC documentary "The Foolish Wise Ones" shown in 1987. At three years old Stephen was diagnosed with autism; he did not speak and lived in a world of his own, but showed an extraordinary artistic talent. Now an adult, he exhibits his work in his own Gallery and has been awarded an O.B.E. Away from arts and science, Vernon Smith, the Nobel-prize winning economist has spoken out about the creative benefits of Asperger syndrome. "I can switch out and go into a concentrated mode and the world is completely shut out," he said in a recent interview. "If I'm writing something, nothing else exists.

Perhaps the most common field of intense interest for adults who have Asperger syndrome is computer science. Satoshi Tajiri, Creator of Pokemon has been diagnosed with Asperger syndrome. He has been described by Nintendo officials as creative, but reclusive and eccentric.

Not everyone with autism will excel in their chosen field and some have skills and interests that cannot by linked with paid employment. Nonetheless they share strengths and traits which are valuable to employers and when it is not possible for an individual to use their special skill or interest in a work situation it is a good idea to focus on these common positive traits of the autism spectrum instead. Jobs that involve routine, predictability,

and precision require strengths that are associated with the autism spectrum, as does work which necessitates logical thinking, tasks based on order, sequencing, organisation and systems maintenance.

Individuals with autism might have difficulty understanding the thoughts and behaviour of other people and might not be well attuned to how others perceive them, so they can be socially odd. However, they are honest, reliable, meticulous and loyal. Focusing on detail is an intrinsic characteristic of people on the autism spectrum, so as employees they are good at quality control, at spotting other people's mistakes, and at tasks which require precision.

Once given instructions, they are likely to carry them out to the letter and to finish what they have started so some attention to work load is necessary.

Rather than try to define what might be a suitable or unsuitable job for a person with autism, recognize their strengths and skills as an individual and build upon these. Clearly defined job roles and descriptions in a work place where everyone knows what is expected of them are helpful aspects for people on the autism spectrum.

As the employer and colleagues develop an understanding of the person's unique needs strengths and skills, so the individual with ASD can also develop the social, communicative and adaptive skills needed to become a valued employee.

An employer comments

"Having a member of our team with Asperger syndrome has been a challenge that has brought huge benefits for all of us, both personal and in our work. I would definitely encourage others to seize the opportunities available."

Helpful links and sources of further information:

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 your 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)

From the autumn of 2010 there will be a Wales Autism Employment Ambassador, funded by the Welsh Assembly Government. The task of the Ambassador is to meet with employers throughout Wales in order to raise to the profile of individuals with autistic spectrum disorders seeking employment and to emphasize to employers the many positive benefits arising for businesses in Wales.

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/

Outside of Wales:

Thorkil Stonne, Specialisterne: a remarkably successful business in Denmark in which most of the employees have Asperger syndrome. www.specialisterne.com

Employers Forum for Disability www.efd.org.uk

British Association of Supported Employers (which includes the former association for supportive employment, AFSE) www.base-uk.org

The National Autistic Society website contains guidance and advice for both employers and employees www.nas.org.uk

Asperger Syndrome Employment Workbook, Roger N Meyer, (2001) Jessica Kingsley, London, ISBN 1853027960 You can read this book online if you visit the Google search engine, type "autism and employment" into the box and click on the "search books" button.

Marc Segar's personal account, "A survival guide for people with Asperger syndrome" has advice about job applications and interviews on page 24 and is available as a book and online.

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 June 2010. This includes the most accurate history to date of autism, the way is currently viewed throughout the world and the approaches being used by governments and those working with people with autism. This book is being is being viewed as a modern 'classic' in the disabilities field.

This Welsh Assembly Government publication has been written by:

Mary Rendell (ASD Regional Support Officer, Mid &West Wales) with help and guidance from people with ASD, their families and carers and professionals from Job Centre Plus, The Shaw Trust and Careers Wales.

Special thanks to:

Samuel; Kerry; Angela; Jenny; and Kirsty.