

**Herefordshire
Disability
United**



Network News

2nd Autism Seminar June 2014



The isolation of
autism

We welcome articles from individuals and organisations to promote their stories or interests.
Please contact the Editor..... details on the back page.

Editorial: Herefordshire Autism Partnership update

Well has it begun to make a difference? Certainly there was renewed optimism around the table when we met on 5th June at the Shire Hall. The well balanced group consisted of those on the spectrum both young and older, representatives from adult social care, education, the 2gether Trust, employment, the Health & Well Being Board, NAS local branch etc totalling about twenty five attendees.

Some aspects are still in their infancy such as the Draft Action Plan. It was agreed that everyone should have the opportunity to offer their thoughts on the outlined plan so far, which John Gorman has established as a starting point.

From the agenda we concentrated on areas which need attention such as hate crime and employment where we had experts in their field to debate and inform.

We even established there are around 170 children in local schools who have been identified as being on the spectrum, but it is felt the truer figure is around 250. This is something which can provide a starting point for better future provision.

The new Education Health Care plan to replace Statementing from September this year may provide better outcomes for those on the spectrum, but being a guinea pig as the process develops will yet decide. Schools have to project "local offers" on their websites so that those looking for better fit for their child might choose a suitable school. This is going to be a huge learning curve which we hope will be successful.

Making use of the expertise around the table seemed a sensible move, with the proposition of sub groups to discuss in depth employment issues, plus applications for grants which will soon be available from the national strategy developed by the government. Volunteers were encouraged to email John Gorman if they wish to join such groups.

Social skills are one aspect of Aspergers which need to be developed, and it was commented on the complete lack of any social group in the county purely for them. The isolation many feel could be dramatically improved if a compatible social function could be developed. The rural nature of this county really means either something central as a start, which could grow into market towns both north and south. This will be on the next agenda.

The actual report from 5th June meeting when available will be on our website.

If you'd like to know about the photo on the front cover, it was taken at Westonbury Mill Water Gardens, Pembridge, Herefordshire. The folly is a dome made from 5000 wine bottles, which sparkle when the sun shines, (not when I went) and is included in a book "Follies of Europe". The gardens are 80% accessible to wheelchairs and have an accessible toilet too, plus café. Open daily 1st April to 30th Sept 11.00– 5.00pm www.westonburymillwatergardens.com



About

Herefordshire Disability United

Herefordshire Disability United is an organisation that has developed to voice the concerns of disabled people and to provide a platform where disability issues can be raised and policies developed.

Herefordshire Disability United (HDU) is an organisation run by people with disabilities for people with disabilities. It was started in January 2011 and its objectives are:

To promote the interests, welfare and social inclusion of disabled people living in Herefordshire by facilitating the following:

- Fostering understanding among policy-makers and practitioners of the needs and aspirations of disabled people.
- Taking part in consultations to make aware issues that affect persons with disabilities
- Raising awareness and debate on disability issues, stimulating the engagement of disabled people within that debate.
- Providing a platform where matters of concern to disabled people can be raised and policies developed.
- Making representations to public sector organisations, voluntary sector organisations, local and central government and local and national business to improve their policies and practices.
- Exchanging information with organisations providing services for disabled people, co-operating with but independent of such organisations.
- Providing information and sources of advice to disabled people.
- Combating discrimination on the grounds of disability by promoting equality of opportunity and a positive image of disabled people.
- Being a democratic, non sectarian, non party political organisation.

HDU newsletter contents

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A date for your diary!

24th September
Hinton Community Centre,
10.30 am-2.30 pm

Employment and disability
Details available soon

Editorial or advertising queries: Contact the editor on 07817 473813 or email info@hdu.org.uk

Contact: Herefordshire Disability United welcomes any feedback on Network News, or any of the services it provides.

Disclaimer: The views expressed in Network News are not necessarily those of Herefordshire Disability United.

Statementing in education

What does Statementing mean?

A **statement of special needs** is a formal document detailing a child's learning difficulties and the help that will be given.

If a child needs help at school - beyond what their teachers can provide - a 'statement of special needs' will ensure they get the right help. A statement is only necessary if the school is unable to meet a child's needs on its own.

Only about 2 % of children need a statement. Parents shouldn't assume that because their child has special learning needs, that they necessarily need a **statement**.

OK, so that's the current situation which is about to change.

The new initiative will bring in Education Health Care plans (EHC).

These new EHC plans will expect Local Authorities to :

- ◆ Work with health and social care colleagues jointly to commission services to deliver integrated support for CYP with SEN aged 0-25.
- ◆ Consult children, young people and their parents, and local providers (including post-16 education providers) ...to deliver the new system.
- ◆ Work with local partners, parents and young people to co-produce and publish a local offer of SEN services and provision to assist young people in finding employment, obtaining accommodation and participating in society.
- ◆ Provide a coordinated education, health and care assessment for children and young people aged 0-25, and new Education, Health and Care (EHC) plans that will replace the two existing systems of SEN statements (in schools) and Learning Difficulty Assessments (in FE and training).
- ◆ Offer those with EHC plans the option of a personal budget.
- ◆ Consider the transition from children's to adult services and whether to use a new power to provide children's services to young people over 18 to smooth their transition.

This new change in provision is expected to start in September 2014, when any new assessment for "Statementing" will come under the EHC plan. Over the next three years we expect a gradual change over for existing students who are already assessed under the old system.

The Helter Skelter Diary

Have you heard of Nicholas Robinson? No not Nick Robinson the political reporter on the BBC, but a young author who has Adult ADHD and Aspergers Syndrome.

I came across an article recently about him in a magazine and then did the usual "Google search". There isn't that much to find and sometimes you need to be devious to get anywhere but I do feel he is worthy to note. So for those who wish to read in depth this is the link: <http://nicholasthered.blogspot.co.uk/>

For others I will explain. The link takes you to a blog, where Nicholas writes his thoughts. Many are quite ordinary, but they also show an insight into his world which seems to run in a parallel to ours with the sentences quite simplistic. You will read about "Nicholas the Red Adventures", basically his daily life showing the highlight currently which is art. Its sad to see he refers to the fact that as he is getting more absorbed into his art, he is speaking less and less, as there isn't a need to express himself in that manner always.

Nicholas admits he has mental health issues and his adventures permit him to immerse himself in a subject which he hopes will give an insight into the conditions and therefore raise awareness of sensitive subjects.

He has a published book, "The Helter Skelter Diary (Diary of Autistic Adventurer)" which is published by Chipamunka Publisher in both hard back and eBook formats. The press release quotes:

"What's it like to be autistic? Does it hurt? Is it funny? Do people think you're odd, or just wonderful? Nicholas Robinson is uniquely well qualified to explain, which he does with candour, humour, and a wide-eyed sense of adventure"

The Little Professor Syndrome

Read about the "Little Professor Syndrome". To check out the whole article try this: <http://www.bbc.co.uk/dna/place-london/plain/A10450694>

Here are some extracts:

"Some little professors' fascinations are so all-consuming that they must eat on dinnerware associated with the subject, eat food shaped or named similarly to the object of their fascination, and clutch a favourite book or model related to that subject."

"Little professors are often very affectionate, and very often inappropriately so".

"When an Aspie becomes physically and emotionally attracted to someone, and has to deal with the fact that that someone has to be interested in them also, then the real trouble begins".

"A little professor might be able to tell you how to get to the moon, but be unable to find his bedroom without a map".

Research Autism

Research Autism is the only charity in the UK exclusively dedicated to research into interventions in autism. They can be found at:
<http://www.researchautism.net/about-us-research-autism>.

Established in 2003 as the Autism Intervention Research Trust, they carry out high quality, independent research into new and existing health, education, social and other interventions. Their goal is the improvement of quality of life and outlook for the individuals affected and those around them.

Current project underway by the charity is:

ACCESS: Autism Employment Online Information Centre

A three year research project

Description: Access is an interactive online employment website which ensures that all parties (whether they are employers and their colleagues, or jobseekers and employees with autism) – have ready access to all the resources they need to make the employment of those with autism as easy and successful as possible.

Impact: Based on the experience of Prospects, the National Autistic Society's supported employment service, this project will provide

- Evidence-based, practical information and guidance for employers inc. the opportunity to understand the perspective of other parties in the employment process and the opportunity to share best practice
- Evidence-based, practical information and guidance for jobseekers with autism

More information: [Access: Autism Employment Online Information Centre](#)

They believe that their website will provide a range of benefits to its visitors, including:

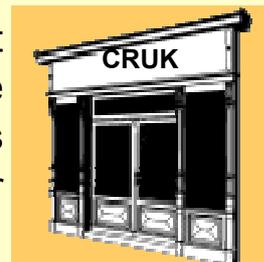
- Practical information and guidance for employers on the employment of people with autism spectrum disorders e.g. relevant legislation
- The opportunity to understand the perspective of other parties in the employment process e.g. employers gaining a better understanding of some of the practical problems facing employees with autism
- The opportunity to share best practice e.g. how to tell an employee s/he needs to improve personal hygiene

Practical information and guidance for jobseekers with autism on how to apply and interview for a job, and on support available for

This information is taken directly from the Research Autism website. Other projects are underway, and a wide range of completed ones are viewable too. An all day event on 1st July in London is bookable called, "Autism and Learning Disabilities".

Volunteering helps gauge employability

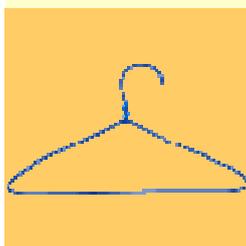
We hear so much about getting people back to work, or in fact getting people into a job in the first place, that I decided to put some thoughts together on what is considered “work experience”. This is based on my role as Volunteer Assistant Manager at the Cancer Research shop in Ross on Wye.



To the discerning customer seeking a bargain when perusing a charity shop, little thought is given to what actually goes on behind the scenes, but the brigade of volunteers who take up the challenge are a worthy crew, without which the charity would struggle to reach its aim.....sufficient funding to find a cure for cancer.

Amongst the regular usually retired volunteers, are several adults with learning difficulties/ disabilities (yes there is a difference). They have their set times/ days mostly about two hours a week when they gain work experience in a sociable environment. Some come with support workers whilst others need no assistance at all. So you will understand that in the Ross on Wye Cancer Research shop we actively encourage people from all walks of life for mutual benefit.

With common rules and regulations in force things like health and safety, capability assessments, fire risk/ evacuation and references to be carried out, (the same standard for all volunteers), differentiation to the subject is essential. However, it is possible to portray the information in an easy to understand manner, before each person is passed to be a volunteer at the shop. There isn't the need for exam passes, just the willingness to work as part of the team and fulfil potential.

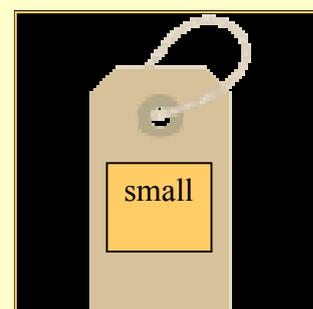


On the first floor out of the public gaze, items are sorted for value and saleability. Baskets of seasonal clothing await new life, to be expertly hung by our special assistants. The repetitive nature of this task is actually a useful learning skill, and mirrors the



recurring daily tasks by which knowledge is achieved. They need to understand order and a pattern to their task:

- ◆ Pick up a garment
- ◆ Take a hanger and hang it correctly
- ◆ Check the label in the garment for the size
- ◆ Find the right size cube and clip it onto the hanger
- ◆ Add a price label on which you also write the size of garment



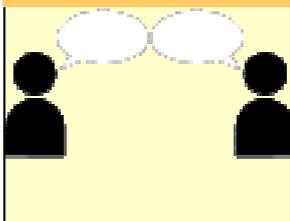
This is where all volunteers start their work regardless of ability.

Capability necessary for paid work

Now this seems a simple task, but the speed at which everyone works determines their ability to be employable. I can tell you that a couple of our special assistants are set a goal.....hang 15 items in an hour, and for this to be achieved support is necessary. Now at the same time the amount of concentration required is immense. With music playing in the background, and light hearted banter they are encouraged to meet their target and raise self esteem being a valuable asset to the team.

On the other hand we have other volunteers who are extremely capable of working on the shop floor, operating the till and chatting to customers whilst also multi tasking. Yet they are not capable of holding down a job. We currently have two volunteers with Aspergers a male and female both under 30 years old. One is still at college taking an ICT course who works one afternoon a week, whilst the other has a Science degree. The issue as many of you will understand is social interaction, or what is acceptable and what isn't.

You said what?
That's impolite



Our male friend, brilliant on the computer operated till would sit with his head in a book, and not look up until a customer stood over him wanting to buy. About a year ago I decided to have a "customer service training session", and he hasn't looked back. He now greets all customers with "Good afternoon", and passes a few sensible comments with them. No longer is his head in the book, although I still need to work on the monotone voice he uses.

Our female likes to move around the shop speaking to customers, having an empathy with young families and their children. She doesn't necessarily understand that customers need time to look around uninterrupted otherwise they won't buy anything. Too much talking puts them off, so the balance is hard to get right.

Both of these capable volunteers however do not appreciate the need for working at pace, something customers may not grasp. Those with Aspergers associate with their needs first of all, and this can be a stumbling block to paid employment. Time is money, which most businesses know means loss of profit, when not kept to a standard rate of time and motion.



Certainly one serious observation with all our special assistants, is that as soon as they are tired, feel slightly unwell, have a medical appointment or any type of worry their focus is absolutely shot. That's when paid employment would prove impossible. I'm sure Job Centres and the Government do not appreciate the emotional turmoil in which they live day after day, and also their families who worry about the future.

Written by Sylvia Nicholls

Care Act and autism

Many of you may be unaware of the next huge document to be unleashed from the government known as the Care Act. It will have a significant impact on many families not just those with members on the spectrum, but for all disabilities, and carers too. I understand there are eighty eight clauses which need to be interpreted and transformed into action by every social care department and local authority. Selected commissioners and authority workers are looking at how to bring it into action by next spring.

On looking at the NAS website, I noticed this latest information.



Details on the rules determining who will get adult social care from April 2015 have been published today (6 June), as part of a Government consultation on the regulations and guidance accompanying the Care Act 2014.

The NAS does not believe the proposals for the new national eligibility criteria reflect the basic needs of adults with autism, on crucial issues such as staying safe, building relationships or being verbally prompted to carry out tasks. They also fail to ensure that adults with autism will be assessed by assessors who have sufficient autism training.

Unless the proposals are changed to cover the specific needs of people with autism, the new system risks leaving many outside of the care system and at risk of harm.

The proposals are still subject to consultation. This means it's not too late for the Government to act. With the stakes so high, the NAS will be launching a new campaign on this issue in mid-June. This will call on the Government to ensure the very real and urgent needs of adults with autism are reflected in the decisions that are made about whether or not they should get support. It will also call for stronger requirements for community care assessors to be trained in autism.

Details on how you can join the campaign and how to respond to the Government's consultation will be available on the NAS website soon.

The consultation on the draft guidance and regulations for the Care Act can be found here:

<http://careandsupportregs.dh.gov.uk/about/>

I would urge you to keep up to date with any campaign which the NAS undertake.

Keep checking the NAS website, and HDU's too for details:

www.autism.org.uk/

www.herefordshiredisabilityunited.org.uk

Employment needs

The world of employment has many unwritten rules, but there are expectations which many of us take for granted. We know there is a start and end to the working day. We have breaks for lunch and maybe a cuppa, and we get paid for the hours we complete. If we need time off, its usually taken as “holidays” or time in lieu, and if we need a doctor’s appointment its usually not in work time.

Now someone with Aspergers, if they are enjoying what they are doing, can work unlimited hours without considering to stop. They see a task set and know when It is complete. However there also may not be any speed to their work, as to them it is not a time and motion study, just a piece of work which when it is finished is over.

The same therefore applies, if they wish to have lunch and relax a little. Being “tied to the clock” isn’t what they can necessarily accept. This of course goes against the grain for the majority of the work force and can cause ill feeling.

Conversations on the work floor may also need to be kept to a minimum, with little said and choice of words exact to fit. Therefore someone who likes to explain everything right down to the last detail, will cause irritation, and the signs will not be noticed, or the glares understood by them.

One thing for certain is the honesty and ability to speak the truth in all situations. This sounds wonderful, but those fellow employees who like to “stretch the truth” will disapprove of the state of affairs in which they find themselves. Again this causes upsets between staff, and the person with Aspergers will feel ostracised, not knowing what they have done wrong. It really can be a minefield.

The idea of a buddy or mentor to assist new employees who have Aspergers is perhaps a good idea. Training is definitely worthwhile for the line manager and colleagues so that individual’s quirks can be easily understood.

To increase productivity clear concise instructions will alleviate anxiety and can be given in electronic form so that the employee can return to them when uncertain. Time tables can be introduced which break up the long day into time slots, to understand each section, with a feedback slot before lunch and also at the end of the day. This can be verbal or again via a technology which they regularly use.

When asking questions one needs to be precise. If you say “Tell me about yourself”, as opposed to “Can you give me an idea about what you have been doing since you left school?”, which is too vague. You also need to tell the employee if they are talking too much, which is common.

Sensory needs are another issue. Too much noise, light and machinery sounds adds confusion, as will an open plan office. This type of employee needs to know their exact place to work, and their precise task. Once managed you have a valuable asset.

Autism, a change in the air!

Is something changing in Hereford for the better?

There are meetings, consultations and connections being made with a growing sense of purpose which is to develop and improve the services in the county for people on the autistic spectrum.

Through a series of meetings, initiated by Hereford Disability United, we have moved from airing our grievances, through sharing our experiences, to establishing the Autism Partnership Group and engaging in open and productive dialogue with members of Hereford Council and representatives from the Department of Health.

Sylvia Nicholls has been spreading the net wider and is in touch with an internet firm working with people with autism.

Started by Nichola Herbertson and winner of the Nominet award for most innovative business, Hao2 uses 3D Virtual World technologies to increase vocational training and employment opportunities for people with disabilities like autism. Sylvia wondered if my son might be interested, - he is and describes Hao2 as “positive and forward thinking”.



As my son Ben finished school and moved into the adult world of work and independence he was diagnosed as having Asperger Syndrome, but being considered too able to meet the criteria for any support, an assessment of need was denied.

The search for work was a lengthy one and support was patchy. One worker who supported Ben through a successful interview was then denied access to the office to help him settle in, which resulted in the employer “letting him go” after three weeks. There were several short term jobs before he found work with Hereford Council on a zero hours contract.



What chance of independence?

That other building block of adult life, independence, now required attention. I contacted and talked with various good/ well intentioned people who work to help people live independently providing practical help and advocacy but they could not assist.

No assessment and no social worker meant no access to any of these services. I spent the first years of my retirement finding suitable and affordable accommodation and supporting Ben through the process of achieving a kind of independence.

If you are living in your own house and the support is provided by your parents, how independent does that feel? Recession resulted in his working hours shrinking away to nothing and he gave up his tenancy and returned home and the search for employment began again.



Last week Ben attended a support group for job seekers, which, as with other services is run by good well intentioned people.



Aged thirty-three years, with much experience in job applications and a veteran of many self-improvement training sessions - (frequently now being run by people younger than he is), Ben was given a blank application form to fill in as an exercise to see how well he could do it.

At home using modern technology, he is communicating via email and Skype with the CEO of an international award winning company and beginning a training programme designed around his skills and interests.

The intention, is for him to begin a bigger vocational training when funding is in place and hopes are high that with hard work and the right support this might be the route to genuinely satisfying work. The landscape is shifting, change is in the air and the potential difference is breathtaking.

Written by Jane Clayton,
a concerned mother

Statistics on autism

Autism now affects about one in 100 children. There are around 100,000 children with autism in the UK, with around half a million family members directly affected by the condition

While overall the number of children with a Statement of Special Educational Needs remains at 2.8%, the number of children whose statement lists autism as a primary need has increased by 5% since 2011. The number of children at School Action Plus2 for whom autism is their primary need has increased by 12%

Recent diagnosis rates suggest four times as many boys as girls have autism.

Many families with autism live in poverty as it costs on average three times more to raise a child with a severe impairment than a non-disabled child.

Families with autism often do not get the right support putting them under immense strain. It has been estimated that the divorce rate of parents of children with autism is 60% higher than average. In a UK study of families with autism one in three were single parents.

Only 11% of carers who have children with autism work full time, and 70% say the lack of appropriate care facilities stops them working.

71% of children with autism are educated in mainstream schools and the remainder in specialist provision.

In schools with pupils with autism, only 22% of teachers have been trained specifically in autism. The majority of training given is typically one to four hours.

54% of all teachers in England do not feel they have had adequate training to teach children with autism



Young people with a disability are more likely to report being fairly or very dissatisfied with their life so far (17%) than young people without a disability (7%) at age 19.

Young people with a Statement of Special Educational Needs at 16 are twice as likely to not be in education, employment or training at 18 than those without SEN.

24.4% of pupils with autism achieved 5 A*–C GCSEs including English and mathematics in 2010/11, an increase of 2% from the previous year¹⁴. This compares to 58.2% of all pupils who achieved 5 A*–C GCSEs including English and mathematics in 2010/11, an increase of 3% from the previous year.

Ambitious about Autism



Over 40% of children with autism have been bullied at school.

Pupils with a statement of SEN are nine times more likely to receive a permanent exclusion than those pupils without SEN; Pupils with SEN but no statement are 11 times more likely to be permanently excluded.

Less than 1 in 4 young people with autism continue their education beyond school.

In a survey conducted by Ambitious about Autism, 43% of parents reported their child with autism had been formally excluded within the previous 12 months; only a quarter of these exclusions were one-off occurrences.

So what is **Ambitious about Autism**? In fact it is a national charity for children and young people with autism on whose website I have found these statistics.

Ambitious about Autism was founded as TreeHouse in 1997. It was founded as a specialist school for children with autism, with five pupils and based in a borrowed room in the Royal Free Hospital in North London. For the last 13 years, Ambitious about Autism has been growing and developing into the national charity that it is today, which provides services, raises awareness and influences policy.

Ambitious about Autism works to improve the services available for children and young people with autism and increase awareness and understanding of the condition. We're also committed to campaigning for change to ensure the needs of people with autism are understood and met. Through TreeHouse School and Ambitious Support we provide specialist education and support.

Talk about Autism is our online community for parents, carers, family members, and people on the autism spectrum to get help and support. It's a great place to ask for advice on any issue related to autism whether you have a child on the spectrum or you have a diagnosis yourself.

The site is fully moderated so we can provide a safe and friendly environment for our members. Register now to join in or take a look at the forums if you want to read the latest discussions. Plus a family blog from Matt Davis: mysonisaac.blogspot.co.uk

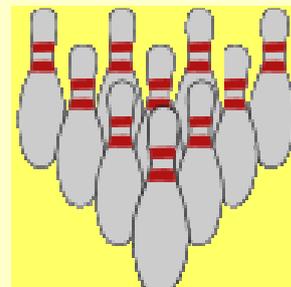
<http://www.ambitiousaboutautism.org.uk/page/index.cfm>

School holidays

.Apologies to anyone who has seen this article before, but with summer holidays coming up soon I felt it a great read and also has useful tips on coping with someone who has autism. It comes from:<http://www.bbc.co.uk/news/health-21969439>

John Williams is a single father and full-time carer for his 10-year-old son, who has autism and cerebral palsy. Both of them dread school holidays but have learned how to manage them, he says, through a process of trial and errors. John refers to his son as "The Boy" to prevent any anxiety when revealing his real name.

"There's one trip we've become good at though - 10-pin bowling. Bowling alleys have a consistency that The Boy finds reassuring. The lights aren't too bright, there's an airiness to the place and there are no surprises. You bowl the ball. It knocks things down. They get up again. Time after time.



But even then, our visit is not like most people's. So, if ever anyone fancies taking The Boy bowling for the school holidays, here's a crash course on how to make the trip a success:

- **Get there early.** The earlier the better. Preferably before the rest of civilisation has woken up. The concept of queuing and waiting is lost on The Boy who has no time for such trivial events.
- **Select your lane carefully.** You want one that's as far away from other human beings as possible. Other human beings cause anxiety and create noise, which only serves to divert attention from The Boy's own attempts to make noise. If Lanes 1-4 are occupied, Lane 37 is ideal.

Beware rented shoes. Never underestimate just how odd a concept it is to swap your own perfectly reasonable shoes for a pair that have been worn by multiple strangers. For the duration of the game, prepare to be asked at least 17 times a minute if his own shoes are safe.

- **Always use the gutter guard.** The Boy may try to convince you that he doesn't want the guards up any more, to block the gutter, as he is now good enough at bowling. He isn't. The barbaric yelp accompanying each ball that trundles slowly down the gutter, will make the noise he made in the library appear like a whimper.
- **Never, ever win.** Introducing the concept of losing to The Boy is important. But this is the child whose frustration with the world has led to him being excluded from nurseries, childminders, after-school clubs, holiday play-schemes, mainstream schools and even a special school. So while he's holding a 15lb bowling ball, it's not the ideal time to take him on.

Smile please! The stress of this trip will probably prevent you from leaving the house again for the rest of the holidays. Take lots of pictures where you're pretending to enjoy yourself. The aim is to fill up 41 pages of the school holiday diary. The other page can be used to write The Boy's name."

John Williams is a comedian who recently performed for the NAS in Camden.

Autism research volunteers wanted

This information below is copied from a PDF sent to me by James Baker.

INSTITUTE OF COGNITIVE NEUROSCIENCE



Participants needed for London-based autism research

We are interested in hearing from adults with a diagnosis of high-functioning autism or Asperger syndrome who would like to take part in our research.

At the Institute of Cognitive Neuroscience (University College London), we have an ongoing programme of research with many different projects for people on the autism spectrum. Our group was created by Professor Uta Frith and our research is now led by world-class neuroscientists.

This work helps us to understand better why individuals with ASD have particular patterns of strengths and weaknesses. Most of the projects involve paper and pencil or computer tasks, games and stories, and we run brain-imaging studies too. Most projects take place at the Institute of Cognitive Neuroscience, Queen Square, London although we sometimes visit people at their homes.

Your personal information will be stored securely and kept confidential. You are free to withdraw from our research at any time. We are flexible about the time of appointments and can see people over more than one session if necessary. You will always be compensated for your time and effort and your travel expenses will be reimbursed.

If you are interested in taking part or would like further information about our research, please contact Flora Thiébaud on 020 7679 5438, email: flora.thiebaut.11@ucl.ac.uk; or check our website: <https://sites.google.com/site/autismicn/home>

Looking forward to hearing from you!

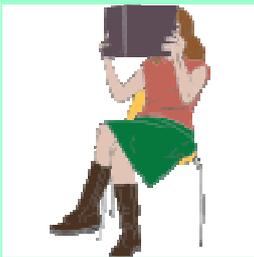
The Autism@ICN team

James runs, Hereford Make C.I.C, a social enterprise, which is a metal, wood and forging workshop open to all, whether you are a hobbyist wanting to develop your skills, a student working in wood or metal, a person wanting to make or repair something themselves, or a professional needing the space and equipment to work with in order to make your business more successful.

Contact details are:

E-mail: hereford_artisans@hotmail.co.uk or Skype 07759 852225

Growing up with Aspergers



My daughter has Asperger's Syndrome but nobody knew until she was fifteen years old as up to the age of eleven her behaviour was of little concern.

At primary school she was initially a 'normal' child but never made any real friends and became somewhat of a loner. Her behaviour came to exasperate her teacher however, probably because she was pedantic and stubborn. She was in the Brownies until aged eleven and enjoyed this, perhaps because it was structured and all girls.

Problems arose when she moved to secondary school. Because she was 'different' she was picked on, especially by boys, and was not very happy there. It was when she was about thirteen that her behaviour became more aggressive; retaliating physically when goaded by a boy in a youth choir she had joined. At school little was done by the staff to help matters and after three years she transferred to John Kyrle High School in Ross.



Things were better at John Kyrle, as staff seemed more aware of anti-social behaviour, both from her and others and acted to stop it, but her behavioural problems continued. It was her head of year that first made my wife and I aware that involving an educational psychologist might be wise. Our GP had not deemed there to be anything wrong other than normal adolescent behaviour but our concerns were growing. On the advice of the teacher we took our daughter to a private educational psychologist who diagnosed Asperger's Syndrome.

This diagnosis led to the commencement of treatment by the NHS at Gaol Street clinic when their psychologists sought to improve her social abilities. This may have had some success as soon after her diagnosis she started attending an NAS social group in Worcester with another local autistic girl. This was only one evening a month but gave them both a first taste of independent socialising. The group ceased to exist a year or so later which was disappointing for all.

It was when she was seventeen that she developed facial cancer that ultimately resulted in the loss of an eye and half her top jaw. Although obviously traumatic it was the Asperger's that helped her through this period. She accepted things as they happened with stoicism and often, good humour. The fact that she was the centre of attention in the hospital, at home and later, on her return to school was new for her, boosted her social standing and helped a lot. Ten years later she is still undergoing reconstructive surgery.

She received great support from her school and after a year's delay, obtained her A-levels and a place at Birmingham University. Her time at Uni was not without problems. She found that she was unable to share a flat with other students.

The need for local social groups

The noise, untidiness and general behaviour was anathema to her and resulted in rows and complaints. The remedy was to pay for a flat of her own on campus, not a cheap option as this was more expensive than many private rentals!



Course work was also a problem in some cases as few fellow students wished to work with her and some projects were solo efforts. The university did provide some help in the form of academic and social mentors but these seemed poorly prepared to cope and of course changed over time.

Periods away undergoing reconstructive surgery interrupted the course as well so it was five years before she graduated with an honours degree in Physics.

My daughter, now twenty seven lives on benefit in her own flat. She has never been offered paid employment despite being interviewed for jobs all over the country. Her disability benefit which makes the rent affordable is paid for her physical impairment, not the Asperger's. It is only recently that the job centre has referred her to an agency that seems to be willing and able to deal with autism and this after several complaints from my wife and I about lack of knowledge and understanding on their part.



Although able to live independently her quality of life suffers from a lack of structure, i.e. employment, and barely any social life. As far as the latter goes Herefordshire has little to offer, (see below), but it is to be hoped that this, and the chance of employment/training, will change as the new Council strategy takes effect.

Written by Colin Boughen HDU committee

Why aren't there any social groups for adults with autism in Herefordshire

My particular interest is with groups providing social interaction for young adults.



The National Autistic Society (NAS) has a branch covering Herefordshire and Worcestershire but this meets in Bromsgrove, 50 miles or more from the south of this county. It does however have a weekly social group for those over 16 years old, meeting on Tuesdays between 1.00 and 4.00pm. www.nasbranch.org.uk/worcesterandherefordshire

Other NAS groups exist in Tewkesbury, Bristol and Avon but none seem to offer much in the way of regular social functions.

This is the same for all other avenues I've researched, e.g. www.youngminds.org.uk

There are services giving advice and help to families, carers and those on the Spectrum but primarily with regard to children. No local government, charity or private organisation seems to offer social meetings for adults. **Where is the equality?**

Colin Boughen

Useful Contacts

NHS Herefordshire

Patient Advice and Liaison Service (PALS)

The County Hospital, Hereford

Mon-Fri 8.30-4.30

Office Tel No: 01432 372986

Mobile Tel No: 07825 681801

Email:

makingexperiencescount@wvt.nhs.uk

Equality and Human Rights Commission

Freepost RRLL-GHUX-CTRX, Arndale House,

Arndale Centre, Manchester, M4 3AQ

Tel: 0808 800 0082 Website:

www.equalityhumanrights.com

RADAR, now at Disability Rights UK

12 City Forum, 250 City Road, London, EC1V 8AF

Tel: 020 7250 3222 Minicom: 020 7250 4119

Email: enquiries@disabilityrightsuk.org

NHS Direct Tel: 111 (free service)

Wye Valley NHS Trust

The County Hospital

Union Walk

Hereford

HR1 2ER

Tel: 01432 355444

Wye Valley NHS Trust

Community Health

Vaughan Building

Ruckhall Lane

Belmont

Hereford

HR2 9RP

Tel: 01432 344 344

Herefordshire Council and NHS Herefordshire

Social Services Adult Duty Desk

Office hours 9am - 5pm

Office Tel No: 01432 260101

Out of hours: 0330 1239309 adults

01905 768020 children

Email:



www.autism.org.uk

email: nas@nas.org.uk

0207 833 2299

Employment and Disability 24th September

Hinton Community Centre, Hereford

Details to follow

Check the website for latest information

Network News is produced by Herefordshire Disability United,

c/o 39 Lea Villa Residential Park, Lea, nr Ross-on-Wye, Herefordshire, HR9 7GP.

Tel: 07817 473813

Email: info@hdu.org.uk

Website: www.herefordshiredisabilityunited.org.uk