

**Herefordshire  
Disability  
United**



**Network  
News**

November 2013

**A  
Unique  
Task  
In  
Strategic  
Management**

**Autism seminar special**



**Person Centred  
Support**



When HDU decided to run the autism seminar we were awaiting confirmation of an Awards For All grant, and are proud to announce this application was successful. Awards For All will enable us to organise four such events during the next fifteen months, when we hope to cover various aspects of disability.

Our initial focus of autism came about through the concern of one of our committee members who, had been trying to establish what had happened in Hereford since the Government Guidelines on implementing the Autism Act 2009 were published in March 2010. These guidelines strategy from the department of health set out a set a clear framework for all mainstream services across the public sector to work together for adults with autism. The national autism strategy aims to put these guidelines into action.

Actions in the autism strategy include:

- ◆ a new National Autism Programme Board to lead change in public services set out in the strategy
- a programme to develop training with health and social care professional bodies (backed by a £500,000 investment)
- autism awareness training for all Job Centre disability employment advisers
- guidance on making public services accessible for adults with autism, like improving buildings, public transport and communication
- a clear, consistent pathway for diagnosis.

So where are we in Hereford now? In July this year realising a local autism strategy consultation was taking place the consultation team was invited to attend our Open Meeting event “Communication and Consultation”, and discovered they were trying to reach local residents who are part of the autistic world. To promote this venture HDU took part and encouraged other local organisations and residents to participate.



I was then contacted by Tom Purser, policy officer at the National Autistic Society (NAS) to see what I knew of the local consultation, at a time when the NAS were running its consultation to update the national strategy. From here the idea of taking some responsibility came into my head, and I offered to organise our own autism seminar, on 27th November. After a meeting in Hereford with Tom we put together some suggestions, and from careful planning locally the event has been constructed. John Gorman (the person at Herefordshire Council tasked with the local autism strategy consultation) also met with Tom, so both national and local connections have been forged.

We all acknowledge cuts in every sector, but this does not mean nothing can be done. A local “Autism Board” should be formed, comprising a cross section of individuals on the Autistic Spectrum, Public Services, Carers/ Parents, and support organisations. Volunteers may well come forward at the event but we must remember, this is not just a lip service operation but an action plan to improve local lives. The seminar outcomes will contribute to the local action plan of autism work in this county.



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.

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The National Autistic Society has a wonderful website covering many aspects of the Autistic Spectrum. It offers coping strategies, advice and information, covering all ages. A quarterly magazine, "Asperger United" is produced by and for people with Aspergers Syndrome, and can be downloaded from the website.

Their main phone number is:  
020 783 2299,.

Other NAS help line numbers are on the back cover of this newsletter



**Editorial or advertising queries:** Contact the editor on 07817 473813 or email [info@hdu.org.uk](mailto:info@hdu.org.uk)

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

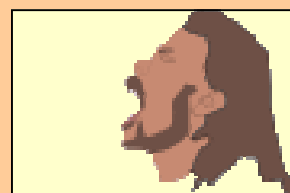
**Disclaimer:** The views expressed in Network News are not necessarily those of Herefordshire Disability United.

## Working within special needs education

For a large part of my later years in education I worked with various students who exhibited special needs. This ranged from a young girl who had been abused as a baby, a teenager who wouldn't attend to school without his mother, a bullied teenager, an 18 year old lad who when driving had killed his sister in an accident, to a 15 year old boy who tried to hang himself. I worked virtually 1to 1engaging them in the national curriculum in small safe rooms within the "Inclusion" section at a regular secondary school. My last year in mid-Wales was the most successful and it was then that I met twin 15 year old boys. For the sake of anonymity I will call them leuan and Tomas who were very different from each other.



Tomas was 5'6" tall, average build and with short wavy hair, whilst leuan was 5'11", thin and with long straight hair half way down his back. Tomas had been diagnosed as having intelligent Aspergers and had a full time support worker, whereas leuan was deemed to be an average teenage student without special needs.



One the day leuan was brought into school by his mother with ligature marks on his neck from trying to hang himself the night before. It would appear his struggle with his brother's Aspergers over the years had taken its toll, and the expectation of GCSEs later that year had tipped the balance. leuan started to show hidden huge frustration, and mood swings, often withdrawing into a corner in absolute silence.

The "Inclusion" room was a large old food tech room with many nooks and crannies, cupboards and attached areas where our collection of diverse students could re-treated as a safe haven. An unwritten rule by those students who were permitted here, was that they knew to which areas they belonged, and only during break and lunchtimes did they move freely within. This created some socialising and supporting each other without adult interaction. Obviously these students were never left unattended and staff rotated their breaks to get some mental relief from the intensity.

Whilst Tomas often expressed sullenness especially when pushed, his support worker had built up a brilliant rapport and could often extend his boundaries to achieve a higher work ethic. He also attended regular classroom lessons on better days, but for him suddenly to have his twin brother in the same complex didn't go down well. In fact as leuan settled in, you would never have believed these boys ever knew each other, let alone be from the same family. The range of emotions each exhibited individually never appeared to have any effect on the other.

leuan had now stopped attending regular lessons, and had recoiled into himself, hiding behind the mane which served him well. Outwardly he appeared artistic, with long bony fingers, and he altered his uniform to be different. But this differentness was specifically aimed at being the "other half" of a human, who was definitely part of the Aspergers' spectrum, his brother.

Written by the Editor



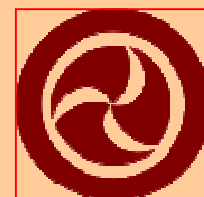
## Does diet help?

How to break into leuan's world became quite simple for me as he had a great sense of humour, liking my offbeat attitude and manner in which I worked. Having a quirky nature proved invaluable, and my approach was to show students how to achieve and be accepted by extending the usual boundaries, demonstrating that rules could be manipulated without breaking them!

I began working in two fields with leuan, his diet and art. Diet because leuan often came into school exhausted and lacking enthusiasm, not because he didn't want to participate but due to his lack of food. As you can imagine by midmorning he was even worse so something had to be done and after a discussion with him, I spoke to his mum. It seemed that apart from the standard three meals a day, he never snacked. I would bring in different exotic fruits and health bars as part of my daily regime and would encourage tasting amongst the students. leuan soon realised he liked the variety, and support by his mother a snack box was brought in daily to maintain a sunnier nature.



As another of my charges Lloyd was into art, I encouraged the two boys to work on similar projects. There wasn't competition as Lloyd was excellent at graphic comic designs, whereas leuan enjoyed Celtic images. This expression of themselves and relaxed approach help improve self esteem, for when other more academic subjects had to be taught too. The social aspect developing went further as Lloyd had realised his bullying days were over and he wanted a future, therefore accepting attendance in both English and science lessons. This saw leuan tag along with him and a friendship ensued where they were both going to achieve, despite their own differing problems.



At this time of term nearing the end of Year 11, study leave came into play at the beginning of June, but before school broke up for May half term, end of year outings were high on the agenda for those who had earned them. Still in need of small group reassurance I suggested to Lloyd and leuan that a trip to Celtica, an art gallery in Machynlleth might be a reward for them, and they were enthusiastic. Strangely though leuan asked if his older sister (at art college) could come along too.



My reply was, well if she travels on the same train and I am not responsible for her then why not? Lloyd didn't object, he enjoyed the company of females, and a day away from the pressures of school was agreed.

I have a lasting memory of the trip to Machynlleth as after spending time in the gallery, we all relaxed on the swings outside. It seemed at last the boys had matured and were able to accept that life was something to look forward to.

I have always been aware that everyone can find fulfilment if shown a different way to approach difficulties. leuan may not have been borderline Aspergers, but living on a daily basis with Tomas, shows the effects on siblings must always be considered too.

## Herefordshire Growing Point



*helping people through horticultural therapy*

**Herefordshire Growing Point** (Registered Charity No: 1006625) provides horticultural therapy to enhance the quality of life of some of Herefordshire's more vulnerable residents.



Benefits include physical and mental fitness, confidence and self-esteem, plus promoting healthy eating.

Based at Holme Lacy, our tutors help participants to explore sowing, growing and harvesting.

Each month we work with about 350 disabled or elderly people ranging from Age Concern Day Centres, 1<sup>st</sup> Key, M.I.N.D, Aspire, Acquired Brain Injury Unit (Ledbury Hospital), Livability and Barrs Court School, as well as other residential homes and projects in Herefordshire.

For more information, please see the website

<http://www.growingpoint.org.uk/contact.htm>

### **Address for correspondence:**

The Courses Co-ordinator  
Herefordshire Growing Point  
Holme Lacy College  
Herefordshire  
HR2 6LL

**Telephone:** 01544 262186

Skype (FREE) 01544 262186



**Email:** [h\\_growing\\_p@hotmail.com](mailto:h_growing_p@hotmail.com)

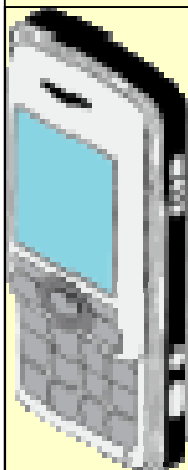
**Herefordshire Growing Point will be present at the seminar today. Take a look at their stand or speak to their representatives.**



**The Queen's Award  
for Voluntary Service**

*The MBE for volunteer groups*

## Legal rights for those with Autism.



What would you think if when buying a mobile phone, enrolling in university or applying for a driving licence, you needed to get all the appropriate paperwork signed by your parents or legal guardian?  
Not much I'm sure.



Just as well you don't live in Mexico! Here a recent court case has brought the issue to public notice, because prior to this legal action it had been very difficult for people with Asperger's syndrome or other forms of autism to be as independent as possible.

A 25 year-old Mexican, with the autistic condition Asperger's has just won the right to make key decisions about his life without parental consent. In fact the Supreme Court ruled in favour of Ricardo Adair by four votes to one. Mr Adair said that Mexican legislation violated the United Nations Convention on the Rights of People with Disabilities. It banned him from doing simple tasks by himself, such as applying for a passport, because of his condition.

"I want to be allowed to decide what to do, where to go, where and with whom I want to live or travel, where to study," Mr Adair told the Supreme Court. His mother encouraged him in the battle for equal rights, which started two years ago supported by a non-profit organisation.

Mexican legislation on people with disabilities was drafted with the intention of protecting them, by taking away legal responsibility for their actions, but Mr Adair's mother says the law is out of date.

"Many people have different levels of disability. Some need more support, some need less. This is about giving each one what they need", she said.

*This information was first seen on the BBC. Full report on their website.*

The BBC website has a number of pages dedicated to autism and Asperger's when in 2009 it ran a series of programmes documenting the conditions. You can discover more by visiting the website as listed here:

<http://www.bbc.co.uk/programmes/b00m5jb4>

Although the 2009 programmes are not available to view the stories are online, and there is also a four minute clip where two people with autism go on a date. Also if you click on the "Related links" on this page you will find four other links for similar stories relating to the condition. They cover:

**[Growing up Aspie, Asperger Syndrome and My Family and Autism, and Autism.](#)**

On 5th November, BBC 4 broadcast a programme "Challenging Behaviour and Autism."

## The Speed of Dark by Elizabeth Moon



The Speed of Dark  
By  
Elizabeth  
Moon

Have you ever read “The Speed of Dark” by Elizabeth Moon?

The story is based in the near future when disease will be a condition of the past and most genetic defects removed at birth.

Lou Arrendale a high-functioning autistic adult, is a member of a lost generation, born at the wrong time to reap the reward of medical science.

Lou lives a low-key independent life, but then he is offered to try a brand new experimental cure for his condition. With this new treatment Lou would think and act just like everyone else? But if he was free of autism would he still be himself? Would he still love the same classical music with its complications and resolutions? Would he still see the same colours and patterns in the world, shades and hues that others cannot see? Most of all would he still love Marjory a woman who may never be able to reciprocate his feelings?

Now Lou must decide if he should submit to surgery that might completely change the way he views the world...and the very essence of who he is.

The Speed of Dark is a gripping journey into the mind of an autistic person as he struggles with profound questions of humanity and matters of the heart.

Elizabeth Moon (the author) is the mother of an autistic teenager. Lou makes a deep and lasting impact on the reader whilst showing a different way of looking at the world.

I came across it by accident in a Kent library around eight years ago, but the book has a recent publication celebrating a new 10th year edition.

*(Story description taken from the Barnes & Noble website. Book available both in hard back and electronic form).*

Orchard Origins is a local group which appears to have two functions; it manages to use unwanted fruit to make delicious food products as well as engage with a diversity of people who can benefit from the out door experience. They assist with managing local orchards and work alongside the Herefordshire Nature Trust in not just preservation but also mental well being.



The Trust has teamed up with Herefordshire Mind to enable those who would benefit from developing new skills to participate alongside the volunteers.

Why not get in touch to find out more? Contact: Lawrence Green or Julie Morton on 01432 356872 or email: [orchards@herefordshirewt.co.uk](mailto:orchards@herefordshirewt.co.uk)



## The Reason I jump!

**The reason I jump** is a book/memoirs written by a 13 year old severely autistic boy, translated from Japanese by author **David Mitchell and his wife Keiko Yoshida**.



The memoirs provide insight into the depths of autism addressing topics such as beauty, time, noise and how he feels about the world around him. It also answers questions such as “why do you always line up your cars” and “why do you jump?”

Once you discover how Naoki Higashida managed to write the original book in the first place you will be absolutely amazed at his resilience. In order to write each word, Naoki had to point to each individual letter on an alphabet grid for someone else to transcribe it on paper beside him. Whilst a computer may have been quicker it would also have been too distracting, and his autism prevented any type of dictation. Every letter was painstakingly chosen and deliberately selected.

Naoki states that every aspect of autism affects his body, and has a consequence in his physical existence. As you read you begin to understand the hints he emits, of what it must be like to have no sensation of where your arms and legs are attached, or to have limbs that feel they are like “a rubbery mermaid’s tail”.

At first glance the book appears to be a manual for autism, and it certainly helps in this regard. However the poetic language he uses raises the profile to being so much more than a self help guide for parents and carers.

Naoki is aware of his “strange weird voice”, because he is “strangling his throat” when speaking. The concept of time makes Naoki anxious, as he cannot feel the passing of each second rushing past him like the landscape as he runs.

In fact this book is quite profound enabling a glimpse of a world we would find hard to imagine. Reading it will enable those who have a son or daughter or sibling with autism to discover some hidden understanding, and perhaps make sense of actions/emotions exhibited by autistic members of the family.

The translators do indeed have an autistic son themselves, and so as its revelations were unfolded, they too discovered hidden depth and meaning.

Whilst we may be aware of films like Rain Man and books such as “The Curious Incident of the Dog in the Night-time”, “The Reason I Jump” brings home the reality of how this teenager’s life needed so much understanding and patience.

***Check on-line more about author: Naoki Higashida***

## Autism article from Aubrey Baillie

Aubrey Baillie is an independent autism consultant and behaviour specialist working in Herefordshire. He provides a brief overview of some newer ways of thinking about autism.

### What's the difference between autism and Asperger's Syndrome?

This question is often asked when I present *Autism Awareness* training. If people on the Autism Spectrum who also have a learning disability are included, an answer sometimes given is that Asperger's Syndrome is a milder form of autism. However, the picture changes if one thinks just about those on the Spectrum who do *not* have a learning disability (estimated to be just over half of all people on the Spectrum).

Then, two different views exist among experts in the field of autism. One view held by Prof. Simon Baron-Cohen at Cambridge University is that although both groups on the Spectrum have a fundamental difficulty in relating to other people and in the non-verbal aspects of communication, they are also different in one important respect. If the ability to speak and understand language develops in the same way as it does in neuro-typical people, then a diagnosis of Asperger's Syndrome should be given.



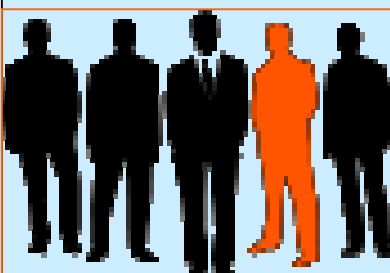
If speech develops later or not all, a diagnosis of autism is appropriate. However, a number of large-scale research studies have followed up groups of children diagnosed with either autism or Asperger's Syndrome.

Most of these studies have found that in adulthood there are no differences between the two groups in terms of their characteristics and life outcomes. This suggests that autism and Asperger's Syndrome may be two different labels for the same underlying condition. It is still possible, however, that hard-to-

detect differences may be found in the future.

My own view is that both diagnostic labels are useful and should be retained, if only because many people on the Spectrum identify positively with their diagnosis of Asperger's Syndrome.

### Is autism a disorder or a condition that presents challenges of varying degrees?



This is a controversial topic. Medical professionals have always tended to talk about a Spectrum *Disorder*. Medical professionals have always tended to talk about a Spectrum *Disorder*. Some parents with children on the Spectrum agree.



## Higher Assistant Psychologist, Hereford PCT/NHS

However, this view has increasingly been challenged over the past 15 years or so, particularly by *Aspies* who think of their autism as giving them distinct advantages; for example, the ability to focus on the small details of life which neuro-typicals tend to overlook – a very useful quality in some occupations!

This newer view of autism is supported by the fact that a number of famous scientists and mathematicians are thought to have been on the Spectrum.

Not all people on the Spectrum are *geeks*. Some are very talented artists and writers. Prof Baron-Cohen, a leading autism researcher, believes autism should be regarded as a condition that reflects a different, but socially useful developmental pathway. Temple Grandin, probably the best known person on the Spectrum expressed her view of the issue in her book:

*The Way I See It: A personal Look at Autism & Aspergers.*

What would happen if the autism gene was eliminated from the gene

Pool? You would have a bunch of people standing around in a cave, chatting and socializing and not getting anything done.”



### Obsessions or *special interests*?



The idea that people on the Spectrum are fundamentally obsessive in many of their activities has recently been challenged.

A different view is that these apparently single-minded activities serve the vital function of helping the person on the Spectrum to manage their often disturbing inner world.

They do this by blocking out the troubling thoughts and sensations that arise as a *result* of sensory disturbances. This more recent view has, in particular, been advocated by Tony Attwood, a leading authority on Asperger's Syndrome. Thus, he refers to activities that are single-mindedly pursued as *special interests* that act as *thought blockers*.

Wendy Lawson, a highly regarded writer and psychologist on the Spectrum refers to these activities as *passions*.

If denied access to their special interest when anxious, frustration at not being able to cope without the blocking activity turns to **anger** and a *meltdown* occurs.



## Meltdowns versus Tantrums

The characteristics of which are fundamentally different to a *tantrum*, as listed below:

**Characteristics of *Meltdowns* vs. Tantrums**  
**Source: *From Anxiety to Meltdown* by Deborah Lipsky**

Meltdown	Tantrums
Overwhelmed by social, cognitive and sensory experiences	Response to frustration
Catastrophic reaction	Involve emotional blackmail
Involuntary response	End more quickly
Need to escape	Others need to adopt a more a non-negotiable stance and be
Others should back off and leave the person be	Assertive and calm

Meltdowns can also be triggered by transitions from one place or activity to another, disruption in routine, sensory overload, and novel situations. When I try to explain to neuro-typical people what meltdowns are I use the rough analogy of a *fuse blowing*.

**A positive joke about Asperger's Syndrome sometimes known as**

**The Balloon Joke**

A guy is flying in a hot air balloon, and he's lost. He lowers himself over a field and calls to a guy "Can you tell me where I am and where I'm headed?"

"Sure. You're at 41 degrees 2 minutes and 14 seconds North, 144 degrees 4 minutes and 19 seconds East; you're at an altitude of 762 meters above sea level, and right now you're hovering, but you were on a vector of 234 degrees at 12 meters per second".

"Amazing! Thanks! By the way, do you have Asperger's Syndrome?"

"I do! How did you know that?"

"Because everything you said is true, it's much more detail than I need, and you told me in a way that's no use to me at all."

"Huh. Are you a clinical psychologist?"??????????

[Continued next page](#)



## Aubrey Baillie

"You don't know where you are. You don't know where you're going. You got where you are by blowing hot air. You put labels on people after asking a few questions, and you're in exactly the same spot you were 5 minutes ago, but now, somehow, it's my fault!

### Where can I find out more about autism and what it's like to be on the Spectrum?

Jessica Kingsley publishes a very wide selection of books about autism, many written by people on the Spectrum. Authoritative and useful videos covering many different aspects of autism are freely available on YouTube.

Links to a selection of these, together with more information about autism can be found on this website: [www.aubreybaillieconsulting.co.uk](http://www.aubreybaillieconsulting.co.uk)



So who is Aubrey Baillie AFBPsS ?

He is the: Higher Assistant Psychologist  
Adult Learning Disability Team, /Hereford PCT/NHS

He lives and works in Herefordshire offering specialist services to adults with an Autism Spectrum Condition (including Asperger's Syndrome) and to their families and carers. These services include the following:

- Diagnostic assessment
  - Assessment of the client's ability to read other people's facial expressions and respond appropriately
  - Help with emotion management.
  - Assessment and support in relation to the many social and emotional challenges of being on the Autism Spectrum.
  - Exploration of sensory issues the client may have.
  - Support in relation to gaining and maintaining employment.
  - Provision of interventions and advice in relation to the management of behavioural issues.
  - 
  - Signposting the client and their family to books and DVD resources to extend their understanding of autism spectrum conditions.
- Provision of high quality interactive training to family carers, PA's and support workers.
- Aubrey is also an Associate Fellow of the British Psychological Society (BPS) adhering strictly to the BPS's Code of Conduct in all professional activities.

Aubrey is also a member of the National Autistic Society

## PAWS...dogs for the disabled



PAWS (Parents Autism Workshops and Support) has grown from the work of [Dogs for the Disabled](#), an innovative charity that has developed the training of assistance dogs to work effectively with children with autism



PAWS (Parents Autism Workshops and Support) has therefore been set up under the wing of Dogs for the Disabled, to bring together the parents and carers of children with ASC to share experiences and to explore the helping potential that a pet dog might have within their family. The project is supported by the National Autistic Society and Lincoln University who are undertaking research in this area to increase our knowledge of the relationship between dogs and people.

Families nationwide are already finding amazing results; some have found their dog to be crucial when intervening in 'meltdown' behaviour; others have found the dog useful when developing a child's verbal skills; and others can happily walk to the school gates so long as their new best friend walks beside them.



Visit: [paws.dogsforthedisabled.org](http://paws.dogsforthedisabled.org) to learn more.

Also check out Facebook, Twitter or Pinterest

Contact details: [Katie Bristow-Wade PAWS Project-Team Leader](#) on 07843 327321 or 01295 252600 (both on Skype)

DDI: 232

Email: [katie.bristow-wade@dogsforthedisabled.org](mailto:katie.bristow-wade@dogsforthedisabled.org)

## The National Autistic Society (NAS)



**The National Autistic Society (NAS)** is constantly updating their work around the needs of those families affected by autism. They offer a wealth of information available which can be downloaded or of course you can contact them via phone and email too. (Details are on the back cover).

During October 2013 a local branch was begun in the West Midlands, and here is the information taken from the NAS website. *The Worcestershire and Herefordshire Branch* run a weekly information and signposting service. This service offers the chance to find out more about autism related issues and what support and services are available in the local area. We also run a weekly social group for adults (16 and above) with Asperger syndrome/high functioning autism (we accept both those with and without a formal diagnosis and also other conditions such as ADHD) as well as their parents and carers. The aim of the group is to offer opportunity to get involved in a range of activities (this can include chess, quizzes, discussion groups, sports and fitness) to help improve social interaction or to simply come along to be with others that appreciate the everyday difficulties for those on the spectrum face and make friends. The group runs Tuesdays 1 - 4pm in Bromsgrove but there is hope to set up more groups across the two counties as we evolve as a branch. We also offer or signpost to monthly parent/carers support groups and will regularly offer fundraising events, which will include speakers and presentations to raise autism awareness.

Contact; Mandy Shrimpton branch officer on 0744 2505736.

[worcsandherefordshire@nas.org.uk](mailto:worcsandherefordshire@nas.org.uk)

The NAS earlier this year ran a "Myth or Fact" campaign about autism. The full report is on their website but here are a few snippets.

**Autism Fact:** 61% of adults surveyed in 2012 said their local authority had never assessed their needs as an adult

**Autism Myth:** All children with autism get a statement of special educational needs automatically.

**Autism Fact:** SEN statements are based on need rather than diagnosis.

**Autism Fact:** 68% of parents surveyed in 2011 said it hasn't been easy to get the education support their child needs

**Autism Myth:** A person with autism can never learn new skills

**Autism Fact:** With the right help and support a person with autism can make progress and reach their potential

**Autism Fact:** The adult autism strategy is the government plan to ensure that adults

## Paul's Story.....how SIL has helped him develop



**Services for Independent Living (SIL)** is a service user and family carer controlled charitable company. A minimum of 51% of the Board of Trustees are disabled people or a family carer.

SIL provides services that enable disabled and older people to live independent lives in their own homes within their own community. They support people with learning difficulties, physical impairments, mental health issues including dementia, older people and family carers.

Below is one example of the type of support currently undertaken by SIL which shows just how person centred planning and co-operation brings happiness and new meaning to each individual.

Paul is a 26 year old man who is on the autistic spectrum. He has a learning disability, and limited verbal communication.

Having routine and consistency both of people and environment is vital for Paul. In the past, when he hasn't had this he has become very anxious, leading him to express his anxieties in behaviours which have limited his community participation.

Over the past six years Paul has been supported by Independent Living @ Home (IL@H). He has a team of regular support workers who have got to know him. (There are four support workers who provide all the support). When a member of the team has left, Paul has been involved in choosing a new support worker and they have shadowed his current team until Paul is confident in them. The team understand and support Paul's routines and rituals. They manage noise levels and visual stimuli to maintain the environment which is comfortable and calming for Paul.

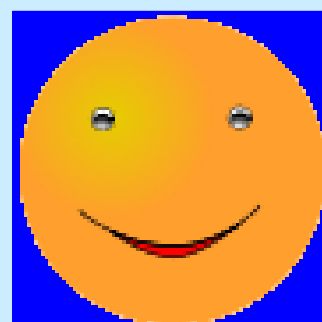
Having these regular support workers from IL@H has enabled Paul to engage in social activities, including going on holiday to somewhere new.

Paul travelled to the Lake District with his support workers and they all stayed in the accommodation together. Paul had not visited this area before, so it was all new to him and not his usual seaside trip. His support workers helped him to manage any feelings of anxiety about going into unknown territory.

Recently Paul's communication skills have developed significantly. He has a good sense of humour and has begun playing tricks on his support workers to make them all laugh.

They say working with Paul is a pleasure and a privilege.

**Contact details: 01568 616653 or [contactus@s4il.co.uk](mailto:contactus@s4il.co.uk)**



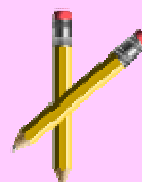


## Does this sound familiar?



When we discover that a child doesn't follow the "normal pattern" it can be difficult to talk about it to others, especially when it is someone close within the family. To start with you aren't sure about how to tell others, and you don't really know what to expect especially without a diagnosis. It can often be the case that a "difficult child" appears to be naughty, and when in public others criticise without understanding. Perhaps the following signs might be familiar to you as someone who has autism within the family.

- ◆ Did not talk until three years old – but points to things and makes a noise, to get attention (and get the subject matter).
- ◆ Needs to be swaddled in a big blanket to calm him down when upset, when very young (not now)
- ◆ Had extreme fear of dogs (now OK with my guide dog)
- ◆ Had fear of hot air hand driers (now OK with this)
- ◆ Doesn't like loud noises
- ◆ Repeats the same phrase or word over and over again
- ◆ Can hit out when frustrated or annoyed, without realising consequences
- ◆ Keen on sensory toys and aquarium fish
- ◆ Likes (and needs) routine
- ◆ Enjoys drawing pictures for hours, quietly
- ◆ Likes action figures e.g. Spiderman, Batman, power rangers, ninja turtles, and pretends to be one very convincingly
- ◆ Goes through phases of watching repeated TV programmes e.g. In the Night Garden, Ben & Holly, Peppa Pig



But, my grandson is a very happy little boy, great fun, very clever, great memory.

Luckily he goes to a special school in Bristol, attached to a regular school where he can mix when appropriate, with his 1 to 1 teacher from the special school. As I have a guide dog he has learnt to overcome the dog phobia. Other autistic children find comfort from buddy dogs which help with their development, and PAWS is one such organisation which support autistic children in this way.

**Becky Bettington, committee member of Herefordshire Disability United**

## Autism and employability with Hao2

With an estimated 433,000 adults with autism in the UK, having only 15% in fulltime work means that there is too much potential going to waste; too many people in this country who could be more independent than they are; in short - too much wasted talent.

This is a tragedy, but not only for individuals and their families, but also for employers, who are missing out on a large national resource of loyal and hard working staff.

Employers need to know that it makes good business sense to employ people who are reliable, punctual and loyal; people who have good attention to detail and concentration levels; people who have excellent problem solving skills and can be analytical, resourceful and creative. What good employer wouldn't want an employee with those skills?

So have you heard about **Hao2** a female led team in the virtual office world?

*This is taken from their website*



Since early 2010, Hao2 has been researching the power and applications of 3D virtual world technologies – we use these technologies to increase vocational training and employment opportunities for people with autism and other complex needs by offering a range of innovative 3D virtual world products and services.

The vocational training services have been designed to meet the needs of people with autism, and help tackle the exclusion of people with autism from employment. Their team, 80% of whom are autistic, is creative, diverse, dedicated and highly skilled.

In 2012 Hao2 won the Nominet Internet Award, winning the category “CBI Most Innovative Internet Business” award. Nominet showcase projects from UK businesses, charities, individuals, and public and private sector organisations, which help to make the Internet a more secure, open, accessible, and diverse experience for all.



Further information about Nominet and Hao2 is on their websites:

Nominet: [www.nominet.org.uk](http://www.nominet.org.uk)

Hao2: [www.hao2.eu](http://www.hao2.eu)

Phone (Skype) 0208 123 4708

Email: [info:hao2.eu](mailto:info:hao2.eu) also on twitter



## Mobile Youth Led Opportunities.....(MYLO) contact 01432 343 932



MYLO offers professional youth and community support to local communities and voluntary sector youth and community groups. Through its unique method of engaging both young people and adult volunteers it has supported communities where there are needs and gaps in youth

work provision. Issues of lack of facilities, anti social behaviour and rural isolation are worked on alongside the provision of positive fun activities.

The challenge is to identify and establish the most appropriate youth provision to meet the individual needs, rights, responsibilities and aspirations of local young people within their communities.

This year MYLO has delivered 252 outreach sessions to 22 rural communities through mentoring, training, activity programmes and networking. It has helped to establish 12 youth projects where Young People have confidence to express their views and opinions and are motivated to get involved with their own local community agendas to establish the most appropriate sustainable youth provision.

*Volunteer mum - "I now feel confident to let my 8 year old son down to the village shop by himself, I realise the young people are not out to harm, they are just being lively meeting up with each other"*

*18 year old NEET volunteer - "I wanted a youth club that offered opportunities that I never had when I was younger to give the younger kids a better chance in life than I had"*

This work has begun to show how young people in the community with adult support can come together and work together in a fun social setting and support young people's aspirations and build social responsibility and social cohesion.

*NH - "The young leader training has made us think a lot more about our responsibilities, especially if we want to keep a Youth Club open"*



For further development of youth work in Herefordshire contact:

The Youth Development Officer

[Richard.Betterton@hvoss.org.uk](mailto:Richard.Betterton@hvoss.org.uk)

Or MYLO co-ordinator

[will.edwards@hvoss.org.uk](mailto:will.edwards@hvoss.org.uk)

The newsletter editor asks:

*Can they help with young people on the Autistic Spectrum?*

## 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](mailto: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](http://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](mailto: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:**

[ASCAdviceandRefferal-](mailto:ASCAdviceandRefferal-Team@herefordshire.gcsx.gov.uk)

[Team@herefordshire.gcsx.gov.uk](mailto:Team@herefordshire.gcsx.gov.uk)



## Autism Helpline

# 0808 800 4104

10am-4pm, Mon-Fri (excl. bank holidays)

## Supporter enquiries

# 0808 800 1050

9am-5pm, Mon-Thurs; 9am-3pm, Fri (excl. bank holidays)



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