

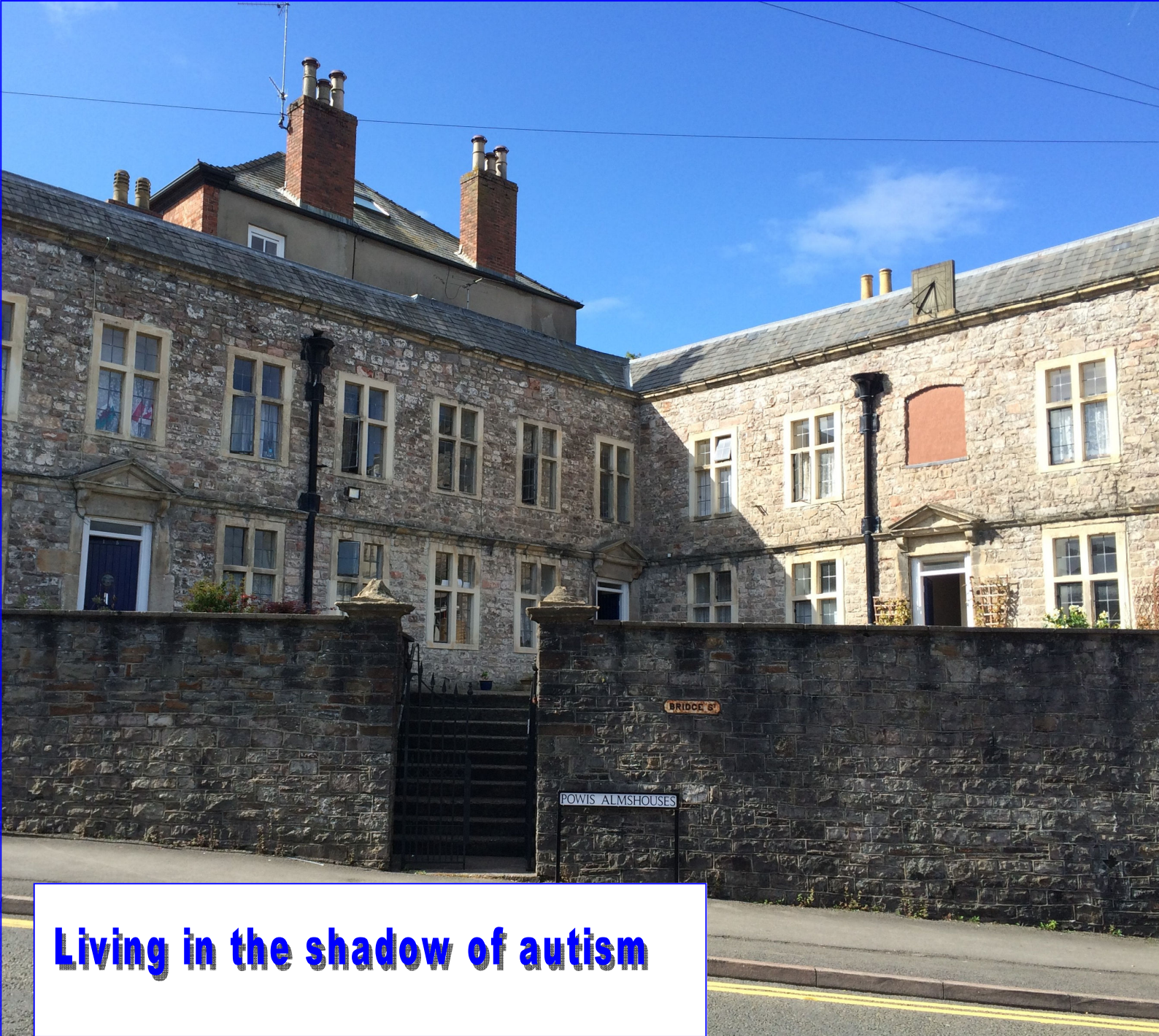
**Herefordshire  
Disability  
United**



**Network  
News**

**3rd Autism Seminar**

**November 2015**



**Living in the shadow 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: **Your help is needed please**

From time to time, its important to get information out and feedback from those who are at the forefront of autism, and this is one such time!

It was identified at the Autism Partnership Board recently that GPs are very important people with regard to those on the spectrum, and in collaboration with Healthwatch the Board are seeking those who are either on the spectrum or their parent/ carers to participate in a survey online. It asks:

### **What do you think about GP services in Herefordshire?**

This survey is based on the recommendations from the Royal College of GPs, because they made **Autism** a clinical priority 2014-2017. Were you even aware of this or perhaps have noticed a change in approach/ understanding towards you?

Its very important to get the picture right across the country, so that both good practise and need is demonstrated. Is rural Herefordshire achieving or neglecting the needs of those on the spectrum? Money or cuts should not come in to this priority. Simple actions by GPs can make such a difference.

You will see from articles in this magazine the effect it has when people receive an assessment and diagnosis.

The survey asks questions such as:

- ◆ Is your GP aware of your condition or need for assessment?
- ◆ Do your medical notes reflect the diagnosis? (at the top)
- ◆ Is a specific code on your notes indicating to the diagnosis to the receptionist?
- ◆ Do you have a Patient Passport, and do you use it?
- ◆ Are appointments lengthened to accommodate your need?
- ◆ Has your GP practice had autism awareness training?
- ◆ Are there good or bad things you would like to mention about the GP practice?
- ◆ Your age and sex
- ◆ The name of the practice

All answers are confidential to the survey, but without them, making Autism a clinical priority will not succeed. Just check out the online link, it will only take a few minutes!  
<http://www.surveygizmo.com/s2396337/Autism-Survey>.

Also you may be interested in attending the Autism Partnership Board meetings in future. Previous minutes can be found on the HDU website.

[www.herefordshiredisabilityunited.org.uk](http://www.herefordshiredisabilityunited.org.uk)

The next meeting is on Tuesday 19th January 10.30– 12.30 at the Kindle Centre.

Do contact if you feel you wish to know more.

**The Editor**



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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Date for your diary!  
 Wednesday  
 16th March 2015  
 “Who Cares!”  
 Hinton Community Hall  
 Hereford

**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.

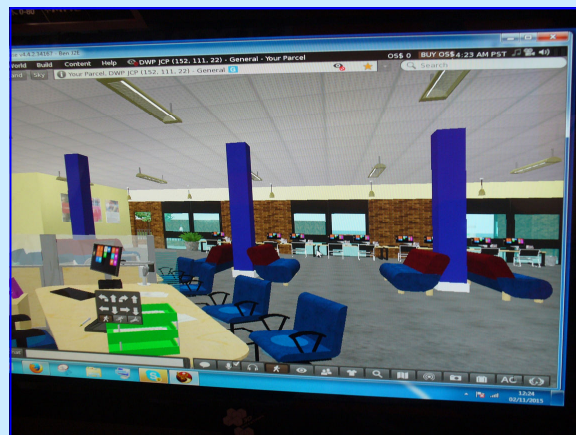
## Success for Ben and his family

At one of the early autism meetings with HDU, I was told about an online company using 3D technology to provide training for people with disabilities such as autism, who find it difficult to get work.

Using 3D virtual worlds the company, Hao2 aims to help develop the skills that employers are looking for; the ability to communicate and co-operate with others, and how to develop ideas and solve problems.

I expressed interest but knew little about how it would work.

My son Ben with an enthusiasm for graphics and design from childhood was very interested.



CEO Nicola Herbertson who founded the company, contacted Ben in May 2014 and worked with him via email and Skype through the summer. He was given a variety of tasks around communicating, co-operating with others, and producing a collection of photographs which resulted in being given the opportunity to train with Hao2.

He has been working four days a week since April creating a virtual world on his own island and completed the course by giving a successful presentation of his work to the tutors and other students.



This is a good news story, Ben is in a good place; he has developed new skills, created something good and received positive responses to his work. However that is not all the story.

This is a story about change.  
Create one change and everything changes.

Committing yourself to one and a half hours each side of a lunch break Monday to Thursday significantly reduces the freedom to go into town as and when you like. It also requires a fixed time of attendance so the long lie in has to go. On the plus side it introduces a fixed structure to the day and a more regular pattern of life.

Learning can be hard, who hasn't come away from a "training day" feeling exhausted and sometimes with a headache! New information or instructions need to be understood and applied appropriately, skills have to be practiced, sometimes it's a struggle and then just as you get to grips with it some more new challenges come down the line.

## Change can be good!

This is a major life change and Ben has seriously committed to it. Naturally some days are better than others, some days he struggles to master something new and he needs to be reminded of all that he has achieved. As a result of all this hard work, other changes have become apparent and there is a subtle shift in family relationships



Working at something he loves, engaging with people not known to his family, doing something that needs to be explained to everyone else, Ben has acquired a confident sense of himself as an individual.

He chooses what he shares with us and sometimes talks about his ideas and what he is doing - I have overheard him and his father discussing the finer points of computer graphics.

We attended a silver wedding celebration recently, a chance to catch up with our extended family; for Ben it was a social triumph all his cousins were interested in what he is doing, two of them are keen on photography, there was much to talk about, and they did.



**Written by Jane Clayton, proud mother of Ben**

## Could you give a child a break?

### Fostering Team advert

We are currently setting up a short breaks service which will provide overnight family based short break care for children with disabilities, giving their families time to have some rest, whilst the child stays for a couple of nights with you and your family.

Looking after a child with a disability can be hard. A little help can go a long way. Anyone can be a short breaks carer however we would be particularly interested in hearing from people with professional or personal experience of children with disabilities, or if you think you have the right qualities we would be happy to talk to you. We will train you and provide all the support you need. All we ask is that you are understanding, patient and committed to caring for a child who has disabilities.

We offer a reliable and competitive payment, 24 hour support, excellent training and so much more. Get in touch with the fostering team.

Call us on 01432 383240

Email us at [fostering@herefordshire.gov.uk](mailto:fostering@herefordshire.gov.uk)

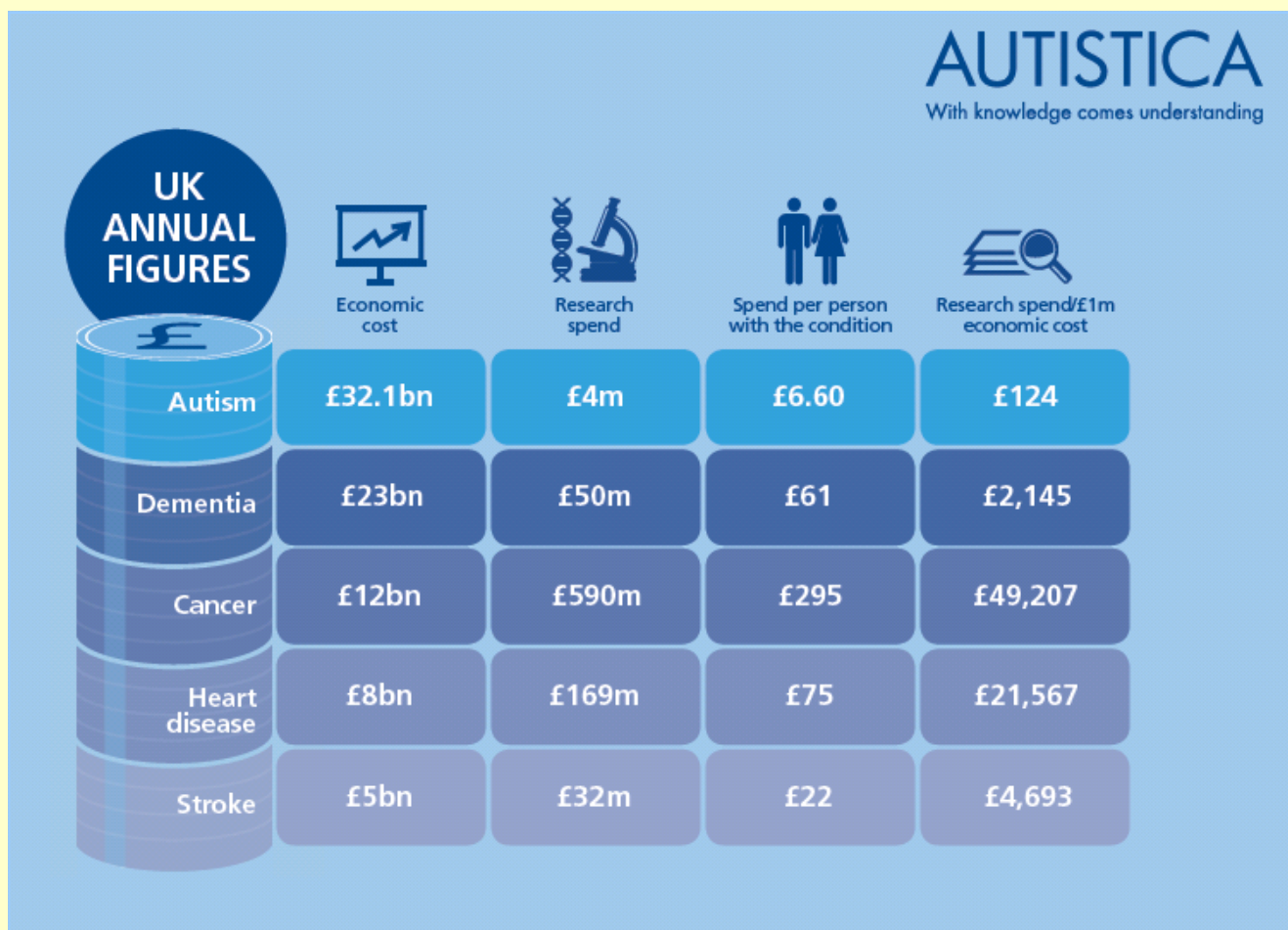
Find out more online [www.herefordshire.gov.uk/fostering](http://www.herefordshire.gov.uk/fostering)

# Autistica and Autism Research

Autistica is the UK’s leading autism research charity, funding groundbreaking medical research guided by community priorities. Our mission is to make a positive impact on the lives of people with autism and their families by improving understanding and advancing therapies and interventions.

Too many individuals with autism and their families tell us that they face a lifelong struggle to access appropriate support and services. Research has the capacity to transform this experience, raise awareness, and ensure that services are based on latest evidence. However, as this table shows, autism research is greatly underfunded compared to other medical conditions.

The UK only spends approximately £4m/year on autism research, which is minimal when you consider the estimated £32 billion/year cost of autism to the economy in treatment, lost earnings, care and support for children and adults with autism.



Given the lack of funds for autism research (particularly in comparison to other medical conditions) it is critically important that every penny dedicated to autism research is spent on the highest quality studies and studies which are based on community priorities.

This is why we consulted with 1,000 individuals with autism, parents and professionals in our One in a Hundred report to develop an ambitious five year research strategy.

# Consultation Results

As a result, these three key areas of research focus were identified:

1. Early intervention
2. Adulthood and ageing with autism
3. Mental health in autism

*“The thing that would make the biggest difference would be mental health. We are beginning to know what ordinary people need to be well and we need to know if that’s different for people with autism.”* Mother, Autistica’s ‘One in a Hundred’ report.

From this broad consultation, we have gained real insight into not just community priorities, but also their concerns and motivations in terms of research. The report showed that 94% of parents worry about the future of their child with autism, and that 75% of adults with autism report that there is insufficient help for their difficulties. A third of respondents had tried interventions they knew had no evidence base, demonstrating both the level of desperation and the lack of options currently available. And, across the board, parents and adults with autism wish that diagnosis had come sooner.

But we are encouraged that so many families and individuals with autism feel positive about medical research. 90% agree that there is a need for a greater scientific understanding of autism, and a similar number feel that more medical research would make a positive difference to their lives. We were heartened that 90% of our respondents would like to take part in research, and we are committed to making this as easy as possible by continuing to fund a UK-wide database for research volunteers – ASD-UK, and promoting research as widely as possible both publically and in government policy.

This is an exciting time in autism research and significant advances have been made in the last ten years. There is an urgent need to harness the strength and diversity of the UK research environment to benefit all those living with autism, and we hope that through continuing collaborative conversations with the autism community, policy makers and funders, we can ensure that our work has the biggest impact now and into the future.

If you wish to know more about Autistica’s research areas, read our strategy or consultation in full, visit our website: [www.autistica.org.uk](http://www.autistica.org.uk)

If you are interested in taking part in research as an individual with autism or a parent, please visit <http://www.autismspectrum-uk.com/> for the databases funded by Autistica at the Newcastle University.

Rebecca Sterry Communications Manager, Autistica.

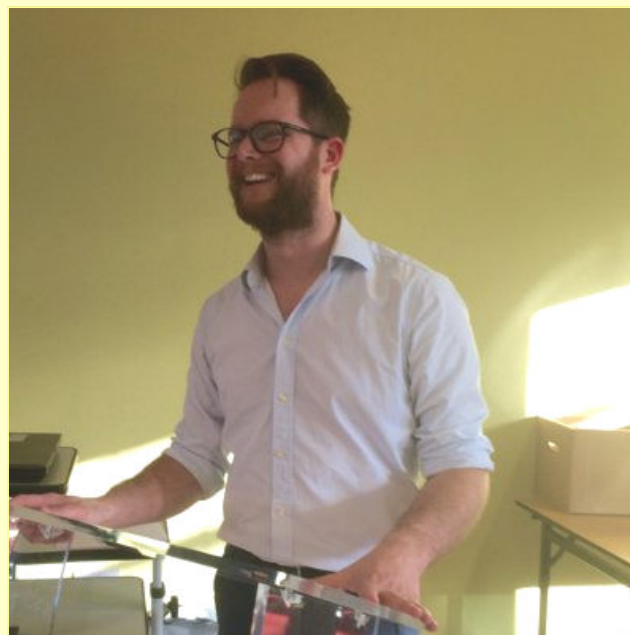
Get in touch: [friends@autistica.org.uk](mailto:friends@autistica.org.uk)

## NHS guidance to autism from the NAS

Since the Autism Act was passed in 2009 we have seen a great deal of progress across the country in improving awareness, diagnosis and services for autism.

However, much of this work has been led by local authorities but did you realise the legal duties apply just as much to the NHS? The 2015 Think Autism statutory guidance is very clear when it says:

“...NHS bodies must not only take account of this guidance, but also follow the relevant sections or provide a good reason why they are not doing so.



If they do not follow the guidance and cannot provide a good reason, they may be liable to judicial review or action by the Secretary of State.”

This guidance includes duties to:

- Designate a health lead responsible for developing, maintaining and promoting a diagnostic and treatment pathway.
- Ensure the prompt sharing of information between diagnostic services and adult social care services about adults diagnosed”
- Ensure that health and care staff who are highly likely to support people with autism, such as GPs, psychiatrists, counsellors and psychiatric nurses are appropriately trained beyond general basic awareness about autism”
- Ensure those in posts whose career pathways are highly likely to include working with adults with autism have demonstrable knowledge and skills to use appropriate communication skills when supporting a person with autism”

At our seminar Tom Purser from the National Autistic Society is going to be taking us through these and as well as bits of good practice from other parts of the country and exploring the question of how we can make sure that the NHS in Herefordshire is doing all that it is supposed to.

Editor's note:

We already have an Autism Partnership Board at Hereford Council, but need more input from the GPs, psychiatrists, counsellors and psychiatric nurses at our meetings.



## Who will care for autistic children later in life?

A recent article in the Daily Mail featured the topic, “Who will care for our autistic children when they grow up?”, and highlighted the same sentiment many parents of those on the spectrum feel that little is in place for them in late adulthood. Citing that those on the milder end of the spectrum can usually lead fully independent lives despite issues with relationships, it emphasised that others need specialist support and where will it come from?

The paper quoted various statistics:

1. Autism affects 1 person in every 100, which equates to around 700,000 in Britain
2. According to a survey 41% of people with autism feel lonely
3. Between 60-75% of those with autism have mental health problems
4. Of the medical records of 33,000 people (looked at by University College London) with learning disabilities including autism, it was found that almost a third of them had been prescribed antipsychotics, even though 71% had never been diagnosed with severe mental illness.
5. Doctors are forced to take the trial and error approach to mis-diagnosed conditions such as bi-polar and prescribe for them. But two thirds of individuals with autism have tried drugs that were not scientifically proven to work for people like them.
6. Autistica, a charity which funds and campaigns for medical research into autism states “Awareness among the health professionals of how to treat people on the autistic spectrum is often very poor”.

Following a father’s moving story of his son James we read about how a “normal son” even at 18 months changed, and the heartache which evolved when autism appeared. This father a GP, Mike and wife Mary a senior lecturer in sociology, watched as their son slowly developed the disorder, and spoke of “the bottomless grief” with James’ increasing behavioural difficulties, not knowing who to turn to.

James appeared to improve during his late teens after structured residential schooling, and complete withdrawal from drugs. But since moving on to independent living in supported accommodation depression has set in again, with so many changes in staff. Anxiety has overtaken his life without the rigid structure. He cannot cope on the bus any more, and he has been handcuffed and dragged off to the cells by police. During the last eighteen months James was put back on Risperidone again, making him drowsy, “zombie like” and gaining weight.

Dr Mike’s concern is of a generation of young adults with autism who 30 years ago would have been institutionalised, but are now being given medications which just act as a liquid cosh.

James’ parents hope that research by Autistica which aims to improve diagnosis and quality of life for those with autism, will result in specific cognitive behavioural therapies which can be put into clinical practice within four years. James is now 23.

## Living with Autism and Beyond

This paper aims to raise awareness of Autism and to educate Neuro-typical (NT) people so that they have a better understanding of Autism, through being well informed. Another aim is to help Parents see more clearly the obstacles in the way of their offspring and how they may be able to assist in getting the right help at the right time for them.

Professor Uta Frith, a Clinical Psychologist states:

"What I've learned over the past 50 years is that not having a special kind of social navigation system is what sets Autistic people apart from the rest of us."

### **What does this quote mean in reality?**

This is the fundamental question which surrounds those on the Autistic Spectrum who live in an NT world. The difficulty is on both sides though. NT people don't understand how Autistic people think and perceive the world. And yet, they are the ones tasked with "solving" this problem! While Autistic people often don't perceive there is a problem and if they do, they also cannot understand how NT people think and perceive the world, but they are the ones who are expected to change. Naturally there is a wide spectrum of intelligence, understanding and so on within the NT world and the Autistic world. What is needed is a blending of the two, not an eradication of one type. It is not wrong to be Autistic, nor is it wrong to be NT.

### **Living within society**

NT and Autistic people need to live together in society. It is not just a matter of "training" Autistic people the NT social norms and skills. It is also important to "train" NT people to be more accepting of Autism and to celebrate those, often, important differences. All parents of Autistic offspring want them to be happy, achieve and live "normal" lives within our NT society. This is because there is no choice. We live in a predominately NT society. When these Autistic offspring reach adulthood and have gained sufficient knowledge to understand the world and society they live in, they may decide they prefer their Autistic world and society. This is quite acceptable and should not be seen as a weakness or something wrong that has to be "corrected". However, what is important is that possible conflicts are avoided.

For example: Being considered anti-social by not wanting to socialise in an NT way is not something that is wrong and that needs to be dealt with. What is necessary is that the Autistic person is "taught" how to play the "NT" game, so that both the NT person and the Autistic person can get along sufficiently, so that they both lead happy and fulfilled lives. By concentrating on the negativity it makes the Autistic person feel inadequate and causes co-morbidity. This approach of making people feel inadequate and in need of help has already been played out in our society concerning old-fashioned attitudes to homosexuality.

Autism is going through a similar phase. We often hear NT people talking about "cures". Autism is a life-long disability, but affects different people in different ways, depending on their intelligence and where they are placed on the Autistic Spectrum.

# Living with Autism and Beyond

An NT person can never understand what it is like being on the Autistic Spectrum living in an NT world. All they see are the manifestations displayed by the Autistic person. This is the same as someone with prostate cancer; those without the cancer cannot fully understand those with it. They may understand the causes, they may sympathise, but they never totally know what it is like for that person.

People on the Autistic Spectrum and NT's will only get to truly understand each other and live happily together when both sides consciously build bridges into and out of the world of autism; by doing so we can begin to bridge the various differences this article draws attention to.

## Making changes

This paper will only concentrate on one aspect: The Parent.

### a) **Acceptance**

It is difficult for any Parent to discover, come to terms with, and accept they have a disabled offspring, whether or not this is Autism related. Sometimes the offspring themselves have difficulty accepting their diagnosis and don't like being labelled as disabled. The Parent has a duty to persuade their offspring to accept the diagnosis and to go forward together because it is necessary and vital for their offspring to progress as much as it is possible during their lifetime. How can we make this easier for Parents?

- ◆ Make Autism acceptable and not something to be feared, cured or repelled, by removing the stigma attached to Autism.
- ◆ State the benefits of being Autistic, and not solely concentrate on the negatives.
- ◆ Show that with the right diagnoses, at the right time, and given the right information and the right help, things can and will improve, but the support must be appropriate to the individual concerned.
- ◆ Provide the right services at the right time to ensure progress occurs.

### b) **Training**

Once the Parent has acceptance of their offspring's situation they can then be trained to cope with it, assist their offspring into obtaining the most life can offer them, and ensure they receive the help they need to achieve this, by providing them with support, information and advice at the right time and in the right manner. How can we get Parents to accomplish this?

- ◆ Provide relaxed group settings so that information can be shared in an informal way, between like-affected people, such as coffee mornings. Sharing information with other Parents can be a very positive way to exchange useful tips and information.
- ◆ Provide more formal, but still relaxed, settings where Parents can be shown techniques which will assist their offspring to cope with an NT society, e.g. calming measures or coping mechanisms.
- ◆ Provide structured life skills training sessions so they can help make their offspring more independent, e.g. cooking techniques using specialised equipment.

**Continued over page**

## Living with Autism and beyond

### c) Letting Go or Not

One of the biggest fears facing the Parent is "What will happen after I die?"

There is a mix of over-protection and pushing too hard to make their offspring ready for independence when their offspring are not yet ready for it.

#### The over-protection stems from:

- ◆ I know best. I will always treat them well. I will always respect them.
- ◆ I will always put them in the centre of my world.
- ◆ I am the only one who fully understands them and their situation.
- ◆ I know their strengths and weaknesses better than anyone else.
- ◆ They could not cope without me. They only trust me.
- ◆ They only feel comfortable with me.

#### The over-pushing stems from:

- ◆ Non-acceptance of their offspring's disability.
- ◆ An unwillingness to accept what they could perceive as "failure" in their offspring.
- ◆ Unsubstantiated hope that their offspring are ready for independence.
- ◆ Financial constraints.
- ◆ An inability to cope any more.
- ◆ Over-reaction to "time running out" syndrome.

The one thing that will actually happen is that the Parent will die, but this may not be before their offspring dies! How can we make letting go or not be more successful?

- ◆ By providing a proper assessment of the offspring's needs as soon as possible. It's all about getting the best support structure in place, which includes Parents, other family members, Professionals and friends. It is important that the Parent does not feel alone, that there are others who are experiencing the same problems as them. By taking into consideration the views of the offspring without their Parent present.
- ◆ By taking into consideration the views of the Parent without their offspring being present.
- ◆ By taking the two views above and analysing them to find common ground and to resolve any issues.
- ◆ The offspring should be involved, as far as mental capacity allows, in all discussions and decision-making meetings.
- ◆ The Local Authority must make sure there is ample provision of various types of housing which could be utilised by someone on the Autistic Spectrum.
- ◆ Person-Centred-Planning, or some other system, should be carried out as soon as it is practicable so that future decisions can be planned well in advance, e.g. going to work, to university or leaving home.

**Written by Valerie Fitch, Sylvia Nicholls and Aubrey Baillie**

Valerie is on the Autistic Spectrum as is her husband and son, Sylvia is Chair of Herefordshire Disability United, and Aubrey is an independent psychologist specialising in Autism

# Autism on Film

## Current project:

Based in Hereford, The Rural Media Company is one of the leading charities in the UK at harnessing media as an advocacy tool for working alongside marginalised communities and enabling them to challenge stereotypes and influence and inform decision makers.



The charity is currently developing Action for Autism Herefordshire, a community film production company of volunteers drawn from people with an autism spectrum disorder (ASD) in Herefordshire, and their Carers. They will be trained, mentored and working alongside media professionals to produce an on-going magazine-style Web TV series themed around autism, targeted and distributed to give local decision makers, service providers and employers a better understanding of autism.



Volunteers with autism and their Carers will co-produce as scriptwriters, presenters and film makers, in a way that gives the 2000 plus people in Herefordshire with an autism spectrum disorder, and the thousands more in their support networks, a powerful media voice for community advocacy that challenges stereotypes and misconceptions.

We are currently seeking funding to make this work happen and anyone with ideas of how to move, help us this innovative project forward should contact Richard Elms:  
Email: [richarde@ruralmedia.co.uk](mailto:richarde@ruralmedia.co.uk)

## About Rural Media

Rural Media has been working in the cultural and charitable sectors for over 20 years, and are highly regarded and connected. They regularly contribute to local and national policy and strategy development, and are invited to speak at UK and European conferences and events.

Rural media provide consultancy for a wide range of public and voluntary sector organisations in project development, business planning, media communications and strategy, fundraising and sustainability.

Contact info:

**The Rural Media Company**, Packers House, 25th West Street, Hereford HR4 0BX  
**01432 344039**

## We tend to view things differently!

### Enabling Autistic People in Herefordshire to Have their Say A conversation facilitated by Aubrey Baillie AFBPsS

*Aubrey Baillie is: a member of Herefordshire's Autism Partnership Board, an independent autism consultant (working with adults on the autism spectrum), social psychologist, qualified teacher and former residential childcare worker*



I want to start a conversation that begins like this:  
How can we better understand autistic people from *their* point of view?

First though we need to bear in mind the following:

Regardless of where we sit on the spectrum of neuro-diversity, we need to develop an **'insider's'** view that gives us *some* idea of what it's like to be autistic. Only then can we build authentic, satisfying relationships with people on the spectrum.

This is a challenge because:

1. Like all of us, every autistic person is unique!
2. There are common misconceptions about autistic people

e.g. *'They're unable to empathise with other people'*

*'They're fundamentally unsociable and disinterested in the social world around them'*

*'Autism is a puzzle with missing pieces remaining to be completed by future research and clinical work'* [This implies there is only one correct perspective on autism spectrum conditions- an **'outsider's'** perspective]

Another difficulty is that, for both diagnostic purposes and autism awareness training, autism is usually defined in terms of *observable behaviours* consisting of 2 or 3 fundamental limitations in a person's ability to:

Relate socially to others in the way that neuro-typical people usually do (by which I mean non-autistic people)

Communicate in neuro-typical ways

Display a non-autistic range of activity patterns and interests

This way of thinking about autistic people has some fundamental shortcomings:

A). It implies their autism consists of fixed characteristics that are central to the condition. Recent neurobiological research suggests something else: these characteristics are *consequences* of brains wired differently in ways that make life very challenging without appropriate support. In other words, the observable behaviours are the best ways an autistic person has for coping as best they can in a world designed for non-autistic people.

## Sensory issues and autism

B). The focus is entirely on an **observer's** perspective; consequently, the autistic person's **insider** experience of living everyday with their condition is ignored.

C). Describing autistic people entirely in terms of what they can't do has its origins in a **deficit** model of autism rather than a **biological / social** model of autism.

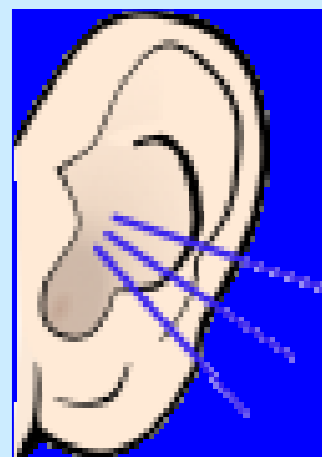
### I invite you now to put yourself in the shoes of autistic people experiencing sensory challenges such as the following:

*My ability to interpret what I saw was impaired because I took each fragment in without understanding its meaning in the context of its surroundings... I'd see the nostril but lose the concept of the nose, see the nose but lose the face, see the fingernail but lose the finger. (Donna Williams) .*

Comment: 'Fragmented perception occurs when too much information needs to be processed at the same time; people with autism may not be able to break down the whole picture into meaningful units. We might process some parts of a whole, for example, parts of a scene or a sentence.'

*Auditory and tactile input often overwhelmed me. Loud noise hurts my ears. When noise and sensory stimulation became too intense, I was able to shut off my hearing and retreat into my own world. (Temple Grandin)*

Comment: 'Shutdowns happen when someone can't deal with all the information coming in – for example if they are experiencing a sensory overload.'



*If I'm looking at something and listening to something at the same time, too much information might come in my eyes and ears at the same time, so I might touch something. That gets information going in a different sense, through my touch, and it lets my eyes and ears have a rest. (Brad Rand).*

Comment: 'So if I am looking at something, and you speak to me, it might appear that I don't 'hear' you. There is nothing wrong with my ears, but my brain won't process what is coming in if it is busy processing what I am seeing.'

[Wendy Lawson calls this 'Single Attention and Associated Cognition' and argues it is the result of an atypical brain configuration linked to a sensory system 'often monopolised by a single sense'].

**So let's now start a conversation! I especially want to give people on the Spectrum an opportunity to say something about how life has been for them**  
**If you want to carry on this conversation on another occasion, please email me:**  
[aubrey@aubreybaillieconsulting.co.uk](mailto:aubrey@aubreybaillieconsulting.co.uk)

Continued overleaf



## Research and books on autism

To find out more about the world of autistic people, Aubrey suggests the following:

*NeuroTribes: The legacy of autism and how to think smarter about people who think differently.* By Steve Silberman. Published by Allen & Unwin in 2015. [This is the first book to give a very detailed account of how 2 doctors discovered autism in the 1940's and how things went awry for several decades after that. It is for everyone who wishes to understand the world of autism from an 'insider's' point of view]

**If you don't have time or inclination to read this, please at least spend 14 minutes looking at a brief YouTube video of a TED talk given by Silberman that captures the highlights: [Steve Silberman: The forgotten history of autism](#)**

*The Autistic Brain: Thinking across the spectrum.* By Temple Grandin and Richard Panek. Published by Houghton Mifflin Harcourt in 2013

*The Complete Guide to Asperger's Syndrome*, by Tony Attwood. Published by Jessica Kingsley Publishers in 2007.

### Self-Help Resources

Especially recommended are two recently published books that give practical advice on how best to transcend the ever present challenges of living with autism, written by people on the autism spectrum acting as mentors + Tony Attwood, the world's leading clinician on Asperger's syndrome:

*Been There. Done That. Try This! An aspie's guide to life on earth.* Edited by Tony Attwood, Craig Evans and Anita Lesko. Published by Jessica Kingsley Publishers in 2014.

*Mindful Living with Asperger's Syndrome: Everyday mindfulness practices to help you tune in to the present moment.* By Chris Mitchell. Published by Jessica Kingsley Publishers in 2014.

### Online resources

Sensory Issues in Autism – a pdf published by East Sussex County Council; freely available at: <http://www.aetraininghubs.org.uk/wp-content/uploads/2014/05/sensory-issues-in-autism.pdf>

Access on-line self-help resources for autistic people; e.g. <http://www.autism-connect.org.uk>

Visit the websites of Jessica Kingsley Publishers to find autobiographies written by men or women on the autism spectrum.

Use YouTube to view videos made by autistic people who talk to the camera about themselves and their life.

The National Autistic Society's website provides very comprehensive information about all aspects of autism.

**A fuller version of this article by Aubrey is on the HDU website**



# Crossroads Care and Autism

Working together to support unpaid carers across Herefordshire:



Crossroads Care, the local carers' support charity has recently been awarded a tender from Herefordshire Council to provide services to enhance carers' health and wellbeing.

Wishing to design the service to meet local need, Crossroads is keen to hear from carers supporting family members on the autism spectrum on what they would find helpful.

Parallel to the carers' health and wellbeing service, Crossroads Care's not-for-profit care agency, would like to explore what other services or supported activities those on the autistic spectrum might find useful.

Crossroads currently works with parent carers to deliver Skills Clubs, youth clubs for those under 16 in Hereford and Cinderford.

Louise Herriott, Crossroads Care's development manager will be at the Autism seminar on the 18th November and looks forward to speaking to attendees or hearing from you in the future.

**CROSS  
ROADS  
CARE  
FOR  
CARERS  
AND THE  
PEOPLE  
THEY  
SUPPORT**

Crossroads care. 01432 355373. [www.crossroadshereford.org.uk](http://www.crossroadshereford.org.uk)

## Gents Pub Lunch Club

Lunch and a bit of male company  
For those men who through ill health are unable to get out as much as they would like to.  
Leominster, Hereford and Bromyard  
Qualified support staff on hand for aspects of mobility or personal care

## Other clubs which Crossroads run in this county

Carers' Social Groups  
Leominster, Hereford  
Ledbury, Bromyard  
Golden Valley

Meet friends, make new ones.

Varied programme of activities and speakers  
Care support on hand  
Assistance with transport

## Finding employment when on the spectrum

Richard was always finding it difficult to fit in. At school he was diagnosed with ADHD and was troubled with dyslexia meaning concentrated learning was a problem.

Yet Richard could work hard at practical tasks especially out doors where he felt more at ease. In fact Richard has strength and will maintain focus on a manual task, long after others have tired by the exertion.



Luckily as Richard grew up living in a rural area where neighbours had farms he gained experience with agriculture, tractors and the outdoor life, but was unable to find and maintain a job. His parents desperate to see him fulfilled and earning, began to realise something may be different about their son, sought advice and at the age of 28 years Richard was diagnosed as being on the Autistic Spectrum. Whilst this began a different approach for the family, Richard was still struggling. He went from one short term job to another, sometimes being taken on by understanding farmers for a season, to other disastrous experiences where he was bullied and miserable. This spanned 15 years of intermittent employment and unhappiness, causing mental health issues, anxiety attacks as well as stress for his aging parents.

Following the regular trend of trips to the Job Centre he finally found a helpful advisor who suggested Richard could set up his own business through the Enterprise Trust scheme. Certainly he would need help with the financial aspect of running his own business, (for which they would offer support), and also meeting clients would need careful consideration, as Richard gets incredibly anxious when meeting new people in new places.

Richard felt a job in the outdoors would suit him best, and as he loves gardening, (although no gardener in fact) this might be something he could pursue. Starting in December 2014 he made a business plan, gathering information on tools, strategy and how to find his customers. The older generation often want help with their garden; someone who will cut the grass, tidy flowerbeds, prune the trees, and generally keep things looking good.

Richard was given three months job seekers allowance whilst all his plans came to fruition. Then the next three months he was on half benefits as customers employed him on a regular basis. Having been weaned off benefits, he is still able to survive a year later, although not making a profit he is breaking even.

One year on Richard has begun to be more sociable, feeling fulfilled, and keeping fit. His clients know his limitations. He is never given a free hand to work without consultation, as pruning would see shrubs reduced to sticks in the ground! But, when customers need someone who can work hard, at the back breaking jobs, Richard is “the man”. Richard lives in Wiltshire although his parents live in Herefordshire.

## Diagnosed later in life!

What effect does it have to be diagnosed with Aspergers later in life? Being keen to understand I met recently with one such gentleman who came to see me accompanied by his wife. I will call them Emma and Craig to maintain their anonymity.

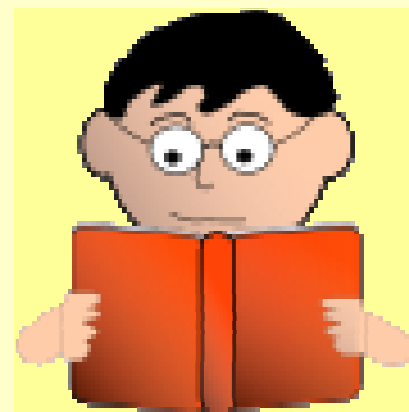
When I sent out the invitation to contacts about the autism seminar, I received many replies from those I knew as well as others I had never met. (That's the power of the Internet). One email from Emma and Craig asking for two places at the seminar, and a brief outline of why, which is when I responded and asked to meet them if possible.

Arriving at my home and welcoming them in, I was pleased to be able to engage and listen to how the diagnosis came about. Sadly it was the culmination of circumstances with Craig's work as a mental health nurse with the 2Gether Trust, when he was dismissed from employment. Craig had worked with them for 19 years.

You see the confrontational outbursts which Aspergers bring was not understood by his employers, and meltdown over two years resulted with Craig losing his job. Is it common that those in mental health authorities do not receive the appropriate training to recognise Aspergers? That's what Craig believes!

Craig, now able to reflect on his childhood and see the pointers towards Aspergers, had never been suspected of the condition. Although apparently quite a loner, and sometimes bullied, Craig had his head in factual books keeping out of trouble and was able to achieve. Obviously he trained successfully to become a mental health nurse and be employed for a long time.

Deciding to see a psychologist whom he knew through his work, Craig was sitting in the counselling waiting room, when he picked up a magazine and read an article on Aspergers. He immediately recognised many of the issues as his own, which then prompted him to seek further tests for an assessment. The diagnosis was confirmed as A Typical ASD, and suddenly things appeared to fall in to place. It all made sense!



There is now another phase to go through. Diagnosis is just the beginning. Emma having supported her husband through the years feels she needs to know so much more. Emma is a Carer for her husband, who greatly requires support too. She would love to speak to others in her position, not for the social chat, but to grasp better understanding of the condition. Sharing would lessen the weight she is carrying. Speaking to others who are coping and have experience in this area is a must.

Craig is keen to move on, and if possible get back to some sort of employment, using his qualifications in the health field. Firstly, its writing a CV, which is something completely new after twenty years, but after six months off he feels able to cope so much better.

**If you know of others diagnosed late in life? Tell the editor please**

## 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

**Our next event to be held at  
Wednesday 16th March 2015  
Hinton Community Centre, Hereford  
“Who Cares”**

**Check out website for details  
[www.herefordshiredisabilityunited.org.uk](http://www.herefordshiredisabilityunited.org.uk)**

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