

Produced by and for people who have autism-spectrum conditions

Asperger *United*

Edition 71 July 2012



Asperger United

Asperger United is a magazine run by and for adults with autism-spectrum conditions (although some parents subscribe on behalf of their under-sixteens). The magazine aims to put people with the condition in touch with each other and to share information so that they can lead more independent lives.

Please note that *AU* receives over 200 letters each quarter so it is not possible to respond to every one, nor for every contribution to be printed. Discussions on editorial choices will not be entered into. *AU* protects the identity of contributors by not printing full names unless the writer asks for his or her full name to be used.

Asperger United is free. To subscribe you, we need your postal address. We ask for a contribution of £6 per year from overseas readers and £10 from professionals and institutions to cover postage costs. Please make cheques payable to the NAS. Organisations requiring multiple copies: no extra fee, please get in touch.

Editor the Goth

Telephone and production support

The National Autistic Society's Publications Department

Asperger United was founded in 1993 by Pamela Yates and Patricia Howlin, in association with the Maudsley Hospital, and Mark Bebbington and Judy Lynch of the National Autistic Society.

This was in response to a recognised dearth of services for people with Asperger syndrome and the potential for self help and networking as a means of support for this group.

The provisions for editor's and sub-editor's post was to develop a publication that was truly the voice of the people it was aimed at. This post also provided the possibility of work experience and responsibility and has benefited those who have held the position. These are Richard Exley, David Wright, Martin Coppola, Ian Reynolds, John Joyce and the current editor, the Goth (who does not wear black).

Pamela Yates provided support and advice to the editors until the publication was handed over to the National Autistic Society in 2000.

The name *Asperger United* was chosen by the group of original readers as the most "appropriate name" for the publication. This was suggested by Anna Cohen.

Please send all correspondence and subscription requests to:

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Email: asp.utd@nas.org.uk

All we need is your name and address and we will add you to the mailing list — free of charge.

Thank you to Graeme Lawson for producing the *AU* logo.

Please note that the views expressed in *Asperger United* are not necessarily those of the editor, the National Autistic Society or those involved in the publication of the magazine.

Contributions for the next issue should reach *AU* by **13 August 2012**

Welcome to the July edition; I hope you've enjoyed the weightier content of the last issue, as there's more this time! Remember, if you feel strongly either way about anything in *Asperger United* let me know — write me a letter or send me an email and I'll take your views into account when preparing future issues. I will also publish a selection of such letters.

I intend making things a bit lighter for next issue, when I hope the theme really will be creativity — I received enough contributions to make this quarter's theme creativity, but other topics seemed to be pressing themselves forward for publication.

One area pushing for more space is pen-pal ads: there are a record number held over for future publication, so if you are one of them, sorry for the wait.

Something *AU* has not advertised before is the existence of NAS conferences. As most people on the spectrum are on benefits or low wages and conferences, even at discount rates, are expensive, I am not sure that they will be of useful interest to readers. Please let me know, and again, that's either way, whether you think they're a good use of valuable space in your magazine or you are overjoyed to have found out about them (or anywhere in between!).

Lastly, plans are coming along for the email notification of when the new edition is available, including a link to the electronic version (a PDF). Once the technology is ready, the ability to register on the NAS website will appear; a request (for those interested) to register will be made in the next edition,

the Editor

the sociology edition — next issue notice on page 5

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Challenges

part two

by Claire

The school Andrew went to is a very highly regarded school. At the time, if I remember rightly, they had one of the highest GCSE pass rates in the county. Andrew also wanted to go to a school out of the immediate area so he wouldn't be at school with the children he went to junior school with: a new start, if you like. He was accepted, which was great, or rather it should have been, as things didn't go quite as planned.

It didn't take long to see that we didn't fit in. Yes, I know the red hair and all the rest of it stands out, but what on Earth does that have to do with my son and how you see or treat him? No one really said anything but sometimes they don't need to! As I have in the past, I found that people take one look and judge and then I speak and they see that not only can I speak properly but can come across as quite intelligent and actually know what I'm talking about, often. I don't talk much but get me started on something I know or love and I'm off! I just don't really do small talk. Anyway . . .

School had no problem with Andrew's extra needs and everything looked good and went okay for a while. Andrew often takes a long time to adjust and settle to new things and this was definitely the case. It was more than a year before he really got into the hang of being at high school, homework, planning, etc., but that's okay, I expected that. Unfortunately the school had decided not to listen to me and make out that he was doing it all on purpose. As far as they were concerned he was intelligent enough so should be like that. That attitude just goes to show how little they understand what they'd taken on and makes me think they didn't pay much attention to his file at all! So I go through everything that had been discussed when he started, again:

- 1 I need to be told as soon as he doesn't hand in work, not after he hasn't handed in three

pieces in a row — this does not help as he just gets more and more behind and then struggles more than most to catch up while still trying to cope with going day-to-day — the school agreed.

- 2 Andrew needs help, or someone else, to write his homework into his planner. If not he will jot down a few notes because he knows what it is at the time but in a week when he needs to actually do the homework he will have forgotten. There were also many cases where he would write nothing as he thought he'd remember and then totally forget. This doesn't help point one or his organisation or homework completion — again the school agreed.
- 3 Andrew needs a space where he can get quiet. If he is getting stressed, angry and generally overwhelmed all he needs is five minutes' time out and he'll be fine. Let him stand in a corridor, whatever, just give him that break — again the school agreed.

Did any of it actually happen? Not a chance!

What actually happened was Andrew ended up months behind on homework, angry, frustrated, down and really struggling with school. Not the work, that was never an issue, but everything else about school. Life then went something like this: Andrew's been naughty; no he hasn't, he is merely showing the behavioural and social problems you were made well aware of. We're punishing Andrew; Andrew gets more frustrated and put down.

(Don't get me wrong I fully support the school punishing him for doing wrong but that's not what was happening. He was not being provided for within school as he should and was then being punished when things went wrong!)

When I tried to get extra support for Andrew, the school SENCo tried telling me he didn't have the medical conditions I claimed and that one

feature (continued) and a notice

wasn't on his record at all. Funny how his junior school never had a problem. Believe me, I know my son's diagnosis! A few teachers helped him with his planner but it always lasted a week after I'd been in and then faded out — the only teacher who kept it up was one that Andrew really didn't get along with. Pure clash of personalities and they had many problems. To me that shows a good teacher — she didn't let their personal issues get in the way of providing good teaching and support for him.

In the end Andrew was excluded. The teachers were actively contributing to the situations arising because they weren't giving Andrew any of the extra support that he needed.

The final straw came when for the third time Andrew was excluded. Now, he was always very honest about things, he'd come home and tell me, explain what happened and we'd go from there. On this occasion the school hadn't even given him a chance to explain or tell his side of the story. Their view was he had shouted and sworn at a teacher and that was the end of it! Completely unacceptable and even after knowing what lead to it I still wish he had reacted differently, but not Andrew . . .

For a minute imagine only having proper use of one hand, now imagine trying to put school books into a full bag one-handed. You can use the other hand to hold open and support the bag but not much in the way of fine movements, control or strength. How easy is it? Now imagine being aware that everyone else has done so and is ready to leave and yet you're still struggling: the books won't behave and do what you need them to, things are falling out, on top of already struggling through the day. Then the teacher in front of the whole class says something along the lines of: "Oh look, it's Andrew holding everyone up again." Would you get mad? I know telling her to shut up was wrong (and I told Andrew so) but I can't blame him, to be honest. So he got a three-day exclusion and no chance to explain himself.

I wrote to the school and would you believe they "didn't receive" my letter! Funny how I sent it recorded delivery. We had looked at other schools and decided that this school may well be

"the best" but they weren't best for Andrew and actually what it seemed like was all they cared about was exam results. In later conversations a support worker, and also Andrew's paediatrician, said they had heard the same from other parents about this particular school.

We applied for a place at another school on the other side of town; Andrew was offered a place a while into the autumn term and the head invited us in for a meeting. Have to admit I was worried they'd see his record and not end up letting him in. He listened while I explained everything that had happened, why I thought it had happened and actually spoke to Andrew directly rather than just about him. They agreed to everything Andrew said he felt he needed help with and we met the SENCo two days later. Everything looked good but I couldn't help thinking I've been here before . . .

Within a week Andrew had the "time out" pass I'd been fighting so hard for for two years but he has never had to use it. What a difference a change of people and attitudes can have. No more homework issues, no more not wanting to go to school (outside the normal teenage stuff!). Andrew goes to swimming club and archery, both free, and is taking a course in librarianship. No more troubles, no more hassle and a happier Andrew!

This is very long, so quick: Andrew has a splint for his leg at night that gives the muscles a really good stretching. He's very lazy about his physio and occupational therapy exercises, grrr, and is planning on going to Cambridge!

The theme for October will be **creativity**, unless lots of articles about another subject happen to be sent in. All creative expression: art, writing, singing, music, problem-solving, even tae kwon do! Writing on any subject is still welcome, as are ideas for new themes, fillers (for putting in small spaces like this) and artwork. Remember, if you want to see different content in *AU*, the best way to change it is to send something in!

Conference notices

by **Alex Tyla**, NAS Marketing Officer

You can book by post, care of *AU* (please include full address, cheques payable to the NAS) or on the NAS website, www.autism.org.uk

Choose the lowest price that applies to you:

£90 (low income); £180 (NAS member);

£210 (if you book by 27 July); £270 (standard)

Women and girls with ASD

**Tuesday, 16 October 2012,
Novotel City Centre Hotel,
Birmingham**

This conference is a response to increasing calls for specific information about autism in women and girls, as well as from women on the spectrum who feel it is important to highlight their specific needs and their differences compared to men.

Autism is an overwhelmingly male diagnosis, but why do women only make up one in four of those diagnosed as autistic? Are women really less likely to have autism or are they under-diagnosed and slipping through the net and, if so, why? Could it be that they are just better than their male counterparts at adapting to social situations? Are they simply more skilled at pretending not to have autism?

This conference aims to explore further the issues around the possible under-diagnosis of women and girls. The keynote speaker will present the latest research and discuss the implications for future research and practice.

The conference will also discuss the challenges that women and girls face as a minority group within an existing minority. Experts will speak on topics including education, puberty and sexuality, self-harm and eating disorders. Plus, there will be first-hand accounts from women on the spectrum about the difficulties of actually getting a diagnosis and day-to-day living, whether diagnosed or undiagnosed.

Who cares? Practical approaches to supporting older people with autism

**Wednesday, 10 October 2012,
Cophthorne Tara Hotel, Kensington,
London**

As people on the spectrum mature, they face the same physical and mental problems of all ageing people. However, they may need support to ensure they grow old in safety and dignity. Parents who are the main care-givers may find it more difficult to cope as they get older. If a sibling or other relative takes over this role, they often struggle to find the information they need. People with autism who don't have relatives risk a future of increasing isolation. Who will protect their interests once their parents are no longer able?

For adults living independently, there are still potential issues. Supported housing is not always appropriate for older people, who might need assistance with physical activities, such as mounting stairs or getting in the bath. Conversely, generic homes for the elderly may not have resources or be suitable for the specific needs of people on the spectrum, particularly people with sensory difficulties.

All of these changes — to carers, housing and their own bodies — can be very difficult for people on the spectrum. Just as we support young people through changes in school, puberty and onwards, we also need to prepare older people for transitions in care-giving and other potential effects of ageing, such as changes in their own bodies or moving to a new home.

Internationally renowned speakers will discuss key topics, including diagnosis, social isolation and practical issues, such as financial planning and benefits entitlement after retirement. Speakers include Dr Wendy Lawson, Professor Digby Tantum, Professor Francesca Happé, Dr Judith Gould (TBC), and Charlotte Holmer Jørgensen.

Pen pals

Pen pal number 124

All right, my name's James. I would like to make some pen-pal friends.

I am 29 years old. I have a flat in Leicester.

My interests are playing guitars; I have three guitars. I go through the rock-school graded exams. I am doing the grade 4. Would like to meet anyone that does this.

Read sometimes.

I do listen to lots of different music. Do have Rock Cod's metal. Do like to watch the MTV and when there's enough time, do enjoy going out to shows, music events.

Would like a friend to go to some more shows with.

My hobbies: I like to go to the cinema at least once a week. Will watch comedies or action films.

Fan of the *Sherlock Holmes* films. Any cinema fans out there?

Have been doing all my driving this year: have had about fifty lessons, passed the theory test. So I enjoy driving. Would like to have the independence. Will be getting my own car this year. Will be having my own car so I can get around. I can get to the shops once a week and it's for my career.

It would be good to hear from as many good people as possible.

How to place a pen-pal advert

- > All you need to do is send your advert along with your name and address (and email address if you want) to *Asperger United*. You can use the Royal Mail or email. The next pen-pal number will be given to your advert when it arrives.
- > Please note that *AU* does not print dating adverts, as it is unable to provide suitable support.
- > Those under the age of sixteen must have parental permission before placing a pen-pal advertisement in *Asperger United*.

How to reply to pen pals

- > Please remember to let us know the name and number of the person whom your letter is for. (All pen pals are numbered by the editor, not the person who sends in the advert.)
- > Please remember to put your address on your letter.
- > To contact a pen pal, please send your letter to *Asperger United*, c/o The National Autistic Society, 393 City Road, London, EC1V 1NG, or email asp.utd@nas.org.uk
- > We will pass your letter on to the person you wish to contact. However, we cannot guarantee the person will reply as that is entirely their decision.
- > Please note that all pen-pal letters sent via *Asperger United* are opened before being passed on.

****Important notice — please read****

Asperger United is happy to publish pen-pal advertisements but we must stress that we are not a pen-pal or introduction organisation. We do not match people up and we cannot monitor letters (other than the first letter, that is sent via us) so please be cautious when releasing personal details in your letters. The National Autistic Society / *Asperger United* cannot intervene or be held responsible for any ensuing correspondence between letter-writers.

Pen pal number 125

Hello.

My name is Michael, I'm 18 years old, I live in Hampshire and I've been diagnosed with Asperger's since I was 2 years old.

I play the drums and I like to draw and create graphics (I'm really good on Photoshop, WordArt and PowerPoint. I also like to spend my time doing word searches because it helps me to take my mind off stuff (ie., stress, worries (etc.)).

My favourite music genre is glam rock/ glam metal from the 1980s and early 90s (ie., Aerosmith, Iron Maiden, Guns'n'Roses and early Bon Jovi). I also like watching films from the 1980s and early 90s (ie., Ghostbusters, Beetlejuice and some of the Child's Play movies). Home Alone is my favourite one because the traps that the bad guys get caught in are always fun to watch.

I hope to hear back from someone soon of my own age or thereabouts.

Pen pal number 126

Hi. My name is Sean and I'm 23 and I was diagnosed with Asperger's in 2001 and I live in County Kerry in the Republic of Ireland. I'm originally from London but traded the city life for the country life ten years ago. I like film, rock'n'roll music, Coronation Street and Star Trek and I also do presentations: workshops on my experiences with Asperger's syndrome for people with the syndrome and parents and teachers and others and have a great love of raising awareness of Asperger's. I would like to meet people who also enjoy talking about Asperger's and somebody I can swap emails or letters with and get to know around my age group.

Pen pal number 127

Hi, my name is Cristina. I am 23 years old, living with parents in Preston. I do wish to move out in the future and I am doing something about it but it is slow moving.

I have Asperger's syndrome, was diagnosed in 2005, before that I was diagnosed with semantic pragmatic disorder.

I like to watch TV and films, reading books (genres for TV, films and books include romance, sci-fi, fantasy, mystery, crime and action), listening to music especially Andre Rieu. I enjoy reading biographies as well.

I also like going out, whether it be for a walk, to the cinema, for a drink or shopping.

I would like to meet people to be friends in or around Preston.

Pen pal number 128

My name is Oliver. I'm 32 going on 130! I live on the Wirral.

I enjoy cooking, walking, horse racing, doing art and computing at college — though it can be difficult to find the right course, I love finding bargains, and the "Asda price guarantee" has given me a new interest.

I can be quite shy, which can come out as being rude to people who don't know me well. But once I get to know people I often encourage banter and give as good as I get.

I would like to be contacted by people of a similar age.

Fifteen pen-pal adverts have been held over and will be printed over the next four issues, Ed.

Pen pal number 129

Hello, my name is Talha and I am 32 years old with Asperger syndrome. I have been in prison without trial since 2006 pending extradition to the USA — a country I have never visited.

I am accused of being part of a conspiracy to provide material support to terrorists in Chechnya and Afghanistan since 1997. I only want a trial in the UK to prove this is not the case.

Some kind people have created a website to explain my situation:

freetalha.org

I have a serious interest in literature. Some well-wishers compiled my aspirations at poetry in a booklet entitled *This be the answer* and organised a reading by novelist AL Kennedy.

I regard myself as a student of Arabic and Islamic culture. I am also trying to learn my parents' language of Bengali but with not much success. I can also be a keen and sincere audience for others to share their interests. It is always uplifting for a prisoner to receive letters, especially when in such uncertain circumstances.

Pen pal number 130

Hello to all readers, write to a friendly man as a pen pal now! 32 years of age, can make friends with anyone as long as your age is between 22 and 32!

Hobbies are photographing flowers close-up, writing poetry and painting, eating out, music, films and walking.

I want to be a model or an actor. Don't laugh at me will you? I have big dreams and want to go far. And I want more friends to enjoy the journey with. Write to me very soon, we'll talk!

Thomas

Finding the best person for the interview panel

by **Caroline**

The best disability support organisations are those which are run not just for but by disabled people. The National Autistic Society has recognised that it needs to increase the participation of autistic people. A project has started which includes autistic people in the interview panel whenever someone is recruited to work at head office. This means that anyone becoming a member of staff at the NAS has had to demonstrate an ability to communicate with an autistic person during their recruitment process. The autistic person asks the candidates questions specifically about autism, to identify those candidates with a passion for autism, and to weed out those with a poor attitude towards disabled people. Recruiting managers then use this information when considering who to recruit.

The first interviews to use this approach took place in March. As I was an autistic interviewer, I can tell you that having someone with autism on the panel asking about autism did indeed reveal what the candidates knew about autism and what they felt about autism. Autistic inclusion has been tried in three ways. For senior roles, candidates had two interviews, a panel of autistic people asked the candidates about autism and another panel of NAS staff ask the candidates about the skills for the job. For other jobs, candidates had one interview and one person on the interview panel was an autistic person, or in addition to the interview the candidates had one-to-one meetings with an autistic person. Autistic people will be supported to take part in any of these types of interview. Once the process is established in head quarters it will be introduced across the UK. Autistic inclusion when recruiting NAS staff is vital because anyone working for the NAS must be positive about autistic people. So look out for opportunities to take part where you live.

letter to the Editor and a notice

Dear Goth,

I'm 32 years old with high-functioning autism and I spend a lot of time being creative through various forms of art ranging from drawing, through to canvas painting, pottery and sculpting.

I'm a big admirer of the works of Salford artist LS Lowry (who may have been autistic himself) with his amazing drawings and paintings of industrial landscapes and I'm a frequent visitor to the Lowry Gallery on Salford Quays in Greater Manchester. I've done many canvasses but I consider my best ones are the industrial landscapes. There is something about industrial architecture which I find interesting; not just the mills and factories but the people who worked in them. Sons and nephews followed their fathers and uncles, respectively, into the mills and factories so much it became a family tradition.

I find music helps my creativity and thought process. I like all kinds of music, not just what I grew up listening and dancing to. Much of my music preference pre-dates before I was born (1960s/1970s). My musical tastes range from the Shadows, the Beach Boys through to the present day.

On the subject of music, I've found that, as I like routines and hierarchies as a result of my autism, to make myself more successful I invented the "routine jukebox". I developed several routines based on things like:

- i time of day/year
- ii weather
- iii shopping/going out
- iv transport

I found this made me more flexible than I was before. This led to a huge improvement in well-being and social skills which I noticed as well as my family and friends.

There were huge improvements too in how I approached and dealt with situations. I suppose I'm lucky because I was among the last that wasn't born after mobile phones came in. I consider all

the aspects. I still write down my shopping lists, I see people in either Tesco's or Asda on their mobiles pushing a trolley asking their husbands or wives at home "do we need more bread again" — they could've saved themselves a lot of bother by checking first then doing the shopping list. I was at a grammar school and I learnt "the Queen's English", which doesn't include textspeak. If I send a text it's in full spelling and grammar, like "See you later at Wetherspoon's mate" not "c u l8r @ Wetherspoons m8". I know that the best computer available is still the human brain. I use modern technology to help me in my day-to-day life. I'm the master of my mobile and Facebook — not the other way round!

Dave

The ARGH autism alert card

A quick update from Kabie: the Autism Rights Group Highland (ARGH) autism alert card, made by autistic people for autistic people, which was featured in the October 2011 issue of *Asperger United*, can now be ordered directly from the ARGH website via PayPal (or credit card):

www.arghighland.co.uk/arghcard.html

You can also still purchase a card by post using cash or a cheque if you prefer:

ARGH
22 Wester Inshes Place
Inverness
IV2 5HZ

(Needs £1 per card plus a first-class stamped self-addressed envelope to send the purchased card(s) to you.)

Strategies for building successful relationships with people on the autism spectrum

Let's relate!

by **Brian R King**

ISBN: 978 1 84905 856 8 £13.99 / \$19.95

Jessica Kingsley Publishers

review by **the Goth**

I found it a huge change to read a book written by someone who saw all of autism's challenges as just that — challenges. He goes on to explain all the solutions he's discovered, many of which I've found useful, and his enthusiasm for helping people is infectious.

However, he never stops being pragmatic: this is a book for real people dealing with real problems. For example, he gives a clear explanation of the need to fidget that you could use to placate the most intransigent tutter. He highlights the problems of expecting pupils to learn the teaching style of the teacher, along with a forceful argument

to persuade the teacher to change. And he spares no feelings in explaining exactly why all social skills groups are completely useless — along with what to do instead.

He doesn't, of course, have answers for everything, and the book would benefit from having his points recapped in bullet lists at the end of each chapter in order to accommodate learning styles which don't take in prose well, but these are the worst two criticisms I have. Sorry, Brian, I know you have a great argument for why I shouldn't give criticism, but I haven't learnt yet!

I recommend this book to everyone.

This book and the one on page 14 are available from all good bookshops and through Amazon's charitable scheme at

www.autism.org.uk/amazon

and if you use this address instead of the usual Amazon one, the NAS gets a donation from Amazon.

To *Asperger United*,

my drawing; is untitled, but it is underwater and about being different and happy. I think the picture expresses more than my words,

Annette

Annette's art is on this quarter's cover, Ed.

At the end of a story,
there always has to be a dog,
waiting for the clue
in black and white.

Every day he awaits,
the opening of the door;
that is the essence of his existence.
He waits patiently, eagerly
only to please
what he does not understand.

After the end of a story,
the dog walks a crowded street,
not knowing where to go,
or who to live for,
only knowing the road
in front of him:
black pavement
below a white sky.

Every day he awakens
into a world
he does not understand
chasing cats
to horizons,
where dogs are not allowed.

At the end of the story,
the door closes,
and faces look just the same,

just too damn gray!

Malakh Ahavah

“Problems in living” and the mental well-being of people on the autism spectrum

part one

by Damian Milton

Within the history of psychiatry and psychology, there are some who would argue that some kind of neurological defect will one day be found for all “disorders” of thinking and behaviour, locating the “problem” within a deficient and dysfunctional brain. There has also been, however, a movement for many decades that has suggested that mental illness was a “myth”, at least when it came to illnesses of the “mind” which had no physical manifestation in some kind of damage to the brain. The former position would suggest that people cannot have psychological “troubles” due to differences of social position. In the accounts of theorists from the 1960s onwards (like Szasz, Laing, and Breggin), biological causes were being wrongly attributed to “problems in living”.

In his article, *The myth of mental illness*, Szasz argued that the perception of “mental symptoms” entailed a comparison of the patient’s conceptual beliefs with those of the observer and the values of the society in which they live. He suggested that many of these “symptoms” were not due to damage to the brain, but were symptomatic of the stress of social interaction. The definition of an illness, whether physical or mental, is often a deviation from a norm, yet for mental health “deviations” these can only be judged, Szasz argued, psycho-socially and ethically, while the “remedy” is one of psycho-pharmaceutical intervention. The only evidence of a “mental illness” existing being the psychiatrist being told or shown of a behaviourally defined symptom. Diagnosis, for Szasz, is thus a value judgement on whether or not behaviours are within “acceptable” norms. In essence, people were being placed into stigmatised social categories.

Like Szasz, the work of Laing challenged the orthodoxy that mental illness was biological, with

no connection to social context, or “problems in living”. Laing suggested that psychiatry was built on false assumptions, diagnosing illness by behavioural conduct, but treating by medical intervention. Laing, however, also suggested that mental ill-health could be transformative, where the individual could gain important insights. A similar thought was expressed by Dabrowski in his work on “gifted” children that were also “over-sensitive”. In my own reading, he attempts to theorise about a sub-group of people that I myself could be said to belong to, characterised by a passive, hyper-sensitive disposition.

The idea that psychiatry was a genuine branch of medicine was also challenged by a number of notable theorists, such as Foucault, Goffman and Rosenhan. More recently, similar arguments have been made by Breggin and Timini, who has suggested that the diagnosis of autism should be abolished. These theorists were often not opposed to the practice of psychiatry as such, as long as the therapeutic relationship was contractual, rather than coercive, between consenting adults, and without state intervention.

Many psychiatrists regard Szasz, Laing and others with similar views as pariahs of the profession, and suggest that “mental illnesses” are becoming ever more measurable, and medications have been shown to be “effective” in treating illnesses such as depression (this is hugely debatable). This “medical model” of “mental illness” has dominated discussions of autistic people having psychiatric “comorbidities”, as evidenced in the NAS article *Mental health and Asperger syndrome* (2011). This discusses a variety of ailments that could affect autistic people: depression, anxiety, and catatonia. What this article often seems to do however, is to frame “problems in living” in medical terminology, locating the source of the “problem” in the “dysfunctional” autistic person,

rather than in a “dysfunctional society” within which they live: “People with AS are particularly prone to anxiety disorders as a consequence of the social demands made upon them.”

The article then suggests that a good way to manage anxiety is to use “behavioural techniques”, or relaxation therapies, or drug treatments (including antidepressants). If anxiety is caused by “social demands” that are placed on one, then perhaps these are not the most appropriate “interventions”!

When reviewing “psychological” treatments for “mood disorders”, the article states that the primary treatment is cognitive behavioural therapy: “. . . as it is effective in changing the way a person thinks and responds to feelings such as anxiety, sadness and anger, addressing any deficits and distortions in thinking.” Such certainty of efficacy seems to simply come from a citation to Attwood.

As someone who, as a teen, narrowly avoided a diagnosis of catatonic schizophrenia, and whose “symptoms” were brought on by extreme stress, who had also suffered psychological trauma from a road-traffic accident, I find it disturbing how “catatonia” is linked to autistic people. The article states that catatonia has a number of symptoms: an increased slowness of movements and/or verbal responses; difficulty in initiating, completing and inhibiting actions; increased reliance on prompting by others; and increased passivity and lack of motivation. As an autistic person who is generally slow in movement and verbal response, who has difficulties with initiation, who may be perceived as needing prompts from others, is of a passive temperament, and often unmotivated outside of my areas of interest, these descriptors are not indicative of a “mental illness”, but manifestations of my autistic disposition. The report states that other manifestations include: freezing, excitement and agitation, or a marked increase in repetitive and ritualistic behaviour. These “manifestations” for me would signal either excitement or stress, both of which are dependent on the social environment.

A full list of references for this article are available on request from the usual AU postal and e-mail addresses, Ed.

Group notice

Hi *Asperger United* readers

It's been an eye-opening few months since we launched **ASPIE** (a social group for adults with Asperger's syndrome in Worcestershire) and from the limited promotion we have done, we keep receiving new enquiries and have now acquired our own premises at

26 Sansome Walk
Worcester
WR1 1LX.

We continue to meet on a Wednesday, 1pm to 9pm for now.

The intention is to open another day or evening and to plan meals out or trips to places of interest. Our thoughts are now turning towards fundraising occasions. We are in discussions with an AS classical pianist and also arranging a party in a park in August. If you are interested or have any other ideas — eg, a barbie on a beach — we'd love to hear.

www.aspie.org.uk

is our website, currently under development by one of our members. We intend to have a members' forum so that we can all keep in touch and we will be recruiting members to post/contribute directly to it. We do like to hear from you so please also continue to email.

If you ever happen to be in Worcester on a Wednesday do please come and see us. You will be very welcome.

Best wishes

Sarah

Chief Aspie

admin@wits-endweb.co.uk

It's raining men on Charing Cross and Notting Hill . . .

by James Christie

James Christie, 47, a Glasgow resident, was diagnosed with AS in 2002 and is a client of the NAS employment agency, Prospects.

After suffering severe psychological trauma at work, James (who has a degree in creative writing) wrote, partly for fun and partly as therapy, a fan-fiction story based on Buffy the vampire slayer. He centred the story on the character of Drusilla (Spike's demonic and deranged girlfriend in the TV series, who was portrayed by the delightful Juliet Landau) and, once it was completed, sent that story, Drusilla's roses, to Miss Landau in Hollywood.

Juliet Landau was "blown away" when she read Roses and, remarkably, an email correspondence sprang up between the two of them. James then decided to take a Greyhound bus trip across the United States (originally to inspire people with autism and in the end to see his dear Miss Landau) and they met on Sunset Boulevard in 2010.

James has now written the story of this encounter:

Dear Miss Landau
ISBN: 978 0 95655 956 2
£8.99
published by Chaplin Books

According to Helene Hanff in *84 Charing Cross Road*, a clerk or some such (Walton by name or maybe not) said of his time at the court of Richard III, "the reader would not credit that such things could be, but I was there and I saw it."

You may not believe the tale of the Rain Man who wrote a story about a TV character (Drusilla the demon from *Buffy the vampire slayer*) and sent that story to the Hollywood actress who portrayed her. Of the man in the street who corresponded with a famous film star (the lovely Juliet Landau) in a real-life parallel of the film *Notting Hill*, who crossed the continental United States for her like the Babbit brothers on their road trip, and who

walked up to that same Miss Landau one Sunday morning in March on a boulevard west of Sunset and gave her a rose. No, you may not believe such a tale. But though you, the reader, might not credit that such a thing could be, I was there and I did it.

At the beginning of the story were the words:

Dear Miss Landau . . .

The words became a heading, the heading an email, the emails articles and the articles a book. The articles themselves were written first from Glasgow, then from New York, Washington, Chicago, Amarillo, Albuquerque, Las Vegas and beyond. And if (as it says at the start of *Dear Miss Landau*) Allah weaves the threads of men's destinies into many strange tapestries, then he most certainly wove a very strange tapestry for me, which I did indeed make my destiny.

If it were a work of fiction, I fear *Dear Miss Landau* would suffer from a surfeit of themes, but with all its frailties and its weaknesses it is a true story which shows what one person with autism is capable of. And if one of us is capable of such things, why could not others be? Well, because people with autism are often unable to excel because of other people's attitudes towards them.

At a meeting of the Glasgow Disability Alliance it became obvious that most of the discrimination people with both learning and physical disabilities suffer does indeed come down to the attitude of their co-workers, managers and employers. And by attitude, I mean bad attitude. While managers talk sincerely of taking great strides towards equality, in practice disabled employees are often sidelined, badly treated and forced out.

In my case, one organisation for whom I went to work completely failed to deal with the question of my autism, Occupational Health failed

to pass my details to the office where I worked and excuses made for the so-called adults who essentially tortured me there came down to feeble comments like: "They don't know any better."

That should not be an answer acceptable in civilised society. However, I ended up signed off on sick leave for six months and was kept hanging for another six while the organisation's HR department tried to cover themselves and avoid an employment tribunal.

I ended up virtually brain-damaged, on the verge of a nervous breakdown and, if it had not been for the efforts of my trade union and the NAS Scotland, I'd probably have wound up as just another unemployment statistic.

However, and surreally, in recovery from this trauma I gained an interest in *Buffy the vampire slayer*, focused (as Asperger's do) on the character of Drusilla the vampire (ironically finding the personality of a soulless murderess more pleasant than some of my former "colleagues") and, for personal interest, decided to write a short story developing the character of Drusilla.

In brief, the writing of that story, *Drusilla's roses*, restored me to mental health. Mailing *Roses* to Juliet Landau led to an email correspondence which restored my faith in human nature and the real-life road trip to California was the genesis of *Dear Miss Landau*. It was indeed like stealing the Enterprise for my Helen of Troy, and if you think that phrase is a cliché, then all I can say is that is truly how it felt at the time.

No, you wouldn't credit that such things could be, but that's the way it was.

Note: the film 84 Charing Cross Road (1987) depicts the growing friendship between a New York author and the staff at an antiquarian bookshop in London across two decades, from the 1940s through to the 1960s. Based on the real-life reminiscences of the author, Helene Hanff, it explores the deepening relationship between the central characters against the backdrop of their shared interests in great literature and the craft of writing.

The Angelbears

by Siobhan

I'm very much into knitting, although a beginner with mum's support I'm doing well. Last year my auntie brought round an article about a lady called Melanie, who had started knitting bears for children in third-world and war-torn countries who didn't have any toys. Hence the start of the Angelbear began. *Take a break* magazine, which the article appeared in, launched an appeal asking readers would they like to knit a bear for a child in need. So I downloaded the pattern for an Angelbear off the Internet, and knitted away. The Angelbear Organisation ask for the teddies to be brightly coloured and jolly, so that they can cheer children up. So I urge any fellow knitters out there to knit an Angelbear, if like me you'll have so much joy making one knowing it'll go to a good cause. I'm on my third box of teddy's and still enjoying it.

The website address for the Angelbear is

www.angelbear.org.uk

A lawyer in your corner

I needed to take my former employers through legal proceedings when they did not provide me with disability support. I was able to do this because my home insurance covered legal expenses. Be ready to assert your rights; check what your insurance covers when renewing your policy.

Caroline

Queer versus odd

by **Cara Dovecott**, the Shadow Queen

The Shadow Queen, like the shadow cabinet, says what the powers-that-be don't see.

One is straight. Boring! Of all the types of personal life available one stuck with convention. One is attracted to the complementary sex, (one won't say the "opposite sex" because men and women are not inevitably adversaries — so says Fillip, the handsome devil), and while it's not always straightforward being straight, one is not gay, and one likes to think that doesn't mean one's gloomy. What if one weren't straight? Would that make one crooked? There must be other options. Unlike my royal counterpart I don't have to provide the throne with an heir or head up the Church of England which surely gives one's personal life room for manoeuvre. If the glossies in one's boudoir are a faithful reflection of society, then these days everyone is swinging from the chandeliers by their underwear four nights a week. Perhaps one's unconventional after all: the light fittings at Mal-Moral are from IKEA.

But then one isn't simply straight. As an Aspie one relates differently, so one's conventional relationship seems odd. One just wants to be left alone: however, one knows that society needs to change and that one's difference demonstrates that there are other ways to live; one finds one's the Queen of Queer. To be queer is more than to be odd, one has to desire social change and orientate one's behaviour accordingly. Queer-curious? Let me share a dilemma with you. One prefers puppies to children so one's Corgi needs a mate. Her Majesty has three Corgis, Monty, Holly, and Willow, one just has "the Full Monty" and he's fussy about his bitches. But, alas, speed dating events for pets are nowhere to be found. Society caters only for the conventional. One decides to host such an event and places an advertisement in the paper shop window. Is this act political? Maybe not. Every relationship which is not a woman and a man raising children subverts convention. These days anything goes, if only one had the social skills to join in.

So does one desire a radical new personal life? Following one's wondering in the previous edition of *AU* about the experience of being gay and Aspie, half-a-dozen readers wrote in. Some were happy to be identified; however, to be even-handed, they are all referred to by pseudonym.

First up Aspie lesbians spoke out about not conforming to gender stereotypes. Alice talked about a female-dominated work place: "I have had problems socialising, particularly with other women, all my life, which made work difficult because it was nearly all female workers (old people's home). I have always got on better with men, for some unknown reason, and I describe myself as the least bitchy person you'll ever know. I think it is this lack of understanding of other women's huffiness and bitchiness that has caused me a lot of problems".

Jane who describes herself as a feminine lesbian found both straight and gay socialising tough: "I thought I didn't relate well to straight women because I was gay but then I realised that I didn't relate well to gay women because I am also too feminine. I now think my difficulties with relating to other women are due more to my Asperger's and not my sexuality".

But Nicola found understanding in the gay community: "I think being gay is actually easier for Aspies than being straight . . . I have always been very open that I am gay and an Aspie . . . I do not see any point trying to hide major parts of myself, and I have found the gay community very welcoming of me, . . . I do not feel discriminated against in the same way as I do within 'normal' society; I think within 'normal' society there is a certain expectation when it comes to gender roles . . . within the gay community though I find that gender stereotypes are far less formed . . . it is more acceptable to be a masculine female".

For Rebecca, conventional roles proved very difficult indeed. She lived for many years as a "straight and repressed Aspie man" and is now starting a new life as a "liberated woman". She spoke about having children because it fitted convention. But fundamentally she didn't fit. Then she wasn't allowed to fit. Rebecca was thrown out of her church. She now runs a group for people with minority sexualities at a new church.

So if Aspies don't fit convention, are we more likely to have minority sexualities? Jane suggested that being born with autism or same-sex orientation could both result from testosterone levels in the womb. Other readers mentioned choice. Being seen as different might make it easier to try different sexualities and be open about doing so. Perhaps gay sex is Aspie-friendly as it avoids having to understand a body unlike one's own. Another option is celibacy, a choice for those who cannot maintain relationships. In a sexually orientated society having no interest in sexual relationships can be seen as odd. Disabled people have fought to be seen as sexual; equally, sex is not compulsory. For Mark there was no choice and no link between being born Aspie and gay. He describes himself as obviously gay but not camp, his behaviour being typically male. He has always known he was gay but came to an understanding that he was Aspie years later, so does not see being Aspie as leading to being gay.

However we end up different, does the gay community welcome Aspies? Nicola had met partners online: "... most of my relationships have started on line, where there is no need for reading facial expressions or body language ... it is better to go to a chatroom ... than go to a dating site ... where there is pressure to meet total strangers with agendas that might not be all that healthy". Offline had not worked for Nicola: "... as an Aspie I find the whole club-scene thing just a no-go: it feels like a meat market full of noise and light and there is no way I can function there". But on the whole the gay community has welcomed her: "I just feel that being an individual is far more acceptable within the gay community than in the rest of society, where conformity seems to be a requirement".

Mark had a similar experience: he and his partner "don't go out to gay pubs or night clubs, etc. (I'm not fond of crowds), ... so I don't feel I have a place in a 'community'. Does online count? I have a few online gay friends ... but some of them don't know about my autism." Offline, Mark, who says he wouldn't know how to flirt, has noticed how others flirt with him: "I wear sunglasses all the time ... (I'm uncomfortable with eye contact). Lots of people stare at me ... make rude comments like 'Innit bright in here?!', 'Oooh! That sun's bright!', 'What you wearing them for?' ... I have had some t-shirts ... made ... my favourite one says, 'It's called AUTISM! Look it up!' If I haven't got one of my special hoodies on then I have noticed other gay men look at me and stare, but not in a rude manner. (I'm not an unattractive person, even if I say so myself!! :-).) *But* if they see me and I have one of my t-shirts ... on then they look at me differently. They tend to *not* notice me as an attractive person".

So with this mixed welcome are gay *AU* readers out and proud as gay Aspies? Mark wondered just how many gay Aspies there are: as it's hard to be out, one can't know. Mark isn't sure he wants to be out as Aspie with everyone. Everyone knows Mark's gay, he can't hide it, but coming out Aspie has been harder. Having the confidence and social skills to know how to discuss something as misunderstood as autism was one issue, knowing whether he'd be treated with more or less understanding was another: "How does one 'come out' to work colleagues? Should I one day go to work wearing one of my special hoodies? Then how do I explain autism to those that may not necessarily understand it? ... Maybe one day".

There's a long way to go before it's easy to be out as Aspie. Jane notes that while the gay community uses pride events, these are less fitted to Aspies: "but I forgot that we don't all want to party in the same way, so how do we achieve equality, find a way to raise awareness and have our voices heard too?"

So there we have it, as I look out of my boudoir window, maybe the grass looks greener because the glass needs to be cleaner. I'm not tempted to trade my beau in just yet: one's lover and one will stay as we are, an odd pair of straight queers.

I sometimes sit back and find it astonishing that some areas of society can have such a negative view of the capabilities of people with Asperger's syndrome and the "label" of Asperger's. To me it just shows that Asperger's is not fully understood by such a large proportion of people and that is quite a sad thing. I am an Aspie and I am also the current WKC Kickboxing World Champion. My Asperger's does not stop me from setting out to achieve any of my goals, if anything it makes me more determined to succeed and show others that I can do it, even if it does mean I have to work a lot harder than they do for it.

I always have very high aspirations and expectations of what I can achieve (and usually in a short space of time), sometimes they are not always realistic and naturally my husband worries about these tendencies, fearing I will stress myself out too much. But as a fighter I am trained never to give up and this is something that I have never done, no matter how hard something got (often to the surprise of my husband). My husband managed to sum it up very nicely with the following remark, "just when I think you have reached your limit and you can't possibly handle this any more, you come out smash down that wall and carry on." And I do. Nobody has ever been able to tell me I couldn't do something. So now I am at the next phase of my life, I have a world title to defend and a stressful year fundraising (I get no funding for my sport) so that I can go with my husband to the World Championships in Canada. Also in this year I have decided to become self-employed and teach kickboxing whilst studying for a qualification in sport and remedial massage — as I said I have high aspirations.

Incidentally I have been able to find little or no help and guidance aimed at people with Asperger's syndrome who wish to become self-employed (and it really is a minefield of confusion!), there isn't even any guidance offered by the NAS. Self-employment is going to be a huge challenge and I am very fortunate to have such a wonderful husband who takes a very hands on approach in supporting me with all I aim to achieve. As part of being a world champion and one who wants to be a successful kickboxing

instructor, I have started to venture into public speaking and the world of school assemblies! I have always been introverted and withdrawn and hated to be on show, I actually hate standing on the podium to receive medals Yet I am inexplicably drawn to public speaking; maybe it is the culmination of many years quietly in the background with a lot to say? I want to be an inspiration, I want to share my success story and I want to prove that Asperger's is not disabling and that no matter what, if you want something enough you can achieve it. I am living proof of that: when I began kickboxing at 13 it took me two years to speak to anyone in my club; at 17 I could barely give a speech to ten people in my English class; but now at 25 I teach classes of strangers every week and I can deliver assemblies to school children without a script in front of me.

I was diagnosed with Asperger's syndrome in my twenties and like many other people who are diagnosed at this stage of their life, I had had many difficulties growing up and adapting to the world as it changed through each life stage. I had struggled immensely going into the world of work and very nearly lost my job through not understanding expectations. When I was diagnosed it felt like a weight had been lifted. I went between the two extremes of being happy to be diagnosed and feeling upset that I had not been diagnosed at an earlier age. But since diagnosis my life has gone from strength to strength. I feel that it has given me a greater understanding of myself and when and how much to push myself to achieve my goals. I am able to structure my life in a way that makes sense to me and can now be productive in achieving my goals. And really I feel from having Asperger's I have a much better awareness of what I can achieve than I otherwise would. I am content to just be me and free to achieve whatever I desire. For me my Asperger's diagnosis has been liberating rather than limiting. I think that us Aspies out there have the responsibility to come and keep smashing those walls down either collectively or individually and I fully intend to use my sporting achievements to raise awareness of Asperger's in both its positive light and in terms of the challenges it poses.

Jo

The rules of *Asperger United*

(contact information for *AU* is on page 2 and again on page 20)

- 1) *Asperger United* is funded by the NAS and readers' donations, and is independent of the NAS. Although it is called "*Asperger United*" it aims to cover the whole of the (reading) autism spectrum. That is, the concerns and joys of any subscriber on the spectrum can be printed, not just Asperger's.
- 2) Pieces that appear in *Asperger United* are credited using the author's first name only, unless the author requests something different. This is done to protect your privacy.
- 3) *Asperger United* administers the copyright of everything that appears and it does this on behalf of the authors.
- 4) *Asperger United* does not use your contact details for anything other than administering *AU*. Your details are not passed on to NAS Marketing, NAS Fundraising or any other organisation without your written permission.
- 5) If you move house, please inform *Asperger United* and include your old address as well as your new address.
- 6) Even if you've paid for the Royal Mail forwarding service (or another forwarding service if you live outside Great Britain and Northern Ireland), you still need to inform *Asperger United* that you have moved address.
- 7) If you want to unsubscribe, inform *Asperger United* and include your address.
- 8) If you want to resubscribe (or subscribe for the first time) inform *Asperger United* and include your postal address.
- 9) If you phone and leave a message on the machine, please speak slowly and clearly and spell uncommon words, as sometimes the line isn't very clear. Please give any phone number you leave twice for the same reason. Remember to give your postal address so that we can find you in our records.
- 10) The current edition of *AU* is available at **www.autism.org.uk/aspergerunited**
You need to scroll down to near the bottom of the page, where there is a link to the PDF.
- 11) You do not have to be a member of the NAS to subscribe to *Asperger United*.
- 12) Book reviews are the most popular thing in *Asperger United*, please consider submitting one. They can be about any book, not just books about autism. Also, they do not have to be short (the Goth keeps most of his reviews short to leave more space for other writers). If you do not want your review to appear in the NAS section of the Amazon website, please make this clear.
- 13) Although each issue is themed, submissions on any subject are welcome. Only some of the letters and articles in each issue will follow the theme. All submissions may be edited, especially for privacy, libel, and for fitting the space available.



Squease vests

by **Robyn Steward**, specialist Asperger's trainer and mentor

www.robynsteward.com

I have always had sensory perception difficulties, particularly around my hearing. About three years ago I was asked by some students at the Royal College of Art to help them design something that would be useful for people on the spectrum.

Now what they designed is on the market. It's called Squease. You may have heard about weighted vests: they work by providing what is known as deep pressure — simply pressure that is quite heavy and can help the wearer to feel calmer. Weighted jackets are effective; however, they have two problems:

- 1 they have to be taken off after fifteen minutes, as the wearer gets habituated (used to it and therefore the effects wear off)
- 2 it may seem a little different to others and this could cause bullying and teasing.

So the team designed a vest that could be inflated (to give deep pressure) and deflated while

being worn, and fit in a specially adapted hoodie.

Whilst they are expensive, if you can get one and respond to deep pressure (for example, liking being covered by several duvets) then this may be helpful for you: it is comfortable and easy to use (it inflates with a hand pump which gives added stimulation).

People use stimulation for different things: some people like deep pressure when they are sad or stressed or anxious.

The Squease vest can also be worn discreetly under a shirt or vest/t-shirt at work or school.

Personally, I'm glad that a group of people have chosen to make an advance like this and have appreciated that discreetness is important to many of us.

Their website is www.squeasewear.com

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