

Produced by and for people who have autism-spectrum conditions

Asperger *United*

Edition 76 October 2013



AU


The National
Autistic Society

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 who have 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 £9 per year from overseas readers and £15 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

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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 Kaczynski, formerly Cohen.

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.

Asperger United is available in **large print** on A3 sheets (double the size of this page). If you need large print, please let us know using the postal or email addresses above.

Contributions for the next issue should reach *AU* by **4 November 2013**

Welcome to the October edition of *Asperger United*.

Last issue's discussion of empathy seems to have struck a chord: I was surprised by the number of contributions specifically and also roughly on that topic — brilliant!

Empathy, and the official view that we don't have any, is obviously a subject many of you feel strongly about, and contributions this issue clearly show that we can and do have empathy for people like ourselves, just like everyone else. However, this empathy is consciously understood, not instinctive — there is discussion

of the difference in this edition. One day I hope we can persuade academics of our understanding.

Changing subject, the Autscope conference was another success: I enjoyed meeting so many readers and contributors over those four days. It is my chance to truly relax around people. The theme this year was *Finding a voice* and the mould-bursting report on this year's conference shows just how creative someone given the job of writing the report can be.

I look forward to all your contributions,

the Editor

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Anxious thoughts

by Tony

I have written this piece in response to the request of the Editor of *Asperger United* for material on mental health. I start off with some biographical information to provide a context. More significantly, however, I draw conclusions from my experience that may be of general interest.

I was born in 1945 and have been prone to “anxiety” for as long as I can remember. My parents were both teachers and they brought up my brother (two years my junior) and me in a typical middle-class household. I attended grammar school then started to read a general degree at university. During my second year at university, things went wrong and I left prematurely. Nonetheless, I managed to obtain a job with a major bank the following month and remained with the same employer and its successors until I willingly accepted early retirement in 2001 (at the age of 56½).

I married in 1974 but we have no children. My wife, since 2002, has worked part-time rather than full-time. While we have a few friends, we tend to keep ourselves to ourselves and we share a major interest in hill walking.

I had hoped that retirement would assuage my anxieties but that was not to be. The stresses of working life were of course removed but I managed to discover others with a vengeance. Since 2004, I’ve undergone two courses of counselling and one of cognitive behaviour therapy. I’ve always been reluctant to take medication but was persuaded to do so for just over a year (from early 2010) as a result of a particularly nasty “downer”.

A breakthrough came in the summer of 2010. I happened to listen to a radio programme about “autism” and “Asperger’s syndrome (AS)” whereupon the light dawned. While I had heard of the expressions, they were meaningless to

me, but some research on the Internet soon upped my game. My wife helped me with a sort of behavioural analysis and, after careful consideration of “the evidence”, our GP confirmed our suspicions of AS.

The three of us decided that there was little to be gained from an “official diagnosis”, at that time at least, and that I should concentrate on self-help. Here are some conclusions arising from my experience since the diagnosis.

AS is probably a neurological condition (the way in which the brain is wired) and not a mental illness as such. However, people with AS are particularly vulnerable to “anxiety” which can lead to mental-health issues, as in my case.

Adults should have realistic expectations of the support available from the various health services. I “bought” one of my courses of counselling and the course of CBT from private providers. The other course of counselling was with the NHS. I formed a high regard for all the therapists; however, none had experience of treating a person with AS so that, in some respects, their efforts were ineffective or even counter-productive. I agree with commentators who insist that people with AS should seek professional help only from practitioners with the appropriate training and experience. It can of course be expensive.

Websites contain a wealth of information and that of the National Autistic Society warrants a special mention. For more in-depth information, I’ve read a number of books about which I could write a further essay. Some of the most useful ones were written by American authors.

An important step for me was self-acceptance. Once I understood the characteristics of AS and had reflected on my own strengths and

feature (continued), two letters and a notice

weaknesses, I had a better idea of who I really am and what drives my anxiety. For instance, social encounters have always been a problem, albeit I've learned to cope (or "get by") adequately with most types. Even so, there are some that I now simply refuse to entertain and, if need be, I justify myself on "health grounds".

Over the years, I've taken on a number of voluntary roles, notably with the local church. I'm better equipped for "back office" tasks than "front office" ones so I've become more selective in what I'm prepared to attempt.

I cast a distinction between "cognitive intelligence (CI)" and "emotional intelligence (EI)". Arguably, the latter embraces "social intelligence" or significant elements of it. In common with many people with AS, I'm reasonably well endowed with CI but short of EI. I am, therefore, making a special effort to develop my EI — often with the help of CI, notwithstanding that EI is essentially intuitive whereas CI involves rational thought. A number of the books to which I've referred are proving invaluable.

The effective conduct of relationships is a specific issue and its true importance is becoming apparent rather late in life. Apart from the characteristics of AS, I am an introvert by nature so that reaching out and responding appropriately to others can be quite a challenge. I tend to view the world beyond the home as a lonely and daunting place!

Do I regret not having learned about the AS sooner? Yes in some ways but, given my age and upbringing, the chances of it being missed were pretty high. Awareness of the condition has been a potential life-changer: at least I know more of the likely drivers of my anxiety and have improved the odds of my working out ways of mitigation, whether by prevention or by cure.

Hello all *AU* readers,

Maltesers are chocolates which are all of the same kind. They are well suited to being put in a box. On the other hand reading *Asperger United* informs us all that we are all different to one another.

Jacqueline writes (*AU*, July 2013): "I do not see myself as autistic. I see myself as Jacqueline, and I have autism." I think I understand the importance of what Jacqueline is saying. I suggest then that we *always* speak of us different as being individuals with autism and *never* again as autistic people.

Individuals with autism are not Maltesers.
Individuals with autism do not belong in a box.

Michael

Hello everyone,

I am wondering how you are finding the whole thing of work/benefits/disability at the moment, particularly the matter of ESA. Many people seem to be struggling with this. I have had a difficult time with it. Anyway, I want to let you all know of a website (and their links) that are seeking to let people know what's happening with the above. There is an e-petition to sign if you are able to. The website is called **wowpetition.com**

I think the government in this country is treating people with disabilities very badly at the moment.

Jed

If sufficient material is sent in, the theme for January will be **relationships**, which follows nicely from empathy. Vote with your contributions: the more submissions on a subject sent in (from different people), the more likely that that subject will be the theme. 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!

Hi,

I should say that I have no qualifications that inform my opinions. I was interested to read the article from June Bowden about feeling an affinity with Aspies through being born blind.

I am partially sighted due to ocular albinism and developed mental-health problems by my teens. All of my problems relating to others, lacking confidence, being clumsy and sensory problems were blamed by everyone on my being visually impaired. I knew it wasn't but I didn't really want to shout about knowing it: I was scared I was crazy. At 31 I discovered what was different about me and it was possibly the greatest moment of my life. Although getting appropriate help, or even the autism-aware workers the Autism Act says I should have access to, is impossible in this area.

It's not new to connect autistic symptoms and congenital visual impairment. A psychologist called Fraiberg noted it in 1977. However, that does not stop a visually impaired person having an autism-spectrum condition. I fear that ignorance among healthcare professionals will be creating a number of Aspies and HFA individuals whose problems are dismissed as being the result of their visual impairment when they need further investigation. I have been denied the treatment that psychologists have said I need as a result of the mental-health problems which I developed directly as a result of the lack of diagnosis. It's a huge relief to know I'm not alone, that I can contact others and no one should be denied the peace of mind knowing who they are and that they are not alone brings.

Also, individuals who have the kind of social problems autism brings should consider a guide dog. My dog is a great source of emotional support for me and I can take her to most places that would frighten me. For example, we went to a hospital last week. It is quite a challenge socially because people are interested in her, but everyone wants to know the same things so I've just learned to say the same things all the time. For people who feel alone, a dog is amazing. My dog has given me something to get out of bed

for when I'm at my lowest and she is sensitive to my feelings and can be very comforting.

Secondly, I have empathy. My feelings are extreme and I become overwhelmed easily. I believe the difference is that I have to actually think what the other person might feel, I do not know instinctively. It developed late. I have problems with controlling how I feel and being able to express feelings appropriately. For example, light touch hurts me and often skin-to-skin contact does too. Most of the people I know believe I avoid touch because of this and that I don't enjoy contact and can't be comforted by it like others. This is wrong: I wear long sleeves all the time so it's hard to hurt me through touch and I am comforted by touch like anyone. I, however, exist as an island without this because I can't figure out when I'm supposed to touch others and where I'm supposed to touch them. Timing is a nightmare for me as I am incredibly clumsy and fear touching inappropriately, for example, brushing against someone's breast, or for too long, or using the wrong level of touch. I might feel I have the same relationship with two people, yet one might want no physical contact but the other might hug. I get the impression that neurotypicals believe I lack empathy as much because I don't touch as because of my expression of the feelings by words.

I think that time and again we, as Aspies, come across situations where we are misunderstood and yet it could be solved with a little bit of education. I know a young HFA boy and like many now he is in a regular class. I am glad these children are supported to allow them to have a fair chance, as all my problems have led to my education failing to reflect my intelligence. Anyway, I feel the biggest thing that might be achieved is that some neurotypical children will grow up with knowledge of autism and will accept us as different rather than wrong. I feel there is a real opportunity, that is probably being missed, to educate children and have them understand their whole lives and make the lives of autistic people better in future.

I'm sorry I've gone on a bit, I don't get much opportunity to express my feelings,

Sarah

Pen pals

Pen pal number 160

Hi, my name is Dinesh, I am 24 years old and I have Asperger's syndrome.

I have lots of interests including going to dance music concerts like Basshunter, Cascada, Ultrabeat, Clubland, etc. . . . I also like watching movies, keeping fit, bowling, snooker/pool, shopping, playing the piano, cinema, eating out, going up to central London and theme parks. My favourite music genre is techno; any dance music with a groovy beat, like David Guetta, Black-Eyed Peas, etc. . . .

I do find it hard to start a conversation with new people and to make friends.

I would like to meet new people and make more friends. I do prefer contacting people by emails as I access it more often. I am looking for a pen pal who is around my age who shares my interests or similar.

Pen pal number 161

My name is Claire, I am 44 and I live in Minehead. I was diagnosed with Asperger fifteen years ago. I would like to find a pen pal similar to my age anywhere in the UK.

My interests are museums, films, tv, antiques and walking.

I originate from Staffordshire and I do not have any friends in Minehead as I find it hard to socialise with people. I attend a day service centre one day a week for people with autism. I also work at a hotel one day a week.

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 162

My name is Angus.

I'm 16 years old and have been recently diagnosed with Asperger's.

I love animals and I enjoy doing active sports like football, tennis and trampolining. My pet hate is having to go shopping on the weekends! I live with my mum, dad and younger sister and our family pet Great Dane called Cleo.

I came here to live in England last year after spending twelve years in South Africa. I find it hard to focus and I am also quite sensitive. I struggle with change, and find it difficult to socialise with my peers, though I find it much easier interacting with people who are a little younger or older than me. Considering how I hate change, I have still had plenty of it in my life, as I have been to thirteen different schools, and with that, have moved house numerous times, due partly to my parents trying to find the right school environment for me, and also to my father's job.

I would love to talk to anyone who shares my interests and has similar struggles.

Pen pal number 163

Hi. My name's Chase and I'm a 23-year-old girl living in south England. I was only diagnosed recently, so I'd like to talk to some more Aspies and hopefully make some new friends. I love music, films and animals, and would like to talk to anyone who'd like to talk back :)

Eighteen pen-pal adverts have been held over for publication in the next four issues, Editor.

Pen pal number 164

Hello people, my name's Scott and I'm 23. I am currently on remand pending trial for one hectic night in which my life has been totally messed up . . . for now. I have only recently been diagnosed with Asperger syndrome (July 2012), and was diagnosed with ADHD last year.

I wasn't sure whether to place a pen-pal advert, but I would like to speak to some people I may be able to relate to.

I'm 23, don't like football, I do weights inside and out, I like talking to different people and hearing about different things, love dogs, and I'm looking forward to travelling to various different countries . . . eventually.

I like all types of music, and my favourite films are comedies.

I don't smoke, and I like to keep healthy, which is why exercise is a big part in my life. I read when I can concentrate for long enough, too, lol.

I hope to hear from some of you soon.

Pen pal number 165

My name is Samantha, and I am 19 years old and am from Wiltshire. I love reading and writing stories of my own, gaming (Nintendo DS and 3DS, but pretty much everything), manga, anime, rock music and anything to do with animals. I was diagnosed with Asperger's at the age of 11 and was home-schooled from the age of 11-16 which was when I went to college and have been for the past three years, studying my GCSEs and studying health and social care. I am currently deciding whether or not I would like to do the highest form of my current course in September. I would love a pen pal of my age group, however do not mind pen pals who might be younger or older :)

Thanks, I can't wait to hear from you soon :)

Too sane for this world?

by Robyn Steward

In 2008, I went on my first trip to the USA. I had just won a travel trust grant, and was due to visit UCLA (University of California Los Angeles) which runs a social skills training programme, then for children and adolescents, now for adults too.

Whilst social skills are a controversial topic amongst people on the spectrum, this programme offers useful strategies for dealing with teasing, for example. The autistic spectrum is so wide that I know many of you will be reading this thinking, “Oh, I don’t need social-skills training”, but some people do, especially around bullying.

When I told people I was going to LA, people said I should also go to San Francisco. Like most people on the spectrum I don’t earn much money so I wondered how I could afford this, the flight wasn’t too much — you can fly from LA to San Francisco for about £50 — but hotels there are expensive.

So I started calling people, and spoke to a man named William Davenport who is a film maker and then was a director of a charity. He said I could stay with him and his family which I did, and as a consequence made many friends, and have returned to the USA annually to give talks and see what I can learn from people and professionals in the autism community there.

Then in 2010 William said he would like to put me in one of his documentaries: I said I would be very happy to.

Earlier this year William came to the UK for the first time and there was a screening at CRAE in the Institute of Education in London.

The film is called *Too sane for this world*, and is a profile of twelve people on the spectrum.

I think it’s a really interesting concept for a film. William was adamant he didn’t want professionals in this film or “voices of god” providing narration, he just wanted people on the spectrum to tell their story, so people could understand what autism is from a personal perspective, and understand how we are all so different from each other. I think giving people a voice is important. I enjoy watching the film, hearing about Kevin who works at Adobe, Greg who built flying machines to get a social life, and Andrew who makes art: the people here are varied, and most of them I have had the pleasure of meeting in real life.

As some of you may be aware Autism Speaks is a big organisation in the USA and believes in finding a cure for autism and preventing it. William’s next film, *Citizen autistic*, is about how terrible Autism Speaks are and how they put a disproportionate amount of their funds raised from families into research. I am also in this film and as part of the filming we went to *A walk for autism*, which was a fundraising event for Autism Speaks, to interview people there. Everyone I met just wanted to help people on the spectrum live independent, productive, happy lives, and saw autism as a part of the natural variation, and were not interested in curing autism.

Also while I am writing this, I wanted to say that I have a book that was published by Jessica Kingsley Publishers in September about women on the spectrum and safety, I’ll be doing a UK-wide workshop tour which is about safety for people on the spectrum. I’m trying to make it accessible for people on the spectrum: please see

www.robysteward.com/tour

for details.

letters to the Editor

Dear AU,

thank you for your article by Neil about empathy, which I read with more than passing interest. One question bothers me. What do you mean by emotion? Do you mean what the dictionary says — “love or fear”? Does everyone really love me or am I unlucky and do they really fear me?

Yours sincerely,

George

Love and fear are examples of emotions. They are not the only emotions. Perhaps a reader would like to explain? Editor.

Dear Goth,

I am 22 years old and was diagnosed with Asperger's syndrome ten years ago, after having difficulties with transition from junior to senior school. After diagnosis I started on a gluten- and casein-free diet and found that this helped lessen the headaches and mood swings that I had previously experienced.

At 15 I had a seizure, followed by another two years later. The paediatrician I saw at the time investigated my diet and concluded that the seizures had resulted from an intolerance of salicylates. I altered my diet to reduce my intake of

salicylates and had no further seizures until last year when I had a third episode. Looking back, I can relate all three seizures to higher-than-normal levels of salicylates in my system. The seizures were not brought on by the usual triggers for an epileptic fit.

Following my last seizure I was referred to a neurologist who diagnosed me as epileptic and wanted me to take drugs to prevent further seizures. He did not accept that a food intolerance can cause seizures and said that the only way forward for me was to take drugs.

After an EEG I was told that I had highly abnormal brain activity and was in status epilepticus despite feeling normal and having no external signs. I was sent to A and E but was later discharged.

I have discovered that 80% of people with ASD show abnormal brain activity, 60% have a salicylate intolerance and 30% have a formal diagnosis of epilepsy. How many of the 30% are wrongly diagnosed and have seizures as a result of salicylate intolerance?

I do not deny that I have had fits but I do not agree that I am epileptic. I feel that taking drugs would be wrong for me and would not be targeting the cause of my seizures.

I have had to surrender my driving licence and have been told that I will not be able to drive again until my fits are

controlled by anti-epileptic drugs.

Not being able to drive has meant that I am once again dependant on others, particularly my parents, for transport.

Has anyone else experienced this problem? I'm sure I'm not the only one; I would be interested to know how other people have coped.

Yours sincerely,

Harry

Hi Goth

Thank you for printing my email address in last issue. Yes I would like to hear from AU readers, but I too would like them to keep writing to AU. To all that do contact me can I please explain that like many “Aspies” I have found gaining employment well-nigh impossible, so am self-employed and as such work very hard for little financial return. This means I do not have as much time as I would like to deal with my correspondence (or tax returns, haha) so please be patient I will answer all correspondence eventually.

Regards

Rob

Please consider writing to AU in response to requests for feedback, then everyone can learn from what you have to say, thanks, Editor.

Don't really go in for titles, best just to read on

by Mark

It's like this...

I came across your magazine whilst ferreting about on the Internet looking for appropriate stuff and thought that it looked just the sort of thing that would be of interest. I may wish to contribute something at some point, but I have not decided what just at present. So this is just to get in touch. Well, that and to see what kind of response I get to a shameless plug for a particular piece of work of mine. That will come at the end. If the response is positive then I will be in touch again when I know a bit more about progress on it.

But first a few jottings to give a general idea of what I am about, possibly with footnotes. I was interested to see that you were mooting the possibility of an issue about relationships. Now, close personal relationships and I have what you might call a nodding acquaintance. I usually manage one every ten years or so, on average. Considering this, it may be ironic that I first became aware that I may have Asperger syndrome (which was recently confirmed through a diagnosis) through becoming involved in such a relationship about a year or so ago. Or it might not be ironic. It might be the sort of thing that happens all the time. Who knows?*

In case you are wondering whether the relationship is still going,[†] the answer is an unqualified "I do not know".

* Possibly somebody does. It sounds like the sort of thing that could be the subject of someone's doctoral thesis.

† This form of words is the sort of thing that people put in pieces of writing. I think it means "I know you are not the remotest bit interested but I am going to tell you anyway". I do not know why it is put in these terms. You probably have to be a writer to know that and I am just a dilettante. You also probably have to be a writer to know why footnotes have to be in smaller print than the main text. The rest of us only know that they have to.

Before I get carried away with this I had better get to the shameless plug. One of my great interests is the cryptic crossword. I have often thought that the Asperger mind is one that is very well suited to solving cryptic crosswords, and so there are probably quite a few people with Asperger's who like to do this. But have you ever wondered[‡] what it would be like if someone with Asperger's actually got to compile the things? Well, that is what the people at the Morning Star[§] newspaper have been letting me do for about the last twelve years or so. The crosswords are published every Saturday. Crossword number 1,000 in the series will be published shortly, and I estimate that I have compiled at least half of them (the rest having been compiled by the late Dr Ifor Torbe who otherwise does not appear in this story).[¶] So they decided that it was time to bring out a book of crosswords. With there being an AS link to the book I was wondering if you might give it a mention when it comes out. The Morning Star is not a big operation and the book is unlikely to be widely publicised, but they would like to get it mentioned where potential solvers might see it. If you are generally in favour then I will be in touch when I know more about when it will be appearing. I will probably be in touch about other stuff anyway, but I think that will just about do for now.

‡ The answer to questions which start like this is invariably no but I shall plough on anyway.

§ The questions that are usually asked at this point are "Is that still going?" and "Isn't that a Communist newspaper?", to which the answers are "Clearly yes" and "Not any more" respectively.

¶ I considered putting this parenthetical remark as a footnote but I figured that I had too many of those already.

Are you taking something for it?

by Victoria

"Are you taking something for it?"

"Everyone feels like that sometimes, you'll get over it."

"I've had that too."

It makes me want to scream! These are some of the well-meaning but ill-informed comments that individuals with Asperger's can receive. Autism can often be confused with mental illness both by the average person and professionals, who can misdiagnose Asperger's for mental illness. I've lost track of the number of times I've tried to explain that it's not a passing phase, I'm not just feeling a bit down, but I interpret the world differently.

Mental "illness" suggests that the condition is passing and can be made better with some sort of medication or treatment. Mental "disorder" is even worse. That suggests there is something wrong, something not normal, something that, again, needs fixing. Asperger's is neither a mental illness nor a mental disorder. It's a perfectly valid way of seeing the world, perhaps just a bit differently from the majority of people.

That's not to say people with Asperger's will not suffer mental illness at some point in their lives. Depression, stress and anxiety, for example, can affect us just as much as neuro-typicals. It is likely we are more susceptible to mental illness due to our differences and living in a society built on certain expectations.

In fact, people with autism-spectrum conditions have often been defined as having difficulties with social interaction, social communication and social imagination. Read that last sentence again. What do you notice? Yep, that word "social". How on earth can autism be a mental disorder or illness, if we are just governed

by our own social and cultural norms and values within a larger, dominant society?

Let's think about it another way. When I am in an environment I feel comfortable in, with people who are kind and tolerant, and doing things I enjoy, then I am as happy as the next person. It is when people tell me I should think, speak or behave differently that I start to feel different, upset, isolated and worthless. So surely the problem is a lack of fit with the environment rather than something inside my brain that needs to be fixed?

There is much to be said for living in the UK in the twenty-first century. Advances in education, inclusion and equality mean we are living in a society which, theoretically, allows individuals to have freedom of thought, speech and choice, cultural and political freedom, and relative autonomy. The reality can be somewhat different, and having a different way of interpreting the world can too often lead to educational, vocational and social isolation. Indeed, there seems to be an ever increasing idea that "inclusion" means being the same as everybody else.

Mental illness need not be an inevitable result of having Asperger's. I believe that through increasing education, awareness and tolerance of others, this issue can be improved. However, changing hearts and minds takes time.

As an individual with Asperger's, and also a teacher of children with autism-spectrum conditions, there are some things I have learned about mental health. First of all, what helps others may not help us. Medication may mask the problem but it doesn't get rid of the Asperger's, which has often led to the problem in the first place. Cognitive behaviour therapy doesn't necessarily work. It can just make us

an article (continued), and a letter

more worried. Why can't I change how I think? Am I getting this wrong? If I have to work on changing how I think, then isn't that the same as brain-washing myself?

The advice I would give about mental health is the same to Asperger's and neuro-typicals alike: stay as physically healthy as you can, spend time with people whose company you enjoy, spend

time on your interests and hobbies, change your environment so that it suits you, focus on your strengths, work on self-esteem, and educate others about yourself and your Asperger's.

Naturally this can be far easier said than done and no two people experience mental-health difficulties in the same way. The key is to work out as an individual what helps you.

Dear Goth,

thought I'd write this story for the *Asperger United* magazine to see if I can get some feedback from anyone who's had similar problems.

Postman from Hell

When I moved about two-and-a-half years ago from my noisy flat in town to a quiet village I thought I would escape many of those who judge my reclusive AS lifestyle I think I have blended in fairly well, my neighbours are friendly enough and probably view me as an eccentric loner — I can live with that. But there is one person I can't escape, who is causing me lots of mental anguish — my postman.

For the first year or so I tolerated his seemingly "offish" attitude towards me, and assumed he was unfriendly to everyone. He rarely said "hello" or "morning" and either said nothing or "Here you are" when handing me my mail. This was starting to play on my mind as I buy almost everything from e-Bay these days (to save money and avoid shops!) so I have to open the door to him a lot. I even put a sticker on my door asking to put items through the cat door, but he never does.

One day I was in my garden and heard him chatting and laughing with my neighbour which reinforced my belief that this man had a strong dislike of me, though I've never given him cause to, as I'm always polite and say hello, good morning, etc., but he'd never reply in kind.

My assumption at this stage was that he resented the obvious fact that I didn't work, as

I am always in mid-morning. I'm not alone in that. Occasionally there would be other stand-in postmen when he was sick or on holiday and they were always your typical, chatty, friendly postmen, so this just highlighted the fact that my regular postman disliked me for some unknown reason.

This started to take its toll on me, so I wrote a letter of complaint to my head Post Office. A few weeks later he (the postman) knocked on my door! and asked me why I'd made a complaint about him! I wasn't expecting this, but kept my cool and told him my reasons, which he just shrugged off. A while later it appeared he'd been replaced as other postmen brought my mail. They were/are always friendly and pleasant to me. Then a few weeks ago the other postman returned . . . and is the same as ever apart from a few sarcastic comments :(I am becoming very upset by this situation and don't know how to handle it?

He also deliberately leaves my gate open, which I don't want as my cats could easily run out into the road. I put an easy-to-open pull/push catch on it, but he never shuts it — the other postmen do.

I am now at the point of cancelling my post delivery altogether so as not to see him again. But then I would have the not inconsiderable inconvenience of having to collect my mail every day from the post office depot six miles away . . . and he will be the cause of it. I really don't know what to do now?

Best regards,

Tom

Empathy — handle with care!

by Dinah Murray

Empathy is one of a cluster of related ideas. It fits roughly between “emotional contagion”, shared physiological responses widely recognised in animals, and “theory of mind” (ToM), sometimes claimed to be central to the human condition but defective in autism. These are all about noticing others’ feelings and interests: empathy is specifically about responding to them with aligned feelings and is thought to be vital for social bonding. Autistic people ruefully note that two-way empathy issues tend to be rife between autistic and non-autistic people, despite the implicit claims to superior empathy among the non-autistic (Damian Milton has dubbed this “the double empathy problem”).

So what exactly is empathy? It includes responding, as in emotional contagion, to another creature with matching feelings and measurable physiological responses — “affective empathy”; it is said to be needed for reflective insight into the other’s perspective, that is, for “ToM” — “cognitive empathy”. Research has shown that autistic and non-autistic people may be equivalently physically affected by emotions (their own or other people’s) but autistic people are less likely to be cognitively affected by them. Is this a problem? Does it mean autistic people are less compassionate?

Both rodents and primates — presumably without “cognitive empathy” (ToM) — may display compassionate, altruistic behaviour towards other (same species) animals, even choosing to liberate others in preference to getting a reward of chocolate. Notably, these animals had their empathic responses measured in response to real, not faked, distress — and there was a clear action for them to take. Most research on autistic empathic reactions has been on faked or at best video-taped materials, where there is no clear route to any useful action, no productive way to help. I think non-productive

empathy may be especially painful to people on the autism spectrum because of the intense all-or-nothing qualities of our concern and drive to action. On the Autism and Empathy website, run by Rachel Cohen-Rottenberg, there is much interesting discussion and in particular many tales of autistic people of all ages showing productive empathy and altruism in natural settings in which there is scope for action.

To feel empathy is to be vulnerable to others’ pains; to do so without any means of alleviating them can be agony. According to Buddhist philosopher Matthieu Ricard, empathy is a necessary doorway to compassion and it is important to learn from it — but getting stuck in it can be disabling. If empathy is not embedded in opportunities for loving kindness it may do more harm than good.

Equally, if empathy is all about social alignment, it is not just about creating “Me and Us”, but also about creating “Us and Them”. It is normal for empathy to be selective, local, partial: typically people distribute their empathy in socially determined patterns. This is another key area of difference between autistic and non-autistic empathic responses — we may not have internalised those social patterns and hence may have a more universal and impartial tendency to feel others’ pain (or not).

Oxytocin, “the hug hormone”, has been hyped as boosting empathy and social bonding in autism. Michelle Dawson in a blog titled *Oxytocin — a cure for autism*, reports this of one research study involving playing a video game with others, “Autistics randomly administered a nasal mist containing oxytocin, rather than a saline placebo, significantly improved”. They became willing to work with one of the players in an effort to shun and discriminate against the other two,

an article (continued) and another

and thereby get more than their fair share of money and attention. They became willing to see the player who shared with them as good and trustworthy, and the player who shared with someone else as bad and untrustworthy. They learned and displayed selfishness and hypocrisy

and us-versus-them thinking. Their objectivity, fairness, and altruism were — temporarily — cured.”

Empathy is necessary, and often a blessing — but handle it with care!

A biologist, a physicist and a mathematician were going out to buy slide rules. They passed a couple walking into a building then entered a shop. Then they tried to make their way out of the shop (assuming causality). The biologist went for the shortest-looking queue she could find. The physicist hooked up an infrared camera and concluded that the shortest queue contained 5.3 people plus or minus a toenail. The mathematician was intrigued by the topology of a top but could not formalise the proposition “ten items or less”. Luckily the physicist knew how to tunnel out.

They walked into a bar (ouch) and ordered banana fritters. The biologist vehemently tried to persuade the barman that bananas are not fruits, and requested some 1,6-dichloro-1,6-dideoxy- β -D-fructofuranosyl-4-chloro-4-deoxy- α -D-galactopyranoside. The physicist pulled a Geiger counter out of his pocket, which he had turned into a TARDIS by adding exotic matter, or at least the packaging had claimed it was exotic, prompting the biologist to check that the radioactive bananas had not damaged her telomere caps.

On the way back, they saw the same couple walk out of the building, carrying a baby. “They’ve reproduced”, remarked the biologist. “No, it was a measurement error”, corrected the physicist. The mathematician replied, “If someone goes in the room now, the room will

be empty, where the inside is the smaller of the regions which the boundary of the room partitions the universe into.”

The biologist began stroking her pet *E. coli*, who carried on with the humdrum of prophase, metaphase, anaphase, telophase. The mathematician did a back-of-the-envelope calculation of when the number of *E. coli* would exceed the number of particles in the universe, then ran out of space on the back and began writing on the front of the envelope. The physicist pointed out that the *E. coli* would form a black hole before then, which would be just as hairless, but you can’t comb a hairy ball smooth anyway. He heroically rescued them from the black hole by letting everything tend to infinity then renormalising it out, to the mathematician’s annoyance.

They were all eager to get back to their work, but for the last 5.4 kiloseconds of pseudonormality they went swimming. The biologist pondered the effectiveness of adding chlorine to water, and almost killed herself when she got ATP and ADP muddled up. The mathematician tried to do a Fourier transform on the ripples in the pool, but his paper got wet, so he switched variables, and x got wet. Finally the physicist pulled out an atomic clock and made sure they escaped in the correct 9,192,631,770th of a second, only to round 675,764,697,855,486 to 1 because “it’s close enough”.

by Angela

Turn the page upside down if you like your titles to be at the top of the page

Group notices

Stim Rock Express

I am writing to tell you about a very special group of people who mean the world to me . . .

I worked with them closely for six months and they inspired me and touched my heart in a way that no group had ever done before. Over the six months of us working together, I was in awe of their courage as they stepped out of their comfort zones, overcame major obstacles and allowed themselves to be challenged in ways they had never been challenged previously.

There are twelve of them and each and every one of them is a unique adult on the autism spectrum. They came into my life during our first formal meeting at the Ladbroke Grove centre in London in October 2012; some were somewhat anxious and unaware of what to expect yet with their hearts open to new experiences.

Over time, they participated in a series of rigorous drama workshops which I designed for them, transformed as a group and created an incredible variety show in London called *Stim rock express*, a semi-professional production of comedy, music and poetry.

I was not entirely sure whether they were fully aware of their own greatness and of what they are truly capable, until the big night. And the show was a great success — the audience were blown away by the talent in the room and the sense of joy and accomplishment was beyond words.

As for me, the project was somewhat a personal victory. I am a firm believer in the potential which lies within the human race (especially when it comes to my dear brothers and sisters on the spectrum) for the first time I had the opportunity to share my vision with the world. Other than being the first autistic person in the UK to create a show performed and

produced entirely by autistics, it was an honour to work with incredible people on such a personal level, another step towards the new world which I am committed to building.

Having successfully completed the pilot of this project, I have developed myself further on this journey by working on similar projects created by others with very similar aspirations and I have continued to run drama workshops for other autistic people elsewhere.

If you are on the autistic spectrum and interested in participating in such a production (complete beginners and professional performers are all welcome!), or you would like to share your creative work on our blog

www.stimrockexpress.org

(we can post on your behalf, anonymously, if you want), please contact me on

stimrockexpress@gmail.com

07704 246 555

Jenny Berman

Project Co-ordinator (Stim Rock Express)
NAS Autism Centre
76C St Charles' Square
London
W10 6EJ

I also want to hear from people who want to set up their own Stim Rock Express group.

In Kent

New support groups set up for adults who have high-functioning autism and Asperger's.

In Dartford, Maidstone, Tunbridge Wells and Gravesend.

The groups aim to increase confidence, social

a notice (continued) and a conference report

activity and awareness of autism in the community.

We are planning trips, guest speakers and newsletters to use the talents of our members.

We discuss issues we have with our autism and promote our positive aspects.

The Dartford group has named itself **AWKS**.

Leonora Bennett
West Kent Autism Supporter
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Mobile: 07715 068 948

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Groups have also been set up in East Kent.

Autescape

report on the *autistic* conference 2013

by **Amanda**

Autism is all too often seen as something that means people do not want to engage socially, as something that means we are happy to be alone. Autescape is a shining example of how this is not so for many autistic people. I believe that autistic people have just as much need for connection, but communication as that means of connection is done in different ways. The whole spectrum of communication differences was shown at Autescape, exemplified by the badge system which enabled everyone to participate, and it was done with dignity and respect. It was wonderful for me to see people in headphones and dark glasses, to see people rocking and flapping, all around me. Wonderful not in and of themselves, but as an expression of the total acceptance of difference that I saw at Autescape, which was inspiring for many other areas of my life.

My friend said, when I told her of my lack of worry after the first day of Autescape, "I bet they love you." At the time that seemed a strange thing to say, as after all, they'd only just met me, but after I thought about it, it kind of felt true. There *was* love at Autescape. There were people with a commonality that the outside world labels as disability, but which is actually so much more than what that one label can contain. It is the filter through which we view the entirety of our worlds,

and that is not wrong or bad or even a disadvantage; it is who we are. When I meet my people, I know, because I feel it. And my people were there at Autescape and the whole thing was imbued with love, expressed autistically, but love nonetheless.

When I first learned about autism, I wanted nothing to do with it. Then, that led I to me, reluctantly accepting it just wasn't going anywhere, and I called myself a person with autism. Now, though, I think of myself as an autistic person, with a family of other autistic people (even if we are far apart). Autescape has meant I see my differences as part of the differences that make up the whole of humanity and as something to be celebrated, not something I need to get away from.

Sparklies in the Dark, on the first evening of Autescape, was a defining moment of the whole experience for me, and I believe it will be a defining moment of my life, too. There I stood, on the threshold to a huge dark sports hall, watching with awe the wonderful brightly glowing lights in a rainbow of colours. Then it hit me that it was more than that, that the hall was occupied by my people and there was no fear of judgment or ridicule. I had never before experienced such a feeling of coming home.

a letter and an article

Dear NAS,

thank you for all your treasured correspondence, I appreciate all the magazines and the *Asperger United*.

I am still quite stressed-out through moving house, a complete nightmare for anyone with autism. Thankfully, I had my social worker, my dad, also a friend to help me. I don't know if I'm coming or going!

Maybe a big article (in the magazine) concerning moving house would help other people like me with coping strategies. I did feel terrible (okay now) when my routine had to change and I don't like furniture being moved about. (I do like everything in its place.)

I've had headaches and a sick feeling in my stomach. It takes a lot of getting used to, a new home. All my energy seemed to drain away. It is an awful thing to say but I'd cope better with a bereavement. My books and letters were the first to come out! My ornaments and stuffed animals were also the first to come out. Familiarity does help, and a sympathetic ear. I'm glad I didn't have to change town!

I empathise with all the other autistic people who have to move house because of the dreaded "Extra Bedroom Tax" and of course noisy neighbours. My senses are very sensitive, that is why I feel the cold easily. I can even hear a pin drop, etc.

I've managed to flood myself with the washing machine also. Panic stations.

I've appreciated your help in the past.

Yours sincerely,

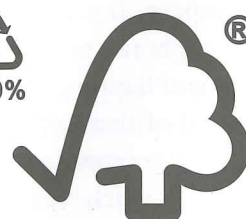
Susan

An article about moving house will only appear if a reader writes one — that's how AU works! Please consider writing one, Editor.

Alternative therapies

by Siobhan

I've been coming to Claire for treatments for two years now, after being introduced by a staff member at the Fountain Project where I volunteer. Claire offered to do a treatment without any touch. I suffer from a form of autism called Asperger's syndrome, and being touched is very difficult for me. Claire offered Reiki to start with, which when I started I had a half an hour treatment. I found this so beneficial the next time I had a full hour. As I've got to know and trust Claire I have branched out to an aromatherapy massage, and I've let her touch me. The massages and Reiki have been immensely beneficial to me, especially as the last few years I've been suffering with depression and anxiety. These treatments alleviate it a great deal; I often go to sleep at night just after having had a session with Claire to the sound of the Buddhist chants that were playing at the time. Claire is a gentle and compassionate therapist, and will listen to any worries I have with the strictest confidentiality.



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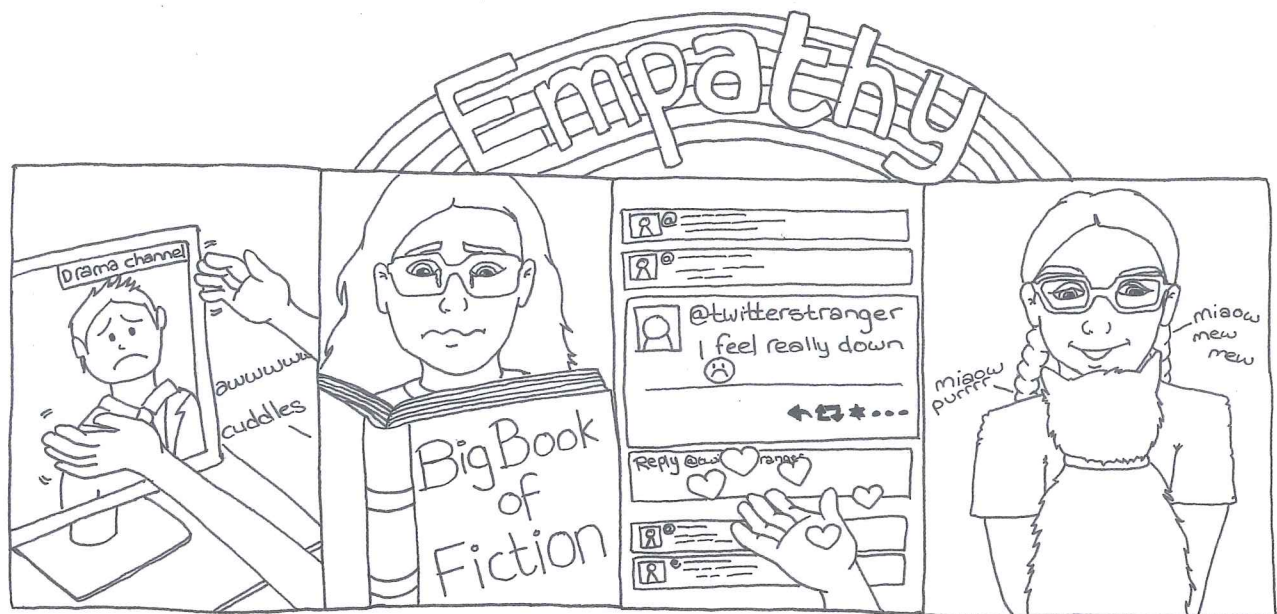
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(contact information for AU is on page 2 and again on page 20)

- 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 be for 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) *Asperger United* is free and is quarterly, published in January, April, July and October. If you do not receive a copy when you expect to, please contact AU.
- 3) 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.
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- 5) *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. Please consider getting involved with the NAS campaigns and events.
- 6) If you move house, please inform *Asperger United* and include your old address as well as your new address.
- 7) 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.
- 8) If you phone and leave a message on the machine, please speak slowly and clearly and spell uncommon words, as 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 your record.
- 9) You do not have to be a member of the NAS to subscribe to *Asperger United*.
- 10) The current edition of *Asperger United* is available at www.autism.org.uk/aspergerunited
You need to scroll down to the middle of the page, where there is a link to the PDF.
- 11) You can sign up for an email notifying you whenever a new edition of *Asperger United* is posted on the webpage above. Email asp.utd@nas.org.uk asking for the notification by email and please include your full name, postcode and let us know whether you want the paper edition too.
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- 13) If you want to resubscribe (or subscribe for the first time) inform *Asperger United* and include your postal address (for the paper version) or email address (for the email notification).
- 14) 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.
- 15) 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.



Dear Sir,

Rob's letter to the Goth (edition 75) resonated with me as I'm also an adult who's had an Asperger's diagnosis in the past couple of years.

Rob says that his depression was in fact his "misguided attempts to conform to the norm." I realized that that is what I've been doing for many years, with various mental-health diagnoses, so that now I have my diagnosis of Asperger's, I've suddenly got a reason why it has all been such an uphill struggle to "blend in".

I was wondering how other people in the same position have "embraced" their Asperger's personality and shed the masks that have to be worn every day — I feel that mine will have to be surgically removed, as they've grown to be a big but uncomfortable and ill-fitting part of me.

How have other people been able to just be themselves? Any tips would be welcome.

Thank you, yours faithfully,

Karen

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