

Produced by and for autistic people

Asperger *United*

Edition 87 July 2016



Asperger United

Asperger United is a magazine run by and for autistic adults (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

National Autistic Society production support: the Publications Team

NAS phone support: the Supporter Care Team

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.

Please send all correspondence and subscription requests to:

Email: asp.utd@nas.org.uk

Asperger United
c/o The National Autistic Society
393 City Road
London
EC1V 1NG

Tel: **0808 800 1050** (free from most landlines) or
Tel: **020 7923 5779** (geographical charges apply)

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 email address or postal address above.

Contributions for the next issue should reach *AU* by **15 August 2016**

Welcome to the July edition of *Asperger United*.

The subject of misunderstanding has generated some very thoughtful pieces, though clearly it's not as inspiring a topic as the last two.

As editor, I am always trying to think of the ways people will misunderstand my choices in putting a magazine together — the most common misunderstanding is that I deliberately didn't choose someone's piece because they are useless, or because I have some sort of vendetta against them. I have had times in my life when I thought that way too, times when I was very low and I was unable to make sense of what was happening to

me — it simplified the world to see things as me-versus-everyone-else. But the myriads of people out there each have their own reasons for doing things which rarely have anything to do with you.

Even with a lighter postbag, I get more submissions than I can print, and those of you who've submitted some things know that I try to respond to every person who submits a letter or article, even if it's just an acknowledgment postcard.

I enjoy reading all the submissions, whether I publish them or not,

the Editor

the misunderstood edition — suggestions for next issue on page 6

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It was just an honest mistake . . .

by Richard

Misunderstandings are a basic part of everyday lives for ASC (autism-spectrum condition) individuals. Inherently due to how we think differently to PNTs (predominant neurotype). On the surface some misunderstandings between autistic persons and PNTs can be quite funny. When you stop to look into it the misunderstandings, it is a huge factor in the misery autistic individuals experience in our lives.

During personal interactions between ASC individuals and PNTs, misunderstandings often play havoc with people's happiness and views of each other. With either ASC individuals accidentally hurting people they care about, by other persons misinterpreting our actions, or often PNTs offend us with their illogical actions.

Far too frequently ASC individuals experience bullying either as violence or passive forms, such as an ASC person being ostracised from a group by PNT members. Often PNTs treat us like that because our actions are largely different and alien to PNT customs and rules. Sadly it is true people often fear what is different to them and ASC individuals typically are different to PNTs.

The global misunderstandings about autism are, lamentably, heavily entrenched into PNT culture and society. This is shown in almost every way PNT culture treats us and portrays us.

PNTs do not fully appreciate the nature of autism, of how every ASC individual is different to each other. PNTs fail to take into account how autism can manifest so differently in men, women, all ages and all "functioning" abilities.

This is particularly evident in the issues around diagnosing ASC in females. Common misunderstandings playing a significant factor in this. With misunderstandings such as ASC is only found in men to how ASC manifests in women.

Typically, women are referred for other diagnoses, such as borderline personality disorder.

Even males have issues getting a diagnosis as some NHS trusts refuse to fund diagnosis in adults. It is shocking to think that even decades after Leo Kanner's infantile autism and toxic parenting have been discredited some people in authority still treat autism as only found children.

A lack of ASC individual's involvement with all levels of research has undoubtedly impaired the research into ASC and subsequently how PNT culture views us. The common misconception that ASC individuals lack empathy or do not have emotions is arguably the most harmful misconception PNTs have. I seriously think Simon Baron-Cohen was not friends with many ASC individuals when he thought up the empathy-deficit theory of ASC. In my own experience ASC individuals typically have too much emotion compared to PNTs (our emotions tend to be more intense than PNTs, even if some ASC individuals express a smaller range of emotions than PNTs); frequently we cannot control our emotions or our actions due to them. ASC individuals do care for people in their lives: often we simply struggle to express that to our loved ones. When you couple that to the communication barriers between ASC individuals and PNTs, it is all too easy for PNTs to think that we lack empathy. It is very telling about how PNTs view other PNT actions, that they label us as lacking empathy because we accidentally hurt them.

The misunderstanding of a lack of emotions in ASC individuals has also wasted time, energy and resources of even well-meaning organisations like NAS and Autism East Midlands. Such as both organisations supporting PDA (pathological demand avoidance). An individual's actions described as PDA are common among the ASC population to the point that PDA does not

officially exist: if you have a PDA diagnosis often you instead have high-functioning autism (HFA) or Asperger's syndrome (I do not approve of terminologies such as "functioning" and "ability" to describe anyone, as I believe primarily it is the environment a person is in that makes them disabled). PDA is not accepted by the NHS due to this. It means that charities such as NAS and Autism East Midlands are wasting charity funds supporting PDA instead of supporting ASC as a whole. With important charities pushing the awareness of PDA among PNTs, it is distracting PNTs away from all the myriad manifestations of ASC. NAS are in effect, indirectly making it harder for ASC individuals to get the recognition and support they need because an individual's actions and traits are not recognised as ASC by clinicians and organisations. These troubles will usually be distressing to the ASC individual.

The PNT belief that ASC individuals are lesser beings than PNTs, as we do not have empathy, emotions or that we are somehow mentally retarded have fuelled the misunderstanding ASC is naturally a disability or disorder. These misconceptions are not only harmful, but also silly, as mental retardation is not part of the diagnostic criteria for ASC.

The popular misunderstanding that ASC is a disability dominates the scientific and academic agenda around ASC research, with decades and millions of pounds being spent in the Western world trying to find genetic causes for ASC. Despite all this effort the best the PNTs have discovered is the obvious, there are no common genes that cause ASC. This is to be expected when you consider the spectrum nature of ASC and sheer numbers of people with ASC (about 700,000 in the UK). ASC clearly runs in families and in many respects is hereditary.

I find it insulting to be told I am disabled as I think differently to PNTs, largely because of my genes. It is no different to PNTs telling a person they are disabled because they are a woman or their skin colour is black; such actions are illegal now in most Western countries. So why is it acceptable for PNTs to label us as disabled?

PNTs use the misunderstanding of ASC-causing genes to not invest in support and interventions for ASC individuals as ASC services typically do not make a profit. Governments, funding research into ASC-causing genes, use it as a smokescreen to avoid taking responsibility of properly supporting the ASC population: why would they make our lives less stressful when they are going to cure us in ten years?

All the research into ASC-causing genes allows PNTs to get away with the systematic oppression of the ASC population. The problem is with the ASC individual for having faulty genes and not with PNT society for not making enough adjustments for us. If PNT society were making enough adjustments, our suicide rates would not be higher than average or our employment rates would not be below the disabled average.

Despite all the misunderstandings PNTs have about ASC, progress is slowly being made towards dispelling these myths PNTs have. For example the ASC prevalence rate in the US has dropped from 1/1000 to 1/68.

We ASC individuals may also be assisting PNTs creating misunderstandings of us. This is as when ASC individuals are involved in research discussing what it is like to be an ASC individual, it is primarily ASC individuals who have HFA or Asperger's syndrome who participate in the studies. This is a biased sample of the ASC population, as the sample lacks ASC individuals who are "low-functioning", this is as usually "low-functioning" individuals cannot express themselves enough to describe their experiences. This means that there is a lack of evidence describing what it is like to be "low-functioning".

As an ASC individual we simply cannot escape the misery misunderstandings cause in our personal lives or how misunderstandings fuel the systematic oppression of us by PNT culture. This all too frequently has horrible effects on ASC individuals, negatively affecting our mental and physical health and our quality of life.

It was just an honest mistake... Or was it?

Autism equality in the workplace

by **Janine Booth**

Jessica Kingsley Publishers

ISBN: 978 1 84905 678 6

£12.99 / \$19.95

review by **Damian Milton**

Whilst it is well known that autistic people can struggle to gain and sustain employment, much previous advice has been aimed at autistic people, often suggesting that one attempts to mask difficulties in order to get work, with the potential negative consequences that can bring. In this book, Janine Booth takes a refreshing look at the employment of autistic people through using a social model of disability to analyse how working environments can change to make the most out of autistic employees.

“Thus far, autistic people have had to navigate, suffer or avoid the workplace. The point, however, is to change it.” (page 15)

This book contains very useful insights into common problems faced by autistic people in the workplace, as well as practical strategies for helping with them. Problems cited range from a lack of understanding from colleagues, to inappropriate support from managers. The author goes beyond the concept of reasonable adjustments however, and suggests that society needs to ask fundamental questions about how work is organised.

This book will be of interest to all who want to work toward making society, and workplaces in particular, more autism-friendly. I would highly recommend it to employers, politicians, researchers, and of course autistic people and their families.

Just seen this (see quote below) in the back issues I have found.

I am essentially like Tom in that I have a limited number of colleagues who I am comfortable to talk to, for brief periods each day. I do not socialise, outside of work, with any colleagues, nor do I socialise with similar-aged friends (I haven't got any outside of work). My only socialising is at a monthly club meeting, and I have a couple of friends there, but both are a lot older than me. If I do go out (ie., a day trip to visit somewhere) it is either on my own, or with my close family. I don't have a Facebook account either. Socialising has never been high on my to-do list — I have too much to keep me occupied doing my own hobbies.

Chris

Quote from Tom:

This does make me wonder, though: from reading *AU* I gather other autistics have more involved social lives than me (or is it that they spend the time I spend with colleagues with their friends?). So I am curious whether I am extreme in having effectively no friends, in feeling such fear for all the intricacies of maintaining any relationship that isn't bound by easily recognisable borders, such as colleagues or therapists (even when they are digital, such as Facebook: I get anxious even thinking about having a Facebook account). Am I alone in being so alone?

If sufficient material is sent in, the theme for October will be **sensory differences**. 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, and artwork. Remember, if you want to see different content in *AU*, the best way to change it is to send something in!

Pen pals

Pen pal number 221

Hello. My name is Kerry. I am 28 years old and come from Nottingham. Was diagnosed with Asperger's at 11 years old, struggling to prepare myself for secondary school.

Have always played a lot of sports. I have played a lot of different watersports (swimming, canoeing, rowing, rafting, surfing). Also tennis, badminton, snooker, bowls. Currently I'm a huge fan of playing ice hockey and watching Nottingham Panthers.

I like playing and listening to music a lot.

I like to get myself going with new things as much as I can, people just need to have a little patience with me early on. It always takes a lot for me to do first time if I'm going to somewhere new with new people, but usually then don't have any issues.

Any big changes, the sooner I can be warned beforehand, then I can prepare myself well.

I'll look forward to hearing from someone with a similar interest.

Pen pal number 222

Hi, I'm Ozflinders, aged 45. (Diagnosed with Asperger's at 42.) I live in Essex. My interests include: wildlife, photography, drawing, writing — lyrics, poems and stories — music and singing, reading about Australia, angels, spiritual things, some of the paranormal and some astronomy. I'd like to hear from male and female pen pals. Hope to hear from you soon.

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*.
- If you get no replies, please don't take this personally.

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.

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

Pen pal number 223

Hi. My name is Jessica and I am 19 years old. I was diagnosed on the autism spectrum when I was 18.

I am shy and find it difficult in social situations as I don't find it easy to make small talk especially with people of my own age. I also struggle with OCD and anxiety.

I am a vegetarian and I love animals. I have four cats — soon to be five — two rescue chickens and some stick insects. I like reading — especially fantasy, sci-fi, dystopian and Harry Potter. I also like playing computer games, sketching and watching football and tennis. I love listening to music especially rock music and I really like Linkin Park, Fall Out Boy and Within Temptation. I also really enjoy bird-watching which I find especially relaxing as I don't have to be round lots of people.

I found it difficult at secondary school because it was large and impersonal and I don't think people understood me because I was quiet and hard-working. I went to college for a couple of years and did an animal care course. Now I'm doing an Open University degree.

I would really like to be in touch with people of a similar age especially in the Midlands but I'd be happy to correspond with people from anywhere in the country.

Many thanks

Jessica

Pen pal number 224

Hello, my name is David. I am 28 years old. I live in Merseyside. I would like a person to write to me, as I don't know anyone else with Asperger's. I was diagnosed at 20. I enjoy films of Disney. I love anything to do with the *Jungle book* and *Beauty and the beast*. My four fave characters are Baloo the bear, Gaston, Marie from *The aristocats* and I like Princess Belle best. I love also to watch *Home and away* every dinnertime. I think Alf is best. I like cats. My beloved pet, Eve Cat, died recently. I miss her very much. I enjoy amateur dramatics. I liked doing the shows of *Oliver* when I played Bill Sykes, but I loved playing the Prince in *Snow White* best. I attend church every Sunday. I also enjoy collecting music and dvds. If you share interests I would love to have someone to write to.

Pen pal number 225

Hello, my name is Joe. I am 31 and I live in Bournemouth. I was diagnosed with Asperger's syndrome in 2005.

I would like to find a pen pal from any county in the UK.

My interests are museums, fine art and debates about AS with others on the spectrum (in particular AS women's views). I would be interested to hear from women so that I can gain a more rounded view on what it means to have AS. Thank you for reading.

Pen pal number 226

Hi, I am Donna and I am 35. I have only recently been diagnosed with Asperger's. I live in Rotherham.

I love visiting churches, cathedrals, museums and art galleries.

I love music and I am a big fan of the Beatles. I love watching quiz shows, the news and soaps on TV.

I also love going shopping and eating out.

I would love to hear from others with similar interests :)

The mind's eye

by **Oliver Sacks**

Picador

ISBN: 978 0 33050 890 2 £9.99 / \$15

review by **Tony**

I loved this book because of its insights into how stroke victims could lose certain faculties but learn to compensate for them by developing tactics in other areas. Also, how strokes could lead to an inability to translate sensory data into verbal terms or interpret input, to make sense of the world. Some people suffered word blindness, others lost facial recognition as an ability. Some were able to talk in an intelligible manner but when asked to analyse what they'd said or done, they couldn't make sense of their thoughts or actions. It affected verbal and visual memory as well as input or output. It was like they never reached a perception point of realizing what they were seeing or a recognition point because their memories of what they were seeing weren't there anymore or available to them.

Some of these difficulties involved abstract knowledge as opposed to objective reality (written or spoken language as "representational" data): could lack of a sense of direction be down to the same magnetic sense in migrating birds, being lost or damaged?

In The Beth Abraham Hospital for Incurables, residents found ways round their disabilities through mimicry — using other sensory input to kick-start memory in lost areas or to communicate in new ways (visual or verbal mostly as for instance, tracing the shape of letters in mid-air or forming words with their tongues). Children's books teach the alphabet by simulacra that resemble the abstract forms of letters, eg, a sail for 4, a catapult for Y.

Phil Beadle, the teaching trouble-shooter, says that there are three ways of sensory learning input — visual, sonic and tactile. This reflects the areas of difficulties for stroke victims as they try to relearn communication skills.

As a side issue, people who are deaf, appear to be dumb to the hearing because they associate mental sharpness with clipped speech. The deaf can only approximate word pronunciation which makes them "sound" like they have learning difficulties. However, given sign language, the deaf can appear as swift and erudite as any voiced person can. This

is because it builds upon a sense they are strong in (vision) as opposed to one they are not (sound). This is the opposite of the blind of course.

You cannot expect a man in a wheelchair to run upstairs or play football because this is his area of weakness, not strength and trying to force him to fit in, under such circumstances, shows weakness on the part of the enforcer, in the brain department. This is why I think positive discrimination is foolish and humiliating to the person with the disability — depending upon their attitude to the situation of course. Ben Parkinson for instance, the Afghanistan combat veteran, has struggled and is struggling now against brain damage and the loss of both legs and it is people like him that push medical science and technology along but on a voluntary level.

This book and the ones on pages 6 and 17 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.

letters to the Editor

Dear Goth,

I have been working on a logical analysis of the evolution of human experience (I am aiming at publication but that will not be for several years yet), which suggests that what is referred to as “autism” actually emerges in response to the “neurotypical” attitude.

The entire project is complex and vast but overall it shows that the selfish, judgmental attitude usually adopted (but “on a spectrum”!) by the neurotypical individual eventually generates the type of person (referred to as “autistic”) who is non-judgmental and selfless (also on a spectrum). What seems to be selfishness in this instance is entire selflessness: if you don’t recognise yourself, you can’t recognise others! Such individuals tend to rely on concrete fact in whatever form (specific to their circumstance) to help them get on in life, generating what are recognised as our various “obsessions”.

Even though this creates a situation where there is a group of people who unfairly judge and take advantage of those in the other group, the project suggests that since the former is a prerequisite (necessary condition) for the latter, this situation is inevitable and must be endured, as it will enable the human species to evolve as nature intended.

Therefore, I can only advise those on the autistic spectrum that they should stand their ground because they are not wrong and don’t need correction, but also point out that their neurotypical counterparts are equally valid members of the human species (they are not wrong either, and it would be inconsistent [hypocritical] to suggest such a thing).

As with everything in the world and universe as we know it: one depends on the other for its existence.

Yours sincerely,

Ann

Dear Goth,

First, a personal note to you: please don’t get disheartened by negative reactions about the different opinions in the articles you select for *Asperger United*! I think it is very important that as many as possible of the different voices are heard, however much I may personally disagree with what they are saying. And to my mind, you are doing a sterling job at making that happen.

Second, I have two contributions for the next issue: a thank you for the reactions to some of the articles you published and a bit relating to the personal note above, about the need to recognise and respect the diversity of experience and opinion that exists amongst the readership of *AU*. [*Both printed below, Editor*]

Regards,

Tom

The Goth was kind enough to print some of my writings (about empathy, for instance) a while ago and to my great delight there were reactions in the following issue. I would like to take the opportunity to thank anyone who wrote a reply: reading them really made my heart jump! It’s always been a life’s ambition to try to change the world for the better, even a little bit, and this really made me feel I was inching closer to fulfilling that ambition. Heartwarming.

I would like to sound a note of support for the magazine as it is now. One of the difficulties we face is that NT media tries to put an NT spin on our stories, or rather: they need an “angle”, which never is an autistic angle. Therefore, having an outlet that prints all our voices is vitally important. I certainly do not agree with everything that is written for *AU* and some of it upsets me, but it’s worth it: the principle of free speech applies to all of us. It’s also important for all of us to recognise that we are as diverse a bunch as any other, well, bunch. Maybe even more so since the thing we share is not based on interest or anything like that.

It's all in the mind

by John

You have in your mind a thought. It is a good thought, intelligently reasoned and perfectly formed. Now you want to communicate your thought and so you open your mouth to speak and what happens? Nothing! You are unable to express your thought lucidly by the spoken word. At best you might utter a travesty of what you intended to say, at worst you might give up.

And now someone speaks to you, clearly and in your own language but he is not making sense. Is he joking? Or being sarcastic? Or does he really intend that you should take him literally? His face gives nothing away and you are too confused to attempt a reply. The best you can do is, "Sorry, I didn't quite get that", and hope your second attempt at understanding fares better.

If you experience either or both of these conditions there might come a point when you will deliberately avoid entering into conversation and perhaps even avoid situations where spoken communication is likely to be required. In my own case I will avoid speaking to anyone on the telephone other than my immediate family and a couple of close friends. It's pretty much the same with face-to-face conversation too. However, on the bright side, I

have no difficulty with written communications when I can take my time to understand properly what the writer means and formulate my own written response.

There's more — I am unable to read out loud. This inability got me excluded from my English literature class at school. The year was 1956 and this particular teacher was very fond of allocating character parts to her pupils so we could read out scenes from Shakespeare plays. I was invariably given a part to read. Perhaps she thought I needed the practice or maybe she took a sadistic delight in my making a fool of myself in front of the class. Eventually I rebelled and was rather rude to the teacher. For this I was taken to the headmaster, given a detention and excluded from her class. I was angry about getting the detention but the exclusion came as a sweet relief. It meant I had more time to study my beloved science subjects, so no harm done really. All the same, I sincerely hope that any kid with similar problems to mine would be dealt with a little more sympathetically in these more enlightened days. It has been suggested that my inability to read aloud might be a treatable phobia of speaking in public. An

attractive idea to be sure but I don't think this can be the case for the reason that I am unable to read aloud to myself in the privacy of my own home.

A few years ago I came up with a partial solution to the problem. By first memorising a text, whether I had written it or not, I found I could speak short passages with only slight hesitation. Using key words or phrases in the text as a prompt, I have been able to expand this technique to a whole side of A4. On a good day, that is.

I also find that I am better able to converse when there is a definite purpose to the discussion as opposed to chattering about the weather or the football results. In my former position as chief chemist I was perfectly capable of technical conversations with my fellows. My problem seems to be with random chit-chat, especially when people say the exact opposite of what they might really mean! I am always aware that my difficulties may make me appear either bad-mannered or stupid and I would hope that I am neither.

I was formally diagnosed with ASD two years ago at the age of 72 after a lifetime of struggling along in ignorance of my condition.

Captain Kirk and the crass interviewer

by James Christie

Over nearly thirty years of working life as an adult with autism, I have disobeyed orders, lost respect for my superiors, publicly rebelled against my “profession”, been embittered by bureaucracy and on one memorable occasion was told by an ex-girlfriend who’d had the misfortune to end up as my manager that I was “the most difficult employee she’d ever had . . .”.

Thanks, dear.

But I also survived and even flourished in the neurotypical world of work, travelled independently in Australia for nearly a year, lived in Glasgow for decades and ground away at writing when anyone sane would have given up. Against all the odds, I then went out on the road again at the age of forty-five to meet with my Hollywood film star on the shores of the Pacific, wrote the book on it and somehow got myself published.

And like it or not, there’s no real doubt left in my mind that without the ornery, bolshie, eccentric and occasionally plain different aspects of the sometimes unlovely persona listed in the first paragraph, I would never in a million years have done all the things I’ve just mentioned in the third.

In Alan Dean Foster’s novelization of JJ Abram’s 2009 *Star trek* reboot, Starfleet captain Christopher Pike tries to explain to a rebellious, disobedient, wilful and cocky repeat offender called James T Kirk why the young man is what Starfleet actually needs:

“That instinct to leap without looking, to take a chance when logic and reason insist all is lost — that was his nature. It’s something Starfleet’s lost. Yeah, we’re admirable. Respectable. But in my opinion we’ve become overly disciplined. The service is fossilizing. . . . Lemme tell you something. Those cadets you took on? Ivy Leaguers or the overseas equivalent, all of ’em.

Oxford omelettes. Sorbonne sisters. They’ll make competent officers. Run their departments with efficiency and class. But command material? People I’d trust with my life when confronted by a couple of Klingon warbirds?” He shook his head dolefully.

Pike and Kirk are fictional, but as the real-life Jimmy Reid stated in his famous 1972 Glasgow University rectorial address:

“Reject the insidious pressures in society that would blunt your critical faculties to all that is happening around you, that would caution silence in the face of injustice lest you jeopardise your chances of promotion and self-advancement. This is how it starts and before you know where you are, you’re a fully paid-up member of the rat-pack. The price is too high. It entails the loss of your dignity and human spirit. Or as Christ put it, ‘What doth it profit a man if he gain the whole world and suffer the loss of his soul?’ ”

While companies the world over proclaim they intend to help individuals reach their full potential in order to achieve dynamic organizational growth, I have personally found that far too often in practice the actual intention (conscious or otherwise) from the interview stage onwards is to encourage a culture of corporate conformity in which (as Ruth Dudley Edwards succinctly commented in the Daily Mail of 25th June, 2013) “risks are not taken, you cover your back, fill in the forms properly and follow instructions to the letter.”

It’s an insidious process, and it does lead to fossilization.

But I think Pike and Reid are right, that Britain has indeed fossilized, and that many, many organizations are failing utterly to make use of the quirky, individual and sometimes brilliant skills

an article (continued), a filler poem, a notice, and a letter

adults with autism can bring to the table because they instinctively feel that such people will not fit in.

Crucially, such people struggle at interview because they can't or don't want to drone out the bland, standard responses. The company hires the corporate clone instead and the conformity goes on.

In my case, I succeeded brilliantly in one historic job which involved restoring part of Scotland's literary heritage because I had qualities which would never have shown up in a formal interview, but failed horribly in a corporate training course which embodied every aspect of the bad management and control freakery I've alluded to in this blog.

So, rather than moan to you that the person you might actually most need is the one you're throwing out at the first hurdle, let's see if there's anyone out there with free will who might like to hire an adult with autism.

Not me, necessarily. I've proved my worth and I'm not going to sit through any more crass interviews.

But somewhere out there, there's another Captain Kirk. An adult with autism who could change the world. An Asperger you're overlooking.

So show me you're not a bunch of fossils, reply to this article, and let me see you do something about it.

James Christie is the author of *Dear Miss Landau*. He was diagnosed with Asperger syndrome at the age of 37 in 2002. He lives and works in Glasgow.

My anxiety is high while my confidence is low,
but in the middle it doesn't show.

Daniel

Resubscription project

notice by the Goth

More of you have received a flier with this magazine asking you to resubscribe. Please respond in one of the ways listed on the flier. People who don't respond will be sent fliers three times, and after that, as they did not respond, their subscription will end.

But please don't worry: if you want to continue to receive *AU*, just respond!

If you have not received a flier there is no need to respond, though if it puts your mind at rest, please feel free to let me know you want your subscription to continue.

Dear Lisa,

I have self-diagnosed myself as having the Nutter's Syndrome you described in edition 85 as the description you gave fits me perfectly.

Is this all on the back of your own research?

Is there any possibility you could point to any sources as I have not found a source about Nutter's Syndrome. These could include psychiatric journals, mental health organizations, mental health websites, magazines you subscribe to or any other links.

Unfortunately there appears to be a vacuum of information about this disorder.

Many thanks,

Ferdy

It's hard to know if Ferdy is serious or if they are playing along with Lisa's joke. Please, for all of you who were confused, Nutter's syndrome is not real, it is a comedy. I will try to make it a little clearer whenever I publish humorous or fictional items, Editor.

Dear Goth,

1) On acceptance, literally. You may recall my very first postcard to you: I stated the “theory” that the people diagnosed with any type of autism were simply nothing more nor less than persons who had/used/use more alpha-wave brain function (8-12 or 7-13 hertz) than “normal” people who successfully grow out of childhood (aged under 12 years, also below 13 hertz) and grow into using mostly beta-wave (over 13Hz).

I await my “theory” to be disproved by anyone. And so until then, I have no reason to think that I am in error. Ignoring the proposal does not make it any less valid, and neither can it be found out via means such as cutting open a dead brain in order to see how it is when alive and thinking. Whatever can scan living brain frequencies, or whoever defined the terms “alpha”, “beta” and “brain waves” in the very first place is what is needed here.

The topic of acceptance is in: if even one word is wrong, or seems out-of-date – even if the transliteration means the same thing – then the whole thing is not accepted. In society, the only way to get a thing accepted unconditionally is by enforcing it as law. And not even always that way. In short: “Does your iPhone use iOS 78997? What? You’re still using only iOS 78995? Then you can’t join our society!”

I might also think that it’s more “acceptable” to society that the “cause” of autism remains “unknown”, since you can’t really give out medicines to make a child grow up faster . . .

2) On acceptance personally for me: although I could write an entire e-book on all of this, supposedly, in order to be accepted within a society, a person does best in making other persons happy. You know, “happy” as in “smiling” or “laughing” and the like.

The rare times in which I speak at length to other people, I try to ask them about being bullied. I have the unique talent of being able to make all bad people very happy, simply upon

sight of me, upon the thought of upsetting me, insulting me, lying about me, inflicting pain, or whatever, of me. But in my technical opinion, a “bully” is no less a valid member of the human species than anyone else. They/we all spend the same money, walk on two legs, have one nose, and all of that. A bully and a victim are both persons who “smile” the same way, and the difference between them might not be found out for several years, if ever.

When I was being diagnosed, I mentioned — a lot — that I was being bullied. And every time . . . they change the subject in order to deal with addressing it. And thus I have come to learn that “society’s” way of “accepting” me is to be not very nice at all to me. Officially. Go figure.

3) This is the main thing I’d like to see published. When speaking to a so-called “expert” — diagnostician, psychologist, doctor, whatever — sometimes I shall say a thing — even just one word — and they misunderstand it. I am not talking about “feelings” or “intentions” but actual words, using the English language. Reading this, you might not get it yet, for the words here are printed and you can read them (and look them up). My gripe is that, you never learn that your therapist has misunderstood your word until you get the report back which is supposedly quoting your own words. Has anyone else had this nuisance occur to them?

This is my main point number one: when I was diagnosed (aged 42/43) with AS, I insisted to the person that “I am a cynosure.” (A thing that attracts attention, even in a crowd.) When I got the report back, he’d written the word “sinecure” (a thing that exerts itself very little, but attracts a lot of money). Readers, please insert appropriate astonishment here. If I were a sinecure I wouldn’t have a problem with my AS or be writing to *AU* about it . . . I’d be filthy rich instead!

4) An earlier contributor said: “As a woman I don’t share a fascination for computers, *Doctor who?* or sci-fi.” Does this mean that I am not a woman? Seriously? This “woman” needs to meet a lot more women, both NT and AS . . .

Believe it or not, this only supports my “theory” that autistic persons are simply ordinary persons who are just unable to completely access all waking frequencies (over 13Hz): we see and enjoy a person playing basketball, but we have no legs and so we play wheelchair basketball instead. Conversely, NTs playing basketball say “That’s not really basketball” instead. The very worst of them just say “that looks stupid (or easy)”. Here is another thing: my “theory”, I think, proves that we (AS) know what we know for ourselves, but if we are taught something by someone else, especially in the midst of frequencies above 13Hz or so (noise pollution) then we have trouble detecting it. We cannot access or re-access it as they do, it damages us, it takes much adaptation before it can be perceived or copied. Yes, memories are a physical thing: most of them are picked up and stored in that thing called the brain . . .

5) Now we consider materials: cotton, nylon, Spandex, Lycra, etc. Find out what you don’t like, avoid that, and then try out other materials.

This may solve the problem, but, believe it or not, the dyes used in the fabrics may be the trouble. This may sound silly or strange to the majority of persons (alas, sorry, this might include the Goth) but this is because the dyes have a chemical effect too. I know this from experience. I am allergic to man-made materials (eg, nylon, polyester, Lycra) and wearing them for more than a day causes hideous itching and rashes which you don’t want to know about, I think.

(Sci-fi trivia: I supposedly share this trait with Doc Brown from *Back to the future*.)

But, after finding out what fabrics can be worn or not, the colour, ie., the dyes, can still cause discomfort. My only example is myself (and my own brother, who is not at all autistic) and I can put Mr Goth in here as well, with great respect to the man. The Goth “does not wear black” and so is obviously not allergic to coloured dyes (um, right?*). I myself, against my own will, can wear nothing but black (!) because coloured dyes cause an allergic reaction. Willpower means nothing, autism doesn’t count. This is science. When I am indoors, I must wear black, because I have eczema, and rashes, and all of those things people don’t want to imagine.

But, only when going outdoors I can wear a white shirt, for I am active and so as if in opposition to it. When indoors, the white shirt itches and causes rashes as if I were constantly being doused in some acid. Thus, I must mostly wear black. I don’t want to, but I have to. Actually, my favourite colours are blue, then green, then white and black. But I can only wear black most of the time. The social effects do not matter, for this is self-preservation, just like a person allergic to nuts cannot eat them, no matter what society tells them to do. To the Goth: even more respect to you, and I even more could never do what you do, because I myself have to wear black(!).

In short (as if I were giving advice): find out what fabrics you are allergic to. Next, find out if you might be allergic to which dyes. The fail-safes are natural fabrics (cotton, silk) which are white. The only trouble with following this suggestion (fact) is that pure cotton and pure silk are nowadays expensive . . . and largely unavailable. I must wear black, but nowadays it is something like 80% cotton, 20% polyester. There is nothing I (as a poor person) can do about this trend. There are no tests (allowed) which reliably test this sort of thing: they claim to, but they don’t. This is again known from my own experience.

Signed, **Pikachu Murray**

PS. Yes, you can print this letter if you like. And alas, yes, at “society”, due to ongoing ill-fortune, I am a very disillusioned person on the inside.

!!!Piiiiii-Kaa-Chuuuuu!!!!

**As Pikachu has addressed me directly in this letter, I feel the need to correct her impression: I find I can only wear certain fabrics, sometimes because of the fabric itself (like wool and polyester), sometimes because of the dye (not necessarily all dyes of the same colour, it depends on the exact dye used) and sometimes because of other chemicals used in production (particularly some bleaches used to make fabrics white), Editor.*

Dear Goth,

living with Aspies is blooming challenging. I went through all my school life never understanding why people communicate, and I could not communicate with them. I never made eye contact with anyone and I was always on my own doing repetitive things that I enjoyed. Many of the peers bullied me, flushing my things down toilets, throwing water and things at me, pushing and pulling and tugging my hair. I used to explode or run away. I spent most of my childhood running away mainly to Stonehenge or to the forests. Running would soothe my head and I loved things whizzing past as I ran.

When I started work I felt very small against all the other ladies in the huge office, so I ignored them and was very focused on my work. I used to be very scared if anyone talked to me. They used to gather and go to the pub but I would run the other way, upset that I could not fit in; it was sad to see them all together and I was alone, yet I rather be alone and in a very quiet place. I hated home because the tv, radio, music, talking would make my head crazy and I could not focus on what I wanted to learn or do, so again I often ran away. I loved finding a tree on its own in a field and I was comforted by the tree, protecting me from the Sun or rain, the sound of the tree would soothe me. Sometimes I find a big rock on its own and sit on it and enjoy looking around the wide space: being closed in was not nice. Often being inside things was noisy. I could walk through town and not notice another human: I got very good at that, filtering things out. This helped me cope.

Then I went for another job where it involved us sitting opposite each other and they would chat about things but I did not want to talk, join in, all I wanted to do was do my work really well. Break times were horrible unless I could go outside and be on my own to recover from the sounds of people babbling and machinery. I then went for another job where I worked on my own making things for quota needs: loved getting things made as quick as I could and counting out nuts and bolts and

d-carriers, buckles and parcel them up but I could not cope with the radios that the ladies liked to listen to, it made me feel overloaded and then I would get more angry. It was tiring trying to block it out, break times again on my own to relax and breathe, could not cope with tea room talking, cups, spoons stirring, newspapers rustle, lunch boxes clicking. I would get angry that lots of things were noisy and wish that these things were not around; I wanted to stamp jump on them and throw them away, wanted to scream “shut up!” Even on buses and trains I wanted to scream shut up and struggled to keep calm: walking up and down train carriages helps me blot out noises but buses are a nightmare. I have learned to cope and have got better blotting these things out.

I like routine and if anything was moved I would get negative trying to find it. Does this make me Asperger’s? My son is highly autistic and Asperger’s and ADHD, my daughter is similar but not high: she has learning difficulties as well as ASD. I was never tested for it because they assumed all my strange behaviour was because I am seventy-percent deaf with some cochlear damage, so I do not hear all frequencies, yet I meet other deaf people and out of the whole deaf college there was only a couple like me with our odd ways.

When my son was diagnosed I was, “Wow, that sounds like what I have.” So I learned how to communicate and try turn-taking, try pick up the body language, which is terribly hard. And since my son, and learning about it, I do not feel like I am the only one and all isolated, confused. It’s a very hard battle, we do not pick it up naturally, strange how people bully us like we are some threat or casting us out because we are not same as them. I learned now, to keep myself happy and busy after my severe depression, I suffer from derealization, which is where things get warped and my senses get mixed up and this usually happens from information overload. It’s time for peace and quiet and slow down and avoid things till I feel better. It does affect your mental health after struggling for so long. Glad they are finding more of them because they are the lucky ones to have people understanding better and to

a letter (continued), two more letters and a review

help them because if you're not diagnosed it's a massive struggle. The best thing is getting to your local group, this will help immensely, seeing there are others like us and share how to cope and manage in a world of mostly non-Aspies.

I am nearly 50 and starting to enjoy life a little bit here and there for the first time. Up until now I was always very sad.

From **Rachel**

Hello reader,

I take the view that if you have a question about yourself, then yourself may be the best person to try to answer it. Can anyone know you better than you know yourself?

For certain, for self-analysis to have a chance to work then self-awareness is a prerequisite. But as Jonathan wrote some time ago, "the human mind is complex and I'd advise caution towards anyone who says they have an answer". And I would include me in answer to me or you in answer to you. But I do believe that self-reliance is likely to be the best option. And it is available anytime and it is free.

Michael

Hello *AU* cricket-lovers,

is there a difference between knowing and understanding? Is there?

I know that some *AU* readers love cricket (I refer to the bat-and-ball game, not the insect). I have no understanding as to why this is. I think I might if it were the insect. I know that some *AU* readers believe in God. I have no understanding as to why challenges to that belief are not universally successful. I know they are not.

Autism "experts" will (hopefully) have knowledge of autism but is it possible for them to have understanding? Autism affects and effects each individual with autism in a different way. It is not the autistic "experts" understanding that is universal — it is the differences.

AU **non-cricket-lover**

The girl at the end of the road

KA Hitchins

Instant Apostle

ISBN: 978 1 90972 839 4

£9.99

review by the Goth

Although it seems like there is always another author on the telly publicising their new novel which has an autistic as a leading character, novels with autistic characters are still a tiny minority of all novels.

So it was a pleasure to discover a novel written by someone who actually seems to understand autism. And KA Hitchins is also aware of all the clichés, both the novelistic clichés and the autism clichés, and they play with them throughout the book: Are they the murderer? Is she stupid? Is he violent? Does the poor thing need help? Is he manipulative? Why do people join the rat race?

And without being heavy-handed, they are resolved one way and another as the story unfolds.

The one tiny let-down in the book is that some of the plot twists are written in a way that is a bit clunky and melodramatic, which detracts from the superb realism of the rest of the narrative, but it's the first novel by KA Hitchins, so it would be unfair to expect perfection. The way the characters are drawn is true to life — they are all very believable and rounded. I am interested in seeing where the author goes next.

Autism and employment study

research advert

by **Lisa Dockery**

Who are we?

Researchers from Goldsmiths, University of London.

What is this study about?

The effects of employment on the well-being and cognition of adults (age 18+). We are particularly keen to hear from adults with autism but other individuals can take part in the study too.

What do you have to do?

1. Well-being survey:

http://ww3.unipark.de/uc/Team_Hill/2c76/

Anyone can complete this. This asks for general information on life satisfaction, mental health and employment (15-25 minutes).

2. Employment survey:

<https://gold.onlinesurveys.ac.uk/autismandemployment>

People in employment can complete this. This asks questions about what type of job you are doing and whether you experience anxiety (15-20 minutes).

These surveys can also be completed over the telephone by calling **020 7078 5168** (we can call you back) or by post. Please request a participant pack by writing to:

Lisa Dockery
Goldsmiths, University of London
Ben Pimlott Rm 106
Department of Psychology
New Cross
London
SE14 6NW

How will this study be useful?

This study could link to funding opportunities for specialist adult autism employment services. Few of these services exist and an improvement in well-being and cognition means many autistic adults would benefit from specialist supported employment services.

Thanks very much,

Lisa

l.dockery@gold.ac.uk

thedockeryexpress.wordpress.com



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 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.
- 4) *Asperger United* administers the copyright of everything that appears and it does this on behalf of the authors.
- 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.
- 12) If you want to unsubscribe from the paper version, inform *Asperger United* and include your postal address. Or to unsubscribe from the email notification, include your email address.
- 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.

Cannibal market

story by Tony

“Roll up, roll up! Get your five a day here!
Support your local butchers!”

“Yes love, what can I get you?”

“We’re going on a picnic — got any pickled
legs or Gurkhas?”

“No but I’ve got some ham burglars.”

“No thanks. How about picnic eyeballs?”

“No, I’m afraid I only have eyes for stew.”

“Pity.” She paused and looked down, ready to
give up.

“I could do you some Sam wedges, finger
food, cheese and bunion crisps . . .”

“No.”

“How about a nice Kate and Sidney pie?”

“No thanks. Got any missionaries or knights?”

“You mean meals on wheels or canned meat?
Sorry, fresh out. If it’s foreign food you’re after,
we’ve got a special — buy Juan, get Wong free.”

She laughed.

“You’re a bit of an entrepreneur, aren’t you?”

“That’s a big word but yes I do have a finger
in every pie, so to speak.”

“I’d heard you butchered your posh friend and
chopped him up for dog food.”

“Oh you mean my pedigree chum. Rumours,
just rumours.”

“Well I think I’ll leave it today.”

With that she waltzed off, happy at the banter,
if nothing else.

Asperger United, c/o The National Autistic Society, 393 City Road, London EC1V 1NG
Telephone: **0808 800 1050** (free from most landlines) or
Telephone: **020 7923 5779** (geographical charges apply)
Email: asp.utd@nas.org.uk
Website: www.autism.org.uk/aspergerunited



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