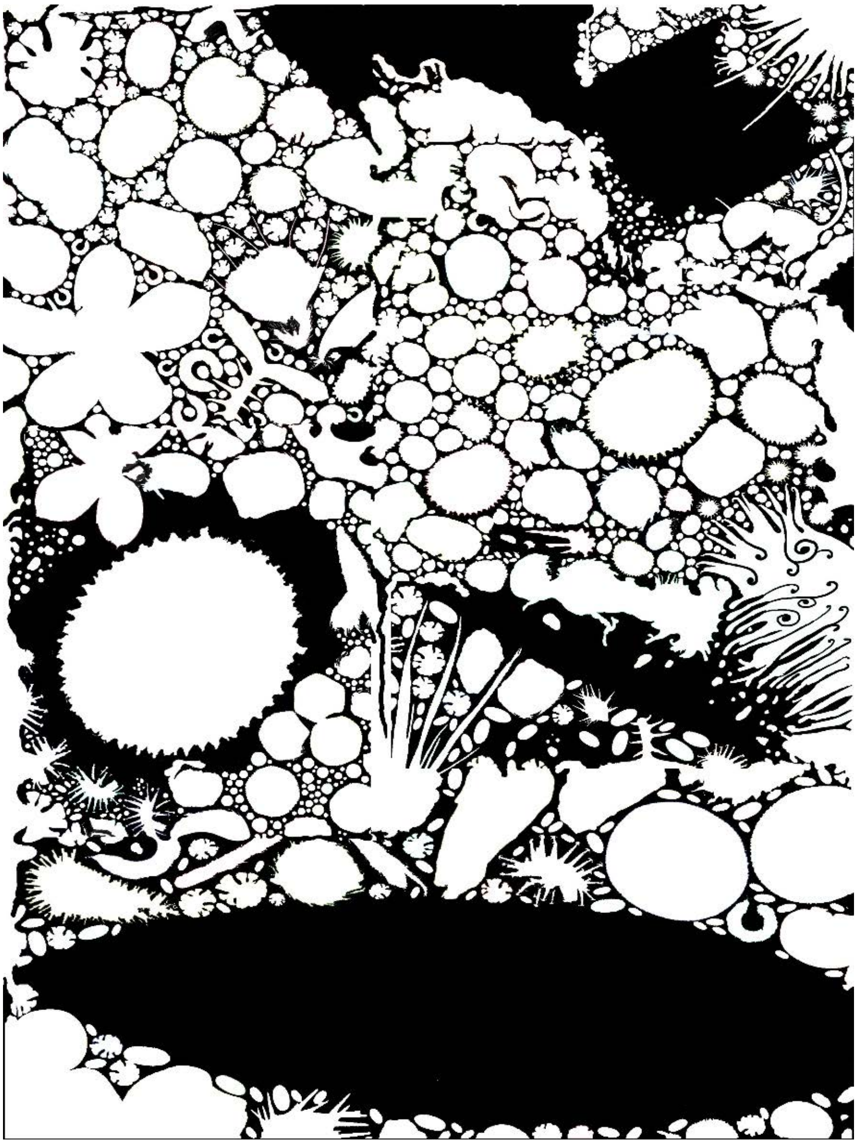
Produced by and for people who have autism-spectrum conditions

Asperger United

Edition **75** July 2013



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

Telephone and production support
The National Autistic Society's Publications Department

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

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

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

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

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

Please send all correspondence and subscription requests to:

Asperger United
c/o The National Autistic Society
393 City Road
London EC1V 1NG
Tel: **020 7903 3595**
Fax: 020 7833 9666

Email: **asp.utd@nas.org.uk**

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

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

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

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 **12 August 2013**

Welcome to the July issue of *Asperger United*, for which there was another bumper crop of submissions.

Topics are merging into each other at the moment, as we move seamlessly from work to menatl health to diagnosis to living, sometimes all in a single letter — and this is no bad thing!

Next month (August) I hope to see many readers of *AU* at Autscape, like last year. I find this event a marvellous way to recover my sanity after months in the wide, hostile world. I look forward to meeting familiar faces, like Steve who reviews *Rubbernecker* in this issue, and hopefully also some new faces. The venue has plenty of space where people can spread out and be alone, and beyond that is some fine Yorkshire countryside, so the more the merrier(!)

The subject of empathy continues in this issue, and it looks like this is a topic of considerable interest. How much empathy, sympathy and compassion do you think you have? I anticipate further letters and articles filling my postbag soon.

Fingers crossed for a good summer: it will be as good as we can make it — there's still very little help — but things are changing,

the Editor

the mental-health edition — the next issue notice is on page 6

Contents

I have wanted to contribute something to the magazine for a long time, but did not know how I could find words . . . but since reading the last edition I received this week, I think I might be able to write something now.

I would like to write about getting a diagnosis as an adult, and how I feel about my diagnosis, including how I feel about the proposed changes to the American diagnostic manual (DSM-5).

I have had psychiatric help ever since I was a teenager living in New Zealand. (I am now 54.) I did not understand what was wrong with me all those years ago: I was admitted to a psychiatric hospital because I could no longer look after myself, I was very neglected and I did not have a family who loved me. The psychiatrists tried very hard to help me, but they could not reach me. They did help me, though, to leave New Zealand so I could try and have a life of my own far away from my family. I came to England first (I was 21 years old) and a psychiatrist in England was very good to me and wanted to help me, but I did not want to go back with him to hospital. I wanted to be on my own. I came to Holland and I have lived here ever since. All the years I have been here I have only known good psychiatrists who have always helped me any way they could.

In 1989 I was admitted once again to a psychiatric hospital, and from this time I stared receiving help from a psychiatrist whom I still see today (I see him now once every six weeks). It is this psychiatrist who has told me that all the psychiatrists who have ever seen me, and tried to help me, have always found it very hard to know what my diagnosis was. He has also not known for many years what my diagnosis might be. He has thought of autism, and he has consulted a colleague who is a specialist in autism here in Holland. Now, after all these years, he says I have an autism-spectrum disorder and I also have a schizotypal personality disorder. He also says that at different times in my life the whole psychiatric diagnostic manual could have been applied to me. (Maybe he was exaggerating a bit? But I have had very many diagnoses.)

I wanted to tell all of this because I have always had a positive experience with psychiatry, even though they did not know until the last few years that I have autism. I have come a very long way since the very traumatized child I once was. There was no help then for me, and it was only when I was able to get help from psychiatrists in my teenage years that I started feeling there maybe really was a world out there that could help me. I have a home of my own now, with a lovely garden I like to work in almost every day. I have friends I meet at my local athletics club every Saturday morning. We run first and then we drink coffee together afterwards. They have slowly become my friends I can be with and I am very glad about that. For years now I also have been able to keep my job doing admin work at the local university hospital. My boss and the people I work with know I cannot handle a lot of social interaction so they do not pressure me too much and leave me alone to work quietly on my own. I have a room where I can work alone. They know I am happiest like this, and they are very happy and pleased with all the work I do. I get good reports about how hard I work and how extremely accurate my work is.

Part of my work is to be very acquainted with the DSM (the diagnostic manual for psychiatry). I am extremely interested in psychiatric diagnoses and for the longest time I have struggled myself to wonder what my diagnose was. These last years I have not been able to decide whether I have Asperger syndrome or high-functioning autism. (My psychiatrist believes it may probably be more the latter). So I was very pleased when the reports came out about the changes in the new DSM and how they see my diagnose just as my psychiatrist does: an autism-spectrum disorder.

I would like to add just one last note to tell how so very deeply grateful I am to Lorna Wing for all her work on catatonia in autism-spectrum disorders. I have read the book she wrote on this subject and

I have recognized myself so much in the people she has known and described in her book. It is the recognition of these catatonia-like states when I was a little girl, and how it appeared again later in my teenage years, and again and again in my life whenever I have become overwhelmed and deeply distressed and had to go back into hospital, that has made it very clear to my psychiatrist (and the specialist in autism he consulted) that this is autism.

I fight now very hard for myself to make sure I do not ever again find myself in situations where people are expecting too much of me. I know others often cannot understand why I need to be alone so much, and why I cannot be among people a lot interacting the way they do. I need my quiet time alone. And I am happy now in my life, and accept more that I have needed to be far away from a family who have never ever been able to accept me the way I am.

I do not see myself as autistic. I see myself as Jacqueline, and I have autism.

I do so hope that all I have written will maybe help someone else, the way other people's words have helped me.

Jacqueline

The journal of best practices

by **David Finch**

Scribner Book Publishing

ISBN: 978 1 43918 974 0 £8.90 / $16

review by **Neil**

On the verge of his marriage collapsing, David Finch discovers he has AS. He investigates the condition, and realises that it accounts for most — if not all — of the difficulties he has experienced in life. He resolves to become the best husband and father he can — and starts to collect notes, thoughts and information in his "Journal of best practices".

This book is well-written and, although there are many references to the journal entries, it is not a transcript of it. Instead, Finch devotes a chapter to each of the problems associated with AS, including: feelings and emotions; finding out about the interests of other people to help make connections with them; empathy; loyalty to family; working out what is really important to you/your family; being a better father; and socialising. A typical entry is:

Go with the flow

Purpose — Flexibility is an essential social skill, like communication. Being inflexible prevents me from experiencing joy which is right in front of me. It stresses me out. My failure to adapt has driven a wedge between Kristen and me. It's making me a bad role model for my kids.

Payoff — If I can learn to go with the flow, then I will be a more stable husband and father. I won't have to live in a constant state of agitation. I may start enjoying things!

Process — Start learning to pick the battles. Learn the difference between critical and favourable outcomes. Emily and Parker never, ever colouring on the walls with crayon would be favourable. Raising kids who don't flip our every time something goes wrong — leading by example — is critical. If necessary, ask Kristen to help define what's important. (pages 120-121)

Usefully, the book includes a reading group guide to help discuss it.

Following on from the review of *What men with AS want to know about women, dating and relationships* in January, I think this book complements it perfectly. AS is fundamentally a social disorder, and it's relationships with others — especially our loved ones — that suffer most as a consequence.

Group notices

Autonomy

The self-help and social group for young people and adults with Asperger syndrome in Shropshire, Telford and Wrekin and the Borderlands.

If it is to be, it is up to me!

If you are interested, please contact Sara or Eric Heath at

autonomyshropshire@yahoo.co.uk

01743 821 363

Dear *Asperger United*,

I have written to you before, several years ago. I am in my sixties and have Asperger's syndrome. I spent several years volunteering for Autism London, until they closed the office in 2011. I am now involved in the Asperger support group known as **ALAG** (Autism London Asperger Group). Details can be seen on the Autism London website which is

www.autismlondon.org.uk

or email **ethney@autismlondon.org.uk**

to book a place and for details of the next meeting (the regular first-Tuesday-of-the-month meeting is held in Kentish Town at 18:30).

Unfortunately, other means of contact are not available,

Desmond

Dear Sir,

I totally agree with Mikey (*Asperger United* 74, page 10). The NAS are doing good work — for children. But what about adults?

I have my hobbies of taking newspaper cuttings, and antiquarian books. But I hardly ever meet anyone except my sister, who lives two miles away.

Yours faithfully,

Michael

Rubbernecker

by **Belinda Bauer**

Bantam Press

ISBN: 978 0 59306 692 8

£14.99

review by **Steve**

Convincing characterization couples with a captivating storyline to suggest that this novel will soon come to rival Haddon's *Curious incident of the dog in the night-time* in introducing the public to the world of the Aspergic in a way that Sherlock Holmes could not quite manage. Like both *The curious incident* and the Holmes stories, *Rubbernecker* is destined, I'm sure, for screen adaptation.

If sufficient material is sent in, the theme for October will be **strategies**. If little is sent in, how about **relationships**? 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!

Pen pals

Pen pal number 153

Dear pen pals,

I'm Richard, I am 30 years old, man, I have autism, learning disability, I am gay.

My interests are walking, meeting new people. I don't go out much as I find it hard to interact with people so don't really meet people on the scene and that can make me lonely but would like to write to and maybe meet other gay men on spectrum to make friends and socialise, as my mates who are on spectrum are all straight, so be nice to get to know other men similar age from 28 to 39.

Pen pal number 154

Hello my name is Rebekah, I am nearly 18 and would like to make some pen-pal friends. I was first diagnosed with Asperger's syndrome when I was 7. I've just passed my driving test and enjoy going out with my friends to the cinema to see the latest films. I like to watch romantic films and comedies. Also I have an interest in cooking and baking, such as cupcakes and curries. I like listening to music as it helps me think. I'm into Katy Perry, One Direction, Westlife, Avril Lavigne and others but it depends on what mood I am in to what music I listen to. I like watching soaps such as *Hollyoaks*, *Waterloo road* and *Coronation street*. I volunteer at the St John's Ambulance Service as I like to help others in need of first aid and make new friends. I would like to hear from new people that are a similar age to me and have similar interests.

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 155

My name is Alicia, I am 21 years old. I am currently under a section of the Mental Health Act in hospital.

My hobbies include music, drums, writing and art.

I would like to hear from anybody who would like a pen pal.

Alicia, if you would write in again with your address, that would be helpful. Otherwise I can't forward letters, Editor.

Pen pal number 156

Dear pen pals,

I am called Rob. I am 42 but like to be called a teenager as don't like to be seen as adult. My interests are music: I designed dance music and I appear on radio! Would like to speak, make friends with people who have talent, interest. Ideally, people over 25 years of age.

Pen pal number 157

Hi, my name is Sammy, I live in Brighton and would like pen pals who are Jewish like me. I am 36, I have OCD and Asperger's.

I like PS3, guitar, Youtube and film-making, eating out and the cinema. I also like cats and dogs. My musical tastes are Bob Dylan and Led Zeppelin.

Look forward to hearing from you.

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

Pen pal number 158

Hi. My name is Daniel. I live in Leeds. I am 37. I was diagnosed with Asperger's syndrome when I was 23. I love to write and share my poetry and sense of humour with others. I consider myself out-going and kind-hearted. I have OCD as well as Asperger's. There is always something going off in my head. I should probably write this advert five times as I have a mini obsession with the number five. I feel interested to hear from people. It would be great to hear from other possible writers, fans of poetry.

At the moment I am doing poetry on the A-Z of science fiction. I like horror movies, a big fan of the first two *Rocky* movies. I also like watching *Family guy*, Russell Brand and Ricky Gervais, plus Sean Lock — three of my favourite comedians. I have had some of my poems accepted for books.

Pen pal number 159

Hello, my name is Rupert. I am 25 years old, mixed race, male, from London. I would like some pen pals to write to.

I was diagnosed with Asperger's in 2011. I also came out as bi in 2011.

I am currently in prison and working on an appeal against my conviction.

I enjoy listening to rock music and heavy metal, I'm into power metal a lot lately. I like reading a bit of fantasy, mainly heroic fantasy with bloody fights and battles. And I also enjoy going down to the gym here at the prison. I go five times a week.

I see myself as a free spirit, and I am a Norse Pagan. I follow the old gods: Odin, Thor and Frigga.

Anyone who writes to me must be 18 or over. Hope to hear from someone soon.

A meeting of two minds

by **Alis**

She checked her e-mail tentatively for the fourth time that Saturday morning. Although their meeting had already been confirmed, she knew that "people like them" could change their minds in a moment's notice.

But there were no new e-mails. Their meeting was still on.

She got dressed, relieved to feel she could wear her favourite holey t-shirt and leave her hair uncombed. Even if he did notice, he would most likely not mind at all.

She arrived at the coffee shop early. She wanted to be early so that she could find a suitable table and adjust to the surroundings before Ross arrived. When there were a lot of things going on, she could easily feel over-stimulated. It was important to sit down in a quiet corner on her own and have a cup of tea, before someone else entered her world.

She was nervous; it had been several years since they first met. She always felt nervous seeing people, but she felt more nervous when there were long time periods between the meetings. She had not seen Ross for three years. Sometimes it felt easier when she saw the same person every day, it became part of her routine; it was predictable, less anxiety-provoking.

It was dead on eleven o' clock. He arrived at the entrance to the coffee shop. He looked just as she'd remembered, possibly slightly older. He was short with a slim build and brown hair. Just the way he positioned his body when standing looked familiar.

She waved at him and he caught her eye. Immediately his eyes set on her location and he strode through the busy coffee shop, ignoring everything around him; he was solely focused on reaching her table.

"Hi," she said.

"Hi," he replied.

It was awkward. What was she supposed to do? Shake his hand? Hug him? But then she remembered he was like her; she did not have to wear her mask. She could behave exactly how she wanted. She did not want to shake his hand or hug him, so she didn't. She simply left the greeting as "hi".

He really hadn't changed. He still had that young, cherubic face and his hair was unusually angled the same way it had been three years ago. His plain white t-shirt was tucked high up inside his trousers. She wondered if his t-shirt was 100% cotton. Did he have to wear clothes that were 100% cotton, same as she?

"Thank you for coming here," she said.

"Not at all," he replied. "Thank you for agreeing to see me. I wasn't sure you would even reply to my e-mail."

They relaxed a little, lowered their barriers, acknowledging they were on the same planet. Ross was not a threat — he was an insider, after all.

Conversation flowed. Although they spoke a different language to the other people in the coffee shop, their language to one another was the same. Other people would not have been able to understand what they were saying.

Ross had interesting hand movements, she liked watching them. They were able to look in each other's eyes, irregularly but quite comfortably.

Parting was easy; there was no pressure or expectation that they would ever meet again. But both of them felt a little bit less lonely that sunny Saturday afternoon.

Hi

I wanted to email as David's feature on *Work* was brilliant. I hope he writes a blog and publishes it on line, as he has a great writing style and he could reach a lot of people.

I'm a NAS Ambassador and in my workplace I am running autism-awareness month. I'm going to share this article and I'd love to be able to share more.

Please feel free to give David my contact details, but crucially please give him the feedback.

Wonderful stuff!! Good for him on getting a diagnosis,

Louise

Dear Goth,

I think it is imperative that Robert understands that he can change his psychiatrist and should do so immediately. It is disgraceful that a psychiatrist in today's world still doesn't accept that Asperger's exists — it seems that maybe it is his psychiatrist that needs help!

I also think Robert comes up with a very sound point — "as the majority of health care professionals are NTs is there any hope of change?" It actually makes me laugh really. NTs go on and on about us not understanding their world — but they don't really understand our world do they? And we do have empathy and we do care — our problem is that we might have too much of it.

Anyway, I just wanted you to let Robert know that I think he should complain and get another psychiatrist.

Regards,

Valerie

Dear Goth,

I have just received the 73rd edition of *Asperger United*. I see it's suggesting mental health as one of the subjects for the July issue. Here is a rather (or at least *I* thought it was) funny incident.

Lunch club at church, the same woman who had bullied me at the Christmas lunch club was at it again. So after putting up with this so long I couldn't cope any longer I went through three doors, slam, slam, slam.

Threw my bag across the floor, the one she had stolen at the Christmas lunch club. I was totally distressed by now, headbanging, the lot.

Out comes this old guy, seventyish. He shouts across the room to me, "Sue, I've . . . been . . . in mental-health work for thirty years." I looked up at him and promptly told him to **** off! He rushed back into the room where they were having lunch with shock-horror-don't-you-swear-at-me as he went.

Out comes my wonderful pastor (as was), "Come on, Sue, let's take you home." So calm, so professional, carries on walking as he says it, and I follow him.

But who in the end got expelled from the church? Me. I was the one who was putting up with the bullying, emotional abuse, exclusion.

I can't fully blame the minister as there are some strong Northern women in the church.

But my health is so much better and I've not had any meltdowns since then, which was February. I was expelled in March.

Sue

AS: where a lack of empathy is positive!

by **Neil**

In June Bowden's excellent article in January, both she and the Editor strongly believe they have empathy and theory of mind. Like them, I also thought I must be empathetic — after all, I cried when watching certain films (eg., *Schindler's list*); when I hear pieces of music (eg., Barber's *Adagio for strings* and Mendelssohn's *Fingal's cave*); and with frustration at man's inhumanity to man (eg., the school shootings in America).

The truth, however, is that this is not empathy: it's compassion and sympathy. Professor Simon Baron-Cohen (SBC) defines empathy as occurring when we "suspend our single-minded focus of attention, and instead adopt a double-minded focus of attention." (Double-minded means we are keeping in mind someone else's mind at the very same time — ie., theory of mind). Empathy, therefore, is our ability to identify what someone else is thinking or feeling, and to respond to their thoughts and feelings with an appropriate emotion.

Aspies lack the processes that enable social reasoning and emotional awareness of others. We can't separate ourselves from our own perspectives, so cannot access the "double-mindedness" required to connect with the perspectives and feelings of others.

This explains why we often think people who are hostile or ridiculing us are being friendly, and why we have a "black and white" approach to people — tending to really like or dislike them. Apparently, it's "creepy" to tell strangers you have only just met your life story and that you want them to be your new best friend.

Similarly, when I have tried teasing, sarcasm or irony it is frequently perceived by others as cruel or hurtful without my intending this in any way. When I was described once as "arrogant, unempathetic and unlikeable" I was devastated.

To find out how much empathy you do have, do an online search for the "Empathy quotient". Out of a possible 80 points I scored just 18 (a typical Aspie score is 20). By comparison, NT men would expect to score around 42 and NT women around 47 — evidencing the very clear gulf between AS and NT.

Society views a lack of empathy as a Very Bad Thing Indeed. In narcissistic and antisocial personality disorders lack of empathy is key to diagnosis. SBC categorises these as "zero-negative" disorders, in that there are no redeeming features to compensate for their negative aspects.

By contrast, despite Aspies also having impaired empathy, AS is characterised by systemising. So, SBC categorises AS as "zero-positive" as Aspies can identify patterns in their lives, including rules of behaviour. This becomes a moral code to which we rigidly adhere. We expect others to do the same — it's only fair! Aspies are often the first to jump to the defence of those we perceive as being treated unfairly.

It is crucial that we (and those around us) not only accept our diagnosis but also learn as much as possible about the condition, its effects, and in particular our strengths and weaknesses.

I can recommend the following books:

Simon Baron-Cohen, *Zero degrees of empathy*, Allen Lane, ISBN: 978 0 71399 791 0

David Finch, *The journal of best practices*, Scribner, ISBN: 978 1 43918 974 0

The Goth did the EQ and scored 29, and does not confuse it with sympathy. He feels he has much more empathy than this for other autistics; it's the rest of humanity he's slower at understanding. Let AU know what you think!

Work

part two

by **Julie**

This piece is about my experiences of work, and my thoughts on the effects of Asperger's in that context. Bear in mind that my own Aspie diagnosis is only about 30 months old, so I am still exploring the concept; and that it came after I stopped work, so I have not had a chance to test any of these notions. So I may be partly or completely wrong. I would be interested in comments and comparisons.

Last time I detailed several problems I was having throughout my career as an electronics engineer. It was not until some months after I left that I was diagnosed with AS. I don't know if it would have helped me to know sooner.

I am trying to analyse those problems in the light of the diagnosis. I have had a few tentative thoughts on the matter:

First: people don't always tell you what they are thinking. There are a number of possible reasons for this:

1) they think you already know;

2) they think you should know, and are being silly or stupid;

3) they think you don't need to know; or

4) they think you are being deliberately difficult.

This brings us to the subject of body language and similar forms of non-verbal communication, which Aspies are notoriously bad at!

Solution? I'm open to suggestions. If your colleagues know you are an Aspie, it may help if you remind them of the fact, and ask if you are missing anything. If they don't know and you don't want them to, you will have to be persistent and diplomatic — again, two things that I'm not very good at.

Second: even when people do respond verbally, they are not necessarily talking the same language as you are! Yes, okay, you are both using the vocabulary and grammar of UK English, but there is a lot more to interperson communications than that. As well as body language, there is the entire collection of cultural assumptions and attitudes which seem to modify apparently straightforward remarks into emotionally loaded challenges, and this "cultural subtext" has been almost completely invisible to me. Again, I don't know whether this is typical Aspie, or a product of my having grown up outside the UK, or a mixture of both.

Some examples of what I mean:

1) You may have noticed that to ask "why" often evokes a hostile response. This is apparently because the listener perceives your simple request for information as a demand that they justify themselves.

2) When someone says "I don't understand you", what they actually mean is: "I disapprove of you very strongly indeed". And of course if *you* say you don't understand something, they think you mean that *you* disapprove. The problem here is this: how can you learn if you can't tell people you don't understand?

(UK English is full of such "polite" avoidances of real problems (not "issues", please!). These politenesses have taken on the meaning of the thing they disguise and have therefore become useless, and a barrier to communication.)

3) Most of you will have heard of similes and metaphors, which are ways of conveying what you mean in a shortened and emphatic form. You may also have come across rhetorical questions, which are sentences phrased as questions but which are actually statements; they don't need answers, but they are used to express doubt about things. They are not always easy to detect. What I have a lot of difficulty with, though, are what I will call rhetorical statements. These are phrased as statements, but they are actually questions, or challenges. They can often seem to have no connection to anything that is being discussed. I find that they leave me wondering what the speaker meant, or thinking, "okay, but so what?", and I don't respond . . . and the speaker gives a smile or a nod and moves on to something else. Only much later, if at all, do I realise that the statement was actually a challenge, demanding a response to check the speaker's suspicions about something, and my failure to answer was taken as a confirmation of those suspicions. Except, of course, that it wasn't a confirmation at all.

In a work environment this can be a serious matter, and (I have just this moment realised!) it may have contributed to the failure of perception that I noticed earlier. It can get you a reputation for being a thoroughly awful person, a reputation which is entirely undeserved, and which (because of the false politeness I also mentioned earlier) no one will ever tell you about.

It is sometimes possible to get people to tell you if they think you have done something wrong at work. You have to keep calm, point out that you have both a right and a need to know, and ask them politely to explain. That approach did work for me once. But first, of course, you have to spot the challenge — and that may not be easy.

If you've read this far, I hope I haven't angered you, frightened you, or confused you, but that it has been of some use, and I would welcome comments through *Asperger United.*

In particular, the subject of work interviews is one I feel requires a separate and detailed discussion. Any takers?

This train is bound for glory

by **Cara Dovecott**

It's a summery evening, after a work-a-day Thursday. I join a gaggle who are chatting in the park, outside a Vauxhall tea shop. There are familiar faces, and I bask not in the sun but the sense of belonging. Autistics live as salt scattered over a plate of chips, a few in every neighbourhood, making life taste interesting for others, but unused to being among our own sort. I have a sense of being at the beach: able to smell the salt air, a sense of holiday.

Everyone makes their way inside what is not just a tea shop but the Tea House Theatre. Harry, who runs it, has created a venue with a genuine welcome, not just an arty vision. Alain, an autistic poet, holds his monthly poetry events here. That event is Paper Tiger Poetry, but to hear the roar, the poems must be heard live — the drama is all in the delivery. There is poetry tonight: Alain and a couple of his regular stars will round off the evening with their virtuosity. But poems are the final carriage on tonight's train of events.

We start, of course, with an overture. Louisa on recorder and Neil on piano. Mellow and clear notes mingle together. The all-autistic drama company, Stim Rock Express, stage their first performance: actors take to the stage, some are dressed like the crew of the Starship Enterprise, except they have a large T on their chests. Another has a green face: for some inexplicable reason the alien wants to drink coffee. Imagine the cheek of coming to a venue that serves forty types of tea and wanting coffee! What planet is he from? This play, which parodies the autistic experience of living in a non-autistic world, is about diversi-tea.

The audience is charmed. After the show there is much excited congratulating between the performers and the audience. Jenny, who set the wheels of Stim Rock Express in motion at **stimrockexpress.blog.com**, promises me that this was just the first of many journeys.

I read with interest the letter from contributor Robert which I found profound and insightful. As I have AS at 50%, to some extent I am able to bridge both worlds — but this itself causes difficulties because people find it harder to understand why every day is such an immense struggle. Perhaps we are too altruistic because we always analyse in order to try to "understand" people; whereas, NT to NT, they seem to react immediately and not put up with silly behaviour we daily undergo.

I work in retail, which is a notoriously pressured environment. It seems to proliferate with NTs who have no insight of their behaviour, let alone understand anyone else's. When I avoid such people, they report me to my manager for not speaking to them. This has gone on my work report as a reason I am not given the next level of responsibility!

We have a new store manager and at last he is beginning to "twig" I am a very intelligent, competent, person with a high level of self-motivation (common traits in AS) but still find people's behaviour difficult to fathom.

I made an agreement with the store manager that, if I become frozen with a situation, I write him a letter with the background, any history between myself and the person, and how it is impacting on me. The agreement is, this letter *is* my thoughts and as sacrosanct as if I had verbally given him a secret. It is not to be filed but given back to me, in the same way a conversation would not be typed out and filed. (You can "test" the person if you are unsure they are trustworthy by offering something uncontroversial first, as it needs the receiver to be a "people" person.) Treat this as a form of scientific experiment on NTs and it becomes easier!

Stage two, which I haven't tried but will, if there is another occasion, is to stand in front of the complainer and ask, what exactly do they want to talk about, as I have been informed they made a complaint — then wait for a response (saying nothing else until they have spoken). If they cannot respond, or are embarrassed, that proves they had no real complaint.

I suspect, "word" has got round about this new way of tormenting and it worked because I didn't react and the manager over-reacted (ie., he might have asked each complainer how this occurred, or else suggested they say to me, "Is there a reason you are [seemingly] ignoring me?").

Years and years dealing with this sort of person saps your energy, doesn't it? As well as wasting years of your life. I agree with Robert, the best way is to find a therapist/counsellor who is more analytical — but, empathy needs to be there too or it becomes psychoanalytical "parroting":

Client: "They are reporting me again for not speaking."

Analyst: "Not speaking?"

Client: "I feel really sad and frustrated."

Analyst: "Sad and frustrated?"

Client [shouting]: 'Why am I paying you to repeat everything I say? You are not helping. You are like a parrot!"

Analyst: "Like a parrot?"

Wouldn't you feel like chucking the analyst after 45 minutes of that! My current counsellor, who is Eclectic, is very good. She listens, then we both work out how the situation has occurred and if there is a pattern. I then come up with a strategy. Importantly, she increases my self esteem by listening to my successes too and praising me, so I feel encouraged to share creative stuff I do outside my paid job. She encourages me to talk about positives and points out when I get into a cycle of negatives. This has been very helpful because I am not always aware of when I am getting in a negative spiral.

Like your other reader, Thomas, I find writing things down very, very helpful. As I am creative, I turn some of this "material" into books and poetry. I have been keeping a "positives diary" for eighteen months, into which I write good things I see and that happen to me and it is comforting to read back. I also write negatives which I kept in a separate journal, but as these days it is more positive than not, I have incorporated the latter into the former.

I also want to agree with another reader, who talks about NAS being mostly for autistic children. I have so many times sought information and practical support but they do not follow up, and ask immediately for praise so that they can fulfil their quotas. I think they are like many other charitable organisations of which George Orwell (I think) said, they exist to employ lots of people and prevent funds (resources) being given to those who need it. That might sound harsh but it is true of many of organisations, eg., CAB, Business Link, various "help lines", mental-health charities, who all pass the same tired old information around without bothering to check if it is correct and up to date. When you actually ask them to *do* something, they say it is not their remit or they have no funding or etc., etc. . . .

I can't remember if we had a subject of "strategies" in *AU* but perhaps it might be useful. I found many strategies in *AU*, so thank you for everyone who continues to write in, despite the ongoing difficulties in this NT world!

A Contributor

Learning the hidden curriculum

the odyssey of one autistic adult

by **Judy Endow**, MSW

Autism Asperger Publishing Company
ISBN 978 1 93457 593 2
£19.50

review by **Cos Michael**, NAS Autism-in-Maturity Project Manager, who is on the autism spectrum

The "hidden curriculum" refers to a set of rules and guidelines that are often not directly taught, but are assumed to be known. There are thousands of items on the hidden curriculum, which is updated every year.

This book is a courageous account of the author's journey to understanding the curriculum, through trial, error, with the guidance of her mentor. It is written with self-deprecation and a great sense of humour. As a "black and white" thinker, Endow has learned, one situation at a time, what reaction is socially acceptable and what is not. Now she finds she is better able to think through new situations and adapt learned strategies, enabling her to work out how to react.

Each chapter covers a different aspect of life, for a person on the spectrum, with examples of "social sins" or gaffes. People on the spectrum will recognise many and be surprised that some are considered gaffes. Most people, with or without autism, will laugh out loud, as many examples are undeniably very funny.

These lists are instructive, not just as learning tools for people with autism, but to give insight about the way the autistic mind works, for people not on the spectrum.

The book is a good read: entertaining, informative and useful to those attempting to understand the social and communicative dilemmas faced by many people with autism.

This book and the ones on pages 5, 6, 15 and 20 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.*

a sports piece

Beware of the werewolves

by **Cara Dovecott**

I live in Brixton: the very paving stones here seem to conspire to overload the senses. Until one Saturday back in April, Brixton was just my slum. But that was when I saw the werewolves.

It was Jacqui who told me they were there. She runs a group for young autistic adults in Lambeth. The group had sounded like a good idea until Jacqui said that one of the men in the group was a werewolf. Jacqui said I could see for myself at the Brixton ice rink, a temporary rink while the Streatham rink was being done up. Curiosity got the better of me so I went.

“Look closely,” Jacqui said as we walked to the edge of the rink, “these are no ordinary werewolves.”

“I can see that, they have gathered on ice.”

“Oh that,” said Jacqui casually. “Legend has it that werewolves in northern climates have mystical powers. When ice sparkles under the light of a full Moon the werewolf can smell the ice, then they use their claws to skate across it.”

“Northern climates? It’s Brixton at the end of April; people are having barbeques.”

“The pack father, Mike, was bitten while living in Toronto. He founded this pack when he moved back to London in 2002. What’s different about these werewolves is how they think.”

“What do you mean?” I asked, trying to keep my voice steady: plain old werewolves in my neighbourhood was scary, ice wolves was something else, but the idea of ice wolves was causing my stomach to clench.

“There are various things which make each of these werewolves unique, but most of this pack have what genetic researchers believe is a demonic canine form of autism…”

“A what?” I interrupt, somewhat breathless.

“An autistic person transforms at full Moon into an autistic werewolf,” Jacqui replied calmly, as if she was talking about her pet hamster. “Why do you think I brought you here?”

I stared at the pack wondering what I was seeing. “Wow, autistic werewolves, this is so cool . . . so what kind of things do they do?”

“Watch.”

There were around thirty werewolves, some just cubs but most much older maybe as old as 25 in human years. They were wearing a kind of armour, bulky as yetis they glided across the ice easily, the light glinted off their helmets, which were decorated with paintings of pointed teeth.

They skated in a circle, then following an order from their leader, they stopped to lie on the ice and do sit-ups. It looked like hard work. Then they were on their feet again, circling.

Next, pucks were released onto the rink and the werewolves chased them over the ice with their sticks. They skated forwards and backwards chasing the puck with great skill.

Mike, the pack father, came over. He explained that skating was a matter of keeping moving: to be still was to fall. So the werewolves had to be constantly interacting with the ice. They gained skill through action and by being part of the pack’s activity. He believed this was freeing for autistics. I watched the werewolves, enthralled; their play looked like great fun. Was I being bitten by the ice-hockey bug?

That night I headed home and checked my copy of *The curious incident*, sure I had missed some key point about full Moons. The facts are these:

There is no upper age limit to transform into a London Werewolf, and you don't have to have skated before to try out for the team.

The London Werewolves meet for the 2013-14 season (September to May), back at the refurbished Streatham ice rink.

The Werewolves practise on Saturdays at 16.30. To find out on which September Saturdays you can try out for them, contact Mike

mike@werewolvesoflondon.org.uk

or on **07904 477 175**.

To try out, wear clothes that will keep you warm and give you some padding. Wear socks that come up over your ankles: you don't want your socks slipping down your foot when you're wearing ice skates. You can hire skates at the rink if you don't have your own (bring money to hire skates). Wear loose trousers, like jogging trousers (if you're a woman, don't wear a skirt). Wear a warm waterproof coat, gloves and a cycle helmet if you have one.

If you live near Slough, there is a special hockey team in Slough, with whom the London Werewolves regularly do battle. See

SPICE (Special People on Ice)
c/o Absolutely Ice
Slough Ice Arena
Montem Lane
Slough
SL1 2QG

07831 669 227

www.spiceskating.org

or if you live near a rink you can contact Mike for tips on starting your own team. For details of the Lambeth young adults group contact Jacqui Thomson (who does not wish to be contacted any other way) at

lambeth@nas.org.uk

I was officially diagnosed with Asperger's quite late in life at the age of 29. Three years on I am still struggling with the condition but I no longer wonder what is wrong with me.

Since university I have struggled to retain work to the point where I became unemployed and turned to the mental-health system for answers which led me to the above diagnosis.

I am still unemployed but after many years of illness, this year I hope to find my place in the world and gain employment and more.

Art is one of the ways I pass my time but I find it increasingly difficult to find inspiration and motivation as I grow older and more disillusioned as I as yet have been unable to find my place in the world and some inner peace. I try to remain positive, keep busy and help others when possible.

I would like to submit an acrylic painting for the cover of an issue. This [on the cover] is one of last year's works for an art show where they were on view for three days and one was subsequently sold to a member of the public.

If you want to know more about me and my art or my other struggles as a person with Asperger's without a trust fund or parents with money, including how I ballooned to twenty-five stone and then lost it all again while dealing with the difficulties autism throws up for people in this situation, then there are other stories I have to offer, lol.

I also do stone carving and digital art as well but for your format these are most appropriate.

If you do use them I find it very difficult to obtain paid work so if there is any feedback of any kind, that would be great, as I take commissions as well as praise, lol.

Keep up the good work ;>

Sincerely

Chris

a letter

Hi Goth,

Many people have mentioned the discrepancies between help offered to children on the spectrum and how little is offered to adults. My opinion on this is that children are seen as malleable, they can be forced onto the three paths that health professionals are happy with: one, conditioned condition, where the patient is convinced to conform to normality. Second that he/she has a condition path where a certain amount of deviation from normal is accepted as long as normality is the goal, and, thirdly, the containment path, where the condition is seen as bad enough to warrant a separation from society. Many parents of children on the spectrum go along with these as though they are the only options, in their mistaken attempts to normalize their offspring. I feel part of the problem is the attempts of health- and social-care professionals to use their empathy on situations they cannot connect with.

Those of us who reach adulthood without a proper diagnosis cannot be forced into these paths — in many cases trying to normalize then results in being diagnosed with mental-health problems that are concentrated upon by the professionals simply because they are within their comfort zone.

Help should be sought if mental-health problems are suspected, *but* I was diagnosed with depression when what was wrong with me was misguided attempts to conform to the norm.

The analogy I use to describe high-functioning autism is of driving a car on a motorway without the ability to see indicators or brake lights. Thought of this way, the best help that can be given is coping strategies and reassurances (not platitudes) that often the panic and distress can be alleviated. Instead of being treated as an "illness", Asperger's should be seen as an alternative consciousness which can have its drawbacks but, when embraced, can be extremely empowering.

Their are many levels of autism but I am sure that in all cases input from "sufferers" would be of much more use than the present system. I feel that a "buddy" system (monitored of course) would be most effective, in both children and adults. Again, personally, I would have benefited from help with tactile/sensory difficulties, and from interactions with counsellors which were adapted to suit me rather than trying to normalize my behaviour. I am sure I am not the only person on the spectrum that would have liked help with intimacy and boundaries.

The biggest step I took was realizing many of my problems were in fact advantages. Then I had to reset my comparison index, ie., be careful who you compare yourself with. Such a pity these realizations came later in my life. This is another reason why adults receive less support, because the thinking seems to be: if you have lasted this long you must be getting something right. This does not allow for those of us simply struggling on and needing specific support.

I would like to feel that we could support each other and am sure that modern technology would make this easier but I have my doubts about social websites, as we can be at a disadvantage in those environments.

Rob

aspyscot@live.com

Rob asked for his e-mail address printed so that, if you have computer access, you can contact him about this letter if you want to. Please consider writing to or emailing AU *as well, Editor.*

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

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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.

Review against a dark background

by **Tom**

The novel *Against a dark background*
by **Iain M Banks**, published by Orbit, ISBN: 978 1 85723 179 3, £9.99,
is available from all good booksellers, both online and on-street

Last April, the author Iain Banks announced that he was dying of cancer. By the time this goes out, he may already have passed away. This news hit me pretty hard at the time, having been through the same thing with my dad (diagnosed with a terminal illness and trying to make the most of the time left) so Banks' announcement stirred up some memories. Furthermore, around the time my father died, I was reading an Iain M Banks novel (he uses that "M" in the middle for his science-fiction works) called *Against a dark background*. To honour Iain M Banks, I will review that book.

Most of Iain M Banks' novels, the Culture novels, take place in a vast universe that contains several highly developed civilisations. This one doesn't, however: it takes place in a star system that's so far from anywhere — even at the fantastic speeds that science-fiction can conjure up — that the inhabitants have no hope of ever reaching the rest of the galaxy. The story's heroine, Sharrow, a commando-type ex-soldier, goes on a mission to uncover an ancient artifact that takes her to most of the star system's planets and through a good deal of its — and her own — history. The attraction of the novel lies in both the terrific adventure story and the humorous and (very) detailed descriptions of the universe the story is set in — both features of many of his books. At one point, the heroes travel with a sect whose members hate their god and insult him at every opportunity; another time Sharrow finds herself in a city that happens to be having its annual no-clothes week. Despite the humour, the story isn't very uplifting in the end, although it didn't affect me much in the way other emotionally intense stories certainly can.

Asperger United, c/o The National Autistic Society, 393 City Road, London EC1V 1NG.
Telephone: **020 7903 3595**
Fax: 020 7833 9666
Email: **asp.utd@nas.org.uk**
Website: **www.autism.org.uk/aspergerunited**

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