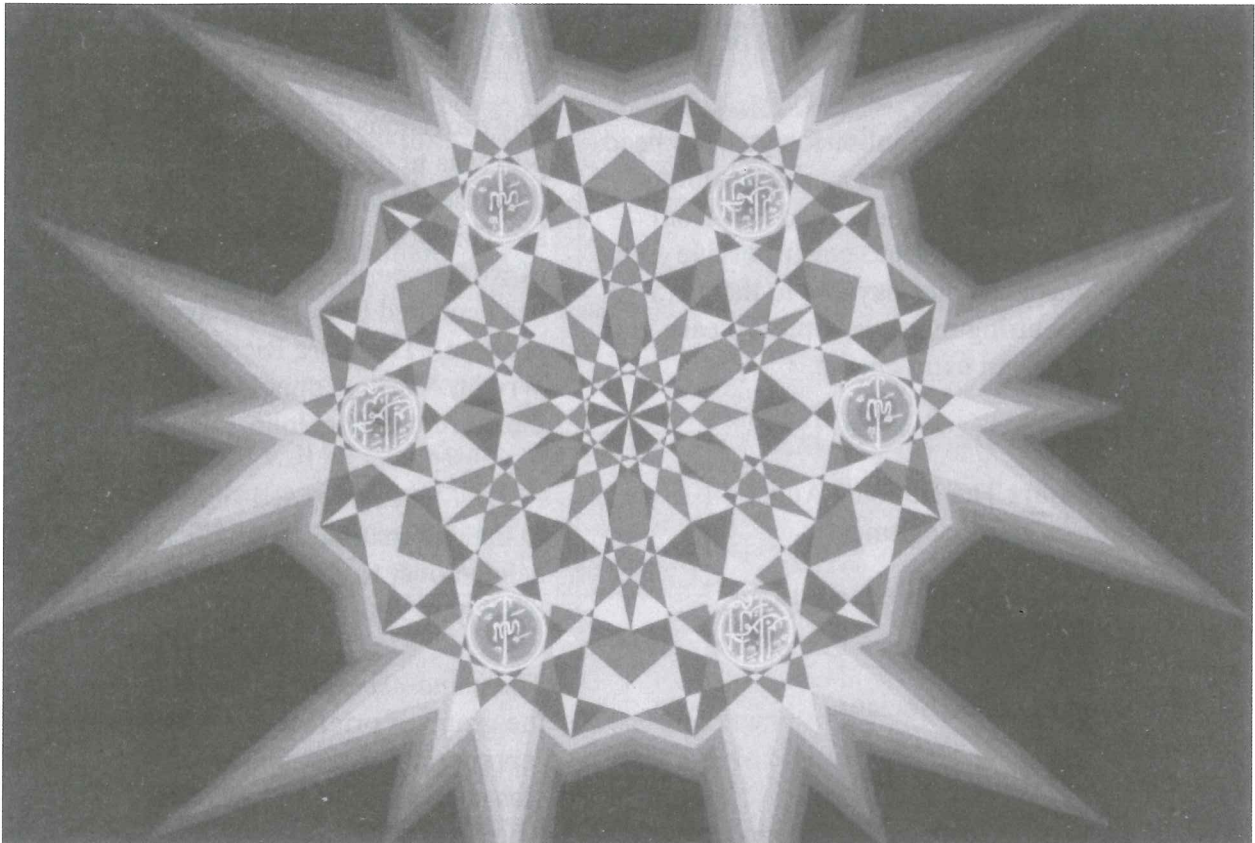


Produced by and for people with autism-spectrum conditions

Asperger *united*

Edition 57 January 2009



© Steven Frisby 2007





Asperger United is a newsletter run by and for people with autism-spectrum conditions. The newsletter aims to put people with the condition in touch with each other and to share information so that they can lead more independent lives.

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

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

Editor John Joyce

Additional support The National Autistic Society's Publications Department

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 George Cox who kindly produced the illustration included here and on page 6, and 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 newsletter.

Contributions for the next issue should reach us by
23 February '09

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 and the current editor, John Joyce.

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

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



Dear readers

Welcome to the first edition for 2009. Hope you have all enjoyed Christmas. Especial welcome to new readers from outside the UK. This edition contains a letter from the Ukraine. I have had a considerable correspondence with people from diverse places there. Maybe one day I will get to see them and their Russian cousins. However, may I now look at something that came to light in the letter to *AU*. Our correspondent alleges that a psychiatrist who did not understand his condition called him "evil". Inability to socialise is not a mark of evil.

Having received this Ukrainian correspondence leads me to request more input from our readers overseas.

Another matter raised in your letters is keeping in touch with past friends. I have been a life member of my school's former-pupils' association since about 1969. This kept me in touch with these members. One of my former work colleagues has contacted me via Friends Reunited. It is not always easy to keep in touch with past acquaintances whose circumstances may have changed since you last met them, as may yours. The final solution is to carry on with life, mixing with those who happen to be around you at the time.

Please continue to display your talent for providing first class material.

Best wishes from your editor

John Joyce

The theme for April will be either **work** or **mental health** depending on which receives more contributions. Writing on any subject is still welcome, so get writing! (Cover art is also welcome.)

the creativity edition

Picture by Steven Frisby	cover
Editorial and contents.	3
<i>My musical life</i>	4-5
feature by Michelle	
Call for volunteers from Tom Lavender.	5
Institute of Psychiatry, London	
Letters to the Editor	6
Pen pals	7-8
<i>I don't act my age</i>	8
poem by Dan	
Letters in reponse to Louisa in the last issue .	9
Book review by the Goth	10
<i>Mindbody techniques for AS</i>	
by Ron Rubio	

Letter about other people from Siobhan . . .	10
<i>On creativity</i>	11
article by Eleni	
Letter about creativity from Louisa	12-13
Letter about the services we need	13
from Christopher	
<i>The lift that never worked</i>	14
poem by Kate	
Book review by the Goth	15
<i>Watching the English</i>	
by Kate Fox	
Letter about life in the Ukraine	15
from Igor	
Notices about NAS Christmas cards and . . .	16
<i>AU</i> book offer	

My musical life

by Michelle

I have always loved music ever since I was a child. At school I struggled with my behavioural problems due to undiagnosed Asperger's but music was one of my obsessions. I tried to learn recorder and sang in the school choirs.

At home I would listen to records and sing along in my bedroom. My brother was playing instruments from a young age so I grew up around music — mainly his guitar playing — which he became very accomplished at and he still plays bass guitar in a band today. But I wasn't interested in the type of music he played — I preferred light classical, middle-of-the-road stuff and songs from the shows. My musical idol for a long time was Andrew Lloyd Webber.

When I left school I was enrolled in a college for students with learning disabilities. I was given the opportunity to have private music lessons there once they recognized I had such a huge interest. I had tried to teach myself to read music, but had never had formal lessons. At the time my chosen instrument was the recorder. I had recorder lessons for a couple of years, learned both descant and treble recorders, and took the Associated Board grade 1 exam in the treble recorder.

After leaving the college after having been there for four years, I eventually moved away from my mother to live in my current home in sheltered accommodation for adults with learning disabilities. I count myself lucky as a person with Asperger's who was accepted into a flat in such a place. I have no daytime occupation apart from going to college once a week. So my main interest is really music. It

started up for me again when I joined a music club for disabled people. This music club (which is sadly now defunct) had its own orchestra, so first I joined as a recorder player, then I decided I wanted to learn the clarinet. I made the decision to buy myself a second-hand one. A short while after buying it I started having lessons. I still have the same teacher now, after about ten years of playing.

The music club folded but I kept on with lessons and taking more exams. I have now got up to grade 5 on the clarinet and I also had theory lessons, which I struggled with initially, but I have now got my grade 5 theory as well. I enjoy playing by myself and with friends of mine: a friend who I met at the music club plays the flute, and she lives nearby so we can have days where we meet up either at hers or mine to play. My neighbours don't seem to mind the noise, in fact some of them say they like it when I practise sometimes in the evening — although I don't leave it to really late at night! This past year I went to a woodwind ensemble residential course, travelling on my own, which was fantastic — and the course was marvellous. Being with people who share the same interests as yourself is liberating because you don't feel so "different". I also got to play a lot as well! I went to a single-reed festival and that was good. One of the nice things about this was the chance to try things, like mouthpieces for clarinets, before you buy.

I also enjoy performing in front of people whenever I get the chance. I have actually been invited to play at a conference for adults with learning disabilities in Manchester — a long way from my home! It is forming part of

a music and arts festival. I am looking forward to this tremendously.

I play various types of music these days. When I was in orchestras I mostly played classical pieces, but I also play popular songs and music, as well as studying for exam-type music and technical studies which I am determined will improve my playing. My

teacher has been very encouraging throughout. She knows how to encourage without putting students under pressure, so I have been able to learn at my own pace.

To merely say that I enjoy playing is an understatement really. All I have to say is once music is in you it takes over your life. I can't imagine my world without it.

A twin study of brain anatomy in autism

Are you a twin with an autism-spectrum condition? Are you the parent of a twin with an autism-spectrum condition? The National Autistic Society is pleased to collaborate with the Institute of Psychiatry on a new study looking at twins with Autism and Asperger syndrome. Richard Mills, Director of Research of the NAS, and Professor Declan Murphy of the Institute of Psychiatry are looking for twin volunteers with autism or Asperger syndrome for this study. We are carrying out a study that aims to identify the brain systems — both brain regions and the connections between them — that may underlie the features found in autism-spectrum conditions, and to what extent genetic or environmental factors may play a part in causing them. This study should provide us with a wealth of data which should help us begin to answer such questions as: what differences in brain regions and interconnections are seen in individuals with an ASC compared with those not on the spectrum? Are the differences seen related to an individual's characteristics and abilities? Are differences in brain regions a result of genetic or environmental factors? We are hopeful that this new study will contribute to

our understanding of the nature of autism and to the development of approaches that will improve the outlook and quality of life for this group. We're seeking identical or non-identical twin pairs, aged 6 to 45, where at least one twin has been diagnosed with an ASC.

The study involves having an MRI brain scan, as well as completing some puzzles and tests at the research centre at the Institute of Psychiatry in London, and some questionnaires at home. Travel expenses will be refunded and participants will be reimbursed for time spent on the project. If you would like any more information about the study or are interested in taking part, please contact:

Dr Tom Lavender
Institute of Psychiatry
Part of Kings College
London

Tel: **020 7848 0939** or x 0984

Email: **Tom.Lavender@iop.kcl.ac.uk**



letters to the editor

Dear AU,

my name is Tee. It was good to see the response to my article about my mentor/life coach. I would like to point out that I am a female.

I am writing to respond to the letters from Louisa and Daniel. The relationship with my mentor/life coach developed over fourteen years to become what it is now. He works full-time in the field of psychotherapy and autism. He provides my service as a voluntary extra role.

As far as I am aware, there are no similar services available elsewhere, either privately, or through local authority provision. I feel that this needs to be addressed, so that people like Daniel and Louisa, in the October edition, can also get their needs met.

Yours sincerely,

Tee

My son, who is 35 years old and diagnosed with Asperger's syndrome, complains that he suffers from lapses of attention (he calls these episodes "absences") when he is out of the house, and as a result is very fearful of exposure to the world. He feels that he is the only person who suffers like this, and so I am writing to ask whether any other persons with an autism-spectrum disorder have experienced this problem, and if so I would very much like to hear from them. More than anything, my son wants to understand why the absences happen, and what (if anything) he can do to overcome them. I would also mention that epilepsy has been ruled out as a cause.

John

NB. There are two different Johns on this page.

Dear Sir or Madam

During or after intense social situations I used to regularly have "system crashes" (or "lock-ups" or "tantrums"), in which I would lock-up emotionally for several days. These caused great pain to me and my partner.

Following the Baron-Cohen thesis that Asperger is hyper-systemising, I stopped systemising, and also stopped collecting data for my systemising to use. The result has been no system crashes in the subsequent eighteen months.

I also now experience less pain and more relaxation in social situations — I am happier just to "hang" with people — and I have experienced a few very pleasant moments of genuine human connection. Life is much better than before. I still can't claim to look forward to most social situations, and I still feel many people don't yet find me easy or enjoyable to talk to, but I feel I can move further forward from here in developing neuro-typical functioning.

Some other people (see <http://unlearningasperger.blogspot.com/2007/06/updates.html>) are finding that although stopping systemising when socialising may not be easy, an alternative may be to focus one's systemising on something else (like college work, or having an "empty mind", or maybe repeat counting to one thousand, or remembering past events, or . . .); that if our systemising is busy on something else, then we may surprisingly find ourselves using neuro-typical functioning in socialising.

I would be interested to talk with anyone trying these or similar approaches for themselves. Maybe if we all explore new approaches and ideas then we will find ways to make life, and particularly our socialising difficulties and isolation, much better.

Very best wishes

John



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.)
- To contact a pen pal, please send your letter to *Asperger United*, c/o The National Autistic Society, 393 City Road, London EC1V 1NG.
- 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.
- Those under the age of sixteen must have parental permission before placing a pen-pal advertisement in *Asperger United*.
- If you prefer, you could try the NAS pen-pal website, which is at www.assists.org.uk/penpal.html Please note that ASSIST (which runs the website) is entirely separate from *Asperger United*.

****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 43

Hello, my name is Colin. I am 40 years old. I live in Cambridgeshire. I was diagnosed with autism several years ago, not sure exactly when, it was a long time ago.

I live on my own and that is something I find difficult. I find it difficult talking to people. Writing things down is a lot easier. I like writing short stories, mostly science fiction and horror. However, I am looking at other genres. Going out to the cinema and watching DVDs at home on my own and with other people is something else I like to do.

I would like to meet new people and make new friends roughly the same age as myself. I look forward to hearing from you, thank you.

Pen pal number 44

Hello. My name is Paul. I currently live with my parents in a little village with my two dogs, Amber and Charlie.

My interests include Doctor Who, in particular the old series, as I like Tom Baker in particular. I also like 80s music such as the early New Romantic era such as Visage and Culture Club, etc. I'm also very fond of films such as the Horror and Sci-Fi genre. I like directors such as John Carpenter, Dario Argento, David Cronenberg and George Lucas.

I would prefer a pen pal around late teens to my age and who shares similar interests so we have lots to write about.

Pen pal number 45

Hi, my name is Seb. I'm 24. I was diagnosed with Asperger's/high-functioning autism when I was 20. I live in Swindon. I am looking for friendship by pen and keyboard, and possibly meeting up in the future. My interests include discussing things in depth to find where and in what form the truth can be found. Also I am into many metal, rock and hip-hop groups including Slipknot, Fort Minor, Muse, Thirty-Six Crazy Fists and Offspring. I'm a total bookworm when it comes to science fiction and futurology. I also like films including comic book films like the new Batman saga, Lord of the Rings, the Matrix, and others. I live in my own flat and do not own a car. I don't like public transport because there's so much to remember and even though you're surrounded by people you're all alone. I do it anyway, though. I'd like to hear from anybody out there who's ever felt alone. I've been there and I know what it's like.

Keep smiling

Seb

I Don't Act My Age

by **Dan**

Could you compare me to a stage?

Perhaps not;

I don't act my age

Pen pal number 46

Euan, age 42, interested in history, watching ballet, theatre, all kinds of music and eating out. Not pub type though.

Pen pal number 47

Julia, age 47, late diagnosis (39), would like to hear from other people on the spectrum who are 40+ and in East Anglia who had late diagnosis — swap experiences of this, also any other relevant info for ASCs of our age.

Pen pal number 48

My name is Simon, and seeing as I enjoy writing letters more than sending e-mails I thought it's about time that I got some pen friends.

I've had Asperger's syndrome all my life, so have grown up with it all my life — but I have only now at the age of 34 been diagnosed and not only with that but also a severe mental health issue called cyclothymia which is a mild version of bipolar disease, so life has become difficult and being unable to work have not been paying my mortgage and could lose my "place of refuge".

As a Christian whose faith means a great deal to me, I find God's grace sufficient for me at this time and spend a lot of time in the things of God and in prayer which helps me to remain steadfast, confident and *alive* in these troubled times.

If you would like to be my friend please get writing. Hope to hear from someone soon.

Dear AU,

I've just read Louisa's letter in the October edition of *Asperger United*, and I empathise with her as I have experienced similar problems with keeping in contact with friends, particularly ex-colleagues from work.

I'm 24 and I'm still best friends with four girls whom I first met at high school. Our friendship has now lasted for well over a decade and is still going strong. However, the same can't be said about my ex-colleagues. When I started my first job following graduation at the age of 21, I became friendly with several of the people in my team and I even used to go out with them occasionally. However, two years ago the team was disbanded and I moved to a new department. Most of my ex-colleagues also moved to different departments while others took redundancy.

For the first few months, I still kept in contact with them on instant messenger. However, it was mostly one-sided — it was mainly me contacting them. Then after some of them had left the company, I sent them each an email or text message wishing them well and asking if they're enjoying their new job. However, in almost all cases, I received no reply at all. When someone doesn't respond to my email/text, I don't send any more, as I don't want to appear pushy.

This means I now have no contact with any of my ex-coworkers. Does this mean they never truly liked me? I wonder why it is so much harder for adults to form friendships than schoolchildren. The only people who have stuck by me are my friends from high school.

Nowadays, I don't bother treating work colleagues as friends; I just treat them as acquaintances. At least then I won't be so disappointed if they move on.

From Victoria

In response to Louisa's letter in the October issue, I agree: if you don't do enough to keep your friends, you will lose them.

I said that "if you need to find some friends, join a group". Well, Louisa says she did this and she got some friends from it. They are no longer in her life, so my suggestion still stands: join another group and make some new friends.

I don't know Louisa, and nothing I write here is meant to be an attack — I'm just trying to answer the points she raises in her letter, and I am trying to be as helpful as I can. I hope that she is able to take these comments in this way. I am very sorry if they upset her — that is very much not my intention.

With regard to keeping friends, Louisa doesn't mention what she did to keep in touch, but I notice that she mentions receiving "an occasional Christmas card". Did she send any? Keeping friends is yet another skill that has to be learned: one has to be interesting, amiable and most importantly, interested in the friend in order to make them feel that the friendship is worth making an effort to maintain. I have lost many friends that I would dearly love to get back, and I find it upsetting to think back over the mistakes I made in trying to keep friends. Also, I think it is in the nature of group interests that most such friends will not be particularly interested in maintaining friendships if they leave the group.

I hope these comments are helpful, and I wish Louisa well in her search for new friends,

yours sincerely,

J

Mindbody techniques for Asperger's syndrome:

The way of the pathfinder

by Ron Rubio

Jessica Kingsley publishers £13.99 / \$19.95

ISBN: 978 1 84310 875 7

review by **the Goth**

I was prepared to be deeply disappointed by this book, as it is both a "self-help" book and attempts to teach you something physical. As a teenager I attempted to learn various physical, interactive skills from books alone: yoga, Russian, meditation and such like, but books alone were unsuitable for this type of learning and the books available were poorly constructed for their purposes. This book is by a man who works with people with ASCs to build their confidence and self-esteem through basic aikido. His concern is with strength of mind and not looking like a victim, rather than self-defence, as this breaks the vicious circle of being victimised because you look vulnerable — the less vulnerable you look, the less likely you are to be victimised. To this end there are chapters on breathing, sitting, standing and walking, amongst others. I would still say that in order to implement the techniques correctly it is necessary to have someone who understands the techniques to observe you — looking at yourself in a mirror is not good enough, especially for an autistic, as you should be concentrating on the exercise, not on studying your image in the mirror — but this book is well-constructed, including pictures and explanations of all the wrong ways to do the exercises, so two people could learn to correct each other whilst learning the techniques. By the end I found myself pleasantly surprised by the amount of care that has gone into the structure of this book, so if you have enough discipline to apply it, I would recommend this book.

Dear AU,

I am a 27-year-old woman with Asperger's. I felt very sad reading the article *Not Quite Dispensable*, in the October newsletter. I too, like Eleanor, feel uncomfortable around certain family friends because of their lack of understanding of my disability. In my case, people have made throwaway remarks, in one case while my mum was in hospital after having broken her foot.

A family friend used to come round to our house and complain about our drains needing sorting, and that there was never any food in our house (which was a lie). I couldn't ignore it like my siblings could, despite their telling me that it was not my responsibility. I took it personally and was so distressed I nearly made myself ill. The worst of it was, I was always busy doing the washing and the housework. It really shattered my confidence.

I now experience a pain in my stomach when I come into contact with certain people, which is down to my nerves and anxiety. My mum says to me that people don't mean any harm, it's just they don't think before they speak; that some people are scared of disabled people and don't know how to deal with them. So they over-do it, by making a fuss of the person they're dealing with.

What I also have had to put up with is insensitive comments from some family members, when describing the difficulties I experience because of my disability and the support I need in my daily life. I always thought it was just me who felt like this: it's good to know I am not alone.

Siobhan

On creativity

by Eleni

Aged 50, I finally got a correct diagnosis — yes folks, it was Asperger syndrome all along. Over the years, creativity has played a huge role in my life. It has stopped me losing my sense of self and has in this way been an emotional lifesaver.

As a small child I made many mud pies for my mum. She was very obliging about these efforts, even putting them in the oven so they could be cooked. Dad would have had a fit if he had found out!

During childhood I was always drawing and reading. The reading was always factual stuff but the drawing was about showing the world as I saw it. Also, exploring ideas about pattern and subjects from the Greek myths and Aesop's fables.

At school, although I found it hard to make friends and couldn't socialise, I could get praise for my neat handwriting and careful drawings. I was especially good at copying pictures and was encouraged in this.

Aged 13, I discovered the delights of music as an expression of

communication. The class was introduced to the instruments of an orchestra and asked if we wanted to learn to play any of these.

I saw a clarinet for the first time and heard its gorgeous "voice". It could go really deep and really high. I was hooked instantly.

I was good at playing by ear and good technically and gained all eight grades of the Associated Board exams in clarinet. Admittedly, it took years for me to learn to read sheet music and my playing lacked emotion, I was told. This was devastating to me as I "felt" the music instinctively.

I had an ear for rhyming verse too and enjoyed this. These might be limericks, verses for family birthday cards or more personal poems. Sadly, again, the feelings I was trying to express were not apparent to my readers! All of these verses swung along jauntily and rhymed, even sad subjects. Ho hum...

Like many people with AS, I'm very visual and find drawing, painting and collages very satisfying.

Pattern and colour really engage me, and anything to do with nature, especially in close-up, can be seen in my portfolio. Also, unlike previous verbal and musical efforts, I can get my feelings and a sense of mood into painting. So painting is my passion — eureka!

The joys of gardening are also an outlet for my creativity. Having designed and constructed a number of gardens and studied the subject, I'm a very able gardener.

It's great exercise, fantastic for working off a temper, lets the mind wander and enhances the environment. It's also a very cheap source of presents for friends and family if you sow from seed and learn to propagate plants.

I'd urge everyone to get creative. Find the thing you are interested in and do things you love doing and put them together. Voila! You will enhance your life and health if you follow this route.

So be it painting, gardening, music, cooking — go there, Aspies!

Dear Editor

Becky's advice to people with Asperger's to avoid becoming opera singers is a bit late for some. A few years ago I was attending a support group where the (neurotypical) facilitator told us that she'd heard from a woman with AS wanting to join the group — and this woman was an opera singer by profession, so the facilitator said. I remember being rather dismayed when the latter went on to say "How nice, maybe we could have a jolly sing-song with her." Quite apart from opera singing being a very different art form from a casual sing-along, it's bad manners to expect professional musicians (or professional sports-people, or indeed professional anyone) to offer their services for free. So much for NTs knowing all of society's rules!

Likewise Becky's advice to Aspies not to "strain their concentration by practising . . . music" has come too late for me, as I managed to pass Grade VIII with merit on recorder when I was 21, before I was diagnosed with Asperger's in fact. Too bad that opportunities for amateur recorder playing are so limited. It's not that there isn't a decent repertoire for recorders — there's plenty of works by Bach and other Baroque greats that feature recorders, plus works by contemporary composers like John Tavener and Arvo Pärt, and even John Paul Jones of Led Zeppelin played recorders on the studio recording of "Stairway to Heaven" — but finding other musicians to play with is another matter. I'm a member of the Devon branch of the Society of Recorder Players, meaning that I go along to their monthly meetings when I'm free and sight-read one part of a piece of music. Three years ago Devon SRP set up a separate "Exeter Recorder Orchestra". It is supposed to be distinct from the main SRP in that its stated aim is to practise (not just sight-read) a selection of pieces with a view to performing them. But in the event we have given only four concerts during all this time, pretty poorly attended at that. And we only meet once a

month, so on the face of it, it doesn't seem that different from Devon SRP. Most of the other members of Devon SRP and/or ERO play in smaller groups, some with other instrumentalists. At the very least this means meeting up in other people's houses, but some of these smaller groups have also given performances. I once spoke to someone who'd played in a group in medieval costume who provided background music at Buckland Abbey (a National Trust property on the other side of Dartmoor). Unfortunately groups such as this don't have auditions as such. It's more about playing with friends, or friends of friends. Indeed this person's advice to me was to make myself known, invite people back to my flat to play ensembles and maybe this just might lead to greater things. I objected, saying that my flat was far too small and untidy, and besides I only have a very limited collection of consort music. Another issue is that I hardly know the names of anyone in the SRP and/or recorder orchestra; I've probably been told any number of names but it's difficult to retain the information if I don't see the other person for another month at least. And this is after four years in Exeter.

Lists of famous people known or speculated to have AS tend to be about scientists, but I have seen some that cite the composers Mozart, Beethoven, Bartok and Satie — albeit I have yet to see the evidence to back up these speculations. I once started a thread on the *Aspies for Freedom* forum on the subject of Asperger's and classical musicians, in which I asked if any forum members had studied at a conservatoire, and whether the proportion of their fellow students on the autistic spectrum was higher or lower than the general population. No one replied to that specific question, so I still don't know.

Returning to Becky's letter — I'm puzzled by her assertion that "the most common career for someone with Asperger's is to be a writer". According to the NAS there are around half a million people with Asperger's in the UK. I

can only think of at most ten published authors on the spectrum. What happened to the remaining 499 990? Like Becky, I haven't read Luke Jackson's books (non-fiction, since you ask) either, not least because I'd long since ceased to be an adolescent by the time I was diagnosed, so a *User guide to adolescence* is of little relevance to me, still less one written by a 13-year-old boy (what would he have to say about menstruation, for one thing?).

Becky seems very confident that everyone with Asperger's can become a novelist. I used to have ambitions of becoming an author when I was a child, but even now (aged 32) I don't

feel I've had enough life experience to write novels, certainly not adult novels which tend to focus on relationships, and I don't feel enough rapport with children to write stories for them. That on top of the perennial obstacle of setting aside time to work on a novel while holding down a full-time job. I know of someone who had her first novel published at the age of 47, while working as a merchant banker, part-time restaurateur, member of various boards of directors and mother of three, but I don't think she has Asperger's.

Yours, etc.

Louisa

For the attention of L Haag

Hello! I read your letter in *Asperger United*. I live in Cornwall.

What I think we need in Cornwall is a centre which autistic adults can go to for socializing, including workshops and guest speakers as appropriate. The article on the back page of this issue of *Asperger United* is the sort of thing we need. I went to Dreadnought until I was 17 and it was wonderful! I now still go to their Pool Centre once a week as a volunteer worker. However, Dreadnought's funding is constantly at risk and the age limit is 18. I also belong to a young adult group which we set up through the NAS West Cornwall branch. Everyone in this group would like to have Dreadnought extended to a higher age. The ones who were lucky enough to go to it found it so enjoyable, useful and helpful.

Two years ago, I was referred to mental health services as I was having problems. I was seen by a mental health nurse who had no experience of AS but who dismissed my needs

and suggested I went to SHARE! My parents took me to a wonderful psychiatrist (privately) and eventually I was seen again by an NHS psychiatrist. The professionals told my parents that there is no experience on AS in Cornwall! I hope things have changed since then! We asked if we could have a named social worker but they said this was not possible as they have such a high turnover of staff. We were told we could contact them again if we needed to. I really think there should be an official framework for AS sufferers so we have somewhere/someone to turn to when we need to. There should be proper counselling with counsellors who understand our condition.

Finally, the question of housing. The letter on page 9 of the last issue of *Asperger United* really sums it up. We need sheltered housing where AS people can live with others like themselves.

Thank you for the opportunity you have given me to express my views.

Christopher

The lift that never worked

by Kate

The day I arrived the lift wasn't working.
It seemed that everyone else used it successfully
But the buttons failed to work for me.
Alone I searched for the stairs.

The promise of belonging had lured me in
The entry code earned after a considerable struggle.
Totally uncertain of myself yet thrilled and excited I entered alone
Certain this was where I wanted and needed to be.

Each flight of steep stairs tantalised me with hope
Of the moment I would join others and relinquish the invisible bubble around me.
How I ached to leave behind the loneliness
And discover my place in the jigsaw of life.

I climbed and climbed
Pausing for breath and the time to analyse each difficult step.
The pain of isolation seemed to lessen with each floor I reached,
Others calling "Hello" as they passed me — and smiled!

At last it seemed I was making real progress
My longed for destination approaching,
The opportunity to rest amongst others —
To "Be" without thinking, analysing, worrying.

I arrived — or so I thought
At the floor where I had yearned to be, with the Everyone I wanted to join
Only to discover nothing had changed.
The door was locked and I remained outside, alone.

Watching the English:

the hidden rules of English behaviour

by **Kate Fox**

Hodder and Stoughton £8.99 / \$17.95

ISBN: 978 0 340 81886 2

review by **the Goth**

This is a book on social anthropology. Anthropology is a study of cultures, so social anthropology is the study of societies within a culture, and unlike most anthropology, Kate Fox is studying her own culture and the societies within it. There are chapters on why the English talk about the weather, on why they use humour, on how they use mobile phones, why conversations differ in the pub. It describes the rules of dress, the rules of food, the rules of the road and many other aspects of Englishness. On almost every page she mentions how behaviour differs with social class and goes some way to explaining why class differences are so important to the English. She does all this with a suitable quantity of self-deprecating and ironic English humour. Whether or not you understand the humour, this book is packed with factual details that have certainly helped me to understand and deal with the everyday difficulties of living out in the world. Even for those who are not English or not living in England, I think there will be plenty of useful information. As a woman, she seems particularly able at highlighting the differences between male and female communication styles, which has enabled me to improve my interactions, as I no longer mix up the rules about communicating with men and women, and can now engage in "male banter" without feeling put-upon. A very useful book.

Watching the English is available online and from all good bookshops.

Hallo, John Joyce!

Thank you very much for issues *Asperger United*. I would like to tell you about my life in Ukraine. My problems with socialising began when I went to the school. I learnt very good but I was not able to make friends. During breaks between lessons I read textbooks; I did not know how to begin conversation with my classmates. My classmates bullied me very much. Every day for me that was spent in the school was like a day that was spent in the hell. In my 14 years I felt that I had been not able to continue to go to school. I went to different kinds of hospitals. Doctors acknowledged that I had been not able to go to school and I began to be home schooled. After the stopping of going to school I began to feel myself better. I studied by myself English and German. Now I study old Greek. I feel a lack of communication and have no friends. With help of publication *Asperger United* I hope to find friends.

In latest issue I received, for me it was especially interesting to read letter of Neil. In his letter he describes how badly he was treated by psychiatrist. His experience is similar to mine. I was also mistreated very much by one psychiatrist. I tried to explain her how hard is to me to socialise but she was not able to understand me. She told me for more than an hour that I had problems with socialising because I did not "like" people and was evil. She couldn't comprehend reasons why I was not able to socialise properly. During my conversation with this psychiatrist I became so severe depressed that I've wanted to die. Also my physical health deteriorated very much. I began to feel myself very exhausted. After visiting this psychiatrist I hardly recovered from the depression and my health improved in a two weeks.

From the letter of Neil I've got that Ukrainian mental health services understand autistic people as good as British ones.

Igor

AU Christmas Card Competition 2009

Our 2008 Christmas card range featured for the first time a card by an artist who has Asperger syndrome.

We would like to extend our range of cards by people who have autism and so we are running a competition for readers of *Asperger United* to design a Christmas card for us. This will go on sale with other cards in our catalogue and on our website to help raise money for the National Autistic Society and also celebrate the talents of people on the autism spectrum.

The winner will get £75 and 50 cards of their design to send to family and friends.

- Designs should have a Christmas theme.
- Artwork should be in colour and at least 190 x 140mm (rectangle) or 148 x 148mm (square), with a strong contrast of dark and light colours.
- Try to avoid the use of shiny colours/objects such as gold, silver and coloured foils in collage work as these are difficult to reproduce.

- Do not fold artwork.

On the back of your design please write your name, age (if under 18), title of card, address and other contact details.

Please send your entries to:

Asperger United
Christmas Card Design Competition
The National Autistic Society
393 City Road
London
EC1V 1NG

Any enquires please call Cathy Mercer on

020 7903 3543 or email

cathy.mercer@nas.org.uk

Entries should be received no later than
Friday, 13 February 2009.

And many apologies for prolonging the festive season even longer than usual!

Ron Rubio's book, reviewed on page 10, is available from Central Books Ltd, the book distributor for the NAS, tel: **0845 458 9911**, on line at **www.autism.org.uk/pubs** and can be ordered from all good bookshops. Fiona Barrington's book, *Not your normal family*, which was reviewed last issue, is also now available from Central Books.

Special offer to readers: readers can get copies of these two books post-free until 28 February 2009. Just send your order with a cheque made payable to

The NAS
393 City Road
London
EC1V 1NG



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

