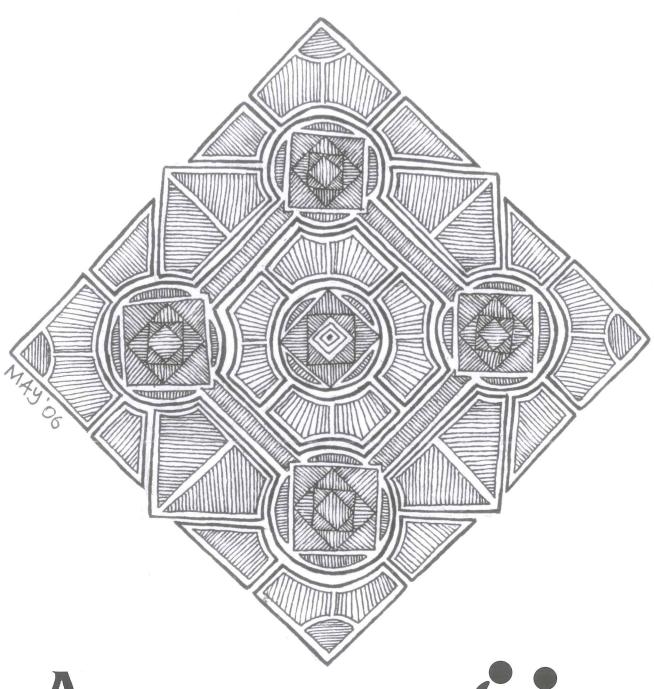
# Aspera and for people with autism-spectrum conditions United Aspera Aspera and for people with autism-spectrum conditions United and for people with autism-spectrum conditions unit Edition 56 October 2008





The National Autistic Society



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.

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 17 November '08

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 latest edition of your paper.

Hope all of you who have had holidays have enjoyed them.

I have just come back from Lourdes where I had a good week. While there I was a "marshal" guiding our group members to their various services and occasionally trying to prevent street accidents by warning fellow pilgrims of approaching vehicles.

Additionally I had the experience of telling

a Mexican visitor to the Legion of Mary Permanence about the organisation in his Spanish language and had a slight experience of German conversation.

What new experiences have you had? Please inform *AU* of it and continue to show your high standard of presentation.

Hope to hear from you all again.

Thank you

Your editor

John Joyce

If sufficient material is sent in, the theme for January will be **music**, or perhaps **creativity**. After that, it will be time to revisit **work** and **mental health**. Writing on any subject is still welcome, remember, so get writing! (Cover art is also welcome.)

#### the living edition

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#### Not Quite Dispensible

by Eleanor

I am a high-functioning autistic girl. On the minority meter that's a 10 in my view! You may call it autism, I call it . . . the disease, the cure, the friend, the enemy that keeps others coming or drives them away! It's everything and anything and nothing to me. I wish it would go away, but if it did, I wouldn't be me would I? I've had some experiences with autism I can tell you!

I was diagnosed with autism aged 3, around Christmas. Merry Xmas mum and dad! Mum noticed it beforehand. Apparently I would scream seemingly for no reason as a baby or toddler, if something dropped on the floor, if the routine seemed to change like mum taking a different route home, or if I couldn't do something right, like tie my shoelaces.

As a very young toddler I would apparently pick up long words such as "delicate", used by adults and use them but in a nonsensical context, to others I was clever, confident and talented for my age, to mum I was far too different to be normal. She decided to get me diagnosed. I was extremely lucky it was noticed so early on; how could I have lived life now, knowing I was different, not knowing why, therefore thinking I was mad?

I was extremely shy and quiet throughout primary school; terrified of being told off, thinking if I did the world would end, in my mind! In contrast I would be loud, confident and chatty at home with my parents, as though I'd been bottling it up all day! If my parents told me off, it wouldn't be so bad. There wouldn't be a classroom audience to watch and, I knew them more than the teachers; I wasn't afraid of being told off by people I knew! I'm not sure why! Despite my

tentativeness I could still throw tantrums in frustration.

I'd feel uncomfortable or awkward around certain people, and I still get these feelings, usually with family members, because I know I can't escape them. One family member upset me because, to bring me up, she would pretend to cry if I didn't do what I was told. As an autistic and as a toddler, I took it seriously and become very distressed with this particular person.

As I've grown up I've been forced to create what I ironically call a schizophrenic personality between my autism and my façade of normality. I feel like it's brave but necessary. Being a high-functioning autistic I'm still autistic but capable of just about surviving in the real world. I have evidence of my intelligence and dedication with my level 5s, 4s and 6s for year 6 and year 9 SATS, and As, Bs and Cs for GCSEs, A levels and coursework.

When I'm at home, in my room, I am in a world of my own obsessing about the most important people in my life, paying attention to me. I see myself as starring in elaborate and beautiful or farcical films. Listening to music appropriate to the themes in my head helps create the illusion. Sometimes these fantasies cause me to run around. I'm not sure why that is, probably lots of energy. I've heard of others doing things like this, such as spinning around, or being in worlds of their own but this is still hard for me to write this as it feels mad. I still feel it's important to mention because it's the part of me that is most recognisably autistic.

As I've grown up I've learnt to be more positive and it's just about worked but for the

last two years, since early 2007, I've found myself in mild depressions. They only last four to eight days but seem intense; as though there's no happiness left to keep me positive. I stay in bed, I won't leave my mother, I won't watch things that may make me feel uncomfortable or things I don't know, I won't eat, I won't stop crying and screaming and I start bashing or slapping my head as though trying to get the thoughts out of my head or give me some physical pain to distract from the mental pain. Mum takes me to see the osteopath, who finds physical problems and can successfully relax me. Mum's taken me to the doctor's to try and get me counselling. Finally we've found a counsellor specialising in autism working locally, so we're giving her a try, because these depressions have kept coming back for the last couple of years. I try

to fight them but sometimes life gets on top of me, more than most due to my autism, and everything seems to turn black. I think these depressions are to do with my autism because I don't think the things in my life would affect normal people in this way, they wouldn't be that sensitive.

I hope this has helped other people with their experiences with autism. Autism isn't necessarily a bad thing, for me it is, but it can be different for others. A friend once told me it can be a gift, just work out how to use it to your advantage, and if you notice something different about your child like my mum did, then, in my view, get a diagnosis. You shouldn't wait because it's hard for someone, and everyone around them, to grow up knowing they're different and not knowing why.

#### Not your normal family

by Fiona Barrington

published by Authors OnLine, www.authorsonline.co.uk

£8.99 / \$13.95 / 11.78 ISBN: 978 07552 0421 2

review by the Goth

This book is subtitled "a single Asperger woman's adoption of two Down's boys" but it is actually her full autobiography, right from birth through her school days to the present day at the age of 50. The adoption of her sons is, however, central to the story she tells.

The book is written with a terseness which is typical of people on spectrum, but her overall style is very readable and very fluid it was a pleasure to read. As you might expect, the book is full of details of her life she brings much more insight into these anecdotes and stories than the authors of many autobiographies, so repeatedly she has illuminated aspects of my own life.

I think this book will be of interest to people who want insight into living in the wider world, and although central, the adoption of two children and the difficulties that she was forced to tackle in raising them are not narrowly presented — many of the problems she has with her sons are applicable to my life and life in general.

It is a pity that such a good book was not taken up by a mainstream publisher.

### letters to the editor



Dear AU,

I have some news which I think both the *AU* and the people of Cornwall will be interested in.

For some time I have been in negotiation with the Cornwall Partnership NHS Trust over the lack of recognition and support for people with Asperger's and at last I have received a letter from the Community Services Manager and it has been decided to look at "setting up a bespoke service to people suffering with AS".

Timescale is approximately six months. What is required to assist this process are for people with Asperger's in Cornwall to let me know what they require in regard to any help, assistance and support they need so that the NHS provides what the people want rather than the NHS giving what they want to, which has been basically nothing so far.

So things have changed in Cornwall — please let me know what you require by writing to me care of AU at the usual address as soon as possible and I will make sure your requirements are passed on to the commissioning manager,

yours,

L Haag

I've newly subscribed to Asperger United so just seen the January and April editions. I was struck by some of the writings about socialising. I have found people appreciate having someone around who is safe and reliable, when out socialising. This is not just someone to guard the coats, drinks, seats, etc. while they go dancing or whatever, which would be taking unfair advantage, but actually just someone to stand or sit with.

I'm 57, have fairly mild AS and have been pretty lucky, but I cannot do friendships or relationships. I tend to get worry-bound home alone, so for years I forced myself to go out and try to socialise — but invariably ended up sitting on my own.

What started to happen about my midthirties was I became useful socially, because I didn't say much, didn't do much, but was "safe and reliable". It meant I got invited out a lot, and seemed to get a crowd around me.

This might not work for everyone, but I can look back on a social life I wouldn't otherwise have had.

Tom

#### Dear Mr Joyce,

may I say how much I enjoy reading Asperger United. It's good to know that I'm not the only one who has difficulties with the condition. I also appreciate how hard it is for some sufferers to live with Asperger syndrome, but it seems that the more mature I get, the more able I am to cope with it.

I've lived on my own for five years, and have now become engaged to a young man

named Colin, who is convinced he has a touch of AS too. We are very happy together, but it does mean that I can no longer respond to any pen friends.

If this letter could be published in the next issue of *Asperger United*, I would be most grateful,

yours sincerely,

**Frances** 



## 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 37

Sometimes having AS feels like being caught in a strange kind of spider's web, overlooked by a bright, enlivening sun. My name is G, 27, male. I like things like Bach and Sigur Ros, Russian books old and new, following sport and politics and trying to be a little positive and hope-filled in a realistic kind of way. It would be good to hear from other people with AS who have an optimistic frame of mind.

#### Pen pal number 38

Hello my name is Jacob and I am 10. I would really like a pen pal, as no one in my family has AS and it can be lonely. I love rock music and fantasy adventure films. I want to be a rock star when I grow up. I am very creative and have a good imagination. I also like nature and wild animals. My favourite animal is a snow leopard. I am learning karate and swimming. I would like to hear from people affected by AS between the years of 8 and 13.

#### Pen pal number 39

Hello my name is Richard. I am 26 years old. My birthday is 17/7/1982. My interests are looking after my guinea pig and rabbits and going bowling. I would like to meet friends to go on holiday with here or a place like Europe or Britain. I like tennis and museums. Also I like cats. I live in my own flat in Devon and I'm looking for a mate who is of similar age to me between 21 and 35 years old.

Tee's article about his wonderful mentor/life coach should be reassuring to all lonely Aspies such as myself, but it's left me none the wiser as to how I might attain his good fortune. I've never had an advocate, for one thing, so there's never been anyone to recommend a mentor to me.

I've made contact with a few life coaches over the years but have not found one who was willing and able to counsel me over an extended period (although some charged me just for the privilege of meeting me once).

Also, I was rereading J's article in the April issue and a line in the final paragraph caught my eye: "If you need to find some friends, join a group that shares a hobby". If only it were that simple.

I write as someone who was a member of many clubs at university, which was some years before I was diagnosed. Hillwalking club, early music society, Christian Union, Scrabble and Green Party, to name a few. Yet to what avail? The friends I thought I'd made disappeared out of my life with alarming rapidity after graduation. Communication dwindled to an occasional email or a Christmas card if I was very lucky. It makes me wonder if they were ever my friends in the first place and if not, how can I be sure of anyone else in the future?

Some may say it's inevitable that you lose touch with friends once you move away (notwithstanding all the hype about university being where you meet your friends for life). But I know of any number of people who manage to stay in touch with friends who've moved far further away. Ironically these are often people who purport to be rubbish at keeping in touch with friends — yet they somehow manage it.

#### Louisa

In the last issue of AU, Tee says he has benefited from the services of a mentor who is an expert in autism. I would be grateful if he could let me know where he found such a service, as I would very much like to benefit from one myself.

#### **Daniel**

#### Pen pal number 40

Hello my name is Michael. I'm male, 35, I was diagnosed with Asperger syndrome in 2002. I started going to an Asperger group in 2007; I find it helps knowing there's people like me. My hobbies are house music, late 80s club dance music, 90s rock music. I like take-aways, Indian, Chinese, seafood restaurants. I like walking, cycling on Dartmoor, coast of Exmouth. I have a cat called Snowball, she is four years old. I work at Tescos. I have a computer and I also like downloading music from the computer. I am looking for pen pals with Asperger syndrome of similar age who share the same interests as me; my date of birth is the 12/7/1972.

#### Pen pal number 41

I'm Colum, have just finished at the Birmingham conservatoire studying opera. Have also done drama training. I live in the West Midlands and I'm also very keen on films, ballet and reading, especially the classics. Am 34 and would like to correspond with like-minded people. I'm keen to expand my social group. I have Asperger syndrome.

#### Pen pal number 42

My name is Jeremy. I'm 50 years old. I live alone in Hereford. I find living on my own very stressful. I would like to hear from people who are interested in aviation, like going to airshows and visiting old airfields. I also enjoy music and travelling to different places.

#### Dear Sir or Madam,

nowadays housing associations provide a lot of flats for people with academic learning disabilities, but there is a desperate need for flats for people with autism. I have a form of autism — High-Functioning Autism — which impairs my communication skills but not my IQ. HFA and Asperger's syndrome are also learning disabilities, but social, not academic, ones. I live in "general needs" accommodation, and I do not always find it very suitable. As special flats are not available, most highfunctioning autistic people live with their parents or live in general flats, as I do. But living alone in a flat can be a great struggle. Typical problems include isolation, loneliness and depression, and I myself feel very vulnerable. Many in general housing have problems with the antisocial behaviour of other residents, such as noisy music, loud parties, litter-lout friends of neighbours, and possibly drug use. I once had a drug-addict neighbour and this was extremely scary. In my flats there are not usually babies, but there have been dogs that persistently bark. Recently there were broken bottles outside my flat; it was over a month and three phone calls to my housing association before they removed them. Autistic people tend to follow house rules strongly, and don't like other people breaking them. But some are vulnerable to bad influences and could be led into drugs by people pretending to be friends, or, in the case of girls, loose sex.

A block of flats for those with autism would be set out rather like those for people with learning disabilities or for older people — they would have a warden on call all the time, and a common room. Ideally the flats would have soundproofing between floors as autistic people often have ultrasensitive hearing — in my case my upstairs neighbour's loud coughing and his loud, foul-mouthed layabout friends irritate me a lot. The staff would be sympathetic towards autism issues and so understand about the oddities and difficulties that go with the condition. Other issues that autistic people often need help with are budgeting and bills,

shopping (if the flats were near a general stores it would be ideal; my one recently closed) and general housekeeping. They need reminding about taking their medication, and stocking up on essentials, such as toilet paper. They often need reminding to look after themselves - for example, I often forget to wash my face and brush my hair. They need help with forms sent by the DSS, housing benefit and council tax benefit, as these bodies are always reviewing their cases, as if disabled individuals will miraculously stop being disabled. Myself, I find these forms unnerving, especially as there is the threat of benefit being stopped. At the moment the council are paying my rent six weeks in arrears and this is stressing me. Some people (myself included) when in certain moods, could be a danger to themselves, and having an understanding person easily and physically available, not remote on the end of a phone line, would greatly help them.

People like me "fall between two stools" as we do not fit the criteria for local learning disability or mental health teams. I am under mental health because I have depression. I am a member of SAFE and ASAP, the Essex Asperger societies. The National Autistic Society do nothing at all to practically help people with HFA/AS. They are mostly for the parents of children with classic autism, who have severe academic learning disabilities. Adults with classic autism are quite well catered for with special housing. Despite some people with HFA/AS being apparently very clever, they are just as vulnerable as those with a classic learning disability. It is reckoned now that one in ninety people have autism, and the numbers are rising, so why is all the special housing geared towards those with academic learning disabilities?

Yours sincerely,

#### Sue

PS. Most people with my condition are less articulate than me and so are unable to explain their situation in a letter.

#### The NAS Christmas card catalogue

You should find a copy of the NAS Christmas card catalogue in your envelope, along with your copy of *Asperger United*. If you do not want it, please pass it on to a friend!

We are especially pleased this year to have a card designed by Peter Myers, an artist with Asperger syndrome, who will be familiar to many readers of AU as he has often contributed his beautiful designs to the magazine. He trained as a precision model maker and worked as an architectural model maker until 1997. Then he worked in a Remploy factory but, since the recent closure of the York Remploy factory, he has been on work experience at York Minster.

We are especially pleased that we are able to demonstrate in this way the talent of an adult with autism: a theme that ties in with this year's very successful campaign — *I Exist* — which champion the rights of adults who have autism.

We apologise if it seems a little unseasonable to send out Christmas card

catalogues in October. In fact, as far as the world of Christmas card catalogues goes, you are receiving this catalogue unseasonably late! NAS members received their catalogues back in August, which sadly is the season for charities to send them out.

How to order NAS Christmas cards

By phone: **020 7751 0090** (Monday-Friday 9am-5pm)

By post: please send your completed order form (on p7 of the Christmas card catalogue) with payment to:

NAS Christmas card orders The Almanac Gallery 130 New Kings Road London SW6 4GG

Please make cheques payable to Autism UK Ltd

or buy online at www.autism.org.uk/christmascards

#### Asperger syndrome in adults

Request for volunteers

The Royal College of Psychiatrists is holding a series of training courses for professionals. Courses will be held in Manchester, Cardiff, Edinburgh and Dublin.

They are looking for local people (local to one of these four cities above) with Asperger syndrome who are willing to talk for about twenty minutes about their personal experiences of living with Asperger's and also what can be done to improve the services and care they receive.

Anyone who is interested, please contact:

Liz Edgar

Regional Development Manager Royal College of Psychiatrists College Education & Training Centre 1 City Square Leeds LS1 2ES

Tel: **0113 366 3248** Mob: **07800 945 197** Fax: 0113 366 3039 **eedgar@cru.rcpsych.ac.uk** 

www.rcpsych.ac.uk/cetc

#### An angular man

#### by William

I would like to tell you about a character in a Dickens novel who might seem rather familiar. The book is the Mystery of Edwin Drood, and the character is Mr Grewgious.

In a story which has its share of shifty, reckless and downright villainous characters, Mr Grewgious is the touchstone of reliability and integrity.

He has tried and failed to make a career as a lawyer, but he nevertheless gains a reputation for being "indefatigable in seeking out right and doing right", and finds his niche as a trusted agent for two wealthy estates. "Fidelity to a trust was the life-blood of the man".

Dickens describes him as ungainly, "with an awkward and hesitating manner; with a shambling walk", and a rather expressionless face: "The little play of feature that his face presented, was cut deep into it". His face and manner are "expressionless of any approach to spontaneity". But "Mr Grewgious still had some strange capacity in him of making on the whole an agreeable impression". "His voice was as hard and dry as himself ... And yet ... he seemed to express kindness".

He lives a Spartan life: "There was no luxury in his room". He lives and works in one small apartment, but his books and papers do not cause any clutter, "so conscientious and precise was their orderly arrangement".

He is painstakingly considerate of others' feelings, notably his emloyee: "I feel constantly apologetic towards him", he explains.

He seems to have quite a lot of insight into his own character. "I do not fit smoothly into the social circle". He describes himself as "an angular man", though it is not clear whether he is referring to his physical awkwardness or to his personality, or both. He says that most young people seem to start life as "buds", but he began as a chip (of wood): "I was a chip and a very dry one — when I first became aware of myself". He makes notes to help him in conversation, "for I have no conversational powers whatever".

We will never know the solution to the Mystery of Edwin Drood, because Dickens died before he could finish it. But it seems that Dickens meant Mr Grewgious, though not a man of action or a romantic hero, to be at the calm centre of the novel. His main role in the story is as the legal guardian of the heroine Rosa. He also becomes her literal guardian, as she turns to him for protection from the villain of the story.

It is a sign of Dickens's great powers of observation that he described such a character in 1870, many years before the autistic spectrum was described by scientists. And it is remarkable that he should have written with such understanding about a character so far from his own gregarious and ebullient personality.

He must surely have met and studied someone in real life who gave him the basis for the character of Mr Grewgious. But it's like life, when excellent literature etches reality.

Please note that the NAS would like to use book reviews printed in AU on the NAS website. Currently, content in AU is for AU only, and reviews already published will not be affected. From now on, if you send in a review of a book (or anything else sold on the NAS website) please state if you do not want the review used by the NAS website.

#### Asperger syndrome and long-term relationships

by Ashley Stanford

Jessica Kingsley Publishers

ISBN: 978 1 84310 734 7

£13.95 / \$19.95

review by Alain

Ashley Stanford has been married to her husband for over fourteen years and they have four children, three of whom have AS. She speaks as someone who has developed coping strategies for sustaining such a relationship. As she points out, the good sides of AS are often intertwined with the not-so-good sides. It is recognising this, and dealing with it, that make such a relationship possible.

Ashley has clearly done her homework and throughout she cites other works on the subject. Despite this, Sanford never descends into indecipherable academic language and maintains a clear narrative throughout.

As with most books that have appeared on the condition, she details the history of AS, from its discovery by Hans Asperger through to current thinking on the syndrome. She then moves on to describe the traits of AS and how they can be spotted. This is important as it gives the book a strong, legitimate basis.

A diagnosis of AS in one or both of the partners can have great ramifications in the relationship, so she examines the possible reactions to it, including depression, denial and other people's judgments. When it comes to reactions, these can vary: some people feel the diagnosis condemns them, but for others, including Ashley and her husband, it comes as a relief. Yet she notes the hardest part for an NT partner is having to rethink one's idea of what makes a successful relationship. This leads into the discussion of the different diagnostic criteria for Asperger's syndrome and how they apply to her husband.

Ashley points out that one of the reasons AS is so hard to spot is that those with AS can

become very good actors — that is, they learn to fake the basic social skills, like eye contact.

Ashley uses the diagnostic criteria given in the Diagnostic and Statistical Manual (DSM-IV). She examines each criterion as it relates to her husband, what it looks like and how it may affect your relationship, plus strategies to help you deal with it.

In doing her research for the book, Ashley discovered many things about her husband that were affecting their relationship. One of these was his dependency on establishing and keeping particular routines — doing things his way regardless of external circumstances. She discusses a routine wherein her husband worked on perfecting images for a colouring book for their children, at the expense of feeding the children and other important household tasks. After seeing this was causing a problem, Ashley offered to take care of the book, knowing it would take her less time, and would free him to take care of other tasks.

This example typifies what Ashley's book is about — patience, commitment and common sense, along with an ability to step outside oneself to view a problem objectively. It's also about finding a way to persuade the AS partner to co-operate whilst empathising with them and making it clear their behaviour is causing difficulties. Ashley writes about the solutions to each problem with clarity. The book comes with a glossary of psychiatric terms and a list of resources she has used.

I cannot recommend this work highly enough for partners of individuals with AS. It will provide a lot of insight and understanding into how such relationships can work.

#### Dear John,

I have Asperger's and in 1991 obtained a job at the HQ of our church in London. Unfortunately I was put in an office with one man who shouted all the time. His normal voice was shouting and other staff described his voice as booming.

As I was fearful of never getting another job, I stayed there for eleven years, becoming mentally ill and having panic attacks. I started having more and more time off so my GP sent a letter to the minister in charge to say that I could only go back to work if I was removed from the man making me ill. The Minister's reply was "take it or leave it", so I stayed.

My health became worse and worse and one morning I left home almost in a coma. As I entered the office this man started his shouting and I lunged towards him to stop it. I was in such a state that I was taken to hospital. Of course I lost my job.

Three years later I was still having panic attacks but was given medication which worked and I felt better than I had for years. However, a social worker, who was under investigation at the time, insisted that I saw a psychiatrist, and this woman treated me so badly that I had a relapse. She shattered my self-esteem. She said I was evil and that I had no feelings for the "poor" man I had lunged at. A few days later I was sectioned and she said I should be put into a secure mental home and that I was liable to attack anyone at any time without provocation.

I was in that place for seven months and my mental and physical health deteriorated and I became like a man with Parkinson's. I only survived because my mother visited every day from 2.30 to 8.00. She almost spent her life there.

She has since been fighting for justice for me and obtained my medical notes. She found letters from my employers and the man I worked with demonising me. They were shocking to read and were the basis of my being sectioned three years after I left my job.

Recently I have tried to get a part-time job in our local hospital and gave as one of my references a man I had worked with who was my best friend and it was sent c/o the church I had worked at. However, the new boss there, another minister, opened the letter and sent another demonising letter to the hospital to stop me getting a job. This was six years after I had left that place. First the local hospital said I would not now get the job, but when my mother explained it all to them they disregarded the demonising letter and destroyed it and I have now been offered the job.

I am writing this to show how autistic people are treated by society. They do not regard us as having a disability and they condemn us for our condition. The mental health services are just as much to blame — to them we are criminals, not people with a disability.

Neil

To pen-pal Torrah: Sean does not have your address — please contact AU, giving your address. AU will then be able to send Sean's letter to you. Thank you.

The books reviewed on pages 12 and 14 are 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.

Special offer to readers: normally postage and packing costs £3.95 but readers can get copies post-free until 30 November 2008. Just send your order with a cheque made payable to the NAS — address on page 2.

## Sensory perceptual issues in autism and Asperger syndrome:

## different sensory experiences different perceptual worlds

by Olga Bogdashina

Jessica Kingsley Publishers

ISBN: 978 1 84310 166 6

£14.95 / \$24.95

review by the Goth

This is a comprehensive look at all the perceptual problems that autists have, along with how to recognise people suffering from each problem and what treatments there are available to ameliorate the various conditions. Despite having already read widely on this subject, I find this book invaluable as a guide to how to cope with my sensory difficulties. The author believes in psychic phenomena, but sceptics shouldn't be put off, as the book is extremely useful whether you believe in such things or not. The book includes a "sensory rainbow" tool for assessing your difficulties and for seeing how your various problems relate to and affect each other.

It seems more and more clear to me that perceptual issues are fundamental to the diagnosis of autism, and that the triad of impairments is not the real core of the condition. Perceptual issues affect a child's ability to observe and learn and this may be all that is necessary to interfere with normal childhood development. For this reason, I now believe that what marks autists out as different is that they are not "sensoritypical", or "ST".

There is much to be gained from this book for anyone who has or suspects they may have sensory difficulties.

#### Carpet stress

by Nick

Oh dear, the kitchen carpet needs a clean, I've just cleaned the other carpet in the lounge and I've rather had enough.

I put my earplugs in and I put the video on, I can't really hear the video and I only occasionally glance up and see it. But I guess I find comfort from it, perhaps it's a reassurance of stability.

I wouldn't be cleaning the kitchen carpet without it. It would be easier to use the vacuum cleaner, but I need to get it out of the cupboard and move things, more disruption, if I'm to clean the carpet I prefer the harder way but the way with less disruption.

So I use the dustpan and brush and I get down on my knees.

The horrid dust goes in my nose and I begin to sweat, I don't like this but it makes me feel less wound up than if I had taken the vacuum cleaner out.

The carpet was a nuisance: I didn't plan for it to be dirty and didn't plan to feel tormented so much by it that I had the urge, the compulsion to clean it instantly.

If I could have left it, sat down and had a coffee and think "I will do the carpet later," I may have taken the vacuum cleaner out. I may have found the challenge less of a torment if had become intoxicated first but I didn't want to do that. Besides I would have to go out and get the drink, crossing roads, dealing with the outside traffic noise, having to pay for the drink and look at the person. I really don't want to deal with any of those things, or I certainly wouldn't do the carpet.

#### Dear Asperger United,

I am writing to pass my comments on a few subjects related to AS but as well I wish to share my story. I'm not entirely sure; I think it's got something to do with talking to somebody who can really understand. What I mean by understanding is telling my story to somebody else with AS, so anyway I'll start from the beginning.

From about the age of 7 or 8 I noticed I was different. For some reason I had next to no friends whilst everybody else had plenty of them. I moved about a bit so went to three different first schools, two different middle schools and stayed at the same high school. It was upsetting and frustrating because every time I moved school I told myself that I would use this as a chance to make friends and keep them but I never managed it, of course, because at break times I wandered around alone.

I was a big target for bullies and I was also overweight, ginger and wore glasses, which made me stand out even more. So you can probably imagine the amount of taunts I put up with on a daily basis and I tried everything to get out of school. I pretended I was ill, tried to sleep in but curiously never "bunked off". This is because I was told it was completely wrong to leave school when I'm not supposed to. The worst thing was I couldn't do much out of school either because I used to get chased by bullies around the streets near my home.

Anyway, I moved to the country and my house was in the middle of nowhere, so I only had to worry about it at school now. I tried to keep my head down as best I could. By now I was in middle school, sixth year. I was very good at hiding, plus I played football a lot. You don't need friends to play football usually — you just join in. Nobody notices you,

although there were a handful of times I wasn't allowed to play because of "unfair teams" or other excuses. Towards the end of year six a major thing happened. Once again I found myself being chased. Unfortunately I ended up leading myself into a secluded area. There were about four year-eight boys and they messed me up fairly bad but thankfully when I went to hospital they said I would be alright, but I had one heck of a shiner on my eye after that.

I was taken to a different school and the boys who attacked me were not punished because nobody saw them do it, plus I wasn't even sure who it was. I could recognise their faces but I was never good with names.

After that I saw a lot of people educational psychologists and other professionals — but none of them ever mentioned AS. Similar things happened throughout my school years but nothing as major as the attack. Then, last January, a woman came to see me. She told me she was a psychologist and I had been referred to her. Anyway, I was admitted to a place called the Roycroft clinic. It's a type of hospital for people with mental disorders. I was assessed and was given a formal diagnosis of Asperger syndrome and when I learned about it I started to realise why my life had been the way it was.

Now here I am living at the clinic, learning new social skills every day, slowly improving and getting prepared for adulthood. The only question I was asking myself was how come it took so long to be diagnosed, with psychologists seeing me at school. I thought one of them would have picked it up. However, I am lucky because the help I am getting and my life ahead of me seem to be making up for it!

Dan

#### The NAS Ladbroke Grove Autism Centre

#### The Tuesday adults social group

A social group for adults during the daytime every Tuesday, to learn social skills and explore our lives. Time during day yet to be decided. So email me with your preference, and we will go with the most popular time.

Are ou over 18? Are you on the autism spectrum? Do you want to explore what it is to be what you are? Do you want to meet others of our kind? Do you want to develop social skills, communication and explore where you go right and wrong with people?

Want to be tutored by high-functioning autistic adults who are married, grown and have jobs, careers and homes? (Everything people like us aren't suposed to?)

My name is Paul Wady and I have worked for the National Autistic Society in its Angel head office for two years. I am making a career out of representing and working for and with my own kind. Diagnosed in my 40s, I have been attending social groups for four years, where I met my wife, who will be working with us.

Autistic men and women, happy, healthy, functioning and able. Guest speakers and workshops, or just plain ongoing work on ourselves. (Or not. It is a social group.)

The centre has a kitchen, dining room, sofas and a meeting room, toilets and secure environment. "Meltdown" spaces available.

The centre is the first facility of its kind in London. Designed as an "Aspie safe house", we can be ourselves and develop as people, safely. (Attendance strictly by appointment. Behaviour must be contained. Meltdown rooms available if you need them. We've all been there. Address, directions and map available upon contact.)

#### paul.wady@nas.org.uk

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Telephone: 020 8962 9610

There is also a group for those aged 12 to 18, held on Mondays between 6 and 9pm.

#### **Competition result**

The winner of the software competition is Samuel, who wins the game development kit. The prize-winning entry was:

 $\infty - \exp(-\infty)$ 

which, for the technically minded, is an

infinity of arbitrary (and thus arbitrarily high) order — no matter what type of infinity you compare it to, it is always possible to find an order which makes this infinity bigger. Very clever. (This was the only infinity submitted.)

the Goth



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