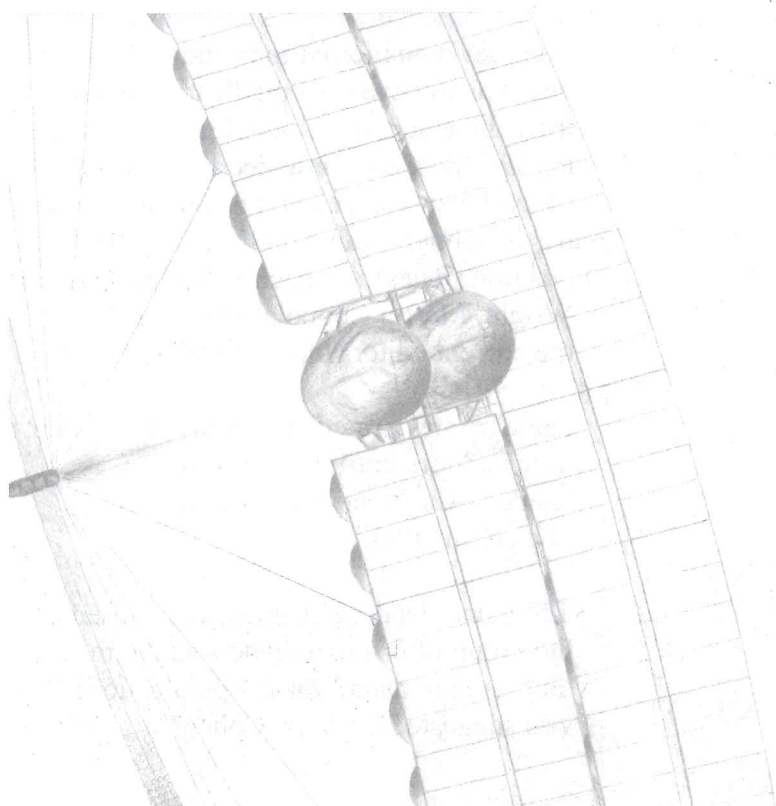


Produced by and for people with autism-spectrum conditions

Asperger

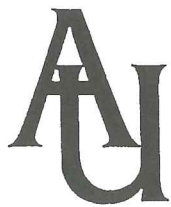
united

Edition 51 July 2007



THE FINAL MIGRATION
Spaceships of the future flying to the
nearest star Alpha Centauri

© Eugene Rodrique 2006



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.

Asperger United is free. 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 made payable to the NAS.

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

Subscribing to Asperger United

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
27 September '07

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,

Thank you for the continued high-quality presentations, and I wish you happy holidays even after having read what follows! As a result of the recent readers' survey I present for your entertainment something about me.

A famous Scottish drinking song proclaims "I belong tae Glasgae", and said city was the scene of my birth in 1944. Both parents were Irish, and they moved to the Elephant & Castle in South London the following year. Before this move I had spent some time with my grandmothers in County Mayo, birthplace of both parents. It is said that the headteacher of St Anne's Catholic Infants' School blocked my entry because of an "abnormality" but nobody knew about Asperger in the 1950s. Five more children were born into the family.

I acquired a Clerical Assistant position in the Ministry of Agriculture. Due to my "A"-level in French, I was promoted to Clerical Officer. In 1979 my concentration on the job wavered and I was downgraded. In October 1980 after having passed the appropriate test I was restored to my previous grade and transferred to the Home Office from whom I retired in 2005. In the last year of my service I was promoted to Executive Officer.

For many years I engaged myself in collecting stamps, and country and Irish music. Even though I have little ability, I have always had an interest in team games like soccer and cricket. This led me to collecting football programmes: I have put myself in financial difficulty, forced to clear out collections twice. I currently hold 23,000 programmes from 8,000 clubs. Since 1985 I

continued on page 11 . . .

If sufficient material is sent in, the theme for October will be **humour**. Not just humorous contributions, but articles and letters about humour, how you enjoy it or struggle with it, etc. Writing on any subject is still welcome, so get writing! (Cover art is also welcome.)

the survey edition

Picture by Eugene	cover
Editorial and contents	3
<i>Readership survey</i>	4-5
feature by the Goth	
Letters to the Editor	6
Pen pals	7-8
Letter about life by Chris	8-9
<i>An organisation for adults with neuro-diverse conditions</i>	10
article by Michael	
Editorial (continued) and notices	11

<i>Living in my own world</i>	12
article by Andy	
Open letter to DS Linney from the Goth . . .	13
Notice about www.researchautism.net	13
<i>Becoming an author</i>	14-15
article by Elkie	
Special offer on Elkie's latest book	15
Announcement about <i>AU</i>	15
Call for volunteers from Laura Crane	15
Goldsmith's College, London	
Call for volunteers from Shivani Sharma . . .	16
University of Hertfordshire	

Readership survey

by the Goth

With the January edition, 3,829 individual subscribers were sent a short survey asking a little about themselves, which sections of the magazine they would like to see changed, and any comments on these changes or about the magazine in general. It was not possible to include bulk subscribers in the survey without considerably increasing the amount of work necessary, so I'd like to apologise to all those who couldn't be included.

I would also like to apologise now for taking up so much of this issue, but hopefully the results of the survey are of interest to the majority of readers. We had 167 replies. The average age of respondents was 42. The average of the 39 online respondents was 36. The average of those who included a contribution was 43.

83 women replied — 50% of respondents, 21 of whom were online — 54%, which is not a significant difference. At least 75% of the readership is male, so obviously women have proved more likely to respond and contribute.

The culture question caused some confusion, but it was important to see how people would classify themselves — I had a long debate with the Publications manager at the NAS over whether it would return any useful information, and whether we should include any examples of answers; to me the idea that someone might reply "youth culture" or "trainspotting" is an advantage, because it tells you the types of article that would interest that reader. 132 people gave a nationality. 46 gave a race (including 3 "Jewish") and 10 gave a creed (not including the 3 "Jewish"). Please note that quotes are used in this article to indicate what people actually wrote and not to highlight the words in any other way.

The most popular answers were "British" — 46 (28%); "White British" — 29 (17%);

"English" — 22 (13%); "White English" — 7; "Western" — 6; "European" and "?" both with 4; and "Celtic" with 3. A total of 7 people gave an answer indicating that they didn't understand the question (including "?"), which I think is good, both because people weren't afraid to say they didn't understand, and to show that many of us have a strong command of the subtleties of language. The most unusual answers in no particular order were "Linux/hacker"; one person who considered themselves "ordinary"; one person who considered themselves not just British but a "Brontë fan" — this is a brilliant way of defining who you are; one "pagan"; and a "hunter-gatherer" — I salute you, but this does make me wonder what you hunt. I'm very pleased to see that one person considered themselves "civilised" and that one person, and only one person, declared "I'm an individual". One person felt unable to answer in less than 200 words!

When asked whether they wanted to see more, less or the same of the various types of content, 70% of all votes cast were "same". However, there was a clear majority of votes for "more" articles and letters, and "less" poetry. Also, more people voted for "more" rather than "less" pen pals and book reviews: currently, all that are received are printed.

Some people might feel that 167 replies was not very many, but from where I was sitting, having to read through, digest and collate, I felt it was a very good cross-section.

Many people put in requests for things to see in the magazine or for information. Much of the information and the technical articles requested can be found in the NAS's membership publication, *Communication*. I realise that membership of the NAS is not free, but there is a limit to what a small magazine like *AU* can do, and it doesn't make sense to

duplicate the efforts of *Communication*. Nevertheless, round-ups of relevant information will appear from time to time.

It is important to remember that *AU* is written by the subscribers, so those of you who put in requests for articles or letters on their favourite subject: the best way to get things started is to write a contribution yourself. But please note that it is not possible for every contribution to be printed. To help this along, and to prevent me being inundated with articles on a hundred different subjects for next month, *AU* is going to suggest themes for future issues, taking ideas from some of the suggestions put forward in responses to the survey. You can see the first example of this on page 3.

A number of people commented upon the quantity of depressing material in each issue. This was split fairly evenly between those who wanted something more uplifting, and those who found others' stories which were similar to their own reassuring. However, *AU* does try to publish a greater proportion of the positively toned contributions that it receives. There were many, many requests for more humour, so I say again, if you want to see more, then you have to get writing!

Generally there was the impression that people didn't know who produced *AU*. It is financed by the NAS; edited by a volunteer with AS — John Joyce — who provides a short profile in his editorial; with the production work being done by me, the Goth. I have HFA and have included a short profile in my letter on page 13. No empathotypical has worked on the magazine for years, and to the best of my knowledge, the only pieces in the magazine to have been written by empathotypicals are some of the notices for research volunteers and two academic conference reports by the speakers: one was about discrimination and the law, and the other generated a lot of letters (it was called *Don't sweep sex under the carpet*). These appeared in issues 41 and 43.

The print run topped 5,000 in April and will top 6,000 this year. This increase in subscriptions over the past two years has caused the cost to more than halve to under £1.50 per copy, due to the cost savings of mass printing — two years ago the print run was only 2,000.

There were a number of requests for colour, but this would double the cost of the magazine, so unless someone has more than £25,000 a year they could give to *AU*, this won't be happening, sorry.

Many people requested either changes or no change. This of course presents a problem, for example, dyslexics and the partially sighted prefer a sans-serif font, but people with poor visual discrimination prefer a serif one, and as *AU* is already printed in serif, others who want no change also want serif. Therefore, unfortunately for those with dyslexia, it will be staying the same, as there was a greater number of respondents with poor visual discrimination. There were some requests for larger print, so we are going to experiment with providing an A3 photocopy of the magazine, available on request, which will be the equivalent of 24-point text. However, this may prove very expensive to administer, so this will only be a trial.

Several people made comments about the articles and letters on "left-wing" sexuality: one's sexuality is surely not a political decision, and finding security for oneself will always be a matter for the individual. People on the spectrum are well-placed to realise that we need to be non-judgmental and accepting of others and others' decisions, as this is the understanding that we ask from others for ourselves.

I'd like to thank all those who completed the survey — which included three from overseas — especially as it had to be returned at your own expense. The information provided will be very useful as we plan future editions of *AU*.



letters to the editor

Dear John,

Re edition 50 April 07 page 6 from Colin.

Reference *Scientific American* November 06 edition "Susceptability to autism is inherited".

Is there any way that my husband and I could be tested?

But doesn't it mean that first there must be an "autistic gene" to do such a test?

Has an autistic gene been found?

It would help if one or both parents have such a "gene" — it would show the reason for one's son's or daughter's behaviour, and how to help deal with it.

For example, the times one's son or daughter says "Why am I like this? Why are things so difficult for me as opposed to my friends?" etc. It would help to understand better. If there is such a "gene", then Asperger's and autism would be easier to understand and explain.

Thank you,

Yours sincerely,

Rosemary

In response to Kelsang in issue 50, it is not wanting a relationship, whatever age. The biggest problem is: I have always wanted relationships, but it was very difficult finding a person who took me for who I am. Most times they told me "disabled/having Asperger syndrome" was the reason why I lost relationships, until my middle thirties. Then I met my angel — been together ten years.

Mark

To whom it may concern,

I have developed an online pen-pal service:

www.assists.org.uk or

www.assists.org.uk/penpal.html

People can still advertise in the magazine but this is better because it is more economical, efficient and more people can contact each other.

What do you think?

Regards,

Basil

Dear Sirs,

A couple of years ago now you placed a review of my book (*Managing with Asperger syndrome*) on the back page of *Asperger United*. Included in the piece was an e-mail address which — unfortunately — after publication was stopped by Hotmail.

Since then I have had a website built which allows people to access and comment and various topics and also e-mail me:

www.aspergermanagement.com

I was wondering whether it may be possible to run a small piece in a future edition of *Asperger United* again stating that the e-mail facility was faulty last time but is now operating satisfactorily.

Would this be possible please?

Stuart Francis



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*.

****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 4

Hi, Andrew, 34, live in Leamington Spa, interests are music (anything from Jefferson Airplane via Pixies via Abba to Throwing Muses or dEUS), playing guitar, reading, Discworld, sci-fi, graphic novels, astrology/esoterica, nature.

Pen pal number 5

I am 36 years old, I love all forms of music including Goth and Cradle of Filth, but not too loud. It helps to get my head sorted out a little. I hate being kept waiting for too long, and I dislike large crowds, nightclubs and smoky pubs. I love reading about Goth and books on autism, autism-spectrum disorders, Asperger's syndrome and other people's accounts of ASD. I suffer from OCD, ADD and AS.

There are not enough AS groups around Shropshire,

and this is very annoying to me. Maybe I should set up my own group instead. I am a great singer, and I can write lyrics and poetry too. It always feels as if I have a double-glazing box around me, and this makes it very hard for me to socialize, as I don't know what to do, or how to go out with people. I would love like-minded AS people to get in contact with me.

Yours sincerely,

Mark

Pen pal number 6

Hello, I'm Pete, aged 43, and live on the South coast near Brighton. I was assessed as having AS last year but self-diagnosed about two years ago. I work part-time (thirty hours a week) in Brighton. I have a lot of varied interests and would love to hear from anyone who just fancies a bit of a chat now and again, especially those of us that discovered autism in ourselves later in life. Would also be interested to hear of any social groups in Sussex or the surrounding areas or if anyone would be interested in joining with me to start one! Prefer e-mail long-term, but letters are nice as well. Hope to hear from you soon and take care.

Pen pal number 7

My name is Mark. I'm 33, and I live in a village called Thornliebank which is a suburb near to Glasgow. My hobbies are playing football and golf and also reading and listening to 80s music like Lionel Ritchie, Aretha Franklin and any easy listening music.

I am a part-time student at Cardonald College in Glasgow where I'm studying a part-time Administration Level 1 course.

I got diagnosed with Asperger's when I was 29. I recently got selected to represent Great Britain in the 2007 world games five-a-side football team that is going to Shanghai China, on the 25 September. I'm flying down to Heathrow and having a reception, and then at 9am next morning it will be a ten-hour flight to Shanghai. So it will be a dream come true for me as there will be about 155 of us, in sixteen different sports going.

I look forward to hearing from you.

Hi Mr Joyce and all other Aspies!

[Please note this letter was written in April]

My name is Chris and I wrote a small article for the July 2002 issue of *AU*, soon after I was diagnosed with Asperger's (at age 42). I have received *AU* since then, and it has been sometimes interesting, sometimes groan-inducing, sometimes informative . . . well, you get the picture. I had always meant to write back, to both inform you of my progress, and to say "thank you" to the people who wrote to me as a result of my article, but I never wrote back — I feel that I was feeling too raw after my diagnosis to do it, then went into depressed mode and started to try to find some "support/help/resources" where I live (IoW) from MIND, MENCAP, statutory services, mental health services, but got little). I suppose you get that a lot. However, it's been, suddenly *five* years, and it has really surprised me at how fast it has gone (being over 40, it's downhill all the way, huh?).

Meantime, I attended the first AUTSCAPE conference (2005), which was great, and I learned a lot about AS and associated conditions, met other autists, at varying degrees, educational levels and ages in their autie journeys. However, I felt that things would take time to develop, and it has done just that over the Autscape e-mail ring. I was surprised that, although *AU* advertised it, there was no coverage about it in the magazine, and hasn't been since — if you want to sponsor someone to cover the next conference, I volunteer (especially as my finances are very limited), and how about its inspiration, AUTREAT (ANI International in the USA)?

Also, I landed a job in 2005: it was at a new residential school which opened that May, and I started that October, following a July interview. I told the then residential manager that I had AS, with its attendant problems, and I was still learning about it all.

I got the job: when I got there, I found that the conditions had drastically changed and I had not been informed. Still, I went ahead, but poor training, lack of support, being away from my family and travelling back and forth to the IoW, misunderstandings between myself and the other staff (finding myself “in trouble” and not knowing what, why or how until after the event was reported), and the totally disproportionate reaction of my managers (I was told at my interview that I would get support from the line manager(s), and, indeed, tried to initiate it, including talking to the resident psychologist, all giving reassuring noises, but doing little — I had to seek supervision, but it wasn’t till I complained about its lack, and after an audit from the school’s funding authority while I was there, was it started). My line manager was not the one who interviewed me, and the new one was a person who was a senior residential worker — not the deputy residential manager — who was working there. He told me flat out, at a “review meeting” that he was not there to give (me) any support, in front of the principal, (and his was also a pro-tem post), who had to clear up the problems of the previous residential manager, who left very hurriedly (“moonlight flit” it was described to me — I was told it was due to “personal problems” but I discovered otherwise).

Also, that wasn’t the only person who had to leave, as I was told on the day I was packing up, another member of staff left soon after starting, a person with a lot more experience than me, because of “changed conditions” at the school: whether they resigned or were fired, I don’t know. But, I did resign, after consultations with a sympathetic local doctor and the new school HR manager. It was that, or be fired, which would have been worse, and it was bad enough resigning. I had such high hopes, and they were cruelly dashed. I returned home and had to reapply for Incapacity Benefit (IB), at the same rate as when I came off it, due to the 52-week rule. I just passed a medical exam,

which I was loath to attend, because of previous poor treatment by the DWP’s tame doctors, looking for people to take off IB for the flimsiest of reasons, but this time it was okay, as the doctor had more understanding of my condition and was able to report it properly. I remain on IB, with the prospect of another ordeal next year, unless I can get a career-based (16 hours a week?) paid job.

Since early 2006, I have been in and out of depressive mode, but getting psychoanalytic therapy (May 2006), due to end next year because of financial pressures on the mental health services to cut back on treatment, but I suppose you’re all aware of that. I take St John’s Wort a day (top dose), just to take the edge off the depression/anxiety, and am trying to get my life in some sort of order, which it is, but in a small, isolated way, except for my wife and daughter, church attendance and Christian beliefs, reading, the Internet, writing poetry (not much at the moment) and doing basic house chores. I go out when I have to (food, papers, therapy, church, meeting teachers, etc.), but stay in, mostly. There are a couple of things on the horizon, but I have been let down before, so I am just waiting to see if anything comes of them.

I am in a quiescent period at this time, but very excited, as I have been asked to do a small presentation at an Asperger’s conference on the IoW, in Cowes, in May 2007, from the service user’s point of view. It is hosted by the IoW Council Education Centre, and has Dr Tony Attwood as its speaker. The two-day programme is on the *Development from childhood to adolescence* and *Adolescence to adulthood*. It is for parents and carers of children with AS/ASD, and professionals. I shall be speaking as a recently diagnosed Aspie on my experiences with “the System”. I will have only fifteen minutes (but am attending, all expenses paid, as a speaker). I hope that I do okay!

Chris

An organisation for adults with neuro-diverse conditions

by Michael

Having been a member of the National Autistic Society, I came across this organisation by chance and started out by going to their club night which takes place on the fourth Tuesday of each month. Mary Colley and others run the organisation (also a registered charity) and decided to call the organisation DANDA. This stands for Developmental Adult Neuro-Diversity Association.

Mary, who I met first at the Day for Autism event back in September 2005, welcomes those with various types of developmental neurological disorders. The main ones being:

- Asperger's syndrome
- High-Functioning Autism
- Attention Deficit/Hyperactivity Disorder (ADHD)
- Dyspraxia
- Dyslexia
- Tourette's syndrome
- Dyscalculia

Besides this, those with related conditions such as ODD and SID are also welcome to join DANDA.

Anyone, whether or not a member, is welcome to attend their central London monthly social night that takes place at the Mason's Arms, 58 Devonshire Street, W1, off Great Portland Street. To be eligible, people must be at least 16 and preferably be able to travel independently and support themselves. These club nights take place on the fourth Tuesday of each month from 7pm onwards.

After joining, one can take advantage of the various activities on offer. For example,

outings to various places, as well as workshops. Mary also has various events at her place. Having been a member myself, I have, for example, attended their annual conference that took place in Kentish Town last summer and a relaxation session at Mary's house. Since joining, I have also found it a window of opportunity to associate more with those with similar needs to me. Being an individual with High-Functioning Autism, I cannot really pretend that I don't find it difficult socialising with neuro-typicals — those without autism and related conditions. So DANDA is a great way to meet new people and make new friends.

I am DANDA's photographer and am responsible for taking photos of any major events that either Mary, the committee or members decide to hold. Already, my photos appear on DANDA's website, eg. the photos I took at the Autism Pride Day and the conference held in Kentish Town, as mentioned previously. They can be viewed by visiting:

www.danda.org.uk

In addition to the varied online information, there are also membership forms and details, for which the following rates apply:

For the waged:

£100 (life membership)

£20 (two-year subscription)

£12 (one-year subscription)

For the unwaged: half price

... continued from page 3:

have visited a number of non-league grounds including that of Dagenham and Redbridge. Many times I have followed a Saturday match with Mass in the local Catholic church.

In 1992 I went through an indifferent period at work and was given an adverse report. In the same year my younger sister heard a radio programme about Asperger and thought I displayed some of the symptoms. I received my diagnosis from Pat Howlin and Pam Yates. I then joined the London social skills group which I still occasionally attend. A year later it was suggested that Asperger/HFA persons should have a newsletter. Since 1997 you have been sentenced to my editorials.

Shortly after my diagnosis I took up an Open University French Course. This was followed by Advanced English and Spanish; together these made me a BA.

I have travelled widely in Europe plus making trips to Australia, South Africa and the US. Every year since 1981 I have made a pilgrimage to Lourdes and I have visited many religious shrines in Europe and the Holy Land. I have been a reader at St Elphege's Church, Wallington, for over thirty years.

I have recently displayed ineptitude at digging the garden and my only service to my widowed mother, now 90, is to accompany her to church and to the shops.

In August I am addressing a workshop at the European Autism Congress in Oslo. Hope to meet a few of you there.

Your Editor,

John Joyce

Eighth international European Autism Congress

Oslo on 31 August, 1 & 2 September 2007

- keynote symposia and discussion
- poster presentations
- opportunities for new generation researchers and operators in the field of autism to present their work

For further information, please visit the Congress website:

www.autismcongressoslo.org

This is a great opportunity to view the fourth International Art Exhibition of Persons with Autism and to visit Oslo and its charming surroundings.

Railway enthusiasts' club and garden railway open day

I'm re-advertising the Asperger Rail Club. This club is designated for railway enthusiasts over 12 years old (including adults) with Asperger's syndrome or High-Functioning Autism who are from any part of Britain. We host regular meetings in South East London and occasional days out including the Clematis Railway, a private garden railway where there will be a special open day on the 22nd September. For details on the Asperger Rail Club, please contact me on

07847 226 081

email: **edwardjonfinla@aol.com**

For information on the Clematis Railway, contact Paul Newman on **01795 521 779**. The railway is located four miles east of Sittingbourne, Kent.

Living in my own world

by Andy

I have found that as a sufferer of Asperger syndrome, that I live in a little world of my own. From a young age, people outside my family could never truly understand me and still struggle to, even to this day! To me my world makes sense but to other people it's very confusing, which has led to a lot of problems along the way!

I always stood out as being different from the crowd at school, right from my first day and nothing really changed right until I left school eleven years later! I spent a lot of my time being bullied at school but I didn't really understand why. To me I was normal and everybody else seemed to do strange things that I didn't understand! It was a very lonely time in my life where I felt very isolated and began to feel very depressed.

The teachers could be just as bad as the rest of the pupils in my class as bullying goes and, however much I tried to get help for it, nobody really seemed that interested. I tried counselling but in my case, as much as they tried to understand, they never really did. The only support I could find was through my family, mainly my mum, dad and my sister.

I now no longer feel angry towards any of the people at the schools I went to. It's only now that I've begun to understand that half the problem was the fact that they didn't

understand me or my problems and that I didn't always want to admit to them. There were some special people I met along the way through my school life, who I will always be grateful to. Hopefully, as people find out more about AS, things will begin to improve.

The best day of my life was when my school days finally ended; I even remember the date: 17th June 2003! It's only now that I've left school that things have started to get better and I've started living life instead of just surviving.

Now three and a half years on at the age of 20 and several different jobs later, I have finally started to feel more settled in myself. I now work as a carer in a home for adults with learning difficulties and really enjoy my job. The staff I work with have been really understanding and supportive about my condition and have helped me through any problems I have encountered along the way. I have now just enrolled for my NVQ2 in Health and Social Care and feel I'm really starting to make progress in learning to manage my AS.

Although we have real ups and downs as AS sufferers throughout our lives, I believe there is still a lot we have to offer the outside world and there is a place for every single one of us.

Thank you for your wonderful article Andy. Good luck for the future. John (Ed.)

Dear Asperger United,

I am writing in response to DS Linney's plea for details of autists in long-term employment, which appeared back in issue 44: I am the Goth and, as well as working on *Asperger United*, for the last year I have had a four-day-a-week basic admin job in central London. I got both jobs through a friend of mine, Tania, who was the NAS contact for *AU* before me and recommended me for both the admin job, which is in the office where she works, and for the job on *AU*. In part due to Tania's recommendation, I passed both interviews. I also edit English translations of PhD theses on special educational needs for a Dutch university, and I am trying to set myself up as a hi-fi consultant, advising people how to get the best sound for their money given their budget, personal listening style and preferred musical tastes.

I have a degree in physics and had been looking for work for over fifteen years, suffering for many years with depression, anxiety and low self-esteem. I was diagnosed with HFA five years ago, four years before getting the admin job; after diagnosis I signed up with Prospects, who persuaded me to volunteer at NAS head office. After three years of data entry and filing in the Advocacy Section I was offered the job at *AU*, initially as a volunteer and then freelance, so I've had to

learn how to keep financial accounts and make tax returns, neither of which has been easy or stress-free — I have also been investigated for tax fraud because I have more than one job and am freelance, which took up a lot of time, was very stressful and took four months to resolve. I can't say any of these four years that I've been both diagnosed and working has been easy, but I've kept on because going back to benefits and loneliness is too grim a prospect. Many years of school bullying have hardened me to the long slog which has no hope of respite, so I find I can keep going, doing something for as long as necessary, no matter how unpleasant. I now wonder how I'll ever earn enough to avoid means-tested benefits when I retire — I'd need to earn at least £25,000 for the rest of my working life.

Between graduating and diagnosis I had two jobs and was sacked from both of them for appearing to be duplicitous, unproductive and having an attitude problem, even though I'd tried my hardest to be a model employee (for instance, the "attitude problem" was an inability to deal successfully with difficult customers, being too honest and open with them).

However, I do enjoy working on *AU* and working with music, and look forward to more work that I enjoy in future.

the Goth

New website

www.researchautism.net

Research Autism is a charity which provides free, impartial and scientifically accurate information on various interventions for ASCs, including treatments, therapies and diets. It is wholeheartedly supported by the NAS.

There was no single place for people to get scientific information about the effectiveness

of all interventions before the launch of this site — much evidence for a variety of approaches is anecdotal, so these approaches are often ignored by academia. It is Research Autism's intent to commission, carry out and support high-quality, independent research into new and existing health, education, social and other interventions.

Becoming an author

by Elkie

Like many of you, I have always spent a lot of time in my own world, apart from the world around me and yet fuelled by it.

At first I loved to lose myself in sounds and colours, movement and tactile experiences. Then, gradually, the sensory experiences would be embedded into stories, what I heard, watched, read and went through myself. Clad in a loin cloth and head band, I used to stalk around in the forest and shoot my arrows at invisible deer. In rags and bandages, I would limp about on crutches, resembling a Vietnamese war orphan. And on a hill in winter, swinging an old axe and with a piece of rope strung across my back, I would turn into Hillary on his ascent of Mount Everest. Maybe not unusual for children, only the intensity with which I empathised with my role was unique: I totally became that person to the exclusion of my own identity. Also, I never grew out of it, though I learned to spend more and more time in the "real" world.

In my teens, becoming fascinated by adventure books, I began to write down stories which were playing on my mind. Fortunately, I had one friend at school who loved to read them. Later, when for many years I worked in gardening, on farms, as a "domestic servant" and other mind-numbing jobs, making up stories saved me from dying of boredom. In addition, I realised what power stories have in bringing a message across to people who would otherwise not listen or understand. So I kept writing.

Encouraged by some people at church, I finally began to approach publishers. After many years of being turned down, I eventually

succeeded, and at the age of 27 I had my first novel published in German. During the next ten years, this was followed by over thirty titles: novels, short story collections and some "Meditations from the mountains". Once, my German publisher asked me for a Celtic historical novel, since at that time I was completing a course in Celtic Studies at Aberdeen University. As with every novel I have written, I identified so closely with the main character that I forgot who I really was. For several months I became Ronan, who ran away from a druid and got shipwrecked on Iona. Perhaps this is how every convincing author works, like every good actor.

Since my German declined, I wrote more and more in English and also had three novels published in this country.

Two years ago, I wrote a kind of autobiography after my diagnosis of Asperger syndrome, as I began to understand my past in the light of it. It was my tutor at university who, after reading the manuscript, urged me to find a publisher for it. I approached every publisher in the field of autism that I could think of, both in Britain and the USA, but without success. So I finally plundered my savings account to publish at my own cost.

There were many organisational tasks to deal with and hurdles to overcome, like applying for an ISBN, registering with the British Library catalogue, finding an editor and a printer and most importantly a distributor for the copies. There are many people whose help I am grateful for, amongst them Cathy Mercer from NAS publications, who gave me invaluable advice.

The book is entitled: *Discovering who I am — growing up in the sensory world of Asperger syndrome* (140 pages, paperback). I hope many of you will be interested in it and find it helpful for gaining and promoting better understanding of the world of Asperger syndrome.

The good news is that this book is available from NAS publications, price £7.99 plus p&p.

Central Books Ltd
99 Wallis Road
London
E9 5LN

0845 458 9911

Or order on line: www.autism.org.uk/pubs

The even better news is that this book is available to AU readers post-free until 30 September 2007.

Send your order, together with a cheque or postal order for £7.99, directly to

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

Announcement

The NAS is committed to making information available to as wide a range of people as possible, so *AU* will now be free to all subscribers (initially for a trial period in case it proves too expensive). Donations are still valued — please see the details on page 2.

Autobiographical memory in adults with autism-spectrum conditions

request for volunteers

Researchers at Goldsmith's University of London are looking for volunteers to take part in a research project assessing aspects of memory processing in adults with ASC. Volunteers must be aged 18 years or over and have a formal diagnosis of High-Functioning Autism or Asperger syndrome. If you would like to take part, or would like any further information, please contact Laura Crane, by post:

Laura Crane
Dept of Psychology
Goldsmiths University of London
New Cross
London
SE14 6NW

Telephone: 020 7717 2226

or by email: L.Crane@gold.ac.uk

The research takes a few hours to complete and volunteers are paid a small fee for their time. The only criteria are that participants are aged 18 or over and have a formal diagnosis of High-Functioning Autism or Asperger syndrome.

I do hope that this research will be of interest to you and the readers of *Asperger United* and would be willing to provide you with any more details that you require.

I look forward to hearing from you.

Making things better

request for research volunteers

Family functioning: its relation to habitualness, behavioural flexibility and mood in individuals on the autism spectrum

What could help improve family life for people who have Asperger syndrome or autism?

If you would like to make a difference to families trying to cope with autism-spectrum conditions, and yourself have Asperger syndrome or High-Functioning Autism, then we would like to hear from you.

In collaboration with Professor Ben Fletcher and Dr Karen Pine at the University of Hertfordshire, I am carrying out research into functioning in families of young adults on the autism spectrum. The findings of the research will assist in developing a family-based intervention that can help families and individuals to cope and to feel less stressed.

If you are over the age of 18 and have either Asperger syndrome or High-Functioning Autism, we would like you to complete a questionnaire booklet. The questionnaire is anonymous, simple to fill in by just ticking boxes and help is available if you need it. This study has the ethical approval of the University of Hertfordshire.

Please contact me on either of the details listed below and I will send you a copy of the

questionnaire to complete, along with a self-addressed envelope for you to return the questionnaire.

Do something different, help us, help others.

For future information or to participate within this research, please contact me on the details given below.

Shivani Sharma
School of Psychology
University of Hertfordshire
College Lane
Hatfield
Hertfordshire
AL10 9AB

Phone: **01707 281 136 / 07886 286 771**

(please leave a message if I am unavailable)

Fax: 01707 285 073

Email: **s.1.sharma@herts.ac.uk**

I look forward to hearing from you and hope that you will be able to assist us in helping others. Thank you for your time.



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

