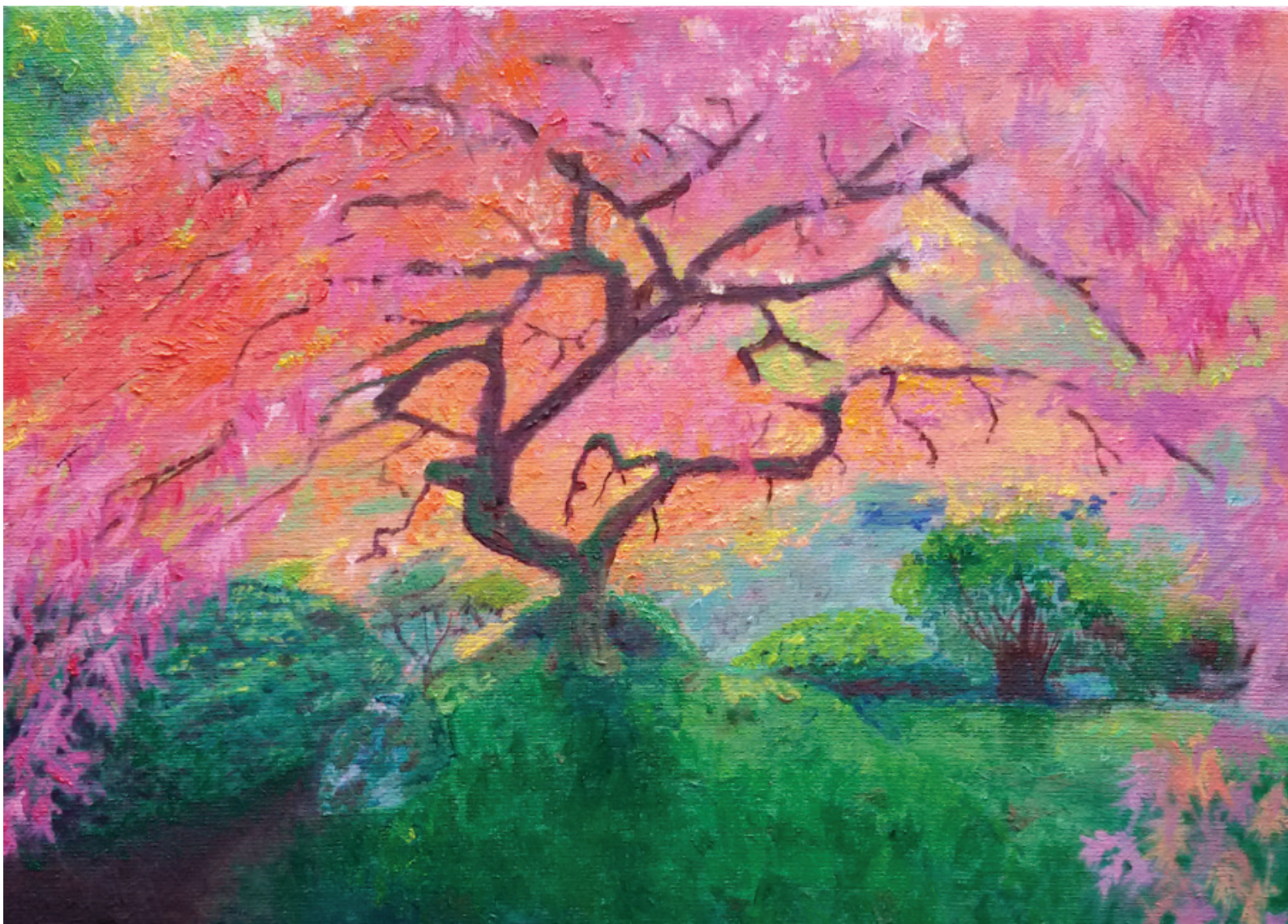


Produced by and for autistic people

Asperger *United*

Edition 92 October 2017



Asperger United

Asperger United is a magazine run by and for autistic adults (although some parents subscribe on behalf of their under-sixteens). The magazine aims to put people who have the condition in touch with each other and to share information so that they can lead more independent lives.

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

Asperger United edition 92 is free. Future printed editions will be on paid subscription. To subscribe you, we need your postal address. Please see the enclosed subscription form for details. Organisations requiring multiple copies and anyone who doesn't have a subscription form: please get in touch.

Editor: the Goth

National Autistic Society production support: the Publications Team

NAS phone support: the Supporter Care Team

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

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

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

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

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

Please send all correspondence and subscription requests to:

Email: asp.utd@nas.org.uk

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

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

All we need is your email address and we will add you to the email notification list.

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

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

Asperger United is available in **large print** on A3 sheets (double the size of this page). If you need large print, please let us know using the email address or postal address above.

Contributions for the next issue should reach *AU* by **6 November 2017**

Welcome to the October edition of *Asperger United*.

Apart from the hundreds and hundreds of survey forms, this was a quiet postbag — you clearly put your energy into the survey.

More than 10% of you returned the survey, compared to the last printed survey in 2007, when less than 0.5% were returned. This shows how strongly you felt about the changes. The survey report is on page 4, and on page 5 is a notice from the National Autistic Society about the changes that are happening to the magazine.

As well as trying to run a paid version of the magazine, which you will have to subscribe to, we are altering the terms and conditions, rule 5 on page 19 — please see the notice about the

change at the bottom of page 18. Instructions for subscription are on the subscription form that is included with this magazine. Extra forms are available by contacting me or the NAS. I hope this new regime will be a success.

So, due to the quiet postbag, as well as publishing most of the letters and articles I received this quarter, I've gone back through the pending folder and picked out several pieces I've been wanting to publish for up to ten years. Everything that's suitable for publication remains in the pending folder until it appears. I hope that the authors are pleasantly surprised to see their efforts finally in print.

As ever, I shall look forward to the postbag,

the Editor

the survey edition — suggestion for next issue on page 11

Contents

Tree in oils cover
art by Tammy

2017 AU survey analysis 4
feature by Holly Judge of the NAS Research,
Monitoring and Evaluation Department

AU developments 5
feature by Mark Lever, CEO of the NAS

The days before Asperger syndrome 6
letter and article by Elkie

Pen pals 7-8

Letters to the Editor 9-11
one about relationships from Nathan,
one about sensory differences from Ian,
one about themes from Michelle, and
three about *Asperger United* from
Ruth, Susan and Selina

What not to say to an autistic person 12-13
article by Lydia

Letter about spinning thoughts 13
from Laurie

Last of the rare-book cataloguers 14-15
article by James Christie

Sexuality – article by Christopher 16-17

Letter about late diagnosis 18
from Graham

Change to rule 5 – notice by the Goth 18

The rules of *Asperger United* 19

Group notice back cover
Connect Ealing – a new social group
by Dan Mayfield

2017 *AU* survey analysis

by **Holly Judge** of the National Autistic Society

As a readership no one can doubt we have very strong opinions on most issues and the responses from our 2017 *Asperger United (AU)* readers' survey are no exception!

Who responded? Out of the 9,700 paper surveys sent out in July we collected 1,042 responses in total (887 on paper and 155 online). This means that around one in ten of the readership responded.

From this sample, 66% of readers identify as autistic, one in ten as professionals and the rest as parents. 28% of parents and guardians of autistic children identified as autistic themselves, and 38% of professionals identified as autistic.

Your impressions and the impact of *AU*: reflected both in the "Why do you read *AU*?" and open-ended-feedback questions, most of the autistic readership feel that *AU* makes them "feel part of a community" and "less lonely".

Over 70% of respondents agree that *AU* is interesting and informative with half sharing their copy with at least one other person (with some copies shared with more than five people, increasing the readership by at least 120%!).

Many parents reflect that *AU* gives them understanding, hope and relief that there are others to connect with their children and, for professionals, perspective.

Your favourite content: 80% of respondents said features and articles are among their favourite content, with letters and stories above 55%.

Autistic readers are slightly more likely to select pen pals and artwork as favourites.

Most readers prefer items to be a page or less, with ideas for future content ranging from: advice

and support, local services and events, puzzles and competitions, hobbies and special interests and latest autism research findings.

Your response to *AU* going on line and print copies no longer being distributed free of charge: now, for the moment of truth . . .

53% of respondents said they *would* read an online version, and a further 25% would have the capacity to print off copies. 22% of respondents selected that they *would not* read an online version and have *no option* for printing a copy.

As well as overall numbers showing that the majority of readers could access the online magazine, some open-ended comments expressed understanding or support for this change, for example: "I have enjoyed this magazine but understand that costs have forced it on line".

However, open-ended comments expressing regret, difficulties or opposition outnumbered accepting comments by six to one, for instance:

"I have difficulty processing information like this", and "I feel sorry for those who will not be able to receive *AU* for various reasons".

Reasons for *not* reading online included: not being able to look at online pages for sensory reasons, not knowing how to access online pages, no access to a computer, tablet or smartphone and less likely to share copies with others.

A universal shift to an online format poses a risk of us losing 22% of our existing readership. However, half of this group said they would be willing or able to pay for a subscription. So, in order to provide print copies of the magazine for these readers and to other people who prefer that format, the National Autistic Society have established a subscription system.

***Asperger United* developments — subscribing to print copies and developing the online magazine**

by **Mark Lever**, CEO of the National Autistic Society

In last month's *Asperger United* I explained, on the back cover, that the charity was planning to develop the online version of the magazine and to stop distributing free paper copies.

We wanted to test the impact of these planned changes before shaping a definitive proposal, and over a thousand of you completed the readers' survey. Thank you.

Holly's article, opposite, gives you more details about the results of the survey. In summary, 22% of respondents said they could not read the online magazine, or print pages and read them.

Establishing an online magazine is a positive development in itself, but the needs of those unable to access or read material online have to be addressed. At the same time, the charity needs to meet the very real financial challenge relating to the magazine's print and distribution costs.

Therefore the charity will continue to produce paper copies of the magazine through a subscription system linked to your ability to pay:

- A "donation" level for professional and overseas subscribers and for people choosing to pay a supplement — by subscribing at this level you will allow us to print and distribute copies of *Asperger United* at a reduced rate to one person (or more) who cannot afford the standard rate. You will also fund the free copies we distribute at events.
- A "standard" rate for people who can afford to pay this rate, which covers all the costs of producing and distributing the magazine.
- A "reduced" rate for people who cannot afford the standard rate.

You can find out more about the subscription system on the subscription form enclosed with this issue of the magazine. If no subscription form is with your magazine, or if you have lost it, please ask for one. You can contact the magazine in the usual ways: e-mail, post, phone — contact details are on page 2.

We will also continue with the development of an online version of the magazine that maintains the same content under the Goth as editor. The online magazine will be more than a PDF on the website, and will allow *Asperger United* to benefit from the advantages of going digital. These include the magazine being available to more people without incurring additional costs and many more back issues and old articles will be available. Also, we'll be able to link from articles to useful related content. You will be able to read *Asperger United* on your phone and tablet, and share and search articles.

There will be an easy-to-print version of the magazine on line.

The subscription system will run for an initial six-month trial period, to see how well it works. The subscription system trial and the development of the online version of the magazine will be undertaken in consultation with autistic members of staff and of the charity's National Forum and with the two hundred respondents to our survey who were interested in providing feedback about proposed developments to the magazine.

We realise that these may be difficult changes for some of you, but I can assure you that the National Autistic Society is committed to this unique and valued publication — written and produced by and for autistic people — and to ensuring it is made as widely available as possible.

Dear Editor,

thank you for *Asperger United*. To be honest, the articles about Dr Who, Tardis and Daleks made me feel more alienated from the readership than ever. As I do not watch television or read science-fiction books, but prefer to spend as much time as possible in the natural world, I have no clue what these people are talking about.

Instead of the many personal (problem) stories, I would like to see more general, research-based articles in the magazine, but perhaps I'm in the minority here.

For an edition on late diagnosis, you might consider including the following article,

Elkie

The days before Asperger syndrome

by Elkie

During the 1970s and 80s, when I went to school, autism was still poorly understood and usually referred to non-verbal and very difficult-to-manage children. The term Asperger syndrome had yet to be coined, though the teachers in our special class for gifted children must have had some inkling of Hans Asperger's work, since their approach to education mirrored many of his recommendations.

Despite this, I left school at the age of 15 to train as a gardener and later work on organic farms, as it was a safer environment to cope with the increasing pressure of my mental health problems (OCD, Tourette's, psychotic episodes . . .). At the age of 24 (still in the 1980s) I spent six months in a psychiatric hospital in very intense psychotherapy. However, I never felt properly understood and much of the advice and intervention didn't really work for me. It did enable me, though, to continue my education and eventually graduate from university and become a teacher for children with special needs.

Early on in my career I was working with a boy who had a diagnosis of Asperger syndrome and his ways of perceiving the world and acting in it was almost a mirror image of myself at that age. I began investigating the newly formed term Asperger syndrome, and the more I read, the surer I became that this explained my

underlying difference to the people around me. Mentioning this to my GP, who monitored the medication I was taking to control my mental health, I was referred to a psychiatrist who in the following three years took me through a variety of assessments, as well as conducting general psychotherapy and referring me to a creative socialising group led by the occupational therapist for adults with Asperger syndrome. So, in a way, my diagnosis of Asperger syndrome was embedded in therapy and came as a relief rather than something to be wrestled with or grieved.

Meanwhile, I've had my autobiography (*Discovering who I am — growing up in the sensory world of Asperger syndrome*) published, had the opportunity of becoming one of the founders of the Autism Rights Group Highland (ARGH), sharing my *Insight into autism* workshop with hundreds of staff in education in the region, holding lectures on autism topics and being involved in setting up the autism module at Aberdeen University. All this would not have been possible without the diagnosis of Asperger syndrome. So I am very grateful for it and for the way my colleagues, neighbours, fellow church members and many professionals are accepting me as I am and respect my unique experience and understanding of autism and Asperger syndrome. This is a far cry from the life I lived in my teens and early twenties.

Pen pals

Pen pal number 252

Dear *AU* readers,

my name is Alan. I'm a 37-year-old gay lad with autism. I thought that I'd start this pen-pal letter to let people similar to me in Northampton, as well as all *AU* readers, get to know me better. I like to socialise with family and friends and also I like to make new friends with autism. I like doing things like bowling, cinema, going to pubs and social events, like Gay Pride, Autism Pride, animal welfare campaigning events as well. I've been bullied on Facebook for being autistic and gay; I have blocked Facebook trolls who are friends with the residents of a local animal sanctuary, due to them supporting this homophobia and hatred towards us vulnerable people with autism. It should be shut down in my view, it's not fit for purpose. I advise all *AU* readers to visit Animals in Need Northamptonshire and campaign. I would also like to express my view that anyone who has capacity with autism who has spent many years detained under the *Mental Health Act 1983* should not be detained unnecessarily as long as they don't pose a risk to themselves or others. I think the *MHA 1983* needs to be scrapped and replaced with something better and fairer. I do like to sometimes read Marvel, DC Comics. I believe there should be a world of animal rights, human rights — including LGBT rights — justice, democracy and peace, not just here in Britain but all over the planet! I'm seeking pen pals from Northampton, East Midlands, London, Bedfordshire with similar interests and views as me, please.

Thanks,

Alan

How to place a pen-pal advert

- All you need to do is send your advert along with your name and address (and email address if you want) to *Asperger United*. You can use the Royal Mail or email. The next pen-pal number will be given to your advert when it arrives.
- Please note that *AU* does not print dating adverts, as it is unable to provide suitable support.
- Those under the age of sixteen must have parental permission before placing a pen-pal advertisement in *Asperger United*.
- If you get no replies, please don't take this personally.

How to reply to pen pals

- Please remember to let us know the name and number of the person whom your letter is for. (All pen pals are numbered by the editor, not the person who sends in the advert.)
- Please remember to put your address on your letter.
- To contact a pen pal, please send your letter to *Asperger United*, c/o The National Autistic Society, 393 City Road, London, EC1V 1NG, or email asp.utd@nas.org.uk
- We will pass your letter on to the person you wish to contact. However, we cannot guarantee the person will reply as that is entirely their decision.
- Please note that all pen-pal letters sent via *Asperger United* are opened before being passed on.

****Important notice — please read****

Asperger United is happy to publish pen-pal advertisements but we must stress that we are not a pen-pal or introduction organisation. We do not match people up and we cannot monitor letters (other than the first letter, that is sent via us) so please be cautious when releasing personal details in your letters. The National Autistic Society / *Asperger United* cannot intervene or be held responsible for any ensuing correspondence between letter-writers.

Eight pen-pal adverts have been held over for publication in the next two issues, Editor:

Pen pal number 254

I am a single female,
I have a degree and various diplomas and certificates. I love animals, my cat died aged almost 22 human years. I look after the wild animals that visit the garden; I live near a park — foxes, badgers, squirrels, and birds. Hypersensitivity is one major problem regarding my diagnosis. I enjoy cooking (mainly Italian/French/American). I also bake — my favourite is chocolate cake; I like the American method. I enjoy watching television (but I hate adverts especially after seeing it once — like brainwashing) sci-fi (*Star Wars* trilogy), period dramas, Disney, science, history, politics and some art. My true affinity is for animals. I play chess, love reading non-fiction, and fiction/faction for anything pre-historical in England and history for period 1066–1300s. Am bilingual and the only child on the autistic spectrum, I am also a Christian. I need to believe in someone greater than myself. I am not an ageist so will be delighted to hear from anyone, anywhere in the UK with Asperger's syndrome or high-functioning. Thank you for reading, it will be nice to hear from you. **JC**

Pen pal number 253

Hello, I'm Cassidy. I am 23. I love cats, and the Muppets, especially Dr Phil van Neuter — the green scientist dude.

I live in the States, and I am proud to be a soldier of my Salvation Army Corps!

I totally look forward to hearing from you.

Pen pal number 255

Hi my name's Kelly and I am looking for a penfriend both male and female. I would really like a penfriend with Asperger's syndrome. I have Asperger's syndrome and would really like someone with the same thing. I would like more friends. I do have interests: I like going to the gym, I like listening to music. I also like the Internet, socialising and I am thinking of taking up knitting. I would like an email penfriend. I hope to hear back from you.

Pen pal number 256

I am Tilly. I am 27 and live in London; I have many interests, including languages, travelling, musical instruments and sports such as badminton, ice skating and tennis.

I like museums and walks to local parks and cafés.

I would like to get to know people with similar interests and aged between 24 and 35 who also live in the UK.

I have a quirky sense of humour and style and look forward to making new friends.

Pen pal number 257

I am Scott and am now aged 57 and would like to expand my pen friends, any age bracket will do.

My interests are horse riding, going for walks, visiting museums and art galleries, current affairs and world history.

I am not interested in paganism or religion.

I also like to try out world food and am interested in different types of drink, whether herbal or alcoholic.

I am interested in the earliest bank notes and coins, especially around Greek and Roman times.

I love all types of world food and drink and enjoy a good curry, chilli con carne and goulash, not to mention German and French food and drink.

I will eat any European or world food from whichever country I'm in at the time; I also like vegetarian food and love a good nut roast or veg curry, or even veg goulash!

I am a floating voter so my party colour changes as often as I change my football shirts, so I may require someone very down-to-Earth who does not mind my changes to team or party!

two letters to the Editor

To *AU* magazine,

I am sending this email, firstly, just to say thank you for the great articles in your magazine.

Secondly, I see a bit about you maybe doing a article on fandom and wanted to add my view.

I'm 32 with AS. I just wanted to say my point of view over my obsessions: *Doctor who?*, *Star trek*, comic books, *Sherlock* and wrestling.

Growing up I absorbed so much information about most of these subjects, and I believe now as I did then that it was for a purpose.

Finding it very hard to relate to people and get involved in social situations, I used my knowledge of these subjects to kinda integrate, as people enjoy these shows as much as I do. I found that having a vast knowledge of these things is a way to relate to my friends and family.

Being so into these means I had something in common with so many others, or at least enough knowledge to hold a one-way conversation.

I believe you need to do an article on this as not so much for people with AS but for carers and parents so they can understand it is normal and take the time to have a conversation about their loved one's chosen thing.

A good example of this is: I have found it hard, as my daughter got older, to relate to her as being a father who finds it hard to express my opinions and feelings.

When she got to about 12 I put on a wrestling DVD and she was hooked. Having that there as a conversation starter has improved our relationship no end.

Through these chats about wrestling I have found she also loves *Doctor who?* and *Sherlock*: a proper fangirl.

We now take time to chat daily about the shows we both love and the arrival of the new

Sherlock on our screens has also led to being able to explain my social insecurities through the way the lead character has social problems: for example, being able to explain my one-track mind through the way Sherlock acts towards subjects that he is interested in.

It's amazing that through a TV show we now arrange days out to go to comic-book shops and Baker Street and so on.

What I am trying to say is, I think parents and carers of people with autism don't realise that our fandoms and obsessions are a gateway to other and more meaningful conversations.

Take time to talk to us about our loves: mine has not only led to a better relationship with my daughter but to a business in comic books.

People think our obsessions are strange but I've not met any type of person who I have said, "Sit down and watch this episode of *Doctor who?*" to and isn't now obsessed themselves.

Nathan

I am an adult male with AS and was diagnosed aged 12. I have noticed from autism websites that many people have numerous problems attributed to AS, particularly sensory issues. I do not have such problems and this makes me feel in the minority and marginalized. I do not like to feel like this, as though I cannot connect with anyone.

I would really like to know if there are other people out there without sensory problems and other needs, which seems to me to distort the condition of AS. I am looking forward to a response or two.

Ian

I hope we get lots of replies to this letter. My experience is that I've never met an autistic person without sensory differences, but I've met many who didn't realise that their sensory experiences were not the norm, Editor.

letters to the Editor

Dear AU,

in the last edition (91) Wendy mentioned some themes. I can relate to the few mentioned, like the one: *How to get out of the big black hole of gloom and doom and Communications tips.*

Sometimes being different comes with its ups and downs. I always find the downs being quite depressing and grey-cloud day. But the ups are much more interesting. For example, when communicating with someone of a different brain (non-Aspie) I always find myself either drifting off or not quite fully understanding. Sometimes people ask “Hey, did you get that?” I mostly say “Yes” because explaining what I didn’t get and what they were explaining means more explaining in an Aspie-non-Aspie way. Also, as for slipping into the gloom and doom of negativity I always find early warning signs are good, but not always noticeable straight away. I always put myself down first and then start missing social events and then everything else after that is like rain, rain, all day and night. I also like to help out and get involved when I’m feeling so hyper and positive. I tend to take on loads and loads and my head has so many ideas that I then kind-of overload and burn out.

So going back to the themes mentioned by Wendy in edition 91, I think a lot of them are really relatable to Aspies and possibly non-Aspies. I also wonder if in the future there may be a lot of Aspies taking over the big-name jobs. Look at Albert Einstein = genius.

Also I would just like to apologise for my grammar and probably tonnes of mistakes.

Michelle

Thank you. Regarding mistakes, no more than anybody else, Editor.

Hi Goth,

I got my copy of AU yesterday and thought I’d respond to some of your ideas for changes. I think it may be important to have a dialogue in AU about it before making big changes because there may be issues some people with less of a wide disability awareness will be unaware of.

So regards the cover, I don’t really mind what you do, though perhaps having a colour front page would be good. There are environmental implications to using a lot of colour in a publication.

My main comments are about the issues dyslexics may have. First I think it’s very important to say individual dyslexics have very different issues. Changing the font may help some but make it worse for others. The same goes for coloured backgrounds or coloured type. I suspect that the best way to make AU more accessible to those with colour issues is to make available information about Irlen testing for coloured filters, and colorimeter testing for coloured specs, because then each person can make their own adaptations and nearly everyone will be able to find a way to make AU readable if it is published as black and white. Once you start changing the colours of the publication and the type you will find that most people with colour issues will not be able to access some part of the publication — for example, I can’t bear a yellow or red background but with black on white I can always use a purple Irlen filter. I find the NAS membership magazine very hard to read because of the variety of colours.

I’d hate to see less info in AU if making space around the text will mean less text on a page. I’d like to see more pages and more frequent issues of the newsletter — if indeed you get 300 or so submissions for each issue then clearly there is a need for this.

I hope this is useful.

Thanks,

Ruth

This letter is from 2009, when there was no space to print it, but I wanted to show that change has been ongoing, and the feelings expressed in this letter are still representative, Editor.

two more letters to the Editor and a notice

Dear Goth,

in response to *Asperger United* reader survey:

I find cutting the funding for the magazine would be a huge loss not only for me but for many others who cannot access the Internet because of disabilities, including that of light sensitivity, and difficulty looking at the screen.

In some cases people with the condition also have learning difficulties, and mental-health issues, anxiety, which makes the Internet not accessible for everyone and having a copy of the magazine in booklet format to make the most of the information provided in my own time and space.

I would be grateful if you could look into funding from other sources so the magazine continues to be available to vulnerable autistic people. A lot of people, including myself, with disabilities

will miss out and not have access to this valuable resource.

As someone who has recently had a late diagnosis at 60 — but I am younger than my years — it is all very new to me. I felt the magazine helped me to relate to others like myself, and possibly making contact with others.

Maybe a small amount could be printed to certain people who cannot access the Internet. Or a copy sent to the local Asperger group so people can read there.

I do not understand why cuts are always made where autistic and mental-health issues are concerned and we are always being penalised instead of being helped.

I do hope you can find a way of funding and printing this great magazine.

Susan

Dear Editor,

putting *Asperger United* on the Internet and making the magazine more costly will really affect me. Because I don't use a computer or the Internet because it makes me stressed using it. And I think *Asperger United* should be free of charge still to non-Internet readers, because some people might not be able to afford to pay any money. Also if this change does happen making charges to *Asperger United* and putting *Asperger United* on the Internet: will non-Internet users still be able to write and how if people can't afford the prices?

From

Selina

Everyone will still be able to write and send paper letters to me, and AU is already on line. The main change is the end of the free paper copy. The free copy is being replaced by a trial for a paid copy. The secondary change is the expansion of what is available on line.

For the foreseeable future, both a PDF of the paper copy (as usual) and a (new) hyperlinked digital version will be on the NAS website. The new digital version will have all the advantages of digital: sharing, linking and searching, as described on page 5, Editor.

The changes to *Asperger United* will continue to be discussed in the next issue. This subject includes the effects of the changes on you, any questions you have about the changes, and any other points you want to raise. (If you haven't read about the changes yet, please see my editorial and the articles on pages 4 and 5.) However, there may be a different theme: if sufficient material is sent in, the theme for January will be **things people say to us and**

other people's understanding of autism. Vote with your contributions: the more submissions on a subject sent in (from different people) the more likely that that subject will be the theme. Writing on any subject is still welcome (though I have a feeling this one will produce lots of letters) as are ideas for new themes, and artwork. Remember, if you want to see different content in *AU*, the best way to change it is to send something in!

What not to say to an autistic person

by Lydia

Just over a year ago, I was diagnosed with Asperger's syndrome; to be honest, it really was not a surprise. What was notable, however, was the amount of seemingly innocent, but actually quite hurtful, comments, on revealing my condition. People seemed to find me scary, wary of even daring to talk to me. Hence, came a list of comments not to say to an autistic person:

"You don't look autistic . . ."

What does that even look like? That's so insensitive, because one thing that's really tough is how we appear to be neurotypical. It's also borderline silly. Please don't ever say that to me. Ever.

"Oh, that was caused by the MMR vaccine . . ."

Newsflash: no, it's not. Also: why are you more afraid of us, on the basis of a cognitive disability, rather than an epidemic disease, that is far more a risk to us all? Ebola, Zika. Also: autism offers so many skills to utilise. Why would we want to see evidence of a conspiracy? (We wouldn't.) It's also irrelevant to somebody when they've been diagnosed.

"Can't you just reason your way out of it?"

No. Just no. Attached to autism is anxiety: as a tied-up disorder, or just as itself, it's impossible to reason with it. Call it a voice, a person, that's convinced it's always right. You can't reason. It affects morale. And logic doesn't always govern everything. Though that's what we're usually known for.

"That noise isn't aimed at you."

So? The best way I can describe it is having non-stop surround sound: it also can't always be filtered fully enough. I'm aspergic, and if

sound is too loud, I hear a roaring in my brain, blocking me from thinking clearly. Others may have meltdowns. You may also be stimming. And that doesn't help. Noise doesn't have to be aimed. I'll block out the noise from the road with headphones, along with rock music. I rock like no one is watching.

"Stop stimming."

Um, no. No. It's a reflex, almost, as if to comfort.

"You're just pretending, for attention."

If my doctor says I'm autistic, then I wouldn't be pretending. It's a recognised condition, as is the autism spectrum. We are not pretending. All we need, instead, is tolerance and patience, the same as everyone else, generally. We don't want excessive attention.

"You're really clever . . ."

Clever is subjective to the individual, surely? For example: I suck at maths, but am far better at anything to do with words. That's not being clever, it's specialising in what your brain is most attracted to. That's my theory, anyway. I was bored of people saying that as a fact. I'm not like Albert Einstein, or Bill Gates.

"Why do you hate people?"

That's usually asked when I hide away in the library. I don't hate people. But the sound surrounding the collective of people is overwhelming, and is for anyone on the spectrum. I don't hate people. I just need time away, due to my senses being fused.

"Anxiety is a myth, as is autism."

Really? I think you'll find they both aren't.

an article (continued) and a letter

“I do try and understand . . .”

To put it bluntly: you won't ever do, unless *Freaky Friday* transpires, and you end up in an autistic body. All that's needed is tolerance and patience, not a pretence.

“Just because you're aspergic, doesn't mean you have a good memory.”

A personal characteristic is a good memory, but recalling factual information is a hallmark of the condition. To deny anything as factual as this is almost absurd. It's an asset academically, and something otherwise incredibly useful.

Asperger's and autism may be an ostensibly controversial disorder, but it really doesn't have to mean for you to be insensitive. There are so many skills, enough to be utilised for the better. Obviously, the list isn't definitive, and you can add anything else.

I will happily print more things that people say which are unhelpful, unthinking, or just silly, as I imagine this is a rich vein. The level of understanding of autism is very poor everywhere you look.

My personal favourite is when people immediately start looking scared of you when they find out you're autistic, Editor.

Do people have spinning thoughts about things which don't matter?

You know they don't matter, although you want or need to check Barnet were or were not a league side twice, not one spell.

You know it doesn't matter you read a supporter attended six hundred consecutive Cheltenham fixtures, although you want to email people about this.

You know it doesn't matter you recall Newcastle could've hosted Barnet, if Newcastle were relegated, from what was Division Two, 1992, as Barnet were promoted, 1993. Barnet were in the division that Newcastle were nearly relegated to, 1992.

These things are interesting, as is Reading hosting Barnet, 1993, Reading in the premier division, 2006.

My mind is reminded, Barnet are one of a few teams who were non-league, later a promoted football league side: Wycombe, Yeovil are others. Doncaster, Colchester are others who were non-league, later promoted to be league sides. However, they were traditional league sides prior to their relegation from the football league.

I forgot Macclesfield were non-league, later a promoted football league side.

Macclesfield hosted Manchester City at league football.

At a tangent, Middlesbrough and Fulham were relegated from the 1986 second division, later they were European finalists.

I could continue, however, does anyone else experience similar spinning thoughts about football or their special interest or obsession?

How do they cope?

I can live without checking whether Barnet were relegated twice as a league side.

However as you can see I have spinning thoughts about football.

Maybe I can write and someone somewhere someday could pay me, as I write at Studley's Programme most home programmes.

If someone paid me however little this would mean a positive about this writing.

I know this is a dream.

As I read at a bus-stop, “Life without a dream is a broken-winged bird that can not fly”.

Laurie

Last of the rare-book cataloguers

by James Christie

Only a few books to go and then so will I. It's been a long journey to a virtual chapel complete with stained-glass windows, weeding and shelving rare books in a reading room not twenty miles from the special collection where I first learnt the library trade nearly twenty-five years ago.

Aspergers can be natural cataloguers but there are few left today, and while I've come to a dignified end, I leave a failing trade in disarray. Between 2010 and 2016 the number of UK libraries fell from 4,290 to 3,765, and 7,933 paid staff were slaughtered while volunteers doubled from 15,861 to 31,403. A 2014 library report confirmed that "the public library service in England is at a crossroads."

And given my long experience of a library "profession" brimful of jargon, bereft of leadership and bare of jobs, I do not believe the Chartered Institute of Library and Information Professionals (CILIP) is able, "to encourage and develop the library workforce and especially new recruits and graduates."

I really dislike CILIP, whose only response to being at a crossroads was to consider changing their name.

Talk about rearranging deckchairs on the Titanic, and then they didn't even do it!

Not that my library life began badly. My library course was mumbo jumbo, but my first job: the extraordinary experience of manually cataloguing antiquarian monographs worth millions of pounds in a stately home.

Aspergers have a firewall between their everyday personalities and the manic nutter subroutine needed effectively to catalogue. If I joke that "cataloguers make accountants look like hippies," I'm not actually joking.

I spent three years living, breathing and stacking books in a library like a time capsule from Victorian days . . .

Time and again, a novel by Jack Finney, defined the delicious possibility that:

"... it may be possible this summer . . . for a man to walk out of that unchanged apartment and into that other summer."

Unlike physical time travel via TARDIS, psychological time travel might be possible, that, if you spent enough time in a room from the past, you might find:

"... doors which let the lucky traveller, still young, walk out into a different summer and another day."

I came close to seeing that other summer and, fascinated by rare books, looked forward to telling my incredible story, hoping to be encouraged and developed.

And then I tried to get another job.

It was a torrid tale of frustration and fading hopes, my skills withering on the vine, my interest in rare books dying for lack of development and my patience shortening like a lit and burning fuse.

Some men endure Thoreau's "lives of quiet desperation." I wasn't one of them, and in 2006 calmly and career-suicidally wrote out how I felt; reasoning that I was doomed anyway and at least I'd avoid ulcers of sheer frustration.

I called it *The Gordian knot*:

"It's not often I start to write an article intending to crucify myself, commit professional

suicide and probably get myself beaten up by a rampaging mob of respectable librarians into the bargain, but I'm now so disillusioned with the profession that I would rather fall on my sword than stagger through interviews mumbling tripe I don't believe about metadata, revalidation, ICT, twelve-digit Dewey numbers and all the other pseudo-professional jargon we have invented."

It sounds funny now. It didn't then. Vampires, Hollywood and authorship were parts of a future I could not know; and I truly believed I'd destroyed any chance of work by cheerfully insulting my colleagues.

However, library campaigner Tim Coates (former managing director of Waterstones) published my death wish on his *Good library* blog and I went on to slag off librarianship in Tim's blog for the next five years.

God, it was fun.

My favourite quote was:

"Senior library managers should be shot out of the USS Enterprise's shuttlebay doors in their underpants."

It was easy to satirize twits who talked tripe about "social cohesion issues, automated tagging based on behavioral pathways, user-endorsed ratings systems and the negotiation of a reference question as opposed to the communication theory of reference interviews," and I did. An email of mine laughing at their daft drivel won letter of the month in the library journal *Update* in 2008.

Nor was I the only rebel.

In a 2012 issue of *Post-lib*, Francis Hendrix wrote:

"In 2003, . . . we commissioned Charlie Leadbeater to undertake a review entitled *Overdue*. It is still the best in-depth look at the sector. He finished by stating that "Unless decisive action is taken now, the decline of our public libraries

could become terminal by the end of the decade. If that happened Britain could be writing off vital social and cultural assets. Public libraries used to be central to the life of many communities but they are increasingly marginalised." The report recommended a ten-year strategy for transforming libraries. Well the ten years is now almost up, opportunities have been lost, all-encompassing government support has gone out of the window and with it one of the mainstays of a democratic and civilised society."

Now it's 2016 and British libraries are f****d. But my satirical blogs were read by Chaplin Books' founder, which led to the achievement of my life's ambition: published authorship.

I also thought my "career" had ended in 2011 when the NHS failed, laughably and amateurishly, to give me the library assistant's post they'd offered me in writing. But in 2015 I got involved with Culter Library in South Lanarkshire — a roomful of rare books near Leadhills Miners Library, where it all began.

If public libraries should fall, maybe subscription libraries like Leadhills will rise again.

It's been a fine and satisfying time showing how my dying art's done. It's a pity my trade will pass away with me, but I can't respect a "profession" so unsupportive, indecisive and inefficient it opens a £189 million library in Birmingham in 2013 and virtually shuts it the following year.

I place the last book on the shelf.

Time to go.

I look to the sky through the stained glass window, and step out into the light.

James Christie is the author of *Dear Miss Landau* and *The legend of John Macnab*. He was diagnosed with Asperger's at the age of 37 in 2002.

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Sexuality

by Christopher

I am a gay man in my forties with a diagnosis of AS, schizophrenia and OCD. Between the ages of 7 and 15 I was sexually abused by elderly men. As an adult, I identify as a gay gerontophile, meaning that I am sexually attracted to elderly men. Traditionally, gerontophilia was loosely defined by the DSM as a paraphilia which was regarded as a discrete mental disorder, much like homosexuality was considered before it was declassified in 1990. The debate as to whether gerontophilia should be considered a mental disorder had involved considerable controversy in the run-up to the publication of DSM-5 and the current consensus appears to be that only distress or impairment (the general prerequisite for most mental disorders) make it considered a disorder: clearly in my own situation that is not the case. I currently enjoy a loving, stable and caring relationship with a man in his eighties which offers me a more meaningful and sexually satisfying experience than the cottaging (frequenting public toilets for casual sexual encounters) which I was accustomed to as a younger man. As a survivor of child sexual abuse, I am drawn to consider whether my adult sexual proclivities are in some way connected to the experience of that abuse. Yet, despite a prevailing view within the popular imagination and in a number of spurious online sources, which draw a connection between child sexual abuse and sexual orientation, there is no reliable evidence to suggest that child sexual abuse is complicit in the formation of sexual preferences, nor can it be said to be a determining factor in contributing to any form of homosexuality. For many years, I too assumed that there was a connection between my experience of child sexual abuse and my sexual preferences in my attempts to conceptualise what had happened to me as a child and its impact on my adult life. Yet I also recall a period of being pre-sexual in early childhood before the abuse took place when I was already attracted to the physical appearance

of elderly men. It would, therefore, seem to be the case that gaining a clearer understanding of childhood sexuality is important in arriving at a more thorough appreciation of child development. In fact, compared to other areas of child development, sexuality is one of the least discussed topics and was entirely unrecognised until Freud's pioneering research at the beginning of the twentieth century. The question does, however, remain, as to whether sexuality is innate or socially constructed. That is to say, whether, genetics or environmental and experiential factors play a part in its formation. I propose that there are elements of both; that in addition to genetics, environment and personal experience are probable factors, though to what degree each is responsible varies from individual to individual. I would also add that these underlying factors are most probably further reinforced by subsequent engagement in sexual fantasy, fixation on a particular object of sexual desire and repeated sexual self-gratification which all contribute to sexual responsiveness and the formation of one's sexuality.

Historically those with developmental conditions were not thought to have any sexual feelings (Irvine 2005) which is related to the more general societal stereotype that people with disabilities were always dependent, incompetent and a-sexual. Although, within the field of academic ASD literature, sexuality has been rarely discussed by scholars, Newport and Newport (2002) suggest that people with ASDs are indeed sexual and do encounter sexual abuse, while there is also some evidence to suggest that children with ASDs are at increased risk of being sexually abused and that this may be related to the unique challenges they face with socio-emotional communication. The time has arrived, therefore, for informed and mature discussion, social debate and rigorous research within the broader context

of sexuality and disability; a taboo which finally needs to be broken.

As Geoff pointed out in edition 77 (page 9), there is a higher proportion of LGBT people among the ASD community compared to neurotypicals, yet prejudice against non-mainstream sexualities within the AS community appears to be a major problem, as intimated by the Goth on page 3 of the same edition. Such homophobia is inexcusable, indefensible and intolerable. Does its presence suggest that there's an uncomfortable expectation of conformism within the AS community which does not welcome diversity? Or worse, outright contempt for the outsider, the new and the different? Such an underlying parochial and regressive mentality within certain quarters of the AS community is surely a target for social and remedial action. Such elements would benefit from thorough critical self-reflection and re-evaluation of the underlying causes of these prejudices and focus on adopting more constructive perspectives. Such prejudices are, perhaps, themselves symptomatic of similar attitudes within other minority groups and of those whose own experience of the world is still too narrow.

Norms can only serve any useful purpose in order to evaluate the alternatives on any given issue. Tolerance and individual freedoms are everywhere under siege by the forces of religious fanaticism, cultural provincialism and irrational authoritarian reaction, while dominant power relations are an ineradicable element of modern society which have implications for all of us in the exercise of freedom and choice. Centuries of attempted social regulation of sexual behaviour (and its by-products, heterosexism and homophobia) are themselves related to the inherent contradictions in earlier historical periods which have been carried over to the next and in which these assume a new, often pernicious, character. Never has there been a greater need to interrogate and contest prevailing assumptions, systemic domination and the canon of normative sexuality which curtail individual choices and freedoms. Only a full transformation of private troubles into public issues can succeed

in rendering the institutions of power accountable to the disempowered.

Not only is there a need for greater recognition of diversity within the AS community, but also within the LGBT community which has yet to fully embrace the complexities of human sexuality. Hindered by misconceptions about gay lifestyles promulgated by the mass media and popular culture, there is an assumption that all gay men are hedonistically promiscuous, enjoy, or are even obsessed with, anal sex, and wear pink and purple. I have neither time for, nor inclination to, be part of the mainstream gay scene, much of which merely seeks to capitalise on individuals and is obsessed with promoting a particular image of young urban gay males, many of whom display prejudice and outright hostility towards or fear of older gay men. This itself is part of the more general social malaise due to decades of mass indoctrination which exalts youth as a desirable state for all to emulate but which is, in fact, a socially constructed and insidious product of the post-war years which created a commercialised and commodified youth industry to serve the interests of a totally administered capitalist society and the promotion of its false freedoms.

After many years of internalising feelings of guilt, bearing the burden of shame, blame, self-abnegation, self-hate and carrying the psychological scars of years of sexual abuse, I am finally comfortable with my own sexuality. It has been a long, often agonising, existential journey in which I have had to renegotiate socially imposed values and the legacy of trauma which has impacted heavily on my ability to determine my own social and functional outcomes. While, for much of my life, my choices and actions have been negatively and unfairly judged by others, as a result I have learnt not to judge but to value and celebrate diversity in all its forms. This is what makes the world a beautiful place. Let's not make it ugly by judging others according to divisive and exclusionary standards which only serve to belittle choice and freedom, while playing into the hands of bigotry and the institutions of power and social control.

a letter and a notice

Dear Goth

Attempting to obtain a diagnosis of Asperger syndrome very late in life has its own particular difficulties. I am thinking here of those, perhaps in their sixties or seventies, whose working life may be over and who will have learned only recently about ASD and recognised that this is the cause of their lifelong problems. They will have grown up during a time when this condition was not known and they will have had to make their way through life without the support and understanding that is now available. During their youth they will have had to knuckle down and somehow conform to society's rigid standards of behaviour or face the consequences! Low self-esteem, misery, psychological damage and worse could well have been the outcome for those searching unsuccessfully for an explanation of their social ineptness and resultant place on the fringes of society.

So what are the particular difficulties that this age group encounter when attempting to obtain a formal diagnosis? A diagnostician will typically wish to talk to parents or others involved in the upbringing of the person to learn something of the history and development of the child. For those in later life this may not be available as parents or others may well be dead. Remember also that this age group will have had more than half a century of disguising their differences in order to fit in and may be able to engage in small talk, eye contact and other "normal" social interactions — so the signs will not be as clear as those displayed by younger people on the spectrum. These difficulties may be enough to prevent a positive diagnosis.

Important change to *Asperger United* terms and conditions

notice by the Goth

The NAS has decided it needs to change rule 5 on page 19 of *Asperger United*. The NAS would like to keep in touch with you about NAS services, support, events, campaigns and fundraising. If you want to hear from the NAS, you can opt in to this on the enclosed subscription form. The NAS will only contact you in the ways you want.

Some may consider that a positive diagnosis is not so important for this age group as they will not need support and help with education and employment, and may not need social security benefits now that they are pensioners. Learning very late in life about Asperger's and realising that you have an explanation for your own particular difficulties during that life is not enough - you need the acknowledgement that a positive diagnosis brings, as this will play an important part in accepting yourself and explaining yourself to others. Having a positive diagnosis withheld when you know in your heart and mind that you are on the spectrum is exceedingly painful to live with.

Perhaps one day we can bypass the diagnosticians and take an MRI scan to determine whether or not we have ASD.

Yours sincerely

Graham



The rules of *Asperger United*

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

- 1) *Asperger United* is funded by the NAS and readers' donations, and is independent of the NAS. Although it is called "*Asperger United*" it aims to be for the whole of the (reading) autism spectrum. That is, the concerns and joys of any autistic subscriber can be printed, not just Asperger's.
- 2) *Asperger United* is quarterly, published in January, April, July and October. If you do not receive a copy when you expect to, please contact *AU*.
- 3) Pieces that appear in *Asperger United* are credited using the author's first name only, unless the author requests something different. This is done to protect your privacy.
- 4) *Asperger United* administers the copyright of everything that appears and it does this on behalf of the authors.
- 5) The NAS would like to keep in touch with you about NAS services, support, events, campaigns and fundraising. If you want to hear from the NAS, you can opt in to this on the enclosed subscription form. The NAS will only contact you in the ways you want.
- 6) If you subscribe to the paper edition and move house, please inform *Asperger United* and include your old address as well as your new address. Even if you've paid for the Royal Mail forwarding service (or another forwarding service), you still need to inform *Asperger United* that you have moved address.
- 7) The current edition of *Asperger United* is available at **www.autism.org.uk/aspergerunited** You need to scroll down to the middle of the page, where there is a link to the PDF.
- 8) You do not have to be a member of the NAS to subscribe to *Asperger United*.
- 9) If you phone and leave a message on the machine, please speak slowly and clearly and spell uncommon words, as the line isn't very clear. Please give any phone number you leave twice for the same reason. Remember to give your postal address so that we can find your record.
- 10) You can sign up for an email notifying you whenever a new edition of *Asperger United* is posted on the webpage above. Email **asp.utd@nas.org.uk** asking for the notification by email and please include your full name, postcode and let us know whether you want to subscribe to the the paid paper edition too.
- 11) If you want to unsubscribe from the paper version, inform *Asperger United* and include your postal address. Or to unsubscribe from the email notification, include your email address.
- 12) If you want to resubscribe (or subscribe for the first time) inform *Asperger United* and include your postal address and fee (for the paper version) or email address (for the email notification).
- 13) Book reviews are the most popular thing in *Asperger United*, please consider submitting one. They can be about any book, not just books about autism. Also, they do not have to be short (the Goth keeps most of his reviews short to leave more space for other writers). If you do not want your review to appear in other NAS publicity about that book, please make this clear.
- 14) Although each issue is themed, submissions on any subject are welcome. Only some of the letters and articles in each issue will follow the theme. All submissions may be edited, especially for privacy, libel, and for fitting the space available.

New social group **Connect Ealing**

Next two meetings 11 and 25 October, 7pm

notice by **Dan Mayfield**

Hello Everyone!

Email: **Dan.Mayfield@nas.org.uk**

I represent a department known as ASSIST which is part of the National Autistic Society. We are pleased to announce that we have begun a new fortnightly social group called *Connect Ealing* which takes place in Ealing Central Library in West London.

Mobile: **07792 137 681**

Details of the group:

Connect Ealing
a new social group for adults with Asperger's syndrome

This group is for men and women with an Asperger's syndrome diagnosis living in Ealing. We meet for two hours in the evening every 2nd and 4th Wednesday of the month.

Every 2nd and 4th Wednesday

We have booked the Green Room in the library for our own private use and congregate there each time.

Green Room
Ealing Central Library
103 Ealing Broadway Centre
The Broadway
London
W5 5JY

For further information regarding times and so on, please contact: **Dan Mayfield**

Welcome!

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