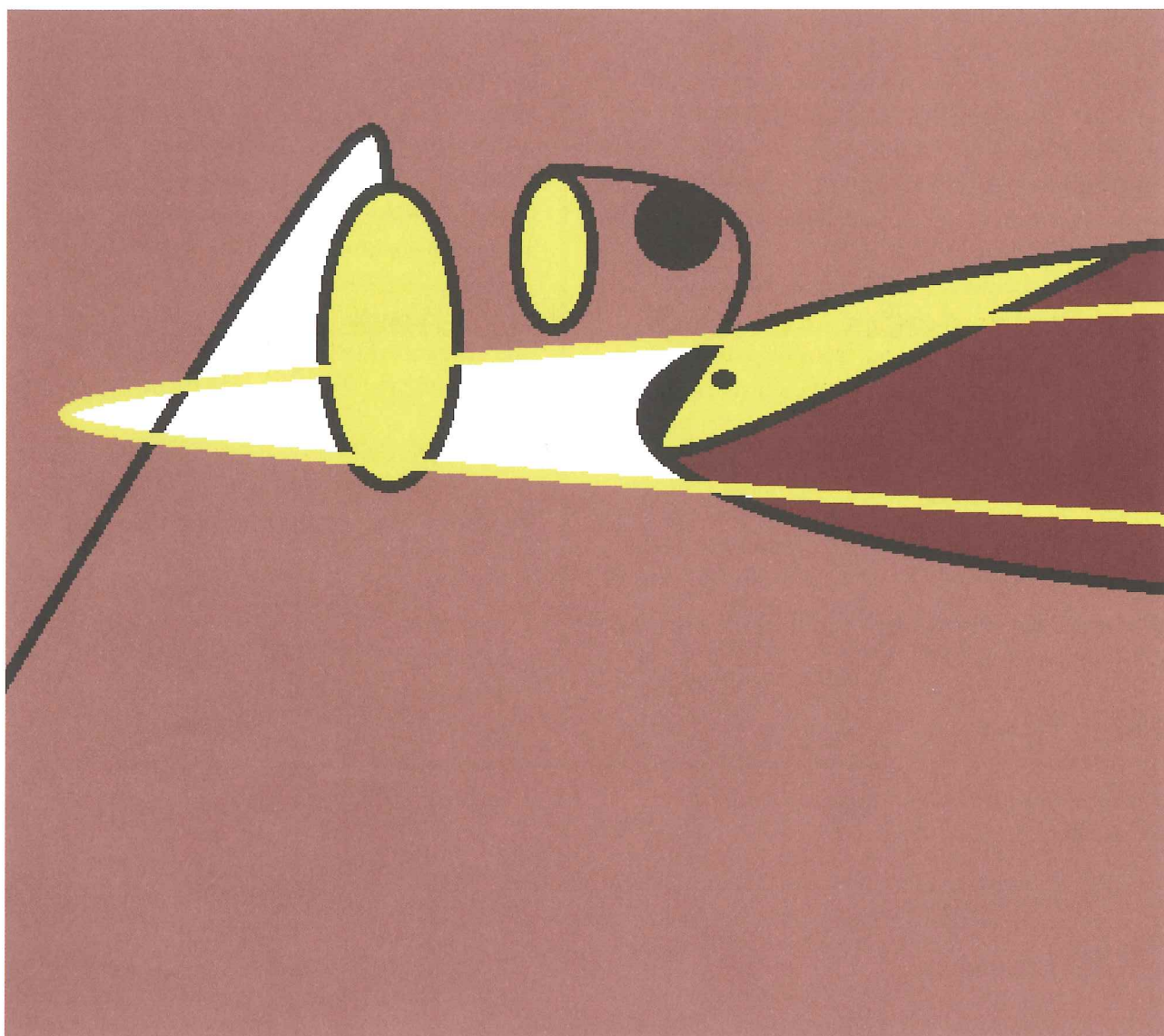


Produced by and for people who have autism-spectrum conditions

# Asperger *United*

Edition 78 April 2014



AU

  
The National  
Autistic Society

# Asperger United

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

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

*Asperger United* is free. To subscribe you, we need your postal address. We ask for a contribution of £9 per year from overseas readers and £15 from professionals and institutions to cover postage costs. Please make cheques payable to the NAS. Organisations requiring multiple copies: no extra fee, please get in touch.

**Editor:** the Goth

**National Autistic Society production support:** the Publications Team

**NAS phone support:** the Supporter Care Team

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Tel: **020 7923 5779** (geographical charges apply)  
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*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.

Email: [asp.utd@nas.org.uk](mailto:asp.utd@nas.org.uk)

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

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

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

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

Contributions for the next issue should reach *AU* by **12 May 2014**



**Welcome** to the April edition of *Asperger United*.

Not surprisingly, there were a large number of responses to Edward's article, and I've tried to represent the spread of opinions fairly, so the more space an opinion gets, the more people there were who wrote in with roughly that view. Balancing opinions like this is something I always try to do in the magazine, but I don't think any editor of *AU* has mentioned it before.

Sexuality also proved to be a hot topic, though I fear I frightened off anyone wanting to write about heterosexuality when I mentioned that letters about other forms of sexuality usually prompt complaints from people who

object to sexuality of any other form. I did not intend to silence discussion of heterosexuality, I only mentioned the complaints as a point for discussion — you are, of course, free to complain!

Also, if you would like to write a contribution about your heterosexuality, please do. In this issue we have mention of every other type, including the catch-all "trans\*", which covers both simple transgendered people and also people who are not simply an X in a Y's body (such as a woman in a man's body) but who are a mixture of X and Y either mentally, physically or both. I wish that was easier to explain in such a small space (and I hope I've gotten it right!),

the Editor

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## the sexuality edition — the next issue notice is on page 9

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## A response to Colin's letter in January

by Alice

"For it is a truth universally acknowledged, that a single man in possession of a good fortune, must be in want of a wife."

Colin — thank you for your thoughts on celibacy. I read your article with mixed feelings, and felt moved to respond, on behalf of people like us everywhere. Firstly, thank you so much for revealing the personal information you did. I don't want you to take offence if I conclude by soundly disagreeing with you. I do it in the most peaceable manner possible, but I felt compelled to write in to encourage any readers who had read your article and who have a moderate diagnosis of Asperger syndrome to believe in love.

Of course, I do agree with you that some people with autism will find a relationship more difficult. This is because we don't always read signals very effectively, and some of us will have formed unhealthy attachments in the past. When I was growing up I would develop an obsession with some poor object or other of my unwanted affections, and I recall the embarrassment even now, with shame. However, I had no social skills at all growing up, and I was completely incapable of forming any familial, filial or sexual friendships. I wasn't diagnosed with Asperger syndrome (AS) until I was twenty-five, at university. I am not two-and-thirty, and the year before last I had the thirtieth birthday of a lifetime, surrounded by about thirty close friends and family (and indeed, there would have been more, if I hadn't been born so inconveniently close to Christmas.)

Such a birthday party would have been unthinkable when I was a friendless teenager of sixteen, and obviously I have developed a lot socially since then. Don't give up on romance, Colin. I've wanted to, so many times, and I've almost come to the very same conclusion that you did — that people with a diagnosis of AS are not meant for a relationship. That's arguable,

of course. You've only got to read some of the stories of those with a diagnosis of AS who are trying to encourage themselves, and others, to keep their marriages alive. What about those who met their romantic partner before they had a diagnosis? Also, it's easy for us to feel that having a diagnosis of AS is the worst thing in the world, and yes, it can seem terribly unfair. There are other couples who have worse calamities to deal with though, such as childlessness, or cancer, or drug/alcohol abuse. There are even partners who go abroad to fight terrible wars, and return to their loved ones completely deformed, and I can only imagine the torment their marriages must go through — and some don't survive the suffering.

I'm not saying that it's easy for us, either, but your romantic failures so far do seem limited. You say you asked out a girl before you had a diagnosis. Well, before I had my diagnosis, I would have been unable to hold down any sort of relationship at all. I think you should try again. I also think it's worth keeping up your friendships with your support group: you never know what sort of interests could develop there, and the best sorts of romances are started through friendship and mutual apparent disinterest. Although I will steer clear of apps like Tinder, which seem to encourage all sorts of one-night stands, I intend to explore online dating again. Some neurotypical girls have had to kiss a lot of frogs before they find their prince, don't forget that. Some of my friends are my age, are not Aspergic and have not had a relationship yet, and I know people who have only met their life partner later in life — my aunt met my uncle when she was thirty-nine. Have faith. You wouldn't want to deprive some poor girl of finding her prince, would you, Colin? The most successful people in business have often failed countless times, and the same is doubtless true of the most successful relationships. Start again, and build a future, with yourself or somebody else, for the future is whatever you want it to be . . .



## Relationships, celibacy, loneliness and the adult Aspie single parent/carers (a response to January)

I am an Aspie diagnosed at 33 but I am also a single parent with three children — one with autism and ADHD (but not so much at school, so no diagnosis of ADHD), one with Asperger's and ADHD, and the other has a diagnosis of global developmental delay although his development is uneven rather than globally delayed and he has some Aspie characteristics (not enough for a diagnosis). That someone can fall into *both* categories is something organisations, online surveys, etc., constantly fail to acknowledge. It also causes major issues, especially combined with having to escape and divorce my ex (domestic violence and emotional abuse of the children). This situation causes very significant difficulties. Like many of us Aspies, I suffer from loneliness and find making friends extremely difficult, but escaping domestic violence and getting my kids to safety meant losing all my friends. Being a single parent with special-needs children has meant I do not have the childcare to go to anything where I might make friends — even the support group for parents of children with autism-spectrum disorders and the support group for adult Aspies are in the evening, when I can't go out.

Before the abuse started I was happy being married and now I miss that. All the advice for coping with divorce focuses on you having a network of friends — friends I can't make. There's no point in trying to be a pen pal as being a busy carer I'd forget to reply. Articles like *Celibacy — the alternative orientation*, for me, encourage the feeling you are left with the worst of all worlds. You can't devote yourself to God (especially if the kids have behavioural difficulties and you can't face going to church knowing they will disrupt the service, and, for an Aspie wanting a friend, church services, rather than smaller Bible-study groups held in the evenings, tend to be useless for making friends), your local support group (which you can't even get to) or anything else — you've the kids to see to. Marriage isn't

an option when you can't even manage to make a friend. No one to turn to in a crisis (unless it's a purely practical one of a sort my mum or dad can help with, and my mum won't throw a tantrum over) let alone just be there for me — my parents have never done emotional support. Yet at the same time you have to be there for and support, emotionally and practically, three children even when you feel like you've nothing left to give or really need some time to yourself to recover from the meetings with professionals that are so draining for an Aspie parent/carers.

Whilst I love my kids very much, being a carer is a very isolating experience even for those without the disadvantage of AS. But you mustn't get depressed — the kids need you and if Social Services get involved your diagnosis can put the kids at risk of being taken into care, because at least some social workers will assume you will be neglecting the kids (they did when my ex's behaviour got the kids put on the at-risk Register and my AS wasn't diagnosed, although they did accept I have AS and they made it quite clear it was because I have AS) and then they put you through hell for it. And talking of Social Services, each child individually must meet their criteria for support totally ignoring the joint burden of care — that is, that you have more than one child to see to. While at the same time being less likely to have access to support because of being a carer, being a carer also increases your need for support — emotional and practical. Being a mum does nothing to ease the loneliness either. Organisations and support groups assume you can get out in the evening because you either have a partner to look after the kids (and also assume you are NT) or you're a childless adult with an ASD. You can't be both in their eyes.

Sincerely,

Vanessa

## Autism in maturity advice service

I'd like to introduce myself and the new NAS service I am working for. My name is Helen Kalia and the service is a new NAS advice service for people aged 40 or over. The autism in maturity service can help with advice, information and support on many aspects of welfare benefits, community care issues and housing.

The kinds of things I can help with include advice on which benefits you may be entitled to, general advice on completing claim forms, what to do if you think a decision is wrong and how to appeal to a tribunal; advice on your entitlement to an assessment from social services, what to do if you disagree with the care assessment and help with charging; advice on tenants' rights, how to apply for social housing and dealing with arrears.

The advice is specifically for people on the spectrum aged 40 or over, their families and carers. You can contact us by phone or email or post. For phone advice call the NAS Autism Helpline on **0808 800 4104** (Monday to Friday, 10am to 4pm). The Helpline will take details of your query and book a telephone appointment for an advisor to call back at an agreed time to discuss your query. For email or advice by letter please contact me directly on

**advice40plus@nas.org.uk**

**Helen Kalia**  
Specialist Rights Adviser  
Autism in maturity  
The NAS  
393 City Road  
London  
EC1V 1NG

## How others see those with Asperger's syndrome

People with Asperger's syndrome are different, and people pick up on it very quickly, especially bullies. Life for someone with Asperger's syndrome and any of the autism-spectrum disorders (ASD) is hard, very hard.

We don't need pity, or charity, but we do need understanding and be treated like human beings. I have finally come to a place where I am comfortable with who I am, but it took sixty years of inner hell to get to this place.

My point is, even though I tend to take a light-hearted approach with my Asperger's syndrome, life for people with an ASD is cruel. We know we are different because people make it very clear to us that we are different.

Sometimes we are recognized or even honoured for are tenacious approach to a particular subject. Yet even those with Asperger's syndrome who have been recognized as brilliant still do not live the fast lane of social acceptance and inclusion. Reality is quite the opposite. Successful people with Asperger's syndrome may be invited to the party and receive glorious praise about there achievement, but when the dust settles, where are their friends? Where are the people who want to know who they are rather than what they have achieved? Where are the social invites because people enjoy their company? I can guarantee you, there aren't any. They are still alone and isolated. Perhaps if I looked disabled they might be more understanding. But people rarely see me as disabled because I do not look disabled. I often hear the snide remarks and condemning looks of "there is nothing wrong with him" or "he looks okay to me" or "he is just lazy". The reality is far from it.

**Norman, an "Aspie"**

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**Hello all AU readers,**

the world of human relationships is easy for me. I have none and happily want none. Happy Easter to you all and keep up the good work by not visiting me.

**Michael**



# Pen pals

## Pen pal number 169

**My name is Adeinne**, I'm 22 years old and I'm from Glasgow, where I live with my mum, sister and awesome pet dog.

I'm hoping that people will have one or more of my interests in common and I would love to write/email other people with Asperger's as I find it very difficult to make friends as my social skills aren't very good. I'm a really quiet, shy person who doesn't have any friends apart from my family.

My interests are animals — I love all types of animals except spiders!! I'm a huge WWE fan and if I had to pick my favourite wrestler I would pick Cm Punk. Sometimes I watch TNA, but not often as I forget when it is.

Some shows I watch are *River city*, *Here comes honey boo boo*, *Toddlers and tiaras*, *Undercover boss*, *Duck dynasty*, *Pawn stars*, *Tipping point*, *Pointless*, *Family guy*, *The Simpsons* and documentaries.

I have recently started to cook by finding recipes from the Internet, although I've had a few cooking disasters, and I also bake cakes.

I enjoy playing online games like *Bejeweled*, mah jong and many more but I can't remember what half of them are called. I also play console games like *Singstar*, *The sims* and *Super Mario*.

Some of my other interests are going to the theatre, the cinema, reading, arts/crafts, shopping, DVDs, science, gadgets, and jigsaws.

I can't wait to talk to people and find out how they cope with the struggles of having Asperger's.

## How to place a pen-pal advert

- > All you need to do is send your advert along with your name and address (and email address if you want) to *Asperger United*. You can use the Royal Mail or email. The next pen-pal number will be given to your advert when it arrives.
- > Please note that *AU* does not print dating adverts, as it is unable to provide suitable support.
- > Those under the age of sixteen must have parental permission before placing a pen-pal advertisement in *Asperger United*.

## How to reply to pen pals

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

### **\*\*Important notice — please read\*\***

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

## Pen pal number 170

**Hello, my name is Julian,** I am 53. I have spent the last few decades in IT. I designed and built my first computers in the 1970s. More recently I have delivered business solutions. My best ever job was in flight-simulation, but when the Berlin Wall came down and the bottom dropped out of the military market, I had to look for another job. I have now retrained for adult education, particularly: English, maths, and IT. I am dyslexic, and understand what it is like to feel you just cannot do it.

I am interested in the fundamentals of all things: science, engineering, maths, literature, language, philosophy, religion, morality, justice, thinking, teaching/learning, life, the universe, and everything. As a guiding and underpinning principle I hold very strongly that,

“Knowing is good, understanding is better”.

I would like to commune with anyone who is interested in this universe in which we live.

I am also looking for collaborators on a project. I am creating a phonic system to help learners read and spell. The system allows tutors to mark up existing text explicitly for specific learners. It also allows learners to look up spellings by how that learner pronounces a word. This means I am currently working on creating a lexicon of words in everyday use. I have created prototypes of software but I need some help making it ready for users. I also need some help in drawing hand positions to help learners interact kinetically with graphemes, and help to improve a font designed to assist in the creation of worksheets. I would also like to find someone capable of creating interesting texts/stories/poems from a very limited word list (don't fear limitation: it stimulates creativity). When ready, I will make this system free to use, so I will not be able to pay for your help, but it would be much appreciated and listed in credits.

I have other projects: placemat games, stabiliser for unicycles, customisable dice. Or do you have a project you would like to explore collaboration on?

*Seventeen pen-pal adverts have been held over for publication in the next four issues, Editor.*

---

## Pen pal number 171

**Hi, I'm Stephen.** I'm 42 years of age. I like writing, walking, keep fit, TV, listening to music. I have Asperger's. I also enjoy karaoke and I have singing lessons, but I am not a Pavarotti!! I do it for enjoyment. I live in supported accommodation and enjoy going out and about. I would like to write to people of a similar age and with similar interests, so please get in touch.

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## Pen pal number 172

**Hello, my name is Luke.** I was diagnosed with Asperger's syndrome at the age of 16. I am currently 18. I mostly play on my Xbox 360 and laptop and enjoy surfing the Internet. I play fighting, RTS, FPS and many more. Mainly as pastimes, I also enjoy drawing, writing and helping people with problems, usually IT-related.

I also love animals, have various pets and look forward to having a pen pal.

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## Pen pal number 173

**Hello, my name is Nathan.** I am 16 years old. I have only had my diagnosis a little while.

I like to listen to the radio, swimming, riding my bike. My favourite day is Friday.

I still go to school but find it difficult. I would like to hear back from someone my age who finds it difficult too, or someone who has been in the situation and how you found it.

I live in Buckinghamshire and would like to make friends with people my age in the area.



## Group notice

A friendly group of ladies with Asperger's syndrome meet up monthly in Devon. We are called **TAD WAVE** (Tavistock and District, Women with Asperger's Voice Exchange).

Our first group meeting was in December, though most of us have known each other for a while. We meet up in a quiet place in Tavistock for a chat, tea/coffee and mutual support, though we also have garden visits and walks planned for when the weather is better. We also hope to gather relevant local information and make it easily accessible to those with AS living in Devon.

Men are welcome to contact us, but the social group is women only at present.

So any West Devon ladies who have AS, or who are on a waiting list for assessment, please contact us if you want to get out and make friends.

Our email address is:

**tad.as.group@btinternet.com**

Our phone number is (12-2pm)

**07707 301 316**

Best wishes,

**Wendy**

If sufficient material is sent in, the theme for July will be **labels** or **fandom** (that could be anything from *Doctor Who?* to furry fandom). Vote with your contributions: the more submissions on a subject sent in (from different people), the more likely that that subject will be the theme. Writing on any subject is still welcome, as are ideas for new themes, fillers (for putting in small spaces like this) and artwork. Remember, if you want to see different content in *AU*, the best way to change it is to send something in!

**Ruth, you write** (January *AU*): "So does this mean we really are loners, wanting to shut out human contact? All evidence I've seen says a big NO to this." Well Ruth, please allow me to provide some evidence to the contrary. I have Asperger's. With regard to humans, I am a loner. I want to shut out human contact. I am not lonely. This evidence is necessary but not sufficient or anywhere near sufficient to prove your NO theory to be incorrect. However, it is sufficient to prove your NO theory to be incorrect in absolute terms. That is to say that your NO cannot be an *absolute* NO.

Ruth, I take a different view to yours with regard to "person first" language. You write: "the autistic person is not separable from their autism." Yes, I agree — I take it as a truism. But, is the statement, "an individual who is autistic is not separable from that individual's autism" any less true? I grant you that such a statement does not read well (what you write reads much better) but would you argue that the statement is less true?

**Michael**

## Core

by **Dan**

Can I compare you to a bowl of fruit?  
So sweet all the way through.  
You are the apple of my eye,  
But I can't see you any more  
Because I have issues at my core.

**Hello all,**

relationships. I have a lifelong relationship with all of you. I do not judge you or lie to you. But beware, I am not a timely companion. I leave too early or too late. Tick-tock.

**Time**

## letters to the Editor

**Dear Goth**

I wonder if you could help.

I read the letter from Harry in the October edition and assumed that there would be an answer for him in the next edition. I was very dismayed to find there was not. A letter about epilepsy, that is.

I suffer from many of the symptoms that Harry has, the difference being I know what causes it, and therefore how to manage it — Irlen syndrome.

I became so interested in this area that I have had in-depth American training to screen and diagnose it. As 80% of autistics have it, I feel it makes sense for you to consider an article if not a whole edition on it. But perhaps the place to start might be for Harry to see if an understanding of the problem might help him. I expect of course that you have never heard of it!

It goes without saying that I have Asperger's, though am lucky not to be too severe, and the career and life experiences that go with my grey hairs help!

Thanks for your good works: I always enjoy reading the mag, despite being a very confident person with a family, that can go any where, talk to anyone, and do anything, it is somehow very comforting to know I am not on my own. Hell, if that is not a silly thing to feel/say I do not know what is!

**Linda**

**Dear Goth**

The letter from Geoff (page 9) prompts me to write, not only because I am a gay male, but also because some forty years ago I attended a CHE get-together at a café/guest house in the Par/St Blazey area of Cornwall. The café was run by a young couple, Brian and Paul, and it occurs to me that this may well be the same weekend that Geoff talks about in his letter!

Geoff's letter was thoughtful and made a number of interesting points.

In his editorial for edition 77, the Goth tells us that complaints are received from some readers when the subject of sexuality other than mainstream is discussed. An individual with an autism-spectrum condition did not choose that condition and has to make his/her way through life in the best way possible — and the same is true of those whose sexuality is not mainstream.

Many of us on the autism spectrum feel that we live life on the margins of society and are not understood or fully accepted — again a parallel can be seen with those who are not heterosexual. It is not too many years ago that epileptics were victims of prejudice or worse.

Readers of this magazine will realise that we are all different and occupy our own individual place in the spectrum of life, and that we should strive to accept other people's differences.

Thank you for the magazines.

**Graham**

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**Dear Geoff via *Asperger United*,**

I am an Asperger man of 33 who would love to have access to a group for gay Asperger men and women. I live in north London, and can travel.

I used to go to a group called "Out on Thursday", based in Hammersmith, but that only goes up to age 25.

I would be happy to join any London-based group, though I am nervous of a group based around people who don't understand relationships.

I am nervous, too, about giving my name yet.



## another letter to the Editor and one more letter

Dear *AU*,

I was fascinated by the thoughts of your contributors in issue 77, a really good edition of *AU*, full of interesting points about relationships. Alex, I'm sorry to read that you are currently detained under the Mental Health Act. You are not alone in getting unhealthily attached: I am in my fifties now and since the age of 14 I have bounced from one major "crush" to another which has caused me a lot of problems. Sometimes I've felt strongly about famous people but mostly it has been just regular people. As these people have always been female I'm

thinking I am probably gay. I had never thought that people with Asperger's were more likely to be gay — thank you, Geoff, for raising that. I have never known how to deal with my strong feelings, I certainly don't want a sexual relationship, but I am aware that my behaviour causes upset for the women I attach myself to. If younger people with Asperger's and autism had some help in this area it could reduce a lot of potential difficulties for them and the people they feel strongly about,

Jenny x

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### My Aspie brothers and sisters

When I saw that the *AU* topic is sexuality, I felt I just had to put pen to paper. I'm a male 24-year-old, and was diagnosed with PDD-NOS (autistic type) as a kid, and with ADHD some years later.

People often ask me about my sexuality, and I'm normally quite hesitant to respond in the rigid terms people expect. I'm not straight, and I'm not quite gay. Most people would class me as bisexual, but I find sexuality as something fluid. I don't buy into the social construct that I've got to label my orientation to fit into a neat little box. My sexuality is something as organic and human as any other aspect of me — it's complex, intricate, and always evolving.

I've had loving, long-term relationships with women who don't believe that "someone like me" could also be interested in men, and I've had male friendships that have developed into romantic relationships. To the best of my memory, I've never been in a relationship with a guy who defines himself as anything but straight. These relationships leave them questioning how they define themselves, but only reaffirm my perspective on sexuality — that this obsession with falling into arbitrary categories is not only antiquated, it's plainly unhealthy.

When I was in my teens, my early experiences of relationships concerned me, sometimes to the

point of illness. I remember asking the school counsellor "Am I gay?", "Am I straight but confused?". Perhaps my autism helps me now to take a less emotive approach to my sexual identity — to accept myself for who I am, not for what others expect me to be.

I appreciate that my views are controversial and there will be people that see my attitude as "nouveau hippy". I'm far from blinkered as to how others perceive this mindset, but this is my perspective. I don't dictate how others should approach their sexuality, nor do I try (or want) to convert others to my way of thinking. Although it may be antithetical to many religious perspectives, this is my life. I have the greatest of respect for those that subscribe to any opposing view — be gay, be straight, but please, be happy.

As people on the autism spectrum, we face a society brimming with stereotypes and narrow-minded preconceptions. Why, therefore, don't we all embrace our uniqueness with pride, whatever our make-up?

My name is Ahi. I am what I am. Hear me roar! If anyone wants to contact me via *AU*, please don't hesitate to write.

Wishing you all strength,

Ahi Silver

## Spectrums

by Beth

This is what happens when worlds collide: alchemy

Above is the opening line from my impending kickstarter campaign to add a new string to my bow as a tantra teacher for LGBT people. I eventually hope to have my own life-coaching business as well as looking into being a sexual therapist and intimacy coach for people on the spectrum amongst other things. I have been exploring sex, sexuality and gender for the past five years and now, two years on from my own Asperger's diagnosis, I have seen a trend in not only increasing diversity but also the fluidity of expression inherent within the Asperger community.

As far as I am concerned, sexuality is not a black-and-white thing: the choices available are not just gay, bi or straight. You are not attracted to either male or female (and intersex). In terms of biological sex, yes these are the options available to us. But there are those of us who are choosing to flit between, combine both or even ignore the socially imposed gender binary. We hear often about masculine and feminine characteristics and this provides a false dichotomy not only in behaviours but also in presentation. This is a very reductionist view of human diversity and although we are stereotypically said to be of concrete thinking, there are many different categories and subsets present within the Asperger community that I've met so far and in observing and talking to people within the communities of non-monogamy, gender exploration and queerness, there is a strong contingent of either diagnosed or self-professing people with Aspergers.

Similarly to those of us choosing to identify as asexual on the spectrum of sexuality and sexual attraction, there are those of us who identify as trans\* or even gender fluid. Language, like identity, is a constantly evolving concept, as is

tantra. Originally a practice of meditation and intimacy from India, it used to be limited to the regimented ideals of gender balancing attributed to biological sex as opposed to self definition of what feels comfortable for you. The concept of queer tantra grew out of the frustration at this limited view of human expression and chose to experiment with polarity through different means as opposed to biological form. The word queer itself has also evolved since it was used to mean purely homosexual tendencies and has been reclaimed by many who seek to not conform to the categories generic in mainstream society.

I have been through many stages of exploration. I was bullied at school for having body hair due to being of mixed race. I was called a he-she and felt uncomfortable with the view of femininity I felt I had to conform to. Until I discovered the word trans\*, I did not feel I could find a category that I could identify with. I am female born, but prefer to view myself as gender-fluid. I have had the privilege to start to confront many of my fears: since April last year I have begun cutting my hair shorter and shorter. Last time I did this, I was bullied and so it has been a very cathartic experience. Currently, I am on a number 1 on the back and sides and I am loving it. I feel the most feminine I have ever felt, and more comfortable in my own skin. Concurrently, I have started experimenting with dressing in stereotypically male clothing — from heading to the male underwear department to buy some boxers to a full-blown photo-shoot as my alter ego Clement McCormack (aka Clem Mc) with drawn-on facial hair.

It has been a difficult and troubling journey. It is, however, one that I am finally starting to delight in. I have been blessed with a strong support network and also Facebook groups of women sharing my latest "cause" of exploring not shaving (a whole 'nother article). I truly believe



there is no one perfect or normal experience just as much as I stand for the unique mix of so-called Asperger characteristics within each person on the spectrum. When asked how to quantify the differences between men and women with Asperger's my stock answer is that it depends on the individual. Although there is some argument that men and women are socialised differently, it really does depend on many other factors as well.

The world would be a better place if we embraced diversity in all its forms and I am happy to carry on my own journey of exploration as I have already seen the changes in the people around me. I am firmly committed to being a part of the wider human race. Though I may have Asperger's, I still see so much similarity between myself and the other people around me. We all have hopes, dreams, and want to be accepted for who we are.

PS. I am happy to be in contact with people interested in exploring this further or to try to explain any of the concepts or language used in this article further.

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**Dear Goth,**

you asked to give opinions on the "autism passport". So here is mine:

When I saw the leaflet, I thought such a passport is a quite good idea for people on the spectrum as a kind of emergency device.

I think — and hope — I won't actually need it for myself. Nevertheless, I copied it twice, using one copy to carry in my bag (for the most unlikely case that one day I will be so overwhelmed that I will be in the need of it). The other one (also in my bag) for presentation in case of meeting another Aspie, who has not heard of it yet, so that he (or she) can contact *AU* to get a copy. Overall, I can give a positive feedback so far.

However, I would like to give a comment on two points:

The first one is not a really important one, but maybe this annotation might be considered funny: because of the conception of this document, I had some difficulty answering the questions, which all contain just a "yes" or "no" as answer with no possibility of gradation, so I felt bad ticking some of the boxes, as many of my problems are comparatively mild (my NT husband laughed about that, when I told him).

The other remark is a more severe one: the passport is entitled for "autism" support, but it means Asperger's or HFA. It is not suitable for classic autistic people. I cannot fill it out for my autistic child, because the main symptoms of that condition are left out (such as not speaking).

Of course, the leaflet was designed to meet the needs of the readers of *AU*, who are high-functioning. But we should make that more clear. Just imagine how the neurotypical common folk think: imagine, you hand the passport out to them and they really read it carefully (which, of course, in my experience, they hardly ever do). Now imagine these people meet a person of the more low-functioning part of the spectrum. They will be astonished that the lack of any speech exists in autism, because it is not listed in the autism passport. I have been in a similar situation already, when a person, who knows the Asperger condition only as "autism", said to me that my child couldn't be autistic, as all "autists" in some kind of personal acquaintance of that person were able to speak, so that my child — according to that person — was just disabled.

Using the terminology of "autism" as well for Asperger's can be harmful to the more affected (classic) autistic people. I noticed this has the same effect on teachers in mainstream schools (at least where I live). They expect an autistic student to be some kind of stereotypical loner, but cannot imagine the existence of the lower spectrum (I suppose, because until very recently, those children attended special schools only).

Regards,

**Mary**

## three letters

Dear Goth,

thanks for the mail out of AU.

I have some concerns about the passport I received with AU. I have written at length my concerns about all these prototypes of passes. I have not included that here — not sure its the right place.

I am sickened by more of the same. In theory the idea is good but only if its pushed to a national, validated, legitimate level, that is, photo id with diagnosis, signed. Something that reminds society it's an offence to treat us with discrimination and outlining the main ways they misconstrue us, not the other way around.

Mainly to spare having constantly to prove at length and reprove my status all the time: this is the most debilitating, degrading act to have to perform on a regular basis, no other disability group have to go through this and yet we are the ones with a communicative disorder.

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### Re the autism passport.

It's a nice idea, but in my experience, since no one has the capacity to appreciate even how such symptoms may affect the individual, let alone understand the reason for this, he/she is in practice still seen to be to blame for behaviour which appears inexplicable and/or extreme, and for any situation that may result, which is the reason that I may soon be of "no fixed abode" status, as I cannot cope with my current housing situation and I am seen to be to blame — by my GP, the police, the housing association and my neighbour, whose noise caused the problem. Even my local MP fails to appreciate the need for urgent action, so I have no alternative. So the only thing I can do is to take "flight" (verbal "fight" isn't working and should it turn physical I will again be blamed).

Yours sincerely,

Ann

Perpetrators who cause us already so much abuse, bullying, disbelief and injustice just use these take-away menus of negative traits against us, as a way to further gaslight us. Also, they are always based on a narrow percentage of people, not the whole rainbow, not to mention the divide between males and females.

I'm more able to give someone a list of the things I do not respond well to, in the form of a hall pass, in the hope that society will make the adjustments to their behaviour when interacting with us. I am fed up and sick of being represented as someone else doing someone else's behaviours for someone else's reasons. Then being perceived by someone else's misunderstanding. Aren't we all trying to get away from being misconstrued, misdiagnosed, misguided?

Kind regards,

Michèle

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Dear Goth,

the passport is great! The autism awareness card was good, as far as it went, but this one is much more informative and helpful.

NT people, through no fault of their own, didn't really know what to make of the other one.

One suggestion: prosopagnosia or face-blindness — failure to recognize faces — could be added. It can affect not only your social life but your career. You come across as arrogant, unfriendly, weird, selfish, cold, etc., etc., etc. — when I walk my dog, I don't recognize people I meet every single day if they are wearing a new coat or I can't see their dog!

Once I didn't recognize my own brother!  
(Wrong context.)

Sam



**I felt compelled to write**, after reading Edward's *Beware the Asperger snob* in the last issue.

I have a diagnosis of AS, and often refer to myself as an Aspie. However, I do not fit into Edward's slightly vitriolic rant against all "Aspies".

As those who know me would testify, I am no narcissist, and the idea of being a "celebrity" would send me into a state of panic. From what was written, my perception of what was said in the Radio 4 programme is very different to Edward's. I do have psychiatric diagnoses — but not self-diagnosed from a "goody bag". I do not fit in with any of the "Aspie" traits portrayed.

I agree with Edward when he says: "Accepting, understanding, and making something positive of our differences is to be encouraged and applauded". This is what I try to do. I also agree that: "Asperger's makes life difficult". The diagnosis can be useful to make sense of the difficulties one has had, and that it is a condition rather than a personal failing. Since I spent my childhood growing up as someone with undiagnosed AS, but no knowledge of this, I naturally assumed I was like everyone else, and became incredibly frustrated by my inability to communicate as I wished, and my own "stupidity" in failing so to do, when everyone else could.

I fully agree that the condition should not be trivialised — as it is, people have a huge problem understanding my social ineptness and communication problems, and how deep they run, because I have an excellent vocabulary and an IQ of 155. I just don't think that using a stereotype of the few individuals with the condition who seem to use it as an excuse, or brush over the issues involved, as "Aspies", is fair on those who, like myself, use the name Aspie.

Within any given group of people there are those with less in the way of conscience and humanity, and this is the same with AS. However, I think that age at diagnosis is quite a big factor in how people with AS describe it — due to different experiences of interaction, and of people around them.

I will explain. I think that, as a rule of thumb, the later in life you are diagnosed, the more problems you will have. If diagnosed young, these days help is there for children, and attempts are made to explain to other children, and watch out for bullying. I'm not saying this always happens or works, but it is likely to — at least to some extent. Thus, those diagnosed young tend to have more positive experiences of people, and of communication — and are thus more likely to appear to "trivialise" the condition, as all they can do is go on their own experience.

Diagnosed at 31, I did not get any help with my condition during the time I was at school. I shouldn't think most people had even heard of AS. I was severely teased and bullied, and got into trouble because of my directness and truthfulness, and went from being an outgoing, confident toddler to a more withdrawn and isolated individual — which has continued. I had it drummed into me how to behave. It was very hard to learn, and led to a tendency to remain quiet so I didn't say the wrong thing. I always have, and probably always will, make mistakes because of the AS.

Those older than myself will, I suspect, have had even more problems at school, since there was, I believe, less tolerance of "bad" behaviour in the classroom. They have had longer to have negative life experiences without being able to make sense of their difficulties, which I believe makes people even more withdrawn and isolated.

Just because I sometimes call myself an Aspie, I shall not be pigeon-holed into a stereotype that I do not fit. I have Asperger's syndrome. I have other issues, mental and physical. I have made many mistakes, especially relationships. In the same way as everyone else, I am unique. I do not celebrate AS — although I do certain skills it has given me, like my observational skills, tenacity and sense of humour. I certainly don't trivialise it — the frustration I still find with communication — and the anxiety and fear — would not allow me to.

But I am still an Aspie.

**Terry**



## two letters

Dear Goth,

I suspect you may be expecting a lot of letters regarding *Beware the Asperger Snob* by Edward . . .

First my credentials:

— I got my AS diagnosis over ten years ago at about the same time as my two sons

— I belong to a couple of AS social groups and have AS friends

— Professionally, I work with young adults who have AS

— Although in a relatively minor way, I try to improve understanding of and provision for those with AS.

Maybe I am not quite the “happy Aspie” that Edward complains of — after all one of the concepts I try to spread is that people with AS are all different. But I have done with feeling extremely sorry for myself. I have had a year of counselling, done much reading and thinking and have moved on. I have learnt to accept myself for what I am — strengths and weaknesses. I do not like my weaknesses, and I am trying to find ways

of overcoming them, but I also accept that I have strengths. Maybe Edward should read the book *Appreciating Asperger syndrome* by Brenda Boyd if he has not done so already.

I strongly disagree with Edward’s first comment: “I suffer from Asperger’s syndrome.” I don’t. To use his terminology, I suffer from acute anxiety problems. I suffer from many sensory problems. I suffer with social communication problems. I even have depression at times. But I am blessed with a good sense of logic. I have a high level of determination. I am blessed with the ability to focus deeply and see things others miss. I am honest and loyal. . . .

I know people who deeply suffer: one has been in constant pain for thirty years unless she takes medication at a level that makes her a virtual cabbage. I have worked with young adults who have degenerative conditions, they have lost the ability to walk or have much meaningful control of their muscles. I was friends with a woman whose new husband dreadfully abused her young son. My life is difficult, but I would not want to exchange places.

I try not to minimise the problems I face when educating others about AS, but I also try to explain any strategies I have found for coping. I was turned down for DLA, and am unsure whether to apply for PIP. Some AS friends get DLA others do not, I am unclear of the reasons why. Maybe my communication problems hinder me explaining clearly enough why I should get certain benefits and support?

As well as the issues we present to the social services departments, we must also think about those with AS who want to work. Only 15% of people with ASD work full-time, even though 79% want to work (statistics from NAS website). If we only emphasise our problems and our suffering, which employer would want to employ us?

Finally, in reply to Edward’s comment, “if you are happy because you have Asperger’s, then maybe you don’t”, I would add: if you are unhappy all the time just because you have AS, maybe you also have depression and should see your GP.

Best wishes,

3Hats

Hello Goth,

I refer to the engrossing and beautifully written article by Edward in the January AU. Edward, I am a “happy Aspie” and it could be argued that I am happy because I have Asperger’s. However, not all “happy Aspies” are as you

believe them to be. This “happy Aspie” does not endorse or engage with the “happy Aspies” you so eloquently describe in your article and further this “happy Aspie” agrees with much of what your riveting writing states. More please.

Michael



Dear Sir,

I have taken *Asperger United* for a number of years and thought the article by Edward, *Beware the Asperger snob*, was the best there has been. His end comment, "But if you are happy because you have

Asperger's then maybe you don't" really hit the mark. One wonders if, instead of it being called Asperger syndrome, it was called village idiot syndrome, how many would then so eagerly claim the label. We are not all physics geniuses with photographic memories

who want to sit in front of a computer all day. It's main impact being how it handicaps one's social skills and if it doesn't, then you haven't got it.

Yours faithfully,

George

Hi,

thanks for such an interesting magazine, however I must take issue with the *Asperger snob* article by Edward.

I have Asperger's syndrome, having been diagnosed in my 40s it explained a lot of my issues. Rather than "suffering" from Asperger's I embrace my differences knowing that the abilities it gives me enables me to do my job, for example, where being an autie is an advantage.

Why should you suffer from a condition which has no long term physical ailment attached to it? You suffer from diabetes, flu or cancer as these have a detrimental effect on your life. Autism can be used to your advantage: for example, in an employment choice. Many employers are now actively seeking out autistic employees for their talents.

If you do suffer as per Edward's argument aren't you inflicting that suffering upon yourself? This rationale can only lead to depression and self-loathing, or worse. I have suffered from almost terminal depression before being diagnosed: post diagnosis my risk of depression has reduced. So how can I be described as "suffering from Asperger's"?

An autistic person can suffer from not understanding what makes them different from a neurotypical person. If the condition is not diagnosed or if post-diagnosis they are not supported while they come to terms with a life long neural condition then, yes, they can suffer from the side effects of autism. Depression

and self-loathing are not exclusive symptoms to autism but are more common. Reduced suffering can only come from understanding the holistic approach of treatment for however long it takes the person to come to terms with themselves.

As for autism being the "in" thing to have, maybe this is more a symptom of society's current obsession with celebrities, however tenuous their talents may be. Perhaps when being gay ceased to be such an issue, was being gay suddenly the in thing any more than doing the "Wainwrights" in the Lakes or managing to read and understand *Zen and the art of motorcycle maintenance*?

Maybe it is a fashion, given the remake of *Sherlock*? It's okay to be autie if you are brilliant, so let's all be autie! Well anyway, once a bored society has moved on we auties are still here doing our thing as we have been doing. The world moves on, we carry on.

I am happy to have Asperger's because, however slightly, I can class myself with such great people as Einstein, Steve Jobs, Bill Gates, and Temple Grandin. My diagnosis changed my life for the better and I wouldn't change how my mind works for even one second.

We auties deserve to be happy and live happy and productive lives. If that makes us snobs then yeah, I know I'm smarter than most people, as are most auties. If that is the price we pay, then so be it. Never apologise for who you are: be proud!

Many thanks for reading,

Jon

## Ask autism: participation conference

by Laura

Me and my partner (both autistic) travelled to London to go to the autism and participation conference organised by *Ask autism*, associated with the NAS. It was ground-breaking in being organised by autistic people mainly for NTs and was about people with autism being included, especially in situations we are commonly in, such as educational settings, work, interacting with social services and on autism partnership boards.

This conference was different to any other NAS conference I've been to in that there were social interaction badges like the ones used at Autscope and Autreat which you could use to signal to others how you want to interact through changing the colours on the badges.

I find the interaction badges help a lot in making things more accessible to me and was happy to see other groups using them. Also, clapping was replaced by flapping, as they do at conferences for Deaf people — both things I would like to see in future autism conferences.

After checking in we had a quick break and entered the introductory sessions, I was a little surprised and disheartened to find out that at least half the delegates seemed to be people on the spectrum like ourselves.

It was positive that we were represented and there were others interested in the subject within our own community, however I was hoping it would be a subject NT professionals would also see the great value in.

Perhaps the lack of NT professionals was in part due to the high booking fee (sadly not just at NAS conferences) and that now professionals cannot get their organisations to pay and are having to take time off and fund themselves — professionals I have talked to definitely had the interest but couldn't get funding to attend.

It was a very busy day, with so many excellent speakers to choose from. The overriding themes for me were: a need to avoid letting ourselves be used by organisations as a token member of a group where we may not get a real say in how things are done, the importance of people accepting they need to change environments and ways of interacting with us to ensure true participation, and something I knew but many don't seem to realise: we don't have to solely talk about personal experience at conferences; we are capable of discussing many varied and relevant topics related to autism and that might be more useful.

Overall the conference was brilliant; I left the conference feeling uplifted and that things could change and perhaps would eventually if we worked for it. I hope it will be held next year and urge everyone especially any professionals who may be reading this to consider attending as it was one of the most relevant and useful conferences I have been to.





## 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 subscriber on the spectrum can be printed, not just Asperger's.
- 2) *Asperger United* is free and 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) *Asperger United* does not use your contact details for anything other than administering AU. Your details are not passed on to NAS Marketing, NAS Fundraising or any other organisation without your written permission. Please consider getting involved with the NAS campaigns and events.
- 6) If you move house, please inform *Asperger United* and include your old address as well as your new address.
- 7) Even if you've paid for the Royal Mail forwarding service (or another forwarding service if you live outside Great Britain and Northern Ireland), you still need to inform *Asperger United* that you have moved address.
- 8) 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.
- 9) You do not have to be a member of the NAS to subscribe to *Asperger United*.
- 10) The current edition of *Asperger United* is available at [www.autism.org.uk/aspergerunited](http://www.autism.org.uk/aspergerunited)  
You need to scroll down to the middle of the page, where there is a link to the PDF.
- 11) 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](mailto: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 the paper edition too.
- 12) 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.
- 13) If you want to resubscribe (or subscribe for the first time) inform *Asperger United* and include your postal address (for the paper version) or email address (for the email notification).
- 14) Book reviews are the most popular thing in *Asperger United*, please consider submitting one. They can be about any book, not just books about autism. Also, they do not have to be short (the Goth keeps most of his reviews short to leave more space for other writers). If you do not want your review to appear in the NAS section of the Amazon website, please make this clear.
- 15) Although each issue is themed, submissions on any subject are welcome. Only some of the letters and articles in each issue will follow the theme. All submissions may be edited, especially for privacy, libel, and for fitting the space available.

## Autscape: an *autistic* conference

Belsey Bridge Conference Centre, Ditchingham, Bungay, Suffolk, NR35 2DZ

Monday, 4 August – Thursday, 7 August 2014

An annual residential conference and retreat organised for and by autistic people.

This year's theme is *Autism through the lifespan*.

What we offer:

- Autistic-friendly environment
- Meet others with Asperger's and autism
- Non-autistics and those without a diagnosis are equally welcome
- Workshops and presentations
- Autistic-friendly leisure activities including a sensory room and *Sparklies in the dark*
- Quiet rural location, outdoor swimming and sports facilities, on-site bar
- Plenty of outdoor space
- Day-time childcare included

- Full board — three meals a day, tea and coffee breaks included in price
- Travel to and from venue arranged from Norwich train station (for extra fee)

Registration opens on 8 May and closes on 1 July. Early registration is advised as places are limited.

Further information regarding the conference, registration and attendance fees is on our web site:

[www.autscape.org](http://www.autscape.org)

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