Produced by and for people who have autism-spectrum conditions

Asperger United

Edition **84** October 2015

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

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:

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)
Fax: 020 7833 9666

Email: **asp.utd@nas.org.uk**

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

Thank you to 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 **9 November 2015**

Welcome to the October edition of *Asperger United.*

A very varied postbag, with contributors taking ideas from last issue in different directions. This is good, as it shows that it made a lot of people think, and I hope this issue will too.

It was good to meet so many readers at Autscape again. This year, though particularly wet, was as good as ever, and in the most beautiful countryside possible. Idyllic, and with thunderstorms to match.

I must draw your attention to the notice on the back cover, about the resubscription project. I'm going to be mentioning it almost every issue from now on, as it's important that you are aware that it will happen, even though you might not get your first flier for three years or more (see the notice for an explanation of the fliers). You will have plenty of opportunity to reply, so please don't worry, just bear it in mind.

I am looking forward to the postbag,

the Editor

the perspectives edition — the next issue notice is on page 17

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A blaze of gold

by **Emma**

As an individual with Asperger's and children on the wonderfully neurodiverse spectrum I feel I must speak out on the subjuct of combating autism.

Why is it when I inform people of the fact my children have autism I am immediately offered unwanted advice, apologies and pity?

The media thats why. The scaremongering by companies like Autism Speaks depicting families with autism as tragic, at a loss and with a child that's "mssing". The absent "i" symbolising a non-identity, a vacancy in humanity and one of the most offensive things my eyes have borne witness to be promoted to the general public and indeed the world at large.

Not myself nor my children nor the whole autism community are "mssing" we are loudly, gloriously and predominantly here.

We always have been, diagnostic toolkits are progressing every day, and autism is now diagnosed more frequently. That does not mean the rates have risen, merely that we are now being recognised as being diverse, not labelled eccentric, naughty, willful, odd and any of the other names that have been tossed around to label people that the neurotypical public have given us.

The fear of the unknown and poorly explained is sure to have effects on the non-wilfully ignorant if they know nothing of autism apart from the bleak disease-ridden epidemic-type picture Autism Speaks showcases.

Working with autism, encouraging and nurturing our children to be all they can be is imperative to our future generations.

Non-invasive therapies, not the ABA thats trotted out and recommeded to newly diagnosed families.

ABA has long been touted as the automatic next step after diagnosis: its aim? To make your child indistinguishable from their neurotypical peers.

Why do parents want this? To stop and conceal the very behaviours our children need to cope, to force eye contact when the feel of it literally can burn? Because "normality" has been pushed to be best. To be different is wrong and to be feared.

Forty hours of enforced recommended compliance behaviour to stifle a child's natural being, their very foundational self? How is this allowed?

Because to walk down the street with your child stimming, sniffing and making sense of their enviroment takes courage, it takes a person who believes their child to be an individual, and it takes, most importantly, a person who will support their child being their wonderfully neurodiverse self.

Too many parents want this, they want to be proud of their loudly stimming child but are told by well-meaning but woefully Autism-Speaks-type informed family and friends that their child *must*, in order to be accepted by society, blend in.

We are not leaving.

We cannot be cured as we are not ill nor diseased.

Most importantly, we are not absent.

In a blaze of gold we are here we always have been and we always will be.

Perspective-taking

for a person with Asperger's syndrome

by **Karra**

After dropping my Prius off at the dealership for servicing early in the morning, I was tired and went home to rest. Long story short, I ended up going to hospital. A while later, my mother and son, Thomas, visited me. That's when I realized my Prius was still at the dealership. My mom offered to pick it up. "I'll get it, honey. Don't worry," she told us. Thomas gave me a long stare. He looked uncomfortable.

"Ok, that would be great, mom. Thanks," I said. Thomas said nothing. He just stared at my mother.

Soon my mom dropped Thomas at my house, then went to the dealership with her husband to pick up my car. The next day she and Thomas returned to the hospital. That's when I said to my mother, "So thanks for dropping my Prius off at my house."

"Sure." She replied.

"You figured out how to turn it off, right?" I asked her that because it was a fairly new car that didn't require a key. It just had buttons.

"Yes. I pushed *one* button," She said.

She was sure she'd done it correctly. Thomas looked at her, then quickly at me.

"What? No! To turn it off you needed to push the 'park' button *and* the on/off button.

There were *two* buttons not *one*. Right mom?" I asked her in a panicked voice.

My son immediately stood up from his chair wanting to interject, but said nothing.

"Um no. The guy at the dealership said there was just *one* button to turn off the car. So I only pushed *one* button," she said, suddenly flustered.

Thomas intervened and said out loud, "Don't worry mom, I pushed the second button to turn the car off."

"What?" my mom exclaimed. "You weren't even with me in the car."

"Yes, I know. But I came out to the garage when you returned. After I saw you get out of the car, I noticed that I could still hear the engine running. So I reached in and pushed the 'on/off' button. No worries," he explained. "It's off, "he said, looking at me.

"Why didn't you tell me that then?" she asked him.

"It wasn't important. And I didn't want to embarrass you," he told her confidently.

My mother turned to me and smiled.

"Thank you Thomas. I'm glad you had her perspective in mind," I said proudly.

Perspective-taking is a concept that we've worked on together for years. It's the ability to understand and perceive someone else's thoughts, ideas, and feelings and how that affects their behavior and actions. Perspective-taking is something that doesn't come naturally to my son. So when he can identify with someone else's perspective is as important as how he perceives someone else's perspective. In this example, Thomas came out to the garage (thinking of her perspective) to make sure my Prius arrived safe and sound (my perspective). This example illustrates that his timing was done and perceived well. My mom is elderly and had never driven my "newer" car before. Thomas obviously understood this.

Dear Goth,

I'm not like other Asperger's people. I'm solitary and don't want relationships just want to be like Doctor Who.

I read July edition of *Asperger United* and feel the Asperger people writing to you are like neurotypicals. They are still social Asperger's even if they are transtar gender. They still want jobs and relationships and to socially fit in just like everyone else?

Personally, I am 53 and solitary Asperger's. The only thing I care about is being like Doctor Who somewhere around Patrick Troughton and Jon Pertwee's Doctor.

I like being like Doctor Who because Doctor Who was an alien and like me spent much of his time as a recluse in his Tardis. A bit like I do as a writer.

*

I was watching this programme on television about age-gap relationships. Normally I don't bother with such stuff, but this was exceptionally good and made me laugh. In the programme there was a lady who married an old-age pensioner. Another lady who married a big fat cowboy trucker and two gay men of different ages, races and religions. What impressed me most was that none of these people cared about what other people thought of them, including their parents.

*

And I thought: if two gay men can get married surely I can lead a solitary self-organised life living to be like the Doctor. Be a kind of hermit, be like Doctor Who on the inside, like the hermit in the film *Robin of Sherwood*, became Herne the Hunter. Especially as I can't be a real doctor within society . . . . What's more, I love the doctors in the thirteenth century as they were more like witches and wizards and I have always had a deep passion for magic philosophy and the occult.

*

For the first time in years I didn't feel tortured or forced to socially compromise and sexually conform to a society I hate so much and I felt happy and at peace . . . .

I am going to stick with this for life,

yours,

Bruce

Do you like music?

Are you on the Autism Spectrum?

Would you like to be a founder-member of an exciting new London-based choir?

This choir is scheduled to start in Autumn 2015 and our meetings will be held in St Martins in the Fields in central London.

If you are interested in joining us and would like to learn more please contact Pam via e-mail:

P.Heaton@gold.ac.uk

for more information. If you do not like to use e-mail you can telephone Pam on:

020 7919 7913

If she is not available you can leave a message on her answerphone and she will call you back. Or you can write to:

Pamela Heaton
Department of Psychology
Goldsmiths University of London
New Cross
London
SE14 6NW

Pen pals

Pen pal number 203

Hi, my name is Reuben, I am 23 years old. I have ASD, OCD, and I strongly believe I have sensory processing disorder. I live in Berkshire.

I have an interest in Japanese entertainment, which includes anime, the bands and music artists in anime. I have a keen interest in learning Japanese. I am also interested in video games. I particularly like games such as *Final fantasy* and *Dynasty warriors*.

I also have a great interest in photography and have sold my work. I mainly focus on nature photography as I'm fascinated with nature. I like reading, writing, watching some comedies and documentaries, and I spend a lot of my time on my laptop. I have an interest in the Chinese zodiac. I am also learning to play the keyboard.

I would like to talk to someone who is intelligent, honest, caring, and understanding.

Pen pal number 204

Hi, I'm Lizzie. I am 32 and I live in Lincolnshire. I was diagnosed with Asperger's seven years ago.

I have a part-time job as an admin assistant. I am very creative. I like fashion, card-making, crafts, music, stationery and cooking. I have found that by changing what I eat, including having raw food in my diet, helps me keep well. I am interested in having some pen pals with similar interests to me. I look forward to hearing from you!

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**
- 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.

Fourteen pen-pal adverts have been held over for publication in the next three issues, Editor.

Pen pal number 205

Hi, I am Russell and I am 36. I have Asperger's. I've only known for six years.

I live in Somerset. I like football and I support Liverpool, England and Real Madrid. I like a lot of sports, especially darts, pool, F1 and snooker. I like socializing and going out with friends. I like going to the pub for meals. I like doing activities. I like drawing, art, reading. I like writing stories and poetry and I also like watching films, watching TV and making things. I go to the library quite a lot. I like computers.

I am very chatty, however, sometimes I can be shy. I like making friends. I can be outgoing and independent, when I want to be. I am quite a creative person. I'm supportive as well. I like going for walks. I belong to a walking group.

I am currently doing a computer course. I am studying databases, spreadsheets and word-processing. I go on Facebook quite often. I like music. My favourite type of music is R'n'B. I like heavy metal/rock music as well. I do listen to hip hop, dance and D'n'B or techno music as well.

I would really appreciate it if I could make some new friends, it would be nice to have a few pen pals to have conversations with.

I look forward to hearing from you :)

Pen pal number 206

Hi! My name is Gabriela, I am 16 years old and live in London. I was diagnosed with autism when I was three.

My favourite things are writing, drawing and piano, however I am good at swimming too.

I attend a drama group. Going there for the last eight years has made me integrate with people who are mainstream and has brought fun in my life.

At school I have three friends and outside school I have one friend. When it comes to building new ones I may find some small difficulties along my path as I haven't found anyone to connect with.

I love going to the cinema and my favourite movie genres are action, adventure, fantasy and comedy. TV shows I love are *Pokemon*, *Bakugan*, *Yu-gi-oh!*, *Family guy* and *South Park*.

I collect Pokemon cards and I have being doing that since the age of 9, plus I enter my drawings in a magazine I buy called *Pocket world*, where they get published.

My mum thinks I am obsessed, but to me, I am a fan. In my mind, an obsession is more than being a fan, it is "over the top."

I would love to hear from others telling me about themselves.

Pen pal number 207

Hi, my name's Abbie.

I'm 19 and I was diagnosed with Asperger's when I was 14 and I live in Merseyside.

I love most things to do with history. Studying it for me is a passion. I also enjoy knitting and I'm learning next to crochet. I also love to write stories and this helps me express everything I need. I really don't know what I'd do if I couldn't write.

I am a kind person that is always trying to help others. I am quiet at first but once you get to know me I'm very outgoing.

Friendships between women: similarities and differences?

by **Ametrine**

I want to share a recent experience with you all of a friendship I had with a NT woman, which blossomed and then sadly died all too soon. I wonder if other autistic women tend to have this kind of experience, as it's not the first time for me.

I am a very spiritually orientated person, and I started attending a Taize singing group. There I met a woman thirteen years older than myself, who had just moved to the area. She is also very spiritually orientated, and she comes across as a deeply honest, open person with a lot of self-knowledge and emotional awareness.

We struck up a friendship and soon we were spending time together at least weekly, and emailing back and forth most days. We became very close very quickly, though I was always aware that she had other close friends from her past, while I don't really have that.

As I got to know her I shared my fears about not usually having close friendships, especially with other women, and that my differences might scare her away, or be too much for her. She assured me that this wouldn't happen, and that if she had a problem with me we would discuss it, she wouldn't just walk away.

We took walks together, and we had a list of planned future activities to do together that arose from our real life and online conversations. We visited each other at home and discovered a beautiful walking route between our homes.

Her honesty and depth seemed to mirror my own, and I felt that although our relationship was neither romantic nor sexual (she's hetero) we had a developing love. We discussed things that are often not discussed, such as hugging and crying, and she said she was happy for me to ask her about stuff like that, and she would think things through and often reply in depth and detail.

Unfortunately this seems to be where things went wrong. She took offence, and soon after she told me she no longer wanted these intense email discussions. Later she said I forced her into intense discussions she didn't want to have.

I was scared and suggested we take a complete break from each other, which I soon regretted, and I tried to re-establish contact. But she replied that she didn't want to see me again, at all. She stopped attending the Taize group, and we ceased contact altogether. We didn't fight, but she kept coming up with different reasons for why she didn't want to see me, and finally she said it's because she defaults to positivity, whereas I default to negativity, and I bring her mood down. I can see where she's coming from, but I feel we could discuss how to do things differently, rather than cease contact and lose the closeness.

So that's the story really. It took me three weeks of emotional distress and struggling to try to work out what happened, before I started coming to terms with the fact of having and then losing this friendship. I think I'll never understand all the levels of how things might have gone wrong.

I've learned that although someone may mean what they say about themselves and what they would do (as I can tell very easily if people are lying) they may not actually have the self-knowledge they seem to, or carry through what they said when it comes to the crunch.

It leaves me curious about the kinds of friendships other autistic women have. Most of my friends are men of around twenty years older than myself (I'm 41), and I find friendships with men much simpler, but also less intense and close, usually. There was something very special about having a close female friend, and something very painful and personal about losing that.

Dear Goth,

re: *Asperger United* cancellation.

Reading about other people's problems may be helpful for some, but I find it too much like a depression newsletter.

From my contact with both the diagnosis service and psychologists I can say they neither understand the people they are dealing with nor show any compassion whatsoever. Since they have no real solutions they are left trying to get me to promote their label and their service.

The autistic spectrum is indeed very wide, so wide that you could classify most of the human population.

I think it's more helpful to address the numerous issues people have rather than dealing with meaningless labels.

I might resubscribe at a later date, but the human mind is complex and I'd advise caution towards anyone who says they have an answer.

Thanks,

Jonathan

Thank you. Balancing the needs of those who benefit from understanding that their experiences are not unique and those who don't want to be depressed is impossible, as the very letter that helps one upsets the other. I wholeheartedly agree that the only actions that matter are ones that improve lives, Editor.

Dear Goth,

the most prevalent relationship in my day-to-day life is an unfortunate one: that with my colleague/boss (the hierarchical arrangement in the company is rather muddled). Why is this unfortunate? First there is me: in order to be able to continue working there I have, over the years, cut out pretty much everything from my life that wasn't job-related. I have no friends to speak of and the relationship with my family is pretty casual as well (though not without pitfalls). That leaves my colleagues for day-to-day human interaction (like most autistics I enjoy a reasonable amount of interaction, I'm just not very good at it). The advantage is that I know exactly where this interaction begins and ends: my work hours and the office. The disadvantage is that the relationship with colleagues isn't comparable to friendship (in their case I don't want to be, either).

So that's the first thing that's wrong, the second is my colleague/boss. She handles the communication with the rest of the company, of which we're a small and separate part, and I spend the majority of my working hours with her around (we all work part-time). So she's important and often around. That would be fine but for her personality: her emotion-handling skills are slightly worse than mine (and mine aren't stellar to begin with) but unlike me, she tends to project her emotions outwardly. For an autistic, that's extremely confusing. So our relationship has had it's fair share of rockiness, and by now I'm certain that I would never have kept a relationship going if we hadn't been colleagues. Trouble is, as I described above, at the same time, there is nobody else. The one other meaningful relationship — one where I get to spill my guts, figuratively — is with my psychotherapist, but that will only be for another year (she's retiring) and with the cuts to healthcare I'm not certain it would be affordable for much beyond that. So, the mission is clear: I have about a year to find another meaningful relationship (however that works) to give me at least some feeling of "grounding" in this world.

This does make me wonder, though: from reading *AU* I gather other autistics have more involved social lives than me (or is it theat they spend the time I spend with colleagues with their friends?). So I am curious whether I am extreme in haveing effectively no friends, in feeling such fear for all the intricacies of maintaining any relationship that isn't bound by easily recognisable borders, such as colleagues or therapists (even when they are digital, such as Facebook: I get anxious even thinking about having a Facebook account). Am I alone in being so alone?

Tom

Dear Goth,

having read the *Asperger United* edition of July 2015, there were several items that struck a chord.

1. The letter from Anne (page 4). I, too, had problems of this kind which dominated most of my life — until I met my husband and it went back in its box. I have a fault or extra duplicate bit on my No. 9 chromosome, which controls the gender. It is generally believed to be the cause of two miscarriages, so we are unable to have a family. I can understand how Anne feels though. As to Elkie's article, when I felt "male" I saw a specialist at a gender identity clinic, which helped.

2. I agree with Steve (page 9) about autism and employment. I am an NAS member. There is not much on the NAS website for adults, so I am preparing a booklet on how to spot autism (AS, high-functioning, etc.) in adults — the top twenty things people need to know. I think there should be more recognition and reasonable adjustment in organisations and society. The trouble is, nobody actually wants somebody with a disability working in their organisation — even though the law says employers must employ at least one or two disabled workers and make reasonable adjustment. I turned to self-employment (and so did my husband) because of the attitude of some companies.

3. The letter from Darren (page 18) got me thinking. Has Darren himself got AS or a related condition? Having mentioned elsewhere that my husband has social communications disorder, he, too, had the same problems with social interaction and inappropriate comments that Darren's friend has. I had to retrain my husband and managed to get him not to do these things. So far, it's worked a treat for us, although I appreciate that some people would find it harder to do this.

Yours sincerely,

Frances-Mary

Everyone printed believes themselves to have some form of autism, except some notices and where stated, Editor.

If I didn't have . . .

by **Richard**

If I didn't have Asperger's syndrome it is unlikely I would have been hypersensitive to certain sounds, smells or touch.

If I didn't have Asperger's syndrome it is unlikely I would have found it very difficult to understand the rules of social interaction.

If I didn't have Asperger's syndrome, it is unlikely that I would have been confused by metaphors and clichés.

If I didn't have Asperger's syndrome it is unlikely I would get in the shower at 9.30pm exactly on every Sunday night like I do.

If I didn't have Asperger's syndrome it is unlikely I would have been misunderstood as I have been by many people.

***

Alternatively . . .

If I didn't have Asperger's syndrome I may not have had an exceptional memory for dates and some things like I have.

If I didn't have Asperger's syndrome I may not have been able to view issues in the rational, detached and logical manner as I do.

If I didn't have Asperger's syndrome I may not have been able to see through the two-facedness and hypocrisy of the society that I live in.

If I didn't have Asperger's syndrome I might have been a heroin addict, an alcoholic or a soccer hooligan.

If I didn't have Asperger's syndrome it is unlikely that I would have written these words.

And if I didn't have Asperger's syndrome, it is unlikely that you would have read them.

Autism and ageing project

by **Cos Michael**

For the last year or so, I've been one of several autistic advisors on a long-term study to find out more about the lives of autistic adults, including older adults. The research will cover all aspects of health, work and support. The research findings should lead to improved support and services for us.

It's called the Autism Spectrum Cohort UK and it covers the whole UK including Northern Ireland. It has already started.

Right now, the team is looking for autistic adults and older people, willing to share their experiences. It starts with a questionnaire and, over time, there'll be more, because the study wants to look at how people's lives change over the years. Later on you might be asked to talk to a researcher, but you can choose not to if you want. Personal details are removed from all findings, so it's completely anonymous.

The researchers want to keep participants up to date with findings as they go along, so they've created a website where they've already posted the first findings. They'll also be using social media.

If you're interested, or just want to find out more, you can call **0191 282 1380** or email **adultautismspectrum@ncl.ac.uk** where the research team will be happy to help. If you prefer post, write to:

Institute of Neuroscience – Henry Wellcome Building
University of Newcastle-upon-Tyne Medical School
Framlington Place
Newcastle-upon-Tyne
NE1 4HH

There are information sheets with more details about the research and more information on the website:

research.ncl.ac.uk/adultautismspectrum

Like them on Facebook:

Adult Autism Spectrum Cohort-UK

Guests in hell

by **Sean**

For autistics there exist two kinds of hell. Every autistic is a shade of one or the other. And we live our hells every day for no other reason than we must.

The first hell, the inside hell, is for those who suffer the harshest our condition has to offer. Imagine being stuck in a glass box. Unable to leave, communicate with the outside world or even to explain your suffering. Your body is not your own, but whenever it doesn't do what it needs to, it hurts. You want to break free, to control your body properly but you cannot. So you despair.

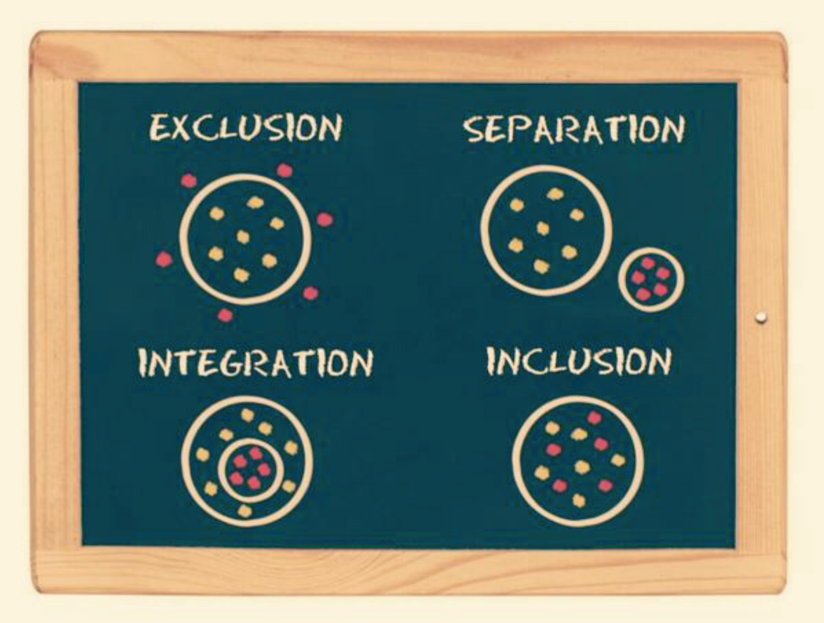
The second hell, the outside hell, is inflicted upon those who managed to dodge the most severe parts of our condition. You have control over your body but not quite fully. Your perception is warped, your movements unbalanced and your knowledge of social cues leaves much to be desired. You are burdened by the knowledge that you are close to normality, to convenience but it will always be out of reach. Your glass box comes when people are around you. Preventing you from being you. You become a silent shadow. The only ones who notice your condition seek to mock and destroy what little confidence you have left. So you despair.

But there is always hope. One day the guests of the inner hell may master their state so it becomes workable. All while savouring the different perception it grants them. For the guests of the outer hell may one day speak and be heard. Silencing their bullies and cultivating friends and allies that protect them from the horrors that society concocts.

A Mile For Autism

by **Lynsey**

As a person with ASD, raising awareness for autism is important to me because there are children and adults who slip off the radar and are missed all the time. So last July I joined in the campaign to walk a mile for autism awareness, choosing to do my mile around my local park and also donating to the cause via text message. Many people living with ASD and their families took part all over the country by walking, running and cycling a mile for awareness. This was set up by the charity Ambitious about Autism, and was a huge success for all people and families affected by autism on a daily basis. I have also raised the issue of people on the spectrum being included in the government care plan, through a campaign by the National Autistic Society called the Careless campaign. I have also written to politicians, as so many of us living alone without care and support cannot care for ourselves or get out into the community and are left living in fear confined within their condition. I also started a blog on autism awareness and mental health. As I am one of those whose ASD is mistaken for mental ill-health I feel there could be a lot of us in this situation and the NHS must improve. If America is up to date with publicising autism why can't Britain do the same? As autism has not received public backing it is misunderstood how lonely and isolated we can be. The neurotypical world does not fully realise how hard it is to live in fear of communication with them and how difficult it is for us understanding their world. I went through a mainstream education and was always isolated through the feeling of difference and constantly ridiculed: my ASD had not been picked up on all the way through school. So I feel bullying in autism is unacceptable and it does happen but doesn't have to if others are educated in awareness of our difference in the way we think, feel and behave overcoming and coping with autism is a life-long journey. Different from the journey of neurotypical self-discovery: it takes far more courage and determination which not enough people consider, let alone understand. If they knew of our jouney of growth from complete lack of self-belief and fear of the neurotypical world to amazing people with amazing talents and capabilities, maybe they would be more willing to accept ASD, and if they could appreciate the world in the way we do the things we notice, that they miss while on there own personal journey of self-development and interaction with each other, maybe they too would be more in awe of their surroundings and more in-tune with the wonders of the universe and the power of the human mind.



author unknown, sent in by **Richard**

The "normals'" innate recognition of aberrant behaviour

— by **an aberrant**

I refer to the interesting letter by Pikachu Murray (*AU*, July 2015, page 10).

Pikachu states that she has been bullied all her life and that her Asperger's syndrome was late-diagnosed. Yes, I wonder if those of us who are different in behaviour are recognised as such by the "normals" first, before we recognise it in ourselves and before it is even diagnosed by medical professionals. I also wonder if "normals" have an innate animosity to those not of their like. Evidence (Pikachu provides some) suggests that this is so.

I was also interested in Pikachu's theory that autism renders us to be childlike. I think there is truth in that theory. I think that many adult "normals", especially those with power, behave abominably. I regard myself, this adult aberrant, this individual with autism, this atheist, to be sometimes childlike but always ethically sound.

Dear Goth,

in response to Steve's letter re the difficulty of becoming an NAS Councillor . . . he makes some good points.

If the NAS really do want to help adults on the spectrum, they themselves will start acting on what they know about autism instead of just paying lip service to being inclusive.

Or is it a case of "do as I say, not as I do"? I've been an NAS member for seven years and am tired of my needs not being addressed in NAS literature. All that seems to concern the NAS where adults are concerned is (a) their difficulties in getting and maintaining employment, and (b) driving forward government policy changes to be more autism friendly.

Whilst these two areas of concern are hugely important, what about our needs as people, eg. socially, legally, health issues, emotionally, suitable housing, and so on.

Do these areas not concern the NAS, and if they do, what are the NAS doing to tackle them, in Norfolk say, where I live?

As someone with AS, living independently, aged 57, I have all sorts of problems in daily life, eg. abuse from neighbours (for being unable to work), lack of financial advice, medical practitioners not making "suitable adjustments" . . . I could go on.

The NAS's responses to all of my approaches thus far have been to send me fact sheets, which are useless to a person who is so stressed that she is having "shutdowns" and can't do it for herself!

I struggle to maintain my independence, some sort of social life and not being in debt on a daily basis and with no help from the NAS on a practical level.

Sadly, I have to agree with Steve's conclusions ie. the NAS are not seriously interested in helping adults on the spectrum.

We're perhaps not cute enough to garner funding for.

Or maybe, we are too damned opinionated to include in NAS discussions that are purportedly on our behalf!

Wake up, NAS. We're too smart to be fooled by empty PR designed to cover a patriarchal attitude!

Eleni

Also, thanks for your comment about Joe's letter.

Some people lie to get what they want, be they male or female, on the spectrum or not!

Life's a bit*h.

Yeah, an interesting read. Thanks.

Dear Steve,

reading your letter about NAS jobs and councillors sounds very similar to issues I have faced in the past for other positions in life when applying for or changing jobs et al.

Reading parts of your manifesto, agreeing on your identified need for all those items, and knowing the problems you're faced with attempting to attain such position, I would like to offer you my support and nomination. Should it be required, your nomination is hereby stated.

Myself, a 41-year-old diagnosed in his mid thirties, holding a job many would want to have. But I know now that if I was diagnosed prior to getting my job, I would be unable to attain it, so forgive me not disclosing my occupation for fear of a peer review and me losing that . . . .

Having been late-diagnosed, I have faced many years of the problems described by others. Firmly established in my third company in my educated field, I decided to declare to HR-management the issue, after which they were reluctant to let me keep my job. I required an assessment to be made by an independent expert, medically qualified, person who could confirm that, given the fact I had held the position for over a decade in total across multiple companies, the diagnosis would not necessarily require me to stop working in my profession.

Personally, the diagnosis has been a positive thing, now being able to explain why I was a certain way, did certain things and (dis) liked certain things more then others. It also explained why I was very good at my job, other areas of interests and many intricate issues in my life.

Interpersonal relationships however in the home, suffered greatly. Instead of being faced with a supporting partner, my wife of a decade with twins gained during the period, I was faced wit many comments such as "I knew it", "can't you be normal", "no wonder I did —— because of your AS", the list goes on.

Having tried, repeatedly, to improve myself, without any local help available for adults after diagnosis, I moved out from the family home, living nearer to my place of work to avoid commuting, creating a more calm environment around me. I don't mind being on my own, I just miss my kids who I don't see enough anymore, they helped me a lot, they're only 7 . . .

Fabian

Being autistic

edited by **Caroline Hearst**

AutAngel

£5 – £7.50 including

postage and packing

review by **Cos Michael**

In this short book, (64 pages) nine adults write about their journeys from discovery to acceptance of their autism. Their stories, like the individuals themselves, are all different, as are the responses of those around them. For anyone who is diagnosed in adulthood and wonders how it is for other people, these accounts allow us to see that discovering we are autistic is one thing, but realising what that means can be a far more complicated journey. It is also a good introduction for families and friends who may be struggling to understand how an autism diagnosis might have a profound effect on the life of their loved one.

Buy at:

www.autangel.org.uk/being-autistic-book.html

or send a cheque to:

AutAngel
6 Haywood Close
Reading
RG13QF

The war of the biscuits

by **Siobhan**

The chocolate digestives lived peacefully on the shelf in Tesco's until one afternoon they were taken. Once they were brought home to Mrs Speed's house she undid them and put them in her biscuit box. The chocolate biscuits felt very intimidated, as some of the other biscuits who were there were quite resentful of these new additions to the biscuit box. There were plain digestives, ginger nuts, Bourbons, custard creams and Jaffa cakes.

The custard creams and digestives looked down their noses at the Jaffa cakes and Bourbons. This was because those biscuits with a hint of chocolate were always eaten first by the humans, whereas the other biscuits were left to go stale and that was a really unpleasant death. The ginger nuts were fiery, and were always bossing the other biscuits about. They would always jump the queue every time the biscuit box was opened because they wanted to be eaten first. But little did they know that these new chocolate digestives wouldn't be bullied by the ginger nuts, like the other biscuits were.

Every time the ginger nuts pushed the Jaffa cakes around when the biscuit box was opened, the chocolate digestives would jump about as high as they could so they'd find themselves being picked by the humans first. The plain digestives and custard creams started to feel guilty seeing how the ginger nuts behaved towards the other biscuits. So the next time the biscuit box was opened when the ginger nuts were pushing the Jaffa cakes and Bourbons about, the digestives lifted the Jaffa cakes and Bourbons up to the top of the box so that the humans could eat them. After the chocolate digestives, the Jaffa cakes and the Bourbons had been eaten, the ginger nuts came to realize that they couldn't boss around any new additions to the biscuit box anymore. As the plain digestives and the custard creams wouldn't tolerate it.

Sadly, though, this was forgotten, as one afternoon Mrs Speed took her grandson Martin to the bakery to buy him a treat. He was spending the afternoon with her helping her sort through some old photographs. Martin licked his lips as he looked at all the cakes and pastries, "what shall I have" he thought to himself. "Do you want a gingerbread man?" asked his grandma; "Go on then gran," replied Martin. So the lady behind the counter having heard his request got her prongers, and put one gingerbread man in a paper bag and handed them to Mrs Speed. "That'll be £2.30 please" said the lady; "Here you go keep the change," said Mrs Speed handing in £2.50. Once Mrs Speed and Martin got home they removed the gingerbread man out of the wrapper, and put him in the biscuit box for Martin to have after his lunch. All the biscuits stared at this new and strange arrival, as half of the gingerbread man's leg had been eaten. Martin had sneakily taken a bite of it when his gran wasn't looking. "What are you?" asked the custard creams; "I'm a gingerbread man," he stammered in fear. He didn't like being stared at one bit, and it made him feel intimidated. The ginger nuts recoiled in horror at him, the Jaffa cakes and Bourbons laughed at him because his leg was missing and he had to hop around. The plain digestives were the only ones who didn't laugh; they were very angry with the other biscuits. What they were doing was bullying the poor gingerbread, they should have known better as some of those biscuits had been bullied themselves. The plain digestives decided to speak to the chocolate digestives about this bullying, as it had to be stopped. If the poor gingerbread man didn't get eaten soon, he may go stale even more quickly than usual with being so unhappy at being picked on.

Later on the biscuit tin was opened again and a few chocolate fingers were dropped in: the attention was now on the fingers. And the gingerbread man was left alone for a while. The chocolate fingers were very jolly and always seemed to be laughing — some liked to dance about and throw themselves up and down. But there were two amongst them that were very different to the others, they were always on their own and ignored. When the plain digestives asked why they were on their own, all the other chocolate fingers would say was, “One’s odd, and the other is slow:, they aren’t one of us”. The poor chocolate finger that was referred to as odd just stood in the corner in his own world. And when the other biscuits tried to approach him to introduce themselves he would cower away in fear. The other chocolate finger who spoke slowly chatted away happily, but the biscuits would laugh at the way he spoke. This made the poor finger burst into tears and walk away, to be with the other finger. “We’ve got to do something about this, it’s wrong,” the plain digestives said to the chocolate digestives. “Just because somebody is different doesn’t mean its right to be cruel to them; the Jaffa cakes and the custard creams should know better. They were pushed about by the ginger nuts,” said a plain digestive.

So it was decided that a meeting be held with all the biscuits together, to talk this through. Meanwhile one of the chocolate digestives would go and sit with the two fingers to try and befriend them. By this point the gingerbread man had joined them, as he too was made to feel isolated. At the meeting the Jaffa cakes, custard creams, chocolate fingers and ginger nuts bowed their heads in shame, as the plain and chocolate digestives told them exactly how they felt about the cruelty towards the gingerbread man and the two chocolate fingers. “Imagine how you would feel if people laughed at you, because you looked different or you were slow to understand what was said to you.” “We are very sorry,” said the biscuits together.” “We would like you to start being nice straightaway,” said the chocolate and plain digestives. “Especially to the gingerbread man as I suspect he’ll be eaten soon.”

All the biscuits together walked towards the two chocolate fingers and gingerbread man, and all said, “We are very sorry we were unkind to you and left you out.” They held out their hands and said, “Can we shake hands and be friends?” The gingerbread man and the two chocolate fingers warily held their hands out to shake the other biscuits’ hands, and with that the chocolate and plain digestives went, “Hurray!” and gave them a round of applause.

Later that afternoon the biscuits all mixed together freely, happily chatting away. The gingerbread man felt accepted by the other biscuits, as did the two chocolate fingers. The biscuits were very patient with the chocolate finger who spoke slowly, and they let the chocolate finger who found it difficult to communicate to only talk when he felt comfortable to. And by the time Martin put his hands into the biscuit tin to collect his gingerbread man, all the biscuits were content and happy. Several custards creams and ginger nuts were also taken to go with Mrs Speed’s cup of tea. But the important thing was that all the biscuits that were left in the tin treated each other with respect and kindness: that was how it should be.

If sufficient material is sent in, the theme for January will be **gender** or **work**. 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!

Empathy

by **Tom**

I would like to say (write) something about empathy because there is some confusion about this term that impacts how people view us: there are two kinds of empathy, namely emotional empathy and cognitive empathy. Emotional empathy is the ability to recognise what others are feeling and having your own emotional response to that. It is by now pretty common knowledge amongst autism professionals that autistics have that ability.

In spades.

I'll come back to that, but first the other kind of empathy: cognitive empathy means the ability to understand what someone is thinking and extrapolating from that. In other words, the ability to understand WHY someone is feeling the way they are. This is where we autistics falter. Common perception is that this is because we don't pick up the subtle and often non verbal signals that indicate someone's changing mood or thoughts, but from personal experience I know that to be incorrect. That's where the spades I mentioned above come in: we autistics don't feel too little, we feel WAY too much. So much that we try everything to stem the tide of incoming sensations, making us appear rigid and unemotional from the outside. We, therefore, DO pick up the non verbal signals that could tell us what someone's thinking or feeling, but these signals get drowned out in the noise of all the other sensations engulfing us. It is very often that I understand all sorts of looks and gestures after a little while, having had time to calm down and process all the other things that were going on.

In fact, that's one of the basic traits of autism: what I would call the intensity of the experience. We experience the world so intensely that we shut down, overload, have melt downs and are socially awkward because we lack the focus and peace of mind to give the right amount of attention to, say, a conversation. Let that be clear: we do not feel too little, we feel too much.

However, let it also be clear that it's entirely understandable for the outside world not to pick this up. My experience with others with autism (co workers for instance) is that, from the outside, it really is deceptively easy to be fooled into thinking that there isn't anything going on inside. Only if you pay close attention and know what to look for, you can see the turmoil behind the passive exterior. That goes for myself, too: even the people who know me best, and are knowledgable about autism, need me to explain what's going on.

So there's a task (for us and professionals): tell the world that we have an abundance of feeling and need protection from that, instead of the casual image of us being unfeeling. The difference is huge: if you think someone isn't feeling anything, you would heap more and more stimuli on them to get a reaction. With people who are quiet (shell shocked, really) because they are already overloaded with sensations, that would be tantamount to - if you'll excuse the rather strong expression - abuse.

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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
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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
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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.

Don't panic!

Resubscription project

An explanation of what will happen by **the Goth**

I am glad to say that previous mentions of this project have not resulted in a lot of anxious replies. I realise that this change will make many of you a bit anxious, so I am trying to introduce it as gently and easily as I can.

Starting in January, *Asperger United* will be sending out fliers asking you to confirm that you want to continue subscribing.

One thousand fliers will be sent out in the first batch. If you don't receive one, you don't have to do anything. The first batch will be to people who have been subscribing for an unknown length of time (due to database errors) and the longest subscribers. Later batches will be to newer and newer subscribers.

If I get no reply to the first flier, I will send out another. Everyone will get three chances to resubscribe, with three consecutive editions. This will avoid problems with fliers getting lost (by you, me, or the Post Office) and give you plenty of time to feel able to respond (I know a large number of readers go through periods of withdrawal when they struggle to deal with things).

I would like as many of you as possible to reply to a flier electronically, to keep costs down, though there will be the usual phone numbers and postal address available for everyone else. All the details of how to respond will be on the fliers.

Again, I really want this to be as easy a process for you as possible, so please get in touch with me — at the usual postal and email addresses — if you have any concerns that I have not covered here.

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)
Fax: 020 7833 9666
Email: **asp.utd@nas.org.uk**
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