

Edition 65 January 2011





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 with the condition in touch with each other and to share information so that they can lead more independent lives.

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

Asperger United is free. To subscribe you, we need your postal address. We ask for a contribution of $\pounds 6$ per year from overseas readers and $\pounds 10$ 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

Telephone and production support

The National Autistic Society's Publications Department

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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 Cohen.

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 $AU \log o$.

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

Contributions for the next issue should reach us by 14 February '11

Welcome to the first colour edition of *Asperger United*. Please let me know what you think about any of the changes. You can also give me suggestions to improve the changes.

Apologies to anyone who was looking forward to the sleep edition — only a couple of very short pieces were sent in, which isn't enough to make a theme. Somehow, both themes, sleep and creativity, seem appropriate for celebrating colour.

On page 19 you'll see a new feature in AU: a list of "the rules". These are instructions for how to do all the most common things that people want to do or know when they contact the magazine. Let me know what you think of them, and let me know if you think I've missed any important instructions out. Also new and on page 19 is the logo of the Forest Stewardship Council. The inner pages of AU are now made entirely of recycled paper and the cover is a mixture of paper pulp from various sustainable sources, including a varying amount of recycled paper. The inner pages are deliberately off-white to make reading easier — it's not because of the recycled paper.

Lastly, for the first time since the NAS took over the running of AU, there's an increase in size (measured in words). A few years ago, when the change from twelve to sixteen pages happened, the size of the lettering also increased, so the number of words per issue actually went down back then. I hope you enjoy the extra items every issue,

the Editor

the creativity edition - next issue notice on page 10

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Miss Simpson's hairgrips

by Elizabeth

Lizzie Moppet's early schooldays had one glimmer of interest. Her teacher, Miss Simpson, wore interesting hairgrips.

Hairgrips featured largely in Lizzie's life. She, herself, wore them; so did her mother and two sisters. The fashion was for long hair, which required the means of control.

Women wore their hair swept up in buns and French rolls — all held in place by hairpins which couldn't be seen. Hairgrips were then needed to keep loose strands off the face. Girls wore plaits, bunches or ponytails, tied with ribbons, which also required hairgrips.

Lizzie's mother wore either a French roll or a plaited bun with a few strategically placed hairgrips to keep the general effect neat. It was a huge challenge, and a special treat, to be allowed to unpin her mother's tresses, remove all hairgrips, comb and brush the hair and remake the style — often with a few extra hairgrips.

Lizzie liked hairgrips so much, she actually wore dozens in her own hair and refused to remove them — even to go to school. She loved all kinds of hair paraphernalia, and liked nothing better than to spend time arranging the hairgrips, rollers, and so on, on her mother's and sisters' dressing tables. She liked to try out the different sizes and types in her own hair.

There was just one thing missing in this quite vast collection of hairgrips in Lizzie's home. Colour. They were all brown.

For a long time, Lizzie had supposed that hairgrips just always were brown, but going to school had introduced her to the idea that they actually came in a small range of different colours. Miss Simpson's were white. Lizzie had never seen white hairgrips before and longed to have some in her collection. She asked her mother if some could be bought. Her mother's answer was decisive and final. "Of course not!" she said gaily, "What would be the point? Your hair is brown!" Lizzie couldn't see what this had to do with anything.

Next, she tried her father. "Well," he said, running his hand over his bald crown, "I'm not sure I'm the one to ask about that. Have you asked your mother?" Lizzie nodded. "And what did she say?"

"She did say 'no', but . . ."

"Well there you are then," he said kindly, "I think there might be enough ironwork in your hair to start a shop!" he joked, "You run along and help your mother, there's a good girl!"

She tried to get the support of her sisters. Perhaps the democratic will would prevail? She was to be disappointed but did get a more detailed explanation.

"The point of a hairgrip," said her older sister, "is to keep the hair in place without being seen. If your hair is brown, you need brown hairgrips. If your hair is black, you need black hairgrips. They're not hair ornaments as such, like slides and ribbons. You don't want people to know they're there. Do you see what I mean?"

Lizzie felt this to be senselessly restrictive. "But I particularly like white ones," said Lizzie.

"I don't think I've seen white ones at our chemists anyway," consoled her sister, "I expect Miss Simpson bought hers in some other place." She then added, "Truly blond hair is very unusual. I don't think there is much of market for white ones. You won't get them around here." Lizzie was disappointed but unfazed.

When she was next at school, she found herself at the back of a line snaking behind Miss Simpson's desk. This presented Lizzie with the opportunity to observe her teacher's hair more closely. It was certainly very blond. Furthermore, the wavy strands held back by hairgrips never reached the French roll at all.

How wonderful it would be to remove those white hairgrips, take the French roll down, and start from scratch to put it all back! Lizzie was convinced that if she had hairgrips like these, she would wear hundreds of them.

As Lizzie was mulling over all this, the line of children had moved forward and she hadn't noticed. Miss Simpson became aware of the stray child behind her.

"What are you doing lurking behind me child?" she said sharply, "Come around to the side in a proper manner!" Possibly, this rather odd child was giving her the creeps.

Having unwittingly drawn attention to herself, Lizzie now became the object of Miss Simpson's venomous attention.

"Why does your mother send you to school with all those hairgrips in your hair?" she demanded. "It looks ridiculous!"

Lizzie knew that everyone at home shared this opinion, which was awkward. She eventually said, "I'm allowed to do my own hair." Miss Simpson looked disgusted, as if she didn't know what the world was coming to. She got rid of Lizzie as quickly as possible with the words, "Go and sit down!"

One day when Miss Simpson was at the back of the classroom, Lizzie had occasion to return a pencil sharpener to the teacher's desk. Everyone was engrossed in their work and Miss Simpson was looking the other way. As Lizzie turned to go back to her own desk, she spotted something on Miss Simpson's big, rectangular desk top: a white hairgrip. Possibly it had fallen out of the teacher's hair or handbag. It may have become uncomfortable and purposely removed. Lizzie knew that hairgrips had a way of turning up in odd places. It was partly how she built her own collection, after all. She stopped dead in her tracks and stared at it.

At home, she could have just helped herself to it. It wouldn't have mattered to anyone. School was different. Rules were rigid and irrational, and Miss Simpson was potentially fierce. Dangerous, even. She often beat the same two or three children as examples to everyone else. If Lizzie hadn't been constantly distracted by her hairgrips, she would have been perpetually frightened of her.

Lizzie looked shiftily around and realised she was unobserved. She looked at the hairgrip and wondered if she could pick it up and handle it. Certainly, trying it out would be going too far. Just taking it altogether would be theft. But it was only one hairgrip and the world was full of them. It could hardly matter to anyone. Would Miss Simpson really miss just one hairgrip?

As she stared at the hairgrip and pondered the pros and cons, the teacher looked up. "Why are you hanging around my desk?" she enquired loudly, with a hint of menace. Lizzie hesitated. "So don't just stand there!" said Miss Simpson, pointing at Lizzie's desk as a nonverbal instruction to get back there. Lizzie went.

Lizzie Moppet never did own a white hairgrip. Her taste for wearing so many waned, and by the time she was sixteen, she'd had enough of hair altogether. Her long hair was cut off.

She would spend the rest of her days with very short hair and perplexed the world with her indeterminate gender and radical feminism. But what did she care for the world's opinion?

Not a hairpin!

The accidental billionaires

by Ben Meznick

ISBN: 978 0 38552 937 2 £11.99 / \$15.95 Doubleday Books

The facebook effect

by David Kirkpatrick

ISBN: 978 0 75352 274 5

£11.99 / \$26

Virgin Books

double review by Neil

Proof, if proof were needed, that Aspies are taking over the world. First Warren Buffett (the world's greatest — and richest — inventor), then Bill Gates and now Mark Zuckerberg, founder of Facebook.

It was Tony Attwood who said that the Internet was invented by and for people with AS, and boy was he right!

The thing I love most is the way in which the uber-geek Zuckerberg gets the better of "super-jock" twins Cameron and Tyler Winklevoss: athletic (both are members of the US Olympic rowing team) offspring from a millionaire who were members of the "best" frat house at Harvard. They knew that the Web was the way to make megabucks, but instead of learning about it they decided to solicit the help of "social misfits who would be grateful for the reflected glory of working for the Big Men on Campus."

Instead, Zuckerberg took a look at their plans and didn't think much of them, deciding

instead to focus on his own project. When it launched to huge success, the Winklevoss brothers were horrified, and tried to muscle their way in through litigation.

Zuckerberg's relationship with his first business partner, Edwardo Saverin, is more interesting from an Aspie context. Zuckerberg and his team of programmers moved to Silicon Valley, California, to develop the project whilst Saverin decided to stay in New York. Unsurprisingly, he felt he was being left out of the loop as the website grew at breakneck speed, and decided to throw his toys out of the cot by freezing the company's bank accounts.

Saverin states this was only to get Zuckerberg to "take notice of him" but from an Aspie viewpoint this would be a declaration of war and not wanting to be involved — so Zuckerberg went out and secured other investors.

When Microsoft payed £180 million for just 1.6% of the company less than three years after it started, it put a value on the business — which had yet to make a profit — of over £10 billion.

Zuckerberg is an inspiration to Aspies around the world. For something designed to get him and Saverin girlfriends it has done that and much, much more than anyone could ever dream.

The Internet Age truly belongs to Aspies — and perhaps an AU reader will be the next Mark Zuckerberg!

Insomnia 1

No sleep today the sleep has gone away bash head against a wall to get some rest at all

Pen pals

Pen pal number 82

Hello, my name is Siobhan and I live on my own in Oxford. I was diagnosed with Asperger syndrome this year, at 60. I had quite a complicated and unusual journey to get there, painful at times.

I came from a "priveleged" background, but had severe teenage anorexia, followed over the years by other eating disorders, depression, anxiety and problems with work and relationships. Now, mainly thanks to excellent psychotherapy, life is much easier and I think I cope and relate better. I have done numerous jobs, mostly voluntary, but have been happiest in "caring" settings such as a day centre run by Mind, and an information centre about mental health. Currently I volunteer in a Mind charity shop, and with several other community groups.

I have become very interested in neurodiversity, and belong to an Aspies' social group. Other interests include country walking and exploring, writing, local history, architecture and heritage, the environment, some travel, music, and anything about people and human welfare. I spent some years with an organisation teaching meditation, and still find this very helpful when I do it! Originally brought up Catholic, I have done a lot of searching and now consider myself agnostic. Just now, I am facing a major renovation project in my house, and finding it daunting!

I would be glad to hear from anyone, but particularly mature people with Asperger's, perhaps diagnosed late in life. If anything in my account rings bells, please feel free to get in touch.

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.

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.)
- To contact a pen pal, please send your letter to Asperger United, c/o The National Autistic Society, 393 City Road, London, EC1V 1NG.
- We will pass your letter on to the person you wish to contact. However, we cannot guarantee the person will reply as that is entirely their decision.
- Please note that all pen-pal letters sent via Asperger United are opened before being passed on.
- Those under the age of sixteen must have parental permission before placing a pen-pal advertisement in *Asperger United*.

Important notice — please read

Asperger United is happy to publish penpal 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.

Hi Editor,

it's a pity that Peter took issue over Asperger's being associated with "other mental health issues".

Surely there are only two kinds of "issues" [differences or phenomena] — these are physical or mental - or both, ie. they affect the mind or body or both. Everyone experiences some kind of phenomena, whether permanent or temporary - schizophrenia, depression, being or becoming physically disabled, developing a "disease" like malaria, losing a limb, becoming mute or developing stress. Labels are necessary for identifying symptoms or phenomena so that they can be diagnosed or treated. It is very difficult to deal with people who do attach shame, derogatory meaning, value or morality to labels. Anyone have ideas about how to answer them? In my view, the more issues you have, the more potentially learned and interesting a person it makes you [if you study the phenomena].

This is my contribution to the sleep / creativity issue:

When I couldn't sleep, I used to lie tossing, turning and fretting. Now, I usually get up and make a cup of tea and then read, write or switch on my computer [Persephone] and doodle about. I find the latter is more effective than worrying and often I then go back to bed and go back to sleep until the alarm goes off. I have woken sometimes and thought of something useful to add to one of my books or to write in my journal. Often, something interesting pops into my head. I think it is being in those wonderful quiet hours, when the rest of the world is sleeping — it feels very peaceful. Does anyone else have a name for their computer?

Regards

Marianne

Dear AU

I wondered if you would be interested in publishing a piece of writing I've done on why I think Asperger syndrome training is important.

I think it is vital for anybody whether they are a professional or a member of the public, who will be coming into contact with a person who has Asperger syndrome to have proper training. Autism is a complex disability that is not always easy to recognize. Because I take things literally sometimes, a simple throwaway remark or joke like for instance "You're bone idle", can cause extreme anxiety and upset in me. To the point of me being ill, whereas most people can just let those types of comments go over their heads, because of my Asperger's I can't. And it doesn't matter if these comments come from a stranger or a family friend or family member, the impact it has on me is utterly devastating. Processing information can be difficult for me sometimes, and I can easily wrongly misinterpret what is being said to me. So it is always best to explain things carefully and clearly, to a person with Asperger's. Being touched can be extremely uncomfortable for me; I can't describe to you how many times in my life I've been on the brink of tears by people pulling my hair, or grabbing me.

One thing you must remember that everybody with Asperger's is affected in a different way, and that must always be taken into account. I think that having Asperger syndrome makes me a decent, kind moral person and I'm proud to have the disability although I have my tough times due to lack of understanding by others. I don't think I'd be the person I am if I didn't have Asperger's, and if a magician was to appear to me and wave a magic wand and ask me if I wanted to be cured I'd say "NO WAY!"

Yours sincerely,

We can change the world by Angela

People have a tendency to form social groups and only empathise with those who are similar to them. This causes problems for anyone who does not conform. In fact, most people have been teased for being different a few times but we are especially unlikely to "fit in". This tribal mentality is also the cause of many wars and corrupt systems. We have to teach people to accept everyone and not consider one person to be more important than another merely because that person is a member of their own family/ peer group/country.

The reason that society is so hard to understand is that it is not logical. For example, David Cameron is planning to spend f_{100} billion on replacing Trident, a nuclear weapon. If that money is spent on eliminating poverty instead, millions (at least) of lives could be saved. Either Trident is not used, in which case it is a waste of money, or it is used, killing large numbers of people. The argument that it works as a deterrent does not make sense. Throughout history, arms races have caused, not prevented, wars. Yet there are people who somehow consider Trident to be necessary. Having Asperger's syndrome does not necessarily mean that we have more problems than normal people. Everyone has problems, and some of us have unique talents which could make incredible improvements to other people's lives.

If everyone spoke honestly then most people would benefit. "White lies" do more harm than good in the long term, since they make it hard to know whether someone is telling the truth. Many of the awkward nuances of language evolved to preserve social hierarchies which should not exist. Small talk does not contain any useful information. By typing the next sentence, I have qualified myself as a hypocrite (again!). Instead of wanting revenge, we should treat others as equals, regardless of what they do to us.

About myself: I used to feel isolated but I never admitted it. When I was five I was excluded from school for biting and attacking teachers. I moved to a different school, and gradually grew out of the tantrums. I was taught to do as I was told, and became more withdrawn. I wished that the teachers would let me learn something new, instead of revising the same, oversimplified textbook material, but I kept waiting for something to change, and it never did. At least I could read books at home and visit the library. When I started GCSEs, problems that had faded before returned. It seemed as if everyone was against me. Tears, screaming and nightmares about blood became more common and, though always quiet, I became more withdrawn. I still do not know why, but I started avoiding food and reached a stage where I would only eat if I was dragged to the table and threatened with having my hair brushed. All that psychiatrists could do was attend meetings, print reports (often in duplicate or triplicate), earn their salaries and refer me elsewhere. I realised that, although I claimed to believe in God, I was really ignoring it. I suddenly found that I was not afraid of food, as long as I could work out a routine, and nothing hurt as much as it used to. I regained the fascination with maths and science that I had once had (evolution and the big bang do not disprove God, in fact the beauty of the symmetries involved can only be from God), and was able to enjoy life. I discovered that people from church had been praying for me, and genuinely cared.

Nonverbal communication

by Elkie

It was a cold winter day, when I ventured out to climb a munro near Lochnagar. The clouds were hanging low and the icy wind forced me to crawl deeper into my anorak. Not really a day for the Scottish hills, so I was surprised when suddenly three figures appeared out of the mist in front of me. With their hoods drawn down to their snow goggles and cheeks and nose wrapped up in a scarf to prevent frostnip, I could neither tell the age nor sex of these three humans, but humans they were, out in this hostile environment to seek challenge and adventure like me.

I caught up with them, and with a brief nod we acknowledged each other's presence, as the muffled voices were snatched away by the shrieking wind before they could reach the ear. During the next couple of hours we took turns breaking trail in the deep snow, stopping frequently to compare compass bearings and altimeter readings and to re-orientate ourselves on the map. Once the leader came to a halt so abruptly that we nearly crashed into each other. A moment later we all noticed the overhanging seracs, and a brief window in the clouds showed us the frozen loch 2,000 feet below. We all realized how close we had rubbed shoulders with death, how easy it was in this white-out to walk over the edge. Carefully navigating around the cliffs, we soon reached the summit cairn, buried under deep snow and glazed with a crust of ice. We shook gloved hands, shared a waterbottle and a chocolate bar around and started moving again before the cold would stiffen our bones. An hour and a half later we were back at the path and slowly emerged from the clouds. I glanced at my watch and kept up a brisk pace to catch the bus, while my companions fell back. Only once did I turn to wave goodbye and saw their hands raised in response. We hadn't spoken a single

word there, up on the mountain. I didn't know their names or age or where they came from, and yet I felt that in this brief time together I had come to know them better than my flat-mates who I saw and talked to every day.

What is it that makes human communication so dependent on words? Why all this small talk and polite conversation, the sharing of personal information which will soon be forgotten again? What about the art of connecting to each other through being and doing, so natural for those who lack a common verbal language?

Like many people with AS, I am longing for social contacts, but I am put off by the barrier of words. What seems to act as a bridge for others, keeps me out like a wall. Yet few are the oportunities to socialize in non-verbal ways once we are grown up. There is, for example, the voice of music when different instruments form a harmony. There is the voice of laughter when we play games, the voice of symbols when we create art and the silent voice of being, the most important part of a person which can only be sensed with the soul. Words easily drown out or distort these subtler voices, yet most people seem to prefer words, and people like me (and you?) remain lonely and left out, until we find ourselves in situations like that winter day where words don't work for anybody.

If sufficient material is sent in, the theme for April will be **sensory experiences** or **work**. 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!

I'm not slow to understand that to care for others equals the biggest success!

by Nick

I sit here and I attempt to read and by the time I reach the end of the sentence I've stopped being able to recall the beginning of the sentence. I may have to read the sentence a few times in order to understand it, but at least I can do that. When somebody talks to me I often don't understand what they say, perhaps because I don't understand or because I don't concentrate, or perhaps a combination of both. It does not seem convenient to keep asking people to repeat themselves and I don't wish people to think me stupid. So books are much easier to use as a tool to learn from.

Perhaps all this is due to a problem with processing. When at school, as far as I recall I was the only person in my class who couldn't speak properly; I was also behind in my reading, among other things.

I just couldn't understand very well what I was meant to be doing or what I was being taught, it all seemed quite confusing and I felt like I just wanted to hide away and I still wish to hide away. I feel society is too fast-paced and people have no time generally for each other.

I feel I need more time to take the initiative, I feel I need people to come to me instead of waiting for me to come to them. I feel I need help to know how to go about things.

When I was at school people would make fun of how I talked; they would tell me I'm stupid and not just the children but the adults were at times the same.

The people at school would have difficulty understanding me and I would be laughed at

when I spoke, I didn't feel normal and I wanted to be out of the way.

I felt frustrated because I felt I was clever and yet the teachers said I wasn't and I feel so many gave up on me; sometimes I feel as an older person I have done the same: I have little ambition, I can't compete with people in the working world. And I would prefer not to work than be a slave in a rubbish job that I do not feel happy or productive in. I would prefer to better myself by learning from my books.

I like to learn about space, the cosmos, and as HG Wells, I think, said, "It is the universe or nothing"; why should I settle for less, why should anybody settle for less?

I still have my dreams and I will continue to dream; nature has decided AS is my path in life and it's an interesting path; an opportunity to learn in a fairly unique way.

I remember when I was being taught how to tell the time and people would get frustrated with me because I wasn't getting it; I took longer than the average person to grasp things. I didn't understand what they were telling me, I couldn't see the simple difference between quarter to and quarter past — seemed the same to me. At the time my lack of understanding led me to only one conclusion, due possibly to the limited way so many people think, and that conclusion was that I am stupid! But what do you think? Do you think that's a limited, stupid viewpoint? What a shame I wasn't taught by others that to be a good and considerate person is the biggest success a person can be; to want to do things to help the people of our society - I will try and be like that!

Hello, my name is Edward. I am 34 years old and was diagnosed with Asperger syndrome at the age of 21. I would like to tell you a bit about me and my life.

I live in a secure hospital where I have been since 2005, and although I have never lived in a secure hospital before, strangely enough I love where I live now and it's one of the best places I have been. On the whole the staff, apart from the odd occasion, are very understanding and caring.

Most of my previous placements, so-called "normal people" have very little patience for people with learning difficulties, and at a previous placement I witnessed co-workers hitting vulnerable people who had severe learning difficulties and couldn't talk, which really winds me up.

For many years I always felt sorry for people who couldn't do anything right. When people say "I don't know why people pick on people with autism, as they have so many talents", even though they are supporting us, it's still just makes me feel sympathy of the people who don't have any talent, because it just seems as if because they're no good at anything, they shouldn't be accepted in society. People are so unsympathetic. I often feel I'm the only one who feels sorry for people with learning difficulties. I have frequently got myself into trouble sticking up for people.

I tried really hard to not get wound up about it, but after a while couldn't help getting wound up about it again. However, I worry less about other people now and concentrate more on myself, in a healthy way. I have an extremely obsessive personality caused by severe anxiety. This was prominent at previous placements when I first came back from spending time with my parents. For example, there was a student who hadn't been brought up by his parents and had a very competent childhood, and I felt really uncomfortable about the fact that I had a good middle-class upbringing and I'd treated my parents badly, and because of this I wouldn't allow myself to relax at certain times and would breathe heavily whilst running my hands through my hair and down my neck, often not allowing myself to sleep at night, much to the annoyance of my roommate.

Although I decided to stop making myself worry, eventually this anxiety would return on numerous occasions even when I didn't feel bad about anything. At times I used to go through the system in my head, but I simply had no control, but if I felt I wasn't worrying I then realised I was worrying, so then there's nothing to worry about, but then upon realising that, I obviously wasn't worrying again, but then I realised I was worrying, because I was worrying about not worrying again, and so on.

I particularly remember having a bad year in 1999 when I kept having to reassure myself that it was okay not to worry, and reassuring myself virtually with every breath I took that it was okay not to worry and that I hadn't tried to make myself worry. For example, every time I breathed I kept whispering to myself, "no, that wasn't it".

Since 2003 I have been troubled with intrusive thoughts about hurting people, most notably when I least want to do it. When I go out in public, my trips out are ruined by horrible thoughts. I can honestly say there is not any part of me that wants horrible things to happen, and it's because I don't want them to happen that I get the thoughts. It causes me so much anxiety, and I liken it to the feeling of when you buy something new and you have this thought about how nice it is — just imagine if I damaged it, wouldn't that be stupid, and really feel you're going to do it. However, at the moment I am not suffering so badly from intrusive thoughts and I'm very happy.

Due to my Asperger's I can work out the day someone was born on, if they give me their date of birth. I don't seem to have any interest in constructive things, such as taking exams or living independently, and I can't concentrate on things I am not interested in such as gardening.

I am very interested in the things I own, for example if I have a letter from someone from a long time ago, I become interested in that person, or if I have a music track on a CD I feel really proud of it because I own it, and I want to research it and find information about it, although, a lot of my anxiety is about whether people are going to let me have certain things, and I have tried really hard to just go with the flow and feel if it happens it happens, but sometimes that is contradicted and is harder than getting angry about it.

Number 9

by **Daniel**

Number 9 You are so fine Sitting on the number line 999 And you're alert To all those who are ill or hurt You are the last single digit in my life And I just want to treat you right Before we go to ten I will tell you when And we'll dance on the number line Number 9 You are so fine

Review of Dasha's journal

A cat reflects on life, catness and autism

by T O Daria

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Jessica Kingsley Publishers

review by the Goth

Dasha the cat's journal is a brilliantly conceived book which analyses the misunderstandings that a family have of people on the spectrum from the perspective of a disinterested observer (the family cat). Along the way, it "cattily" pokes fun at the stupidity of those researchers who aren't cats. I found it wonderfully uplifting to read a book which describes my world in the way I would describe it, and not have myself reduced to a list of problem behaviours and misunderstandings. Dasha's view of autism isn't perfect, though for an introductory text it's excellent.

For a long time I avoided reading this book because I thought it would be another book about the similarities between feline behaviour and autism, all of which are very superficial and anthropomorphic. Dasha wonderfully avoids being felinomorphic throughout the book, but tries, successfully, to comprehend autistic behaviour for what it is: perfectly normal reactions to the world as we experience it. Now if I could only get a few more researchers to take on that view, maybe I could stop them all barking up the wrong tree!

Used, useful or useless

some thoughts on the subject of employment by A Lint

Used, useful or useless: some people don't know the difference and when I wipe a thousand bottoms for the minimum wage I swear it puts all heaven in a rage. A line in a song goes "I was looking for a job then I found a job and heaven knows I'm miserable now" - ring any bells? Well there is always the "Mcjob" market, that "hire 'em, fire 'em" world; wages might just cover your rent, if you cram your flat with people and split your expenses - no? You lazy waster! Get a degree then — it's a sausage-machine experience, washed down with a flagon of jargonese, to help you digest it all. Then you can apply for wages that fund big mortgages but it's a flimsy paper "yes" to that rock-hard question; a flimsy paper "yes — we will pay you more for doing less".

Money: "That clinking clanking sound that makes the world go round" . . . and round . . . and round ad nauseam . . . aaargh, stop! I wanna get off.

Some really earn their big wage serving the community, but none of them would cope as a full-time care worker, I'd put money on that.

Don't want to give up, but there's that thing about flogging a dead horse, however revolting a spectacle that would be it wouldn't be as cruel as flogging a poor live one — to stretch the analogy and bring in a donkey, a stick and a carrot, too much stick and not enough carrot; anyway, I ain't no donkey. Is that what the benefit trap is for? — those who don't respond like a donkey in a game of carrots and sticks. For example, in the workplace one must form alliances, which are not the same as friendships. So, if something goes wrong one is not the isolated "patsy" but has others who will help defend one's actions, especially if a "blame game" ensues. It often feels like you don't have to break the law to commit a crime, as evidenced by the government: they make the rules, they have letters after their names and they are careerists, experts at deflection. They know who is useful and how to use them but they've not got a clue as to who's useless, or worse than useless — for

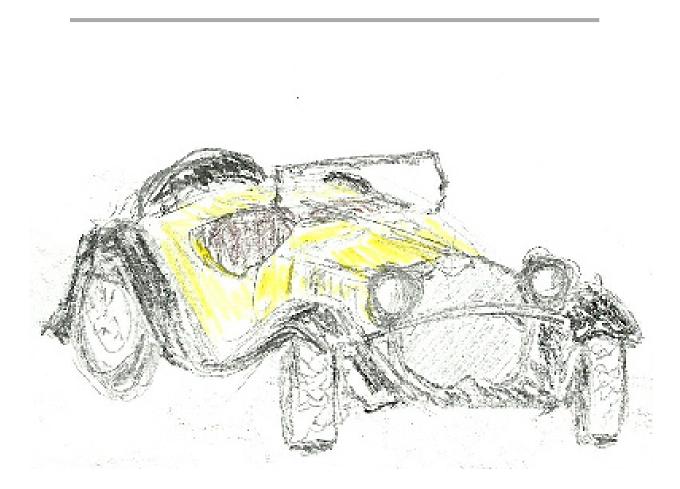
that they'd have to look in the mirror and stop pointing the blame at the victims of the situations they create.

'Twas ever thus; it's better to be alone than in bad company and life is not easy. To enjoy it we must ignore attempts to sabotage our well-being and refuse to compromise on that. So let them "syndromise" the highly individual people if it makes them feel clever: by so doing they make of themselves a collective majority of mediocrity, but mediocrity can be as dangerous as any form of extremism and just as tiresome.

Our task is to enjoy our lives and if, for you, that means getting a job then don't give up, if not, then welcome to the club, you're going to need as much self-motivation as any jobseeker does; being "time-rich" and "moneypoor" is no more isolating than being "money-rich" and "time-poor". Stamp out self-pity, where there's one cockroach there's thousands: a sense of humour will do it because God is a comedian and laughter is the best

medicine. Much worse things have happened to much better people than myself: Jesus for example, what syndrome they'd cook up for him today? He was not neurotypical but his persecutors were and they weren't breaking any laws because they made the laws. 'Twas ever thus, amen.

The Goth knows from his own problems with jobs that things often seem against us, but hopes there are others (apart from himself) who have advice to help those struggling with getting and maintaining employment which can be published in the next work edition.



Yellow car

by Kevin

Do not stereotype autistic people and non-autistic people

by David

I am going to do this article in two sections.

Autistic people:

One cannot generalise what autistic people are good at. Many autistic people have coexisting conditions. In fact a higher proportion than the general population have co-existing conditions. One cannot say that autistic people have an eye for detail. They might have for example dyspraxia, dyslexia or attention deficit disorder. Some autistic people have bad eye sight.

It is even more wrong to stereotype Asperger people as they only have a few autistic traits.

Not everyone with the label Asperger syndrome for example is over-honest. At the moment the label of Asperger syndrome is given to people with poor social skills and who have been unsuccessful in life. The way of diagnosing Asperger syndrome is going to change because a new brain scan has been recently invented. Diagnoses might in future be decided by the result of a brain scan instead of a pattern of behaviour. We do not know if people will be labelled as autistic if their behaviour is autistic but if the brain scan does not reveal autism.

Non-autistic people:

One cannot generalise what a non-autistic person would be like, as there are so many other neurological disorders. Yes, being on the autistic spectrum is a disorder but if you look on the Web you will see autism is one of many disorders, if that is any consolation. If you are not autistic you can have communication problems because you are deaf or blind.

Many people become blind or deaf in old age. Deaf people cannot tell by the tone of voice whether someone is angry or sad. Blind people cannot read signals by looking at faces. In later life it is possible to develop schizophrenia or senile dementia without being autistic. The symptoms of those two conditions can be similar to autism. Some people can acquire autistic-like symptoms by having a stroke or damaging their head in an accident. If an autistic person has a brain injury it might be difficult to know if the brain injury is causing the behaviour or the autism is causing the behaviour.

It is true that society lays down norms and some individuals do not fit into society's norms because they have a difficult personality and no one fits into society's norms all the time, or wants to. One can be over-persistent and be insensitive to other people's feelings without being on the autistic spectrum.

Autistic people find life harder as it is a lifelong disability and the ones listed above often develop long after birth. Asperger people find life harder as it is an invisible disability, hard to diagnose and they often cannot even get on with fellow people who are labelled Asperger. Asperger people could find it even harder to get on with each other than non-autistic people because two people with communication problems can lead to quarrels.

The lift that never worked

by Kate

The day I arrived the lift wasn't working. It seemed that everyone else used it successfully But the buttons failed to work for me. Alone I searched for the stairs.

The promise of belonging had lured me in The entry code earned after a considerable struggle. Totally uncertain of myself yet thrilled and excited I entered alone Certain this was where I wanted and needed to be.

Each flight of steep stairs tantalised me with hope Of the moment I would join others and relinquish the invisible bubble around me. How I ached to leave behind the loneliness And discover my place in the jigsaw of life.

I climbed and climbed Pausing for breath and the time to analyse each difficult step. The pain of isolation seemed to lessen with each floor I reached, Others calling "Hello" as they passed me — and smiled!

At last it seemed I was making real progress My longed-for destination approaching, The opportunity to rest amongst others — To "Be" without thinking, analysing, worrying.

I arrived — or so I thought At the floor where I had yearned to be, with the Everyone I wanted to join Only to discover nothing had changed. The door was locked and I remained outside, alone.

Insomnia 2 (a few nights later)

Twitching, twitching, twitching the night away pills and potions just won't work whatever people say.

An open letter to those who kindly responded to An item for publication? in July

by Paul

I would like to offer my sincere gratitude to those who took the time to respond to the article I wrote in July's edition. Their comments in the October magazine resulted in some sadness, as they confronted an assumption of mine that the "milk of human kindness has gone off." I was jolted out of my pessimism of human intention when I received gifts from the abovementioned fellow travellers. The journey of life is problematic, especially when it is difficult believing others do care. When those of us who live such a solitary, and frequently lonely existence meet kindness, it does come as a shock that others may actually and sincerely care. Many of us have such solid and reinforced psychological defence mechanisms, against the harshness of others, that when another approaches in kindness our default reaction tends to be one of suspicion: for we are the perpetual observers, on the look out for a trip-up. For those of us who see the world as so threatening, this reaction isn't surprising. However, not only is it shame for us that we don't receive "the kindness of strangers" we also deny the other the opportunity to give of themselves.

Risk! Risk! Risk! We need strength to step out and choose to accept the gift from another. I, myself, really struggle with this. Is it *really* true that another could show concern for someone like me?

I need to be careful here that I don't come across as some hugely deficient human being, who can't cope with life. I can cope; I'm still here! However, I do believe my experience of struggle is common for those on the autistic spectrum. Ironically, I accept all human beings experience the inevitability of loneliness, for I believe no other human can know us at our deepest level; but the greatest sadness is reserved for those who struggle substantially to connect with our fellow creatures. It's as though we receive crumbs as opposed to the meat another may want to give. The inability of those of us to interpret another's kindness results in a poverty to both involved in the interaction. It appears that NTs don't need to put in much effort to receive a major return from another; their intuition isn't as faulty.

Returning to the kindness of others: with the comments of Colin, Rev. John, Fiona and Tim, a connection with God can only occur if this Being allows it. If He/She/It won't open the door there's nothing more I can do; plus, the refusal to open the door seriously undermines my self-esteem and to continue knocking is something I am tired of doing.

An especial thanks to Tim for helping me to see my experience is considerably shared by himself, meaning there is a meeting at depth with another human being. A shared experience reduces my isolation.

Something good and wholesome can come at us out of the blue. The above companions are an example of this. This level of unpredictability can give us some hope for change. For nothing is set in stone.

From another angle, we find every now and then we become aware we have some surprising strength to have another go. My hope for us all is that those times of relative solidity may be coupled with an opportunity for change, and that the opportunity may be grasped by a willingness to take a risk, so that we may enter into a period of healthy and positive experience. I, myself, am thankful these occasions do come along.

The rules of Asperger United

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

- Asperger United is almost entirely funded by the NAS, but is run as a separate organisation. Although it is called "Asperger United" it aims to cover 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) Pieces that appear in *AU* are credited using the author's first name only, unless the author requests something different. This is done to protect your privacy.
- 3) *Asperger United* administers the copyright of everything that appears and it does this on behalf of the authors.
- AU 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.
- If you move house, remember to inform AU and include your old address as well as your new address.
- 6) 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.
- 7) If you want to unsubscribe, inform *AU* and include your address.
- 8) If you want to resubscribe (or subscribe for the first time) inform *Asperger United* and include your postal address.
- 9) If you phone and leave a message on the machine, please speak slowly and clearly and spell uncommon words, as sometimes 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 you in our records.

- 10) The current edition of AU is available at www.autism.org.uk/aspergerunitedYou need to scroll down to near the bottom of the page, where there is a link to the PDF.
- 11) You do not have to be a member of the NAS to subscribe to *Asperger United*.
- 12) Book reviews are the most popular thing in AU, 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).
- 13) 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.







Educating children with complex conditions

understanding overlapping and co-existing developmental disorders

by Winand H Dittrich and Rona Tutt

ISBN: 978 1 84787 318 7 £21.99

Sage Publications

review by Elizabeth Wady

Despite the title, this book is definitely for people of all ages, not just children.

On the first page we are told that complex conditions include Autistic Spectrum Disorders (ASDs), Attention Deficit Hyperactivity Disorder, dyspraxia and dyslexia. This logical layout continues through the book. Each chapter starts with an outline and also includes key points and questions for the reader, cleverly placed in lightly shaded boxes. The light colour means you can easily ignore these boxes if you want. A summary of key points is provided at the end of each chapter, together with an up-todate list of further reading.

The most useful chapter is probably number four which takes nine areas of difficulty for many on the spectrum and suggests methods of improving them. Of particular relevance to those with an ASD will be the sections covering attention, organisation, communication and motor skills. Numerous strategies, most of which can be used without instruction, are presented for dealing with these areas. All of the strategies can also be downloaded from the website (**www.sagepub.co.uk/dittrich**).

The chapter on brain function may be of interest to some and is very informative. Chapter five concerns the environment and therapeutic issues and is best avoided. Very one-sided arguments are given together with much incorrect information.

Overall, an informative book, the formatting of which makes it wonderful for those with an ASD to read!

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