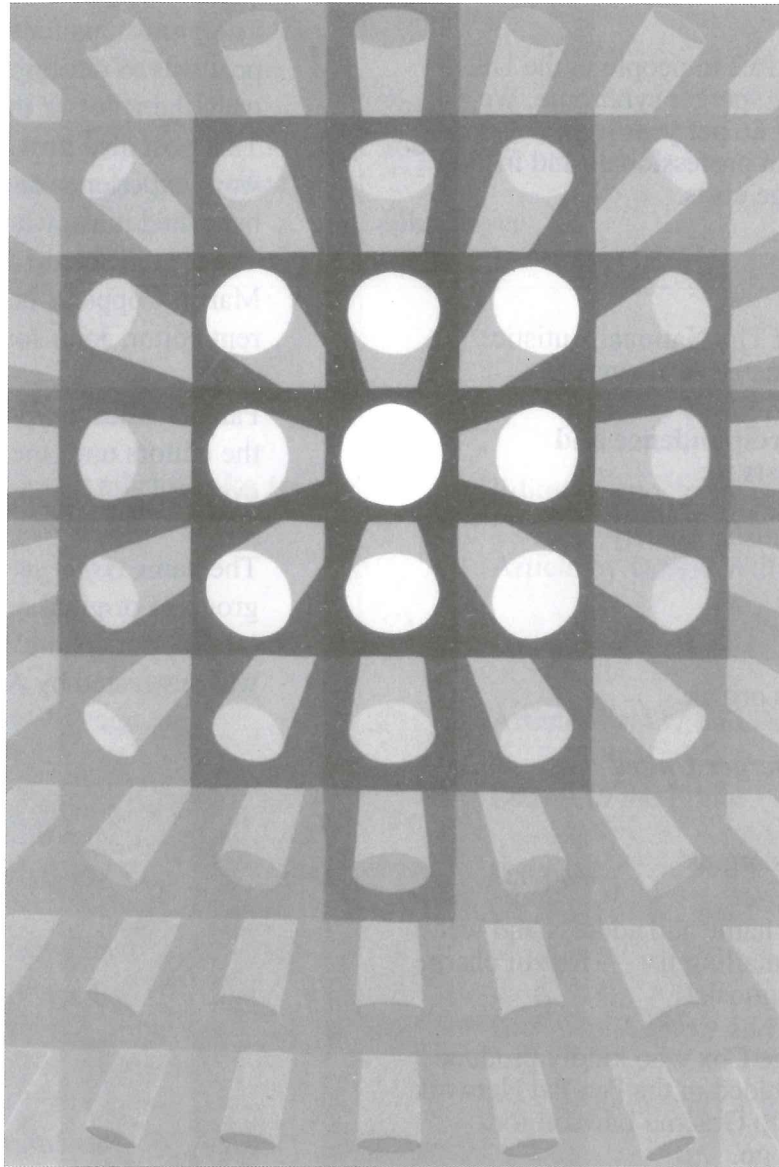


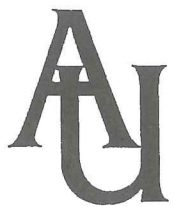
Produced by and for people with Asperger syndrome

Asperger *united*

Edition 45 January 2006



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Asperger United is a self-help newsletter run by and for people with Asperger syndrome. The newsletter aims to put people with the condition in touch with each other and to share information so that they can lead more independent lives.

Asperger United is free to people in the UK with a diagnosis of Asperger syndrome. We ask for a contribution of £6 per year from overseas readers and £10 from professionals and institutions to cover postage costs.

Editor John Joyce

Additional support The National Autistic Society's Publications Department

Please send all correspondence and subscription requests to:

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All we need is your name and address and we will add you to the mailing list — free of charge to people with a diagnosis!

Thank you to George Cox who kindly produced the illustrations included in the Pen Pal Network section. 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 newsletter.

Contributions for the next issue should reach us by 1 March '06

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

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

The provisions for editor's and sub-editor's post was to develop a publication that was truly the voice of the people it was aimed at. This post also provided the possibility of work experience and responsibility and has benefited those who have held the position. These are Richard Exley, David Wright, Martin Coppola, Ian Reynolds and the current editor, John Joyce.

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

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



Dear Readers,

Happy New Year and welcome to the latest edition of your newsletter.

Hope you have all enjoyed Christmas as I have. As I write I await the final result of my Open Univesity Spanish Course which, should I be successful, will result in a BA degree as well as a diploma. I am also undertaking a course for the Catholic Certificate in Religious Studies at the Christian Education Centre in Tooting Bec.

Since our last meeting members of the London Social Skills Group and some of our other

Asperger brothers and sisters have been to tea at the Houses of Parliament where matters of common concern were discussed with Angela Browning MP who presents our case before the Commons.

Please continue to send your high-quality material for inclusion in *AU*,

Thank you,
Your editor,

John Joyce

in this edition

My Empty Stomach speaks to me

Tells me to go to Synagogue
There
I become even hungrier
Enjoy the beautiful singing
Which is a lovely form of prayer
Not a concert
On this very special day
Makes me reflect
On world hunger
On how to be a better person
On how to be a better Jew
Before I depart this earth
How many more Yom Kippurs will I fast?

David

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The story of the first autie-run global not-for-profit employment service for all people on the autistic spectrum

by autistic author **Donna Williams**

With one in every 160 people now diagnosed on the autistic spectrum, job opportunities are booming for non-autistic people to make money from families of people with autism and government funding set aside to help those with autism. If you type in 'autism and employment' on an internet search you get masses of advertisements for often attractive highly paid work opportunities for non-autistic people to help 'us'.

Yet many people on the autistic spectrum have abilities of all kinds, sometimes hidden, sometimes not so hidden. I knew of one so-called 'low-functioning' functionally non-verbal autistic man who had a vast knowledge of homeopathy, another who could read in several languages, another who ran in charity runs, another who mowed fields and another who delivered the local paper. I know of a young autistic girl without functional speech who designed autism-friendly dolls which then got made. There were those who loved to shred paper and could offer to recycle the contents of your wastepaper bin. There were those who loved to dress up in costumes and others who liked to wash dishes, dust or polish things. If these people weren't employable in conventional jobs had anyone ever thought of setting up a service where they could list a skill and charge per task or by donation instead of languishing in residential care, often with no occupation to fill their time?

And there were those we never hear of because they are considered too 'able' to really be

noticed; an under-employed taxi driver, a bookkeeper in a regional town, a mime artist in a remote area, a cartoonist, an experienced but self-taught actor and comedian, a scriptwriter, a music producer, a piano teacher, a technical writer dreaming of writing for travel brochures and of course those who had tertiary qualifications from engineering to psychology and teaching but who struggled to get more than a part-time job in a fast-food outlet.

So in September this year we were ready to launch and began our new website **www.auties.org**

It was exciting because it has been made by people with autism spectrum disorder and it seemed from all our searches that it was the first website of its kind dedicated to the self-employment of people across the whole of the autistic spectrum worldwide in every working field.

We decided to expand the site to businesses which considered themselves 'autism friendly' as part of trying to make the mainstream world more accessible to people on the autistic spectrum. We were hoping to provide a very practical way to promote abilities in those with disabilities.

We emphasised that we had sections for people with ALL kinds of unusual skills at ALL levels of functioning and that nobody should ever cancel themselves out.

I hurt myself
I promise
Time flows backwards
I see a fainting woman
screaming for air
She's broken and sore
I just don't care

Maria

How Asperger's syndrome makes life for me

Always feeling a stranger in a foreign land, never part of the world, that's Asperger's. Do I come from another planet, another solar system's life evolution, is there any way to find a route "home" to the life I am meant to be living in? Or is this it? Endless questions, but no certain answers — uncertainty, a state that Asperger's people hate. Obsessive thoughts, compulsive, ritualistic behaviours that consume hours of each day and sap and drain my energy. Am I mad? Or is it simply Asperger's at work like a malevolent disease bacterium in my brain forcing these recurring, monotonous, repeating thinking patterns, a wheel of stale images turning round in my mind's eye for the ten-thousandth re-analysis to explain them to myself — but always no answers, no certain conclusion.

Outwardly I try my best to look and behave as normally as I can. Regular appearance, easier to look "conservatively dressed" now that I am middle-aged — 44 years — but still I feel like I'm an actor on the world's stage, playing out a part of life that I feel no commitment or sense of belonging to. I keep hoping for a door to open into my real life where I can belong, but the doors

are either invisible or locked or both or perhaps there are no escape hatches. Again, is this it? So, I carry on, take each day like a part of a long, drawn-out routine. "You are doing very well," my counsellor assures me. Yes, outwardly I do some "things" but do these "things" really have any meaning to me? Again, no sense of belonging to any of the things I do. But where would I belong? This sense of apartness, alienation from human life is Asperger's hard edge for me.

Is it karma or Cosmic Justice that has driven me into this corner? Am I to blame, and if so, what can I do about it? Just carry on with what you are doing, the neurotypical humans I can talk to tell me. Act. Pretend. But never really here. An alien spy from another world system? I watch humankind and feel the glass, invisible wall between the neurotypical world and mine.

Well, I could go on, but other *Asperger United* contributors say it all just as explicitly, so I will sign off here for now and thank you for letting me share something of my life with Asperger's syndrome, our common inheritance.

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Asperger syndrome and cultures by David

I think it would be interesting to do research into how people with Asperger syndrome who come from minority cultures cope with being different from the general population and to consider other problems which may be encountered. It is important to be aware that we are not only who we are because of Asperger syndrome but also because of life experience and the family we are born into. Asperger syndrome is not a culture; it just makes it more difficult to cope with our different life situations. Coming from a minority culture can make life more interesting and complex.

For example we celebrate the Jewish New Year in the Autumn at the time of the harvest. This year the Jewish New Year is 5766 and is on October the 4th and the Day of Atonement is a twenty-five-hour complete fast from Sunset on October the 12th to Nightfall on October the 13th. We must not fast if it is going to make us ill. I only started fasting in 1999, aged forty-two, but being born into a Jewish family was important to me from an early age. We are not just a religion, we are also a culture and a people. As my poem on page 3 shows, fasting last year made me feel really hungry from when I rose in the morning but satisfied that I am part of a tradition which has been going on for thousands of years.



Dear John,

Thanks for this month's excellent *AU* magazine. I am writing to ask a question regarding benefits that may or may not be available to AS people. I am 48 and got my diagnosis last December, but I am still 'living' on jobseekers' allowance, £56 a week, which I find impossible to get by on — so I am getting more and more in debt on credit cards, etc. I have been unemployed for ten-plus years and prospects of a job seem slim. What I want to find out is why many people who I know with AS get much more money than me, and some tell me that I should get the same.

I am not very good at asking for help, certainly not face to face and I have no family and few friends to go to for help. I tried the Citizens' Advice Bureau but they said they would look into it, but never called me back! (Seven months ago.) The jobcentre was also unable to help. I have applied for incapacity benefit and income support but was turned down because I am 'physically' capable of work, which I am because I have done many hundreds of hours voluntary work. But they didn't take my mental capabilities into account. I have an IQ of 122 which means I am not stupid but like many AS people I find interacting and communicating with others very difficult.

So can you please give me any information about whether I can get increased benefits? I was told I could get reduced bus/train fares too?

Thanks for reading this far! Your *AU* magazine is great and I always look forward to it.

Tom

Dear Editor,

I'm organising a club called the Asperger Rail Club. This club caters for anybody who's over the age of 12, including adults, diagnosed with any type of ASD and shows an interest in railways. Also, the Club hosts regular meetings and occasional trips out. If you're interested, please get in touch through *AU*.

Edward

Dear *AU*,

Michael (October issue) asks for similar experiences with wheelchair users putting him down. I am wondering why the only detail he supplies is their disability, and whether this is relevant?

Perhaps Michael would do well to remember that wheelchair users, and people with Asperger's, are members of the human race too. And just as likely to have the same negative attitudes that anyone else might.

A wheelchair-using disability activist with Asperger syndrome [name and address supplied]

Dear Mr Joyce,

Further to our announcement in *AU* last year, I am pleased to inform you that the Asperger's syndrome support group that I was in the process of setting up with Colin will now meet at:

CVS Centre,
Wych Elm,
Harlow,
Essex;

on the second Tuesday of every month from 7:30 to 9:00 pm. Refreshments are provided, so would each person who attends please bring £1.50 to each meeting to help with the running costs. The next two meetings are on the 10th of January and the 14th of February. Contact **Tim** on **07815 792 113**.

Art exhibition

The Centre for Autism and Developmental Disorders organises an exhibition displaying artwork by artists and students with an autism spectrum disorder. The opening will be on 7 February 2006, from 4:30-8:00 at the Institute of Psychiatry, De Crespigny Park, London SE5. The event includes talks, buffet, and a piano concert. Please contact **Dr Eva Loth (020 7848 0681 or E.Loith@iop.kcl.ac.uk)**



How to reply to Pen Pals

- Please remember to let us know the name of the person who your letter is for.
- 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 penpal letters sent via *Asperger United* are opened before being passed on.
- Those under the age of sixteen must have parental permission before placing a pen pal advertisement in *Asperger United*.

****Important notice - please read****

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

Hi. My name is Louise, I am 26 years of age. I live in the South Wales area. I have had Asperger syndrome since I was 17 and I like to make new friends.

My interests are drama, watching romantic films and listening to pop and romantic music. I would like to have a pen pal the same age of any sex from the UK.

My name is Robin. I am 55 years old and male. I live in Hampton, South West London and I have Asperger syndrome, obsessive-compulsive disorder and general anxiety disorder. I would like to meet persons of either sex and any age who have autism or Asperger syndrome. My interests include needlework, visiting museums, galleries and historical places, nature, conservation, plants and flowers, going to flower shows, philosophy, spirituality, theatre, reading, art, listening to classical music, history, historical novels.

Hello everyone,

My name is Simon. I am 15 and live in Burton. I have Asperger's syndrome. I didn't know until the age of 13. I have always wanted to meet other teenagers with Asperger's for quite some time now. I am a black belt in karate; most of the leaders don't know I have Asperger's! I am also interested in football, rugby, hockey and playing my PS2. I enjoy going into town with my friends and having occasional Indian meals with my family. I feel embarrassed to admit that at the moment I haven't got a girlfriend. Sometimes I think it has to do with what I am.

I am interested in meeting boys and girls of a similar age.

Thank you for reading this,
yours sincerely,

Simon

Dear AU,

Firstly thank you for sending me and my daughter our regular copy of *Asperger United*.

Can you please make it known that ASD has now been replaced with Autism Spectrum Condition (ASC) by those who know better, and as usual it filters down last to those who really matter, although I must add I do prefer "Condition" to "Disorder".

Thank you,

Christine

ASC is better. Perhaps all such psychological conditions should be so labelled. This does not represent "political correctness" — it is true correction. Maybe it would sound flippant, but has anybody heard of "Autism Spectrum Order" as opposed to "Disorder"?

John, Editor

WHILE THE CAT'S AWAY



THE DOG GETS FRUSTRATED

Hi. As always I much look forward to reading each issue of *Asperger United* and only wish it came out more times a year.

I wanted to write with reference to Eugene's letter as when I was reading it, it sounded like parts of it were my life. I was diagnosed with social anxiety disorder a few years ago but did not want to believe it. I had thought for a while I may have some sort of autism but on asking my psychiatrist I was told no. But I was not convinced. So I had a private assesment done and I was diagnosed with Asperger's syndrome at the Maudsley Hospital in London. They were surprised it had not been picked up before, especially the amount of different people I had seen, and the problems I had had in my childhood. I was diagnosed at the age of 25.

I also often find doing social activities a problem and there are many places I would like to go on holiday, but I have no one to go with. I would not feel safe going abroad alone. I got to know people at work but very rarely saw them outside of work. It is the same at college.

It is nice in a way to know I am not alone.

This is just a short note for DS Linney:

There is supported accommodation, I think, in Hastings for some, though it does not seem to be for high-functioning people. I am told there is a place in Somerset.

As far as work goes, the best way I found was to find something you enjoy and then do some voluntary work. Show them what you can do and get yourself some experience; it really helped me to get into work.

Charlotte

Someday, God willing, AU will appear more often. I believe we are getting enough material to make this possible but the NAS Publications department is over-stretched already.

John, Editor

Kitchen Blues

Come back, Sweet Bird of Youth,
All is forgiven;
As I listen to Blues Box on Aero,
And Elmore James' magic playing,
Echoes round my kitchen —
As I stand at the sink preparing my greens —
Without you, and a fine host,
I would not have survived puberty;
Would never have had the courage
To take that fateful step into manhood;

Not that I had much time for you then:
In fact I missed out on Monty Python, too.
Busy — marrying, fathering, gathering,
Partying; busy with the business of life;
Keeping up appearances, with the Joneses,
With the traffic, with the flow.
Bobbing along like clueless corks,
Until someone pulled the plug out,
And down we go!

It's a business too, at the bottom;
Slower, but old echoes die hard —
There's still the drugs and booze,
But at fourteen, I hadn't started that.
I was alone in an expanding universe,
With nothing at the top,
And nothing that I recognised below.

Others appeared to suffer too,
But we didn't know the lingo,
The knowledge of the mature imago;
And things came and went and
Sex was imagined, with one or two,
And Kennedy was shot, and history
Moved on, and pop went the Beatles —

A sort of bubble, as far as I's concerned,
Till Radio Luxembourg played some blues,
And in my Hell I discovered,
That others had been there too,
And it really wasn't such a bad place —
Over-full ashtrays, beer stains on the carpet,
A stench of staleness, well-worn,
And someone had left a guitar,
And an old harmonica lying around,
And made it bearable after all.

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Where is the future?
When you do not have a past
Waiting for each day to end
For time to run it's path.
I don't think this is living
I do not have a life,
Nothing seems important
I have no will to strive.
My spirit is long gone now
and emotions all but dead
I spend my time just dreaming
Of the life I should have led.

Tom

Autism, testosterone and the extreme male brain

by **Emma Chapman** of the Autism Research Centre, Cambridge

Autism and Asperger syndrome are neurodevelopmental conditions characterised by social and communication difficulties and repetitive and restricted behaviours. They are more prevalent in males, with a ratio of four males to one female for autism, and as high as nine males to one female for Asperger syndrome. Therefore one way to understand AS may be to look at normal sex differences in the mind and brain and how they may be extreme in those with AS. With respect to autism the focus falls on extreme behaviours in the social and emotional world and not in other areas of well-defined sex differences; physical development or sexual identity for example.

A recent theory that aims to understand sex differences is the Empathising-Systemising model. According to this theory 'Empathising' is the drive to work out another person's emotions, thoughts and intentions. The ability to empathise is not merely cold cut emotion recognition; it further involves feeling an appropriate emotional reaction in response to the other person's emotion. Evidence suggests that females are better and more spontaneous empathisers, whilst men are on average better at tasks requiring the ability to systemise. 'Systemising' is the drive to analyse, break down and put together systems. It is based on finite and deterministic rules and exact inputs and outputs. This can apply to a huge number of systems including maths, physics, music, computers, economics, taxonomies and sports to name but a few. The ability to systemise allows someone to work things out according to 'if-then' rules, ie. 'If I do this then this will happen'. An exact eye for detail is essential for good systemising if the correct input-output rule is to hold. Evidence suggests that men are better and more spontaneous systemisers than women.

The E-S theory does not suggest all women have a 'female-like' empathising brain (type E) and that all men have a 'male-like' systemising brain (type S). In fact some women are better at

systemising than empathising, and vice versa. The central claim of the E-S theory is only that more females than males will on average have brain-type E and more males than females on average have brain-type S. An extension of the E-S theory is the Extreme Male Brain Theory of autism, which says that these observed sex differences in the general population closely resemble the profile of social and emotional differences seen between those with and without autism spectrum conditions (ASC).

Evidence suggests individuals with ASC perform poorly on tests of empathy, such as emotion recognition from either entire faces or just eye regions. They also perform poorly on tasks of Theory of Mind, which involve working out the desires, intentions, and mental states of others. People with ASC are worse on empathising tasks than typical males, who in turn are worse than typical females.

However, research has shown that individuals with autism often perform better than typical males and females on tasks of systemising, such as the 'Embedded-Figures Task' where a target shape must be found within a larger picture. Findings such as this are understandably more robust for individuals with High-Functioning Autism and Asperger syndrome. The evidence seems to show that ASC may be characterised by an extreme form of the male brain, showing difficulties on tasks involving empathising and strengths in systemising abilities.

Sex differences in the general population on tests of empathising and systemising in part reflect differences in brain structure and function. These differences are known to be influenced by levels of testosterone produced by the foetus in prenatal development during a period critical for sexual differentiation. This has led to predictions that autism itself may be influenced by levels of foetal testosterone (FT).

The foetal androgen theory of autism

predicts that elevated levels of FT may lead to the development of the extreme form of the male brain. This theory builds on several lines of evidence:

(a) Levels of FT are inversely correlated with measures indicative of future social development, eg. reciprocal eye contact, and language development, eg. vocabulary size, in early infancy. Importantly infants who later go on to be diagnosed with an ASC often perform poorly on these measures;

(b) Levels of FT are positively correlated with narrow interests during childhood, a diagnostic characteristic of autism;

(c) There is a marked sex difference in ASC, the condition being far more common amongst males than females, with an incidence ratio of 4:1 respectively across the full IQ range. This difference rises further to 9:1 amongst children diagnosed with Asperger syndrome. Crucially males are on average exposed to FT levels 2.5 times higher than females during the prenatal period;

(d) There is evidence that the ratio of the lengths of the second and fourth digits (2D:4D) may be negatively correlated with foetal testosterone. Moreover individuals with autism generally have lower 2D:4D ratios than people without autism spectrum conditions;

(e) Congenital Adrenal Hyperplasia (CAH) is a genetic defect of the adrenal cortex that causes over-production of foetal androgens that predominantly affects girls. Individuals with CAH show superior systemising skills, which are comparable to those with ASC. Girls with CAH are also more likely to exhibit play preferences typical of boys (ie., ones with mechanical objects like a toy car) of the same age, and to show more autistic traits. CAH is a condition usually evident at birth, indicative of the influence of the high levels of testosterone in the prenatal period.

The influence of testosterone on cognitive development and function is not an all-or-nothing situation. Even those exposed to extremely high levels of FT before birth will have a range of FT levels and a range in their empathising and

systemising abilities. This variability may help account for the heterogeneity of symptoms seen even within individuals with HFA and AS.

Additionally other genetic influences will cause differences in brain structure and development aside from the influence of testosterone. These differences may modify brain development between individuals exposed to the exact same levels of FT. As yet the exact brain mechanisms underlying this are unknown; prenatal brain development being very difficult and controversial to study.

The foetal androgen theory of autism also infers specificity in the action of testosterone on particular regions of the brain (eg. the amygdala) and the behaviours associated with these brain areas. It does not suggest for example that individuals with ASC, be they male or female, are more likely to be physically masculine or have a stronger sexual identity one way or the other. Sexual development as fundamental as this is associated both with different regions of the brain to the cognitive abilities mentioned here and is also likely under the influence of other, different factors throughout development.

The foetal androgen theory therefore posits that varying levels of testosterone may act upon the brain before birth to shape an individual as being more male or female like. This is in respect to both empathising and systemising skills as evidenced by average sex differences on these measures in the general population (E-S theory). Furthermore it posits that exposure to extremely high levels of foetally produced testosterone leads to the development of a brain that is socially and emotionally distinctly male, or type S, relative to the general population (EMB theory). This brain type is born out in the characteristic behaviours of autism spectrum conditions.

Complete references for this article are available by post or e-mail from Asperger United at the usual address.

I'm writing in response to the letter from Louisa in issue 44 on the subject of intergender relationships. She is interested in whether AS women find it easier than their male counterparts to form relationships, as is claimed on some websites, and even cites one American website as claiming that Aspie women have more success than neurotypical women.

Firstly, if it's any comfort to her, I'm nearly 50 and I've not had a relationship with anyone either!

I believe that Louisa's and my experiences are typical of Aspie women, and that Aspie women find it more difficult than any other group to form a relationship, for the following reasons:

a) For historical and cultural reasons, it has mostly been taboo for women to take the initiative in starting a relationship. All a female could do was hope to get 'noticed'. There was no scope at all, that I know of, for straightforward questions and answers that I would need to make any headway.

b) For an intergender relationship to make progress, there is a heavy reliance on the male's ability to 'read' the subtle signs of the female — and Aspie women probably aren't giving any signs anyway, because they don't know how to!

c) Not being able to look someone in the face, or not liking too much close physical proximity, or uninvited contact, or needing clear literal speech to understand meaning, are all serious impediments to forming an intergender relationship. This applies to male Aspies too.

Also, in my own case, people don't always look the same when I see them again, so I have to start again from scratch just to get used to them. It can even make me wonder if it's really the same person. I might only have their voice to go on, for example.

d) If a girl, or woman, has a realistic view of what she could be dealing with, she will know that to misread, or misunderstand, the situation could mean she finds herself out of her depth or treated violently. To make a mistake could be dire.

The British criminal justice system has never been sympathetic to women victims of violence.

Women are always assumed to know what they're doing in their dealings with men, and are often blamed for their own misfortunes (the 'she-asked-for-it' culture).

I personally find men scary (because they're unpredictable, incomprehensible and potentially dangerous) which makes me nervous, which makes me more likely to get things wrong.

e) Although men like to think they are the 'rational' sex, they adopt the most irrational approaches in their attempts to strike up a relationship, or sexual encounter, which Aspie women can't hope to respond to on the spur of the moment. I quote the following examples from my own experience as a young person.

First example. When I was about twenty (though I looked much younger) I accepted a lift from a strange man. Of course, I now realise this was a foolish thing to do, but he seemed nice and kind and we conversed in a general way to pass the time. This consisted mostly in me listening to his problems (I'm a good listener).

He was only going for part of the distance I was to travel, and when we reached the point where I had to get out, he said, "I will take you the rest of the way if you make it worth my while." I thought he wanted me to pay him a fare as you would in, say, a taxi, and I patiently explained that I didn't carry money on me because I didn't have any, and that if I did have any, I would buy a rail ticket and so would not be accepting lifts from strangers in the first place. The fact that he couldn't deduce this on his own seemed 'thick' to me, but I treated him kindly (people are allowed to be thick!). He accepted my explanation and I got out. I never saw him again.

Some days later, a relation asked me about my journey. I cited the incident with the above motorist as an example of how thick some people can be and she was horrified. Apparently, it was me that was 'thick'! My relation knew straight away, and without having been there at the time (how?) that what the man wanted was sexual favours in return for giving me a lift! I found this incomprehensible, not just that someone could make such a suggestion to someone like myself

who was basically respectable and minding their own business, but that they would do so in such cryptic terms as to make it impossible for a strictly literal, intelligent and educated person to understand their meaning. I thought my relation must be mistaken (after all, why would anyone notice me for any reason whatsoever?) and continued to accept lifts from strangers!

With hindsight, I am horrified at the danger I might have been in had the man not accepted my 'refusal' (I did not have a diagnosis for AS until my early forties).

Second example. I had a curious experience with a young male work colleague. We were standing in a group when he said, "What are you doing this evening?" I truthfully replied, "Oh, I'll have a meal, do some washing and perhaps watch some television." He looked dumbfounded and didn't say anything else.

I could tell from his and other people's looks that I was getting it wrong but didn't know how they were perceiving the situation. I'd been asked a straightforward question in my own language and I had replied to it equally straightforwardly and politely. How could I be in the wrong? As far as I was concerned, this was a work colleague, not a potential suitor. How was I to know he saw things differently? (Again, why would anyone notice me for any reason whatsoever?) Aspies desperately need interpreters, and advice, in these situations.

I can never make sense of the day's events until I've spent some time sitting quietly at home in my own space. Other people think I spend too much time on my own 'doing nothing'. This time is actually vital to my mental survival and I've had two nervous breakdowns caused by being deprived of it and over-pressured. Several days passed before I realised how things were (and then I wasn't sure). "What are you doing this evening?" is actually a classic chat-up line that men use with women. They really mean, "Would you like to go out with me this evening?" Though why they can't just say that if that is what they mean is beyond me.

It caused me a lot of anxiety as I wondered what else I might be getting wrong and who else I might be offending – even though I realised he meant no harm and was probably paying me a compliment in his way. Some time later, he accused me of messing him about, even though I'd only ever listened politely to his (unasked for) conversation. I found this unforgivable, as well as incomprehensible. Had I not listened politely to his conversation, that too would have been wrong.

If websites are claiming that AS women are better than AS men at forming relationships, and even better than NT women, I can only express my disbelief and warn people interested in the truth that they can't believe all they read on the Internet.
Elizabeth

Dear AU, I was recently browsing through some back issues of your magazine when I noticed a letter by Louisa (edition 42). Her letter made me realize that I was not the only one who had experienced problems with my local AS support group.

I was diagnosed with AS at the age of 23 and I joined the group in the hope of finding some friends. I had been a loner for the majority of my life and had also been a recurrent victim of bullying, not just by other people but by family as well.

I joined the group a damaged person and unfortunately left the group a damaged person still. I wish I had never joined.

I met someone in the group who I thought of as a friend, but they ended up making my life a misery to the point where I thought about suicide.

Thankfully, I am much better now.

The group leader did not do anything about it except for suggesting that the so-called friend was more useful than me just because they had been diagnosed with AS in childhood and that they had a book about their AS published.

Hearing this made me feel worthless and above all, hurt. I left the group.

I don't want people to feel sorry for me, but I would like this letter to be a warning to the lonely and vulnerable that want to join AS support groups.

Please be cautious as support is not all you might get.

From a Kate Bush fan [the writer withheld their name and address, Ed.]

Replying to Louisa's letter in edition 44: I am in my forties and never had sex education. Having Asperger's syndrome is so, so confusing. I feel that what there does need to be is a sex survey project for people who have AS. Disabled people like to feel sexy, attractive and beautiful, like other people do. I have a wife (not disabled) and two children; I'm a very, very lucky person. If I had had sex education at school it would have helped a great deal but words are so confusing. My own body confuses me such a great deal: really snotty, hayfever, asthma; double incontinence, bladder and bowels. . . . Please understand that a person's own body, for people who have Asperger's syndrome, is very, very confusing. One of the things here is *surveys* for people who have AS. More research needs to be done. The words "snog" and "pet" are really confusing; mostly I say words "that mean what they say". These days one word can mean two different things. This is even more confusing for people who have AS. "Pet" I find more difficult to understand than the word "snog".

On a separate issue, I am in my forties and had AS diagnosed in the early '90s. I have a "forced sleep" problem. Professionals say the sleep trouble is at night. Me, I say it is in the daytime. As a child in the daytime I would flicker in and out of sleep. In the last few years the forced sleep in the daytime has really attacked my life. I have a few minutes warning, have to find a chair, then I'm asleep for three hours, half a day sometimes. I do not feel tired. I do not want to go to sleep. My throat and lips are very often dry like I have been in a desert; my feet ice-cold like thick blocks of ice on them; my balance goes really dizzy. This happens anywhere: garden, house, town. . . . When I have a sleep it's not over for me when I wake up: I'm still sleepy, dizzy, having trouble with my balance. When I make a cup of tea, after a few minutes I'm still trying to make a cup of tea. I have to put all my concentration on one thing, like making a cup of tea. If the forced sleep happens in the morning, I am in trouble: it affects me for the whole day. People have said I am "depressed": I have said lots of times that if I

was I would say so — a person has to help themselves before anybody else can help them. . . . I have been to Papworth sleep centre for a day and a half having tests . . . nothing was found. However, I was told it has something to do with my disability being AS and if I was born with it, it would not have shown on the tests.

I have been put on different types of tablets: tablets make a person sleepy and this is on top of the forced sleep. Also they make me really, really aggressive. I have a family of my own and tablets make me worse. I struggle to just stand up when forced sleep is happening. I have had only one week's stay in hospital for observation of forced sleep in the daytime. They found: it is not depression; I sleep well at night. Forced sleep did happen during my stay. Forced sleep drains me and I am losing weight. I was told that nothing else can help me, not a clue what the forced sleep is or how much worse it can get.

Do any readers who have AS have forced sleep in the daytime? Have they been on any medication of any kind? Do they do anything for dry throat and lips? Have they found anything that does not help, anything that does help? Did they have the forced sleep as a child? What age did they become aware of the forced sleep?

I would like to say that this is not a project or research, I'm just trying to find help with forced sleep in the daytime, thank you,

Mark

My name is Peter, I am 23, and I live in Cleveland in North-East England. I was diagnosed with AS when I was nine. My main interests are football, computing and various types of music. I also try to go to the gym whenever possible. I would like to write to both male and female pen pals. Hope to hear from some of you,

Peter

Sitting Pretty

Too little Knowledge
Is not enough?

Too little knowledge
To call their bluff

Too little knowledge
To call a halt

Too little knowledge
To catch a colt

Too little knowledge
And you soon lose face

Too little knowledge
All your instincts cry 'bolt'

Too little 'instincts'
And your security is lost

Sereee

Hello, my name is Paul Wady. I have two groups to tell you about. I met with Giovanna, the NAS lady who facilitates support groups around the London area. I am applying to be a volunteer around such groups, and wish to start my own high-functioning Asperger's support group. Several Aspies I know have expressed a desire for a group just for the higher-functioning. We all see this as appropriate for our needs. So I want to get one together.

I have lots of ideas about being Asperger's and autistic. Here is a vision of what I have in mind in a support group:

- No one needs communicate or talk if they don't want to.
- We are all free to speak our own language, to relate in our own individual frame of reference. Our own talk.
- We will all try and relate to each individual's way of being and relating. Eye contact is not essential.
- This is not a Neurotypical Space.
- We will follow the advice of Aspies like Jim Sinclair, founder of the Autistic Network International, and learn to be free.
- No need for the NT game here. It is a NON-JUDGMENTAL SPACE.

It doesn't matter how much the NT world has made us think that our ideas and feelings and experiences are weird. Here they are simply our individual experiences, and we can share them.

I am not working at the moment, and am on a National Council of Journalism training course.

I look forwards to talking to more Aspies in future. I'm no big deal, just trying to make sense of it all.

Secondly, I teach a meditation class in the North London Buddhist Centre on the Holloway Road. It is Aspie only. I am developing a synthesis of my twelve years in the Friends of the Western Buddhist Order, retreats and study, to facilitate my kind to be ourselves.

Every Friday evening I can, I will be leading a special meditation group for people with the condition. I have been diagnosed as high-functioning autistic, and have been practising with the FWBO for over eleven and a half years. (I can be reached on **020 7684 7504**, or **Hoxtonpaul@yahoo.co.uk**)

The class will be primarily a silent space. We will meet, then I will lead everyone through a period of meditation, clearly and concisely. This will last either 20 or 25 minutes. We will then have the option to sit in the shrine room, or have tea in silence. The last part of the class is free discussion.

We start at 7:45 and conclude some time after 9, depending on how we all feel. The centre requests a donation of £3. First attendance is free. The practices promote self-awareness, and of others, and peace of mind.

North London Buddhist Centre, 72 Holloway Road (**020 7700 3075 or 1177**);
Highbury & Islington tube; buses: 43, 393 and 271

Book review by the Goth: *Glass Half Empty, Glass Half Full*

by Chris Mitchell

This is an unusual book in that it is written by a man where most autobiographical books about autism are written by women. It is both very readable and well-written, with a detached and honest account of his childhood, family life and life prior to diagnosis. He gets on well with his family, and they are happy that he has written this book, and happy with the book, despite some implied criticism of how they brought him up. Indeed, it comes across as less aggressive than some accounts, so it is particularly insightful for parents and other empathoticals who might find more black-and-white descriptions of their mistakes hurtful.

As with every book written by someone on the spectrum that I have seen, it is a short book, giving a snapshot of his difficulties and joys before

and also after his diagnosis, giving highlights of specific problems and pleasures. Overall I think it would be a good book for someone who recognises himself in the author, or as a starting point for deepening your understanding of your brother, son or friend, or, if you are already interested in this condition, to broaden your understanding of the ways that it presents itself.

Glass Half Empty, Glass Half Full by Chris Mitchell, Paul Chapman Publishing, ISBN 1-4129-1162-1, is available from all good bookshops for £17.99, or special offer from AU for £15 (until 28/2/06). Just send your order, together with cheque or postal order made payable to the NAS, or your credit card details, to *Asperger United* at the usual address.

What would you like from membership of the National Autistic Society?

The National Autistic Society membership scheme aims to provide ongoing advice and support and information to all affected by autism and Asperger's. We want members to feel that they receive real benefits from their membership.

We do not have enough adult members who have Asperger syndrome, and would like to increase our numbers and representation in this area. For this we would like to ask for your help. If you are a current, previous or potential member what would you value and/or like to get from NAS membership? Are there any specific services that would benefit you?

A full list of the benefits that are currently available can be found on our website www.autism.org.uk/joinus. Benefits include:

- *Communication* magazine — the leading magazine devoted to ASD sent out four times a year
- 10% discount on all books and materials in the Publications catalogue

- low-cost personal liability insurance for parents, carers or guardians of people with an ASD
- *Autism Update* — a bi-monthly e-mail bulletin of recent articles and publications

We are currently in the process of developing a members-only area on the website. What would you like to see in this area?

We would like to do more to welcome those with AS into the Society. If you have any ideas please e-mail me (lintilla.turner@nas.org.uk); I would be very grateful for your feedback. You can also write to me:

Lintilla Turner
Membership Department
The National Autistic Society
393 City Road
London EC1V 1NG

If you are not a member and are interested in joining please call us on 020 7903 3662 or e-mail membership@nas.org.uk.



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