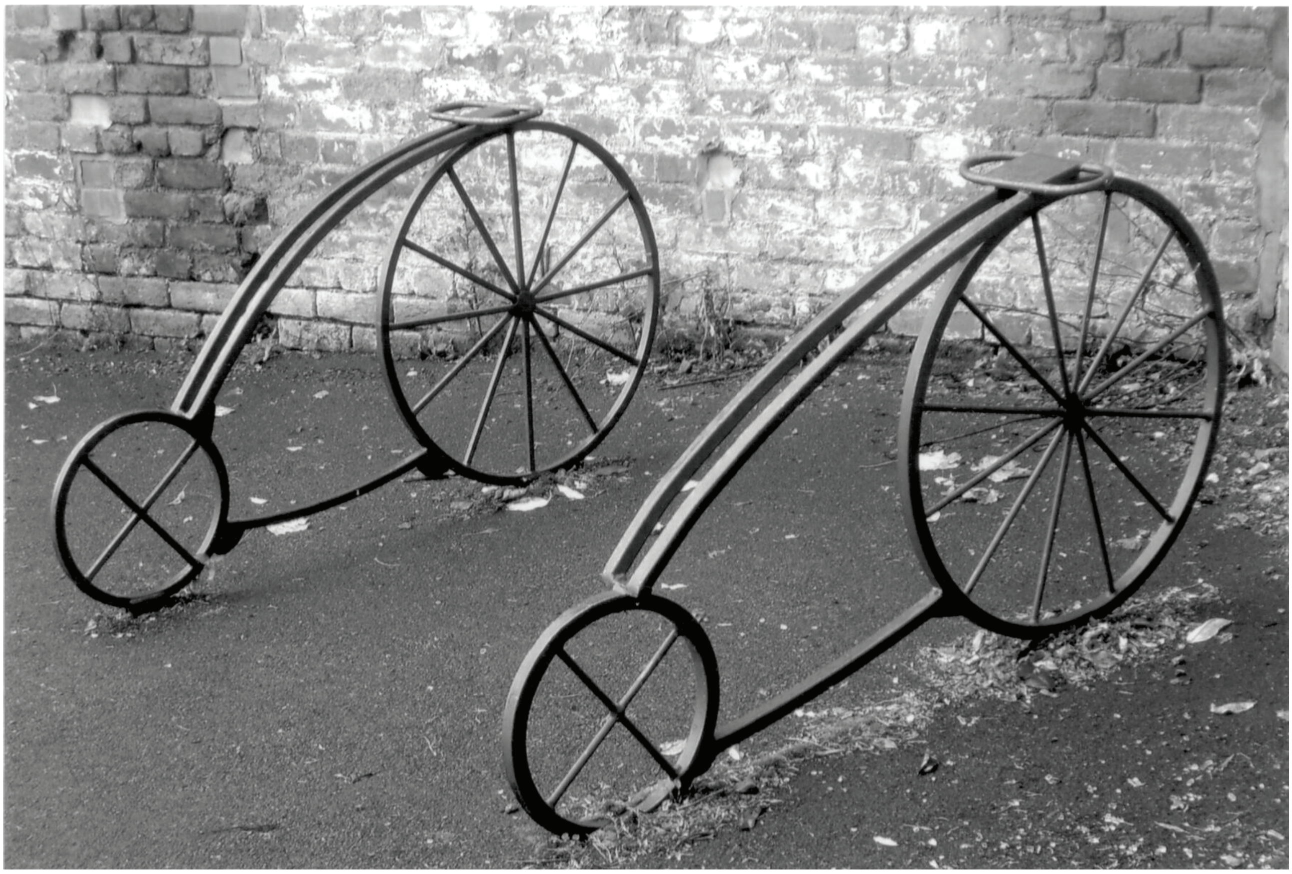
Produced by and for people who have autism-spectrum conditions

Asperger United

Edition **83** July 2015



The National Autistic Society

Asperger United

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

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

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

Editor: the Goth

National Autistic Society production support: the Publications Team

NAS phone support: the Supporter Care Team

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

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

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

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

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

Please send all correspondence and subscription requests to:

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

Tel: **0808 800 1050** (free from most landlines) or
Tel: **020 7923 5779** (geographical charges apply)
Fax: 020 7833 9666

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

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

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

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

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

Contributions for the next issue should reach *AU* by **17 August 2015**

Welcome to the July edition of *Asperger United.*

Another bumper postbag (that includes my virtual postbag, for anyone who's wondering) so it's been particularly difficult to select which pieces get to appear and which I hold over for future issues.

I used my usual criteria for deciding what got in, and find that exactly a third of published contributions are by women (not counting transgender) and again, it's the longer pieces which are more often by women.

Gender is again a hot topic, and as it's impossible to print everything, here's what my postbag looks like: it seems that at least 80% of correspondents who mention their gender do not fall neatly into black or white. Similarly, it's at least 90% of correspondents who mention their sexuality that don't fall neatly into the heterosexual or homosexual camps.

According to the best research (and similar results have been found both sixty years ago and ten years ago), this is broadly in line with people in general. However, most people are reluctant to talk about it except in anonymous surveys — people don't think so much about the consequences of what they say when anonymous, so they are often more honest and forthright in what they say then.

I am looking forward to a lively postbag,

the Editor

the women's edition — the next-issue notice is on page 13

Contents

It looks and sounds like a woman so must be a woman

by **Pete**

Society seems to have black-and-white ideas about who is male and who is female. There seems to be no flexibility for someone who feels genderless or a mixture of more than one gender. In my experience I feel people have a gender on a sliding scale (known as the gender spectrum) and the ones who show the strongest identify as transsexual, transgender or another type of gender variance. The widely accepted term is trans*. I identify as trans*. I feel more male than female even though I have a female body. I am also grateful to people who make allowances and accept trans* folk as people.

I started feeling like my body was wrong when I had to start using female toilets. I just didn't fit in there: this feeling intensified until a few years ago when I decided to start exploring my "male side". I started using the male toilets at my local trans*-friendly bar, where I felt more at home. At first people wouldn't accept that I was a guy but eventually, with the staff's help, the situation improved. The bar even put signs in the toilets:

> "If you feel someone's gender doesn't match what's on the door follow these steps: Don't worry about it, they probably know better than you do"

We have gender-neutral toilets in both the "male" and "female" cubicles. More are gender-neutral toilets than male or female cubicles.

Apart from being misgendered (people calling you by pronouns which don't fit with your gender — when done on purpose this is a form of transphobia) the hardest part is deciding what to do about your feelings surrounding your gender. I could decide to stop after changing my name, or could go onto take hormones or could have surgery to change my sex organs to match with my gender. I find making these sorts of decisions really difficult as I would also have to decide whether to have my eggs frozen (with four genetic diseases in the family I'm unsure) or to have children (no job or partner making bringing up children harder). Also, the timescales at the gender-identity clinic (where trans* people can go for NHS support) vary from patient to patient. It is frustrating and confusing, the wait and the number of specialists you need to see, especially if you are going for the full surgical option. I also have post-traumatic stress disorder and chronic pain disabilities which can cause further complications. A year after going to the gender-identity clinic I'm just about to meet my doctor. I keep changing my mind about what type of body I would like which is causing extreme anxiety.

My family are divided about my gender but I have lots of support from my home help, my online and offline friends. There are some secret Facebook groups for people who feel unsafe about "outing" themselves.

Although studies into how female or male folk on the spectrum present themselves are useful, I feel the characteristics of autism can apply to any gender. I have a mixture of coping strategies, scripting being one of them: I observe a conversation on the tv or in real life, then try to replicate how those people interact. This makes others think my autism is mild but there are times when I have meltdowns or shutdowns.

I've also been through the denial stage, where I was blaming everyone else for my problems when most of them were about miscommunication. I was angry and resentful as a teenager — something I'm pleased to say has gone.

Despite my transexuality, I still have quite a bit in common with autistics who are happy that their gender matches their sexual organs. I have the feelings of how I fit into society, what type of job I would like to do after my university, etc.

Dear *Asperger United*,

I was unofficially diagnosed as Asperger's aged 31. According to well-known experts on the subject, it is more difficult to diagnose in women because they copy more easily than men the social behaviour of their peers. I think this is what I do. When I tell trusted friends I am on the autism spectrum, they usually respond with "it does not show". Well, no, to them it does not because I am doing such a good job at covering it up. But they do not have any idea what toll this takes on me. I can only do it for so long before I need solitude and outdoor space.

Maybe this is a difference between men and women with Asperger's. Maybe men feel the same way. To me, being a woman is nothing more than one forty-sixth of my genetic make-up. I happened to be born with an X chromosome instead of Y just as I happened to be born with blonde hair instead of brown. Black, white, men, women or transgender — to me people are just people. The only criterion I use is whether they are interesting to me, and for those who are not, whether I have to tolerate them or can ignore them.

People sometimes think I am a young lad, just like the Watchtower ladies who asked me only yesterday to hand their leaflet over to my parents when they got home. This does not bother me as being a woman is such a small part of what I am. What is in my brain and in my heart matters more to me than the casing that houses these organs.

Cheers,

Anne

A particular woman

by **A Peculiar Son**

The particular woman is my mother who nearly died giving birth to me.

The fact that my mother survived childbirth and lived for another four and a half decades is the most important factor in my life. I bonded only with my mother. Her guardianship was my salvation.

My mother did not understand why her son was peculiar. Her son was "normal" at home but not "normal" when others entered the home. And not "normal" socially. My mother concluded that her son was chronically and severely shy and that his peculiar way of being was predicated on his shyness. An understandable and reasonable conclusion.

People like to socialize, like to have friends, like to have a partner, like sex, like to celebrate birthdays, like to party, like to go on holiday, like to drink coffee and alcohol (not necessarily at the same time), like books, like films and and — and on it goes. I am a person but I do not like any of these.

"Socialize" can have a different meaning to the one above. It can mean to make someone behave in a way that is acceptable to society. Individuals may feel or be pressured into conforming, against their nature, in order to be acceptable to society. I think this is where mental health/drugs/alcohol problems can kick in.

I do not have such problems. I am certain that that is because of the mother that I was blessed to have. This particular woman, this individual mother, did not try to change my individual nature, my natural way of being: she accepted it, she protected it, for although it was peculiar, she knew that for me it was benign, for she witnessed a happy child, a happy teenager and a happy adult. Of course, my natural way of being would at times frustrate and even infuriate her. Her son forever dashing to his bedroom to avoid any and all visitors to the house was not easy for my mother to explain to such persons. And sometimes her explanations were not exactly kindly towards her son. I understood.

I lived with my mother all my life until her death. Death meant the end of her corporeal form. My mother has been dead for almost two decades now but I have never felt her death, I feel her to be alive. I speak as an atheist.

Gender identity

by **Elkie**

Until the age of 15, I was a boy. A Red Indian boy, to be precise. During the summer I wore nothing but a loincloth and a headband, swinging from branch to branch high up in the trees, galloping bareback on my pony across the grasslands, shooting rabbits with bow and arrow and roasting them over the fire lit with flint.

During the winter my body was kept warm by woollens and furs, as I still spent most of the day out in the woods and the snow-covered fields. My name was Blue Bird, though the teachers at school didn't know that. They didn't know I was a Red Indian boy, but they accepted that I never wore a dress or skirt and that I preferred climbing trees to playing hopscotch or skipping. But then, school wasn't the real world, anyway, and only took up a few hours in the mornings.

But things changed when I was 15. My body changed. My breasts began to develop and my monthly period started. How could this happen to a Red Indian boy? Instead of wearing the loincloth, I was now sweating in long trousers and a woollen cardigan to hide the curves of my body. I still climbed trees and rode bareback, but when I started training as a gardener, some men at work made lurid comments and on occasion tried to touch or kiss me (yuk!). Even my cousins, who had always been like brothers to me, started behaving differently and it was no longer appropriate to share a tent or a bathroom with them. The worst was, when people called me Miss or Mrs. Who did they mean? My mother?

Over the years I had to accept that the Red Indian boy had turned into a woman. I learned how to dress and behave amongst people, though when I'm out in the wild, with only the deer and the birds for company, no one can deny me the pleasure of slipping back into my natural self. They say it's all part of my Asperger syndrome, though it doesn't mean that every woman with AS starts off as a boy. And yet, it's not uncommon for women on the autism spectrum to have difficulty with gender identity. Since Wendy Lawson has undergone a sex change to become Wenn, more and more autistic women are coming out to express their issues with gender identity. So perhaps some of you, readers, have similar experiences and realise that you are not alone in this.

Hi there fellow Aspies.

I am a 73-year-old male OAP with a very late diagnosis for Asperger syndrome which was organised by an AS consultant in northern England when I was 71; I am a Lancastrian; the consultant remarked that I am the oldest he has helped with the diagnosis, I wonder if this is a record?

I have been a member of the NAS for eight years and have read the articles in *AU* and other NAS publications about the struggles encountered by other people with an ASD, such as being marginalised and discrimination. I am in a dispute with my local council concerning my exclusion from certain public facilities for alleged misconduct when I retaliated against a bully who threatened me with violence; no action was taken against the bully.

The NAS publications have helped me to cope with being different, and the positive diagnosis has helped me to understand the reasons for my being unique and special.

Regards from

Stormin' Norman
an Aspergian free spirit

Pen pals

Pen pal number 198

Hello, my name is Ben. I am 25 years old. When I was 10 I was diagnosed with AS.

I enjoy writing, walking, gig rowing, playing chess, swimming, reading, pottery, and drawing.

Over the last few years I have studied world folklore, including ancient alien visitations, and highly advanced civilisations.

While looking into this, I came across a subject called the hollow Earth. The hollow Earth has fascinated me ever since, and it led on to more interests including vast luminous caves and tunnels beneath the Earth's surface, and the Galactic Federation of Light. I have shared my interests with others. It's a fascinating subject for everyone to look into.

I would like to hear from anyone who shares the same interests.

Pen pal number 199

Hi, my name is Simon. I am 16 years old. I live in London and have autism. I find socialising and making friends difficult, and I want to have a pen pal. I don't know many people with Asperger's or autism but I would like to make new friends.

My interests are eating out, going to the cinema, *Batman and Robin*, *Avatar: the last airbender*, history, and comics. My favourite music includes Michael Jackson and Elvis.

I wish to hear from someone with similar interests. Thank you for reading this.

How to place a pen-pal advert

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

How to reply to pen pals

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

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

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

Pen pal number 200

Hello my name is Amber, I am a 20-year-old student from London. My characteristics meet the spectrum mildly. Despite my differences I prefer not to label myself for the time being as I shouldn't feel separate and people with learning disabilities are individually gifted.

At school it's really difficult to pass anything that I'm not entirely interested in which links to why I find socialising difficult too as people I meet find my obsessions boring. It's hard to accept as I don't have many friends.

I like acting and I adore crafts: I'm fascinated by culture and creativity. I like African and Aztec art, I like bright colours but my favourites are baby blue, baby pink and silver. I am interested in cuteness, eg. oriental products. I like cute onesies, trendy wear and formal clothing. In books I like traditional storyline, Greek mythology, manga, non-fiction and romance.

My other interests include Zumba, volunteering, travelling, being proactive, attending futuversity, helping people, being creative, meeting new faces, horse riding, going to church, going to restaurants and trips.

Places I dream of visiting with a friend or relative are countries that are sunny and artistic were we can all have fun, such as China, Morocco, Hawaii, Jamaica, Puerto Rico and Aruba, Ghana. I also like traditional products. My family are Caribbean and I recently had a yummy sweet Caribbean pastry sausage.

My ambitions include going to university and finding a job related to art and hospitality which is why I wish more places in the UK would provide a wider range of joint degrees.

I have always been shy and people think I'm being antisocial. I'm a socially awkward, anxious individual; life has been difficult without a true friend. What I really need is a friend who's caring, patient, open-minded and kind.

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

Pen pal number 201

Hi, my name is Jack. I have recently been diagnosed with Asperger's syndrome. I am 19 and from Newcastle. I love Harry Potter, video games, theatre (especially musicals), the original *Star trek* and my religion (Catholicism).

I'd love to have someone to write to. So I look forward to a chat.

Many thanks,

Jack

Pen pal number 202

Hi I'm Jo, I live in a lovely Leicestershire village, and I'm 45 years old. I was diagnosed with Asperger's when I was 43. I'm a mother to one son who is now aged 18.

I have a great love of animals and nature. I founded my own pet-care business, due to my love of animals, which I enjoy as I get to meet lots of different dogs, and lots of other animals too. I especially like the Japanese Spitz breed, and had the pleasure of having Holly, a Japanese Spitz in our family for over fourteen years until last September and still miss her lots, as she was my little furry friend! I am also finishing my degree in sociology which I have enjoyed studying for.

I enjoy going to the cinema and like watching a variety of different genres. I also enjoy walking in the countryside and travelling.

I would like to write to a pen pal with a similar age, and preferably female, but male pen pals are welcome too. I look forward to writing to you, especially if you have an interest in dogs and nature.

Dear Goth,

I know I have whinged to you about this sort of thing before — but it just gets worse. Not only does the NAS require three references for any of its job vacancies when the rest of the world manages to get by with just two, but I now discover that to stand for election to be an NAS councillor, a member must secure two nominations from NAS members. This is surely another unnecessary obstacle in the way of those on the spectrum. After all, the stereotypical autistic will have neither a real occupational history nor will he be blest by an abundance of friends — and the NAS hierarchy indisputably know this. I thus believe these carefully constructed requirements have been put in place in an attempt to preclude the meaningful participation of those on the spectrum. Call me cynical if you will (and you can't say I ascribe to the "cock-up theory") but why otherwise can't a member of long-standing (say three years) be permitted the option of self-nominating for election, and then allow the NAS membership to vote on the basis of the candidates' manifestos?

I would be interested in hearing your readership's comments about my concerns — and if you enable this, could the respondents indicate whether or not they are NAS members? I ask this because, as you know, I do seriously wonder if the NAS really wants to cater for adults on the spectrum (as opposed to the more lucrative child-and-family market) and if my theory is correct, it would predict that a significant number of your readers are free-loading non-members (I mean this non-perjoratively as I recognise the rationality implied).

If I were to have stood for election, a few things I was going to include in my manifesto, and fight for, were:

(1) every NAS branch should develop an "adult" section with the aim of focusing on adult provision in its territory;

(2) the NAS should develop geographical-area forums within which members can regularly discuss service provision and which feed into regional or national forums — this to prompt the NAS hierarchy into action;

(3) all newly-diagnosed should be offered local mentors who can introduce them to relevant local activities and give individual help and advice;

(4) Autism Awareness Week should have a post-childhood strand;

(5) autism awareness cards should come with the option of a personalised, hosted webpage that, via a linked QR code, would allow the holder to alert not just the police, but also inform the medical services about the holder's tactile and other preferences and dislikes such as is attempted by the NAS's unwieldy health passport;

(6) . . . well I could go on but it's in danger of becoming hot-air if I can't put my ideas forward.

Best wishes

Steve

Hi Goth,

thanks for forwarding the replies to the advert for the **Autism Rights group in the Bristol and Avon area** in the last edition.

Could you print my contact details in the next edition. Mentioning that we are happy to look into ways we can support other groups set up in the South West. I have been asked to do that to make us more approachable.

James Deane

07895 541 872

jamesdeane@myway.com

Dear *AU*, Goth, reader of *AU*,

I often type long and interesting letters to you, yet haven't the guts to send them or to deliver them. And often my mail, both incoming and outgoing, is interfered with. So here is a postcard and a much shorter letter for you which I shall try to hand-deliver instead.

Brain waves are listed in order from waking to sleeping as beta, alpha, theta and delta. Beta being the waking state and alpha the state in which children (and all animals) are in. Consider the proposal that autism is a brain which has more conscious connections to the alpha state, which is why the more "severe" it is, the more childlike or sensitive the person is. Neurotypicals are "successful" beta people, while persons like me, with Asperger's syndrome, are highly beta, but will still run away very fast from a small child who decides to start throwing stones or the f-word at me.

I am an NAS member, a female, late-diagnosed (I'm forty-odd), depressed, bullied all my life, with a lot of useful information to say that society finds both interesting and does not care about. Thank you for reading anyway (if you did) and have a nice day.

Signed **Pikachu Murray**

PS. If you like, and to save space, omit the first paragraph about sending postcards (and if you are curious, the first three-or-so issues of *AU* came to me as partially opened, so I am telling a truth there, thank you).

Please note that the sorting machinery used (by the Post Office and other distributors) can batter envelopes enough to pull them open — it doesn't mean that someone has been looking. AU goes from the printing press to the loading of the delivery-van without being touched by humans — it is pre-sorted by the enveloping machine and sealed in mailbags, one bag per van. Pallets of bags are then delivered to sorting offices around the country, Editor.

Dear *Asperger United*

Ref: the late diagnosis issue.

Thank you so much for this feature. I found it so helpful, at times a little teary but very encouraging.

I have struggled for the past five years to get my GP to refer me for a diagnosis after a particularly bad bout of management bullying led my counsellor and two of my work colleagues to suggest I may have Asperger's. I have done the on-line test and read Joanne Whiley's book, as well as many others, and it is like a light has gone on.

I am normal, just not their normal.

The only way I can stop the workplace bullying is to have a formal diagnosis as they will not recognise self-diagnosis.

Thank you for the encouragement your magazine gives.

Debbie

Dear Goth,

re edition 78, the sexuality edition: although (or, in part, because) I'm bisexual, I was a single mum with very similar experiences to Vanessa (page 5), so it was really nice to see her piece included.

Loved reading Graham's gay piece and Michèle letting off steam too; nice to know you care about all of us!

Thanks,

Jackie

I brush aside my artistic flare, that paints a picture, but
I don't care.

Dan

Dear Goth,

what can I say about this last issue on late diagnosis? Only one word seems to adequately describe the frustration and heartache that these reminders of my own failure to get a diagnosis (I'm 63, both my parents and all blood relatives as far as I know are dead) and that is Arghh!!

My brother responded similarly to Pamela's family and said having Asperger's didn't excuse my atrocious behaviour (no, but it might explain it). The longest job I held down lasted four years and that was because I loved it, spending a year in one town, then a year in Clydebank, followed by two years in Glasgow proper. Social anxiety? I sweated like a pig at interviews, grinned like an idiot and stumbled through questions that to me seemed totally crazy. All my jobs, almost without exception, were short lived and unskilled. Sometimes the fact that I was weird didn't come up, as I was working with other social outcasts anyway. The leaflet job that lasted four years ended up with me collecting odd things off the street as I made my rounds (yellow plastic BB ["ball bearing"] shot from kids' toy guns, jewellery, model cars, toy figures, etc.) and putting them in egg-like containers. I sent them to friends who quickly lost interest in these free gifts.

I've never had many long-lasting relationships, friendships or even stayed in the same place for long spells (Cambridge three times, London the same, Northampton for a brief spell, Edinburgh, Inverness). Michael's comments, about NTs believing everyone must be social, reminded me of the lyrics of a song I once wrote: "Conform, conform — do what I say! Conform, conform — do things my way!" With regard to Ann's comments, I think the problem with the autistic is that they are like Candide by Voltaire — too honest and straightforward for NT society, which is based on lies and sham (no real empathy, as someone said).

Our creativity is because we are open and innocent — blunderers in Wonderland, where most people's genuine side is hidden behind defences in depth (Mine! Fields). You do or say something quite innocently and they explode at you because of it. For instance, in my last job (ever?), someone who was ill asked for his colleagues to send him all the jokes they could think of. I did and was sacked because of it (didn't censor the collection well-enough it seems — Tracey 192, perhaps even you would be put off by this particular joke book!).

I write jokes, aphorisms (as an attempt to understand how this world works), short stories (Elkie, this is the closest I get to serious articles), a method for building English-language vocabulary (nine proposed volumes, plus a junior one, four of which have been completed, nearly: as my wife's mentor used to say, you teach most what you need to learn). I've also created a DIY method of fashion design (trivial pursuit), a padded vest that makes wearing a rucksack more bearable and several other ideas, including how to handle floods during a monsoon. I've also made montage designs and drawn various artwork pieces. So with all this creative output, why aren't I better known? Go back to the piece that mentions social ineptitude and you'll understand my failure to start a business, which I didn't want to do anyway. (Is there an agency that we could channel our creative efforts through?).

Amy, you mentioned lack of female contributors — well this last issue was full of them and included three covering double pages by individual writers as well as numerous others (I think the ratio was definitely reversed).

Sensitivity? Don't mention the migraines, temper tantrums and panic attacks from sensory overload, the hatred of loud music, the skin-crawling, reaction to bright light, food fads and scented-candle fetish — all of which takes you back to my initial response to the NT world, of Arghh!!

Tony

Females with autism — the tragedy of ignorance

by **Planet Autism**

It's been known about for a while now, but still nothing is done about it. The diagnostic criteria for autism were all researched on only males with the condition. So why, we must ask, bearing in mind the recent revision of the DSM, did they not revise those criteria with this evidence in mind? The ICD is also currently under revision: no doubt the WHO will ignore this glaring anomaly too. Autism isn't the only condition in which females present differently. To my surprise, recent research showed me that this is the case with ADD/ADHD and bipolar too (but then of course they are genetically related to autism). They say "it's a man's world" and in many ways it still is. Females are suppressed, ignored and mistreated in religion, culture, employment, so it's not too much of a stretch to point out the misogyny present in the medical profession too. You can't be autistic — you are a girl, just a hysterical/neurotic woman — mindset.

The NAS has information on autism in females, and research is out there highlighting that females are more able to mask their difficulties, more likely to be compliant, less likely to act out in the way males do, as well as having better compensatory abilities, and yet so many females still struggle to get diagnosed with autism due to the stereotypical beliefs that prevail among clinicians. So many autistic females are misdiagnosed too, with disorders such as anorexia (anorexia rates are higher in autistic females so clearly the cause of anorexia is not being looked at adequately), BPD and generalised/social anxiety. Some research claims that females are genetically protected from autism and that this is why the rates are at least 4:1 for males to females. I dispute this, I personally believe there is no difference in the rates of autism between males and females, it's just recognition that is the issue. In this research, it states: "Instead of focusing on specific male risk factors, our focus needs to change to understanding how the male and female brain differ and what that means for autism risk," and: "A lot of what we do in research and intervention are things we have learned from researching boys, and this needs to be addressed," says Ami Klin, chief of autism and related disorders at the Marcus Autism Center at Emory University in Atlanta, Georgia. He points out that girls are often excluded from studies.

So why, when there is so much evidence out there of this problem, are autistic girls being ignored? As a female parent on the autistic spectrum myself, with two autistic daughters, two of us faced much difficulty in obtaining diagnosis. The clinical expertise is just not there, and it astounds me that UK clinicians are not kept up-to-date with latest developments in autism research.

Girls are diagnosed later than boys when they do get diagnosed, often meaning years of struggling in the school system without support for their difficulties. The later you are diagnosed the more likely you are to suffer mental-health difficulties. Females are so much less likely to be referred for assessment: "Although there has been a dramatic increase in the number of children diagnosed with autism spectrum disorders (ASD) over the past decade, statistics indicate that boys are being referred and identified in far greater numbers than girls. In fact, referrals for evaluation of boys are approximately ten times higher than for girls (Attwood, 2006)."

I wonder how many times someone who suspects they are autistic is assessed and not diagnosed (assuming correct diagnostic outcome)? I would imagine the numbers are infinitesimally small. So would females be asking to be assessed without reason? I was once asked, having said I felt different from other people, how would I know that? That's the weirdest question. You can't really explain something like that you just know, from watching and listening to others — their views, experiences, interactions, etc. — that you are not like them.

The biggest problem for many autistic females is that they internalise their difficulties, they are passive. In the education system this means they are model pupils, they don't disrupt the class and just fade into the background, so no problem — right? This is why so many autistic girls end up with anxiety, depression, anorexia, self-harming, school phobia. The more years you go undiagnosed, the harder it gets. By the time a girl hits secondary school the social expectations soar and the concurrent decline in their ability to cope becomes greater. Primary school is relatively easy. If your daughter doesn't have a close clique of friends it's easier to disguise, as they are all running around playing randomly at that age: friendships can be fickle. But, in secondary school, the playing subsides and it's all hanging together in gangs gossiping and bantering, and someone with autism finds that extremely difficult, so their differences are highlighted, meaning they become a target for bullies.

Lorna Wing described sub-types of Asperger's: active-but-odd, passive*, aloof and stilted. I once did a poll of Asperger's females on a forum and so many said they fit the passive sub-type. This would lead to the logical conclusion that there are many undiagnosed females out there. If the parent doesn't realise their child's traits could be autism and the school doesn't pick up on it (parents often rely on schools to point out where their child is having difficulties and advise regarding referrals and interventions) then the child misses getting diagnosed. Boys on the spectrum will often be more aggressive and schools will then want something done about the disruption of their classes.

So why did the DSM ignore this issue? It's bad enough that they removed Asperger's as a diagnosis — even Autism Speaks published a study declaring that Asperger's is a distinct form of autism, so overall more people will struggle to get diagnosed with ASC, but as females are already at a great disadvantage in having their condition recognised, this is compounded and the problem will not get resolved unless action is taken over the diagnostic criteria and training of clinicians. There are countries outside of the USA that use the DSM, including sometimes in the UK. The ironic thing is that females with autism pass on the genetics to their children (I know others outside of my own family) and research has also identified the womb environment as contributing to autism, and yet females are tragically ignored.

*

*Passive sub-type:

"Often amiable, gentle, and easily led. Those passive rather than aloof from infancy may fit AS. More likely than the aloof to have had a mainstream education, and their psych skill profiles are less uneven. Social approaches passively accepted (little response or show of feelings). Characteristic autistic egocentricity less obvious in this group than in others. Activities are limited and repetitive, but less so than other autistics. Can react with unexpected anger or distress. Recognition of their autism depends more on observing the absence of the social and creative aspects of normal development than the presence of positive abnormalities. The general amenability is an advantage in work, and they are reliable, but sometimes their passivity and naïveté can cause great problems. If undiagnosed, parents and teachers may be disappointed they cannot keep a job at the level predicted from their schoolwork." Quote attributed online to Lorna Wing.

If sufficient material is sent in, the theme for October will be **more women** or **work** or **gender**. For the women theme I don't just want contributions from women. Any contribution that features women or a particular woman fits the theme. Vote with your contributions: the more submissions on a subject sent in (from different people), the more likely that that subject will be the theme. Writing on any subject is still welcome, as are ideas for new themes, fillers (for putting in small spaces like this) and artwork. Remember, if you want to see different content in *AU*, the best way to change it is to send something in!

Never too late

by **Paul**

This is truth not fiction. It's my life experience, never told before.

It was 2006 that I first met my Patsy.

She lived in Texas, and we met as only crazy people do, emailing briefly through a fringe website, knowing nothing of one another. She was American and "over there" (a big place). I was English and over here (. . . a small island, as American Bill Bryson noted).

She'd dreamed of the UK half her life and read all the books . . . so . . . next, we said "let's meet up" . . . like you do . . . "it's only 5,000 miles . . . let's do it".

So we did. She went to her airport. I went to mine . . . to meet her . . . whoever she was.

Officialdom in the UK wasn't happy. Heathrow was on red alert for terrorists, and a black uniformed squad with sub-machine guns kicked open doors while, distanced from both time and reality, I waited out the long hours for her release from Customs and Immigration . . . the hours grew, belief dwindled, and I was in short-term parking (final charge to get my car back was around £120).

Patsy gave the sandy-haired customs man my mobile number and he at last called me around my fifth coffee. Our two stories finally accepted, I heard the words, "Okay, she'll be coming through Gate Four".

Patsy seemed strange, right out of the blocks! Attractive but abnormally upset by the unexpected events; just sitting, tearful and saying little. My knee-jerk thought as we sipped consolitary drinks in the café was, "Oh boy, this is a mistake; I want out".

But old Mr Fate had other plans . . . he had his big iron band around us both . . . 5,000 miles and six hours in C-and-I is no trifle . . . we were invested . . . something was making it all happen.

*

A relationship ensued and we were newly energised. Summer 2006 was long, hot and dry. We talked, went out, argued, stayed in, went on holiday, argued, loved the river to bits, went to music events and restaurants, argued, re-homed a cat, argued. In the end, the arguing was the main event. We resolved, rationally, to separate . . . no doubt about it, this we could agree on was a "Real-Sound Decision" . . . rooted in logic . . . one problem here, love and Mr Fate "don't do" logic. They were having none of it. I had been slowly "going under" for some time and against my will. Just didn't want her to go, but why the hell couldn't she relate to me . . . typically . . . neuro-typically?

I sat alone in my office, in trance, engaging the unconscious — it solves stuff better than the conscious, which is too parochial to be trusted. I could identify specifically odd behaviour within categories, but they made no sense. I sank down deeper and dwelt on the last novel I read. High-achieving science and math people, like Patsy, apparently were found in the City of London where they could be counted upon to number-crunch way better than anyone, yet they couldn't form client relationships for toffee. They were said to be "high-performing autistic" or people with "Asperger's syndrome". What the hell's that, I thought? So I Googled it, and . . . *eureka* . . . as I slowly read each peculiar characteristic on the list . . . *it was Patsy*, in profile. My God!

I thought, "This could save us, but how to tell her? . . . and we need to be sure".

Patsy was sceptical at first, but analysed it and got positive. It was she who found the NHSapproved consultant and arranged our joint visit. We went along and in a couple of hours her history since babyhood was reviewed and my observations fed in. Visual tests were done. The consultant had no doubt . . . Asperger's was the explanation.

Patsy was 39 years old . . . this was late diagnosis.

*

Late perhaps, but never too late for a life change. Now we had a framework — boundaries got recognised. Some stuff she'd be good at, others not. Hang on, isn't that just like most people?! She was still red hot academically but no point expecting the touchy-feely social stuff. She'd always choose social avoidance and "special interests" (obsessions to everyone else). Right, we could live with that . . . and we damn well would!

She'd gradually coped better and better down the years whereas, at 20, her social inability had been painful. If she could achieve all that, so can others . . . they must never, never give up. First change was to be resignation from the stressful job with high social contact. She'd work in my business now, doing private analysis.

We sat together overlooking our favourite lake, surrounded by woods . . . woods we weren't out of yet. Patsy's mum had fought breast cancer for six years but latest news was bad. She said, "I must leave everything I've fought for here and go look after Mom". We knew it had to be done.

It was to be five months till the end. With the Atlantic separating us once again, Patsy's AS focus transcended any NT approach. She believed in a cure when others couldn't, so her grasp on her mum's daily needs was total and that nice lady had her own special girl there right to the end. We Skyped nightly to ease the stress of all those relatives . . . too many . . . too much noise.

She chose to sit alone at the memorial service, high in the balcony, above all the others, to say her last farewell. No role left now.

So . . . Heathrow again, planes dominating from above, car parks infinite; together again right where we came in . . . yet somehow stronger. Fate had shown an AS/NT team was a broad enough church to handle most stuff life can throw. But new challenges loomed, this time in my family. My elderly mum could no longer cope and Patsy now stolidly cares for her, with AS focus, while I work, make social contacts, switch, adapt, improvise. That's one AS stalwart, one NT improviser — quite a team, but our better-late-than-never diagnosis shone the light along our path . . . and the rest was down to a little love . . . and Mr Fate.

Group notice

by **Peter**

Blackpool adults with Asperger's support group (BAASG) is a Blackpool-based support group set up to help adults with Asperger's syndrome and HFA (high-functioning autism). Whether you have a professional diagnosis or are self-diagnosed, come along to a future meeting at Tesco's community room on Clifton Drive.

BAASG was formed in 2014 by Julie Reilly, a recently diagnosed Aspie, frustrated by the lack of help and support for adults with Asperger's syndrome and HFA in Blackpool.

Please come and look at our website at

http://baasg2014.wix.com/baasg

and if interested please email:

BAASG2014@hotmail.com

to confirm your attendance, due to Tesco's community room being in the staff area you must be there by 7 pm. in the foyer area.

An essay on the social graces

by **Joe**

NB. All places and personal names have been changed. An additional story that involved a friend of mine follows my story.

A short time ago I visited a friend, Bob, for St Valentine's weekend. As he knew I was single, he thought it might be nice to introduce a friend of his to me, since he was meeting me with his girlfriend. I was interested to meet his friend, Alice, and they all came for drinks at the hotel.

The first thing I noticed was that she seemed to be rather shy (nothing wrong with that). The second was that she almost reprimanded Bob over a comment he made about his fondness for her person. I was quite shocked by her tone of voice and by the fact that my friend was made to feel humiliated over something quite trivial.

At this point warning bells should have been going off in my head about her — however, I ignored this and carried on without saying anything. All four of us have Asperger's.

We later swapped e-mails. At this point I felt that things were going well and that a good rapport was developing between us. She had shared a personal matter with me and I shared a similar matter with her. I felt that this was drawing us together as potential friends.

One morning I was on the mobile to her about meeting up with our friends for a picnic. It was all planned, then I checked my e-mails and one from Alice stated that despite enjoying our chat, she now felt uncomfortable. She went on to say, and I quote: "I feel that you are looking too deeply into our friendship and want something more."

She went on to say she could not go through with the picnic, and informed me that she was going to tell our friends that I was no longer coming as I had lost interest in meeting up!

I told her in no uncertain terms that she was not to contact me ever again. I also got on the phone to Bob to tell him my side of the story. I reassured him that I would still be coming along.

I can only assume that Alice somehow wanted me to behave in a certain way towards her (perhaps in a crude manner). When she did not get what she wanted, she had to make up a story and create a situation to try and disrupt my existing friendships. I suspect it was jealousy.

The story concerning my friend John involved a date with a young lady he met at an autistic group, Belle. A date was arranged for a pub meet. However, she asked John if she could bring her mother and several products along. He agreed to this, thinking perhaps she needed moral support.

How wrong he was! He also took moral support, in the form of a friend. Eventually that lady in question arrived with a whole entourage of people and proceeded to present a meeting about selling beauty products for a whole hour. She even made out that John and friend were ambassadors for the products (which was a lie).

I believe Belle had seen John give a speech a few weeks before and wanted to emulate this. Both women lied, for different results. However, the outcomes would appear to show that both had no consideration for others' feelings. Is this something that happens when some AS women want particular outcomes? Who knows?

I would welcome any comments or feedback on this essay and would be most interested to hear of other male and female readers' own experiences. Have they been good or bad?

I hope it is clear to everyone that situations also occur where the man fails to adequately consider the feelings of the woman. Please take that as given, Editor.

How to succeed in employment with specific learning difficulties

— a guide for employees and employers

by **Amanda Kirby**

Human Horizons Series, Souvenir Press

ISBN: 978 0 28564 246 1

£8.99

review by **Nick**

To find joy in work, wrote the great American novelist Pearl Buck, is to discover the fountain of youth. The infamous prediction of John Maynard Keynes that most of us would now, thanks to mechanised labour, be working, if at all, an average of fifteen hours a week seems as distant as the sepia-tinged photographs of Keynes at Bretton Woods in 1944. Hard work is praised and represents the path to fulfilment. As Noel Coward said, work is more fun than fun. But amidst all the rhetoric around the purity of good honest toil, it can seem harder than ever to actually find a job today and if you have trouble with, for example, social interaction or organising your time or with painful anxieties finding, and keeping, a job can actually seem impossible. Struggling in these ways can leave you feeling isolated and lacking purpose. But, as Professor Amanda Kirby shows us in her book, there is a way, to succeed in employment we must find strategies, ask for help and — most important this — celebrate our strengths. As the very comprehensive sub-title to the book suggests, you can find tailored and clearly-written assistance for whichever combination of conditions you have and whatever stage you are at, from picking the right career to making the application and succeeding at the interview to coping once you have the job and protecting your well-being and mental health, as well as advice on some of the unwritten rules on socialising with colleagues outside of work. A particular strength of the book is the advice for employers. Sometimes a little knowledge is dangerous and stereotypical assumptions around the conditions covered can be as much a challenge as total ignorance. If an employer wants to help, but doesn't know the best way to do so, you can lend them this book (and even if they don't want to help, lend them this book as it will tell them about their legal responsibilities to you in providing reasonable adjustment). Above all, there are lots of reasons for an employer to value the contribution your unique talents will bring. It is possible to find a job, find some joy and whilst eternal youth maybe a little ambitious, Kirby's book is the place to start on the first two.

This book and the one on the back cover are available from all good bookshops and through Amazon's charitable scheme at

www.autism.org.uk/amazon

and if you use this address instead of the usual Amazon one, the NAS gets a donation from Amazon.

a letter

Dear *AU***,**

I'm e-mailing in response to the letter sent to *AU* from Alex in the January issue.

Alex: I have a friend who is very similar to you. I know he has a major problem with relationships and can't seem to understand them properly.

He has had help from both me and Autonomy in Shropshire to try and make him understand why it's inappropriate to do certain things. Like, we were in a pub and he fancied the waitress. He kept asking her to go and get everything and change this and that for him, mainly because he wanted her like his little slave and so he could look at her inappropriately. He also fancied my sister and kept demanding that she like him on Facebook, even though my sister didn't want to.

The biggest problem was that he didn't quite know how to talk to people, and how to increase his friendships. He also never saw how many friends he did have because he told me that I was his only main friend in Autonomy; what he didn't quite get was the fact that a lot of people also found him nice to be around, but he just had to learn a bit more self-control over his actions.

Even with me he started insisting that he came down to see me every single week and getting annoyed with my family if I wasn't there to take him everywhere. He even sent me a very nasty message demanding that my car was there every Wednesday, regardless, for him. At this point I put my foot down and tried my best to explain to him that we all have different friends and they are all there for us. I also tried to explain that he needs to get out of the repetitive habit he's got himself in, which was to go to Telford every day for a milkshake in a café, except on Wednesdays when the café isn't open, and on that day to do nothing (which is why he was so insistent on coming to see me on a Wednesday). He didn't work and kept saying that he had no skills to work and no money, no car and was annoyed and fed up with it. I work with an events firm and I offered him some work as they needed extra staff, but when I told him you need to be working at 7 am. he said to me he didn't normally get up till 10 am. and I thought he needs somehow to get out of this rut. I was also going to see if he wanted to help with me in the Scouts, but after seeing his attitude towards girls it put me totally off wanting him anywhere near Scouts (although it might have done him good).

He also needs to be taught that he can't harass women the way he does. This is why most women are scared of him. It's not that they don't like him, it's just his attitude scares them away. At times I think his attitude is more winding people up than actually serious, but he needs to learn that sometimes it's inappropriate and if he wants to build up a nice relationship it takes time. You need to find the right person and don't go head-first straight into them, start by just being friends with them and their friends, and see if they like you as well, and build on it. It doesn't happen overnight unless your watching a Disney movie!

Just treat women with a respect and they'll begin to like you. You'll stop having trouble with being arrested and be able to eventually meet the one that is right for you.

Hope this helps,

Darren

100%

FSC

www.fsc.org

RECYCLED

Paper made from recycled material

FSC® C011842

The rules of *Asperger United*

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

1) *Asperger United* is funded by the NAS and readers' donations, and is independent of the NAS. Although it is called "*Asperger United*" it aims to be for the whole of the (reading) autism spectrum. That is, the concerns and joys of any subscriber on the spectrum can be printed, not just Asperger's.

2) *Asperger United* is free and is quarterly, published in January, April, July and October. If you do not receive a copy when you expect to, please contact *AU*.

3) Pieces that appear in *Asperger United* are credited using the author's first name only, unless the author requests something different. This is done to protect your privacy.

4) *Asperger United* administers the copyright of everything that appears and it does this on behalf of the authors.

5) *Asperger United* does not use your contact details for anything other than administering *AU*. Your details are not passed on to NAS Marketing, NAS Fundraising or any other organisation without your written permission. Please consider getting involved with the NAS campaigns and events.

6) If you move house, please inform *Asperger United* and include your old address as well as your new address.

7) Even if you've paid for the Royal Mail forwarding service (or another forwarding service if you live outside Great Britain and Northern Ireland), you still need to inform *Asperger United* that you have moved address.

8) If you phone and leave a message on the machine, please speak slowly and clearly and spell uncommon words, as the line isn't very clear. Please give any phone number you leave twice for the same reason. Remember to give your postal address so that we can find your record.

9) You do not have to be a member of the NAS to subscribe to *Asperger United*.

10) The current edition of *Asperger United* is available at
www.autism.org.uk/aspergerunited
You need to scroll down to the middle of the page, where there is a link to the PDF.

11) You can sign up for an email notifying you whenever a new edition of *Asperger United* is posted on the webpage above. Email
asp.utd@nas.org.uk
asking for the notification by email and please include your full name, postcode and let us know whether you want the paper edition too.

12) If you want to unsubscribe from the paper version, inform *Asperger United* and include your postal address. Or to unsubscribe from the email notification, include your email address.

13) If you want to resubscribe (or subscribe for the first time) inform *Asperger United* and include your postal address (for the paper version) or email address (for the email notification).

14) Book reviews are the most popular thing in *Asperger United*, please consider submitting one. They can be about any book, not just books about autism. Also, they do not have to be short (the Goth keeps most of his reviews short to leave more space for other writers). If you do not want your review to appear in the NAS section of the Amazon website, please make this clear.

15) Although each issue is themed, submissions on any subject are welcome. Only some of the letters and articles in each issue will follow the theme. All submissions may be edited, especially for privacy, libel, and for fitting the space available.

Birth of a killer

book one of the Saga of Larten Crepsley

by **Darren Shan**

Harper Collins Children's Books

ISBN: 978 0 00731 587 1 £6.99 / $9.95

review by **Matthew**

This book is number one in a set and I don't normally read fantasy books like this — about vampires — but once I started I couldn't put it down.

In total I finished the book in three hours.

I've read many of Darren Shan's books before, so I already had a suspicion it would be good.

Darren Shan's use of characters and settings is phenomenal: I felt connected to the main character, Larten Crepsley, at the end of the book.

Although the story is pretty dark, it is great that Shan has used a unique style to entwine all the characters, and the connection between all the characters, and the love between them all is great, it actually feels real.

The way this story is written, helped me to imagine that I am actually there, and watching it happen.

It's a book that I would recommend to all who are into this genre; I am definitely going to read the entire set.

Asperger United, c/o The National Autistic Society, 393 City Road, London EC1V 1NG
Telephone: **0808 800 1050** (free from most landlines) or
Telephone: **020 7923 5779** (geographical charges apply)
Fax: 020 7833 9666
Email: **asp.utd@nas.org.uk**
Website: **www.autism.org.uk/aspergerunited**