

Produced by and for people who have autism-spectrum conditions

Asperger *United*

Edition 69 January 2012



Asperger United

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

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

Asperger United is free. To subscribe you, we need your postal address. We ask for a contribution of £6 per year from overseas readers and £10 from professionals and institutions to cover postage costs. Please make cheques payable to the NAS. Organisations requiring multiple copies: no extra fee, please get in touch.

Editor the Goth

Telephone and production support

The National Autistic Society's Publications Department

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

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

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

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

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

Please send all correspondence and subscription requests to:

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Tel: **020 7903 3595**
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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 newsletter.

Contributions for the next issue should reach *AU* by **13 February 2012**

Welcome to *Asperger United*. Officially, it's now 2012 — though you may be reading this in the last week of 2011! That's publishing for you, and the post, which can take up to fourteen days using the mass-mailing, cheap offer from the Royal Mail that *AU* uses.

As I mentioned last time, in 2007 I conducted a readership survey, and one of the results of this was that a significant number of people were interested in a gazette being published in the magazine of social groups and other services. With limited space, this didn't happen until now, but I've published everything that has been sent in in the last six months (unless, of course, I've misfiled something and didn't find it in time — please remember that I am fallible before you send me angry letters of complaint, though please do point out if you think I've missed something).

Surprisingly, for me, the ads fitted on a double-page spread (pages 14-15), even though there are many more groups out there. People send in requests for themes and letters saying how much they want this or that to be featured, but few send in articles (or adverts in this case) on that topic. The same thing happened with the “theme” of addiction — I have received only five letters on the subject, the latest of which is on page 6.

My point is, we have to support each other and do things for ourselves, and if we expect others to help when we ask, we need to make an effort to help others. I will look forward to a further crop of social-group adverts for next issue.

Yours hopefully,

the Editor

the relationships edition — next issue notice on page 10

Contents

Art by Tingting	cover	Letter about coping from Ron	11
<i>My dad</i> – feature by Aida	4-5	Book review by Melissa	11
Featured letter from David	5	<i>Asperger's syndrome for dummies</i> by Gina Gomez and the Goth	
Featured letter and a letter about	5 & 6	<i>Why I am single</i> – article by Robert	12-13
driving lessons from Olly		Adverts for various groups	14-15
Letter about her doctor from Annette	6	<i>Autscape 2011</i> – article by Chen	16-17
Letter about alcoholism from Peter	6	Film review by Walki	17
Letter about computer mice from Kathleen	6	<i>Four minutes</i> directed by Chris Kraus	
Pen pals	7-9	<i>The house-“share”</i> – poem by Jenny	18
Letter and a poem about imaginary friends	9	The rules of <i>Asperger United</i>	19
from Lisa		<i>Just too intense</i> – poem by Susan	back cover
Letter to the Editor	10	about problems with services, from Ruth	accompanied by a letter

My dad

by Aida

I am the daughter of an Aspie. I'm not sure if I have AS myself. I feel strongly that I have it, but I don't display all of the characteristics people with AS are supposed to have. Most of all, I am not obsessed with any topics, so I have nothing to talk about excessively.

My dad is 67 now. We are from Vienna in Austria, and he claims that he had been diagnosed as a child by Dr Asperger himself, having been sent to him because of his unruly behaviour. He only came out with it a few years ago. Dad has all the characteristics of somebody with AS, but we didn't know anything about it back then, so everybody assumed he was just being eccentric.

My dad is very intelligent and knowledgeable, especially in maths, science and technology. He plays the violin and conducts choirs and chamber orchestras, and he picks up foreign languages quickly. He surpassed his teachers at school, but dropped out and hasn't got any formal qualifications. Nevertheless, he had worked as a high-profile engineer for decades. He isn't good at managing his finances and everyday tasks like paperwork, so he got into debt. He gets a small pension today and lives in social housing.

The most remarkable thing about my dad is that, even though he had it tough at times, he is so positive and loves life. He has a strong sense of justice and integrity, is helpful and generous, and doesn't care about somebody's appearance or possessions. He tends to surround himself with people who share the same interests as him, and in these circles he is comfortable enough to enjoy socializing. He never had difficulties finding partners, and his relationships are relatively durable, provided they give him the freedom to be himself.

Sadly though, I have to say that he didn't treat my mum well. He repeatedly cheated on her

and splashed the money out, so sometimes there wasn't enough left for our basic needs. I don't know why this was so. She used to suffer from depression and has low self-esteem. Anything outside the social norm frightens her. Maybe dad subconsciously treats people the way they think they deserve to be treated; that would explain a lot.

So where does that leave me?

Dad never spent much time with me; he wasn't at home a lot. When I was 12, he left. I used to see him regularly, and while he still had his job he paid a good amount of maintenance, more than he ever gave my mum when he was still at home. However, I always felt that his new partner was more important in his life than I, or than my mum ever was.

I have been living in the UK for more than a decade now. We e-mail each other. He seems pleased whenever I write, and he seems to think well of me. It is always me who initiates the correspondence though, and after a few mails the exchange dies out on his side, until I write him again (after plenty of time to give him space). With his partner he seems different, he seems to miss her more after a day than he misses me after a year.

On bad days (which are not that often, luckily) I tell myself that I'm just not good enough in his eyes to earn his sustained affection, just like my mum. On good days I say to myself that maybe he is the way he is because he feels that he can be himself around me, that he thinks he doesn't have to prove his love for me with meaningless gestures (just what *is* the point if he already told me once he loves me?).

He says he is not sure whether I have Asperger's, and it doesn't matter if I do or don't because I certainly have the intelligence of an Aspie. I wish.

feature (continued) and two featured letters

I don't know why I'm crying now.

It's very strange. I will always be grateful to my mum, she did her best to bring me up. Every single day she struggled to look after me, even when she was depressed and short of money, while my dad would occupy himself elsewhere. I can never repay her for that. However, if somebody told me that my mum was not my biological mother, I'd believe it straight away without any doubt. With my dad though I just know that his blood flows in my veins. I just wish he had given me more of a manual for the traits he passed on to me — whether by nurture or nature I can't say.

He might not be a picture-book dad, and I will never be sure if I am important to him, but I'm still glad he is my dad. He showed me the sea and the sky above and the wind in between, and taught me to love them. He gave me a glimpse of what it is like to live life to the full, and that's more than most people get.

My name is David and I am 44 years old. I live in London and I have Asperger's. I have problems concentrating, carrying out tasks, and organising things. I sometimes feel irritated at people's ignorance who don't see it in me. I feel scared to argue back with people. My biggest annoyance has been my elderly parent who is in his 80s. At 80 he started to lose his hearing and had to wait a year for his hearing aid. A lot of what I have said to him in the past five years has fallen through deaf ears because he hasn't used the hearing aid as often as he should. I shout and he doesn't like it, but I shouldn't feel guilty. When any parent shows too much of their own pride and doesn't pay enough attention to their son can be very stressful. I have had to suffer in silence in the last five years. I get a lot of intolerance from many. My previous GP was useless. At least I feel more comfortable with the modern doctors as they are trained differently, more down-to-Earth and you can talk to them, providing you don't bore them to tears.

I have had a few "girl-friends" but only two proper girlfriends, both of which never worked out for various reasons. I do want a girlfriend but don't know how to find someone who I might love, I don't go out to any nightclubs or any social clubs that people here go to.

My personality is such that I am outgoing, I like banter with people and enjoy people's company, however I find meeting new people initially nerve racking. I sometimes feel lonely and isolated and wish I had close friends I could share my interests, hopes and dreams with.

I don't want people to judge me before they get to know me and sometimes I put up a "barrier" and they don't get to know the real me.

I am proud of my achievements and the barriers I have encountered and overcome and I am not ashamed of my diagnosis of Asperger's — however I get frustrated with people who don't see past the label and judge me and so I am not always upfront with people. People sometimes say to me "hey, you don't look like you have Asperger's"; I ask myself what do they expect me to look like?

I am me — I want people to like me for me, for my sense of humour, for my generous nature and my willingness to love and to be loved back.

My dream would be a very simple one that most people take for granted on a daily basis — and that is to have a group of friends I could invite round to mine for dinner parties or just for a chat, a partner that I could go home to every day — somebody I loved and cared for and who loved and cared for me. Just a simple dream — that most people take for granted.

My flatmate and me are both on the spectrum but seem to be on a different planet: what I mean is we are both independent but also not independent in various areas.

Olly

four letters

Dear AU

I'm usually very quiet, my head full of thoughts. From reading the October 2011 edition asking about relationships for next publication:

I had to think for a while about this. And my result is my GP. I've lived in this borough a year and a half and for the first time I have a GP who actually listens to me. Especially as I have difficulty talking. He helped me get the ASD diagnosis. For me, the most important is that I can feel comfortable to say "I don't understand" when he explains something and instead of being annoyed by me or trying to rush me out the surgery for the next patient slot, he asks me what is it I don't understand; he allows me time to point, and communicate my confusion to him. He doesn't make me feel stupid, a waste of time.

Even when I'm stuttering and stammering he doesn't try to finish my sentence, just reassures me to take my time. My GP helped me get the address for community social care and provided paperwork to support my letter of request. I've been assessed as an extremely vulnerable adult. I'm beginning to get the help I've needed all along. Age 37. Asperger's syndrome. No family or friend support. Having a doctor that has believed and helped me has been a giant relief for me.

Annette

I have had my provisional driving licence since 07 and haven't had any lessons to date. The main reason is I'm unable to find a driving instructor willing to take me on — when I tell them I have high-functioning Asperger's, they panic due to lack of knowledge.

I would like to know and also hear from fellow readers who have managed to pass their driving test, which driving schools they used and whether they told the company.

Olly

Dear Asperger United,

In response to your letters regarding alcohol and drug addiction among Aspies, I am a recovering alcoholic, having now been dry for about five months. I have to say that I was luckier than the others in that I was able to get the help and support I needed to stop drinking.

I started going to AA meetings but I decided it wasn't right for me once I'd realised what the Twelve Step recovery programme entails. However by now I was committed to sobriety and my quality of life had significantly improved. One thing that helped me a lot was the support I received from my friends and unlike most recovering alcoholics I had an alcohol-free social life.

Secondly, I was lucky enough to live in one of the few areas with a local group called Dual Diagnosis for people who have both mental-health problems and addictions to alcohol, drugs, gambling, etc. It meets every Wednesday evening at Stockport Wellbeing Centre. I found that this group gave me the necessary help and support which your other readers couldn't get.

Peter

Hello!

A friend has loaned me the October edition of your very interesting magazine. I'm dropping you this line with reference to the letter on page 18, about difficulty with using a computer mouse.

It's worth remembering that all actions on a computer can be done via the keyboard, and a mouse isn't an essential tool. Qualified typists know this from long ago! Also, sight-impaired people navigate around a computer screen using the keyboard — you can't use a mouse if you can't see the arrow!

I just thought this might be of practical help to some of your readers.

Kathleen

Pen pals

Pen pal number 105

Hello, I'm Emma and I'm 14 years old. I was diagnosed with AS when I was 10. I have one sister called Clare who is my best friend.

I would like to write to females only, please. My interests are learning Spanish, listening to music (Selena Gomez), watching television (*Only Fools and Horses*, *Doctor Who?*, *Casualty*, *Harry Potter* films, *Holby City*) and spending time with my family.

Pen pal number 106

Hello, my name is Clare. I am nearly 17 years old and I was diagnosed with AS when I was 4. My sister Emma is my best friend. I'm interested in Katy Perry, Selena Gomez, *Twilight*, *Harry Potter*, *Waterloo Road*, playing on the Wii and Playstation 2, playing the keyboard and reading. I would like to write to females only, thank you.

Pen pal number 107

Hi, my name is Jonathan, I'm nearly 15 years old and I was diagnosed with Asperger's in 2002.

I like listening to music (mostly but not exclusively alternative rock), browsing the Internet (including Twitter and blogging), politics, geography, science, watching comedies, dramas and documentaries, walking and cycling. I play piano and the guitar. I also play chess though I'm not particularly good.

I'd love to talk to anyone around my age or older who shares my interests.

How to place a pen-pal advert

All you need to do is send your advert along with your name and address (and email address if you want) to *Asperger United*. You can use the Royal Mail or email. The next pen-pal number will be given to your advert when it arrives.

How to reply to pen pals

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

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

Asperger United is happy to publish 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 108

Hi, my name is Phillip. I was diagnosed with Asperger's syndrome at primary school. I am now 19 years old and a maths student at university. I am really keen on developing a friendship and a relationship with females with Asperger's syndrome. My interests include playing tennis, writing poetry, watching science fiction television programmes, exploring the great outdoors and meeting people.

If you are of a similar age, I look forward to your reply.

Pen pal number 109

Hello, my name is Nathan. I am 11 years old and have Asperger's syndrome.

I live in West Sussex and have just started secondary school.

My main interests are computers, cars and playing racing games on my Xbox.

I struggle a bit socially and often feel I am "different" to the others at school. I would love to hear from other children like me, who would like to chat by email. So please reply to me by email.

Pen pal number 110

Hi my name is Gemma. I live in London and am 18 years old. I was diagnosed with Asperger's syndrome when I was 12 years old.

I'll soon be going to university to study history and my hobbies include surfing the Internet, films, reading, graphic novels and writing.

I would like to hear from anyone around my age or thereabouts.

Pen pal number 111

Hola, my name is Katie. I live in South Derbyshire with my mum, brother, and sister. I am 24 and have ASD and OCD.

My main passion is Spanish and Latino culture. I have been fluent in Spanish since passing my A-level.

My hobbies include belly dancing, walking, eating out, and listening to Latin pop.

I would like to meet anybody with similar interests around my age who is caring, honest and understanding. If you speak Spanish, that's a bonus!

Pen pal number 112

Hi, my name is Jadea, a 28-year-old woman from Newcastle-upon-Tyne.

I'm self-diagnosed and awaiting official diagnosis, which at this point is just a formality. I live independently, although after losing my job three years ago I've regressed a little, this has meant trouble finding work and I feel I have lost many friendships, but I don't plan on slipping easily back into old habits.

My "special interest" is women's/sexual health, which isn't the easiest of subjects to discuss, so you'll be glad to know I'm also interested in a few more normal things too: environmentalism, music (mostly rock), religion, activism, disabilities, Internet, shopping, cats, walking, and being creative.

I'd love to hear from others near Newcastle, but letters from anyone within my age group in the UK would be great — I get on better with men, but am open to writing to women and genderqueer people too. The idea of pen pals interests me, but I've never been brave enough to try it, so if you reply please be gentle with me!

Pen pal number 113

My name is Lyssa, I am 25 years old with Asperger's syndrome. My interests are reality TV and soaps. I also like animals, cooking and listening to music.

I would like to speak to people my own age or a little bit older. I like to talk to people with similar interests.

Hope to hear from you soon.

Pen pal number 114

Hi, my name is Bryan. I am 24 years old and live near Blackpool. I was recently diagnosed with Asperger's but have suffered with OCD since I was about nine years old.

I have no friends as those I make seem to take advantage and/or mock me. I am fed up with being lonely and would love to correspond with like minded people who would accept me and like me for who I am.

My main hobby is metal detecting, but I also enjoy cooking, painting, playing video games, and I have just taken up piano lessons. I like to listen to music; Queen and Mozart are two of my favourites but I like some of the current stuff too.

I look forward to hearing from anyone. Thanks.

Firstly, great publication. It's wonderful to see something that allows us to express ourselves. So, the theme is relationships — I wondered if you'd consider this submission. It's a poem; a sonnet but not quite a sonnet, to my imaginary friend, Jack. We have a rather complicated relationship. I know I "should" have left all my imaginary friends behind like my classmates did many years ago, but somehow I can't bring myself to, and I'm not sure if I'd want to. Anyway, here goes,

Lisa

Pen pal number 115

My name is Kimberley, I am 28 and was diagnosed with Asperger's in June. I live in South Wales. I live with my mum and I have a boyfriend. I like history, *Family Guy* and *Harry Potter*. I am looking for a pen pal from all walks of life all over the country.

Pen pal number 116

Hello, my name is Jonathan, I am 31 and from Bournemouth, although living in a residential home in Bath.

I have spent most of my life in hospitals and prisons although this is now in my past.

I have never had any friends and would love to develop friendships. I may have a difficult past, be overweight and find it difficult getting to know people, but I believe I make up for it with loyalty and being caring.

I love football (Bournemouth and Man Utd), going to matches and travelling, visiting cities. I also love guinea-pigs — I have five. I like cinema and bowling. My special interest is lifts.

I would really like to hear from anyone who won't judge me on my past with possibility of meeting up in time. I am fairly independent so anyone of a similar level would be great.

Oh, Jack, you are so different
Yet differences betray our union
Of mind, of body, of soul and thought.
We hide ourselves behind veneers-
Our veils for our tormented souls.
We do not belong on this Earth
Heart bleeds hidden, heart beats grudging.
I would follow you to the end
But my mind, ever logical,
Knows you are not

real.

letter to the Editor and a notice

Dear Goth

You wanted to know about adult social groups. Here is my experience of what happened when a local organisation started.

I went to an event at the local leisure centre, which was extremely non-autistic friendly — there was a loud air-conditioning sound and just a big hall with stalls around, no structure and quite overwhelming.

Was told there was an adult social group starting, and, as we've seen little specific autism provision, I was quite excited.

Unfortunately the organiser chose an out of the way venue, so my first difficulty was getting there and my second that I could not leave at any time as I was dependent on others for transport arrangements. However I felt the meeting went quite well, and looked forward to continuing attending. Only, more meetings never happened. We were told there would be meetings, but evidently the adult group was no one's priority. Then we were given a date on which a Christmas meal would be arranged, but clearly no one followed it up until the last minute, when we were told that the restaurant was booked up and we'd have to go another day. I couldn't cope with the change and didn't attend.

Then no more meetings were arranged at all, and myself and a man who had kept in touch so we could go walking together, heard nothing for several months.

And then, someone in the organisation decided to start a new group. But for this one you had to give a lot of medical details when you signed up, and get someone else to guarantee you would behave yourself in the group! There was also a

whole page of rules. (Shouldn't a group of adults write our own rules?) My friend and I were highly offended at this. I don't know if the group ever got started; I heard they were having difficulty getting a minimum of three AS adults to sign up!

These experiences made me feel very let down and belittled by the organisation, sad to say, as I was so happy initially to see they would be active locally to me.

Ruth

PS. Forgot to include my thoughts on listing social groups in *AU*: why don't you produce a continually updated, separate document that you can send or email to people on request, and maybe once a year include the latest edition when *AU* is mailed out?

And yes, you absolutely should say whether a group is NAS, run by a parent or professional, or "by us and for us". And include as many different ways of contacting group organisers as possible — email, phone, postal addresses . . . and website details . . .

I have forwarded details of this complaint to the organisation in question and will update readers if there is a reply.

*To answer the postscript, I wish I had the money to produce a continually updated, separate listing of social groups! Sadly, most of the suggestions made to *AU* are too expensive to do.*

Whether the groups listed are by us and for us or not is not clear from the information sent in by some of the groups, so sorry, people are going to have to find out by contacting the groups they are interested in. This is not ideal, but I have limited time to chase people for complete information, Ed.

If sufficient material is sent in, the theme for April will be **living**. All the problems and joys of day-to-day living, eating, organising yourself, getting up, whether you prefer being unclothed while at home (which the Editor suspects is quite common), your social life, and anything else. 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!

How I coped with high-functioning autism

Dear Sir,

having passed state retirement age, I have been reflecting that, with my autistic traits, the only time in my life when there was any level of control or direction was the fifteen years during which I was “on parade” in a boy scout military band.

I was capable at teaching the boys how to play the highland bagpipes, the only activity I ever tried that I was any good at.

Whilst more recently working as a cleaner in a nursery, I noticed a baby boy two years old. I could see that he was always in trouble with the other babies and with the nursery nurses. (Perhaps he was autistic.) My immediate reaction was to salute him and give him a religious and political reason for behaving. His reaction to this was dramatic. I seemed to have given him a reason for living and I noticed an improvement in his countenance every time I walked in the room.

Could it be that some autistic people need to be under military discipline all of their working lives?

Yours faithfully,

Ron

Asperger's syndrome for dummies

by **Gina Gomez de la Cuesta** and
James Mason the Goth

ISBN: 978 0 47066 087 4

£15.99 John Wiley and Sons

review by **Melissa**

Although the content of this book is abstract, all topics are placed in clearly systemised categories which are very autistic user-friendly. The book draws on a broad range of topics related to Asperger syndrome, from causes and characteristics to pros and cons for both children and adolescences with ASC. All topics are discussed in detail in a simple, clear and basic format.

There are many books about autism theory's concepts, but this one looks primarily at the facts and bases the concept of autism on the more recent and up-to-date factors.

What I like most about this book is that it is primarily based on fact. Most of the books I've read are primarily based on theories and opinions of ASC, which

can be misleading. Asperger syndrome can mean different things for different people, and when one learns that they or someone they know has Asperger syndrome, one rarely understands the notion of what it means. Often very few people ever get the “big picture” and end up reading about just one concept of ASC and believe only that one concept to be the case.

A book like this one is important to give people the big picture of what is Asperger syndrome and what it means for you as a person.

I like how they have used the term ASC to describe one affected by autism rather than use the term ASD, which stands for autism spectrum “disorder”. I can clarify that autism is not a disorder, so what is Asperger syndrome? . . . this book will tell you.

This book is 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.

Why I am single

by Robert

If there was a machine that would translate my thoughts into the volumes that would describe my experiences, emotional reactions and surmises, and edit them into a form comprehensible for everybody else, then it would be easy to build up a contribution to the Asperger awareness field. But I can't, so I just inexpertly put a small part of it into words as the opportunity arises.

As part of difficulty in forming relationships with people, I think that forming that extra-special relationship, that may be long or short term, result in marriage (or fall short of actual marriage) is the hardest one of all.

Having Asperger syndrome is not alone a reason for inability to form that relationship, as many are successful at this, but is in many individual and quite different cases a large contributing factor. Our experiences shape us in conjunction with the qualities inherent with us. Not only does Asperger syndrome manifest itself differently in every single case, but every person with it differs in their other inherent attributes, which are generally no more atypical than any other person's inherent attributes. I don't even know all my inherent attributes, neither can I adequately recall all relevant experiences, or describe their effect on my personal development.

I don't know how true it may be of any other, but my belief is that in my case the combination of Asperger syndrome with my other inherent qualities and my experiences in life are what have made me unsuccessful. And I think it is largely due to experiences in combination with Asperger syndrome, especially with no diagnosis.

I was brought up in a totally loving way, and my pre-school development was "normal". I'm sure my parents' love never diminished. With my instinctive behaviour lovingly appreciated and photographed (giving a snapshot available today:

the fact that my father was behind the lens on photos of my play says more about his love than words) I naturally developed my self-esteem.

As I entered school I offered the world a clean sheet to write on, and utterly innocent too. The prevailing attitudes of society then (and possibly even now) made writing on this "sheet" cleanly completely impossible. There were positive experiences in my early schooling but by 7 I was beginning to experience school negatively and this generally worsened gradually until I was about 15. I will try to summarise succinctly now:

Peer group. Difficulties in understanding their motives. Always cried when picked on at first as I couldn't understand it. Innocence used as a weapon to bully me with. My dislike of rough physical activity was used to make me feel inferior. Unable to articulate to defend against such tactics as claiming my being bullied was all my fault and that I was the guilty party. Worst of all, my naïveté was used as a weapon to brand me as a homosexual at my public school, which was enthusiastically used by many boys, including in a particularly disgusting way by some boys in the Upper VIth (17-18 years old) when I was 13-14 and unable to defend myself verbally or physically. I finally overcame the extreme bullying largely in my O-level year when I focused on working for the exams, impressing many, and getting the best O-level results in my (bottom!) class. As a boarder from 8, I had no respite from the peer group, which was at its worst during the first year and a half (from age 13). Although the social situation improved I was thoroughly disenchanted and at 16 quit private education to do my A-levels at a state sixth-form college.

Teachers. Too rigid in their frame of reference. Too intolerant of slow learning, unable to accept that I struggled to grasp concepts. Too disciplinarian in dealing with

poor performance. Not enlightened enough to look at what I produced as a chance to learn about me if it didn't conform tightly with their expectations. On occasion showing up my poor performance to the boys in a way which encouraged their ridicule — this in itself was a form of bullying. An expectation to conform more rather like peer group.

Parents. Although done lovingly, my parents made a bad choice in sending me to board. As far back as 1972 it was possible to assess a boy's personality to say whether boarding would probably be disastrous — I think it was possible to observe me more than was done, and then make a choice appropriately. Also their acceptance of the spontaneous me seemed to change, as they pushed me to behave differently and to leave aside things I was instinctively interested in to do different activities (particularly joining in more with other boys). As I was bullied for my behaviour over the years, I almost became a non-person, trying to do and be what others wanted — a meaningless lifestyle, like a vegetable.

If school is to benefit the child, then it must be sure to consolidate the self-esteem. Sadly, it can often send it into reverse, and in my case when I moved to my public school it reduced my self-esteem to virtually zero, so that I withdrew into a psychological cocoon. This has a knock-on effect that is thoroughly wasteful in the many years of young adult life spent struggling to catch up with where your development is supposed to be. An absolutely tragic and unnecessary waste. The good work done by my parents was almost totally undone (although obviously not in all senses as I retained the resolve to carry on and fight) and had to be rebuilt.

At 16 I was in a mixed class for the first time since I was 6, was not only inexperienced, but my self-esteem was shot to pieces, so I stood little chance there. I was not physically unattractive, although I looked rather weak in the mouth, and lack of self-esteem certainly doesn't appeal. This didn't get any easier as years went by, and I gradually made friends better with both men and women, met people through dating agencies, even

took an au-pair girl out, with a very gentlemanly attitude, hoping it might develop into something more — it never did.

Another critical factor was a lack of diagnosis. I don't know how I might have got on with women I met had I already had a diagnosis. My experience now tells me that being able to talk knowledgeably on specialised subjects while appearing socially very naïve doesn't appeal. With experiences that enhanced my self-confidence and a diagnosis, would some girls somewhere have given me a chance? I don't know!

By the time I was diagnosed at age 38 I had built up my self-esteem and started achieving meaningfully, and since then have developed in leaps and bounds, but also I have lost a lot of time with settling into marriage and parenthood. Single life sets habits to some extent. After trying out various forms of arranged dating, I have decided that it isn't worth it. It smacks of being desperate, which ruins the chances, and in my case brings too much immediately obvious baggage to the dating table. I think it won't come from such a source.

My attitude now is to enjoy life, enjoy doing the things I do, and if a development in that direction comes my way, hopefully I'll take it! My father was 41 when I was born. I'm 46 and if I did ever have a chance to become a father, I would be considerably older. Certain workplace strategies like exposing someone's lack of sex life and making them feel inferior to you because you have had a very active sex life are thankfully now recognised as bullying and not tolerated where I work. Another annoying experience is when, on discovering your lack of girlfriends, somebody asks "Are you gay?" — this is generally by people of immature years though.

Although parenting is very difficult and not being one allows me to pursue my hobbies, I can never describe how much it hurts sometimes to compare my life with those who've got their children. At other times I tell myself that I've done very well given my circumstances and stride boldly on.

all the adverts for groups that were sent in

Hi, I run a website called **AS Support Group Online** or ASSGO for short. Please can you plug our link in your publication as the website lost a lot of visitors due to having to change the domain address. I started the website in 2004. The address is **www.assupportgrouponline.org**
I have Asperger's syndrome myself. I was diagnosed at 17, a year before I started the website.

Emma

Hi everyone,

I have set up a **football scheme** for young adults with HFA and AS. The scheme is run in **Barnet**, North London. The main idea of the scheme is to guide them through their FA level-1 coaching badge. We also aim to teach them life skills like healthy living, communication, responsibility and social skills. We will run this like a real football club, we have a great venue with a club house, we have kits and training tops and will arrange matches in the future with other like-minded teams. The club is open to anyone of any ability as long as they have a willingness to learn.

If you want to know any more please contact me on **07580 441 877** or **waynethorpe1@hotmail.co.uk**

Thanks

Wayne

The Friday alternative

A social group for young adults 18 years and above with Asperger syndrome.

Evening pub meeting every 4 to 6 weeks in Exeter, Devon.

Further details:
Kevin Hickson
07813 318 357

Dear Sir,

I wish to re-advertise the **Asperger Rail Club**, can you please mention this in the next issue? The web address for the ARC is **www.asprail.co.uk** and my telephone number is either **01626 680 140** or **07982 868 757**. My postal address is as follows:

The Lighthouse,
Reed Vale,
Teignmouth,
Devon
TQ14 9EH

I hope to hear from you soon.

Yours sincerely,

Edward

Hertfordshire NAS Resource Centre

Social groups: these are for adults. There are three groups which meet weekly during term time. There are two in St Albans on Mondays and one in Stevenage on Fridays. These groups have activities such as pool, table tennis, cookery, indoor football and weekly discussions.

Music and drama groups — for adults and young people age 16+. These are in St Albans on Tuesdays and Royston on Thursdays.

Pub group — the last Thursday of each month for adults in Watford.

We have a full-time liaison worker to support young people, adults and their families in gaining the support and services that they need.

For further information and details of how to apply for any of the above please contact:

Phillip Hanscombe or **Alison Carpenter** on
01442 247 046

Or email: **phillip.hanscombe@nas.org.uk**

Football for players with a disability

I am the chairman of **RCT Tigers DFC** — a pan-disability football club based in **Pontypridd**. We provide opportunities for players from 6 to adulthood. This includes training and competitive opportunities and the opportunity to progress up the development ladder to national level.

Around 80% of our players are ASD — a pattern I see repeated in most clubs we play against. We have grown from our inception in 2007 to around thirty players and expect to continue to grow. All of our coaches and volunteers are either family members or professionals working in SEN. We have also sponsored a number of our players to attend coaching courses.

Originally we were set up by Rhondda Cynon Taff County Council but are now self-organised and funded. We were named as SWFA Club of the Year 2011.

In this time we have also arranged many social events — seeing both rugby and football internationals. We believe a football club is about being part of a bigger family and we have an active social programme for parents and players to match this belief.

It is worth mentioning to readers that clubs such as ourselves are very friendly environments, both for players and carers. (We have seen and heard it all — and guess what? It does not phase any of us whatsoever!)

Anyone interested in taking part in clubs such as ourselves should contact their National Football Association who will put them in touch with the nearest club!

Russell Sherwood
Chairman, RCT Tigers DFC

russell.sherwood@rcttigers.co.uk
www.rcttigers.co.uk

01443 791 293

Asperger drop-in groups

offered by the **Wessex Autistic Society**:

Alternate Wednesdays 2 pm to 4.30 pm, Dorchester

Alternate Wednesdays 2 pm to 4.30 pm, Yeovil

Every Wednesday 2 pm to 4 pm, Bournemouth

Please contact me for further information, regards

Karen Wilmshurst

Advocacy Services Manager
The Wessex Autistic Society
South Grove Cottage
Trinity Street
Dorchester
DT1 1TU

Telephone: **01305 213 134**

Email: karen.wilmshurst@twas.org.uk

Website: www.twas.org.uk

Information and Advice service can search the Wessex area for you: **01305 213 135**

Scarborough self-help group for adult females diagnosed with Asperger's or HFA.

This is a new group that was formed in December 2011. We will have a regular meeting venue by January 2012 so please email **Sharon** for the location and when the group will next meet:

norscope1@yahoo.co.uk

There is also the **NAS Autism Services Directory**:

www.autism.org.uk/directory

info@nas.org.uk

020 7903 3599

which is a database of all the groups and services that the NAS knows of. You can write care of *AU* for this or any advert here.

Autescape 2011

by Chen

Last summer, I went to Autescape, which is an annual autistic conference.

Autescape is organised and run by autistics and for autistics, including, of course, aspies.

Autescape 2011 took place in Ackworth, West Yorkshire, lasted three days, and was themed *Owning autism*. Like in previous Autescapes, the vast majority of people who came were aspies, although autistics from all over the spectrum were invited. Most people were Brits, but there were also people from the Netherlands, Belgium, Germany, Switzerland, Norway, Sweden, Israel and New Zealand. The overall number of people at Autescape 2011 was about 80. This places Autescape among the main autistic-run conferences in the world.

Autescape 2011 was the sixth consecutive Autescape I came to, and I greatly enjoyed this reunion with friends, whom I met at previous Autescapes. I also enjoyed meeting many new people, who came to Autescape for the first time.

Like previous years, this Autescape featured various presentations, all delivered by autistics, as well as workshops, leisure activities, formal and informal discussions, social opportunities, and more, all specifically orientated to the needs of autistics. As in all previous Autescapes, attendance in the presentations and in the other activities was optional. Occasionally, I chose to sleep late in the mornings and miss the first presentations, although most presentations were very interesting.

Among the presentations which interested me the most, was a presentation entitled *Owning the languages of autism*, given by the Dutchman Martijn Dekker, who is among the main figures in the autistic community in Europe. He explained, among other things, how different choices of words can assist us to advocate for ourselves, and

how we can take control of the discourse of autism, to be more effective in self-advocacy.

Another presentation which I found very interesting was entitled *Use it or lose it. How autism has been owned, and how to claim it for ourselves*, which was given by the Englishman Larry Arnold, who is a well-known figure, both in England and internationally. He explained, among other things, the history of discourse within the field of autism, where we are currently at in terms of self-advocacy, and how we can focus the “ownership” of autism discourse to ourselves, so we can be more effective in our self-advocacy.

A third presentation, which interested me a lot, was entitled *Specialisterne Scotland — passion for details*, which was given by the Scotsman Alastair Cooper, who works as a computer software test analyst at Specialisterne. He described the activities of Specialisterne, an IT company which employs mainly autistic IT personnel.

Other presentations were entitled “*Pitfalls in autism diagnosis and support: reflections from an autistic doctor*”, “*Owning our support: personalisation — theory and reality*”, “*Owning autism research*”, and “*An insider’s critique of the dominant psychological models of autism*”.

After most presentations there was plenty of time to ask questions, and there were discussions about the presentations, in which people were free to express their own thoughts about the subjects which were presented.

Leisure sessions included, among other things, drawing mandalas (beautiful, intricate, colourful circles), playing table tennis, and singing rounds.

In the late afternoon and evening, I enjoyed walking in the beautiful grounds, participating in spontaneous discussions, drinking tea and wine, and drifting into occasional daydreams.

On the second and third evenings, we held *Sparklies in the dark* sessions, in which we played with sparkly objects, such as glow sticks, battery operated sparkly balls, sparkly flying discs, etc. If I remember correctly, this was the second consecutive Autscape which included *Sparklies in the dark* sessions. I enjoyed them very much.

As in previous Autscapes, I found the spontaneous discussions to be even more interesting than the scheduled presentations, as the spontaneous discussions allowed me to get to know other autistics, to explore our commonalities and our differences, and to somewhat quench my insatiable thirst for meeting other autistics and for building social bridges.

On the last evening, we held an entertainment evening, in which participants demonstrated their considerable artistic abilities. A few women sang songs, accompanied by a pianist. One man told a story. Another man recited a poem he wrote. A musical duo played the mandolin and the ukelele. The atmosphere was great. I was greatly impressed with the talents on show.

Like all good things, Autscape 2011 had to end. I went to the station with some fellow participants and enjoyed chatting with them, until each of us took their train. I was sad to have to say good-bye, but I am hoping to keep in touch with many of them for many years to come, and to see most of them again at Autscape 2012.

Autscape 2012 is scheduled to be held in July, 2012, at Belsey Bridge Conference Centre, in Norfolk. All autistics, from anywhere on the autism spectrum, who are interested in meeting other autistics, or in hearing presentations by other autistics, are very welcome to come.

For further details, please visit:

www.autscape.org

Full contact details will be advertised later this year.

Chen is an autistic Israeli. He enjoys travelling to various countries, meeting various autistics and helping to develop the rapidly emerging autistic culture. He volunteers as a spokesman for ACI — the Autistic Community of Israel (an organisation by autistics, for autistics).

Four minutes

Film review by Walki

This 2008 film by Chris Kraus is about Traude, a deeply repressed woman and a piano teacher. She treats people around her with great contempt. She's been living and working at the same places most of her life, since WWII. What went on for her and turned her into a bitter spinster is the background piece of the movie.

In the foreground, we see her dealing with Jenny, a piano prodigy doing time in jail for a murder she chose to go down for. Jenny is a constant explosion of anger and violence.

They share, despite great differences, a huge passion for music and also for life. Traude might have spent her life waiting to find someone as gifted as she was. Jenny is so much more. Traude wants Jenny to enter a national competition and convinces the prison's authorities that it'll be excellent for their public image. Jenny is given no choice in the matter.

While most people are wary of Traude and keep at a reasonable distance from her bluntness and verbal aggression, Jenny never hesitates to confront her and defy her. During the hours spent together at the piano, they develop a relationship of mutual respect and tentative trust, slowly opening up to each other and sharing strength and vulnerability.

This remarkable movie mixes humour and gritty reality, with a sense of truth and intelligence. The final scene, the four minutes promised by the title, is the flamboyant cherry crowning the cake.

The house-“share”

by Jenny

Do you want to see my latest poem? No?
Do you know what I think, feel or dream? No?
Do you know what my favourite colour is?
How I like my coffee? No?
Do you actually care? No?

Are you interested in listening to what I have to say?
Do you mind if you don't get all your own way?
Would you care if I were cold in the car if I asked so bold?
Do you know when it snows I can't feel my fingers or toes?
Do you see me as me? Does it really matter to thee?
NO?

Then you ask why we not partners be.
But you don't see me you really don't see.
But that's okay, I'm a second sister to you.
But don't ask for sex, I'm not a lover to you.

Just a sister to you.
Because you are blind and cannot see.
Someone has to take care of thee.
And love you, brother, unconditionally.
And love you so that you can walk free and be thee.

You do not need to pretend for me.
Love, or give or defend for me.
Just take what life offers and use it to the full.
And don't worry about the expected general rule.

Be happy and let me be.
Someone who needs to be needed by thee.
Someone who watches as the bird flies free.

Deep in the soul, below pain, below all the distractions of life, is a silence vast and grand — an infinite ocean of calm, which nothing can disturb; nature's own exceeding peace, which surpasses logical understanding . . .

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 cover the whole of the (reading) autism spectrum. That is, the concerns and joys of any subscriber on the spectrum can be printed, not just Asperger's.
- 2) Pieces that appear in *Asperger United* are credited using the author's first name only, unless the author requests something different. This is done to protect your privacy.
- 3) *Asperger United* administers the copyright of everything that appears and it does this on behalf of the authors.
- 4) *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.
- 5) If you move house, please inform *Asperger United* and include your old address as well as your new address.
- 6) Even if you've paid for the Royal Mail forwarding service (or another forwarding service if you live outside Great Britain and Northern Ireland), you still need to inform *Asperger United* that you have moved address.
- 7) If you want to unsubscribe, inform *Asperger United* and include your address.
- 8) If you want to resubscribe (or subscribe for the first time) inform *Asperger United* and include your postal address.
- 9) If you phone and leave a message on the machine, please speak slowly and clearly and spell uncommon words, as sometimes the line isn't very clear. Please give any phone number you leave twice for the same reason. Remember to give your postal address so that we can find you in our records.
- 10) The current edition of *AU* is available at www.autism.org.uk/aspergerunited
You need to scroll down to near the bottom of the page, where there is a link to the PDF.
- 11) You do not have to be a member of the NAS to subscribe to *Asperger United*.
- 12) Book reviews are the most popular thing in *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.
- 13) Although each issue is themed, submissions on any subject are welcome. Only some of the letters and articles in each issue will follow the theme. All submissions may be edited, especially for privacy, libel, and for fitting the space available.



Just too intense

by Susan

If you see me cry
On a bench in your area,
Don't try to ask me why
I am breaking my heart;
You won't understand how I can't cope
With so much intense stimulation —
Crowds of people are making me suffocate,
So many cars are making me feel sick.
I can't cope, take me out
Of this pollution-filled city
Into the comforting quiet countryside
Where I feel safe and loved.

Dear Goth,

I am writing to tell you that the amazing poem you printed in the most recent edition of *Asperger United* (68) called *Of another world* by the talented Penelope really struck a chord with me.

I had tears in my eyes when I read the poem and could relate to the sentiments as I have high-functioning autism. I have felt since I was a child that I don't belong to such a confusing, unforgiving and ununderstanding world. If I tried to join a drama group or keep-fit class in the past I always felt left out and not as accepted as everyone else. I love the phrase "Alone in a room full of people" — it is exactly how I felt.

I also enjoyed the poetical short essay called *Wrong planet syndrome* by another talented writer who's name is Sarah. I do get more confused by the human race and am becoming more sensitive to it. I have in sorts cut myself off from the all-pervading chaos. I like nothing better than to read historical or religious mysticism books, watch DVDs, eg. *The most haunted* or on a nice day I'll go countryside walking. I like to write about horrible injustices to the Government or councils also. I wish I could be in the *right* planet some day.

Keep up the good work on *AU*.

Yours sincerely,

Susan

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Telephone: 020 7903 3595

Fax: 020 7833 9666

Email: asp.utd@nas.org.uk

Website: www.autism.org.uk/aspergerunited



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