

# AU ASPERGER UNITED

Produced by and for people with autism and Asperger syndrome

No. 17 September 1998



## IN THIS ISSUE

Regular News | Letters to the Editor | Pen Pal Network |  
Features | Talent section including poems, drawings and  
Part Two of the short story by Thomas Simmons





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

*Asperger United* is produced by an editorial group consisting of:

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National Autistic Society

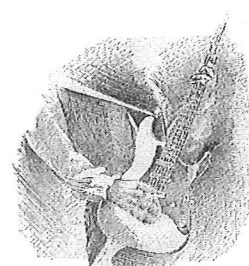
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c/o The National Autistic Society  
393 City Road  
London EC1V 1NG

**Fax:** 0171 833 9666

**For all enquiries about**  
*Asperger United*  
Telephone: 0171 903 3557



One of  
George's  
illustrations

**Thank you to George Cox who  
kindly produced the Pen Pal  
Network and Talent Scout  
illustrations.**



**Asperger United logos by  
Graeme Lawson.  
Thank you Graeme.**

## Dear Readers,

Welcome to the Summer edition of *Asperger United* and many thanks to all new subscribers who completed the form in the last edition and all who have contributed articles to this edition.

What say you, friends, to the following ideas:

- Any readers who have been on an unusual holiday are invited to describe their adventures.
- For the future particularly appropriate to those with acting and musical skills; do you think an Asperger Theatre company would be a good idea?
- To all with culinary ability; give us an idea of easy recipes which any

of us might be able to follow. Also, may we have contributions on gardening, tips on sewing, darning and other clothing repair. In fact almost any self-help ideas you can suggest.

- Have any of you had any experience of being a 'media star' (ie on radio, TV or in the press local or national), on account of your abilities and achievements? Please describe the event which gained you notice from the media and the experience of being in a radio or TV studio or a press interview. In this edition I describe a visit to Broadcasting House for an elimination round of *University*



### Challenge.

- Any of you making their mark on education are invited to write in stating their achievements.



That's all for now.

Your Editor,  
**John Joyce**



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## Seeking information for future editions

We are requesting articles on the following topics for future editions of *Asperger United*.

### Employment

- Getting, keeping, advancing in and changing jobs
- Losing employment, failing to get a job/new job
- Financial, social considerations stemming from unemployment

All readers with or without jobs may be able to contribute to this section.

### Relationships

- Marriage
- Divorce
- Sexual relationships (failures and successes!)
- Making relationships
- Girlfriends
- Boyfriends
- Health and sex issues

### Further Education

- A'Levels
- University courses
- College courses
- Problems with funding
- Problems at University





Tim Lee outside Buckingham Palace during his day at the reception, for Young Achievers, held at the Palace.

## A Visit to Buckingham Palace

Two years ago I obtained work experience in the post-room of MBNA Bank in Chester. After a year I was given a permanent position which I enjoy very much.

Last month a gold edged invitation arrived through our letter box inviting me to a reception for Young Achievers to be given by the Queen and Duke of Edinburgh at Buckingham Palace. As I have Asperger syndrome my parents wrote and asked the Palace if my mother could accompany me as my carer. My mother and I had a lovely evening in the state rooms at Buckingham Palace. I shook hands with the Queen and told her about my job. I also spoke to Prince

Charles and Prince Edward. There were a lot of famous people at the reception including TV stars, sports people and young MPs. My entry in the guest list said 'Timothy Lee - overcame a disability to obtain employment'.

Since then I have had my photo in the local paper with a short report on my trip to the Palace.

**Timothy Lee**

### Reply from the Editor

Thank you for your letter. A future edition of *Asperger United* will highlight all sides to employment: ie. getting a job, keeping it and advancing in it, how to obtain a job, changing jobs, how to handle failure if it arises and living without employment. Also we hope to look at financial and social considerations for those without employment in future editions of *Asperger United*.

## Congratulations to William Rice

William was appointed the Treasurer/Secretary of the Inverclyde Autistic Group at their meeting in June. The group is to be registered as an NAS Branch later this year and William will continue his role throughout this exciting time of change. (See William's letter on page 8).



## Useful Internet address

The following internet site has a section specifically for people with Asperger syndrome. This section is ONLY for those individuals who are on the autistic spectrum and provides a safe place to communicate and meet others. There are links to other pages for parents and professionals.

The address is:

<http://www.udel.edu/bkirby/asperger/support.html>

## A visit to Broadcasting House

Many readers may know from these pages in previous editions that your Editor is pursuing an Open University course currently at second level of French. This article describes an attempt by me to be selected for a team to represent the Open University in 'University Challenge'.

My first act at the end of 1996 was to write asking to be considered for a team. Early last year I was then sent a paper containing twenty questions and requesting answers from memory or personal knowledge, ie. not consulting any reference books. Many of the questions were on material which I do not readily remember like the name of the composer of Oscar-winning film music. Admittedly I did find some answers from reference works. However, I was selected to go forward to a further elimination heat at Broadcasting

House, an imposing building at the end of Regent Street. Even for those who were there for a short visit it was necessary to have a security pass. All of the candidates for teams representing the Open University, two Oxford Colleges, two London University colleges and one other were brought into a room.

This was the elimination studio and the procedure was just as it had been for me to reach there. However, on this day in May last year, all the questions in this test were taken from previous programmes of 'University Challenge'. I think my success rate was 11 out of 20 with the rest not being answered. I was not selected for the team, which proceeded to reach the Final, setting record scores twice, including the Semi-final, and boasted the oldest contestant in the show's history, a lady of 73.

I have since been invited to take part in the qualifying competition for this year's team but was not selected.

**John Joyce**



## Visit of Social Skills Group to Angela Browning MP at The House of Commons

Members of the Social Skills Group, which meets at the Maudsley Hospital, met Angela Browning at the House of Commons on Thursday 7 May 1998. We met Angela Browning in the Central Lobby and she took us down to one of the tea rooms, where, over sandwiches, cakes and tea, we discussed with Angela Browning issues connected with Asperger syndrome and high functioning autism.

Angela Browning pointed out there was no simple test to enable children to be screened for Asperger syndrome or autism. She thought The National Autistic Society should have a separate awareness week for Asperger syndrome. When it was suggested that it should not clash with World Aids Day, as it did last year, she pointed out that any week would clash with something. (She possibly ignored the exceptionally high profile of AIDS; I think Autism Awareness Week is moving in any case\*). It was pointed out that awareness can itself cause difficulties if it leads to stereotyping.

I pointed out that graduates with Asperger syndrome and autism or, for that matter, with other disabilities, have a lower earning capacity than those with a handicap. It is, therefore, unfair to expect disabled students to pay the same fees, especially when fees are effectively remitted for students with low parental income. A disability such as Asperger syndrome makes far more difference than parental income to future earning capacity. Angela Browning acknowledged all this but, sadly, was unable to offer any hope of special treatment for disabled students.

The need for proper work at proper rates of pay was mentioned.

Members of the group mentioned

contacts with authorities resulting in problems and anxieties. Technology enabling automatic form filling could help, as could care managers. Angela Browning was worried about proposed legislation which appeared to make it impossible to receive in-patient psychiatric care without being sectioned under the Mental Health Act.

We discussed support for those with Asperger syndrome or high functioning autism when parents are dead or no longer able to help. Action must be taken before the crisis comes. Independent living means different things to different

people. Parents need to learn how to help their children help themselves.

After tea, Angela Browning took us in two groups on to the terrace of the House of Commons. She also gave us tickets to the Strangers Gallery, where we watched the proceedings of the House of Commons. Thanks to Angela Browning and to all those who attended.

**\* Note from the Editor:** the next Autism Awareness will infact be taking place at the beginning of May 1998.

**Robin Oliver**

## End of the autistic line

With the mind of a child, aged 37, I wondered what I will do when my parents die. I suppose all families with autistic children must ask themselves this question from time to time. Children after all grow up, become stronger and more active, while parents by the nature of things must inevitably become less able to cope.

I was one of the lucky ones, able to respond to my parents help and benefit from the remedial education which gave me a life. Others however will always need care and attention throughout their lives, and in most cases long after their dads and moms are dead.

Even now, I too sometimes need help and tolerance by the community, so that I don't get kicked out of the local club while 'line dancing', (which I love) because I was uncoordinated, or told by the local university, 'we don't play this sort of music'. I do have feelings even if they can't be expressed and it is hard to defend myself against peoples' ignorance of autism. I can only say that I am doing my best and learning all the time, thanks mainly to fate.

If the teaching enables me to live normally, I will have made it.

Otherwise even though I am a concert pianist, a pilot and can write well, when my parents have gone, I too will go into care. 'It's life Jim, but not as we know it', but I hope because I can't talk properly, you don't put me somewhere too hidden from society.

**Mark Bishop**

### Reply from the Editor

What happens when our parents die?

This is a question often asked by people with Asperger syndrome and autism. Please send us in your thoughts about this. In the above letter Mark Bishop discussed his fear about the future – despite his obvious ability.

Perhaps we should take this opportunity to remind people of their rights as a person with Asperger syndrome or autism. Everyone has the right to live as 'normally' as they are able and are entitled to the help they need to do this. One must be strong enough to stand up for their rights and obtain help from the NAS or their local Autism Society in doing so.



Please do continue to send in articles which raise important issues and concerns.



This section deals with letters and correspondence from overseas. Please send all letters and correspondence to: *Asperger United*, c/o The National Autistic Society, 393 City Road, London EC1V 1NG, United Kingdom.

## A letter from the Nigerian Autistic Society

Dear *Asperger United*,

Thank you very much, John, for sending us a card for the Nigerian Autistic Society and wishing me a Happy Easter. Frankly, I cannot recall where I met you in Nigeria. Please kindly let me know who you are. I am beginning to feel that you could be of some assistance to us, by God's grace.

The Nigerian Autistic Society's needs are many. At present, we are trying to complete a pilot model classroom for autistic children. The next huddle is to furnish the classrooms with tables, chairs, cupboards and educational toys.

Hopefully, the Diplomatic Association at Abuja has responded positively to assist us with some furniture to be made locally through a carpenter.

We will be needing computers and some talking software to help improve communication for autistic children. We intend to use the English language for our autistic

children in Nigeria.

Our Corporate Vision for the next ten years 1998-2008 aims to:

- Provide services and general welfare for autistic children and adults
- Encourage partnerships and affiliations internationally
- Integrate and educate autistic children within a normal school environment using the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH).
- Help autistic children become more responsive to others as they learn to understand the world around them through specially trained teachers using structured programmes that emphasise individual instructions in order to lead autistic children to nearly normal lives.

Very truly yours,  
**H. V. Blankson**  
Executive Director  
The Nigerian Autistic Society

### *Reply from the Editor*

Thank you for your letter of 15 March which I recently received. I have not yet been to Nigeria nor do I recall having met you.

I have the addresses of many Autistic Societies on a list, published by The National Autistic Society, and this was the source of your Society's address.

My congratulations to your Society on its advances in treating autism and Asperger syndrome. It is my hope that, through publishing your letter in *Asperger United*, you

will receive either the material you need or the money required to buy it.

Perhaps English is the only suitable language in which to carry out instruction, even though it may also be necessary to translate some of the material into Ibo or Yoruba for some of your pupils because they may come from a non-English speaking background.

May God bless you, your Society and its clients.

## A letter from the Worldwide Autism Association in Switzerland

Dear *Asperger United*,

I send you a copy of *Bottlemail*, the newsletter of the organisation I am building up. I want to start the regular production in August 1998. The Autistic PenPal Club, now called the Worldwide Autism Association is an organisation which has the aim of organising penpalships between people with autistic spectrum disorders by publishing a penpal directory, explaining to people what autism is, organising international meetings and publishing *Bottlemail*. We are also working on an information brochure.

I have reached people in some European countries, the USA, and in Australia. I will give you more information about the project later.

Yours sincerely,  
**Patrick Frey**

### *Reply from the Editor:*

*Dear Patrick*

Thank you for your letter. I hope that by publishing your letter in *Asperger United* you get some response from our readers.

*Dear Readers*

*Bottlemail* has been sent to us but cannot be published in full. It resembles *Asperger United*.



## About my life by Antony Cresswell

*My name is Antony and I am 26 years old. I was born in Nottingham in the early 70s.*

My father left home when I was just two weeks old and my mother could not cope with me on her own. We both went to live with my grandparents and aunt.

My early memory is of my mum shouting, screaming and crying. She was on the verge of a nervous breakdown. My grandparents looked after my mum, my aunt and me. My aunt was also going through a bad patch and suffered with her nerves. It was an unstable childhood and due to my mother's mental and emotional problems I did not form the child and mother bond. I thought that my grandmother was my mum.

My mother eventually recovered and re-married and wanted me to live with them instead of my grandparents. I felt torn between my mum and my grandmother as both told me to live with them. I remember my grandmother pleading with me on her knees and, with a tear in her eye, she said "You are my life, I can't live without you". I realised that I must stay with my grandmother or be responsible for her death.

I attended mainstream school and found it hard to mix with other children. It was very difficult at Comprehensive school as I was bullied due to my difficulty in social interaction. My grandmother passed away at the time of my school exams and I went into denial. I failed all subjects due to bad timing and bullying.

Since school I have had a number of different jobs including being a gardener, caretaker, clerk, security guard and army medic. I had similar difficulties in employment and I was the victim of practical jokes and ridicule.

An area of my life that made me feel dejected was the fact that I did

not have a girlfriend and this made me, and still does make me, feel depressed. At the age of 19 I did meet a woman who was eight years older and autistic. I got married and we had a baby girl who I love and care for very much. The relationship was not a success

and it was making me ill and I decided to get divorced and live elsewhere. I found myself visiting my estranged wife and daughter every day because I had developed an abandonment fear from childhood. I found the fear of being alone unbearable and I also had to clean and cook for my estranged wife and daughter because of her level of autism.

We both then decided it would be more conventional for us to live together but have our own separate lives. I have had a few casual relationships and would prefer a more understanding lady friend for friendship and possible relationship. I would like a girlfriend with Asperger syndrome who may have been in, or still are in, a similar predicament. I would like to hear from ladies with Asperger syndrome who have, or who are married and may have, children. What are your experiences of and how do you cope with your children?

With my spare time I enjoy a pint or two down town and I enjoy studying Religion and Psychology. I like to keep fit and enjoy meditation and prayer and consider myself a bit of a mystic.

**At the age of 19 I did meet a woman who was eight years older and autistic. I got married and we had a baby girl who I love and care for very much.**

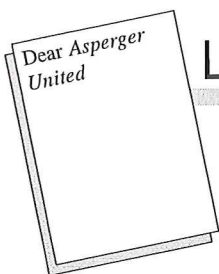
### Calling all feature writers

Please do send in articles about your experiences, hobbies and interests.

We are keen to include articles 'about your lives' in further editions of *Asperger United*.

Please send all articles to The Editor, *Asperger United*, c/o The National Autistic Society, 393 City Road, London EC1V 1NG.  
Fax 0171 833 9666.





## Letters to the Editor

Please send all letters to: **Asperger United, c/o The National Autistic Society,**  
393 City Road, London EC1V 1NG / Fax: 0171 833 9666.

### Are people with Asperger syndrome entitled to a bus pass?

Dear Asperger United,

Why do people with Asperger syndrome not get a bus pass?

Local transport companies offer travel permits to the over 60s, deaf, blind, people in wheelchairs etc. But why is there no travel permit for people with autism or Asperger syndrome?

I believe autistic people are just as disabled as deaf or blind people but sadly autistic and Asperger cases are overlooked when it comes to transport authorities.

I rang a member of our local transport company to ask why. He said that the reason why it's so overlooked is because he has never met anyone with autism go on to one of his buses.

I have a nephew who is autistic who is now six years old. I believe that he will have problems in the future and I also have Asperger syndrome as well.

Let's have free transport and a fair chance for our autistic friends and relatives. They deserve it.

Yours sincerely,  
**George Handley**

#### **Reply from the Editor**

Dear George,  
Thank you for your letter. As autism is in fact a disability people with autism or Asperger syndrome are entitled to free travel passes. Please see your local Citizen Advice Bureau for help with this. You may need a letter from your doctor to help you to overcome difficulties related to ignorance of this disorder.

Dear Asperger United,

Thank you for publishing my letter and the kind remarks regarding my speech (printed on page 14 of this edition).

In April I was featured in an article that appeared in my local paper, in which I spoke about my experiences of having Asperger syndrome and the daily battles I live with. The feedback that I received was very favourable.

My work with the NAS office in Glasgow is continuing. I often talk to parents and professionals, who visit the office, and hopefully enhance their understanding of autism and Asperger syndrome. I have also assisted with the training of some volunteer befrienders.

On 29th June, I was appointed Treasurer/Secretary of the NAS Inverclyde Branch. The Branch should be officially registered by the time of its next meeting on 31st August. I am excited by this new role and hope that the Branch will highlight the need for services that are appropriate for those of us who are autistic, especially regarding appropriate support for adults which is non-existent in Inverclyde; exacerbated by the fact that the Glasgow office know of only one other adult who has been diagnosed in the Inverclyde area which has a population of approximately 90,000.

I am also looking forward to working with other Branches. During the last four months, seven have been formed in Scotland. I hope that through working, both individually and collectively, we can achieve the establishment of both services and provision of support, that are urgently required.

Best wishes  
**William Rice**

### Proud to be different

Dear Asperger United,

So many letters printed outline the downside of Asperger syndrome. But it's not all bad. OK, there are times we struggle and feel terrible that we're not like the majority of people but everyone has something they don't like about life. I'm proud to be different, pleased to appreciate things people don't see even when they are pointed out to them. And like all the so-called normal people our lives have stages and some are more happy than others. I was very unhappy between ages 12 and 20 years and was in hospital, but now I have a council flat and look after my cats and dog myself. I haven't got a job because that would be too stressful but I get disability benefits and can take my dog out all day if I want to. I sometimes get anxiety or depression but I know it won't last for ever, even if the Asperger syndrome will.

I would like to say to Nicola Wills who wrote 'Judge not and he shall not be judged' that often people who see Asperger people as weird are pleased if we can tell them why we're different, and some think we're snobs because they don't think it's a physical problem in our brains.

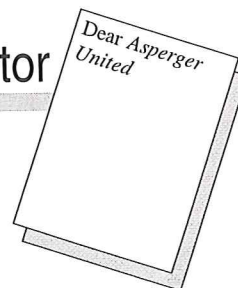
That's all.

Peace and harmony  
**Joanna Lavender**

#### **Reply from the Editor**

Thank you for your letter and for your response to Nicola's article.





## In reply to Nicola Wills' article, in Edition 16

I was really pleased when I read the feature 'Judge not and ye shall not be judged' by Nicola Wills in edition 16 of *Asperger United*. I was pleased because I realised that she had been through a similar life to me - which was comforting to know. I always used to think, before I found out that I had Asperger syndrome two years ago, that I was the only one who was suffering with what I've suffered with - now I realise I am not.

I too was shunted - even though nobody ever told me 'to get lost' to my face. I could tell by the way people ignored me that I wasn't liked and I quickly realised that any students who didn't just felt sorry for me. You know the old line, 'oh, it's all right, we'll be your friend'. I realise now that it doesn't work like that. Friendships are built, it's a two-way process and if anybody comes up to you and says that they probably feel sorry for you.

The problems throughout the whole five years in my secondary school are now plainly obvious to me (even though they weren't to me back then. The reason I had no friends, but just acquaintances, was because of my approach to people, ie. body language, eye contact etc, was completely different to everybody else's because of my Asperger syndrome. I also expected something that most ordinary people never expect - for other people to make the first move which never happens. Unless you are gobsmackingly gorgeous, which most people aren't, you have to make the first move. Finally, basically because of the impairment of Asperger syndrome, which all people with it have - the impairment

of two-way communication and interaction - how can you expect to make friends if you won't ask them about themselves, listen to them, help them and care for them etc. Something which I have only just learnt in the past year.

So, although I fully sympathise with Nicola Wills I realise that even though she couldn't help it because she, just like I, didn't know until years later that we have Asperger

syndrome. I know both of us have brought it (in a very small part) on ourselves. But on the other hand, I think she, just like Jasmine Lee O'Neill, is right when she says that society discriminates against things it doesn't understand and doesn't ask questions about different things (ie autistic minds). This really annoys me and is a sin of society.

**Tim Webster**

## In reply to the Survey on Sexual Behaviour, in Edition 15

*Dear Asperger United,*

I have recently received Editions 13, 14 and 15 of *Asperger United*. I have enjoyed reading the news, letters and note the intelligence behind the articles which makes me proud to be a person with Asperger syndrome.

I found the survey on sexual behaviour, relating to adults with autism, of particular interest and agree with the survey's five principal hypotheses. I would like a professional in this area to submit an article on sexual behaviour of the autistic for I feel that this is both a necessary and often neglected area of importance that society tends to sweep under the carpet. Sexual behaviour can be a bit of a delicate subject at the best of times and combined with a disability which can be another delicate subject it can make it even a taboo.

I strongly believe that all human beings have sexual urges that naturally predispose the individual to sexual advances and encounters and I believe a person with autism is no different. I feel that if for some reason or another the individuals need for

sexual companionship or the predisposition for reproduction is unsuccessful this may result in sexual frustration and even sexual deviant behaviour. This subject must be addressed for the welfare and sanity of mind of the person with autism who naturally wants a sexual relationship. I am also interested to know the statistics for a person with autism or Asperger syndrome to have a sexual relationship, for marriage and for having a child. Another subject loosely connected is the statistics for a child having autism and Asperger syndrome whose parents are autistic.

**Antony Cresswell**

### *Reply from the Editor*

Thank you for letter and for introducing the topic of sexual behaviour. We intend to discuss this subject in a future edition of our magazine.





## How to reply to a Pen Pal

Please do remember to let us know the full name (including the surname) of the person who your letter is for.

If you would like to reply to any of the letters or requests for contacts then please send your letter to: **Asperger United, c/o The National Autistic Society, 393 City Road, London EC1V 1NG.**

We will pass your letters on to the appropriate person. However, we cannot guarantee the person will reply as that is entirely their decision.

### **Antony Cresswell, Eastwood, Nottingham**

I am 26 years old and was diagnosed with Asperger syndrome just a few months ago. Although I went to a mainstream school I wish that I went to a special school due to my problems, but the school and my parents just thought I was a bit aloof. I had been given conflicting diagnoses in my early twenties and one psychiatrist said it was a personality disorder, another said it was manic depression and then said it was schizophrenia. I was even put on anti-psychotics - I felt very confused with all these conflicting diagnoses until finally a psychiatrist had an idea it was Asperger syndrome and a specialist confirmed his suspicions.

I have interests in psychology, psychiatry, criminology, religion and the occult and enjoy studying them. I like to keep fit and go down town for a couple of pints. I would like to hear from people with Asperger syndrome or autism with an interest in any of the above and any ladies who are also looking for a relationship.

### **Erica Dudzus, Ontario, Canada**

I am a Canadian student and am very interested in autism. Could you possibly post on the Noticeboard that I am interested in corresponding with people with autism/Asperger syndrome. I would like to get your opinions and attitudes towards the disorder, as well as get to know your different outlooks on life.

Thank you.

#### **Reply from the Editor**

Thank you for your letter. We are establishing contacts with North America and hope, eventually, to have a website on which all our news may be stored. Meanwhile, your letter has been printed in *Asperger United* in the hope that there will be a response from our readers.

### **Amber Roberts, Wrexham**

My name is Amber Roberts and I am 28 years old. I have a son who is 5 and autistic and I have Asperger syndrome. Would anybody like to write to me? I collect dolls - is anyone else interested in them? I like all types of dolls and repair them. It is very hard having my son and it is much harder having children than I thought.

Write to me if you like.





## About my life by Christopher Williams

*In this article I intend to write about my own personal experiences of living with the diagnosis of Asperger syndrome.*

I was finally diagnosed when I had attended therapy sessions at the Harper House Children's Service, who are based in Radlett, Hertfordshire, in May 1994. Everybody in the council system had known for quite some time what the cause of my difficulties were.

My medical problems could have related back to my own birth at the Stepping Hill Hospital in Stockport, Cheshire, in December 1976. It was discovered that my mother did not have a comfortable labour and had to have several injections before I was born because she did not have enough energy available to deliver me herself. I appeared to have problems relating to jaundice and I had a sign of breathing before I was born, and this could have been noticeable by a red mark on my cheeks which appeared at the time.

During the majority of my time at primary and secondary school it was discovered that I would not be able to make friends and felt like I would never be a part of a major peer group; I had felt totally isolated and left out. Then when I was at secondary I had been subjected to a lot of bullying, what with people ridiculing me and making me feel like as if I was one hell of a joke. I had afterwards felt totally suicidal when I had felt that nobody liked me or wanted to know me. I felt totally unimportant and unnecessary to have around. The latter part of my educational career was dogged by - teachers at school, the social workers to whom I was involved with at Haringey Social Services Department, the Specialist Careers Advisor from Haringey Education Department and the various medical professionals from the services to whom I had been referred to - all

placing quite a lot of pressure on me because they all felt that I had learning disabilities and that I was not becoming independent enough, and stating the fact that I was unready for entering any college of further education. I sometimes felt completely rejected and sometimes, even now, still do, if I would ever have a chance of getting a place in employment.

Problems relating to my physical well-being were discussed quite a lot during the course of my tenureship at White Hart Lane School in North London, but nothing was ever sorted out about devising a specialist Physical Education programme and putting such a programme into action. Referrals had been made by the school to my general practitioners based in Wood Green but unfortunately my general practitioners had felt that I should not be able to participate in any PE activity because of the fact that I would not be able to concentrate due to the distraction of other students who might cause quite a lot of accidents (eg knock me over).

I had found it difficult to cope in a class of Sixth Form students and so it was decided that visits to examine alternative educational placements, as well as an examination of my problems and difficulties, needed to allow my family members to come to a better understanding of them. Following several abortive attempts to make a diagnosis of these problems in the past couple of years prior to my final diagnosis of Asperger syndrome in May 1994 by the Harper House Children's Service in Radlett, Hertfordshire.

Two months beforehand, in March 1994, my social worker had applied to the Department of Social Security in order to enable me to have entitlements to Disability Living Allowance for the first time. I

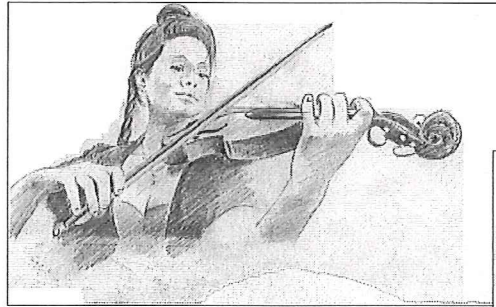
had experienced some terrible difficulties whilst I was still living with my own family at home in London. So, on 5th April 1995, I had finally left home and moved to rather inappropriate accommodation, which was a residential home for people with learning disabilities in Tottenham. I was supposed to have lived there for only three weeks but then it turned out that I would be living there for six whole months until a more suitable placement was found.

One of my own deepest regrets was having to tear up my old photographs of me when I was an infant and having to dispense with them in the dustbin or flash them down the lavatory; although I did this because I felt really upset due to the kind of life which I had personally been living up to this point. I had also felt some anger towards my mother whilst I was doing this.

During my first day at the residential home in Tottenham I did not sleep very well due to the fact that I had stayed up late that morning and hardly had any sleep at all. I had never felt so tired in all my life. I also felt rather uncomfortable with being surrounded by people with all kinds of learning disabilities. Again, I felt totally isolated and could not believe that there were absolutely no placements for people with Asperger syndrome in the Haringey Council area.

Out of the three residential placements which were suggested by Haringey Council Social Services Department I had chosen a placement in Great Harwood, Lancashire, by the name of Merlewood, which is a residential home owned by The National Autistic Society and I finally settled in on 22nd September 1995. I moved out of Merlewood and am now living in a two-person shared accommodation in Rishton which is still in Lancashire. I have never felt happier being so independent or having a life which is so full of bliss.





## Three poems by Antony Cresswell

### Take me down to Paradise City

Sensory deprivation with cataleptic  
rhythm is my den.  
Cold and hoary, weeping over the  
pilgrim of foreign desire.  
I the lone one. I the master of my  
own fate.  
I see without eyes that which is in  
your heart.  
Take a page from my book of life  
and read between the lines, for I am  
like a hidden thing, a secret of  
Solomon. Now my kin rest in peace  
and dwell in my words, the words of  
which will never die.

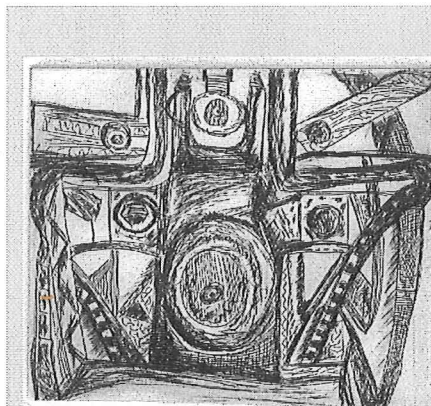


### Passive Passion

Tingling with hyper-awareness,  
estimating time and judging  
distance.  
Factors out of my control, delusion  
and false preconceptions.  
Make haste for thought and  
emotion, casting shadows on my  
horizon of hope.  
I am the piper of temptation, piper  
of thought and emotion.  
Like wine my taste betters with age,  
age is existence, existence is  
experience.  
Forever a slave to temptation, Satan  
rides high on my back.  
Like a kiss under the mistletoe the  
magic in me ignites desire.  
I desire thought possession, but  
control I do not have.

### Paranoia

I am a scarecrow in a frozen sea,  
the seagulls come and land on me.  
This world is a mass of solid  
obstruction, to it I do not belong.  
Like a square peg in a round hole, I  
just don't seem to fit.  
I see things slightly different so  
please condemn me for what I say  
or do.  
In life I lick honey of the razor's  
edge, bitter sweet, bitter sweet.



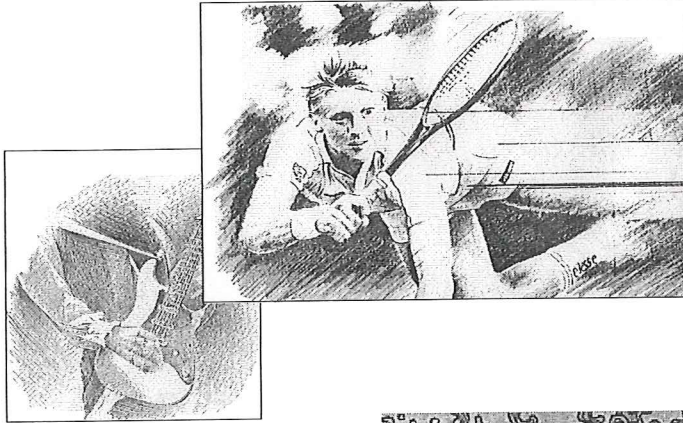
### Etchings by David Braunsberg, 1998



David Braunsberg, 1998

Please send all poems, short stories,  
drawings and paintings, (as well as  
Christmas card designs!), to The Editor,  
*Asperger United*, c/o The National Autistic  
Society, 393 City Road, London EC1V 1NG.  
Fax: 0171 833 9666.



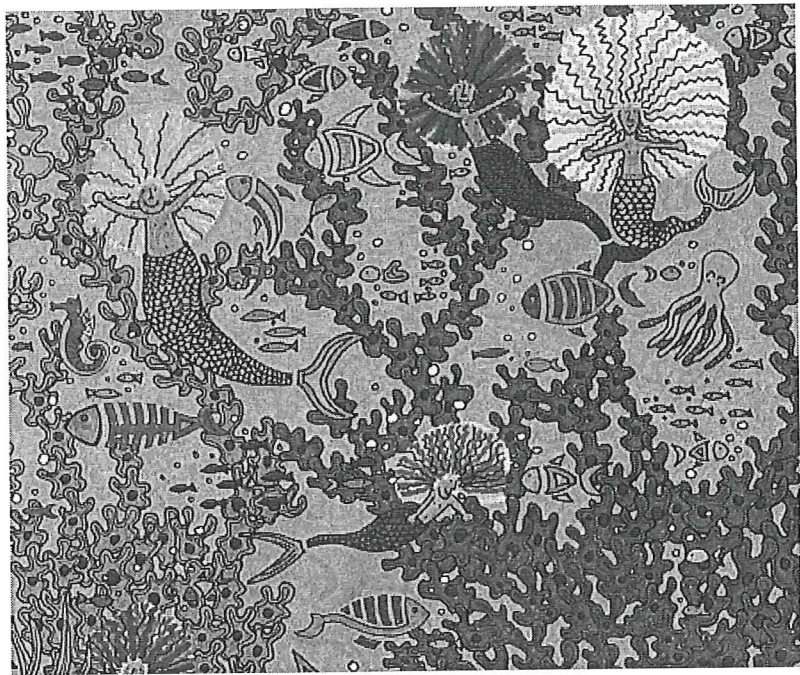


Illustrations by George Cox

## Design a Christmas card

Will all artists/budding artists please send in your ideas for our very own Christmas Card!

**We are waiting for your drawings to arrive.**



A close-up of *Fish* by Peter Myers, 23 April 1998

## Part two of the Short Story by Thomas Simmons

By the flickering candlelight, the necromancer sat by an ancient wooden desk, hunched over a large book. As he turned the yellowing pages, large clouds of dust billowed into the air, slowly settling on the bottles, jars, books, and other assorted clutter on the desk.

It was only a small room, with three of the four walls covered in selves of ancient, dusty books. Most of the room was filled with the desk, which was covered in all manner of strange items and apparatus. There was a large wooden door in the other wall, although it was rarely used; the necromancer spent most of his time here.

He slammed the huge book shut, scattering more dust around the room. He then reached across the desk and slowly, carefully, pulled a large silver bowl in front of him. It seemed to be full to the brim with crystal clear water, which scattered the candle-light across the walls.

The necromancer muttered a few arcane words, and the water turned black. On the surface of the water, vague shapes and colours could be seen. He mumbled something else, and the shapes began to get more detailed. Soon he could see a fire; in a forest clearing. Sitting around the fire were three men; two warriors and a wizard. They seemed to be talking.

Suddenly, the wizard stopped talking. He looked around, as if searching for something. He stopped. He appeared to be looking directly at the necromancer.

The necromancer gave a wry smile. So you know I'm watching, he thought. He snapped his fingers, and the image faded, and the water became clear once more. He slowly got to his feet, and shuffled off towards the door.

**Continued in the next edition of *Asperger United*.....**



## **A Speech** *by William Rice*

**The following speech was given by William Rice at the Renfrewshire autism and Asperger group conference on Saturday 6 December 1997 at the Tannahill Centre, Paisley.**

Good afternoon ladies & gentlemen. When I was diagnosed as having Asperger syndrome a year ago, it brought an overwhelming feeling of relief, together with a deep sense of pain at 25 lost years.

With the diagnosis came the promise of answers to a multitude of questions, and hope that with the correct emotional and practical support I would be able to have a life rather than a tortuous day to day, year after year struggle to simply survive. No friends, no job, no purpose, no hope. I went nowhere, I did nothing and when I did venture out I felt, like a visitor from another planet, unable to comprehend my inability to interact with anyone or to escape from my invisible but heartbreakingly real prison.

Desperate to be part of the world, but constantly rejected by employers and virtually everyone else. All the time asking why? What does everyone else know that I don't?

It is impossible to comprehend the isolation and despair that I felt, so much to give and unable to escape from my glass cage to give it. Self loathing is always a threat and on many occasions it overwhelmed me.

I started an employment training scheme last year before I was diagnosed. Hoping for some desperately needed social contact and left with my inability to interact socially glaringly exposed – yet again. As at school and college the work wasn't a problem. I left college with a Higher National Certificate in Business Administration – but as always, the social aspect caused me all kinds of

problems – wanting to communicate, to get to know others and not having any idea how. At least at college and on the I was spared the bullying that I had been subjected to at school. Bullying that left me in tears for hours every night, at the thought of the psychological hammering that I knew I had to endure each day. This was compounded on most occasions by the knowledge that the bullying was being led by someone whom I felt I had every reason to classify as my best friend. The trauma inflicted and the scars that have been left, simply cannot be imagined.

At the beginning I mentioned the relief I felt when I was diagnosed and it **was** a relief. Since the day I started school I had always been very much aware of being different and painfully conscious of this invisible barrier, whatever it might be, keeping me apart from everyone no matter how hard I tried to join in. Of course, there were thoughts of what might have been had I been diagnosed 5-10-15 years earlier, but I knew that I couldn't dwell on such thoughts. The diagnosis of Asperger syndrome was like being reborn. I was now going to clearly see the complete picture of my life, rather than one small distorted corner. I craved knowledge, I desperately wanted to finally understand me, I wanted my parents and those I know to understand me and the difficulties that I struggle against, every moment of every day of my life.

For the first two weeks I felt exhilarated with this newly found knowledge, but this feeling didn't last, and my rebirth began to feel like a death sentence. No hope, no purpose, no life. Just as before, but now with a label attached as added confirmation. My overwhelming sense of relief having evaporated, I was left to accept the reality of the diagnosis without this shield to protect me. The book *Autism & Asperger Syndrome* by Uta Frith, was extremely painful to read and yet so vital to my understanding of

autism, Asperger syndrome and me.

I began this year with renewed determination to make progress. I began attending the psychiatric day hospital in Greenock for social skills training. I was extremely apprehensive after my experience on the employment training scheme.

On that first morning I sat, looked at no one and said nothing. Not by choice, but because I had no idea about how to start a conversation. On a few occasions others attending the various groups tried to talk to me. I replied as briefly as possible, and the conversation ended. I didn't know how to maintain a conversation.

After two weeks of saying nothing, an opportunity arose at the discussion group. We were asked where we would like to be. Everyone else opted for a city or country. I chose a job, meeting and marrying someone special, and a family of my own. In effect, to be like everyone else and not different. It was the first time I had ever expressed such feelings to anyone outside of my parents or a professional.

With my Support Worker, Diana, I became aware of how to start and maintain conversations, both with those attending the Day Hospital and those I knew outside.

I began three conversations the following day and felt as though I'd climbed Mount Everest with a piano on my back. That's exactly how much of an effort it was for me. Immediately I began to feel the difference, and everyone began to notice it. Those I was attending the hospital with told me that they thought I was just quiet – in other words, by choice. I sighed. They were not the first to have this misconception about me.

I began going to the cinema – yet another monumental effort – to do something most people wouldn't give a passing thought to. I still go regularly, but I'm always very aware if I'm the only one there on my own. On some occasions I feel so uncomfortable because of this,



that I watch the film, constantly thinking about leaving. The same thing happens when I go to a pub - I only drink Iron-Bru by the way - even though I've been in the pub on numerous occasions and know some of the staff, on several occasions I have left within 10 minutes.

I knew I wasn't alone, and that there are others like myself, but I'm still felt like a visitor from another planet - so lonely and isolated. Meeting others like myself through the Asperger Social Club run by the Strathclyde Autistic Society, had a profound effect on me - equal to that of the diagnosis.

Finally after many months and so much effort, I was able to accept myself for the person I am. I am more at ease with myself, to the extent that I have been singing at Karaoke Evenings when I'm with one of the three friends I made whilst attending the hospital - none of which I could realistically dreamt of saying even eight months ago.

Having undertaken some voluntary work with the Strathclyde Autistic Society, I am currently working in the Admin Section of the Social Work Department in Greenock on a Rehabilitation Employment Programme. Everyone so far has been impressed with my work and how well I get on with my colleagues which is due to everyone in the office welcoming me as part of the team, and a conscious effort by myself to try and put into practice what I have learnt. As with all aspects of my life anxiety is a major factor, particularly regarding doing everything correctly.

Even though I have settled in well, interacting with my co-workers still presents difficulties - what to say, or not to say, and when.

Although I have made much progress, there are many aspects of my life that will always remain problem areas. Going out, even when I'm with someone, close proximity to others, establishing and maintaining friendships and relationships, adapting to change and dealing with setbacks are some

of the many problems I will always be faced with. It would be easy to conclude that as I have made substantial progress that I don't need any support. To do so is a failure, to recognise the magnitude of the problems I have mentioned, and the basic fact that autism and Asperger syndrome are life long disabilities.

The aim of any support network should be to enable those similar to myself to live as full a life as possible. Any degree of impairment in socialisation however subtle, has a devastating effect on the life of the individual. A phenomenal effort is required to make any progress, and it is all too easily undone by any setback. I've had more than my fair share of devastating setbacks. It is due to the practical and emotional support of my Support Network that I am able to stand before you today. I owe those concerned a limitless debt.

The progress I have made would have been impossible without the correct support - not just any support. Before I was diagnosed, any help I received failed due to a lack of knowledge and understanding of my difficulties. This is one of the reasons why it is vital that a diagnosis of autism or Asperger syndrome is made as early as possible. This will enable emotional and practical support to be given to those who are diagnosed and their families at the earliest opportunity. Problems in the medium and long term can be identified and a strategy implemented to plan for them. A 5 year old has the potential to make so much more progress than someone who is 25. A diagnosis made whilst someone is still in the primary education age group can help in tackling many problems including problems that are faced by those transferring from primary to secondary education.

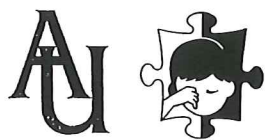
As years pass without a diagnosis, problems increase. Secondary education was for me a horrific nightmare. During this

period into adulthood, one's peers form intimate relationships, get married and have children. This increases the feeling still further of being quite literally, alienated. Employment can be extremely difficult to find and further education is a wasteland regarding provision of support for the autistic individual. Studying for a Higher National Certificate is hard work. It becomes even harder when you are all too aware of the barriers that exist between you and your fellow student. This further increases anxiety levels. Appropriate support for those with autism and Asperger syndrome would be of considerable benefit and may well encourage someone to enter further education who otherwise would not. It is essential that professionals listen to the person with autism and Asperger syndrome - whether or not they have been diagnosed - for they are the real experts living with the problems of being autistic every day of their lives.

All of us who are autistic have different needs and requirements which is the reason why it is so vital to listen to those who are autistic and their families.

Parents and professionals should recognise that as much as those of us who are autistic can learn from them, they too can learn so much from us. Working together, parents, professionals and the autistic person themselves, have the potential to improve the quality of life for the autistic individual. However this requires ongoing support that meets the specific needs of each individual. There is a passage in the book *Autism - The Invisible Children* which concludes: "Work with me, to build more bridges between us".

All of us here today can help build those bridges and a greater understanding of the difficulties that those with autism and Asperger syndrome live with throughout their lives, and the emotional and practical support that is required.



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