

AU ASPERGER UNITED

No. 15 February 1998



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syndrome
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Produced by and for people with autism and Asperger syndrome



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:

Editor John Joyce

Sub-editor Martin Coppola

Assisted by Pam Yates, The Maudsley Hospital's Home Based Team for Autistic Individuals

Additional Support from The National Autistic Society

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Dear Readers,

The editorial team wish you all a happy and prosperous New Year.

We also thank those of you who have contributed to the magazine during the past year and invite all our readers to submit examples of their skills and knowledge.

Special thanks are due to Robin Oliver who chaired our Conference in October and to all who have made their first contributions to this edition, particularly any who have reported or commented on the conference.

If any regional readers who could not attend the conference would like to have the opportunity of a such a meeting on home ground, maybe you can let us know and we will be able to give you ideas on subjects for discussion and for specialist speakers, obtaining speakers and sorting out an appropriate venue.

As you will see in this edition, we have received support from The Prime Minister (printed on page 4) and correspondence has been started with The Department of Health (a copy of my letter to Paul Boateng MP is printed on this page). We hope the Government will be able to give more substantial backing when they are able to spend more freely.

Your Editor



John Joyce

Mr Paul Boateng
House of Commons
London

Dear Mr Boateng

DISABILITIES-ASPERGER SYNDROME

I write as an Asperger person and editor of *Asperger United*, our in-house magazine to ask whether your department knows much about our disability, which is defined as a developmental disorder usually exhibiting itself to the public in what other people may consider unusual behaviour or, in some cases, extraordinary mental feats.

Should you, Mr Dobson, Ms Jowell or any member of your department be interested in becoming better informed about us and our disability, a social skills group is run at the Maudsley Hospital on the fourth Monday of each month except January and August, and you and any of your colleagues would be most welcome. This month we are holding our meeting on Monday the 15th because of the proximity of Christmas the following week.

We held a conference on 28 October, to which The Prime Minister was invited but apologised for being unable to attend. In my reply to Mr Blair's office, I offered to send our magazine there. I also asked if they might ask your department if you were interested in receiving such information. A reply from Number Ten suggested they would approach your department. If this has not happened you may reply directly to me.

I hope you do not consider this a cheeky approach.

Yours sincerely,



John Joyce

At the time of publication no reply from Mr Boateng had been received.

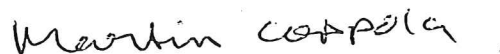
Welcome to our new Sub-editor

The Sub-editorship vacancy has now been filled! We welcome Martin Coppola as our new sub-editor. Martin's main responsibility will be the co-ordination and collection of material for the newsletter.

Hi Fellow Autistics,

May I introduce myself; you may not already be aware but I have recently been invited to join the *Asperger United* editorial team as sub-editor. My name is Martin Coppola, I

am 28 years old and I am looking forward to taking part in this venture and giving it my all. I hope that as well as giving, I will gain something from it and hope that it will be a long and successful partnership.



Martin Coppola

Feature The Conference for People with Autism and Asperger Syndrome

The PM supports Asperger United!

The letter which is printed opposite was received from The Prime Minister, Tony Blair, in response to a letter sent from the Editor, John Joyce. John wrote to The Prime Minister, informing him of the Conference for People with Autism and Asperger syndrome, which was held last October. We thank The Prime Minister for his response.

The Prime Minister
10 Downing Street

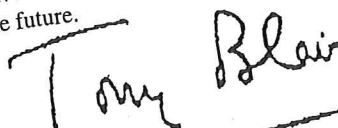
October 1997

I very much regret that I am unable to take part in your conference. I do hope the day will be a great success and that you find the programme enjoyable as well as informative.

It is very important that this conference has been arranged as one of a number of events marking the 750th anniversary of the Bethlem and Maudsley Hospital. The hospital has long been recognised as a centre of excellence. Most people will never have heard about Asperger syndrome, they have no idea of what is involved or of how it affects people's lives. At the Bethlem and Maudsley there are people who do understand and are seeking to help.

The Government's role is to provide the framework within which good quality services can be provided. We are committed to the principle that services should be tailored to give the right level of help and support to enable people to realise their potential and play their part in the society in which we all live. It is of course important that those who provide services should listen to and involve the people who use them. After all, those of you who have Asperger syndrome, have a unique perspective on what it is and what is needed to enable you to live your daily lives. The very fact that you are attending the conference shows that you are determined to do what you can both to yourselves and to help others with Asperger syndrome and Autism. You have a very valuable and unique contribution to make.

Today provides an opportunity to learn about yourselves and about each other and to think through some important issues. I hope it goes well and that you have a thoroughly enjoyable day. I wish you every success both now and in the future.

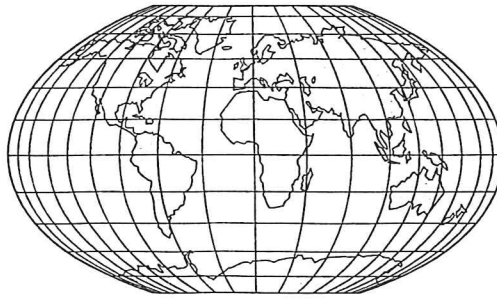


Tony Blair

Robin Oliver reports on the conference

The conference, which I chaired, was held on 28 October 1997 at the Institute of Psychiatry in London. After my opening, Dr Anthony Bailey of the Maudsley Hospital spoke about Asperger syndrome, which I was diagnosed as having two years ago. Pat Howlin, who diagnosed my condition, spoke on employment issues. I am among those supported at work by Prospects, The National Autistic Society's supported employment service. David Moat, of The Asperger Advisory Service, spoke on accommodation, community care assessments and support networks. Five of us then described our own experiences of various types of accommodation. In the afternoon, we had group discussions, all too short, on making and keeping relationships.

The conference helped us to feel that we mattered and could make a difference, and enabled us to meet others with Asperger syndrome and autism, and care workers. Members of a social skills group which I attend every month at the Maudsley Hospital acted as helpers; we wore a yellow badge. I thank them all, along with Pam Yates, the other organisers, the speakers and all who attended.



Autism International

This section deals with letters and correspondence from overseas.

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Christmas Greetings from around the world

I received a number of cards, which represent responses to my Christmas greetings to the world of autism/Asperger syndrome. Most of the replies are from Christmas 1997, apart from the one sent by APPDA, in Lisbon, which was sent a year ago. The countries represented are Chile, Russia, Croatia, Philippines, Czech Republic, Autisme-Europe in Brussels and Portugal. Some of these greetings seem to represent the hard work of our friends with autism. A letter from Eulalia Monge de Barros, of the Chilean Society, is also enclosed. Communications were also received from Ireland, Nigeria and Poland. Almost all the replies were in very good English, some of my greetings having been sent in varying qualities of other languages

from Irish to Polish.

Thank you to the following people for their thoughtful Christmas and New Year greetings:

Miroslavia Jelinkova, Autistic Club of Prague
Autism Society of India
Sergey Morozov, 'Dobro' Autism Society
Autisme-Europe
Paula Catrola Jacob, Portugal
Autism Society of Croatia.

John Joyce

.....

A letter from Chile

Dear John,

I owe you an apology. We received your very interesting note last May. I tried to find out about any young man with Asperger syndrome you could get in touch with, but there was no one known in our region. I will try to get in touch with different groups emerging in Chile, in the provinces, in the near future.

We are far behind in the matter of autism. In 1981, with a group of parents from Santiago, we founded the Asociacion Chilena de Padres y Amigos de los Autistas, *ASPAUT*. It promoted the organisation of groups through the country, to share what we knew and help create options for this population. In 1987 we started in Vina del Mar the first free educational programme for autistic children with just six children and volunteer teachers. *ASPAUT* has now another one on Santiago.

In 1995, with a group of teachers, a psychologist, a lawyer,

and other professionals, we founded *ANDALUE* - which in Mapudungun, the language spoken by our Native American Indians, means 'a place where the sun shines', or 'where the sun is born'. *ANDALUE* is a non-governmental organisation of development promoting the advancement of autistic people. We already have a school in Limache, a small town placed about an hour from Vina. It aims to provide education to autistic children from low income families living in the country side. We have now nine youngsters who come to school three mornings a week (that is all we can afford right now). Our plans for next year are to increase their number and have them from Monday to Friday, and to provide respite care with the help of a group of Swedish citizens interested in backing a project. There are many good ideas just waiting for financial backing.

This letter is continued on page 10.

Feature Autism, Asperger syndrome and Residential Options

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Wishful thinking on group homes

David Shamash writes

As a sufferer of Asperger syndrome, I attended The National Autistic Society's AGM in March 1997. The idea of a group home for people with Asperger syndrome was discussed there. If it means people sharing a house it is not likely to work out. People with Asperger syndrome are accused of not knowing what other people are thinking. Well, I think I know what those who think a group home for people with Asperger syndrome is a good idea are thinking, but I strongly disagree with them. They think because people have the same label they all have the same disability, and will get on well together. People mistakenly believe that people with Asperger syndrome have a great deal in common and their needs would be met in a group home solely reserved for people with Asperger syndrome. People have these mistaken ideas because they judge people by labels instead of as individuals.

No, the truth is that people with Asperger syndrome are very different from one another and on the contrary, what they have in common would make it very difficult for them to live communally. I have mixed with people with Asperger syndrome and what we all have obviously in common besides having at least an average IQ is difficulty in relating to other people. We have different interests and different characteristics, ie being talkative or taciturn, being quick or slow and forgetful. Some people with Asperger syndrome cannot budget, others can but are hopeless at finding their way around.

There would be difficulties in sharing the kitchen, washing machine and the television room, and the fact they have Asperger syndrome would not make it any easier to share the house. In fact, it would make it even harder because people with Asperger syndrome find sharing even harder than people who have not got Asperger syndrome.

If there is going to be a group home then there would have to be ground rules and it may be necessary to have all the

meals communally so there would be no problems sharing the kitchen while they cook their own food. That is not a good solution either because many people with Asperger syndrome like their independence and would probably break the rules openly as they are very honest. One way or another there would be clashes all the time.

After having lived in a group home for nearly three years, I am much happier in my own flat and I think the best solution for people with Asperger syndrome is to have their own flats with reliable support, so they do not have to share a house with people they are unlikely to get along with. Of course, it would be a good idea to have a club where they could mix socially if they want to.

'People have these mistaken ideas because they judge people by labels instead of as individuals.'

Note from the Editors:

Readers, we hope to continue our series of comments and information about residential and housing options for people with autism and Asperger syndrome. David Shamash has given insight into his experience of a group home and living in his own flat. If anyone else would like to write in giving us details of their particular hopes or experiences we would love to hear from you.

You and I

I am a resident. You reside.
I am admitted. You move in.
I am aggressive. You are assertive.
I have behaviour problems. You are rude.
I am noncompliant. You don't like being told what to do.
When I ask you out for dinner, it is an outing. When you ask someone it is a date.

I don't know how many people have read the progress notes written about me. I don't even know what is in there. You didn't speak to your best friend for a month after they read your journal.

I make mistakes during my check-writing program. Someday I might get a bank account.
You forgot to record some withdrawals from your account. The bank called to remind you.

I wanted to talk to the nice-looking person behind us at the grocery store. I was told that it was inappropriate to talk to strangers. You met your spouse in the produce department. They couldn't find the bean sprouts.

I celebrated my birthday yesterday with 5 other residents and 2 staff members. I hope my family sends a card. Your family threw you a surprise party. Your brother couldn't make it from out of state. It sounded wonderful.

My case manager sends a report every month to my guardian. It says everything I did wrong and something I did right. You are still mad at your sister for calling your mom after you got that speeding ticket.

I am on a special diet because I am 5 pounds over my ideal body weight. Your doctor gave up telling you.

I am learning household skills. You hate housework.
I am learning leisure skills. Your shirt says you are a 'couch potato'.

After I do my budget program tonight, I might get to go to McDonalds if I have enough money. You were glad that the new French restaurant took your charge card.

My case manager, psychologist, R.N., occupational therapist, physical therapist, nutritionist and house staff set goals for me for the next year. You haven't decide what you want out of life.

Someday I will be discharged - maybe. You will move onward and upward.

This poem was written by someone at Lutheran Social Services, Midland, USA.

**We are keen to include your
feature articles in *Asperger
United*.
Please do continue to send
them in to us.**

If you would like to submit a feature article please send it to:

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

or fax it to us on 0171 833 9666

**Please continue to send in
news, poems, short stories
and other articles to us.**

Letters to the Editor

.....

To all my friends and helpers that I've known in life.

My first thoughts when I was growing up are of when I knew that one day I would be an adult and I could lead a free life like I knew I could lead right now while I am living at Elmsmead.

Next my thoughts are of the food that we eat and what enjoyment I can get while eating that food. Of course, we all need to eat but I like too many sweet things unfortunately.

When I was first told that I had to stay at Wellington Road (it didn't have a name), because of my Grandmother recovering from a car accident, (not at Wellington Road, but in Bury St Edmunds), I was shattered. I stayed there for two weeks and then went back to my school in Devon. Two months after, I went back to my school and had a 'School Social Worker' come to say I had a place offered in Elmsmead. I looked forward to what is to be this next, adulthood life living in Elmsmead and I am most grateful to Bev and Steve for their kindness towards me.

There have been many, too many good times here, but also some sad and angry times. However, we get over those upsets and when I say too many good times I don't mean it wrongly - I mean it is good to have too many good times. As a young 'Head of Residents', I don't want to leave this house *ever!!*

It also amazes me how quickly time has gone! I still remember when Sam W our member of staff had her son, Jake, three years ago now.

I must go now but I will write again soon.

Love from Samantha Hope.

●

Another letter from Samantha!

Dear Asperger United,

My name is Samantha Hope. I like living in Taunton and it

Please send any Letters to the Editor to:

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London EC1V 1NE**

Fax 0171 833 9666

is very much a home here. I also like going to the pub and I have a lovely Peach bedroom with a lovely four poster bed.

Here is a photo of me at school when I went to Broomhayes School in North Devon, which used to be in Westward Ho! when I was there, but is now in Bideford. I have blue eyes and blonde hair.

Samantha Hope.

Reply from the Editors:

Thank you for your letters Samantha. I am pleased to hear that you are enjoying Elmsmead. Perhaps you can

send us some more information about Elmsmead to include as a feature in a future Residential Options section. Also, thanks for the great photograph. Sorry we can't publish the photograph (it would not show up very well in black and white!)

●

Dear Asperger United,

Would you let me know who to contact in the NAS to ask if they might be interested in using any of my Duck and Goose paintings for postcards or posters as I have recently started to paint some more. I can let you have photos of them if you let me know. I have a gallery that are interested in making some prints.

Leon Powell

Reply from the Editors:

Thank you for your letter Leon. I do hope that the gallery you mention make prints out of your photographs. Judging by the photographs we have already seen, your work is excellent and certainly deserves a wider audience!

If any of our readers are interested in seeing or receiving a sample of Leon's work, perhaps they could write to him c/o Asperger United.

PEN PALS

If you would like to reply to any of the letters or requests for contacts then please write to:

Asperger United, c/o The National Autistic Society, 393 City Road,
London EC1V 1NE.

We will pass your letters on to the appropriate person.

From Amy Prior

My name is Amy Prior and I am twenty years old. I go to William Morris College in Gloucestershire. I would love to have a boyfriend in the holidays and also to write to. I am enclosing a photograph of myself. I hope to hear from you soon.

Reply from the Editors:

Sorry Amy, we can't publish photographs.

Stephen McCarthy, Romford, Essex

My name is Stephen. I'm an intelligent, good looking 30 year old. I would like to meet people, male or female, who, like me, have the special ability Asperger. I have my own flat and have varied interests including religion and music. I live near Romford, Essex, but I would be interested in hearing from anyone anywhere.

Nigel Wood, Nr Oswestry, Shropshire

I would like some Manx pen-pals, who are autistic and have Asperger syndrome. I am 25 years of age and am interested in music. Please reply soon.

Caroline Aiken, Hartlepool

My name is Caroline Aiken and I am 32 years old. I was diagnosed as having Asperger syndrome last year and would like to hear from others with Asperger syndrome. At the moment I am a secretary for a local support group for the parents and carers of children with autism. My interests include listening to music, horse-riding, reading and science. I'd like anyone to write to me, no matter what your interests are, and I'll answer all letters.

Note from the Editors:

We hold a list of people in the United Kingdom, other parts of Europe and the world, who would like a pen pal. If you are interested in having a pen pal please write in and let us know.

Talent Spotting

Congratulations!

Congratulations to Therese J. on gaining her PhD at Cambridge University. Therese we would love to publish your paper in this newsletter if you are happy for us to do this!

Note from the Editors: Please write to us letting us know of any good news on personal achievements that you would like published here.

Colour by Derek Dodd

The world is full of colour
It is Autumn once again
And leaves of golden on crimson
Are lying in the lane

There are brown and yellow acorns
Berries and scarlet hues
Yellow pears and brambles
Where coloured pheasants run

Yellow, blue and orange
Russet, rose and red
A gaily coloured pageant
An Autumn flower bed.

Note from the Editors:

We would like to thank Derek Dodd for the above poem which we all think is excellent.

Autism International

A letter from Chile *continued from page 5*

As you see, we have no such thing right now as *Asperger United*, maybe because the children we attend are severely handicapped. I'm sure there may be a few as clever and able as you, but they are not organised and probably have no diagnosis yet. We have no publication of our own, that is another dream for the future. Could you help us with your experience?

It's great to know all you have done and your plans for the future. You are certainly a model for youngsters all over the world and a source of inspiration and hope for their families.

I would feel very proud if you could go on writing to us. I'm getting old now but very active. My youngest girl who is 22 years old this year, is severely autistic and has no language. She tells me what she wants by showing an object related to

a certain activity, such as the car keys, or a dish, or a bottle of Coca-Cola and a glass, but there is so much she would like to communicate but is unable to.

Vina del Mar is a city by the Pacific Ocean. There used to be many gardens around but now they have been replaced by tall buildings to accommodate visitors from Santiago, the capital city, and from other countries, especially in the summer.

I hope you can understand my English. Your Spanish is certainly great.

From Eulalia Monge de Barros, Chile.

In tribute to Marc Segar

The Editorial team of *Asperger United* were greatly saddened by the death of Marc Segar, shortly before Christmas. Many of you may have known or been aware of Marc, who himself had Asperger syndrome, through his work in raising awareness, the articles he wrote for *Asperger United* and the public talks he gave about Asperger syndrome. In the past, *Asperger United* has printed extracts from Marc's booklet, *A guide to coping specifically for people with Asperger syndrome*.

The booklet is now available from The Early Years Centre, 272 Longdale Lane, Ravenshead, Notts NG15 9AH, priced at £4.00 + p&p, with the proceeds going towards a memorial fund set up in Marc's name.

Marc will be sadly missed by all those who knew him.



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