

Produced by and for people with Asperger syndrome

# Asperger *united*

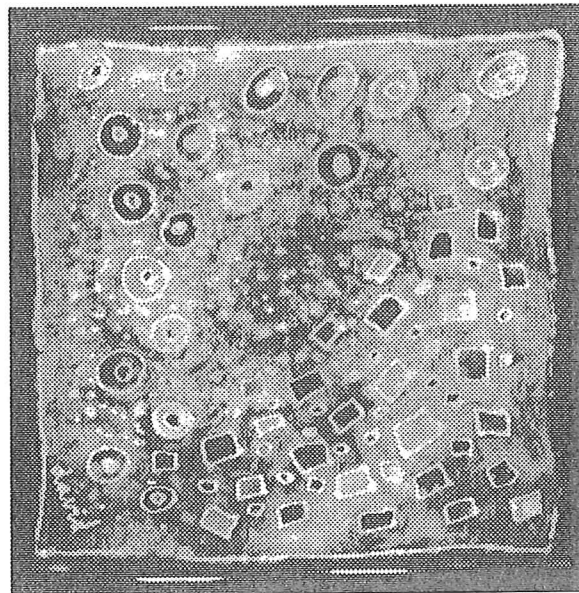
Edition 25 New Year 2001

## Making my talent work for me

**A**s a young child I had severe autism. At the age of four I could not talk, understand language or interact socially. At home I was a nightmare! However I was lucky enough to attend the Sybil Elgar School and from there I went on to normal schooling.

I was accepted at Hampstead School in Cricklewood – reluctantly because they had no experience of children with autism. Fortunately the deputy head mistress here was very able and sympathetic and if I was teased or bullied I would go to her. I was in a class with children of my own age and began to develop my art and interest in batik.

After school I took a three-year course in Furnishing Design and Textiles at the London College of Furnishing. I then started weaving tapestries and experimented with new textile techniques at art colleges in the USA and Canada. I also learnt to paint on silk. I have sold my work in several galleries and through an organisation which promotes craftwork produced by disabled people.



In 1997 Prospects arranged a placement for me in the etching department of the Architectural Association School in London. I worked part-time preparing materials for students. I also learnt etching techniques and was encouraged to produce my own work. My inspiration came from stored mental images of buildings and natural forms.

Unfortunately this work placement ended after seven months when the teacher I assisted returned to his native Hungary.

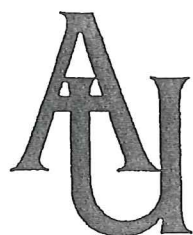
For the past two years I have attended a print-making course to develop my use of coloured inks.

Apart from etchings I also make useful silk objects such as scarves and evening bags.

Finally, a few words about two of my designs.

The first picture, painted on pale mauve silk, illustrates my feelings when I am under pressure. The mass of shapes reminds me of times when my mind cannot concentrate on one particular thing but spins off into different directions.

Continued on page 12 (back page)



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

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

**Editor** John Joyce

**Additional support from** The National Autistic Society's Publications Department

**Please send all correspondence and subscription requests to**

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London EC1V 1NG.  
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**For enquiries about *Asperger United***

Tel: 020 7903 3543  
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Email: [asp.utd@nas.org.uk](mailto:asp.utd@nas.org.uk)

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

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

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

Welcome to our 25th edition! Hope you all enjoyed the previous issue and those who were at the Maudsley conference found something to interest them.

I hope those who were unable to come will forgive me if I use my editorial to thank all contributors to the conference.

Don't worry if you gave me something - we're going to carry on printing work from this conference in future issues of AU. In fact, we've got so much that I've had to edit some of the pieces here. My apologies but it's the only way to give everyone their say.

I have been on two trips since October, to Dublin and Las Vegas in America.

I spent a weekend in Dublin for a conference organised by the Central Committee of the Legion of Mary, a Church body to which I belong.

Here is an interesting story from this conference.

A group of Legionaries in Glasgow received a strange request. Our organisation has its 'weapon' which kills nobody. It is a medal called the Miraculous Medal, first struck in Paris in 1830 at the request of St Catherine Laboure who received the design from the Virgin Mary.

The strange request came from the Master of a local Orange Lodge. The man asked for a medal for his dying child. This is strange because the medal is a Roman Catholic symbol and the request had come from the Orange Order which is a traditionally anti-Catholic body.

My thanks to Cathy Mercer of the NAS for becoming my guide from that agency to all contributors and readers.

May I now take the opportunity to wish you all the compliments of the Season - Happy New Year!

Le redacteur - your friend

John Joyce

## Contributions needed for the next edition of Asperger United

*Asperger United* is published quarterly in January, April, July and October. Please send in any stories, articles, poems, pen pal requests and letters.

### Contribute to your newsletter

We are always looking for new ideas and stories to fill the pages of the newsletter. We would like to hear any news, receive articles about yourselves, see your artwork and read your poems and short stories. If you can email us your articles we would be very grateful

**Send all contributions to:**  
**Asperger United**  
 c/o Publications Department  
 The National Autistic Society  
 393 City Road  
 London EC1V 1NG.  
 Fax: 020 7903 3767  
 Email: asp.utd@nas.org.uk

Deadline for contributions for the next issue - 1st March 2001.

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## Nicky's fight for proper schooling

Nicky Raithby, from Nottinghamshire, lives with his grandparents, brother Matt and dog Emma. He has just finished his first year at a mainstream secondary school. Here Nicky outlines the problems and successes of his schooling.

At infant school Nicky coped very well as the teacher understood his condition, but junior school was a very different.

"Teachers don't always understand the condition and that makes my life very difficult. I feel like a piece of rubbish that has been tossed out of a car window because it's not wanted. I've been to three schools so far. I wanted to make friends but people just ignored me or carried on teasing me. I thought that nobody liked me. I started to get into trouble for things I couldn't help doing. In spelling tests I would write words down in the order that I learned them. The teacher would give me nothing, even though I had got them right but in the wrong order. I started fighting and the school called in somebody to talk to me. She was a teacher to help children with behavioural problems."

Things improved but the bullying went on so Nicky was moved to a new school with a new teacher. Here Nicky was happy until his teacher left.

"I felt angry, sad, lost and abandoned. Someone else came but it wasn't the same. During the last year in primary school my mum and dad died. I felt like a candle had been blown out. A giant chunk of my life was missing and I had nobody to help at all."

The move to secondary school was particularly difficult for Nicky.

"There were a lot more people and it took me a long time to work out where I was going. Break times are meant to be a time of rest but to me it was a battlefield."

Last December Nicky went to a tribunal. Because of this his classroom help was changed and he was taken off contact sports. There were no alternative games lessons so Nicky was made to pick litter.

"I wanted to tell them to shut up but that would have just given them pleasure. In the summer term we did athletics and I joined in. I won the long jump at sports day and became the year seven long jump champion. That made me real proud because my whole class was depending on me."

At the end of his second year Nicky is exhausted with the changes he has encountered but remains positive.

I'm proud of  
“ having  
autism ”

"I go to a mainstream school and teachers don't always understand me. I try to cope by thinking of the good things in my life. I belong to a model railway club. I love going because it takes my mind off all the things that are stressful for me. I am now making train pictures on the computer and framing them. I also enjoy writing and poetry. I can write down my feelings through letters and poetry. I'm proud of having autism. Some people don't understand and that makes me feel very angry because they listen and don't take it in. If they had taken it in, they could help others to cope with life and not feel so insecure."

*Thank you, Nicky.*

*There are lessons here for all of us.*

*John Joyce*

*Editor*



## BBC radio needs you!

**A**re you passionate about Radio Drama?

The BBC are seeking fresh new talent for the airwaves.

The *Exchange* is looking for new writers with disabilities, including Asperger syndrome, who would like to partake in a series of introductory radio writing skills workshops. Working closely with experienced writers and BBC producers, participants will exchange ideas and explore writing for the radio.

If you think this is for you, please send the following:

- One short scene of radio drama for two actors taking the title 'Adrenalin Rush' (or a subject of your choice) as your spring board

- Your C.V.

- A stamped addressed envelope.

Send to: Zoë Marchant  
BBC Radio Drama  
Room 6065  
Broadcasting House  
Portland Place  
London W1A 1AA

Closing date for accepting scripts: Friday 2nd February 2001

If you have any queries please ring  
Zoë Marchant on 0207 765 3847  
or email her on [zoe.marchant@bbc.co.uk](mailto:zoe.marchant@bbc.co.uk)  
or write to her at the address above.

## Your Life Story

**W**e are a team of psychologists and psychology research students working in Austria and England.

We are interested in you and your Life Story. At this point not many studies have directly addressed adults with Asperger syndrome themselves to give them a chance to give their own point of view and reflection of their life experiences.

We would like to learn how you got along in life, how things were for you when you were a child, an adolescent and how things are for you today. We would also be interested in finding out about your special abilities and interests as well as the difficulties you may have encountered in your life and how you overcame them.

Similarly, we would be interested in talking to parents and partners of adults with Asperger syndrome and high functioning autism. Our goal is to find out about their personal view of the development and life of their child or partner.

In order to do this we invite interested persons to take part in an interview. This will take about 2-3 hours. Home visits or other arrangements - e.g. interviews over the telephone, questionnaires - are possible at a time to suit you. We re-imburse travel costs.

Participants should be between 20 and 60 years of age and have a diagnosis of Asperger's syndrome or high functioning autism. Parents and partners are more than welcome to contact the same email address or phone number to arrange meetings.

If you are interested in taking part in the study - or know of individuals who might be interested - please contact me as soon as possible. Thank you for your interest!

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London SE5 8AF  
Telephone: 020 7848 0038  
E mail: [K.Hippler@iop.kcl.ac.uk](mailto:K.Hippler@iop.kcl.ac.uk)



### Asperger syndrome as seen on TV

*Dear Asperger United,*

I was very pleased to see a letter from Richard Briand in the autumn edition of *Asperger United* in reply to my letter about a character from an episode in spring 2000 of *Holby City* who had Asperger syndrome. I have cable television at home and I hope that the episode of *Taggart* that Richard talked about will be soon be shown on cable television.

I noticed that he also went into great detail about people who have 'appeared' to have Asperger syndrome on television. Perhaps Richard might be interested in looking at my website 'Asperger syndrome - from the Horse's Mouth.' This looks at Asperger syndrome and autism from my personal point of view.

On the front page of the website is a top ten list of celebrities who may have Asperger syndrome but were never diagnosed. These are mostly comedy characters to add humour to the subject.

On page four of my website there is a more detailed serious look at the portrayal of people with Asperger syndrome and autism and also a look at recent television programmes that have covered the subject of autism. On the same page is an article about something that I found offensive in a recent television programme.

My website address is:  
[www.webspawner.com/users/asperger](http://www.webspawner.com/users/asperger). You can also go to  
[www.webspawner.com/users/asperger/pagefour.html](http://www.webspawner.com/users/asperger/pagefour.html).

I was going to write to give my website address anyway, but after seeing the letter, I decided to kill two birds with one stone and do this!

Yours sincerely

George Handley

### The Leicester Social Group

*Dear John Joyce,*

I find making friends hard as I have Asperger syndrome so the Leicester Social Group I go to is wonderful!

We do a range of activities such as

- Pool – which I'm good at
- Going to pubs and restaurants
- Discussions
- Lots of music!

I have made a lot more friends since joining the group. I think that many people with Asperger syndrome are like me and find doing and saying the right thing hard. So I say to readers – a local AS support group is fabulous!

Heidi Whitmore, Leicester

*Thank you, Heidi. It's good to know that Leicester has a social group for people with Asperger syndrome. I hope to visit Leicester again and perhaps see the group at work.*

*Best wishes - John Joyce*

*Dear John,*

I was pleased to receive my first copy of *Asperger United* and really enjoyed reading it.

Are there any people with AS in the Leatherhead area who would like to get together and set up an informal group?

I'd like to meet up with people with similar problems and perhaps arrange some social activities.

Please get in touch with me via NAS Publications!

Alex



## How to reply to Pen Pals

- To contact a penpal please send your letter to Asperger United, c/o The National Autistic Society, 393 City Road, London EC1V 1NG.
- Please remember to let us have the full name (including surname) of the person who the letter is for.
- We will pass your letter on to the person whom you wish to contact. However we cannot guarantee that the person will reply - that is entirely their decision..

### Rain and Traffic - a poem

It's raining -  
Icy particles shattering all around.  
There's a two mile tailback -  
Tyres bruising the concrete ground.

Sports cars -  
Those streamlined creatures  
that grace the road.  
My Mum's Metro -  
Sluggish and battered  
like a metal toad.

Ominous clouds  
Stealthily moving in  
Across the bleeding sky.  
The whole world's in a comedown -  
Even the tankers have  
Their own reason to sigh.

As if nothing  
And no one  
Has ever known what love is.

And the rain is not cleansing  
And the fire is not soothing  
And the breeze is not liberating  
And the traffic is not moving.

Anita

Colchester

### Welshman seeks penpals!

I am a 17 year old eccentric  
Welshman with the nickname Nook.

I have Asperger syndrome and long  
to meet somebody who thinks like  
me.

My main interest is rock music and  
I'm a big fan of the groups Kiss and  
Metallica.

Other interests include:

- pro-wrestling
- maths
- crosswords
- my Christian faith
- sprint running.

I look forward to hearing from you!

### Chris from Reading

I'm 29 and would like to hear from  
young ladies in the Reading area of my  
age.

I've got a degree in genetics and work  
for Royal Mail. My hobbies are: films,  
reading - especially science fiction -  
music, tv and computers.

I promise to answer all letters!

### Advice wanted!

Alan lives in Staffordshire in his own  
flat but originally hails from Brighton. He  
misses the seaside and his friends and  
would like to move back. He'd like to  
carry on living independently.

Alan wants to hear from anyone who's  
moved back to their roots after a while  
away - especially if they've moved to a  
new address and not to their original  
home.

Write to Alan with your experiences!





# On being ordinary - readers' responses

*In the autumn issue of Asperger United Maria Theophanous wrote an article which touched a nerve in many readers. Maria felt that there was too much stress in Asperger United on people who were doing brilliantly - she felt she had to speak out for the ordinary people with Asperger syndrome who struggle along from day to day. Here are some reader replies.*

## Dave's response

**A**fter reading 'On being ordinary' I felt a comment or two from me was needed.

I am 29 and was diagnosed with Asperger syndrome two years ago. I had spent most of my life until then knowing I was different but not quite knowing how. Life was very frustrating for me even as a child. I was afraid of going out and joining in with others and was a loner.

As an adult I went on college courses or schemes and jumped from job to job. I was successful in all the jobs I had but dealing with people around me caused me problems. I did everything I was told but I tended to be taken advantage of and even bullied.

Having a diagnosis answered all my questions and I felt better knowing that I wasn't just weak or lazy.

I have been very fortunate in that an Asperger project was set up for Northamptonshire at the time I had my diagnosis and I have benefitted so much from that. Claire Leadbeater the

project leader visits me and has helped me in lots of ways. The Asperger project also runs group days/evenings out every month and I get to meet other Asperger people. So I am very grateful to NAS and the Asperger project.

Thank God for AS because I still have a childlike innocence about me. When I was at university I was in with the in crowd but I found I didn't like their way of life. I was afraid of people but I'm not anymore. In fact I'm finding out I have a lot to offer people. I still suffer exhaustion which for some reason has got worse as I've got older but in a lot of other ways I've improved.

I would say to people like Maria: don't give up hope, seek Asperger groups if possible and do everything you can within your means and remember that you have something to offer people.

There's so much to say and I will give some of my coping strategies.

Here's a useful list...

✦ avoid newspapers - very cynical negative evil things.

✦ avoid violent and lustful films. They will influence you to feel this way.

✦ fill your life with as many positive things as you can find. Watch good films and read good books.

✦ Find a hobby. Some colleges run

adult day courses in pottery/yoga etc and they're cheap or even free if you claim benefits.

✦ Music makes a big difference in how I feel. I think it's worth avoiding disturbing music that is negative and depressing. I buy Christian music these days - Delirious are my favourite group!

✦ If not working find voluntary work.

✦ Keep clear of computer games.

✦ Exercise is important. I dread public places but you will find that during the week or early mornings at weekends swimming pools and gyms are quiet. Some gyms offer people on benefits low entrance fee. You can even buy home equipment to use.

✦ Cinema and theatre can be fun. I love these but unfortunately they don't exist in my part of the world!

✦ If you don't have an Asperger group in your area try talking to someone about starting one! We go to pub quizzes, Alton Towers, cinema and much more. You will also find that some people with Asperger syndrome do drive so you can get a lift.

All the best - Dave Moran

*Thank you, Dave. This is an extremely important paper.*

*John Joyce*

## Sheila from Ireland replies

## How I built my own Asperger Website

**I**t has taken me weeks to put the letter together to help answer Maria T's article 'On Being Ordinary.'

Perhaps being positive can be, for some of us, just another aspect of 'pretending to be normal?' Liane Willey in her book of that name gives us the answer: don't!

Yes, Maria, there are other life-long strugglers and changing the habits of a life-time isn't easy. I think one has to find a new way of seeing things – especially oneself.

Like John I often turn to the One who knows us better than we know ourselves – and likes us!

I'd strongly recommend a book I stumbled upon in a time of great crisis, which continues to inspire me: *Simply Sane* by Gerald May. It's just that – down-to-earth simplicity and sanity.

A very happy new year to everyone

Sile Murphy - Irish spelling for Sheila!

Co. Dublin - Ireland

**I** never thought I could do it!!

I first became interested - mildly - in the internet in 1997. It was still in it's relatively early stages and there was not half as much information on Asperger syndrome as there is now. Then in 1998 I was told about my having Asperger syndrome. The fact that I was just left with a 'label' and told no information about AS has more to do with NHS Psychiatry and its problems - but that's for another time and place.

I was naturally interested in my condition and over several months I began to familiarise myself with the many hundred Asperger/ Asperger related websites on the internet. However, I did not contemplate building my own site until some people told me that the language that all websites are written in (HTML) is relatively easy to master and comprises a series of fairly logical open/close tags. Previously I found the whole idea of getting this information onto the world wide web a mystery. How do people do it, I thought?

Then one Sunday afternoon I decided that I would go for it!! Luckily, due to some free server space that an American company was offering I was well on my way.

Then due to another stroke of luck I came across the best online tutorial for website building that I could have hoped to find. A man called David from USA had cleverly built a tutorial

that even the man on the street could understand. I visited his tutorial pages regularly and soon I had learned enough to have a nice (but very basic) web page up and running!! Superb!! Soon, with the use of search engine listings and word of mouth, I was getting responses from all sorts of people with a fascination about Asperger syndrome: parents, carers, people with AS - anyone and everyone.

Eventually, as my enjoyment of learning to build my website (Ben's Asperger Room) grew, I decided it was time to move over to the services of Healingwell.com - a website hosting company specialising in health/medical forums (in simple terms - the people who give you the blank pages to use for your website). Healingwell was where I settled after a few disasters along the way such as a company in Canary Wharf. I paid them £8 for a domain name (address) and then I - and the general public - could hardly ever access my website!!

Healingwell is great. The man who runs it is always contactable in person and he actually has an interest in Asperger syndrome and other medical conditions. I now have 'Ben's Asperger Room' online 24 hours a day every day all year round for people to visit. Please feel free to take a visit – [www.asperger.healingwell.com](http://www.asperger.healingwell.com) or email me – [benrgood@yahoo.com](mailto:benrgood@yahoo.com)

I'd even be happy to get you on the road to building your own website - just say the word!!

Ben R. Good, London



## Post 16 education - your stories wanted!

**A**ndrew Powell is Project Officer for the National Autistic Society working in the ex-Avon area. He works with people who have Asperger syndrome to find out what support is necessary to live independently and to ensure access for people into college, employment and other services.

His research has shown many people did not get the support they needed in Further Education and Higher Education colleges/universities. Many people started courses but were unable to continue them because staff did not understand how people with Asperger syndrome learn best or because the campus did not seem a very friendly place.

He is trying to put together a booklet of first hand accounts from people with Asperger syndrome about their experiences at college or university. This booklet will be made available to lots of young students to help decide whether Further Education or Higher Education is for them.

If you went to a Further Education or Higher Education institution, and can spare a few minutes to write one side of A4 on your experiences, please do help so that other people with Asperger syndrome can benefit from your ideas.

Rough notes are fine, but please try to include details on these seven points:

1. where you went to college/ university
2. which course you studied, and whether you were able to complete it
3. when you were at college/ university
4. what aspects of being at college/ university were enjoyable
5. which aspects of college/ university life you found less enjoyable
6. what support you received from the college/university
7. what support would have been of most help to you.

Please send contributions to:  
Andrew Powell  
National Autistic Society  
Church House, Church Rd  
Filton, South Gloucestershire  
BS34 7BD  
(0117 974 8420)

*An excellent project -  
well worth supporting!*

*John Joyce*

*Editor*

## Book On Young Asperger People

I have an important request for anyone with Asperger syndrome aged 13 – 25 anywhere in the UK but especially in Swansea, Liverpool, Belfast, Glasgow or Dundee.

I'm writing a book about young people with AS and your families:

- your lives and experiences
- how AS services could be made better
- any creative work you've done such as poems, short stories and artwork.

I'm trying to be positive and honest!

If you want to be interviewed please get in touch with me as soon as possible - please contact me via the NAS office.

With thanks  
Anita - Colchester

*This is a very good idea Anita.  
I wish you every success.*

*If you're young and Asperger  
You'll know where to look -  
Will you be found  
In Anita's book?*

*Please let us know  
How you get on  
And do not stop  
When this one's done!*

*John Joyce*



## Help needed - for Asperger United!

### Talks on Asperger syndrome

My name is Desmond Meldrum and I am in my fifties with a recent diagnosis of Asperger syndrome.

I would be happy to give talks on my exercises to any organisation or individual within the Greater London area. I have written three books (as yet unpublished) on the subject and am currently working as a volunteer at Autism London.

I can be contacted through Autism London on 020 7704 0501.

*Asperger United* is written by people with Asperger syndrome for people with Asperger syndrome. That makes it completely unique!

The NAS has now made *Asperger United* free to anyone with Asperger syndrome. All you have to do is ring, write or Email us and we will put you on the mailing list!

You can help us by

- telling anyone you know about *Asperger United*
- writing to us - about anything that you think will interest readers
- sending us any artwork or designs
- sending us donations to support *Asperger United*! All donations are welcome - no matter how small!

### Conference News

Many of the articles in this issue come from a big conference on Asperger syndrome at the Maudsley Hospital 17th October 2000.

Many people with Asperger syndrome shared their experiences and several more people have been inspired by the conference to write to us.

This means that we're not able to fit everyone's contributions into this issue!

But don't worry: if your contribution is not in *Asperger United* 25 you may find it in Issue 26. Or 27... Or 28...

Just watch this space!

### More Conference News

NAS Training are running two more conferences on Asperger syndrome:

- Monday 5th February – Chelsea Village, London
- Wednesday 14th March - the Manchester Conference Centre.

They're both aimed at people with Asperger syndrome as well as parents and professionals.

For further details contact:

NAS Training, 4th Floor, Castle Heights,  
72 Maid Marian Way, Nottingham NG1 6BJ

Tel: 0115 911 3363

Fax: 0115 911 3362



## Making my talent work for me

(continued from page 1)

The second is an etching inspired by cathedral spires and images from my trips abroad. Elements of the Chrysler Building in New York, shown behind the cathedral dome, have influenced this image.

*Thank you, David.*

*I enjoyed reading this and I also enjoyed your talk at the October conference. Your artwork looks great here but seeing it in colour in your slide show was even better!*

*John Joyce*

*Editor*

## We want more art!

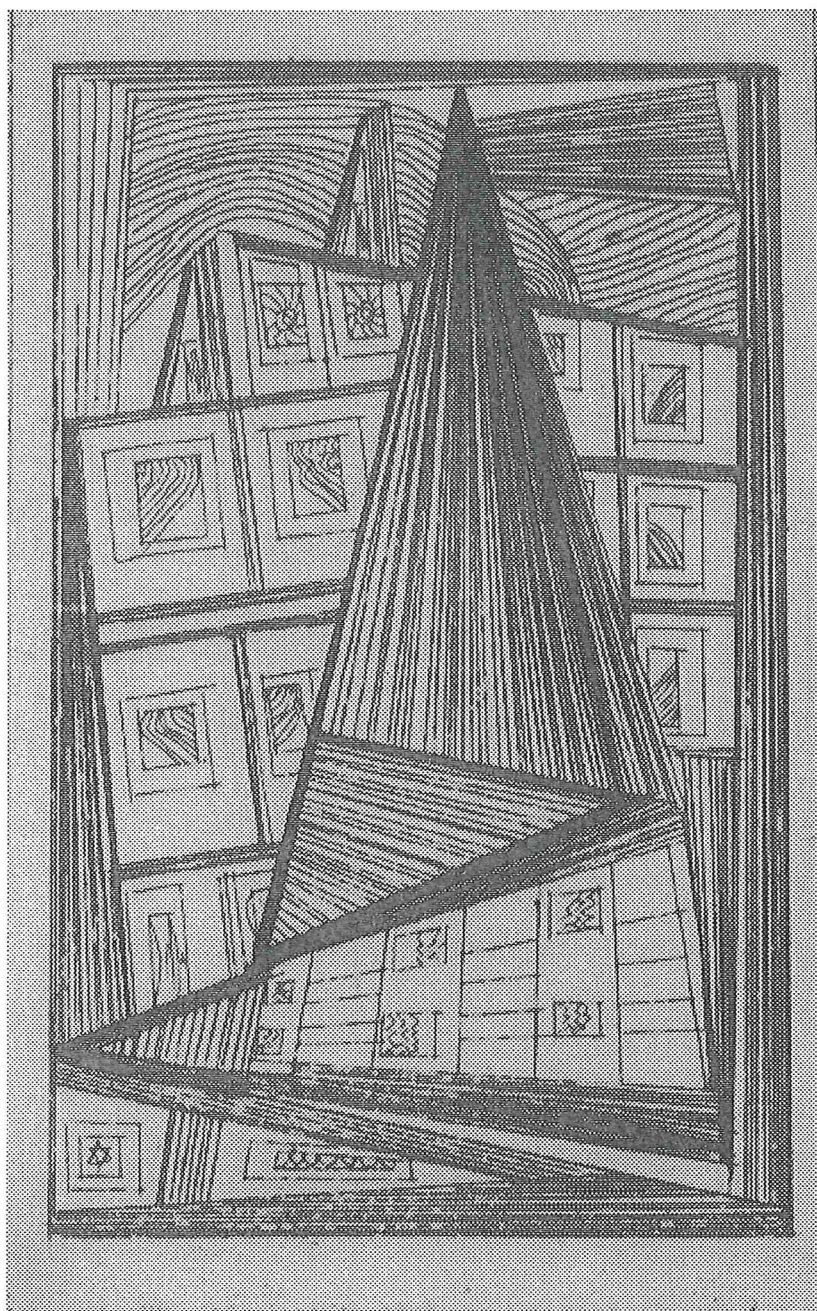
We get lots of articles sent to *Asperger United* but not enough artwork!

A picture paints a thousand words and brightens up *Asperger United*. We've had some fabulous designs from a few artists but we'd like more.....

*Asperger United* is printed in black and white so black and white drawings show up best - preferably with more white than black. Designs with strong contrast of dark and light are ideal and fine line drawings reproduce especially well - large areas of black don't!

If you draw or paint or design please send a copy of your work for *Asperger United*.

We'd love to see it!



Asperger United, c/o The National Autistic Society, 393 City Road,  
London EC1V 1NG.  
Telephone: 020 7833 2299. Fax: 020 7833 9666.  
Email: [asp.utd@nas.org.uk](mailto:asp.utd@nas.org.uk)  
Website: [www.nas.org.uk](http://www.nas.org.uk)



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