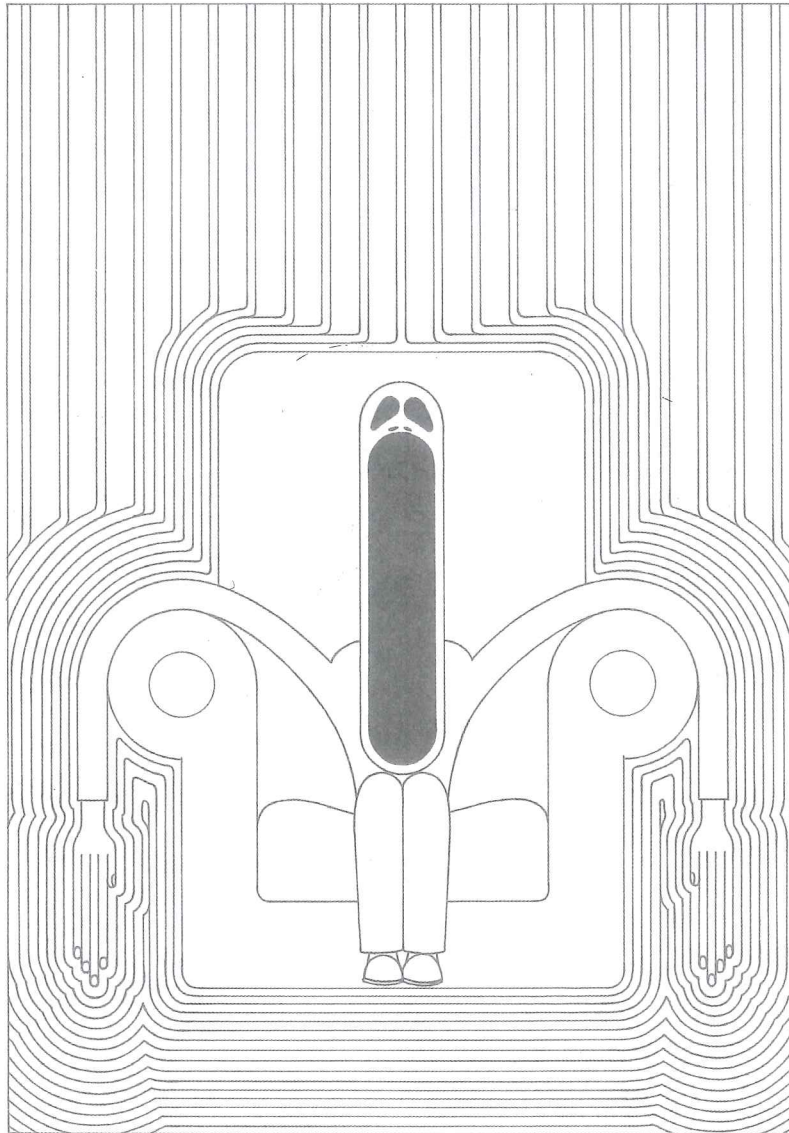


Produced by and for people with autism-spectrum conditions

Asperger *united*

Edition 54 April 2008



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AU


The National
Autistic Society



Asperger United is a newsletter run by and for people with autism-spectrum conditions. 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.

Please note that *AU* receives over 200 letters each quarter so it is not possible to respond to every one, nor for every contribution to be printed.

Asperger United is free. We ask for a contribution of £6 per year from overseas readers and £10 from professionals and institutions to cover postage costs. Please make cheques payable to the NAS.

Editor John Joyce

Additional support The National Autistic Society's Publications Department

Please send all correspondence and subscription requests to:

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Subscribing to *Asperger United*

Tel: 020 7903 3595
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Email: asp.utd@nas.org.uk

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

Thank you to George Cox who kindly produced the illustration included here and on page 6, and to Graeme Lawson for producing the *AU* logo.

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

Contributions for the next issue should reach us by
26 May '08

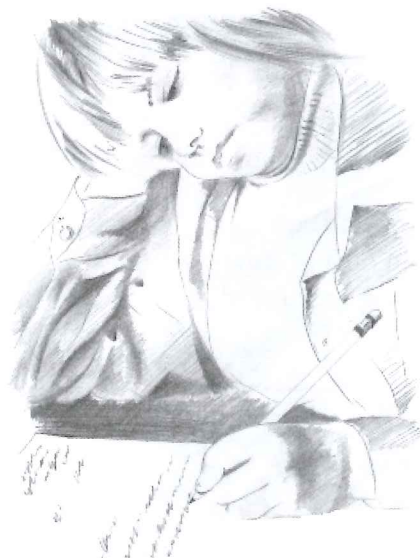
Asperger United was founded in 1993 by Pamela Yates and Patricia Howlin, in association with the Maudsley Hospital, and Mark Bebbington and Judy Lynch of The National Autistic Society.

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

The provisions for editor's and sub-editor's post was to develop a publication that was truly the voice of the people it was aimed at. This post also provided the possibility of work experience and responsibility and has benefited those who have held the position. These are Richard Exley, David Wright, Martin Coppola, Ian Reynolds and the current editor, John Joyce.

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

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



Dear readers

Welcome to the April edition of your paper. I have had a fairly quiet year so far, as befits living with an elderly parent.

I have become interested in internet-dating sites and have corresponded all over the world. There are "chancers" using these sites in order to get to this country. I played along until the request for money was made then let the matter drop. But I have also developed "friendships" with ladies, to some of whom I have been required to explain AS.

I use inverted commas because no matter how close I may feel to any of these ladies, I

have to remember that I may never meet them. There have been some suggestions that I might make husband material, all based on the profiles and photos presented. I have been tempted to give at least one correspondent serious hope that I would go to see her in the Philippines and possibly arrange a wedding date, tentatively this October *when I'm 64*.

I might go there when I draw state pension.

My vote of thanks to all who have contributed material for this edition. You have all done very well. Please keep it up.

Best wishes for the rest of the year
John Joyce

If sufficient material is sent in, the theme for July will be **relationships**, including friends, family, love, sex and shop assistants. Future themes will include **music** and **living** (see announcement on page 11). Writing on any subject is still welcome, so get writing! (Cover art is also welcome.)

the mental health edition

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artwork by Peter Myers

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How I learned not to hate humanity

by **Genyin** (diagnosed with ASD at 30 years old, now 34)

Definitions

ASD: Autism-Spectrum Disorder (including Asperger syndrome).

NT: Neurologically Typical (ie. not autistic).

AC: Autistics and Cousins — people with ASD and those near the autism spectrum but not definably on it.

I don't know how old I was when I started to hate humans. I recall feeling constantly invaded and made demands of from early childhood. Even something as trifling as a request for my attention, directly or indirectly stated, led me to feel put upon. That was *my* attention, right? MINE! Leave me be!!!

I remember as a little girl lying in the bath, looking at my feet and hating my human body because surely humanity was the cause of all this rejection, the overload no one else seemed to react to, the constant invasion and demands and so on. Humans caused it and I looked human, and that was horrible.

So when I read David's letter on page 6 of the January 2008 edition of AU, containing the statement "Rejection has resulted in a strong hatred of humans", it set me thinking about why I no longer feel that way.

I still experience rejection, especially on the days my voice and words are less free flowing, audible and understandable. Sometimes I experience rejection when I try to describe how my ASD affects me to someone who will only see me as "normal" and able. A few months ago I experienced this in such a severe way from my sister that I haven't seen her and my nephew (and new baby niece born end of January) since August.

But these days I don't hate humankind. I'm not pretending. The world hasn't become a more accommodating place, that's for sure. But perhaps I have decided to be a more accommodating person.

There can be a tendency among people on the autism spectrum to think that everyone should go out of their way for us, but we don't have to change anything. We may even believe that we can't change anything. We're autistic/AS and we're rigid and that's just how we are. That's me. Everyone else's job is to accommodate me.

Surprise; it's never going to happen. We, ACs, are simply not everyone else's priority. In some situations we have some protection by law — against harassment and employment discrimination, for example. But the average person in the street, or in a shop or in the pub, has no more responsibility towards us as ACs than they have towards any other human being.

They have other priorities, other points of view, other life experience, different education and so on, which means they don't see as we do in the context of their interactions with us. We may see prejudice where they see someone acting ungraciously. Society tells them they deserve to be treated with respect and they perceive one of us as disrespectful, perhaps. They don't usually understand even basic disability issues, never mind something as esoteric as ASD.

Yet every one of us, those of us with ASD and all the people without ASD, are simply doing our best with the information and life experience we have. There are nasty, exploitative people, but the vast majority of people don't fall into this category.

When it comes to ASD most people are ignorant in the pure sense of the word — they simply have no idea. Or they have some surface understanding but they don't really know how it works and they aren't suspecting that people they see, know, will have ASDs.

Perhaps if we're still struggling with anger against the human race a useful way to channel it is to share our stories and help educate people. Perhaps with its new campaign for adult ACs the NAS can help facilitate more of this to happen. Perhaps AU can print our stories for a sympathetic audience, and we can help each other by writing in in response to any stories that trigger something in us.

We can, if we wish, join ACs all over the world through various forms of online interaction, helping and being helped by each other and having the opportunity at times to share our thoughts and experiences with parents of AC kids who want to hear adult AC perspectives. We can join online groups of active ACs who successfully fight against prejudice and wrong preconceptions. We can join activities like Autscope (UK/Europe) and Autreat (US), meeting other autistics face to face and experiencing being part of an autistic-friendly environment for a few days.

We can't change much by resenting the ignorance of others. All that leads to is misery all round. We can change how we react internally and externally to such ignorance. Of course in some situations we must demand fair treatment. In others, where we are not being specifically abused (physically, sexually or verbally) we can try to educate, or at least to tolerate. They really don't understand these ASD aliens in their midst. That's why they expect us to be like themselves, and expect us to want to be (if they consider our feelings about it at all).

My experience is that when I try to accept other people where they are at then they become more accepting of my oddnesses in response. But it has to start from me — to them I am not a priority, and nor should I be. I am just one person.

And accepting that things/people are as they are, while at the same time working to bring change, allows me to be one much happier person.

"Don't blame the entire human race for a fault that only you can see"
— line from a song by The Christians.

Staffordshire Adults Autistic Society conference

The conference, to be held on 7 May 2008, will have seven autistic adults speaking about their lives, plus speakers from all over the UK and international speakers. The conference is free for ASC adults: we just ask for £10 to cover your lunch and drinks. Parents are most welcome to attend (£25) and professionals (£60). We also have Carol Povey attending from the NAS, talking about adult services. To find out more and to book a place, go to www.saas.uk.com/conferences.php

Requests for jokes — get your name in a book if your joke is printed!

The NAS is working on a book for teenagers who have a brother or sister who has an ASC. People with an ASC often have an excellent sense of humour. Please send your jokes to:

Teenage siblings book
Publications Department, NAS
393 City Road
London EC1V 1NG
Tel: 020 7903 3595
publications@nas.org.uk



letters to the editor

Dear Editor,

I am a 60-year-old academic looking for a support group for adults with AS and I wonder if any of your readers can help. I can travel by train in the Exeter-Salisbury area.

I would also like to hear other people's views on disclosure. After diagnosis — what then? What are other adults' experiences?

I personally feel stigmatised, not by those who acknowledge that I suffer from AS, but by those who believe there is no such a thing, far less that I could suffer from it, or even imagine that I could. They have no idea how much energy it takes every day to act normally!

Good luck with the "Mental Health" issue.

Sam

This is a message for David, whose letter was in issue 53: you are not the only one left out — this Asperger's thing affects so many different people in so many different ways, and to different degrees.

I am 58, and, like you, I have struggled through life.

I only found out about Asperger's and ADHD recently, and my initial reaction to my diagnosis was (in common with many others) a huge sense of release and relief that there is a good reason for all my failures in life.

But the downside is that I have now given up even trying to maintain any meaningful relationships — like you, I have worked out that I really don't much enjoy relationships because I don't understand how they work. I regard myself as "disabled" — just as people who are confined to a wheelchair have to come to terms with their inability to walk, so I try to come to terms with the fact that I will never "bond" with another human being.

Kevin

Hi,

I would like to send an answer in your magazine to David who spoke of his rejection and strong hatred of human beings.

David you are not alone in being 50 and rejected: I am in the same position.

Relationships: I have a degree in disastrous ones, friends very few, tolerance of the condition is low.

I am as yet undiagnosed and fighting the system to get the diagnosis.

A love of teddy bears: yes, I have loads but also cats which I find are non-judgmental and tolerant of my many-faceted moods.

I was bullied at work, which I no longer do, at school by kids and teachers, by professionals who should know better (psychiatrists, GPs, social workers, etc.); labelled (wrongly) anti-social (how does anyone become social?), arrogant, nasty, with a "Victor Meldrew" syndrome . . . the list gets longer!

I frequently fall out with people without trying because, as I have learnt, AS has a tendency in some people to cause them to speak without thinking. This makes Tesco's a nightmare.

David you are not alone, loneliness is a fact of life when you are different and takes a lot of handling, do as I try to do, try to be independent, blunder through your life being yourself and if they want to reject you that is their loss!

You are better than any of them — whoops — was that arrogance?

Jon



How to reply to Pen Pals

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

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

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

Pen pal number 22

My name is Jonathan and I am 19. I live in Manchester, and I was diagnosed with Asperger's syndrome at the age of 12. My hobbies include: ICT/computers, trains/trams, *Dr Who*, going to the cinema, and listening to music. I would like to hear from others my age, male or female, to write to/socialise with.

Pen pal number 23

My name is Andy and I have three specific learning difficulties, called dyscalculia, dyspraxia and Asperger's syndrome. My interests include Tom Cruise, football 1888-2007, rugby 1865-2007, WCW 1989-2001, melodic rock music and a former NWA and WCW wrestler called Sting.

Pen pal number 24

I'm Edgar, am 29 yrs old, was diagnosed with Asperger's in '97. I'm looking for more friends with the same condition I have (male or female, age 20 onwards). My hobbies are badminton, table-tennis, pool, listening to CDs, watching DVDs, walking. I'm a member of a charity called ASAP (Asperger Syndrome Adults and Parents) which I joined in Sept '05, which is a branch of SAFE which I joined in '98.

When I first joined SAFE I had no idea what it was like, ten years on I really enjoy it: I feel like I fit in. I'm also on the ASAP committee which has really boosted my confidence. I enjoy being part of the team.

Look forward to hearing from you soon.

Pen pal number 25

Hi, I am Leon, I am thirty-five, live in Buckinghamshire and have a very nice home and am fairly self-sufficient. I was diagnosed with Asperger syndrome in 1996.

My job as a supermarket check-out cashier is perfect and I enjoy it most of the time.

My hobbies are water birds (ducks, geese and swans) and fish. I have many fish tanks and I make wildlife films of them and many of the water birds. Painting is another passion of mine and I have many wildlife paintings.

I have my own special ducks and geese that I have watched and filmed for years. I not only have photos of them but have made videos of their lives and it's great fun. This hobby gets me out in to the fresh air and I have three favourite lakes that I visit regularly.

One of my best geese is called Mr Shark and I have been watching and filming him over the years and I have a video of him and his life. He is very happy and eats out of my hand and lives with a duck. He thinks he's a duck, as on the farm he was hatched out with ducks. I love watching and filming wildlife.

I also like science fiction and write about new species in my own world. I am kept quite busy as I go to art classes with my best friend. There is a great arts centre where I live.

I do sometimes get depressed as I often feel that people tend to dismiss me as stupid, as they may find me eccentric; I give this type of person a wide berth. I realise that sometimes I am wrong and am being over-sensitive. I think that most people like me, as I try to be friendly.

I would like a bigger garden and would grow more things, but I have got a garden pond (I find pond life fascinating to watch) and just a few nice shrubs. Looking forward to hearing from you.

Pen pal number 26

Hello, my name is Sean and I am 13 years of age. I have Asperger Syndrome and I would like a pen pal, either male or female, from 10 to 15 years of age, who also has AS.

My hobbies are computer games such as *Final fantasy* and *Polar wars*. I enjoy playing *Dungeons and dragons*, which is a fantasy role-playing game. I am also interested in astronomy and anything to do with Japan. I have been to Nebraska, America, twice to visit my grandparents.

My favourite element is fire. My favourite TV programmes are *Becker* and *Two and a half men*.

I live in the Shetland Isles, which are islands north of Scotland.

Pen pal number 27

Hi, my name is Vicky. I am 16 years old, I was diagnosed when I was 14. I love the word cheese and the name "Bob". I also like art, music and computers can be fun at times.

I am looking for a pen friend of any age, as it can be lonely at times.

Pen pal number 28

My name is Callum, I am 10 years of age and I have Asperger's syndrome.

I am looking for a pen friend of similar age who likes *Dr Who* and *Thunderbirds*. I like books, going to musical theatre and drama, I am learning to swim.

It would be really nice if I could write to someone as I am being home-schooled at the moment.

Autism and getting on the road to mental health

There is a tendency amongst us to listen to what is said, take it literally, and feel bound by it. This is our problem: most people, even if they listen, even if they take something literally, they do not necessarily feel bound by it.

We — you — should not feel bound by everything that is told to you.

If you do feel bound, you are placing an enormous onus on yourself that most people would not choose to shoulder.

However asocial you feel you are, the truth is that everyone needs someone. There will always be times when you need someone's help, no matter how independent you try to be. If you only contact people when you need help, you will be a burden to other people, because they will always know that you are asking them for help, before you even speak to them. You need to develop friendships with understanding people; people who will take some of your difficulties into consideration and who gain some little enjoyment from your company. You need to see these people several times a year just to "say hello" so that when you see them for help they will not feel put upon, and they will be sympathetic (in the best possible sense) and helpful. This is friendship: friends feel valued by helping friends; help strengthens the friendship.

David said that he can't cope with friends, but that is then a puzzle for him to work out: if you are too rigid, you must learn to give or take — somehow we must all find two or three friends, and professional services could help with this. Bizarre though I find the whole thing, friendship is the most rewarding problem that I tackle in my life. I have felt like killing myself. I have tried to kill myself on three occasions. It was my friends who helped me through difficult times like these, though I destroyed several friendships in the process. Destroying a friendship is painful, but it gives an anatomical insight into how

friendship works, and into where you went wrong. It also teaches you whether the friend was worth having — not all friends are.

Some friends try to take advantage of you because they see that you are vulnerable; these are not really friends, they are cheats. Real friends do not try to make you feel bad about destroying the friendship, they are just upset. Real friends reappear when you thought you'd destroyed everything.

With friends, you can get through life with less stress than without them, no matter how isolated you choose to be — even hermits living in the Moroccan desert have friends who visit from their monastery. The one thing that friends need is for you to make some of the effort: if they are always making the effort, then they do not feel valued as friends, and I think this is true whether they are autistic or not.

The effort you make could be all sorts of things: not talking too much, taking a shower and putting on clean clothes before meeting them, absorbing all they have to say and not criticising them. It all depends on who you are and who they are, but it is fantastically rewarding, and life is worth it. When I've not had any friends, I've not been able to hold down a job, because there was no one to turn to when I was struggling.

They support you when you need it, so you also need to support them when they need. This isn't very hard — listening is a good form of support. Ask questions about their life and make the effort to take an interest in their answers. Friends mean you are not isolated, so you are not lonely, so you are not so easily nor so deeply depressed. If you need to find some friends, join a group that shares a hobby; take up a new hobby if you have to. Ultimately, it's down to you to make friends, but your new friends will help you!

J

Asperger syndrome and mental health

by Becky

I am writing this on a ward in a mental hospital. They admitted me here just over a week ago with severe depression and “complex post-traumatic stress disorder”. Other labels I’ve acquired include generalised anxiety disorder and mixed personality disorder — but the only label that they overlook is Asperger syndrome, which is the original label I was given, and the one that makes the most sense to me.

Why do they overlook it? Because AS is neither seen as a mental health problem nor a learning disability, the label of AS on its own is not a reason to receive treatment or support. However, had AS on its own been a reason to receive some support I really doubt I would have ended up here.

The truth is I tried to take my own life, and there is a certain amount of grief in that, knowing that things got so bad that you deliberately tried to end it in a moment of despair, anger and just not coping any more. I was deeply depressed and think that all I really needed was someone to talk to and some practical support. But instead it escalated to an extreme, and now I am on anti-psychotics and anti-depressants and locked up in a psychiatric ward.

The nurses won’t talk to me. A patient who tries to commit suicide, represents something attention-seeking and manipulative to them, which could not be further from the truth. So I have stayed in my room too afraid to come out, too afraid to talk to anyone and desperately isolated. How is anyone supposed to get better here in such an overwhelming and difficult environment? No one told me when meal-times were or showed me around the ward, so in a complete daze I didn’t eat or leave the room for a couple of days.

Eventually I told someone I was hungry and because I had missed dinner they gave me a Cuppa Soup and a packet of crisps, apparently a nutritious enough meal to sustain you throughout the day.

And so deeply depressed and introverted I am kept on this ward with chronically schizophrenic and often quite unpredictable, sometimes aggressive, patients. I lie on the bed in a panic as the alarms go off yet again and patients are restrained and escorted screaming and swearing to their rooms. I remain alone in mine, frozen in fear and blocking my ears to shut out the high pitched alarms. I’ve never been this frightened before.

Then after a few days of this, I get given four hours’ leave a day to wander the streets and do what I like. Not one nurse asks where I am going and they do not care, so long as I am back on time. So although I am not considered safe enough to go home, I am safe enough to wander aimlessly for four hours — alone with no explanation and without telling them where I am going. No question about how I am feeling and if it is safe to go out. Where is the logic in that? If I was going to try and kill myself again I’d have plenty of opportunity to do so. I don’t understand why I can go out for four hours but can’t go home.

There is no real care here. The only interaction is “medication time” when staff knock on the door and order me to take my meds. The rest of the time is endless boredom and isolation, except for my four hours’ leave. Yet they still won’t let me go home and say I am too “unwell”. This judgment is based on one-hourly checks where a nurse peers through the window and ticks the chart. No interaction, not even to say “hi”. I know hardly any of the staff names here. I do not

know who I can talk to or ask questions. Every day I tell someone I want to go home, and every day they tell me I have to stay. That if I don't come back from my four hours of freedom I'll be sectioned under the mental health act.

I know that this could have been prevented if somewhere out there was a support system for adults with AS. I was asking for help, but was ineligible for Social Services and became so increasingly isolated and alone. Depression became so bad I attempted suicide. I am lucky I did not die. Yet according to research up to 65% of people with AS suffer additionally with anxiety and depression. Mental health services say AS is not a problem they can deal with and learning disability services turn away

any one who has a normal IQ. So it is a case of falling through the gaps in the system until it reaches crisis point. It shouldn't be this way.

I think this is an issue that has been ignored for far too long. Psychiatrists and psychologists in the mental health system need to have training on what AS is, to learn to recognise the symptoms and enable accurate diagnosis. Once people are diagnosed then there should be follow-up care, should that person feel it would help them. I would argue that there need to be autism-specific services for adults on the high-functioning end of the autism spectrum, or who have AS, as there are for those who are much more severely affected by autism and meet criteria for learning disability services.

Autscape 2008: Action and inertia

www.autscape.org

Giggleswick, North Yorkshire, UK

Tuesday, 29th July, to Friday, 1st August, 2008

Autscape is a residential conference and retreat organised for, and run by, autistic people. With successful events in 2005, 2006 and 2007, this will be the fourth annual Autscape. Participants in previous years have come from across the world to discuss issues affecting autistic people, and have enjoyed the chance to interact with other autistic people in a tranquil and secluded countryside location.

Autscape is designed as an autistic-friendly environment. Effort is made to minimise sensory and social stressors, and autistic people are not expected to conform to NT

social standards. Non-autistic people are also welcome. All we ask is respect for "autistic space", a non-judgmental attitude and an open mind. Registration is due to open in late April and space is limited, so ensure you register promptly. For further information, visit our website at **www.autscape.org**

Email: **info@autscape.org**

Telephone: **07941 343 026**

Write to: Autscape, 4 Falcon Street, London, E13 8DE, United Kingdom.

A future theme of **living** will cover accommodation, money, shopping, support, socialising and other topics to do with day-to-day existence and the problems we face.

A blessing and a curse

by Caiseal Mór
(pronounced "Cashal Moor")

Jessica Kingsley Publishers, £12.99 / \$18.95

ISBN: 978 1 84310 573 2

review by the Goth

Folk! this book has a powerful opening. Especially in light of recent media coverage regarding a cure for autism. There's a lot of swearing because the writer's Australian. The writer was also abused as a child, so there's even more swearing. Perhaps it should have been called "A blessing and lots of curses". He's a *Dr Who* fan, but you get the impression not one word is over the top or gratuitous; they're there to illustrate the truth. Not that I'm suggesting being a *Dr Who* fan is over the top or gratuitous. He mentions his love of *Dr Who* because of what it says about him — it's there to illustrate his point, not just there as another little fact about him to fill out the book. Every word has been carefully weighed and found necessary.

I love this book. It speaks directly to me, has many parallels with my own story, albeit his version is much more extreme. As he says himself, he is a born storyteller. The casual ease with which he must be able to entertain a group of people jumps off the page. It had me laughing, it had me crying. An empathotypical person reading it will be able to see that someone who behaves like an idiot can be an intelligent and articulate person with autism. It describes his childhood, his travels and his work, all in a beautifully lyrical, lilting style of prose that aches to be read. He does a very good job of explaining why autistic people need to learn things for themselves, and that explaining things to them is ineffective, even when the lesson to be learned

is that copying a fledgling and trying to learn to fly by jumping off the balcony repeatedly is not going to work. I make the mistake of trying to explain where people are going wrong all too often.

In my interactions with people I react in the way that I think people expect me to react. If I don't get it quite right I might seem a bit gauche or odd, but still people will assume that I am feeling what they think I should be feeling. I think Mór comes across in the same way, as he has been very fortunate at various points in his life; apparently getting along with people, who, if nothing else, were very tolerant of him.

He has, obviously, been deeply unfortunate in his life as well, but he has discovered the trick of letting go of things. Don't let the b*****s get you down! Are you afraid of being thrown out? Is the worry eating away at you and ruining your sleep? There is no need to worry; the streets will keep you if no one else will. I discovered this trick at the age of 31, and my life has mostly improved since. I am lucky in that since leaving school I've always had a few friends, even if they have all refused to let me stay with them. I think that is what everyone needs to survive: a few friends.

It has inspired me to read his many other books, including his fantasy fiction, and get his CDs.

Shame, despair and hope

by Fiona

Do you find it difficult to use a toilet if anyone is nearby? If you are male, are you unable to use the urinals if another man is there? If so, you are not alone. A few months ago I discovered that the condition which dominated my teenage years, causing untold shame and distress, is shared by many thousands, possibly millions of people and has a name — paruresis, or shy bladder syndrome.

My first memory of this problem was when I was six years old, during the long winter of 1963. The water in the pipes of the outside toilets at school froze and some men were sent to fix them. The shock of finding men in the girls' toilets, opening the doors (which had no locks) made it impossible for me to go to the toilet and I had to endure afternoon school in great discomfort.

Later that year I had my first nervous breakdown, due to stresses at home and at school and started making frequent trips to the toilet. My brother teased me unmercifully, calling the toilet my home and making nasty comments every time he saw me go there. This led to a huge sense of shame over needing the toilet, which eventually made it impossible for me to go if there was anyone nearby. The strain of this problem, together with stresses at home and lack of friends at school (due to my undiagnosed Asperger's), led to a more serious breakdown at eighteen and admission to a psychiatric clinic. By now I was in despair, but this proved to be a turning point.

During my six week stay at the clinic I was given cognitive behaviour therapy, which involves gradual exposure to the thing you most fear. Eight stages were involved, starting with using the toilet with a female nurse standing halfway down the corridor and ending with two men shouting and banging on the door. It was terrifying, but it worked and more than thirty years later I can say that I am still 99% cured. The experience of facing up to my fears has also helped me to deal with other sources of anxiety in my life and enabled me to do many things that seemed so scary, like leaving home, getting a job, learning to drive and having a family.

There is now a charity called UK Paruresis Trust (UKPT) which helps people with this condition and runs workshops using cognitive behaviour therapy. Their website is www.ukpt.org.uk and the address is PO Box 182, Kendal, Cumbria, LA9 9AE. I believe that this problem is particularly common in people with Asperger's because of our high anxiety levels and experiences of being bullied. My father, who probably had a mild form of Asperger's, once told me that he found it difficult to use urinals when other men were present. There are so many people suffering in silence, but help is available.

If any women sufferers would like to contact me through the magazine, I would be happy to correspond with them. Male sufferers would probably find more relevant support through the UKPT message board.

Results of the *Everyday worries* research survey from issue 49

can be found at www.pc.rhul.ac.uk/clindoct/STORE/AspFinal.htm

Thank you to all those who took part.

My name is Bekki. I was born in a pit village. I was a baby when my mam told a doctor that she thought I may be autistic, but she was told to stop being silly, that there was nothing wrong with me. So I went through school not knowing why I was so different. I was bullied at school, never made friends very easily. I went from junior to secondary school making no social progress. Don't get me wrong, I was good at things such as maths, English and science. It was the social aspect that always led to trouble. I ended up skipping classes and was eventually excluded from school just before I took my GCSE exams, although they did agree to let me sit my exams as long as I left the building afterwards.

After I left school, with six GCSE passes, grades C-E, I went on to work at a local garage as a trainee car valet. I really enjoyed this job, but after a misunderstanding with another member of staff, I was dismissed. I took this as a personal attack and retaliated by damaging one of the cars in the garage. I didn't know then that there was a reason why I found it hard to be sociable.

I then got another job, as a domestic/tuck-shop assistant, which I also enjoyed. But it was only a matter of time before I was summoned to the office and told that *things* were not working and that fellow employees could not work with me. At this news I just lost my temper big time, I vandalised the property, then returned and threatened the boss with an imitation firearm. I had lost control totally. I just could not understand why people seemed to hate me so much.

I was sentenced to two-and-a-half years in prison, the first year of which I spent in and out of trouble, until I was eventually diagnosed by the prison doctor as having "Asperger's". I finally understood why I was so different. I also realised why people struggled to work with me.

I was released twice before I managed to sort my life out. I found it very hard to adjust

to real life, after spending time in prison. Prison gave me a routine that I couldn't get out of. I re-offended twice just to get back in.

In January 2005 I was released for the last time. I was told about a place called ESPA who offered college placements for people with AS and autism. I was offered an assessment and when that was successful I started at one of their colleges that year.

I didn't think I'd be able to fit in; I thought my past would make it hard to make friends, but it was so different from what I expected. My fellow students looked up to me, as I had a little more life experience than them. They started to come to me for advice, and I was asked to become a "peer mentor", supporting other students with their problems. I decided then that I wanted to become a counsellor and started a qualification in this area. I also joined some college committees, including the student committee and equality and diversity committee. I was nominated by the principal of the college for a regional award in equality and diversity after working to promote equality in the college. Although I wasn't the overall winner, I did reach the finalists.

I was at ESPA two years, before the LSC pulled out of funding, although I still visit regularly and get involved. I have now just completed my level 2 in counselling and I am due to start my level 3 any day now. I had my story published in *Pick me up* magazine in November 2007. I have also set up my own website www.livingwithaspergers.co.uk in a bid to help others in my situation.

Now I can't believe I have come so far. As I often say to fellow ESPA students, "I crawled from the gutter and reached for the sky". If I can do it, anyone with AS can achieve their dreams. It's a shame it took prison for me to be diagnosed.

After I was diagnosed I wrote the poem on the next page, which expresses my feelings about my late diagnosis.

From pillar to post

Passed from one doctor to another,
Given one explanation after the other.
There's nothing wrong, she's very bright,
To me she seems quite alright.
Maybe family counselling would help a bit,
She's just rebelling, get used to it.
Her co-ordination isn't a real problem;
She's just a little clumsy; there's nothing wrong,
She likes to collect things, but all kids do,
She's a little shy, that's nothing new.
She doesn't like flashing lights, but the EEG was OK.
She has panic attacks, but what can I say?
Lots of people have them, but it doesn't mean it's anything serious
She's just a rebellious teenager; she could do without all this fuss.
It's her fault she's ended up inside, there's nothing we could have done,
Maybe she'll learn from experience, what's done is done.
But along came the prison doctor, who knew what was what,
Scrolling through hours of CCTV footage, he knew what to spot,
He said those words that finally made sense of the past,
She's autistic; she has Asperger's, an answer at long last.

Experiences of using mental health services

My name is Bekki Perriman. I am looking for volunteers living in London to take part in a research project about Asperger syndrome/ High-Functioning Autism (AS/HFA) and mental health. I am studying a Graduate Diploma in Psychology at the University of East London, and my research is focused on the experiences of service users with a diagnosis of AS/HFA of using mental health services. This is an important area to research, as it is becoming increasingly common for people with a diagnosis of AS/HFA to have their support needs met by mental health services, rather than autism-specific support organisations. Research has also shown that there is a high prevalence of additional psychiatric diagnosis among adults on the spectrum, for example depression and anxiety.

I am interested in representing what your views are of using mental health services. What has been helpful, what has been difficult, and whether you feel AS/HFA is understood by mental health professionals.

The research will involve taking part in a semi-structured interview, lasting approximately thirty minutes to one hour. I am only able to interview people in the London area. If you live outside of London and would be interested in taking part, I can send you a questionnaire based upon the interview.

If you are interested in taking part please contact me by email: u0418841@uel.ac.uk or zbekbiz@yahoo.co.uk

Please note that the two Bekkis on pages 14 and 15 are not the same person, Ed.

I Exist — latest campaign from the NAS

Thank you to the *Asperger United* readers who responded last year to our survey about experiences of adults on the autism spectrum. Your views have directly informed the second phase of the *think differently about autism* campaign, which is called *I Exist*.

I Exist is the message from adults with autism and Asperger syndrome who have said in great numbers that they feel isolated, ignored and unable to access appropriate support services.

The campaign will first call on local authorities and the Government to find out how many adults with autism, including Asperger syndrome, there are in their area and in the UK as a whole. Without this information, the needs of adults with autism will never be fully recognised, and people will continue to be excluded from local services.

Later, the campaign will focus on two issues which people with Asperger syndrome have identified as having a negative impact on their lives. These are:

1. Many adults with Asperger syndrome do not receive the support they need because they fall between learning disability and mental health services.

"The authority's social services refuse to support or even acknowledge Asperger syndrome as a unique disability requiring specialist intervention." — Adult with AS

- Over 60% of adults with Asperger syndrome or High-Functioning Autism said they had had difficulty in accessing support from their local authority and/or health service.

- Over half of these were told that they did not fit easily into mental health or learning disability services.

2. Many people said they wanted more social support, yet it is here that the difference between the support you want and what is available is most apparent.

"Up until now I have never known anybody else who has Asperger syndrome other than myself so it was really nice to finally meet someone like myself. I don't feel alone anymore."

— Social group member with AS

The campaign is calling on local authorities to establish a clear route to enable adults with Asperger syndrome and High-Functioning Autism to access assessment and services.

They should also fund social support services, including befriending, social programmes, social skills and life skills training.

We hope that these demands accurately reflect what you feel we should be campaigning on.

As always, we want to hear your feedback and suggestions. Tell us whether you think we've got it right, and what you would like to see us campaign on in the future by emailing thinkdifferently@nas.org.uk or calling 020 7923 5799 (voicemail).

Please visit the campaign website, www.think-differently.org.uk to find out more about *I Exist* and how you can get involved.



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